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Feasibility of Anthropometric Measurements for Large-Scale Application in the Irish Longitudinal Study on Ageing in People with Intellectual Disability (IDS-TILDA): An Exploratory Study

A thesis submitted to the University of Dublin, Trinity College
for the degree of Doctor of Philosophy

March 2014

Janet Swinburne

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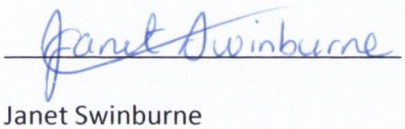

Janet Swinburne

Summary

Background: Malnutrition, either as under- or over-nutrition, is a risk factor for increased morbidity and mortality, and overweight and obesity represent one of the most pressing public health concerns of our time. Effective identification, prevention, treatment and monitoring of malnutrition require effective and high-quality assessment to guide interventions and measure their success. Yet no nationally representative anthropometric data on adults with intellectual disability (ID) exists in Ireland. Although anthropometry (the study of human body measurements) is a widely used tool in ID research, limited attention has been paid to the harmonisation of measurement procedures between studies, and there has been no work solely focused on the methodology of anthropometric assessment in this population group. Limited attention has also been paid to the development of strategies to reduce the measurement difficulties and barriers often reported.

Aim: The aim of the study was twofold: (a) to determine the feasibility, validity and reliability of performing anthropometric measurements on people with ID aged 40 years and over, as part of the pilot study for the national longitudinal study on ageing in people with ID in Ireland (IDS-TILDA), and (b) to develop a research field tool to guide the baseline assessment of anthropometry in adults with ID, including measurement standards, and an approach that maximises the participants' understanding of the measurement process.

Methods: A descriptive cross-sectional survey design was employed. A mixed-methods approach was used to produce both fixed anthropometry values and descriptive details on the measurement experience. Both the classical measurement theory (Fisher 1950) and the familiarisation theory (Bateson 1966) together with the Cone of Experience model (Dale 1969) were influential in the design of the study. The computer packages SPSS and NVivo were used to analyse the data. *Sample:* A cohort of 77 people with ID (26 males and 51 females) aged 43-94 years took part in a follow-up anthropometry measurement session after completing the IDS-TILDA home interviews. *Outcome measures:* Standing height, weight, waist and hip circumferences, and two surrogate measurements: ulna length and mid-upper arm circumference. Measures were performed according to the International Society for the Advancement of Kinanthropometry (ISAK) standards and components of the Malnutrition Universal Screening Tool were used to widen the reach of the measures to all participants. A familiarisation protocol was integrated into the study design. All the measurements were taken in duplicate by an accredited ISAK anthropometric technician.

Analysis: To determine the percentage of valid readings, each measurement was assessed against strict validity criteria and compared to the total number of measurements taken on that specific measure. Based on the valid readings secured, four precision estimates were calculated: the technical error of measurement (TEM), the percentage TEM, the intraclass correlation coefficient (ICC), and the coefficient of reliability (R). The constant comparative method was used to analyse the qualitative perspectives reported on the familiarisation procedures used.

Results: According to the findings, the anthropometry module was highly feasible to deliver as part of the IDS-TILDA study and was acceptable to all participants with varying levels of abilities. Overall, high rates of valid and reliable anthropometric measurements were achieved. The measurements that strictly required standing positions had lower eligibility rates than those taken in either a standing or seated position (69% vs. 99% respectively). This confirmed the importance of surrogate options being included as standard practice in anthropometry studies. Both ulna length, as a surrogate for estimating standing height, and mid-upper arm circumference, as a surrogate for estimating the Body Mass Index category, were feasible and acceptable to all participants. The intra-examiner reliability was very high for all measurements (TEM <1 cm or 1kg; %TEMs < 1%; ICC ≥ .998; and R ≥ .9982). The familiarisation protocol was very positively received by participants and all relevant key stakeholders.

Conclusion: The study revealed that highly rigorous anthropometry and data-collection protocols, based on generic reference methods, can be successfully operationalised with adults with ID in field research. The methodology employed will serve as a model for IDS-TILDA and others seeking to research anthropometry in this population, and will support increased precision of measurements, improved interpretation of anthropometry data within and between populations, and increased awareness, knowledge and understanding of the measurements among people with ID. The benefits of the familiarisation procedures developed for the anthropometry module were highlighted, along with the potential benefits of replicating the familiarisation procedures in other health screening tests involving people with ID. The research field tool developed offers researchers, for the first time, a universal starting-point for the systematic design, development, implementation and evaluation of baseline anthropometric measurements in adults with ID of all abilities. Lastly, this study represents an important milestone towards the goal of ensuring that the right of people with ID to be included in anthropometric-related surveillance is fulfilled, and that high-quality anthropometric data is collected for them both in Ireland and beyond.

Dedication

This thesis is lovingly dedicated to my parents,

Kathleen and the late Michael Swinburne.

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"It always seems impossible until it's done" – Nelson Mandela

Many people have supported me on this PhD journey and I want to convey my gratitude to them here. First, I wish to express my indebtedness to my supervisor, Prof. Mary McCarron, and co-supervisor, Prof. Philip McCallion, for their support, guidance and unwavering belief in my potential. Thank you for having the faith and belief in my passion to look at anthropometry beyond the 'act of measurement' alone for people with intellectual disability. Providing space for me to grow and learn and find my own path, while having you both there to provide advice when needed, was much appreciated.

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List of Abbreviations

ADDIE	Analysis, Design, Development, Implementation and Evaluation
BMI	Body Mass Index
CI	Confidence Interval
DEXA	Dual-energy x-ray absorptiometry
DS	Down syndrome
ELSA	English Longitudinal Study on Ageing
HC	Hip Circumference
HRB	Health Research Board
HRS	United States Health and Retirement Study
ICC	Intraclass Correlation Coefficient
ID	Intellectual Disability
IDS-TILDA	Intellectual Disability Supplement to Irish Longitudinal Study on Ageing
ISAK	International Society for the Advancement of Kinanthropometry
ISD	Instructional Systems Design
MUAC	Mid-Upper Arm Circumference
MUST	Malnutrition Universal Screening Tool
NIDD	National Intellectual Disability Database
OP	Operational Protocol
PDA	Personal Digital Assistant
PIQ	Pre-Interview Questionnaire
R	Coefficient of Reliability
RA	Regional Administrator
SD	Standard Deviation
SHARE	Survey of Health, Ageing and Retirement in Europe
SLÁN	Survey of Lifestyle, Attitudes and Nutrition in Ireland
TCD	Trinity College Dublin
TEM	Technical Error Measurement
TILDA	The Irish Longitudinal Study on Ageing
vs.	versus
WC	Waist Circumference
WHO	World Health Organization
WHR	Waist-Hip Ratio

Chapter 1: Introduction

This chapter introduces the thesis by providing its context and foundation. It outlines the background of the research, the research problem, and several key elements framing the focus of this study. Additionally, it describes the significance of the research. It concludes with an outline of the remaining chapters.

1.1 Background of the Study

Over the next two decades, Ireland will experience marked changes in the age structure of its population. A significant increase in the number of older people will have implications for the nation's health, social and economic institutions (Department of Health & Children [DoHC] 2008). It is estimated that the number of people aged 65 and over will more than triple between now and 2050, compared with a projected overall population increase of around 35% (Central Statistics Office 2007). This would mean that the number of people aged 65 and over will significantly outweigh the number of children under five years old in Ireland. Increased longevity, declining fertility and the ageing of the 'baby boom' generation are all contributing factors to this demographic change. As both the proportion of older people within the total population and life expectancy increase worldwide (Tirrito 2003), key questions arise for all countries on how best to meet the needs of its ageing society. In order to plan and respond to the changing needs of an ageing population, data on the health, well-being, social, economic and environmental circumstances of the population must be gathered and tracked in each country, to assess how circumstances change, individually and in combination, over time, and to identify the factors that influence successful ageing and the development of disease and disability as people age.

In response to Ireland's impending demographic transition, a major inter-institutional initiative, The Irish Longitudinal Study on Ageing (TILDA) was launched in 2006. TILDA is being led by Trinity College Dublin (Principal Investigator, Prof. Rose Anne Kenny) in collaboration with a number of institutions in Ireland and longitudinal studies on ageing in Europe and the United States. It represents the most ambitious and comprehensive research study on ageing ever to be undertaken in this country. TILDA aims to involve a nationally representative sample of between 8,000 and 10,000 people aged 50 years and over, charting all aspects of health, economic and social circumstances for at least a ten-year period. The study represents a major step towards building the evidence base needed to plan and develop appropriate health, medical, social, economic and environmental policies, and to guide future service provision.

Both home interviews and health assessments are to be used in a series of data-collection waves once every two years. To strengthen its comparability, TILDA's methodology is closely harmonised with other leading international longitudinal studies on ageing, such as the Health and Retirement Study (HRS 1992) in the United States, the English Longitudinal Study on Ageing (ELSA 2002) and the Survey of Health, Ageing and Retirement in Europe (SHARE 2004).

Similar to the general population, marked changes in the life expectancy of people with intellectual disability[1] (ID) are occurring worldwide (Carter & Jancar 1983, Puri *et al.* 1995, Janicki 1996, Holland *et al.* 1998, 2000, Patja *et al.* 2000, World Health Organization [WHO] 2000b, Evenhuis *et al.* 2001, Kerr 2007, Emerson & Hatton 2008) due to many factors such as medical advances, improved education, public health and living conditions. In Ireland, the continuing growth of the older proportion of people with ID has been captured over the years in the National Intellectual Disability Database (NIDD) since its establishment in 1996 (Kelly *et al.* 2007). Yet, compared to the general population, we have relatively limited information on the age-related physical and mental changes that people with ID experience (Factor 1997), and none of the leading international longitudinal studies on ageing, such as the HRS, ELSA and SHARE, reports the inclusion of this population in their sample composition. Similar to other countries, the sampling frame selected by TILDA, the Irish Geodirectory, will unintentionally preclude many people with ID from being selected. However, unlike most other countries, Ireland is well placed to address this inequity, as it has an established NIDD from which a representative sample of people with ID can be drawn. In combination, all the factors led to the launch of a parallel supplemental national study in Ireland, called an 'Intellectual Disability Supplement' to the Irish Longitudinal Study on Ageing (IDS-TILDA), in 2008. It is also being led by Trinity College Dublin but under different leadership (Principal Investigators, Prof. Mary McCarron and Prof. Philip McCallion).

The close harmonisation between the two studies (IDS-TILDA and TILDA) has not only become a national landmark for ageing research in Ireland but also worldwide. It will ensure for the first time that the differences and similarities between the population groups nationally are systematically ascertained over the next ten years, so that future policies, services and resources meet the needs of people with ID as they age. Although IDS-TILDA is conceptually comparable to TILDA, which in turn is closely harmonised with other ageing studies (e.g. HRS, ELSA), thereby allowing for within- and between-country comparisons, IDS-TILDA also takes

[1] Intellectual disability is defined as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills" (AAIDD 2013).

account of the issues that uniquely affect the lives of people with ID. Until now, no country, using representative samples, has directly compared the ageing of people with ID with the general ageing population. This partnership between population groups positions Ireland as a leader in mainstreaming people with ID into national research programmes, and paves the way forward, as the universal model for other countries to follow in the future. Its timing could not be more important; with evidence suggesting people with a lifelong disability, inclusive of people with ID, are one the fastest growing but smallest groups of older people (Bigby 2004). Comparatively, the IDS-TILDA study seeks to recruit between 750 and 850 people aged 40 years and over, targeting 10% of the total population aged 40 and over with ID, across all levels of disability and living circumstances. Equivalent to TILDA, participants will be interviewed every two years about their health, social, psychological, economic and environmental circumstances, for at least a ten-year period.

1.1.1 Framing the Context of the Study

Similar to TILDA, in preparation for longitudinal investigation, a pilot study was undertaken to assess the acceptability and feasibility of the IDS-TILDA interview-based questionnaire for people with ID and other key respondents, such as family members, support workers and nurses, where required. As part of the pilot, one component of TILDA's pilot health assessment module, anthropometry assessment, was also tested in the IDS-TILDA pilot study. This thesis (exploratory study) focuses solely on the anthropometry module of the IDS-TILDA pilot study, including its design, development, implementation and evaluation. The results of this study will guide future planning on the anthropometry assessment in IDS-TILDA and produce knowledge that can be used by others studying anthropometry in this population. Based on the feasibility and acceptability of the anthropometry assessment module to people with ID, and the retention rates from the interview stage to the measurement stage (separate home visits), the suite of physical measures included in IDS-TILDA's health assessment may be expanded upon in future waves of data collection, similar to TILDA, if resources allow.

1.2 Anthropometry Assessment

Anthropometry is the hallmark technique of biological anthropology, a branch of science that studies the measurement of the human body, which has become increasingly important in health assessments across this century (Ulijaszek & Lourie 1997). Anthropometric studies and the inclusion of anthropometry parameters in health-related studies can help to identify nutritional problems such as under-nutrition and over-nutrition and identify groups with specific nutritional and health needs to be addressed in policy development and programming (de Onis

& Blossner 2003). Anthropometric data can also be used to track trends, and monitor and evaluate broad changes in nutritional status over time. With ageing, changes in body composition occur, including quantitative and qualitative progressive loss of skeletal muscle mass and body fat redistribution, with greater accumulation in the intra-abdominal region compared to the subcutaneous abdominal area, independent of disease development (Newman *et al.* 2005, Baumgartner 2006). Modifications in nutritional and physiological status, such as decrease in body weight and height, also occur (Dey *et al.* 1999). Almost two decades ago, before the impending demographic transition ahead became an increasing subject of attention, the World Health Organization (1995, p. 270) has recommended "not only that the elderly be included in surveillance but also that they are specifically targeted for nutritional surveillance since they may be prone to hidden deficiencies that can be corrected by nutritional and health programmes", and also that the elderly be seen as "a group at risk".

Longitudinal studies are therefore required to determine the magnitude of changes in anthropometric measurements with ageing (Perissinotto *et al.* 2002). Not surprisingly then, both the international (e.g. HRS, ELSA, SHARE) and the national (i.e. TILDA) longitudinal studies on ageing have all recognised the need to collect this data and include anthropometric measurements as part of their health assessment modules. Equally, longstanding nutrition-related surveys such as the US National Health and Nutrition Examination Survey (NHANES 1971) and the UK National Diet and Nutrition Survey (NDNS 1992), and recent cross-sectional studies in Ireland, the North/South Ireland Food Consumption Survey 1997-1999 (IUNA 2001), the National Adult Nutrition Survey 2008-2009 (IUNA 2011), and the Survey of Lifestyle, Attitudes and Nutrition (*SLÁN*) (Morgan *et al.* 2008), which involve older adults as part of their sample composition, all recognise anthropometry as a key component of nutritional assessment. However, strikingly absent across all of these well-known studies is the reported involvement of any and/or representative samples of people with ID. By virtue of the sampling frames used, the majority (if not all) were unintentionally precluded from being selected. This information gap urgently needs to be bridged, so as to ensure that evidence-based planning and evaluation of public health policies and actions are inclusive of one of the most vulnerable and marginalised groups in our society. This exploratory study represents a first step in this endeavour.

1.2.1 Key National Policy Positions

More than two decades ago, Ireland along with 158 other countries signed the World Health Declaration on Nutrition (FAO 1992). One of the seven themes in this declaration was the need

to assess, analyse and monitor the nutrition status of citizens, but to date Ireland has not included representative samples of its population of people with ID in any of its national nutrition surveillance activities (e.g. detection, treatment and prevention), if included at all. At the early stages of this study, the two policies that stood out were the Obesity Taskforce Report (DoHC 2005) and the Cardiovascular Strategy 2010-2019 (DoHC 2010a). Both identified the need to halt the rise in overweight and obesity in the Irish population (with prevalence rates based on the national cross-sectional studies noted earlier) but neither explicitly mentioned people with ID or the clear lack of evidenced-based data available on this population group. Of particular note, the Obesity Taskforce Report recommends:

- a national database of growth measurements (weight, height, waist circumference (WC) and BMI) for adults to be developed by the Population Health Directorate (later confirmed as a strategic priority for action by the Health Service Executive 2008), and
- routine measurements of height, weight and WC to be taken in primary care

These recommendations, the national reports mentioned above (along with the national 10-year target set to reduce overweight and obesity detailed in the Cardiovascular Strategy) and the national survey position (i.e. lack of ID representation) collectively confirm the urgent need to raise the anthropometry profile of people with ID. Only then will the national research and policy gap begin to be addressed. It is vital that people with ID be included in all future national anthropometric-related initiatives and surveys, to inform policy and service provision. The HSE Population Health Strategy (2008a, p. 5) has recognised that "there is a clear need to reduce the gap in health inequalities". In support of this mission, the results of this study offer researchers, clinicians and policy makers the guidance needed on conducting anthropometric measurements with people with ID of all levels of abilities. IDS-TILDA provides a critical opportunity to begin filling this information gap and show how representative samples of people with ID can be included in national research.

1.2.1.1 A Nutrition Paradox: Overweight/Obesity and Underweight

Excess body weight is the most serious public health challenge of the 21st century for the World Health Organization European regions (WHO 2007a). Rates of overweight and obesity among the adult population continue to rise (WHO 2007b), with serious impacts on the health and well-being of citizens (WHO 2006a, 2006b). Both weight statuses are major risk factors for a number of health problems, including but not limited to diabetes, hypertension, high

cholesterol, cardiovascular diseases and some cancers (National Institutes of Health [NIH] 1998, WHO 2000a, 2007a), and may contribute to functional decline and disability in the elderly (Janssen *et al.* 2002a). There are also psychosocial and economic consequences of being overweight or obese, which have significant implications for an individual's health and well-being. The fiscal costs of treating the current and ever-increasing health problems attributed to overweight and obesity will no doubt significantly affect health services and society as it ages. Ireland has not escaped this growing epidemic (DoHC 2005, HSE 2008b, Morgan *et al.* 2008, DoHC 2010a, 2010b); the prevalence of overweight and obesity has continued to rise over the last decade.

At the other end of the spectrum, older adults, particularly the elderly, are reported to be at increased risk of under-nutrition (Visvanathan 2003, Hickson 2006) compared to younger adult populations. This results in high risk for acute illness and death (Kushner 1993, Seidell *et al.* 1996, Beck *et al.* 1999, Hengstermann *et al.* 2007). Consequently, as the population ages, timely assessment and monitoring, and the formulation of strategies to prevent, manage and treat the varying nutritional statuses of the Irish population will be of prime importance - especially given the increased risk of overweight/obesity and under-nutrition coexisting (a nutrition paradox) in older populations. The World Health Organization (2003a) described the nutrition paradox as a challenge and is one that is taking over many parts of the world with detrimental effects, if immediate action is not taken. National research surveys, such as *SLÁN* in Ireland, play key roles in tracking trends and informing policy, programmes and services.

Despite the global and national attention on the overweight and obesity epidemic, Ireland has not addressed or responded to the nutritional health of its population of people with ID. Similarly, no population-specific research has been commissioned to establish the prevalence of underweight, overweight and obesity in this population group, so as to direct policy and practice. Up until 2007, except for one small survey (n=157) in one service provider in the west of Ireland (McGuire *et al.* 2007), no published research on the island has specifically focused on the nutritional health of this population or included related questions within a wider investigation. Based on proxy-reported height and weight (n=130) used to calculate Body Mass Index (BMI), McGuire *et al.* revealed that 68% (n=88) of people with ID were overweight or obese. The clear lack of baseline BMI data on this population group, nationally and regionally, at a minimum, is alarming – especially since international research has consistently reported the same rising trend in overweight and obesity among people with ID (Rimmer & Yamaki 2006). Many studies indicate higher rates of obesity compared to the general population (Rubin *et al.*

1998, Harris *et al.* 2003, Marshall *et al.* 2003, Emerson 2005, Rimmer & Wang 2005, Yamaki 2005, Draheim *et al.* 2007), raising further concerns about unmet needs in the population of people with ID. Comparatively, it is also reported that they are at increased risk of being underweight (Hove 2004, Emerson 2005, Bhaumik *et al.* 2008). With the population ageing and the possible onset of diseases and declining health, we may witness an increased proportion of people with ID at risk of underweight in future years.

Based on the international evidence on people with ID, and the global epidemic of overweight and obesity in the general population, it is clear that this population group in Ireland are likely to face the same (if not greater) weight status challenges as other citizens. However, until data is gathered on representative samples of people with ID, this position cannot be definitively confirmed.

1.3 Significance of Anthropometry and People with Intellectual Disability

IDS-TILDA and its inclusion of anthropometry assessment in the landmark study is timely. It represents the first national step towards filling the Irish information gap on anthropometry in people with ID. Internationally, this study breaks new ground in research on this topic by providing for the first time an in-depth examination and understanding of the methodology of anthropometry assessment and use with people with ID of all levels of abilities aged 40 years and over. Based on the findings from this study, necessary guidance on how to conduct anthropometric measurements with this population group is available to key stakeholders in policy, research and practice, so as to improve outcomes for individuals with ID. For example, the findings support and direct future developers and implementers of both the proposed national database of growth measurements and measurement of baseline anthropometry parameters in primary care (see Section 1.2.1) in Ireland, to include people with ID. This will allow the nutritional status of people with ID to be monitored alongside the general population. Since optimal nutritional well-being is an important determinant of health, this is even more critical as the population ages and as needs become more complex.

People with ID should not be overlooked in anthropometry assessments nationally, regionally, locally or on an individual basis for reasons such as the perceived difficulties of undertaking such measurements, or an inability to achieve high-quality assessments in this population. These are unacceptable justifications for the under-representation or exclusion of this population group from nutritional surveillance-related activities. People with ID should and need to be afforded the same opportunities to have their baseline anthropometric measurements taken (at

minimum), similar to the general population, so that the necessary programmes, services and information are targeted correctly, and sufficient resources are allocated for that purpose. There is also a need to identify reversible or preventable causes of malnutrition; this cannot be achieved without high-quality evidence-based data. People with ID need to be treated as full and equal citizens with the same, if not greater, needs than the general population. They have the right to benefit from the outcomes of nutritional surveillance programmes offered to all other citizens. In order to support people with ID to age well in an ageing society, as many of them will face greater challenges and possibly have more complex needs compared to their non-disabled peers, we need to understand their body composition using anthropometry measures (a key component of nutritional assessment), and the changes and influences it has on their health and well-being over time. Anthropometry has been described as "the single most universally applicable, inexpensive and non-invasive method available to assess the size, proportion and composition of the human body" (WHO 1995, p. 1), yet no measured anthropometry data has been published on this population group in Ireland.

If anthropometric data is not collected on this population group, the Irish health system is unlikely to be able to meet the current and future need to treat overweight and obesity-related diseases and conditions, and the elevated health risks associated with underweight. Similarly, the necessary prevention, treatment and management of these weight statuses will not be accessible to people with ID, as their needs will not be planned for and insufficient resources will be allocated to respond appropriately. Without this data, it will also not be possible to fully evaluate health and dietary status, disease risk and body-composition changes that occur with ageing, or identify any protective effects of overweight or obesity in old age. Overall, there has never been a more important time to understand how to conduct precise, high-quality anthropometric measurements with people with ID of all levels of abilities, while maximising their awareness and understanding of the measurement process and the importance of nutritional health. The overall impetus of this study was based on the right of people with ID to have the choice to take part in nutritional surveillance and to benefit from all related health promotion activities designed to meet the specific needs of the population and/or target groups. Importantly, this study did not seek to make the use of anthropometry more complicated in this population group than it needs to be, but rather it sought to address the core concepts of ensuring high-quality data was collected, that such measurements were accessible to all persons with ID and that they became active participants in the process, beyond the physical act of measurement alone. The study represents the potential for a significant advance in the use of anthropometry measurements in ID and general research and practice.

1.4 Structure of Thesis

This thesis is divided into six chapters.

- *Chapter 1* provides an overview of the context of investigation and introduces the broad concepts that will be explored further in the next chapter.
- *Chapter 2* builds on the concepts discussed and presents an analysis of the literature.
- *Chapter 3* outlines the aims and objectives of the study, and the research methodology, and provides a detailed account of the research design, from the analysis stage through to the evaluation stage.
- *Chapter 4* presents the findings of the research study in three phases: the response rate and demographic, health and lifestyle data; the feasibility and measurement status data; and the reliability of the measurements and hypotheses tested.
- *Chapter 5* discusses the main findings drawn from the analysis of the data, presented under the broad themes of the study's objectives.
- *Chapter 6* summarises the general conclusions of the study and presents the key anthropometric and methodological learnings and contribution to ID research. It also outlines the main strengths and limitations of the study and recommendations for research, education, practice and policy.

1.5 Conclusion

This chapter has described the background of the research, and provided a general introduction to anthropometry assessment and key national policies. It also looked at the 'nutrition paradox' of overweight/obesity and under-nutrition coexisting, and highlighted the overall significance of anthropometry assessment in adults with ID in Ireland. The knowledge gap in the pertinent literature and the significance of the current study was also clarified. Finally, it outlined the content of the following chapters.

Chapter 2: Literature Review

2.1 Introduction

This review of literature builds on many of the concepts introduced in the previous chapter and provides foundational information for establishing the study and the related components. An overview of the key published knowledge-base pertaining to the core study of anthropometry is reviewed. The chapter is divided into three phases.

- *Phase 1* discusses the ageing population of people with intellectual disability (ID) and the nutritional health and assessment status of this population group.
- *Phase 2* discusses the anthropometric measurements of key interest to the study.
- *Phase 3* discusses key methodological factors related to measured anthropometry.

The chapter ends with a summary of the findings, including the deficiencies found in the literature, which formed the basis and justification for conducting this study, and highlighted a need for further exploration of several key issues with researchers and clinicians in the field.

2.1.1 Search Strategy

A comprehensive literature search was undertaken using various information sources to identify all key literature (published and unpublished) on the study and use of anthropometric measurements and people with intellectual disability (ID). Combinations of the following approaches were used:

- searching electronic databases (PubMed, CINAHL, Science Direct and Google Scholar)
- visually scanning reference lists from relevant studies
- reviewing websites of key organisations, associations and studies (see Appendix 1)
- reviewing non-journal-type publications (conference papers, books, and research, organisation and government publications)

Supplemental searches were also completed in key journals (see Appendix 1) to increase the sensitivity of the search and ensure that no key literature was missed. Contact with study authors, researchers, experts/clinicians, equipment manufacturers and relevant organisations was made (and systematically recorded by date, contact name, type of communication, query made and the outcome). All searches and contacts covered both the ID and generic fields. Crucially, the searches undertaken were re-run several times throughout the research study to

ensure that no recent publications were missed. It was also necessary to revise the search when new areas of relevance were identified, as the researcher's understanding of the topic developed. For all electronic databases (and the supplemental searches), key words were used (see Appendix 2). Words were searched separately, followed by combined word searches or sets of words using Boolean connectors. Records of the searches completed were kept and dated. The systematically informed approach of Tranfield *et al.* (2003) was used to guide and structure the identification and clarification of the literature selected (i.e. recording the key search strings, database type and number meeting the criteria of the study) and minimise bias (Cook *et al.* 1997).

All searches were limited to information (research studies and all other publication types) published or available in the English language. Most of the literature accessed was primarily but not exclusively published in the last 15 years. No date restrictions were applied to searches to ensure no pertinent information was missed. However, not all of the literature obtained is referenced in this study. Only those items from which material was quoted or that were directly referred to are documented in the references list. The software programme EndNote was used to handle the references. The Harvard referencing system (as adapted for use by the School of Nursing and Midwifery, Trinity College Dublin [SNM TCD]) was used throughout this thesis (SNM TCD 2013). The search results were assessed for relevance to the study. This process was framed and guided by Webster and Watson's (2002) concept matrix, with each article assessed against key concepts and categorised accordingly. On completion, another matrix table was developed for each concept to capture key details (i.e. author, year, study type, subjects, study design and findings), which is similar to the matrix table described by Cho and Egan (2009). All the information collated was then methodically analysed and synthesised.

Of particular note, the research studies referenced in the first phase of searching conducted are dated 2008 or earlier, which reflects the evidence available at the analysis, design and developmental stage of this study (Chapters 1 to 3). The research studies referenced in the second phase of searching conducted (i.e. the analysis, interpretation and evaluation of this study findings – Chapters 5 and 6) are dated 2013 or earlier.

2.2 Phase 1: Ageing Population, Nutritional Health and Assessment

2.2.1 Ageing Intellectual Disability (ID) Population

Over the last decade, marked changes in the life expectancy of people with intellectual disability (ID) in Ireland have occurred among all age cohorts, particularly among those aged 55 years and over (Kelly *et al.* 2008). Although increased longevity in people with ID is one of the great biomedical and biosocial triumphs of modern times, the life expectancy of this population group remains proportionally lower than that of the general population (Patja *et al.* 2000, Bittles *et al.* 2002, Kelly *et al.* 2008). Their average age of death in Ireland is suggested to be 45.68 years (Lavin *et al.* 2006). Even more alarming is the striking difference between the Irish life expectancy figure and those in other countries; for example, in New York State, longevity is reported at 66.1 years (Janicki *et al.* 1999) and in Australia, the figures range from 58.6 to 74.0 years (Bittles *et al.* 2002), depending on the person's level of ID (e.g. it is lower for those with more severe levels of ID). Although the life expectancy of people with ID is increasing over time, the wealth of international research highlights that people with ID continue to have higher mortality rates (McGuigan *et al.* 1995, Hollins *et al.* 1998, Durvascula *et al.* 2002, Merrick 2002) and experience significant health inequalities compared to the general population; for example, high levels of unmet health needs and excess disease burden (Evenhuis 1997, Schrojenstein Lantman-de Valk *et al.* 1997, Barr *et al.* 1999, Cooper 1999, Kerr *et al.* 2003, Ouetellette-Kuntz *et al.* 2005, Melville *et al.* 2006, van den Akker *et al.* 2006). Yet, "all citizens should have equal rights to health, and fair/equitable access to health and health information according to their needs" (McConkey *et al.* 2004, p. 165). Despite this, there has to date been no national population-based research conducted on the ageing of people with ID in Ireland. Critically, the 'Intellectual Disability Supplement to TILDA' will over time identify the factors that contribute to reduced life expectancy in Ireland, including those linked to aetiologies.

2.2.2 Nutrition Transition and People with ID

Currently Ireland, like many other countries worldwide, is experiencing marked changes in the nutritional status of its population, with the prevalence of overweight and obesity continuing to rise (Morgan *et al.* 2008). The World Health Organization (2003b, p. 1) has stated that "obesity has reached epidemic proportions globally, with more than one billion adults overweight – at least 300 million of them clinically obese – and is a major contributor to the global burden of chronic disease and disability". While there are no national statistics on the prevalence of overweight and obesity among people with ID in Ireland, based on a cross-section of international research conducted, similar rising trends have been reported, and in some cases,

even higher prevalence rates than in the general population, depending on the sub-group of people with ID studied (Bell & Bhate 1992, Beange *et al.* 1995, Prasher 1995, Martin *et al.* 1997, Rubin *et al.* 1998, Robertson *et al.* 2000, Draheim *et al.* 2002, Janicki *et al.* 2002, Marshall *et al.* 2003, Melville *et al.* 2005, Moran *et al.* 2005, Yamaki 2005, Bhaumik *et al.* 2008). However, several methodological issues, such as small sample sizes, different sampling strategies, lack of matched comparison groups, use of different measurement tools or methods to gather anthropometric data and different cut-off points to define weight status, among other factors, make it difficult to estimate the prevalence rate accurately in people with ID and/or to compare the findings directly to the general population. Despite these limitations, the ever-increasing prevalence of overweight and obesity, and the negative impact of this or the increased risk to the health of individuals with ID have been highlighted in these studies (see Rimmer & Yamaki 2006 for a full review of obesity and people with ID). The increase in overweight and obesity was identified as a priority for action by the International Association for the Scientific Study of Intellectual Disabilities (Lennox *et al.* 2002). Although the same priority has been identified for the general population in Ireland (DoHC 2005, HSE 2008b), both the Government and the research community have, until now, paid limited attention to the nutritional health needs of Irish citizens with ID. As discussed in Section 1.2.1.1, national health surveys have not reported representative samples of people with ID in their sample compositions, nor has there been any specific research commissioned to target the nutritional health of this population. There is a strong need to challenge the inequality experienced by this population group in Ireland. Using standardised methods, weight status data on nationally representative samples across all levels of ID and living circumstances is needed.

2.2.2.1 Nutritional Status and Risk of Co-Morbidities

Elevated weight status increases the risk of co-morbidities (e.g. cardiovascular disease, diabetes mellitus) (Must *et al.* 1999), functional decline (Launer *et al.* 1994, Friedmann *et al.* 2001, Jensen & Friedmann 2002), impaired quality of life (Ford *et al.* 2001), the use of healthcare resources (Wolf & Colditz 1998) and mortality (Calle *et al.* 1999). Worryingly, studies also suggest that adults with ID are at risk of developing obesity at an earlier age, with a peak in prevalence occurring about twenty years earlier than among the general population (Rimmer *et al.* 1995, Moran *et al.* 2005). In the general population, the prevalence of overweight and obesity, as defined by Body Mass Index criteria, is reported to peak at around age 50-60 years (Chapman 2008). If obesity is occurring at an earlier age for people with ID, then the onset of obesity-related diseases may be contributing to the shorter life expectancy experienced by some of this population group. Chronic diseases, such as diabetes, cardiovascular disease,

hypertension and stroke, and certain forms of cancer, are a serious threat to health, quality of life and longevity (Strong *et al.* 2005, WHO 2005, Nugent 2008) but many are largely preventable and treatable conditions with healthy lifestyle changes (e.g. optimal nutritional health, weight status, physical activity). The impending risks for people with ID are deemed even higher; evidence suggests that they are four times more likely (Dupont *et al.* 1987, Disability Rights Commission 2004) or at increased risk than the general population to die prematurely (McGuigan *et al.* 1995, Hollins *et al.* 1998) from preventable causes. People with ID are therefore especially vulnerable; with population ageing and the increased risk of chronic disease, the evidence further points to the urgent need to establish, monitor, prevent, treat and manage overweight and obesity in this population group in Ireland.

Only once national evidenced-based data on anthropometry parameters becomes available can an intersectoral, collaborative approach be taken at national, regional and local level to address the weight and body composition findings. The early identification of nutrition problems (to minimise or reverse negative impacts) or of those at risk of malnutrition (under- or over-nutrition) is critically important so that treatment and prevention strategies can be put in place to support people with ID to maintain good health and quality of life as they age. It is clear that both nutrition and weight status play key roles in the development, susceptibility and outcome of chronic diseases and disability, so particular attention needs to be paid to one of the most marginalised groups of Irish society, people with ID, both now and as they age. However, the marginalisation experienced is not unique to Ireland; across United Nations members it has been noted that "people with ID and their families are among the most marginalised in our society" (Inclusion International 2008, p. 3); however, unlike in Ireland, many other countries have conducted research on overweight and obesity, even if it is not to the same scale as that covering the general population.

At the other end of the spectrum is underweight. Although underweight is less prevalent than overweight and obesity, and has received less attention in the literature, it is reported to be proportionally more common in people with ID than among the general population (Simila & Nishanen 1991, Beange *et al.* 1995, Kennedy *et al.* 1997, Rubin *et al.* 1998, Aldridge *et al.* 2000, Molteno *et al.* 2000, Robertson *et al.* 2000, Braunschweig *et al.* 2004, Emerson 2005, Moran *et al.* 2005, Bhaumik *et al.* 2008), particularly among those with severe or profound ID (Stewart *et al.* 1994, Beange *et al.* 1995, Hove 2004). This may be due to a higher level of eating (e.g. swallowing, chewing) and drinking problems. A striking review of the characteristics and circumstances of 211 people with disabilities (most of whom had ID in addition to two or three

other disabilities) who died in care between 1991 and 1998 in New South Wales (NSW), Australia, revealed that 42% had been underweight, and that some died because of critical illnesses not being treated (Community Services Commission 2001). Subsequent inquiries from 2003 to 2005 identified similar trends due to many avoidable reasons such as services not adequately identifying or addressing the health needs of people with disabilities, such as nutrition and swallowing difficulties (NSW Ombudsman 2006). Similarly, following the deaths of six people with a learning disability (LD) in the UK, a landmark report published by Mencap, 'Death by Indifference' (2007), exposed the unequal healthcare and institutional discrimination that this population group often experienced in the healthcare system. Urgent calls were made for both an independent inquiry into the six cases outlined in the report and a confidential inquiry into the premature deaths of people with a LD in the UK (Mencap 2007). Collectively, the evidence reinforces the importance of not underestimating the risks associated with underweight, unintentional weight loss, or inadequate nutrition, and highlights the need for this weight status (underweight) to be monitored as closely as overweight and obesity.

While, again, there are no national statistics on the prevalence of underweight in people with ID in Ireland, a review of 25 studies by Gravestock (2000) concluded that between 35% and 72% of those with severe ID were significantly underweight, suggesting much higher prevalence than among their counterparts in the general population (Kennedy *et al.* 1997, Roberston *et al.* 2000, Corish & Kennedy 2003, Morgan *et al.* 2008). Combined with the ageing process, where weight loss is common among the elderly, the physiological decrease in appetite and food intake that accompanies normal ageing can be augmented by acute and chronic disease (Gariballa 2004); this may put all people with ID at increased risk of under-nutrition as they age. In the general population, it is reported that the risk of underweight may be greater for some people in later life, particularly the elderly, and especially those who are institutionalized (Morley 2001, Gariballa 2004) as compared to younger adult populations (Kushner 1993, Seidell *et al.* 1996, Beck *et al.* 1999, Mamhidir *et al.* 2006). Yet the risk of underweight in older people is often overlooked (similarly to the ID population) despite the many negative health outcomes (McWhirter & Pennington 1994, Kopelman & Lennard-Jones 2002, Visvanathan *et al.* 2004), such as falls, hospitalisation, lengthy hospital stays, and postoperative complications (Beck *et al.* 1999, Harris & Haboubi 2005). Under-nutrition is related to increased mortality (Romero-Corral *et al.* 2006), risk of bone fracture, susceptibility to infections, delayed healing of wounds, more pressure sores and specific nutrient deficiencies, which can lead to a variety of health-related conditions that can greatly affect quality of life (Crawley 2007) and increase functional dependency and healthcare needs (e.g. more frequent readmission to hospital). Physical

dependence on others for adequate nutrition, severity of eating difficulties, and dysphasia appear to be common factors associated with underweight in individuals with disabilities (Thommessen *et al.* 1991, Reilly *et al.* 1996, Kennedy *et al.* 1997). Despite similar methodological limitations, as discussed earlier in relation to overweight and obesity research in this field, the increased risk of under-nutrition for people with severe and profound ID, and among all persons with ID in their older years needs to be seen as a growing concern, due to the lack of evidence-based data in Ireland. This is particularly the case given that the life expectancy of people with severe and profound ID is reported to be much shorter than for those with higher levels of ID (Strauss & Eyman 1996, Chaney & Eyman 2000, Patja *et al.* 2000) and among people of all levels of ID who are partially or fully dependent on the support of others to meet their nutritional needs.

In the general population, much of the international and national nutrition-related research and policy focus has been on the growing obesity epidemic (WHO 2000a, 2007b, James 2008, HSE 2008b, Morgan *et al.* 2008), including among the elderly (Villareal *et al.* 2005, Popkin 2006, Andreyeva *et al.* 2007, Jenkins *et al.* 2007). However, as its prevalence decreases in extreme old age (Kennedy *et al.* 2004) and greater weight loss (or less weight gain) occurs with increasing age (Williamson 1993, Hughes *et al.* 2002), with population ageing and the rise in chronic diseases we may witness increasing rates of under-nutrition, which may become a major public health problem. Nationally, Ireland has begun addressing under-nutrition by publishing guidelines on preventing under-nutrition in acute hospitals (DoHC 2009). In future it is expected that a more comprehensive strategy, similar to that for overweight and obesity, may be extended to include nursing homes, primary care, and community-care settings. To ensure that the needs of the population of people with ID are not unintentionally precluded from any future under-nutrition, overweight and obesity action plans, access to annual high-quality data on the weight status of representative samples of people with ID is and will be essential in Ireland. Monitoring the nutritional status of national populations as they age is of prime importance for formulating preventive strategies to lower mortality and morbidity rates, improve quality of life and reduce healthcare costs, and people with ID should be afforded the same right to benefit.

2.2.2.2 Malnutrition and Body Composition Changes with Ageing

Malnutrition is defined as "the state of being poorly nourished" (Hickson 2006, p. 4), indicating that one or more nutrients are lacking, consumed in excess, or taken in the wrong proportions. Often the word 'malnutrition' is used (and viewed broadly) in the context of under-nutrition, but in this study it is viewed within the context of under- and over-nutrition. As discussed

earlier, both under- and over-nutrition are common in older adults (e.g. Bannerman *et al.* 2002, Jenkins *et al.* 2007); the causes are extremely varied and may be attributed to one or a combination of factors such as dietary, medical, physiological, social, living and/or economic circumstances. Anthropometric methods (see Section 2.3.1) of nutritional assessment are probably one of the most widely used (Gibson 2005) in epidemiological, clinical and population studies. However, in assessing body measurements to determine the status of malnutrition in older adults, the body composition changes that occur with ageing must be considered (Mangoni & Jackson 2004, Hickson 2006); both sarcopenia (loss of skeletal muscle) and increasing body fat are seen as hallmarks of the ageing process (Evans & Campbell 1993), as well as expanded extracellular fluid volumes and reduced body cell mass compared to younger adults (Baumgartner 1993, Baumgartner *et al.* 1995). Even though these patterns are difficult to identify using conventional anthropometric measures, such as BMI, waist, hip and mid-arm circumferences (Baumgartner 2000), anthropometric data provides valuable proxy indicators in large population groups and a platform to identify and guide areas for further research. Access to anthropometric data on people with ID in Ireland in the future will not only support the establishment of vital reference data on this population group, but also guide, for example, the interpretation of the data as people age, and whether cut-off points or methods used to assess malnutrition need to be revised to identify those at risk. Given the importance of this data and the complexity of assessing the malnutrition status of people as they age, it is essential to ensure that the anthropometry methods used are valid and reliable.

2.3 Nutritional Assessment

Nutritional assessment is defined as a comprehensive evaluation of information from dietary, medical and medication histories, anthropometry, laboratory data and clinical examination (August *et al.* 2002), either alone or, more effectively, in combination. Other variables such as age, gender, cognitive and functional status, psychosocial wellbeing, and socio-economic and environmental circumstances, are also important factors to consider in nutritional assessment and intervention pathways. For the purpose of this study, the focus remains on anthropometry. The importance of appropriate nutritional assessment cannot be understated (Seres 2003). In clinical practice and epidemiological surveys, anthropometric measurements represent an important component of nutritional assessment to evaluate the prevalence of underweight, overweight and obesity conditions in populations, which are important risk factors for severe disease and disability in the elderly (Jensen & Rodger 1998, Visser *et al.* 1998). Their future inclusion in the IDS-TILDA study will provide for the first time the evidence needed to ensure that health and nutrition policies, programmes and services take account of the needs of people

with ID, since this population group, particularly as they age, may be more prone to hidden nutritional deficiencies (e.g. people with dementia may develop problems with eating and drinking). The findings will also raise the profile of their nutritional needs and support co-ordinated multi-sectoral action at national, regional and local level. Until now, people with ID have often been treated as a low priority and excluded from mainstream targets (Disability Rights Commission 2006, Mencap 2007); for example, to reduce the rate of obesity within a specified timeframe. Yet the rationale for reducing the risks associated with underweight, overweight and obesity is the same for all population groups (including to reduce chronic disease and disability, increase quality of life, and reduce health inequalities and healthcare costs) (Bourn 2001, Department of Health [DoH] UK 2003).

2.3.1 Anthropometric Assessment of Nutritional Status

Anthropometry is the single most universally acceptable, inexpensive and non-invasive method to assess size, proportions and composition of the human body (WHO 1995). It is suitable for evaluating broad nutritional status in population studies with relatively large sample sizes. Initially, the use of anthropometry focused largely on infants and young children, and on characterising health and nutritional status, and predicting performance, growth and survival. However, recent advances demonstrate the relevance of anthropometry throughout the life-cycle, not only as part of individual assessments but also for epidemiological surveys to reflect the health and nutritional status of population groups. Measures commonly used in both individual assessments and epidemiological surveys include weight, height, BMI and circumferences (e.g. waist, hip and mid-upper arm) (Duren *et al.* 2008). Although more sophisticated techniques have been developed to assess regional body composition (e.g. computed magnetic resonance imaging and dual energy x-ray absorptiometry) and provide accurate evaluation of nutrition status, they are expensive to apply and lack portability. The simplicity of the anthropometry measures allows them to be used in large population studies to indirectly estimate body composition changes over time, and particularly in clinical and field situations where access to technology and resources are often limited (Hughes *et al.* 2004). However, despite the perceived simplicity of such anthropometry measurements, the potential for errors is relatively high. The precision of anthropometric measurements plays an important role in delivering meaningful information on the subjects' nutritional status (Alvero Cruz *et al.* 2005). But, for example, "inaccurate measurements of height and/or weight can cause significant inaccuracies in calculation of BMI, which is used as a guide for identifying persons at risk for disease" and estimation of prevalence of underweight, overweight or obesity (Engstrom *et al.* 2003, p. 1). Until more recently, the extent to which measurement error can influence

both the measurement and interpretation of nutritional status was little considered in the generic literature (Ulijaszek & Kerr 1999) and is largely absent in the related ID literature (see Section 2.5.3).

Standardisation of data-collection methodology (measurement and standardisation protocol), rigorous training and effective equipment calibration and maintenance were among the quality-assurance measures included in the World Health Organization's (WHO) Multicentre Growth Reference Study (MGRS) on infant and children, used to maximise the validity and reliability of the results and minimise the risk of anthropometric measurement errors (de Onis *et al.* 2004). Addressing these key considerations in anthropometric assessment can significantly reduce the risks and limitations. Similarly to other longitudinal studies on ageing in the general population (as discussed in Section 1.2), the value of acquiring anthropometry data in the ID population cannot be understated, as it will provide a much-needed snapshot of nutrition status over time, and should help to identify groups at risk of poor functional outcomes in terms of morbidity and mortality (Gorstein *et al.* 1994). The inclusion of such data in the IDS-TILDA study also falls in line with the World Health Organization's (1995) recommendation for all countries to collect anthropometric data on older adult populations (particularly the elderly) at regular intervals, coupled with monitoring of their health and functional status as they age, in order to fill the numerous gaps in knowledge on the use of anthropometry to assess physical status in the elderly.

2.3.2 Anthropometric Use and People with ID

In 1986, Kelly *et al.* reported that only a small number of studies have investigated the prevalence of obesity in ID populations (even though it had been recognised as a major health problem for the general population), while "the findings of these studies were limited due to the nature of the sample employed and/or criteria used to determine obesity" (p. 168). Over the next two decades, increased research on obesity and overweight, and to a lesser extent underweight, was undertaken internationally, using both self-report survey-type methods (Fujiura *et al.* 1997, Rubin *et al.* 1998, Barr *et al.* 1999, Aldridge *et al.* 2000, Robertson *et al.* 2000, Hove 2004, Emerson 2005, Moran *et al.* 2005, Yamaki 2005, Yen *et al.* 2005, Lennox *et al.* 2006, Wallace & Schluter 2008) and direct[2] measurements (Kelly *et al.* 1986, Bell & Bhate 1992, Frey & Rimmer 1995, Prasher 1995, Lea 1999, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Harris *et al.* 2003, Marshall *et al.* 2003, Braunschweig *et al.* 2004, Hove 2004, Moore *et al.*

[2] Note: Use of the term 'direct' in this context refers to measured anthropometric parameters such as height, weight, etc.

2004, Prasher *et al.* 2004, Chapman *et al.* 2005, Melville *et al.* 2005, Fender *et al.* 2007, Stanish & Draheim 2007, Draheim *et al.* 2007, Bhaumik *et al.* 2008, Melville *et al.* 2008). The only research undertaken in Ireland consisted of one self-report study (McGuire *et al.* 2007). Despite the increase in research, similar observations made by Kelly *et al.* (1986) continue to be made in this research field; studies selecting ambulatory subjects only (e.g. Rimmer *et al.* 1995, Draheim *et al.* 2007); studies using different methods to gather anthropometry data (typically height and weight) such as medical records (e.g. Moran *et al.* 2005), direct-measurement (e.g. Stanish & Draheim 2007) or verbal reports (e.g. Yamaki 2005); and greatly varied sample sizes, such as under 50 people with ID (e.g. Braunschweig *et al.* 2004) to over 1,000 people with ID (e.g. Bhaumik *et al.* 2008), along with several other important limitations (see Section 2.5).

All the self-report-type studies reviewed that collected anthropometry data were primarily based on height and weight values used to calculate BMI, similar to equivalent studies in the general population. While both of these parameters also feature highly in the studies that took direct measurements, several of the studies included many other measurements such as waist and hip circumferences. In the current literature review the direct-measurement studies showed a striking lack of standardisation and/or harmonisation of the methods employed to collect this measured data (see Section 2.5). No best-practice standards have been developed and there is an absence of research specifically on the methodology of conducting anthropometry measurements among people with ID. There is also a lack of alternative measurement options available for people with ID who are unable to stand for height and/or weight measurements (see Sections 2.4.1.2 to 2.4.1.4). This gap needs to be addressed to ensure that the eligibility criteria of studies can be widened to include all levels of ID (relevant to the topic under study) and/or that, if selected, all people with ID are able to participate using alternative measurements, if necessary.

Several of the studies that reported missing anthropometry data (particularly the studies that directly measured anthropometric parameters) cited elements that could be potentially be reduced or avoided such as: a lack of chair scales or hoist available for those who were non-ambulatory, unable to stand or for whom physical limitation made it difficult to achieve the necessary stance, and/or a lack of co-operation or tolerance for the measurement(s), (Bell & Bhate 1992, Marshall *et al.* 2003, Moore *et al.* 2004, Merriman *et al.* 2005, Fender *et al.* 2007, Melville *et al.* 2008, Wallace & Schluter 2008). Review of the literature on measured anthropometry in the ID field found no guidelines on techniques or strategies in order to maximise the participation of people with ID of all abilities, reduce any potential anxieties and

concerns about the measurements, educate about the measurement process, or increase the validity and reliability of the results, nor did it find an emphasis on the importance of accessible equipment. More details on some of the methodological limitations of research completed on this topic in the ID field (e.g. reference methods, validity, reliability, training, equipment) are given in Section 2.5 (and integrated into parts of Section 2.4). Measuring the nutritional status of a population requires accurate and precise measurements; given the vulnerability of anthropometric measurements compared to more sophisticated techniques (e.g. dual energy x-ray absorptiometry), robust methodologies are necessary, while making the necessary standardised disability accommodations is essential to widen the reach to all.

2.4 Phase 2: Anthropometric Measurements

2.4.1 Selected Anthropometric Measurements

In TILDA's pilot health assessment, four anthropometric measurements were selected (height, weight, and waist and hip circumferences) to contribute to the understanding of the health status of the study population and enhance interdisciplinary research possibilities. In the current study, the same four measurements will be tested among eligible participants, along with two additional surrogate measures, one for standing height, and one for when both standing height and weight cannot be secured, to widen the reach of the anthropometry assessment module to all persons with ID and with varying abilities. An overview of use and interpretation of the key measures selected is discussed from Section 2.4.1.1 to 2.4.1.6.

2.4.1.1 Body Mass Index

Body mass index (BMI) is a simple index of weight-for-height that is commonly used in nutritional and epidemiological surveys worldwide to estimate, albeit crudely, the prevalence of underweight (<18.5kg/m^2), healthy weight (18.5-24.9 kg/m^2), overweight (≥25.0-29.9kg/m^2) and obesity (≥30.0kg/m^2), and the associated risk of co-morbidities (WHO 2000a). BMI cut-off points, as indicated between brackets above, are calculated by dividing a person's weight in kilograms by their height in meters squared (kg/m^2). The basis for the classification of cut-off points stems from observational and epidemiological studies which related BMI to risk of morbidity and mortality (Higgins *et al.* 1987, Lipton *et al.* 1993, Colditz *et al.* 1995, Chan *et al.* 1994). Despite the usefulness of BMI at population level, it is acknowledged that it has limitations, such as that it may not correspond to the degree of body-fat distribution in different populations due, in part, to different body proportions (WHO 2006c). BMI is unable to distinguish between fat and free fat mass (muscle mass) and visceral fat, and it can produce

false negatives (e.g. people who are tall but who have excess body fat may not be captured as obese) and false positives (e.g. people who weigh more due to muscle, not fat mass, such as athletes). However, despite its limitations and the important caveats that apply to its interpretation, BMI is an internationally accepted population-based measure for adults. It is used to monitor nutritional trends, estimate prevalence of underweight, overweight and obesity, raise political awareness, and guide policy development, programmes and services. Use of the BMI in adults and older people with ID raises a number of issues for consideration in IDS-TILDA; for example, the validity of BMI measure for adults with Down syndrome due to short stature, suitability of the cut-off points for older persons, and the relationship between BMI and mortality with increasing age. However, the measurement of weight and height in adults with ID and the broad BMI classifications is the main focus herein.

2.4.1.2 Standing Height

Obtaining accurate standing height measurements in some people with ID (Bell & Bhate 1992, Marshall *et al.* 2003, Fender *et al.* 2007, Wallace & Schulter 2008) and, more specifically, in their older years, as in the general population, may not be possible or may be difficult due to disability, illness, spinal deformities and/or osteoporosis (WHO 1995, Brown *et al.* 2000, Kirk *et al.* 2003, Shahar & Pooy 2003, Hirani & Mindell 2008). Furthermore, age-related height changes due to thinning of the discs of the spinal column and diminution in the height of the vertebrae (Cline *et al.* 1989) have the potential to affect the validity and reliability of the measurement, and have implications for the interpretation of BMI, which assumes that height remains constant. Yet the validity and reliability of measured height and the interpretation of BMI findings in older people with ID (e.g. inverse associations with mortality) have not been reported in the studies reviewed (Bell & Bhate 1992, Prasher 1995, Lea 1999, Marshall *et al.* 2003, Moore *et al.* 2004, Chapman *et al.* 2005, Melville *et al.* 2005, Stanish & Draheim 2007). At present there are no guidelines on the degree of spinal curvature that would invalidate the measurement of height, but there are clearly individuals whose height should not be measured because of kyphosis or other postural problems (WHO 1995). In such cases, alternative height measurements such as ulna length[3] (Elia 2003), arm span[4] (Jarzem & Gledhill 1993), knee height[5] (Chumlea *et al.* 1985, Cockram & Baumgartner 1990) and demi-span[6] (Lehmann *et al.* 1991) have been shown to be useful surrogate measures and demonstrate high correlation co-efficient with height in older people, as the length of long bones, such as those in arms and legs

[3] Distance between the elbow joint and the midpoint of the prominent bone of the wrist
[4] Distance between the tips of the middle fingers of each hand when both arms are extended laterally
[5] Distance from the top of the patella to the bottom of the foot
[6] Distance between the mid-point of the sternal notch and the middle finger on one arm extended laterally

do not change with age, unlike vertebral height (Sorkin *et al.* 1999). However, the review of the ID literature found that alternative height measurement options, if required, were not standard practice in studies with older or all adults with ID. Two studies did report revised positioning options for standing height, supine position (Lea 1999) and lying prone (Marshall *et al.* 2003). But considering the vertebral height changes that occur with ageing and the difficulties or inability often reported in measuring standing height in some adults with ID, particularly in later years, the necessity to include a surrogate option for standing height needs to be addressed.

While none of the four alternative measures (ulna length, demi-span, arm length and knee height) commonly used in the general population (e.g. de Mendonca 2000, Weinbrenner *et al.* 2006, Marais *et al.* 2007) has been validated with adults with ID aged 40 years and over, an in-depth review of the validity, reliability and practicality of the measures by Elia (2003) found ulna length to be the most practical measure for people with disabilities and/or with difficulties moving their limbs into correct measurement positions. Its use in clinical or practice settings with people with ID is unknown. However, guidelines targeted at the general population from the National Institute for Health and Clinical Excellence (NICE 2006) in the UK and the Department of Health and Children (DoHC 2009) in Ireland both recommend the use of the Malnutrition Universal Screening Tool (British Association for Parenteral and Enteral Nutrition [BAPEN] 2003), which suggests that ulna length be used as an alternative to standing height, when standing height cannot be measured. In the general population, ulna length was not found to offer any advantages over demi-span or knee height in the accuracy of predictions; all three generally predicted height equally well and significantly better than arm length, which can be affected by joint stiffness (Elia 2003). The Gauld *et al.* (2004) study involving children with disabilities also found ulna length to be accessible in those with severe disabilities, and its landmarks to be readily identifiable in those with muscle weakness and joint deformities. To guide IDS-TILDA, the feasibility, validity and reliability of ulna length as a potential surrogate needs to be tested on a sample of adults with ID aged 40 years and over with varying abilities.

2.4.1.3 Weight

A person's weight is one of the two parameters needed to calculate BMI, yet (as noted in Section 2.4.1.2) obtaining and/or securing this reading has not been possible for some people with ID involved in anthropometry-related studies (Bell & Bhate 1992, Marshall *et al.* 2003, Chapman *et al.* 2005, Fender *et al.* 2007, Melville *et al.* 2008, Wallace & Schluter 2008), as it required them to stand still on a floor scale. In these studies, access to and use of a wheelchair scale was not reported as an alternative option, nor the use of a surrogate BMI measure such as

mid-upper arm circumference (see Section 2.4.1.4). Beyond these studies, others such as Bryan *et al.* (2000) found that 15% of 118 participants could not be weighed due to unavailability of suitable, accessible scales in the community, and van Schrojenstein Lantman-de Valk *et al.* (2000) reported that, for people with severe ID, weight monitoring is more difficult, especially in wheelchair-bound people or people who are less ambulatory. Widening and ensuring access to anthropometry screening among all levels of ID and abilities, where possible, needs to addressed, to ensure data is representative of the total population and those targeted for prevention and treatment are those most in need.

2.4.1.4 Mid-Upper Arm Circumference

Absent from anthropometry studies that measured height and weight in adults with ID was a surrogate option for when either weight and/or height (standing or surrogate height) could not be taken or secured, so that an estimated BMI category could be calculated. In such circumstances in the general practice, the mid-upper arm circumference (MUAC) is often used to estimate BMI category, using the Malnutrition Universal Screening Tool (MUST) discussed earlier (BAPEN 2003), and endorsed by both the NICE (2006) and DoHC (2009) guidelines on nutritional support in adults and preventing malnutrition in acute hospitals, respectively. Broadly, MUAC is a general indicator of BMI. If MUAC is <23.5 cm, BMI is likely to be <20 kg/m^2; if MUAC is >32.0 cm, BMI is likely to be >30 kg/m^2. However, the association between MUAC and BMI, and the validity of MUST for estimating BMI category from MUAC (BAPEN 2003) in people with ID aged 40 years and over has not been reported in the literature, and requires investigation. If MUAC proves feasible, valid and reliable, its inclusion in the IDS-TILDA will ensure that BMI (measured or estimated) data is available (at minimum) on all people with ID.

Interestingly, the combined use of BMI and MUAC has been proposed by some researchers, with suggestions that such a classification might prove better able to discriminate between at-risk individuals and those who are thin but not at risk (James *et al.* 1994). Since MUAC also detects changes in body composition (Burden *et al.* 2005) and "is particularly sensitive to body weight gain or loss" (WHO 1995, p. 345) unlike BMI, which may fail to identify unintentional weight loss (McKinley 2004). MUAC is frequently used in nutritional surveys with older adults in the general population (Burr & Philips 1984, Finch *et al.* 1998, Rahman *et al.* 1998, Corish & Kennedy 2003) and in some of the longitudinal studies on ageing (e.g. Pelaez *et al.* 2000, Miller *et al.* 2002, Visser 2006, Enoki *et al.* 2007). Given the known limitations of BMI and risk of underweight increasing as the population ages, the inclusion of MUAC in the IDS-TILDA anthropometry module for all persons with ID, and not only as a surrogate for measured BMI

when required, may prove very valuable. For example, as people age, redistribution of adipose tissue mass and the relative decline of skeletal muscle can occur even when there are no significant changes in BMI (Ding *et al.* 2007), but such changes may be detected with MUAC.

The use of MUAC is absent from ID anthropometry research with adults with ID. Although in one study, Moore *et al.* (2004) used the words 'upper arm circumference' and 'forearm circumference' interchangeably in their paper, they are different measurements. Upon closer inspection, it appeared that the forearm circumference, and not the upper arm circumference, was measured, as the generalised regression equation developed by Kelly and Rimmer (1987) to calculate the percent of body fat in males was used by Moore *et al.* In the future, the use of MUAC in IDS-TILDA has the potential to determine whether people with ID falling below specific MUAC cut-off points have elevated morbidity or mortality, and whether age-specific cut-off points are required, due to the redistribution of subcutaneous fat towards central areas of the body during ageing. But first, we must examine the measure itself, and the validity and reliability of MUST to guide its future use in the IDS-TILDA study.

2.4.1.5 Waist and Hip Circumference

Waist circumference (WC) is a convenient measurement of abdominal adipose tissue (Ross *et al.* 1992, Pouliot *et al.* 1994, Han *et al.* 1995) that is unrelated to height (Han *et al.* 1997), and correlates closely with BMI (Lean *et al.* 1995) and total body fat (Lean *et al.* 1996). It is a strong independent predictor of obesity-related morbidity (e.g. diabetes, hypertension, heart disease) (Janssen *et al.* 2004, Yusuf *et al.* 2005) and mortality risk (Bigaard *et al.* 2003, Ross *et al.* 2008). Although WC and BMI are interrelated, it is now firmly acknowledged that WC increases health risk beyond that explained by BMI alone (Janssen *et al.* 2002b, Ardern *et al.* 2003, Karter *et al.* 2005). WC measurement is particularly useful in people whose BMI is categorized between 18.5kg/m^2 and 34.9kg/m^2; however, over 35.0kg/m^2, WC has little added predictive power of disease risk beyond BMI (Bray & Bouchard 2003). Over the years there has been much debate over which indicator - waist circumference or waist-hip-ratio (WHR) - is the best predictor of health risk, as many of the research findings have been mixed. For example, Price *et al.* (2006) found WHR to be a more efficient predictor of mortality in older people than WC or BMI. In contrast, Woo *et al.* (2002) reported that WHR is not a useful measure in predicting health outcomes in the elderly. Across different population groups, age, gender and disease status, the evidence continues to be mixed.

Although WC alone is reported to be more powerful in predicting future health in longitudinal studies (Chan *et al.* 1994), research has shown that hip circumference (HC) has a relation to health and disease, but in an inverse way, such that a relatively large HC is associated with lower risks of diabetes and coronary heart disease (Han *et al.* 2006). Increasing evidence is also demonstrating separate and opposite associations of WC and HC with lifestyle and cardiovascular disease risk factors (Han *et al.* 1998, Seidell *et al.* 2001). Given that waist and hip circumferences reflect different aspects of body composition (Seidell *et al.* 2001); there is value in obtaining an insight into these circumferences separately, particularly in longitudinal research, as the use of WHR alone may not detect small but significant changes over time. WC is reported to be less vulnerable to measurement and calculation errors (Dobbelsteyn *et al.* 2001) in comparison to WHR. While the inclusion of WC and HC measurements is not as widespread in ID research compared to the generic literature, they are gaining ground, particularly WC (Kelly *et al.* 1986, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Braunschweig *et al.* 2004, Moore *et al.* 2004, Merriman *et al.* 2005, Fender *et al.* 2007, Stanish & Draheim 2007). Further research is needed to determine the usefulness of both measurements in predicting future health risks and/or protective factors as people with ID age, but first the methodology of WC needs to be examined more closely.

2.4.1.5.1 WC Measuring Site, Over Clothing or Bare Skin and Clothing Effect

Currently, no consensus exists on the optimal protocol for WC measurement in either research or practice, and no scientific rationale is provided for any of the measurement protocols recommended by leading health authorities such as the World Health Organization or the National Institutes of Health in the United States (Ross *et al.* 2008). As a result, WC has been measured in a variety of ways, both in the generic and ID literature. An in-depth review by Wang *et al.* (2003) on the differences between the four main landmark sites[7] commonly used in research, found that WC measured immediately above the iliac crest has a higher correlation with total body fat than the WC values measured at the other three measurement sites. Given the different sites used in ID research, midpoint (Braunschweig *et al.* 2004, Merriman *et al.* 2005 [not clearly specified]), level of iliac crest and anteriorly at the umbilicus (Kelly *et al.* 1986, Moore *et al.* 2004), umbilicus (Carmeli *et al.* 2003) and in a few cases unspecified (Cotuguna & Vickery 2003, Fender *et al.* 2007, Stanish & Draheim 2007), to help ensure practicality and reliability, use of a single bony landmark site (i.e. iliac crest) would minimise the risk of measurement error within and between observers repeating measurements over time in the

[7] (1) Immediately below the lowest rib, (2) at the narrowest waist, (3) the midpoint between the lowest rib and iliac crest, and (4) immediately above the iliac crest

IDS-TILDA, as opposed to the midpoint site selected by TILDA, which requires the identification of the midpoint between two landmark sites. Ross *et al.* (2008) found no substantial influence on the association between WC measurement sites and morbidity or mortality. The iliac crest landmark site is widely used in surveys and health programmes, including the NHANES survey in the United States (2007), the *SLÁN* survey in Ireland (Morgan *et al.* 2008), and Special Olympics International (2007). Current Canadian clinical practice guidelines (Lau *et al.* 2007) and the National Institutes of Health (NIH 1998) in the US also recommend measuring WC at the top of the iliac crest. The identification of one reference point may also support the participation of all eligible participants with ID, compared to the three reference points needed for the midpoint site. For example, Merriman *et al.* (2005) reported that not all participants agreed to have waist measurements (midpoint site), which may have been in part due to steps required and/or anxieties or concerns about the measure itself; no preparation, aside from the group meeting (staff and participants) at the consent stage, was reported as having taken place.

Although, different WC measurement procedures, anatomical landmarks and cut-off points are widely reported in the literature, two striking gaps to emerge from the review of the ID literature on this parameter were: specification of whether WC was taken on bare skin or over clothing (Kelly *et al.* 1986, Carmeli *et al.* 2003, Cotuguna & Vickery 2003, Moore *et al.* 2004, Braunschweig *et al.* 2004, Merriman *et al.* 2005, Fender *et al.* 2007, Stanish & Draheim 2007), and if over clothing, the effect of clothing on the measurement. In the general population, the 'clothing effect' has only been investigated in children and is reported to be 0.5cm (McCarthy *et al.* 2003), and needs to be investigated with an adult population. As the WC measurement may in some cases be taken over a single layer of light clothing in IDS-TILDA, verification of the clothing effect in adults is of paramount importance, and specification of the WC measurement conditions in the methodology, data collection and reporting is critical in ID research.

2.4.1.6 Self/Proxy Reported Height & Weight Values

The 'self-report' height and weights of adults with ID is most commonly reported by health workers/guardians, and/or the values were taken from medical records (Fujiura *et al.* 1997, Rubin *et al.* 1998, Robertson *et al.* 2000, Janicki *et al.* 2002, Hove 2004 [or measured, if records were not available], Emerson 2005, Moran *et al.* 2005, Yen *et al.* 2005, McGuire *et al.* 2007, Henderson *et al.* 2007); fewer surveys involved combined efforts of the participant and health worker/guardian (Barr *et al.* 1999, Aldridge *et al.* 2000, Yamaki 2005, Lennox *et al.* 2006). In the general population, the accuracy of BMI derived from self-reported height and weight has been questioned on the basis that individuals generally tend to overestimate their height and to

underestimate their weight (John *et al.* 2006, Gorber *et al.* 2007). While there have been no studies investigating the difference between measured and self/proxy-reported values with older people with ID, many studies of the general population have reported systematic errors in self-reported BMI in both adults and the elderly (Roberts 1995, Hill & Roberts 1998, Gunnell *et al.* 2000, Kuczmarski *et al.* 2001, MacLellan *et al.* 2004, John *et al.* 2006) or raised concerns about the accuracy (e.g. Flood *et al.* 2000, Basterra-Gortari *et al.* 2007) of self-reported values. It has been noted that under-reporting of weight and over-reporting of height may increase with age, resulting in underestimated BMI scores (Kuczmarski *et al.* 2001). Research on the differences between measured and reported values in older people with ID is required given the wide application of self/proxy reported height and weight values in ID research, particularly as inaccurate estimates can lead to wide discrepancies in BMI classifications. As BMI is reported not to be sensitive enough to recognise small yet clinical significant weight losses (Shatenstein *et al.* 2001, Cook *et al.* 2005), the monitoring and reporting of weight as continuous variables may also prove very useful, if self-reported values are used in IDS-TILDA over time.

2.5 Phase 3: Methodological Factors – Measured Anthropometry

The assertion by Steinfeld *et al.* (2002) that "anthropometry is, at first glance, a relatively simple scientific endeavour. However, when it is better understood, like all science, it has many complexities" (p. 11-12), captures the essence of the key learning gained from the review of the ID literature on measured anthropometry. Although several of the key methodological learnings have been discussed in the previous section, equally important factors are presented below.

2.5.1 Research Tool on Anthropometry Assessment

The literature search failed to find any research or practice tool to guide the assessment of measured anthropometry in adults with ID, the selection of baseline measurements, and the key considerations needed to conduct such measurements, aside from the standard ethical principles that apply to all research (e.g. ethical approval, recruitment, consent). As no common starting-point exists for researchers, particularly for novices conducting research in this field, this gap urgently needs to be addressed to avoid some of the limitations of previous research.

2.5.2 Reference Methods for Measured Anthropometry (Standardised Procedures)

Although "standardised anthropometric techniques", such as those of the World Health Organization (WHO 1995) or Lohman *et al.* (1988), "are necessary for comparisons between clinical and research studies", and "those interested in using anthropometry equipment and methods should consult these resources" (Duren *et al.* 2008, p. 1,140), the review of the

anthropometry-related studies in the ID literature found only two studies that implied the use of a reference method for conducting one (Merriman *et al.* 2005) or all of its measurements (Rimmer *et al.* 1995) that are of interest to this study (e.g. skinfold measurements were excluded from the review). Uniquely, one study (Lea 1999) detailed the protocol applied in an appendix at the end of the research editorial; another reported that standard methods were used, but no details were provided (Carmeli *et al.* 2003). The remaining studies provided limited and variant details of the procedures followed (Kelly *et al.* 1986, Bell & Bhate 1992, Frey & Rimmer 1995, Prasher 1995, Lea 1999, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Harris *et al.* 2003, Marshall *et al.* 2003, Braunschweig *et al.* 2004, Moore *et al.* 2004, Melville *et al.* 2005, Draheim *et al.* 2007, Stanish & Draheim 2007, Bhaumik *et al.* 2008, Melville *et al.* 2008). Another study (Starr & Marsden 2008) referenced a different study (Fender *et al.* 2007) for details of the anthropometry measures and related methods employed, but, on review, this study did not specify the methodological details applied or any related reference methods, protocol or guide used. The fact that most studies set their own standards, often providing limited detail, makes replication and comparisons difficult. The use of generic reference methods (e.g. WHO 1995, Lohman *et al.* 1988) with this population group needs to be tested further. Of note, the lack of standardisation is not unique to ID; similar findings are found in the literature due to the multiple anthropometric traditions (Norton & Olds 1996, ISAK 2001). For example, in the ageing studies, TILDA, ELSA and HRS, each has set their own anthropometry standards, and while there are similarities, there are also unique differences.

2.5.3 Validity and Reliability of Anthropometric Measurements

High levels of error can render statistical comparisons invalid, and errors can artificially inflate the variance associated with a particular measurement (Bailey & Byrnes 1990, Goto & Mascie-Taylor 2007). Due to the sparse methodological details in many studies, it is unclear what criteria were used to determine if measurement readings were valid or not. Similarly, despite the risks of imprecision, only one study involving children with ID was found to statistically examine the precision of performing anthropometric measurements in people with ID (Stevenson *et al.* 2006). Two other studies measured reliability, one in a sub-sample of 44 subjects (Kelly *et al.* 1986) and the other with 30 subjects (Rimmer *et al.* 1995) to determine reliability, but reliability was not assessed in the full sample in either study and/or reported for each measurement. Review of the use of duplicate measurements found that only one study reported taking duplicates of all the anthropometric parameters tested (Stanish & Draheim 2007), while another reported the mean for each circumference but not for height or weight

measures (Kelly *et al.* 1986). Again, the reliability of the readings was not reported in either study. In comparison to the generic literature, this finding on 'reliability' was not uncommon.

A lack of uniformity in the methods employed in collecting reliability data has also been noted (WHO MGRS 2006), even though it has been suggested that since 1990 more studies are reporting measurement error values, where previously it was seen as unfashionable to do so (Ulijaszek & Kerr 1999). However, without data on levels of measurement error and the use of comparable reporting methods in ID research, particularly in studies with two or more data-collection time-points, how can we be sure that findings of variance show a true difference and are not the result of a measurement error (e.g. from the tester, equipment, measurement conditions, standards)? Failure to report the validity, reliability and precision of measured values has implications for interpreting the conclusions and for the overall quality of the study. A finding of no statistical significant difference or relationship in a study might just mean that the error was too large for the difference to be detected. Moving forward, it is imperative that standardised measurement procedures be developed and reported, and that the validity and reliability of readings be determined in order to increase the certainty of inferences about similarities and/or differences within and between population groups. Knowledge of the error margin expressed by means of the Technical Error of Measurement (TEM) (and %TEM) would give an accuracy index of the readings and represent the measurement quality and control dimensions (Perini *et al.* 2005). Given the importance of valid and reliable data and the implications for the decision made or the direction, it is critical that both concepts be explored in further detail in this population group. On consideration of the high risk of errors associated with anthropometry and lack of duplicate measurements reported, one might expect training to have featured strongly in the methodologies of such studies, but many of those reviewed did not report undertaking any specific training in order to standardise techniques.

2.5.4 Anthropometry Training

Many of the studies reviewed did not report the completion of training as part of their methodology, which in itself makes it difficult to assess the quality of data collected (Kelly *et al.* 1986, Bell & Bhate 1992, Frey & Rimmer 1995, Prasher 1995, Lea 1999, Carmeli *et al.* 2003, Harris *et al.* 2003, Marshall *et al.* 2003, Braunschweig *et al.* 2004, Moore *et al.* 2004, Chapman *et al.* 2005, Melville *et al.* 2005, Draheim *et al.* 2007, Fender *et al.* 2007, Stanish & Draheim 2007, Bhaumik *et al.* 2008, Melville *et al.* 2008, Starr & Marsden 2008). Of the few that made references to the completion of 'training' or measurements being conducted by 'trained' personnel in the literature (Frey & Rimmer 1995, Rimmer *et al.* 1995, Cotugna & Vickery 2003),

there were some limitations noted: the main limitation across the studies was the lack of detail reported; in particular, what training entailed, what constitutes being 'trained', the methods used, how training was assessed, and the knowledge, skills and expertise of trainers.

Another limitation observed in the literature relates to the details (or lack thereof) reported on the persons conducting the measurements. In some studies, it was unclear who conducted all of the anthropometric measurements specified (Frey & Rimmer 1995, Stanish & Draheim 2007). For example, in Frey & Rimmer (1995, p. 1,440), it was stated that "skinfolds were taken by two trained investigators" but no reference was made to who assessed height and weight, or what training had been completed by the investigators. In other studies, the methodological section did not specify who conducted the measurements, but it is assumed to be the authors (Prasher 1995, Braunschweig *et al.* 2004, Moore *et al.* 2004, Draheim *et al.* 2007, Starr & Marsden 2008). Lastly, it was noted that, among some of the studies that did not specify any training, the background of the data collector was given, which was frequently a healthcare professional (Lea 1999, Carmeli *et al.* 2003, Marshall *et al.* 2003, Chapman *et al.* 2005, Merriman *et al.* 2005, Fender *et al.* 2007, Bhaumik *et al.* 2008). This may lead one to assume competence in anthropometry assessment based on their professional backgrounds, even though no specific training in anthropometry was reported. Yet, in the general anthropometry literature, Farkas (1996, p. 12) reported that "it is well known that the examiners skills are the most important requirement for the accuracy of measurements". Overall, anthropometry training needs to be explored further.

2.5.5 Measuring Equipment

More often than not, the brands of equipment used to conduct the anthropometry assessment were not specified (e.g. Bell & Bhate 1992, Prasher 1995, Rimmer *et al.* 1995, Barr *et al.* 1999, Lea 1999, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Braunschweig *et al.* 2004, Prasher *et al.* 2004, Melville *et al.* 2005, Fender *et al.* 2007, Draheim *et al.* 2007, Stanish & Draheim 2007, Melville *et al.* 2008, Starr & Marsden 2008), and calibration checks were not reported (e.g. Bell & Bhate 1992, Prasher 1995, Rimmer *et al.* 1995, Barr et *al.* 1999, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Marshall *et al.* 2003, Braunschweig *et al.* 2004, Moore *et al.* 2004, Prasher *et al.* 2004, Fender *et al.* 2007, Draheim *et al.* 2007, Stanish & Draheim 2007, Melville *et al.* 2008, Starr & Marsden 2008). Among those who discussed calibration in their methodologies, mixed details were provided. For example, Merriman *et al.* (2005) just reported that calibrated scales were used but did not provide any further details or any details of the height calibration checks. In contrast, Kelly *et al.* (1986) and Lea (1999) reported that height and weight scales were

checked before data collection commenced, but Kelly *et al.* did not report if the measuring tape had been checked for accuracy. The most frequent checks (before each testing session) were reported by Frey and Rimmer (1995).

Reporting of access to and use of accessible equipment to widen the reach to all participants taking part in anthropometric studies was often absent from the literature. Yet individuals who use mobility aids, such as a wheelchair, walker or stick, may face barriers and be unable to provide anthropometry baseline data as a result of inaccessible equipment. All people with ID should have an equal opportunity to be assessed, where at all possible, and this right should not be denied without reasonable efforts being made to remove any barriers. Access to accessible equipment will benefit all, particularly in an ageing society. For example, people with ID should not have to be excluded from height and/or weight measurements because there is a lack of chair scales or other alternative (e.g. Fender *et al.* 2007, Wallace & Schluter 2008), because they are unable to stand, or due to contractures (Melville *et al.* 2008), unless all other options have failed. Several studies of people with disabilities have identified inaccessible medical equipment, such as scales that cannot accommodate a wheelchair, as a major barrier to health services (e.g. Premo *et al.* 2002, Scheer *et al.* 2003, Drainoni *et al.* 2006, Kroll *et al.* 2006). The role of equipment – in ensuring that the measurement reading is valid, and the types selected to increase accessibility for all persons with ID – needs to be examined further.

2.5.6 Use of Accessible Materials for Anthropometry Measurements

Strikingly absent from the literature on anthropometric measurements with adults with ID was any reference to the use of accessible materials on the measurement process. Given the measurement non-cooperation by some people with ID reported in some studies (e.g. Bell & Bhate 1992, Marshall *et al.* 2003, Wallace & Schluter 2008) and the general screening barriers documented in the literature that may exist for some of this population group, it was expected that standardised accessible materials would have been developed on this routine but important health screening test. Some of the general screening barriers reported include: anxiety, fear and reluctance to be examined, difficulty complying with instructions, lack of understanding of the screening test (Lennox *et al.* 1997a, Sullivan *et al.* 2004), behavioural problems (Lennox *et al.* 1997a, Aspray *et al.* 1998), language and communication difficulties (Lennox *et al.* 1997a, Iacono & Davis 2003) and lack of accessible information (Cumella & Martin 2004). A lack of adequate consultation time (Lennox *et al.* 2007b) was also reported as a barrier in health screening.

It has been reported (Barr *et al.* 1999) that many people with ID feel uncomfortable because of unfamiliarity with physical examination and various screening procedures, such as weight measurement, and some may need to be prepared for the consultation through progressive familiarisation with the setting and the removal of cues associated with previous negative experiences (Hogg 2001). The development of accessible materials and the exploration of familiarisation in anthropometry assessment with people with ID need to be examined further; together these actions may work towards reducing the anxieties and concerns that some people with ID may have, and build on and improve the measurement experience for all people with ID.

2.6 Conclusion

This chapter has reviewed the literature on anthropometry parameters. Based on international evidence, the prevalence of overweight and obesity in people with ID appears to be rising, similarly to the general population. Paradoxically, as people with ID age, the risk of under-nutrition may also increase. Currently, there is no epidemiological data on the weight status on people with ID in Ireland. This gap urgently needs to be addressed. While the international research completed in this area is of great importance and value, we need to ensure closer harmonisation of the methodologies employed to conduct anthropometric measurements, so that studies are independently robust but also allow comparisons to be made within and between population groups. Research is urgently needed to understand and address the methodological issues identified in this chapter. Before designing the methodology for this study, some of the key areas that require further attention and discussion with researchers and clinicians are: surrogate measurements, waist circumference (sites, bare skin or over clothing, and the clothing effect), the practice of taking duplicate measurements, equipment used, training, accessible materials, and the experience of undertaking the measurements in practice (see Section 3.5.1.2).

Chapter 3: Methodology

3.1 Introduction

This chapter presents details of the theoretical approach in this research and the methods and procedures used to conduct the study. It shows the design of the study, the sample population and related demographics, the sampling frame, the data-collection procedures, and the methods used to analyse the data. Most of the information presented is framed within the themes of the conceptual framework that guided the study, known as the ADDIE model of instructional development. ADDIE consists of five stages: **A**nalysis, **D**esign, **D**evelopment, **I**mplementation and **E**valuation.

3.1.1 Aim of the Study

The aim of the study was twofold. The primary aim was to determine the feasibility, validity and reliability of performing anthropometric measurements on people with intellectual disability (ID) aged 40 years plus, as part of the pilot study for the national longitudinal study on ageing in people with ID in Ireland (IDS-TILDA). The secondary aim was to develop a research field tool to guide the baseline assessment of anthropometry in adults with ID, inclusive of measurement standards, and an approach that maximises the participants' understanding of the measurement process.

3.1.2 Objectives of the Study

The objectives of the study were to:

1. determine the percentage of participants eligible for each measurement
2. determine the percentage of valid measurements obtained for each measurement
3. assess the intra-examiner reliability, technical error of measurement and intra-class coefficient for each measurement, and determine the reliability of the results
4. determine the correlation between the left ulna length score and measured height
5. evaluate the relationship between the mid-upper arm circumference (MUAC) score and body mass index (BMI) measured score
6. evaluate the difference between measured and self-reported height, weight and BMI
7. determine the correlation between Malnutrition Universal Screening Tool (MUST) estimated height, measured height and self-reported height
8. determine the difference between waist circumference measurements taken over a single layer of clothing and on bare skin

9. assess the suitability of the equipment selected to conduct the measurements
10. evaluate the contribution of familiarisation to anthropometry assessment

3.1.3 Setting the Scene for the Methodology

From the outset, the researcher sought to produce practically relevant knowledge, yet maintain the rigour of good scientific research required in the assessment of anthropometry (physical dimensions of the human body) in people with ID. Fundamentally, the key learning from this study will support and guide the future inclusion of anthropometry assessment within the health assessment module of the national longitudinal study on ageing in people with ID in Ireland, the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Also, the subsequent field tool developed will be of value to all researchers assessing anthropometry parameters in this specific population group.

3.2 Philosophical Approach

The study employed a descriptive cross-sectional survey design, with its main philosophical basis positioned within the positivism paradigm, but with distinctive influences from the post-positivism paradigm. A mixed-methodological approach, using both quantitative and qualitative data-collection methods, was used to produce both fixed anthropometry-related values (inferential statistics) and descriptive information on the measurement instruction and experience. This hybrid approach sought to benefit from the strengths and minimise the weaknesses of each methodological approach (Masadeh 2012). Both the classical measurement theory (Fisher 1950), and the familiarisation theory (Bateson 1966) together with the Cone of Experience model (Dale 1969) were influential in the design of this mixed-methods approach. All of the above components were conceptually framed within the ADDIE (Analysis, Design, Development, Implementation and Evaluation) model (see Section 3.3.1).

3.2.1 Research Paradigm

The concept of *paradigm* was first coined by Thomas Kuhn (1962, 1970), one of the most prominent historians and philosophers of science. The word originates from the Greek word *paradeigma,* which means to represent something or offer it as a model (Knill 1991). Kuhn uses the term to represent the underlying assumptions and intellectual structure on which research and development in a field of inquiry is based (Dills & Romiszowski 1997). Since then there have been many academic definitions, critiques and questions made about this concept and where it fits within the research course of action. Nonetheless, paradigms seek to set the context for a research study by shaping how the issues are examined (based on sets of beliefs, values, and

the nature of knowledge) and what methods are preferred for different investigations (Ford-Gilboe *et al.* 1995). It is widely accepted that quantitative and qualitative research methods involve very different assumptions about how research should be conducted, its view of knowledge, the role of the researcher and subjects in the study, and the causal relationships. The decision on which research paradigm is most appropriate for a research study depends on the research question or problem, while the philosophical assumptions one holds have implications for the research questions one asks (Pesut & Johnson 2008). In social-science research, two of the major philosophical doctrines are positivism and post-positivism. While both are often cast in opposition, post-positivism simply represents a further development of the original concept, as it shares most of the key philosophical assumptions. Elements of both doctrines were applied at different stages of this research study to support the theories and methods employed. As suggested by Blackburn (2005), a paradigm does not impose a rigid or mechanical approach but can be taken more or less creatively and flexibly, which supports the combined use of paradigms in this study.

3.2.1.1 Positivism and Post-Positivism Paradigm

Positivism is predominantly referred to as the philosophy based on scientific methods or scientific ideology, which stems from the rationalistic, empiricist philosophy that originated with Aristotle and was developed by Francis Bacon, John Locke, August Comte, Emmanuel Kant and others (Mertens 2005). It is concerned with uncovering truths and facts conceived in terms of specified correlations and associations among variables (Gephart 1999, Denscombe 2002) through observation, testing and measurement. The primary purposes of the research are to identify underlying causal processes and to produce useful knowledge that can be applied to solving problems (Albarran *et al.* 2006). This approach supported and guided the development of this study, which primarily sought to test and measure anthropometric parameters.

However, the positivistic belief that the "absolute truth of knowledge" (Phillips & Burbules 2000) can be established needs to considered carefully in this study. One cannot be absolutely positive about the claims of knowledge when investigating body measurements using basic indirect methods (non-invasive), such as measuring waist circumference with a measuring tape. While more sophisticated methods, such as DEXA (dual-energy X-ray absorptiometry) scanning, provide the most accurate results, they are not feasible options in large epidemiological field studies, such as the IDS-TILDA study, due to cost and lack of portability. Nonetheless, the knowledge obtained using basic indirect methods is based on value-free, observable facts that correspond with what is being measured, as long as standardised procedures are

operationalised by accredited / trained personnel, and the results are valid and reliable. The researcher, an accredited anthropometrist, strived to produce valid, reliable and unbiased data on the topic under study by following the operational protocol developed, and then transfer what existed in reality (measurement results) to what is known by the researcher (value of the findings).

Whereas positivists separate themselves from the world they study (Healy & Perry 2000), which was appropriate in terms of conducting and analysing the anthropometric measurements in this study, the researcher also adopted the post-positivism position to empower participants as part of the measurement process (e.g. increase their understanding of the measurements, the equipment) and enhance the measurement outcomes. Crossan (2003) has suggested that post-positivistic research produces findings with a focus on meaning and understanding the situation or phenomenon under investigation, which involves the researcher together with those being researched (i.e. as a collaborator rather than an expert, focusing on the process before measurement), and focuses on the in-depth study of a small sample.

Post-positivists work from the assumption that any piece of research is influenced by a number of well-developed theories apart from and as well as the one which is being tested (Cook & Campbell 1979). Notably, this position supports the combined use of the familiarisation theory (interactive learning process, see Section 3.6.2) in tandem with the measurement theory (measurement of anthropometric variables, see Section 3.6.1) in this study, which separately represent influences from the post-positivism and positivism paradigms respectively. Post-positivist approaches are interpretive; this has led to an emphasis on meaning and understanding, seeing the person, experience and knowledge as "multiple relational and not bounded by reason" (Henriques *et al.* 1998, p. xviii). In parts of this study, the researcher assumed "a learning rather than a testing role" (Agar 1988, p. 12), the latter of which was required during the actual measurement of the physical dimensions of the human body. The adoption of the learning role enabled the researcher to identify and assess the causes that may influence the measurement outcomes by careful observation and measurement of the objective reality that existed "out there" in the world (Creswell 2009), such as those witnessed during the measurement visit. The combination and use of the positivism and post-positivism paradigms at different stages of the study provided a richness of understanding from a scientific perspective, but it also provided new insights into the measurement process and experience of using familiarisation procedures and accessible materials with older adults with various levels of intellectual disability. The use of both paradigms complemented the study's mixed-methods

design, which sought to understand the use of generic anthropometric measurements in this specific population more completely and beyond the act of 'measurement' alone. As suggested by Creswell (2005), the mixed-methods approach seeks to gain a better understanding of the research problem.

3.3 Epistemology of the Study

The mixed-methods approach adopted blended two theories, the measurement theory and the familiarisation theory, and one model, the Cone of Experience (see Section 3.6.2 for further details) to achieve the aims and objectives set out. For the most part, particularly in the measurement of the anthropometric parameters, the researcher and the participants were independent of one another (objective research role), but in the evaluation of the responses to the familiarisation steps integrated into the design, the researcher attempted to lessen this distance. Critically, the mode of operation of the study was guided by the development of instructional procedures (operational protocol). The ADDIE model of instructional design was deemed the most suitable framework to guide the instructional development required. A sample of the key tasks in each of the associated ADDIE steps is presented in Table 3.1.

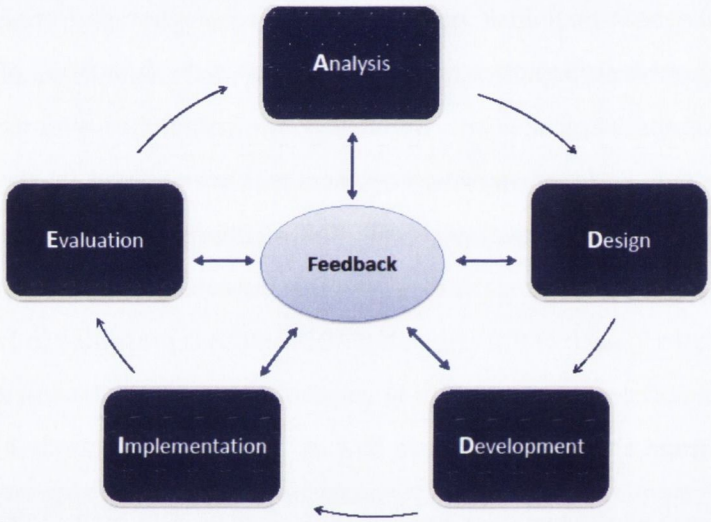
Table 3.1: ADDIE Steps and Sample Tasks

Steps	Sample of the Key Tasks	
Analysis	Carry out needs analysis of topic, target group and environment (context) Identify the gaps and perceived need for instruction Define the problem and determine possible solutions and instructional tasks	Formative Evaluation
Design	Define the learning and performance objectives Plan a strategy for designing the instruction (inclusive of learning domains) Plan the sequence of delivery and assessment criteria	
Development	Develop sample plan and sample selection Develop the inclusion and exclusion criteria Develop the instruction and associated materials	
Implementation	Implement the delivery of the instruction and materials (exploratory test)	
Evaluation	Review the formative evaluation feedback and conduct summative evaluation Assess the overall effectiveness of the instruction and materials developed Identify key learning and future improvement opportunities	

3.3.1 Conceptual Framework

The ADDIE model of instructional systems design (ISD), which incorporates five steps from needs analysis to evaluation, formed the conceptual framework guiding this study. The word ADDIE is an acronym; each letter refers to one of the major processes that comprise the general instructional systems design process known as **A**nalysis, **D**esign, **D**evelopment, **I**mplementation, and **E**valuation. Figure 3.1 shows the sequential steps of the ADDIE model.

Figure 3.1: The ADDIE Model



(Adapted from: Piskurich et al. 2000, p.29)

On review of the original source of the ADDIE model, Molenda (2003, p. 37) stated that the ADDIE is merely a "colloquial term used to describe a systematic approach to instructional development, virtually synonymous with ISD". It seems not to have a single author (Molenda 2003) but its major processes have been widely used and it forms the foundation element of ISD. The wide variety of ISD models described in the literature (e.g. Dick & Carey 1996, Kemp *et al.* 1998), all share the core elements of ADDIE in the development of instructional systems.

In practice, ADDIE provides a practical framework to ensure that the instructional design process does not occur in a random manner and instead follows a systematic approach that proceeds through steps that build on each other with a series of inputs, processes and outputs. Each step therefore depends on the successful completion of the preceding phase. While the ADDIE steps are constant (cyclical process), for the purpose of this study only one cycle of the process was completed. A unique feature of the model is the process of continuous evaluation. It forms part of each of the ADDIE steps, and revisions are made to the instruction design

process where appropriate (see Figure 3.1 – feedback lines). All the feedback from the first four steps of ADDIE is documented (formative evaluation) which feeds into, and forms part of, the final evaluation step of the instructional development process (summative evaluation).

3.4 Exploratory Study Design

Based on the aims and objectives, an exploratory study design was chosen. This design enabled the researcher to (a) test the feasibility of the anthropometric module, including the logistics of the design, and the validity and reliability of the measurement results, and (b) gather critical information about the entire process to help justify the inclusion of the module in the national longitudinal study on ageing in people with intellectual disability (ID) in Ireland (IDS-TILDA). This study was conducted as part of the IDS-TILDA pilot study and with one of the sites involved in the national study.

3.5 Research Methodology and Needs Assessment

The combination of quantitative and qualitative methods in one study, known as a mixed-methods design (Tashakkori & Teddlie 2003), seeks to complement each method, and allow for a more complete analysis of the research problem (Greene *et al.* 1989, Tashakkori & Teddlie 1998). It also provides the opportunity to compare, validate and triangulate results, while providing illustrations of context for trends and the opportunity to examine experiences along with outcomes (Plano Clark 2010). The exclusive use of either quantitative or qualitative methods in this study would not have provided a complete understanding of both the anthropometric measurement results and details of the experience and the contextual factors. Despite the study being of mixed design, the most dominant method used was quantitative.

3.5.1 Anthropometry Needs Assessment

Analysis Stage of ADDIE

Once the study topic, anthropometric measurements, and the target group, people with intellectual disability aged 40 years and over, were confirmed, the first stage of the planning process was the completion of a systematic needs assessment. A needs assessment is "the process of identifying and measuring areas [such as anthropometry] for improvement in a target audience, and determining the methods to achieve improvement" (Coverstone 2009, p. 1). Applying this to the current study, the researcher sought to determine the nature and extent of direct[8] anthropometry use in research and practice, and the procedures and equipment used, and identify the priority of such measures in this age-specific population. The researcher also

[8] Reminder: Use of the term 'direct' in this context refers to measured anthropometric parameters such as height, weight, etc.

sought to identify the gaps between the desired goal of harmonised instructional methods and the current status in research and practice, and then classify the problems and causes, and determine possible solutions and instructional tasks needed to achieve the desired outcomes.

3.5.1.1 Methods Used to Conduct the Needs Assessment

Multiple methods can be employed to collect the data required for analysis. In this study, four methods were used:

(a) a detailed literature review (Chapter 2)
(b) email/telephone exchanges with researchers and clinicians
(c) meetings/focus groups with adults with ID, researchers and clinicians
(d) an onsite visit to a weight-management service

3.5.1.2 Themes of the Key Items Followed Up (Post Literature Review)

Importantly, the central component guiding the focus of inquiry in the last three methods of the needs assessment (i.e. email/telephone, meetings/focus groups, and the onsite visit) was the findings from the literature review undertaken. Both national and international disability and generic literature on anthropometry was examined as well as the grey literature in Ireland. A close examination of the literature was undertaken and the important issues that needed to be reviewed in more detail, or clarified further, due to the limited details provided, were noted. The most appropriate method of follow-up was then chosen for each issue. A breakdown of the types of organisations and personnel consulted, excluding one of the focus groups (with adults with ID, see Section 3.5.1.6), is provided in Sections 3.5.1.3 to 3.5.1.5. Collectively, all the information obtained from the needs assessment assisted with the design and development of the instructional procedures, which sought to address the gaps identified.

The key items to be followed up from the literature review conducted were identified and recorded (n=76). The qualitative responses as recorded for email, telephone and meeting exchanges were combined and coded into categories, as set out in Table 3.2. The items identified reflected outstanding queries, often due to the lack of detail in the articles or publications reviewed, and/or further understanding of the items was sought. During the exchanges, clarifications were provided, perspectives were shared, problems were anticipated and more tailored solutions were identified. This process allowed for more informed decisions

to be made and strengthened the accountability and transparency of the decisions made about the PhD study. The themes of the categories (see Table 3.2) were ordered using the patterns of frequencies recorded (ranked from the most to the least frequent[9]). Insights into the details of the categories listed in Table 3.2 are provided in Appendix 3.

Table 3.2: Themes of the Key Items Followed Up (Post Literature Review)

Themes of the Key Items Followed Up	
Waist circumference (WC) measuring site	Joint Position
WC taken over clothing or on bare skin	
Anthropometric training	
Clothing effect – WC over clothing	
Experience of measurements in practice	
Transfer of knowledge (research to practice)	
Measurements undertaken in practice	Joint Position
Measuring equipment	
Surrogate measurements	
Review of proposed PhD study	
Nutritional status of specified population	Joint Position
One or two measurements of sites	
Accessible materials	

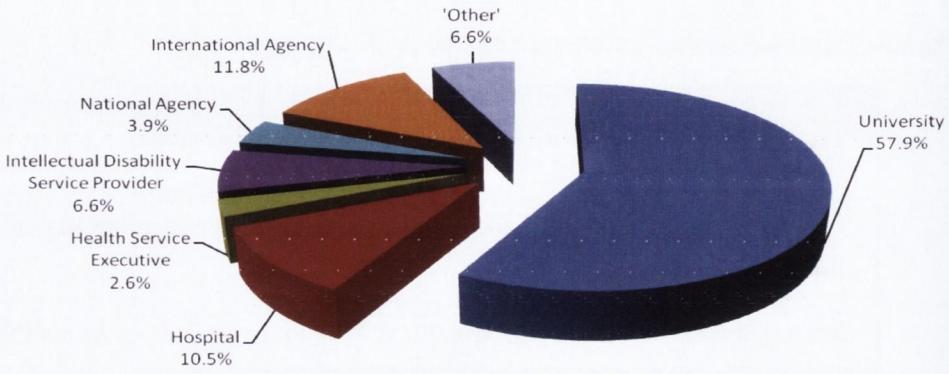
3.5.1.3 Types of Communication, Organisations and Personnel Consulted

A record of all the communications made via email, telephone, the onsite visit, and meetings was kept. A total of 76 communications were recorded, with email representing the main mode of communication used at 91% (*n*=69), followed by telephone (*n*=3) and meetings/focus groups (*n*=3) at 4% each; an onsite visit was the method used least, at 1% (*n*=1). The types of organisations contacted are outlined in Figure 3.2. Universities represented the most frequent type of organisation contacted, at 57.9% (*n*=44), followed by international agencies at 11.8% (*n*=9), hospitals at 10.5% (*n*=8), intellectual disability (ID) service providers at 6.6% (*n*=5), national agencies at 3.9% (*n*=3), 'other' – representing mixed locations (involving a range of

[9] The themes ranked least frequent are no less important than those ranked most frequent. All categories, irrespective of their placement, contribute equally to our overall understanding of the phenomena of interest.

clinicians and researchers at meetings and an equipment company) at 6.6% (*n*=5) and, lastly, the Health Service Executive at 2.6% (*n*=2).

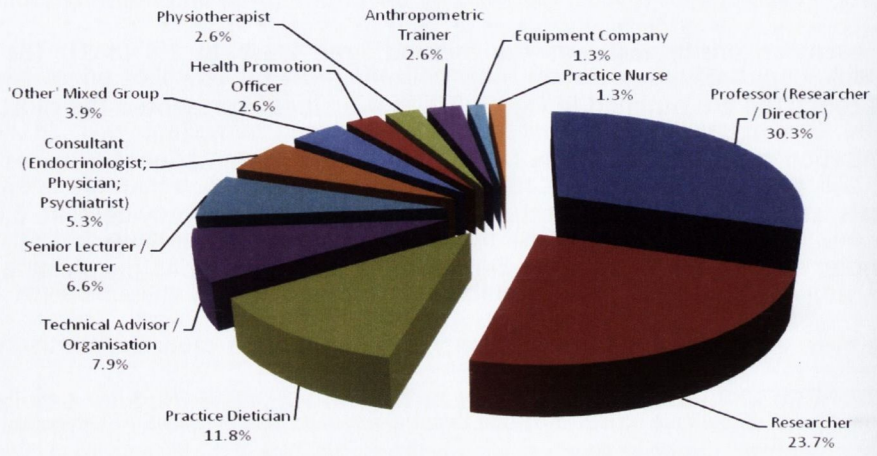
Figure 3.2: Types of Organisations Contacted



3.5.1.4 Backgrounds of Personnel Consulted

The types of personnel contacted varied widely, see Figure 3.3. The majority, 30.3% (*n*=23), of those contacted were professors working in research and/or were directors of departments, such as Human Nutrition. Researchers represented 23.7% (*n*=18), 11.8% were practice dieticians (*n*=9) and 7.9% were technical advisors/organisations (*n*=6). Others less contacted but with no less significance were: lecturers (6.6%; *n*=5), consultants (endocrinologist, physician, psychiatrist) (5.3%; *n*=4), physiotherapists (2.6%; *n*=2), anthropometric trainers (2.6%; *n*=2), health promotion officers (2.6%; *n*=2), an equipment company (1.3%; *n*=1) and a practice nurse (1.3%; *n*=1). Lastly, 3.9% (*n*=3) of the personnel contacted were classified as 'other', which represented a mixed group of clinicians, researchers and a family advocate. The backgrounds of the personnel consulted covered both the ID and non-ID fields.

Figure 3.3: Backgrounds of Personnel Consulted



3.5.1.5 Geographical Locations of Personnel Contacted

The geographical locations of the personnel contacted were classified into seven countries worldwide. Ireland was the main location of those contacted at 57% (n=43), followed by the United States at 16% (n=12), the United Kingdom at 13% (n=10), Canada at 7% (n=5), the Netherlands at 4% (n=3), Denmark at 3% (n=2), and Australia at 1% (n=1).

3.5.1.6 Consultation with Adults with Intellectual Disability

While the researcher did not consult directly with adults with ID for the sole purpose of exploring the topic of anthropometry and its importance or not to them, as part of her role as Project Manager of the IDS-TILDA study she organised two accessible consultation workshops and facilitated one of them with this target group. A total of 17 adults with ID (5 males and 12 females) aged 40 years and over from different types of residential circumstances agreed to take part in the workshops, which lasted approximately one hour. The main purpose of the workshops was to explore what the term 'ageing' means, the positives and the negatives, the challenges, and what is important to them as they get older. While neither of the groups mentioned 'anthropometry' or 'body measurements' during the workshops, both groups did mention the importance of 'diet and eating the right foods' as they get older.

To begin to understand whether this population group are reaching their optimum nutritional health, as highlighted by the target group, there is, first, a need to understand the overall prevalence of underweight, normal range, overweight and obesity in this population. To obtain the prevalence figures, we need to gather anthropometric data, similar to the general population. This information can then be used by professionals and policymakers to highlight areas of concern for intervention to support people with ID to 'eat the right foods' as they get older, with specific attention to areas such as their dietary intake and physical activity levels. Again, while the consultations were not conducted for the sole purpose of this exploratory study, the importance of nutrition was identified, and anthropometry is one of the four methods used in assessing the nutritional status of populations (Gibson 2005). The other three methods are dietary intake, biochemical assessment, and clinical assessment.

3.5.2 Conclusions Drawn from the Needs Analysis

3.5.2.1 Harmonising Instructional Methods and Improving Involvement of Participants

Based on the findings from the literature review and the consultations undertaken, there is a need for closer harmonisation of the methods used to assess direct anthropometry in adults

with ID, while adapting to individual needs, where required. The need for accurate assessment of body composition in epidemiological studies is critical alongside the need to develop alternative methods and techniques that can not only provide accurate and similar information but also be feasible to use in a larger cohort of adults with ID with varying levels of ability. The collection and precision of such measurements play an important role in informing, developing and delivering meaningful information on the nutritional status of this population group. However, both the validity and reliability of the measurements results needs to be specified. An understanding of the measurement experience, including the reasons for attempting but not obtaining measures, non-attempts and refusals, and the use of equipment in practice, is also needed.

Of equal importance is the need to develop and integrate steps as part of the anthropometric procedures developed that will build a foundation of knowledge and understanding of the measurements among adults with ID, as opposed to solely focusing on the act of measurement alone, which in itself has been shown not to be universally standardised. To advance the decision-making process, all the information gathered was collated and key learning from the consultations was analysed using NVivo (see Section 3.12.4.1 for further details on procedures followed) and then compared to the literature review findings. All the data was critically appraised and guided by the two important steps described by Sackett *et al.* (1997): (1) Deciding whether the information is valid (how close to the truth it is?) and (2) Deciding how significant the information is (if it is clinically – or rather, for the purposes of this study, scientifically and practically – important?). In light of the insights gained from the needs analysis and the gaps identified, key measurement decisions were made for this study.

3.5.2.2 Insights Achieved from Consultations Conducted

As reported in the literature (see Section 2.4.1.5.1), there was similarly no universally accepted site for waist circumference (WC) measurement among consultees. Agreement on the 'iliac crest' site for this exploratory study was supported by leading professionals in the measurement field, particularly as it is a bony landmark that can be palpated and located over a single layer of clothing and on bare skin, unlike the other sites. Similarly, there were mixed views and experiences on taking WC measurements on bare skin and/or over-clothing. Ideally, WC measurements should be taken on bare skin but it was recognised that circumstances may require them to be taken over clothing (single layer). However, the effect of clothing on adult measurements has not been examined, nor did consultees mention measuring the thickness of clothing and its influence on the outcome. In terms of anthropometry training, the availability,

attendance, duration and content were very varied. A number reported that those measuring had medical, nursing or nutrition backgrounds, which implies knowledge and skills in this area. There was no standardised training or programme found except for the International Society for the Advancement of Kinanthropometry (ISAK), which mainly trains sports scientists.

Difficulties measuring weight, but more profoundly height, in older adults and people with intellectual disability (ID) were noted. Alternative height measurements, such as demi-span, knee height and ulna length, were used with persons with ID, where needed; in some cases, if neither weight nor height could be measured, mid-upper arm circumference (MUAC) was used. In practice, the Malnutrition Universal Screening Tool (BAPEN 2003) recommends the use of both ulna length and MUAC, as surrogate measurements, if needed. Many encountered difficulties with basic measurements (height and weight) and noted that they take significant time to complete. As a result, several refrained from expanding on the type of measurements conducted beyond height and weight. Against such difficulties, reported engagement with people with ID prior to measurement was cited by only one consultee. No reference was made to the use of accessible materials or strategies employed to engage, educate and empower people prior to and during the measurement process to counteract such difficulties.

Various brands of equipment were used and/or recommended by consultees. Seca was the most dominant brand of weighing scales and portable stadiometers reported, and was equally dominant in the literature. The use of a portable wheelchair scale for those unsteady on their feet and/or are wheelchair-users was recommended and deemed feasible in practice. Lastly, there was no consensus on the use of single or duplicate measurements; the method varied per measurement and consultee, but duplicates were more frequently reported for waist and hip circumference measurements, as documented in the generic and ID literature. The value of anthropometry assessment in this population was supported by researchers/clinicians, and the importance of nutrition as people age was indirectly identified by the adults with ID consulted.

3.5.2.3 Key Measurement Outcome Decisions from Needs Analysis

As noted earlier, based on the triangulation of data sources used to conduct the needs analysis, including the perspectives of those consulted, the following decisions about the measurements to be tested in this exploratory study were made:

- Standing height using a portable stadiometer
- Ulna length as a surrogate for standing height using a segmometer

- Weight using a portable flat scale or a portable wheelchair scale
- Mid-upper arm circumference as surrogate for BMI using a non-flexible tape
- Waist circumference (WC) measured at the iliac crest using a non-flexible tape
- Hip circumference using a non-flexible tape

A key factor in the selection of four of the six measurements (standing height, weight, waist and hip circumference) was the inclusion of these measurements in the pilot study of the Irish Longitudinal Study on Ageing (TILDA) in the general population. If the selected measurements proved feasible with adults with ID, future comparisons between the national ageing studies could be made on these parameters, if the data were collected. The inclusion of a surrogate height and BMI measure for this population group was determined on the basis of the reported difficulties sometimes experienced with measuring height in an older population and with people with ID, and, in some cases, on not being able to measure either height or weight, which are both required to calculate BMI. The feasibility, validity, and reliability of all six measurements selected will be tested in this study.

The clothing effect will also be examined in an adult population and, unlike in other studies that examined this effect with children, the researcher will measure the thickness of the single layer of clothing using a skinfold calliper. To calculate the clothing effect, WC will be measured over clothing and on bare skin with specific eligibility criteria. Similarly each measurement will have its own specific eligibility criteria (see Section 3.7.2.3) and, unlike in other studies, two measurements will be taken, where possible. Critically, all of the measurements will be directed by a detailed operational protocol, inclusive of steps that will gradually familiarise participants with the measurements over time before any are attempted. To support the familiarisation process, accessible materials will be developed and given to participants at different stages of the data collection process. The flow of information released will be sequenced to gradually build awareness and understanding. In terms of training, the internationally recognised ISAK anthropometric training course will be undertaken by the researcher in the United Kingdom and, in Ireland, the researcher will attend TILDA's training for nurses on anthropometric measurements as part of their pilot study on ageing in the general population. Selection of equipment, the stadiometer and the scales was guided by the findings from the literature review and consultation undertaken with researchers/clinicians, while the non-flexible tape and segmometer were selected as both are recommended by ISAK.

3.5.3 Position of the Analysis Stage within the Research Design

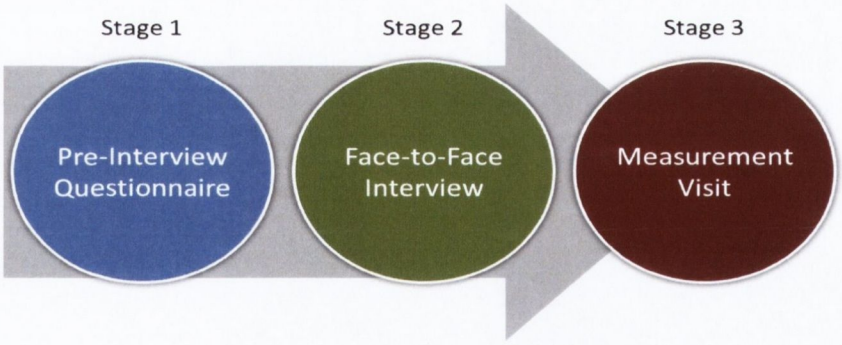
Collectively, the activities of the analysis stage primarily reflected the influences of the post-positivism position. Throughout the needs analysis and the resulting learning process, the outcomes were reviewed and the relevant modifications to the direction of the enquiries were made to strengthen and improve the decisions made by the researcher for this study. Both the literature review and consultations undertaken in effect also ensured content and face validity.

3.6 Designing the Instrument

Design Stage of ADDIE

Based on the findings from the needs analysis conducted, the aims and objectives of this study were determined. The overall feasibility of the study was viewed within the context of three dimensions: applicability, acceptability, and practicality (Andrews *et al.* 1994). The co-ordination of ethical approval and the selection and recruitment of the sample for this exploratory study (measurement visit) were guided by the IDS-TILDA pilot study design, which it was embedded within (Stage 3). Figure 3.4 provides an overview of the sequencing of the data-collection stages of the IDS-TILDA studies[10], which is inclusive of the measurement visit.

Figure 3.4: IDS-TILDA Data Collection Stages



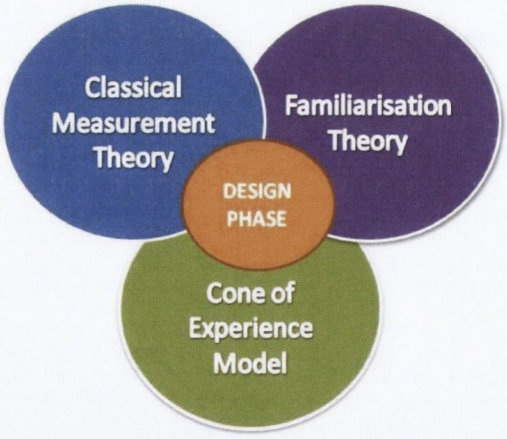
During the design phase of the IDS-TILDA studies, the researcher incorporated all the links necessary between the studies (exploratory study and IDS-TILDA pilot and national study), which included the details of the measurements visit in the university and local site ethics applications, on the consent form, the information booklet, and all the associated materials for families/guardians (e.g. agreement form and information leaflet). Also, as part of the design phase of the interviewers' operational manual, the researcher included the following items for

[10] IDS-TILDA Pilot Study and one site from the National IDS-TILDA Study

expansion: the inclusion and exclusion criteria for the measurement visit; instructions for interviewers on reaffirming participants' consent to participate; key information on the measurements proposed; dealing with queries; and responsibility to link with the researcher regarding the outcome of this related discussion. To standardise and ensure that the key information required was communicated, the researcher identified the need to develop a Measurement Communication Form for interviewers as part of the design phase of this study. This form would be completed by interviewers and returned to the researcher following each interview. A summary of the logistical process and related content for interviewers, and the interchange between the interviewer and the researcher, is given in the development phase of ADDIE (see Section 3.8.3).

For the measurement visit itself, the instructional strategy and associated materials were decided upon and included: a detailed operational protocol; an Anthropometric Measurement Results Workbook; and accessible materials (Appointment Card, Measurement Information Booklet, measurement showcards, and a measurement record card). While the criteria and content of each component was influenced by the findings from the needs analysis, the instructional design process was shaped by two theories and one model (see Figure 3.5).

Figure 3.5: Design Stage: Theories and Model in Anthropometry Assessment



3.6.1 Measurement Theory

Anthropometry, the scientific study of human dimensions, requires well-defined procedures to produce valid and trustworthy estimates of the attributes of concern. Fundamentally, measurement theory and its related concepts, "the directness of measurement, levels of measurement, measurement error, reliability and validity", guide the development and use of

measurement methods (Burns & Grove 2010, p. 328). In practice, the translation of measurement theory principles to behaviours helps to ensure the integrity and relevancy of the measurements and the data that result from them (Krebs 1987). Although there are several measurement theories, the classical measurement theory (Fisher 1950) was deemed the most suitable for this study on the basis of its central tenet, which evolved from the assumption that random error is an element that must be considered in all measurements (Waltz *et al.* 2010). This assumption not only reinforces the importance of developing instructional procedures, such as the operational protocol, but also highlights the importance of gaining an understanding of the measurement conditions and the validity and reliability of the results.

Classical measurement theory assumes that each person has a true score that would be obtained if there were no errors in measurement, but in practice the researcher can never observe the true score, only an observed score. The theory proposes that every observed score composes the true score and an error score. The true score is the value of the attribute possessed by the person being measured and the error score reflects the influence that random error has on the observed score at the time of measurement. The influence of random error (any chance factors that randomly affect measurement) on the observed measurement is called 'error of measurement' (Waltz *et al.* 2010). The nature and magnitude of these "errors have some fairly predictable consequences related to the usefulness and interpretation of the measurements" (e.g. on the reliability of the measured values) (Himes 2009, p. S4).

While systematic measurement errors are those which consistently affect the individual's score because of some particular characteristic of the person or the test that has nothing to do with the construct being measured (Crocker & Algina 1986), or they may relate to error in function; for example, if the measurement equipment was not calibrated to zero. Both biological and technical factors can cause or contribute to error; for example, the posture and movement of participants, the high consumption of fluid and/or food just before the measurement visit, the time of day the measurements are taken (i.e. diurnal effect on height), the application pressure applied or function of the equipment, the palpation skills of the anthropometric technician (i.e. identification of landmarks) and the amount of subcutaneous tissue over the landmark site. Systematic errors, if present, will affect the validity but not the reliability of the findings (Waltz *et al.* 2010), but are potentially predictable (Kane 2010).

These concepts and the findings of the needs analysis were all fundamental to the design of the instructional procedures and processes in this study. In particular, they directed the researcher

to consider and develop methods that would reduce the occurrence or magnitude of random and/or systematic errors arising. The items listed in Table 3.3 formed the blueprint of the measurement procedures for extension in the development phase of ADDIE (see Section 3.8).

Table 3.3: Blueprint of the Measurement Procedures

Key Themes of the Measurement Procedures
Measurement standard (each measurement): Purpose; Eligibility for the measure; Equipment required and set-up guidelines; Preparation required; and Detailed instructions on how to take the measurements
Right-side positioning and personal space of participants
Landmarking sites and avoidance of parallax error
Accepted difference between 1st and 2nd round of measurements
Selection of measuring equipment and quality-control measures
Familiarisation and demonstrations of the measurements
Key checks and briefings to maximise outcomes
Setting up and safety of equipment
Well-being and safety of participants
Eligibility and non-eligibility practice considerations

Similarly, the principles of the classical measurement theory together with the findings of the needs analysis informed the researcher about the broad themes to be covered in the Anthropometric Measurement Results Workbook developed; these are set out in Table 3.4.

Table 3.4: Blueprint of the Anthropometric Measurement Results Workbook

Key Themes of the Anthropometric Measurement Results Workbook
Checklist of the preparation phase
Measurement status: measured, attempted not obtained, not attempted or refused
Record of the measurement result in the units required
Time of measurement, where applicable
Measurement conditions, where applicable (e.g. flooring, positioning)
Validity of measurement and any problems experienced
Reasons for invalid measurements
Reasons for attempts but non-obtainment
Reasons for non-attempts and refusals
Details of any problems with equipment
Any other information related to the measurements

3.6.1.1 Validity and Reliability of Measurement Results

Central to measurement theory were the technical concepts of validity and reliability, both of which the researcher sought to explicitly report as part of the measurement results. While the blueprints (Tables 3.3 and 3.4) identify many of the important related validity and reliability factors for expansion in the development phase of ADDIE, further considerations were noted in more depth by the researcher as part of the design phase. In particular, on the theme 'validity of measurements', the following needs were identified: (1) to understand validity beyond whether or not the reading is valid and (2) to gain an insight into any problems experienced in the administration of the protocol, which may or may not have contributed to the validity status. A breakdown of the categorisation of the validity status theme was identified for the next phase of ADDIE and the development of the Anthropometric Measurement Results Workbook:

- No problems experienced, (a) valid measurement obtained
- Some problems experienced, measurement (b) valid or (c) invalid

For the latter two options (b) and (c), the need to obtain the related details of the experience was noted. Gaining an insight into the experience of problems encountered and the effect on validity was not only deemed critical for the interpretation of the findings, but also was seen as

providing important information for the future training of those conducting measurements with this population group. Central to the development of this theme was the identification of the need for clear definitions on how each validity category is defined within the operational protocol developed. See Section 3.8.9.2 for details on the validity-related items developed.

In terms of reliability, aside from the related themes included in the blueprints, the researcher also included the criteria of repeated measurements in the design of this study to assess the consistency of the results (see Section 3.8.6). However, only the findings of the validity options (a) and (b) would be used to determine the reliability of the results at the analysis stage of the study. The level of accepted difference between the readings was also noted as a key factor to be specified in the development phase of ADDIE. Lastly, to assess the reliability of the results and express the error margin (accuracy and measurement quality and control), the methods, Technical Error of Measurement and Intraclass Correlation were identified as part of the design phase (see Section 3.12.3.2). The selection of these methods was guided by the International Society for the Advancement of Kinanthropometry (ISAK), the training body for anthropometrists, through which the researcher sought to become an international accredited anthropometrist. The securement and successful completion of accredited training was key to maximising the validity and reliability of the study findings (see Section 3.8.4).

3.6.2 Familiarisation Theory

Absent from the needs analysis were details on any universal familiarisation, guidance or motivational strategies used to support people with intellectual disability in the lead-up to and during the anthropometric measurement process. A detailed search of the literature was thus undertaken to source a model to guide the design and development of familiarisation techniques, inclusive of guidance and motivational strategies. The results led to Bateson who developed the familiarisation theory in 1966; it suggested that, as people become familiar with an issue, this reinforces them to endorse a stronger decision due to the general reduction in uncertainty or anxieties about the issue proposed (Saur 1992). The theory was developed and tested on risk-taking and risky shift phenomena. Early tests reported that the shift observed after familiarisation remained quite comparable to the shifts observed after group discussion (Bateson 1966, Flanders & Thistlewaite 1967). However, a few years later consistent failures to replicate this effect (Bell & Jamieson 1970, Teger *et al.* 1970, Stokes 1971) made it hard to back up the theory (Suar 1992). As a result, there is very limited reference in the generic literature to this theory and to its development. The dictionary definition of familiarisation – "to make someone learn or experience something so that they know about it" (Macmillan Dictionary

2009) – shows clear links to Bateson's theory and the experience of becoming familiar with something. In the field of sports performance and strength testing research, the broad application of 'familiarisation' has been reported (e.g. practice trials before testing) and over the years, it has continued to gain ground in this testing field (e.g. Atkinson & Nevill 2001, Ploutz-Synder & Giamis 2001, Dias *et al.* 2005, Sirotic & Coutts 2008).

Despite the limited reference to the theory, its concept has also been successfully applied on an individual basis as opposed to group application in the field of intellectual disability (ID), mainly in studies assessing levels of physical activity and fitness. Lavay *et al.* (1990, p. 285) advocated that "it is critical that persons with *intellectual disability* be familiar with the testing protocol". Examples of studies that have used the familiarisation concept include the testing of physical performance (Lahtinen *et al.* 2007), cardiorespiratory fitness (Schurrer *et al.* 1985, Seidl *et al.* 1987, Cressler *et al.* 1988, Reid *et al.* 1989, Pitetti & Tan 1990, Rintala *et al.* 1995, Fernhall *et al.* 1996, Pitette *et al.* 2001), fitness test training (Andrew *et al.* 1979, Kittredge *et al.* 1994), graded exercise testing (Fernhall & Tymeson 1987), strenuous exercise (Maksud & Hamilton 1974), physical activity assessment (Temple & Walkley 2003) and fitness testing (Pitetti *et al.* 1988, Rimmer *et al.* 2004), and a travel training project called Transport Pathfinder Scheme in the United Kingdom (UK) (Department for Education and Skills UK 2004). Essentially, the familiarisation procedures were developed to assist subjects with maintaining adherence to a set cadence, procedures or the motivation necessary to produce a maximal effort (Rintala *et al.* 1995) and maximise the validity and reliability of the results. Central to the familiarisation was the importance of the subjects having a thorough understanding of the test requirements to not only improve the validity and reliability of the findings (Seidl *et al.* 1987, Lavay *et al.* 1990) but also its significance for informed consent (Reid *et al.* 1989, Pitetti *et al.* 1993, Reid *et al.* 1993, Rintala *et al.* 1995) before and during the research process.

While generic familiarisation protocols are lacking, the use of strategies to familiarise subjects, such as practice sessions, is captured by Rintala *et al.* (1995) who studied people with intellectual disability and cardiorespiratory fitness. Rintala *et al.* reported that they allows both (a) the person being measured to become familiar with the protocol, the environment (if not familiar), the safety measures and the researcher performing the measurements; and (b) the researcher to adjust the protocol to ensure the safety of the person and validity of the measurement results. Three of the four types of guidance described by Carnell *et al.* (2002) were used to support the delivery of familiarisation activities (and help the learning process): verbal guidance, visual guidance, and manual guidance (as required). Mechanical guidance,

which "makes use of an object or piece of apparatus to shape the skill", was not used (Carnell *et al.* 2002, p. 157). Harris (2006) has suggested that instructions may need to be continuously reinforced and modified for purposes of comprehension, and mastery of the protocol is necessary to ensure high motivation to put forth a maximal effort. Interestingly, while much of the attention is focused on the lead-up to a test/activity, Reid *et al.* (1989) noted that the familiarisation process is divided into two parts: the familiarisation before, as indicated in the example above, and the familiarisation after testing, which involves explaining what the results mean and providing any further information necessary to the subject, such as a copy of their measurement results.

The inclusion of the familiarisation concept in the design of this study reflected the researcher's wish to use different methods to inform, educate and empower participants to make informed choices about the measurements, maximise their execution of measurements undertaken, and gain an understanding and sense of ownership over the knowledge being created. This would mean collectively forming an educative experience for the participant and the researcher, resembling concepts of the participatory research paradigm, and leading the researcher to adopt the role of a facilitator to support the development of a mutual sharing of knowledge and skills with participants (Lloyd *et al.* 1996). This is not to deny that an expert/lay-person relationship between the researcher and participant does not exist, but rather that such a position can be reworked into a more favourable, emancipatory position (Kitchin 2002) in the lead-up to and after the actual measurements. However, the key challenge for the researcher is to balance the perceived simplicity of the measurements with the attention to detail needed on the procedures to obtain maximum rigour and performance on each measure, where possible. This is reflected in the statement by Agni Celeste that "the most complex things are the simplest" (Quotations Book 2012, p. 2).

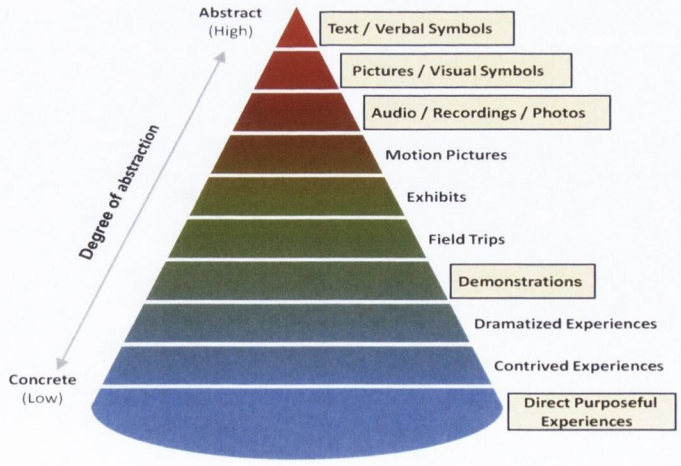
In order to build the participants' familiarisation with the measurements proposed, the researcher decided to impart small amounts of visual and text information about the measurements and the associated visit at each of the interaction stages of the research process (see Figure 3.6). Throughout the design phase, the researcher also frequently considered the famous quote commonly attributed to Benjamin Franklin and the Confucian Philosopher, Xunzi: "Tell me and I forget, teach me and I may remember, involve me and I learn".

Figure 3.6: Interaction Stages of the Research Process



It was the researcher's belief that repeated exposure to small amounts of information would lead to participants becoming more familiar with the measurements over time and less anxious about what they had to do as part of the visit. To frame the types of learning methods that would be used to deliver the instructional materials and procedures to be developed, the researcher referred to Edgar Dale's Cone of Experience (Dale 1969); see Figure 3.7. The Cone of Experience was developed by Dale in 1946 as a way to describe various learning experiences. The cone essentially depicts methods from the most concrete (e.g. direct experience at the bottom) to the most abstract (e.g. text at the top). Dale believed that any or all of the methods could be used, depending on the needs of the learner, and stressed that it was important to "not mistake the Cone device for an exact rank-order of learning processes" (Dale 1969, p. 128). Notably, only one of the methods requires literacy, which widens the reach and accessibility for all participants.

Figure 3.7: Dale's Cone of Experience



(Adapted from Dale 1969)

The blueprint of the sequence of delivery, the types of methods, instructional materials and procedures and the types of guidance selected to build the participants' familiarisation with the

measurements and the visit itself are outlined in Table 3.5. The methods selected are also shown in Figure 3.7. The development of the associated materials and procedures required is outlined in the next stage of ADDIE (see Section 3.8).

Table 3.5: Blueprint of the Methods, Instructional Materials/Procedures and Guidance

Stages	Type of Methods	Instructional Materials / Procedures	Type of Guidance
Recruitment	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo	• Consent form* • Information booklet* • Guardian agreement form & leaflet	• Text • Visual
Interview	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo	• Briefing by interviewers • Measurement Information Booklet*	• Verbal • Text • Visual
Appointment	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo	• Key reminders via telephone • Appointment card with reminders*	• Verbal • Text • Visual
Measurement	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo • Demonstrations • Direct Experience	• Researchers ID • Ice-breaker dialogue • Briefings by the researcher • Measurement showcards* • Demonstrations • Get to know the equipment • Practice option • Conduct measurements • Record the results on a record card* • Explain key learning (debriefing)	• Verbal • Text • Visual • Manual

*= Accessible text and illustrations

3.6.3 Key Influential Factors in Design Phase

As part of the design process, five important factors were identified as having the potential to influence (independently, collectively, or in any combination) the successful implementation of the operational protocol developed: communication access, environmental, structural and attitudinal barriers, and time pressure. Each factor was addressed as part of the development stage of ADDIE within the context presented below, but all five factors are inextricably linked.

3.6.3.1 Communication Access

Effective communication with participants is a key methodological concern, particularly for the successful application of the familiarisation and measurement procedures developed. Communication in the broadest sense means:

> *"... any act by which one person gives to or receives from another person, information about the person's needs, desires, perceptions, knowledge, or affective states. Communication may involve conventional or unconventional signals, may take linguistics or non-linguistic forms and may occur through spoken or other modes." (National Joint Committee for the Communication Needs of Persons with Severe Disabilities 1992, p. 2).*

Communication access relates to its application, and developing communication that is clear, comfortable and easy to understand and interact with, regardless of your preferred style of communication (Swain *et al.* 2004). It covers communication in spoken and written form that is face to face or remote (Swain *et al.* 2004), and requires the researcher (both in their role as a sender and receiver in the communication process) to be adaptive, flexible and innovative.

It was clearly important for the researcher to develop accessible materials (written and visual) and to use accessible language to enrich the lines of communication between the participant and the researcher. The need to closely observe, respect and respond to verbal and non-verbal cues by participants was also deemed critically important. To maximise verbal and non-verbal communications with participants and reduce any potential barriers that might impact on the experience, the integration of brief guidelines to promote optimal communications with participants into the operational protocol for the measurement visit and among interviewers, as part of their role in the research process, was identified as a necessary part of this design phase; for example, checking if any assistive aids are needed, such as glasses and/or hearing aid. It was fundamentally recognised that 'accessing' is not just about reaching the other person, but about "doing sensitive things to make ourselves available to access from the person with intellectual disability" (Seale & Nind 2010, p. 9). It is also about consulting with and actively involving people with disabilities in matters relating to them, as supported by Article 4.3 of the United Convention on the Rights of People with Disabilities (UN General Assembly 2006). Applied to the design of this study, the involvement of people with ID in the review of the accessible materials developed before the implementation of the study was identified to ensure that all related materials are presented in a style and format that would be understood.

Lastly, to assist with the preparations for the measurement visit (e.g. booking the appointment) and the initial introductions with the participant, the researcher identified key themes for questions to be developed and included as part of the Measurement Communication Form for interviewers. The information obtained would provide the researcher with the key details required on the communication status of each participant and proxy present at the interview, where applicable, before making contact and undertaking the visit. If proxies were present, this

information would help the researcher to maintain the continuity of support (i.e. by having a named contact) where applicable (e.g. to support the staged release of measurement information to participants and/or be present or available if needed, with the participants' agreement). The themes of the questions to be developed were:

- Interview date and the person with whom you made the appointment
- Type of interview and main respondent (participant, participant and proxy, or proxy)
- Name of the proxy present and relationship to the participant, if applicable
- Methods of communication used by the participant during the interview, if applicable

3.6.3.2 Environmental Barriers

Environmental conditions, such as excessive background noise, movement of others in close proximity, poor lighting, ventilation or room layout (e.g. furniture set-up), are all factors that may impact on the measurement visit and were considered as part of the design phase of this study. As the location for the visit is selected by participants, an awareness of environmental barriers and the impact they may have on communication access, levels of concentration and motivation, and conditions for the actual measurement was deemed to be critical. It was considered necessary to reduce the risk and/or magnitude of any potential environmental barriers affecting the experience, and to integrate brief guidelines on promoting optimal measurement conditions as part of the operational protocol developed. Also, to prepare for the visit and any adjustments that might be required, key themes for questions to be developed and included in the Measurement Communication Form were identified.

The key themes were:

- Presence of Diabetes, Osteoporosis, Varicose Ulcers, Chronic Constipation, Multiple Sclerosis, Cerebral Palsy, Scoliosis, Muscular Dystrophy, Spina Bifida and/or Oedema
- Wheelchair usage, if applicable (e.g. uses a wheelchair or does not use a wheelchair)
- Level of steadiness walking and standing reported, and self-rated eyesight reported
- Participant's availability and preferred place/time to have the measurements taken
- Car parking facilities available close to the participant's house (and/or day centre) and whether the entrance is flat or has steps (e.g. for moving equipment into the house)

3.6.3.3 Structural Barriers

The success of implementing the familiarisation procedures in this study would depend to some extent on participants receiving the accessible materials issued. If they were not present at the interview and/or did not live independently or receive post directly, there would be an unintentional risk that the materials issued might not be passed on to the participant as intended. To reduce the risk of this structural barrier occurring, the need to develop instructions on the importance of participants receiving the materials issued as part of the design of the interviewer and researcher operational protocols developed was identified.

3.6.3.4 Attitudinal Barriers

Individual and third-party (family member/support worker) attitudes might greatly affect how the participant experiences the measurement visit. Reducing any potential negative attitudes of and/or towards the participants and their ability in terms of capacity to understand the procedures and/or ability to take part were key factors considered by the researcher during the design phase. Although the use of the familiarisation procedures seeks to reduce the risk of any potential attitudinal barriers by improving knowledge of the measurement process, the quality of support acts, such as support workers, the interviewer and/or the researcher, could influence the personal attitudes and motivation of people with intellectual disability (Flynn *et al.* 2002, Seale & Nind 2010) towards the measurement visit or the measurements. To reduce the risk of attitudinal barriers occurring, the researcher identified the need to develop and integrate brief guidelines on supporting the participant in exercising their right to decide if they wished to participate in all, some, or no part of the measurement visit, within the operational protocol and the instructions for interviewers. More specifically, the following items were also identified for inclusion in the operational protocol developed: use of positive reinforcement and verbal encouragement, and clear explanations and expectations.

3.6.3.5 Time Pressure

On the day of the measurement visit, the successful implementation of the familiarisation and measurements procedures will depend on the allocation of sufficient time, due to the number of activities included in the design (i.e. before, during and after the measurement process). Similarly, sufficient time will need to be given during all communication exchanges between the researcher and the participant, and at each decision-making stage – for example, at the start of the visit and before each measurement. Each instruction and/or task will require different amounts of time, depending on the abilities, confidence and/or motivation of the participant.

Allowing participants sufficient time to absorb, process and respond to the researcher and/or to complete tasks was deemed essential. To reduce the risk of time pressure, it was considered necessary to integrate within the operational protocol brief instructions on 'time' as part of the guidelines on scheduling appointments, communication exchanges and decision-making stages.

3.6.4 Position of the Design Stage within the Research Design

Throughout the design stage there was an ongoing evaluation to ensure all the factors from the needs analysis were addressed. This process also ensured the continuous assessment of the relevance and effectiveness of the study design, and the completion of any required improvements. The design stage not only sought to outline the steps needed to investigate anthropometry, but also to identify the related factors for description and exploration in the development and implementation stages. The activities of the design stage reflected the influences of both the positivism and post-positivism paradigm positions. The contribution of the measurement and familiarisation theories and the Cone of Experience model towards the standardisation of measurements and the integration of mechanisms to promote and increase participants' understanding of the measurement process, was a crucial part of the design stage.

3.7 Development of the Sample Plan and Sample Selection

Development Stage of ADDIE

The development stage of the study and all of the associated activities are outlined in four concurrent sections (Section 3.7 to 3.10 inclusive). This section presents details of the study population, the sampling frame, procedure and selection process, together with the details of sample size and composition. Also presented are details of the inclusion and exclusion criteria and the recruitment process to the IDS-TILDA studies and the measurement visit.

3.7.1 Study Population and Sampling Selection

Since 1995, Ireland has, and continues to expand, voluntary registrations on the National Intellectual Disability Database (NIDD), which gathers information on the specialised health and social services currently used or needed by people with intellectual disability (ID). The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need (Kelly *et al.* 2007). Each person with ID registered on the database is assigned a personal identification number (PIN) and only the regional administrators (RAs) have access to the corresponding contact details of the PINs within their region. The use of PINs by the NIDD protects the confidentiality of the people

registered. It is the responsibility of each RA to update its records annually, which feeds directly into the database. The database is housed at the Health Research Board.

3.7.1.1 Application and Approval of Sampling Frame

Following the review of the study design and the ethical approval granted by Trinity College Dublin Faculty of Health Sciences Research Ethics Committee in 2008 (see Appendix 4), the NIDD Committee approved the use of the database as the sampling frame for the IDS-TILDA pilot study. Agreed terms and conditions were outlined by the committee and adhered to by the study management team, including the researcher. At no time during the selection or recruitment stage were the contact details of the selected PINs or the list of PINs selected released to the study team. Only the broad demographic data on the sample selected (i.e. gender, age, levels of intellectual disability and type of residential circumstances) was known for the purpose of ensuring the overall representativeness of the characteristics and variability in the total population aged 40 years and over registered on the NIDD.

3.7.1.2 Estimating the Size of the Target Sample

In the national IDS-TILDA study, it was estimated that between 750 and 850 people would be recruited, representing 8% to 10% of the total population aged 40 years and over registered on the NIDD. On this basis, an overall response rate of between 75 and 85 people was sought for the IDS-TILDA pilot study, representing the broad demographic composition of the planned national study. The securement of this response rate would also provide sufficient insight into any deficiencies in the design of the proposed measurement visit (exploratory study), so that they could be addressed before proposing its inclusion in the national study. Based on the 50% response rate or less commonly reported in social research (O'Brien *et al.* 2006), the selection of 160 PINs from the NIDD was deemed sufficient to obtain the desired response rate.

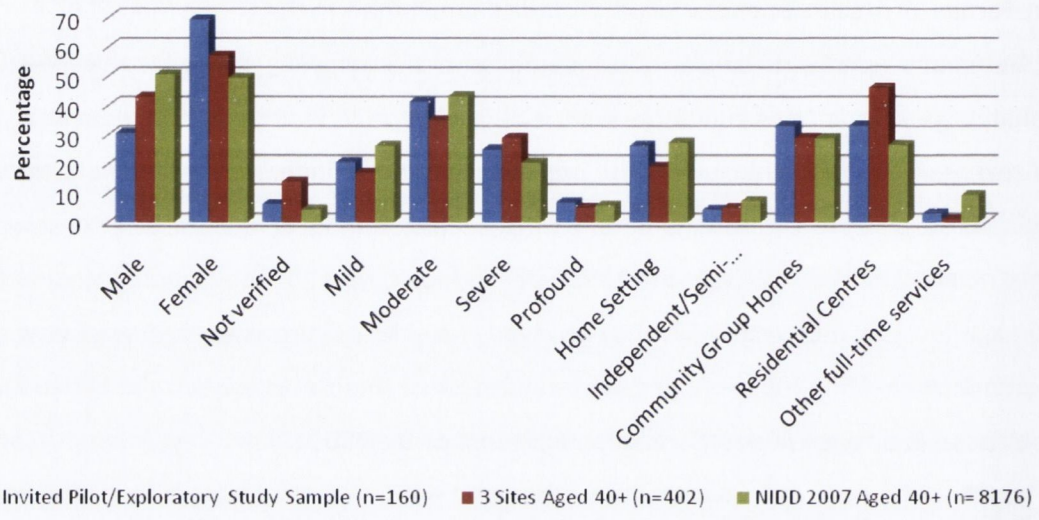
3.7.1.3 Breakdown of the Sample Composition

From three purposively selected sites (service providers), two rural and one urban, a random selection of 160 PINs, representing people with ID aged 40 years and over, was drawn from the 2007 NIDD. The PINs were drawn by the research analysts who manage the database at national level. In total, 402 people with ID were registered on the NIDD aged 40 years and over at these sites. On review of the characteristics of the sample drawn, the sites selected were deemed to sufficiently represent the different age bands, levels of ID[11] and type of residential settings for the IDS-TILDA pilot study when compared to the distributions of the total population registered

[11] Categorised according to the International Classification of Diseases – 10 (ICD-10)

on the database aged 40 years and over. See Figure 3.8 for a brief overview of the key variables targeted.

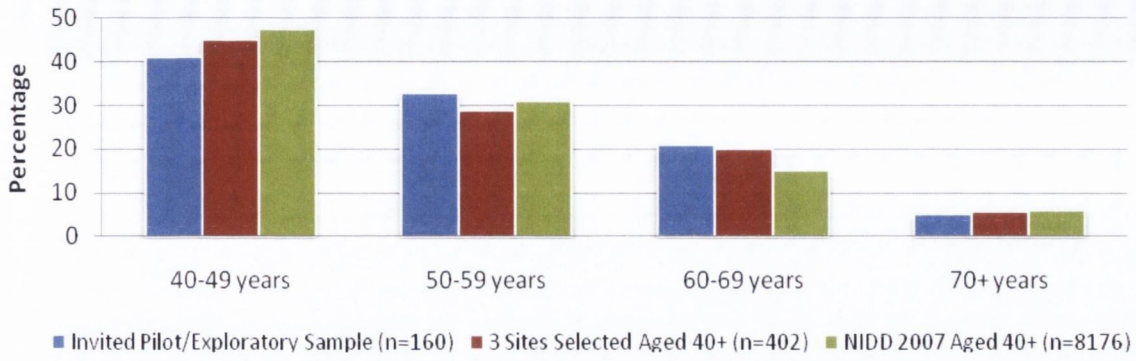
Figure 3.8: Gender, Level of Intellectual Disability (ID) and Living Circumstances of Pilot Study, 3 Sites and National Intellectual Disability Database (NIDD) Dataset



On review of Figure 3.8, it is notable that the gender distribution between the population groups is not closely represented. The invited IDS-TILDA pilot sample had 20% fewer males and 20% more females in proportion to the total population of males and females aged 40 years and over on the NIDD. However, one of the three sites selected is predominantly female (urban service; 98% of the sample invited were female and, within this site, 81% of the people registered on the NIDD aged 40+ are female). Despite this limitation in the sample drawn, the gender ratio in the IDS-TILDA pilot study was not the key variable of interest for testing the feasibility of the recruitment and data-collection procedures. Priority was given to the representativeness of age, levels of ID and residential circumstances of the random sample selected from the three sites in comparison to the same characteristics of the total population.

Although two of the sites' residential service was mainly campus-based, all types of residential circumstances were represented. As a counterbalance, the third site solely represented the variety of community living circumstances. Between the sites, all residential circumstances were adequately represented, as was the age distribution of the population (see Figure 3.9).

Figure 3.9: Age Distribution of the Pilot Study, 3 Sites and the NIDD Dataset



A summary of the selection and recruitment process, and the integration of the exploratory study within the IDS-TILDA pilot study, is presented graphically in Appendix 5.

3.7.1.4 Supplemental Exploratory Sample

Although 160 PINs were selected for the IDS-TILDA pilot study, a supplemental sample was required. Twenty-eight people with ID aged 40 years and over (PINS) from one of the first three sites involved in the national IDS-TILDA study were selected and included in this exploratory study. The aim was to recruit a minimum of 10 people. The rationale for extending the exploratory sample reflected the release of a new portable stadiometer by Seca to measure standing height (Seca Model 217) at the end of the primary data-collection phase (IDS-TILDA pilot study). The new Seca Model 217 was released to replace the long-standing portable Seca Leicester Height Measure, widely used in field research internationally and nationally, as in this study, and which has been on the market for more than 10 years. It was felt that this new model might address the observational findings made on the use of older model (see Section 3.7.1.4.1). The inclusion of this supplementary sample also enabled the researcher to test the uptake of a 'clinic-style set-up' at a central location for participants to have their measurements taken. However, irrespective of this 'clinic-style set-up', it was left to the participant/proxy to select the location for the visit.

3.7.1.4.1 Observational Findings Supporting the Supplemental Sample

During the primary data-collection phase of this exploratory study, 89% (*n*=33) of the sample (*n*=37) attempted the standing height measurement using the Seca Leicester Height Measure and were observed as being cautious stepping onto the baseplate, which appeared to be due to the raised side rims (see Figure 3.10). It was noted that the rims reduced the space available for participants to adjust the position of their feet on the baseplate, where needed. A wider

baseplate would have eased the adjustments made. None of the observations made had been anticipated by the researcher or reported in the literature, and they will be discussed further in the results chapter. As a result of these findings and given the release of the new model of the portable stadiometer, the researcher deemed it important to test its function with a small sample of people with ID aged 40 years and over as part of this exploratory study, given its aims. Interestingly, Seca (2010), the manufacturers, describe the new model on their website as a "cleverly designed assembly system"; and notably it does not have the raised side rims present in the previous model. The findings on the use of the new Seca Model 217 with participants from the fourth site will also be discussed in results chapter.

Figure 3.10: Side Rims - Seca Leicester Height Measure vs. 217 Seca Model

Seca Leicester Height Measure



217 Seca Model

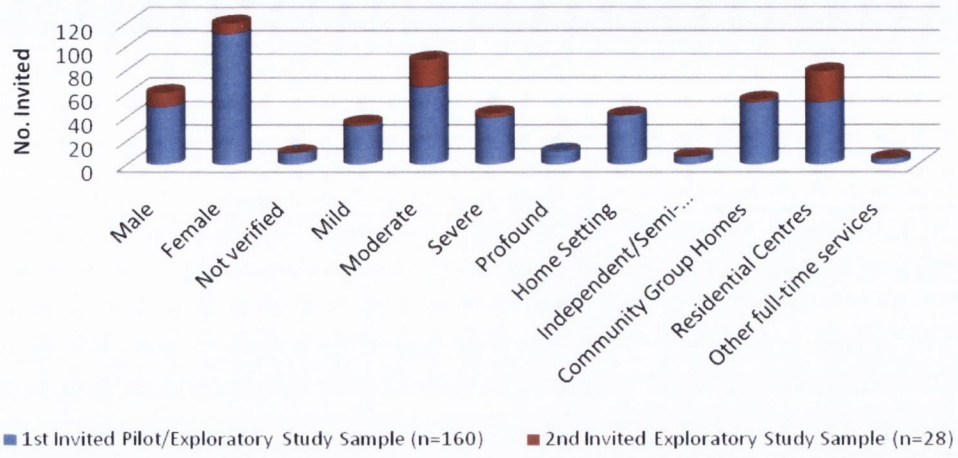


A summary of the selection and recruitment process, and the integration of the exploratory study within the national IDS-TILDA study, is presented graphically in Appendix 6.

3.7.1.4.2 Breakdown of the Supplemental Sample Composition

The supplemental sample (n=28) became the fourth site involved in this exploratory study. The site was located in a rural setting, resulting in three of the four sites being classified as rural. As the supplemental sample sought to primarily test a new piece of equipment as part of the visit, more weight was given to the representation of the levels of ID, with the preferred levels falling into the mild and moderate range, which occurred (89%, n=25). See Figure 3.11 for a visual depiction of the influences of the supplemental sample on the study's primary sample.

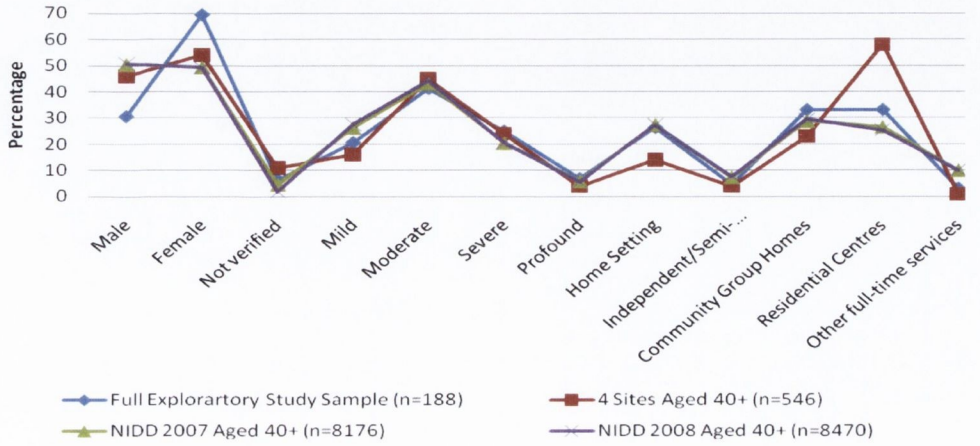
Figure 3.11: Gender, Levels of ID and Living Circumstances – Exploratory Study



3.7.1.5 Final Sample of the Exploratory Study

A total of 188 people with ID aged 40 years and over from four sites were invited to participate in this exploratory study. Collectively, the study sample (*n*=188) reflected a significant amount of the variability in the total population of people with ID aged 40 and over registered on the NIDD (see Figure 3.12). As previously noted, the random sample under-represented males, which was not unexpected as the total population of males across the four sites was lower than the percentage of the total population registered on the databases. The key variances sought from the random sample drawn included: sufficient spread of age, levels of ID and living circumstances – and these were achieved. These variances maximised the probability of being able to test the feasibility and organisation structure of the measurements and the visit itself with a sample that had similar variances to the total population on the NIDD.

Figure 3.12: Gender, Levels of ID and Living Circumstances – Full Exploratory Study Sample, Population of Sites and the NIDD Datasets Aged 40 years+



3.7.1.6 Summary of Sampling Method

From three purposively selected sites, a random sample of 160 people with ID aged 40 years and over and registered on the NIDD was drawn, with an additional random sample added (*n*=28) from one of the sites involved in the national IDS-TILDA study. A total of 188 people were invited to take part in this study. Research analysts at the NIDD selected the sample consistent with the inclusion/exclusion criteria provided. Each person aged 40 years and over with ID within the four sites (and registered on the NIDD) had an equal chance of being selected to participate in this study (and the related IDS-TILDA pilot and national study).

3.7.2 Inclusion and Exclusion Criteria

3.7.2.1 Criteria for the IDS-TILDA Studies

To be eligible for study selection and participation, a person had to meet the following criteria:

- Be 40 years of age or older with an intellectual disability
- Be registered on the National Intellectual Disability Database (NIDD)
- Be accessing services from one of the four sites selected
- Be one of the PINs selected from the random sample drawn from NIDD 2007/2008
- Provided written consent, where possible
- Provided family/guardian written agreement, where required

Exclusion Criteria

The following exclusion criteria applied to the selection and participation in the study:

- Be 39 years of age or younger with ID
- Not registered on the NIDD
- Not accessing one of the four sites selected
- Not one of the PINs selected
- No consent or written agreement received

3.7.2.2 Criteria for Measurement Visit (Exploratory Study)

To participate in the measurement visit the participant had to meet the following criteria:

- Fulfilled all of the inclusion criteria detailed in Section 3.7.2.1
- Reaffirmed their agreement to the measurement visit at the end of their interview or requested the researcher to contact the participant/proxy to discuss further

The presence of the following criteria precluded the participant from measurement visit:

- Did not fulfil all of the inclusion criteria detailed in Section 3.7.2.1
- Decided to withdraw their agreement to the measurement visit at the end of their interview or over the telephone with the researcher

3.7.2.3 Criteria for Each Anthropometric Measurement

Although the participants may have met the inclusion criteria for the measurement visit, each of the six anthropometric measurements has its own specific eligibility criteria which also need to be met by participants (see Appendix 7). The details of the criteria in the Appendix are presented in the following order: standing height; weight; ulna length (left and right); mid-upper arm circumference; and waist (over clothing and bare skin) and hip circumferences. For all measurements, participants (and proxies, where applicable) were advised to wear light clothing, defined as: a light t-shirt, shirt or blouse with short sleeves and loose-fitting trousers or a skirt of light material. Heavy clothing, jeans and belts were to be avoided where possible.

3.7.3 Recruitment to the IDS-TILDA Studies and the Measurement Visit

With the securement of ethical approval from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin and the four sites (ID service providers), together with 188 randomly selected PINs from the NIDD dataset 2007 (n=160) and 2008 (n=28) which met the inclusion criteria, the next stage of the study was the recruitment of participants. As discussed in Section 3.7.1, only the regional administrators (RAs) had access to the names and addresses of the selected PINs. To ensure the maximum confidentiality of the selected PINs, a joint letter from the Health Research Board (HRB) and the study management team was issued explaining the recruitment process and the critical role that RAs play in this process. Once the joint briefing letter was issued and its receipt verified, the PINs were issued by the research analysts in the HRB to the two RAs supporting the IDS-TILDA studies[12]. Each RA had two sites. The PINs for each site were checked by the RA to ensure that the circumstances of those selected had not changed since the yearly update was provided to the HRB. For example, the person might have decided to remove their name from the database or be deceased. Once the RA confirmed that all the PINs were active, the corresponding number of invitation packs required for each site was released to them. Each sealed invitation pack contained:

[12] IDS-TILDA Pilot Study and one site from the National IDS-TILDA Study

- Letter of Support from the Respective Organisation
- Accessible Letter of Invitation
- Accessible Information Booklet
- Accessible Consent Form and Stamped Addressed Envelope
- Family/Guardian Pack (Letter of Support from the Respective Organisation, Briefing Letter, Information Leaflet, Agreement Form and Stamped Addressed Envelope)

On receipt of the invitation packs, the RAs matched each PIN to the name and address of the person selected, affixed the address labels and sent all the packs on an agreed date. All the packs were pre-stamped for ease of posting by the RA. After posting, the role of the RAs in the study was complete. Any queries from potential participants were directed to the study management team. The contact details of the selected participants only became known if the person returned their consent and/or agreement form to the office and/or made enquiries. See Appendices 8 to 14 for copies of the materials enclosed in each invitation pack. Embedded within the materials issued were details of the measurement visit. If the participant was interested in the taking part in the IDS-TILDA study, they were consenting to all three of its stages (i.e. the pre-interview questionnaire, the face-to-face interview, and the measurement visit). Further details on the written and verbal consent process are presented in Sections 3.13.4 and 3.13.5.

3.8 Development of the Materials and Operational Procedures

Details of the development of the materials and the review undertaken are presented below, followed by the data collection stages, details of the operational procedures developed for the measurement visit and for the interviewers, and the training completed by the researcher.

3.8.1 Development of the Invitation and Measurement Materials

Prior to seeking ethical approval, the researcher as Project Manager of the IDS-TILDA study and working with the Principal Investigator, developed and designed the draft layout, content and illustrations for all the invitation materials to be issued to the invited sample and their families/guardians, which included the accessible materials for the measurement visit. The researcher sought to convey the key messages required in each document using plain English, without being patronising or over-simplifying the text. Several guides were used to assist with accessible writing, design and layout while keeping in mind the broad level of ability of this population: the National Adult Literacy Agency (NALA) *Simply Put* guidelines (2008), Mencap's *Am I making myself clear?* (Mencap 2002), EasyInfo Guides (EasyInfo 2004) and *Make it Simple:*

European Guidelines for the Production of Easy-to-Read Information for People with Learning Disability (Freyhoff *et al.* 1998). To ensure that all the materials (including the references to the measurement visit in the IDS-TILDA materials and the separate materials developed for the measurement visit itself) were truly accessible for the different levels of understanding, the researcher organised a series of external reviews. Details of the reviews undertaken are provided in Appendix 15.

3.8.2 Data-Collection Stages and Placement of Measurement Visit

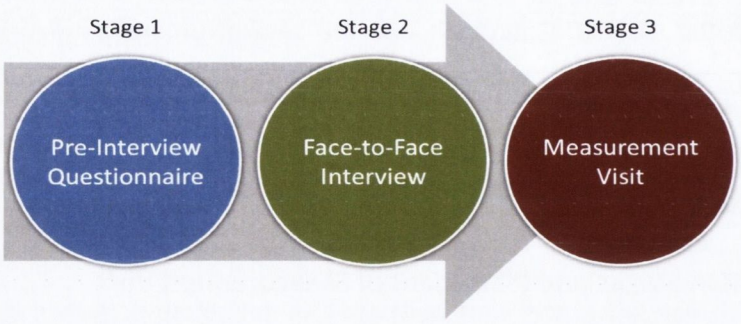
3.8.2.1 Local Letter of Support from Selected Sites

On receipt of the ethical approval from each of the four sites (see Section 3.13.1), a local letter of support for the IDS-TILDA study was requested and signed by the respective chief executive officers. This letter was then included in the invitation packs issued (see Appendix 8). Selected participants were informed in this letter that their decision to take part or not would in no way affect the current or future services offered to them, but that they would very much encourage all selected participants to consider taking part in this very important study.

3.8.2.2 Data Collection Stages

As outlined in the design stage, the data-collection process in the IDS-TILDA studies had three stages (see Figure 3.13). The first stage was the release of a postal questionnaire, called a Pre-Interview Questionnaire (PIQ), seven days before the interview was completed by the participant and/or family member/support worker who knew the participant for at least six months. The PIQ was checked and collected by the interviewer at the start of Stage Two, which was the face-to-face interview structured on the study's Main Questionnaire. If a family member/support worker actively participated at some level (periodically or completely) in Stage One or Two, they were referred to as a 'proxy' on the data-collection record forms, to indicate the type of administration method used by the interviewer. A proxy is a person authorized to act on behalf someone else (Collins English Dictionary 2009). The third and final stage of the IDS-TILDA studies was the measurement visit, which was arranged on an agreed date after the interview with those who reaffirmed their agreement to have some anthropometric measurements taken. Only those that fulfilled the inclusion criteria discussed in Section 3.7.2.2 were eligible for the measurement visit.

Figure 3.13: IDS-TILDA Data-Collection Stages



In line with the process consent method discussed in Section 3.13.5, participants/proxies were fully informed of the purpose and nature of their involvement at each of the three stages. It was emphasised that every stage was optional. At Stage Three, participants were also advised that they were not committing themselves in advance to agreeing to all eligible measures, but that they could decide at the time whether they wished to complete the specific measurement or not. The well-being of participants was the priority at all times (see Section 3.10.2).

3.8.3 Development of the Interviewers' Instructions

In order for participants to successful navigate through the data-collection stages, particularly at the end of Stage Two, and its link with Stage Three, instructions were developed for interviewers and included in the operational protocol for interviewers (see Appendix 16 for further details). The researcher also briefed the interviewers on the instructions developed, as part of their interview training. Importantly, irrespective of the decision made by the participant on the measurement visit at the end of Stage Two (i.e. reaffirms agreement, withdraws or is undecided), interviewers were advised that they needed to complete and return the Measurement Communication Form (see Appendix 17) to the researcher after each interview (see Appendix 16, Section 5). Critically, this form assists the researcher's preparation for, and delivery of, the measurement visit where agreement was reaffirmed. The key variables identified in the design phase (see Sections 3.6.3.1 and 3.6.3.2) were included in this form, together with: the participant's individual ID number; age; level of intellectual disability; perception of weight status (e.g. overweight, underweight or about the right weight); whether the participant was on any special diet (e.g. diabetic) and if yes the type; and any specific comments/questions made by the participant and/or proxy about the measurement visit. No personally identifiable information was recorded on the form as per the study's privacy policy.

3.8.4 Researcher Training for the Exploratory Study

Details of the anthropometry and contextual training completed are presented below.

3.8.4.1 Anthropometry Training

Prior to the development of the measurement procedures and the related considerations, the researcher completed international anthropometry training. The obtainment of accredited anthropometric training and securement of sufficient experience were of critical importance to the researcher, even though the researcher was an experienced nurse and had familiarity with the measurements. The researcher felt that while familiarity increased understanding of the measurements, it did not equate to in-depth knowledge of the theory and practice required to ensure that the appropriate measurements were selected, operationalised, and accurately interpreted. Himes (2009, p. 54) has confirmed that one may hear the comment "anyone can measure height and weight" in practice or research, and "although one must actually agree with the language, if not the intent, of this easy declaration, many health professionals" (and other researchers conducting these measures within other disciplines) "are unaware that there are consequences for the usefulness and accurate interpretation of Body Mass Index (BMI) data that follow from decisions made concerning data collection" (e.g. data on the prevalence of BMI patterns help in the targeting of interventions and monitoring changes over time).

3.8.4.2 International Anthropometric Training Completed

Although no national or international accredited anthropometric assessment training courses exist in Ireland, the researcher secured a place on the internationally accredited programme developed by the International Society for the Advancement of Kinanthropometry (ISAK; see Appendix 18), which mainly targets sport scientists. The researcher attended and successfully completed two ISAK training courses (Level 1 & 2) in the United Kingdom (see Appendix 19). The first course took place at Heriot-Watt University, Edinburgh, and the second course at the University of Portsmouth, in 2008 and 2009 respectively. Both courses were completed before the pilot study commenced in mid-2009. Certification assisted the quality-control assurance needed and was critical to the development, assessment and interpretation of the measurements in this study. A key element of ISAK is the objective maintenance of quality assurance by requiring that all levels have to meet initial technical error of measurement (TEM) criteria (see Table 3.6 and Section 3.12.3.2 for further details). Table 3.6 shows the target percentage TEM for inter- and intra-testers required for obtaining accreditation and profiling as accredited technicians at Level 1 and Level 2 (post profiles).

Table 3.6: ISAK Accreditation Technical Error of Measurement

ISAK Accreditation Technical Error of Measurement					
		Level 1 (% TEM)		Level 2 (% TEM)	
		Post Course	Post Profiles	Post Course	Post Profiles
Inter	Skinfolds	12.5	10.0	10.0	7.5
	Other	2.5	2.0	2.0	1.5
Intra	Skinfolds	2.5	7.5	7.5	5.0
	Other	1.5	1.5	1.5	1.0

3.8.4.2.1 IASS Training Programmes (Levels 1 and 2) and Examination

Combined, the total number of training days completed by the researcher for Levels 1 and 2 was seven full days of theoretical lectures and practical sessions (9am-6pm), which included a practical examination at the end of each level. Candidates were required to achieve at least an 80% pass rate at each level. Following the successful completion of the practical examinations, the researcher submitted the post-training profiles required for assessment. The total number of anthropometric measurements completed and submitted as part of the post-training requirements for Levels 1 and 2 was 2,240 measurements. The high standard of training and attention to detail expected by ISAK ensures comparability and consistency of measures made by ISAK-trained anthropometrist technicians. An ISAK-trained anthropometrist follows a very exacting set of procedures, unless otherwise specified, with tight guidelines on accuracy.

3.8.4.3 National Contextual Training on Anthropometry in TILDA

As noted earlier, the IDS-TILDA study is inextricably linked to the TILDA study on ageing in the general population, which is turn is closely harmonised with the United States Health and Retirement Study (HRS) and the English Longitudinal Study on Ageing (ELSA). TILDA, HRS and ELSA all include some anthropometric measurements in their health assessment module (clinic and/or home assessment) (see Table 3.7). On the basis that the researcher was piloting selected anthropometric measurements within the IDS-TILDA pilot study, it was imperative to learn and understand the training provided to both the interviewers and nurses involved in TILDA's pilot study. Rather than exclusively reading TILDA's protocols, the researcher attended the related sections of both the interviewer and nurse training provided in mid-July 2008.

Table 3.7: Matrix of Anthropometric Measurements in Selected Ageing Studies

	Standing Height	Weight	Ulna Length	Mid-Upper Arm Circumference	Waist Circumference	Hip Circumference
Exploratory Study	√ x* 2	√ x 2	√ x 2	√ x 2	√ x 2 - Iliac Crest, Over Clothing & Bare Skin	√ x 2
TILDA Pilot Study	√ x 1	√ x 1	X	X	√ x 2 - Midpoint, Over Clothing	√ x 2
ELSA Study	√** x 1	√ x 1	X	X	√ x 2 - Midpoint, Over Clothing	√ x 2
HRS Study	√ x 1	√ x 1	X	X	√ x 1 - Level of Navel, Over Clothing	X

*by number of measurements **plus Sitting Height x 1

3.8.4.3.1 TILDA Interviewer and Nurse Training Attended

The topics covered in interviewer training sessions attended were: the background and design of TILDA's pilot study; the role of interviewers in the health assessment module as part of the interview; and the related communications required with the health assessment personnel. The topics covered in the nurse training sessions attended were: the background and purpose of the health assessment module; its link with the interview data; and the specific protocol for measuring and recording the anthropometric measurements selected (height, weight and waist-hip ratio). During the practical session of the nurse training, the researcher acted as the subject for the measurement demonstrations. Although TILDA's measurement protocols were slightly different to standards set by ISAK, it was still very useful to attend the training – in particular, to learn how TILDA sequenced the health assessment module with the interview and understand more fully the similarities and differences between the two pilot studies.

3.8.5 Development of Measurement Standards

Central to this exploratory study and the operational protocol developed was the development of measurement standards. The standards developed and included in this study primarily reflected the standards set by ISAK (Marjell-Jones *et al.* 2006). Slight adjustments from the ISAK standards were made to suit the inclusion of the anthropometry assessment module as part of a wider study on ageing (see Section 3.8.5.1 for details of the adjustments made) and the needs of the target population, and address the specific objectives of this exploratory study. Detailed

descriptions of the standards set and followed for each of the six measurements are given in Appendix 7. The standards are presented in the following order: standing height, ulna length, mid-upper arm circumference, weight, and waist and hip circumferences. Each standard has six main headings: purpose of the measurement; equipment required; eligibility criteria; briefing and demonstration instructions; preparation instructions; and measurement instructions (inclusive of guidelines on recording the data).

Adherence to the standards necessitated sensitivity to the dynamic interplay between the need to stay with established protocols for each measurement to ensure standardisation and comparability, such as the ISAK standards, but also develop new protocols which reflect not only new knowledge of growth, but also the hypotheses forming the basis of a particular study (Ulijaszek *et al.* 1998, p. 26). While the researcher sought to test the application of standard measurement protocols with older adults with ID, a few key adjustments were made to widen the assessment of reach and use within a field study and the population group. The researcher also sought to expand the concept of 'measurement' beyond the act of measurement only, which in the context of anthropometry relates to the 'measurement of subjects'. This study, as noted in Section 3.6.2, sought to develop and take steps to enable and empower the subjects, people with intellectual disability, as part of the measurement process.

3.8.5.1 Key Differences between ISAK Standards and the Exploratory Study

There were five differences between the ISAK standards and those developed for this study:

Standing Height: The researcher did not apply the gentle upward lift through the mastoid processes (requires the tester to place their hands on each side of the participant's face) while the participant's head is in the Frankfort plane position, as recommended by ISAK, as it was deemed too invasive and may distress some participants. However, participants were asked to take a deep breath to fully stretch their spine. A demonstration of the request was given.

Ulna Length: Ulna length is not one of the 39 measurements listed in ISAK's anthropometric profile of sites. A similar length measurement, Radiale-stylion[13], by ISAK, positions the subject's forearm, hanging down by their side, but this was not followed. Instead the participant's arm was folded across their chest (alternative positions such as their arm placed across his/her stomach was possible, if needed) and measured, as recommended in the Malnutrition Universal

[13] It represents the length of the forearm, the distance between the Radiale and Stylion landmarks.

Screening Tool (MUST). This tool was used to predict standing height (BAPEN 2003). The MUST position aided the measurement of all participants, as it could be taken in a standing, sitting or lying position, which was an important consideration in this study.

Mid-Upper Arm Circumference: The researcher did not take the measurement on the right arm (unless required) or use the radiale site (one of two landmarks required for the measure), recommended by ISAK, as MUST was used to interpret the measurement findings. Instead the measurement was taken on the left arm (or right if the left was not possible), as recommended by MUST. The olecranon process site was used, which replaces the radiale site used by ISAK.

Weight: The weight or estimation of clothes was not calculated as advised by ISAK nor was measurement restricted to the standing position. Instead light clothing was worn and weight was measured in either a standing or seated position.

Waist Circumference: The narrowest point of the waist on bare skin, as recommended by ISAK, was not the selected site. Instead the researcher measured waist circumference at the iliac crest, a bony landmark, as it would have been very difficult to accurately locate the narrowest point of the waist when the measurement was first taken over one layer of light clothing. This site, iliac crest, as discussed in the literature review (Section 2.4.1.5.1), is widely used in the general population due to it being a fixed landmark.

The ISAK standard for hip circumstance was not amended. Although slight adjustments were made (as detailed above), all the other standards set by ISAK and MUST, on each of the selected measurements, were complied with.

3.8.5.2 Measurement-Related Factors

As well as the standards set for each of the six measurements, there were five measurement factors to be addressed as part of the measurement process. Two of the factors were the avoidance of parallax error (e.g. by reading the measurement in the researcher's line of sight in front of the value) and the right-side positioning of the researcher to the participant for all measurements (awareness of and respect for their personal space) unless left-side positioning was otherwise required. The third factor, the process of landmarking sites, concerned only three of the six measurements, ulna length, mid-upper arm and waist circumferences. The two final factors were the time of day when height and weight measurements were taken, and the

position of participants (e.g. standing) for the ulna length, mid-upper arm circumference and weight measurements. Details of the instructions developed are provided in Appendix 20.

3.8.6 Measurement Reproducibility

To assess and improve the reliability of the study's findings, duplicate measurements were taken in rotational order. Several statistical approaches were used to determine the reliability of the anthropometric measurements in this population group (see Section 3.12.3.2).

3.8.6.1 Accepted Difference: First and Second Round of Measurements

From the outset, it was acknowledged that there were likely to be differences between some of the first and second readings. The types of measures at increased risk were length and girth measurements, but differences could occur in any of the selected measurements. While the application of measurement standards, use of validated equipment, and completion of accredited training should reduce the degree of difference between measurement readings, it was not possible to control the influences the participant might contribute, and/or predict what other influences might arise during the measurement process until the study was complete.

No accepted margins of error exist for the selected measurements within this population group; the results of this study will provide some initial indicators. The limits of difference set were for the most part informed by the ISAK targets for Level 2 anthropometrists (see Table 3.8). However, the limits were defined as figures as opposed to percentages for ease of use at measurement visits. In practice, if the difference between the first two readings was larger than the limit set, participants were asked if a third measurement reading could be taken. The procedures developed to brief participants on the readings sought are detailed in Appendix 30, Section 4. A reminder of the accepted difference between the readings of each measurement was included in the Results Workbook developed (see Appendix 21).

Table 3.8: Accepted Difference between Measurements

Difference Between Two Measurements	
Type of Measure	**Maximum Difference Accepted**
Height, Girths and Lengths	0.5cm
Weight	0.5kg
Clothing thickness	0.2mm

In other studies on ageing that take dual anthropometric measurements (not common practice for all measurements; see Table 3.7); the accepted differences between the first and second readings are much larger than in this exploratory study. For example, in TILDA's pilot study and the ELSA study (in the United Kingdom), nurses were advised to take a third measurement if waist (over clothing) or hip circumference readings differed by more than 3cm.

3.8.7 Selection of Measuring Instrumentation

Three of the six brands of equipment (segmometer, anthropometric tape and skinfold calliper) selected for this study are recommended by the International Society for the Advancement of Kinanthropometry (ISAK). However, no specific brands of mobile scales or portable stadiometers were recommended by ISAK. Following the literature review and consultation with researchers and clinicians in the analysis stage, two scales – one wheelchair scale and one flat scale for mobile use – were selected along with a portable stadiometer commonly used in practice and field research in Ireland and internationally. Details of the brands chosen and used are provided in Appendix 22. To evaluate the practicality of the equipment selected, an evaluation question on each piece of equipment was included in the Anthropometric Measurement Results Workbook developed (see Section 3.10.5).

3.8.7.1 Quality Control Measures for Equipment

The selection, purchase, and use of the most appropriate measuring equipment was critically important in order to maximise the number of participants measured and to produce valid results based on all the measurement standards being met. Equally important was the maintenance and functioning of the equipment. The researcher devised and implemented schedules for checking the calibration of the equipment used. The frequency of calibration depended on the type of equipment and rate of use. See Appendix 23 for details of the daily and weekly calibration checks and the record form completed. Of note, all the equipment used was new and calibrated on purchase, but it was also checked before the study commenced.

3.8.8 Integration of the Familiarisation Steps

Central and unique to this study and its operational protocol were the steps taken to gradually build the participant's awareness and understanding of the measurements, from the initial recruitment stage into the study (invitation packs) right through to the time of the actual measurements. The development and use of the accessible materials sought to engage and promote the participant's maximum understanding of the measurements yet be short and concise and hold their interest. The inclusion of the researcher's photo on the accessible

materials issued also sought to contribute to building a connection with participants before meeting in person, especially with the Appointment Card (see Appendix 24) as the content was limited compared to the Measurement Information Booklet (see Appendix 25).

A mix of text and verbal symbols, pictures and visual symbols and a photo was used by interviewers, as instructed, to gradually build the participant's familiarisation with the visit, the measurements and the researcher. To manage the transfer of communications between the interviewer and the researcher, the initial contact made by the interviewer, and the issuing of the Appointment Cards to participants, instructional guidelines were developed (see Sections 3.10.1.1 to 3.10.1.2.) However, for the measurement visit, instructional guidelines were not only developed for the integration of the familiarisation approach in the build-up to the measurements, but also key checks and reminders of the steps to be taken were included in the Anthropometric Measurement Results Workbook developed. Details of the related instructional guidelines developed for the visit are presented below (Section 3.8.8.1).

3.8.8.1 Meeting, Briefings and Demonstration of the Selected Measurements

On meeting the participant, the researcher showed their identification badge and introduced herself. A copy of the Appointment Card was available as a reminder, if needed. Ice-breaker dialogue between the two parties was initiated and undertaken, where possible. If the participant was unable to verbally communicate, the dialogue was adapted accordingly. Five minutes was allocated for the ice-breaker session. The connection of this visit to the IDS-TILDA study was noted during this time. Visual aids (e.g. booklet) were used to clarify the connection, and the need for any assistive aids (e.g. glasses) by participants was sensitively checked.

After the procedures on written consent and verbal consent/assent were completed (see Section 3.10.1.4), the preparation phase was undertaken; it included two checks and two briefings relating to the familiarisation process. The two checks linked directly to the section on verbal consent/assent and sought to confirm that the researcher had shown and checked the receipt of both the Measurement Information Booklet and Appointment Card. If the booklet had not been received, a copy was issued. The reasons for non-receipt of either item were recorded in the 'Final Questions' section of the Results Workbook under the space for 'any other information'. The first briefing provided a general overview of the measurements, using the accessible showcards as a guide (see Appendix 26). This briefing sought to reinforce the learning the participants were to have obtained from the personal review of the booklet before the measurement visit took place, as advised by the interviewer and the researcher. The

second briefing concerned the inclusion of the participant's rights (to stop and ask questions at any time, have a break or end the visit) within the overview of the measurements.

At each relevant measure and before checking the participant's willingness to undertake the measurement, the researcher briefly described the measure, its purpose, how it would be taken and what to expect, using the measurement showcards. A demonstration of the steps involved was completed, including showing the participant the anatomical sites, where relevant, that were sought, and a short explanation of how the equipment worked. Where appropriate, participants were encouraged to look at and feel the equipment (i.e. measuring tape and segmometer only), and were also given the option to practise or try out the measurement with the researcher's support, until they felt comfortable enough to complete.

Collectively, all of the instructional procedures that led up to the day of the measurement visit and the steps detailed above sought to familiarise and empower the participant as best possible about the measurements before they made the final decision on whether or not they wished to take part in each measure. Ensuring that the power of decision rested with the participant irrespective of the formal method of consent/assent given was paramount in this study. If necessary, this position was sensitively communicated to a third party present (e.g. proxy), while providing additional positive reinforcement to the participant on their right to decide. Hale *et al.* (2007) suggested that allowing participants to become familiarised both with the test and tester may ease problems concerning misunderstanding of the required tasks ahead. Although some studies do not account for potential learning effects when measuring the phenomena of interest, this study sought to minimise the learning effects, by supporting participants to become as familiar as they could be with the steps and instructions given, particularly at the demonstration stage, in order to achieve maximal efforts in the task performance (e.g. standing height).

During the measurement process, guidance (verbal; visual with showcards; demonstration; and/or direct assistance such as guiding the participant's feet into the correct position with their permission) was given as often as required. Participants were given time to absorb the guidance given. On taking the actual measurement, the participant was kept informed about what the researcher was doing, using short, clear sentences, and pausing when appropriate. At the end of the visit, the findings were explained to the participant (and proxy where relevant and with permission) and a copy of the readings was written on an individual Measurement Record Card (see Appendix 27) for the participant's own record (see Section 3.8.10 for further details).

Throughout the familiarisation and measurement process, clear communication (see Section 3.10.3), an awareness of verbal and non-verbal cues of participants and a positive attitude were very important. In addition, ensuring that expectations were simple and clear, and positive reinforcement, verbal encouragement and support (e.g. 'try your best', 'you can do it', 'you did very well', 'you did it', 'you're good at this', 'that was a great try', 'you've been a great help') was given before, during and after each measurement was essential, even if the participant was unable to complete the measurement. If the participant made a procedural error, the instructions and demonstrations (if required) were sensitively repeated and the participant made a new attempt, where possible and appropriate. All of these actions not only sought to support the validity and reliability of the measurement performance, but also to create an enjoyable learning experience for participants, increase their motivation to take part, and reduce any anxiety, fears and/or embarrassment they might have about the measurement process (see Section 3.10.2 for further details on well-being). Importantly, a further indirect benefit of the familiarisation process is the potential for participants to become more familiar with these selected measurements in the future outside of their use in this study.

3.8.9 Development of Anthropometric Measurement Results Workbook

The development of a standardised form to capture key measurement details and elicit the experience of implementing the operational process developed was critically important. Subsequently, a paper-based Anthropometric Measurement Results Workbook was developed by the researcher (see Appendix 21) based on the components identified in the design phase (see Section 3.6.1, Table 3.4). To guide the specific content details, the researcher reviewed the forms used by the English Longitudinal Study on Ageing, the US Health and Retirement Study, the Scottish Health Survey, and the UK National Diet and Nutrition Survey, for recording a range of different anthropometric measurement readings. A combination of questions and response options from these studies were used and/or adapted in this study. Most of the workbook consisted of pre-coded response options, to ease completion.

3.8.9.1 Main Components of Anthropometric Measurement Results Workbook

Aside from the participant and researcher ID numbers and the date of the visit requested on the cover of the Anthropometric Measurement Results Workbook, the remainder of the workbook was broken up into 11 sections, labelled A to K. Section A captured the eligibility checks (i.e. written consent, verbal consent/assent and withdrawal) required and Section B captured the status of the briefings and checks completed. Aside from the two checks and two briefings relating to the familiarisation procedures discussed in Section 3.8.8.1, the two remaining checks

on the form related to maximising the comfort and ease of the measurement process (see Section 3.10.1.6 for details of how both checks were integrated into the visit).

The bulk of the workbook, Sections C to H, comprised each of the six measurements, one measurement per section. Each section captured the first, second and third (if required) round of measurement findings and all the design components specified in the blueprint - see Table 3.4 (e.g. eligibility, measurement readings and related conditions, validity status of reading). A reminder of the accepted difference between the first and second measurements was included on the form. The procedures developed for recording each round of measurements are detailed in Appendix 30, Section 4. At the end of each of the six measurements, two main evaluation questions plus related filters were included: one relating to the use of the equipment, the other seeking to find out if there were any relevant measurement details not covered already and to obtain the associated details, such as the nature of proxy support given. The latter part of the workbook, Sections I to K, comprised instructions for completing the accessible Measurement Record Card, three main evaluation questions plus related filters on the Appointment Card, the Measurement Information Booklet and the measurement showcards, and, finally, an open space at the end of the workbook for any feedback, observations and reflections by the researcher.

3.8.9.2 Guidelines on Classification of Validity Status

As outlined in the design phase, the categorisation of the validity status proposed in Section 3.6.1.1 was developed and included in the Results Workbook under each measurement (see Appendix 21, Sections C to H). Of equal importance was the development of clear guidelines on how each of the three validity options was defined. Option (a) represented the fulfilment of all of the standards and no problems were experienced. Similarly, Option (b) represented the fulfilment of all the standards, but some problems were experienced in the administration process, which required more attention or adjustment. For example, the location of the bony landmark took longer than normal or the equipment (e.g. weighing scales) was not functioning correctly at the time of measurement but was fixed. Option (c) indicated that one or more of the standards was not met; for example, the participant did not have their head in the Frankfort plane position, or the equipment did not function correctly and the reading was invalid. A description of the problems experienced irrespective of whether the result was valid or not was requested; where the problem(s) resulted in the measurement being invalid, the researcher was required to code the reasons for the invalid measurement (see Appendix 21).

3.8.10 Development of Measurement Record Card

The final element of the familiarisation process designed for this study was the development of the accessible Measurement Record Card for participants (see Appendix 27). At the end of the measurement visit, a copy of the measurement results, without interpretation, was given to each participant unless they expressed their wish not to receive a copy of their results. Although the results were not interpreted, as the primary goal of the study was to test the feasibility of carrying out the measurements as part of a wider study on ageing, an accessible booklet, *Keeping Well*, was provided to each participant; this booklet consists of health information for people with learning disability as they get older (Down's Syndrome Scotland [DSS] 2007). As part of the debriefing process, an overview of the Measurement Record Card and key learnings from the measurement visit were discussed with the participant, such as their feedback on the accessible materials developed. As a reminder, on the inside of the Measurement Record Card, a brief synopsis of the study, and the purpose of gathering the information, was included. Such details provided participants with any necessary reminders of the visit if they decided, for example, to show or discuss the readings with their general practitioner, family member or any significant other. Finally, if three results existed for a particular measurement in the Results Workbook, only the closest two results were recorded on the participant's Measurement Record Card.

3.9 Pre-Piloting Measurement Standards and Results Workbook

No pre-pilot was undertaken with the target group (people with ID aged 40 years and over) prior to the commencement of this pilot study. The rationale for this decision reflects the underlying purpose of this study: to pilot the measures with 10% of the sample required for the national IDS-TILDA study. However, as part of the post-training required for ISAK accreditation, the researcher recruited 40 volunteer subjects who were 40 years of age and over (range 41 to 85 years) from different socio-economic backgrounds, which enabled the researcher to experience the measurement of older adults and test the use of the equipment selected for the pilot study (except the wheelchair scale). Due to the number and type of measurements required by ISAK, and the duration of the assessment, it was deemed more appropriate to recruit people without an ID for the purposes of this training requirement.

3.10 The Implementation Plan

Besides the measurements process and the related standards, and the familiarisation steps discussed above, other key instructional procedures were developed. Details of the actions needed in the lead-up to and the day of the measurement visit are presented below.

3.10.1 Preparatory Work and Onsite Checks

3.10.1.1 Receipt and Review of the Measurement Communication Form

On receipt of the Measurement Communication Forms from the interviewers, the status and outcome of reaffirmed interest in the measurement visit was reviewed. If the participant (or proxy where relevant) was undecided, the researcher telephoned them and discussed the proposed visit and addressed any questions or concerns. For those who decided to withdraw their consent/agreement, either at the interview stage or following the telephone call, their communication forms were reviewed and filed in a locked filing cabinet. Finally, for those who reaffirmed their agreement to go to Stage Three, their geographical location was reviewed by their individual PIN number and, if other participants were due to interviewed in their area, the researcher placed the form on hold until other forms were received. The researcher sought to cluster visits on the same day or in the same week, where possible, to minimise disruption to a household where more than one participant were taking part in the study or were within close proximity of each other, and to reduce costs and maximise productivity. If no other participants were due to be interviewed in their area or the gap between interviews was longer than two weeks, telephone contact was made with the participant/proxy.

3.10.1.2 Initial Contact and Issuing of Measurement Appointment Cards

In most cases, initial contact with the participant/proxy was made by telephone; for contact made in person, the same principles applied. Introductions were kept short and concise, with one item discussed at a time. To begin, the researcher introduced herself and who she worked for, and reminded the participant/proxy about their recent interview and agreement to take part in the measurement visit. The researcher then thanked them for reaffirming their interest. Following this, a suitable date, time (preferably morning or early afternoon to reduce possible diurnal effects on height, where applicable) and location for the visit were agreed. A brief overview of the preparation needed on the day of the visit was also provided (e.g. advice to wear light clothing, a short-sleeve t-shirt or shirt and loose-fitting trousers or skirt).

On scheduling appointments, the allocation of sufficient time for the visit was discussed. Forty minutes was advised, even though the measurements only take approximately 15 minutes. The participant/proxy was informed that additional time was required to set up the equipment, and brief, demonstrate and debrief the participant after the measurement process. However, it was noted that some appointments would take less time, if, for example, the equipment was already set up and/or fewer measurements were being taken. If appointments were made with proxies

and the participant was likely to need support from them on the day, the researcher encouraged the proxy to select a date and time that suited them both, where possible. The continuity of support and involvement in the study was deemed important, where support was required. In all situations, the importance of the participant looking at the accessible Measurement Information Booklet (and proxies explaining the key messages in it, where required) before the visit was emphasised.

The researcher also informed the participant/proxy that an accessible Appointment Card (see Appendix 24) with the key details discussed would be sent to them the next day. In the interim, a contact number for the researcher was provided in case the card got mislaid in the post and they needed to change the scheduled date or time. All the written correspondence issued was addressed to the participant personally by name. Also, for the purposes of security and continued development of the relationship with the participant, the researcher placed a photograph of herself beside her full name on the front of the Appointment Card.

3.10.1.3 Off-Site Preparation for the Measurement Visits

On the day measurement visits were scheduled, the researcher reviewed all the Measurement Communication forms for that day, prepared all the materials required (see Appendix 28), and checked and cleaned the equipment before transferring all items to the car. Details of the calibration checks completed on the equipment are outlined in Appendix 23. The equipment was cleaned between readings if necessary, between measurement visits, and at the end of every day when in use. All the surfaces that the participant and researcher touched were cleaned with an anti-bacterial swap. The researcher also used antibacterial hand gel after cleaning the equipment, between measurement visits, and at other times where necessary. All onsite cleaning and hygiene practices (e.g. use of an antibacterial hand gel) were completed in a relaxed manner while ongoing dialogue was maintained with the participant.

3.10.1.4 Placement of the Consent Checks and Third-Party Support

Following the introductions at the beginning of the visit (as discussed in Section 3.8.8.1 and see Appendix 29, Section 1), the researcher set the scene of the consent and agreement procedures involved in the visit (see Table 3.9) before verifying the participant's verbal consent/assent to participate further. Next, the researcher checked that the participant had received the accessible Measurement Information Booklet issued at the end of their interview (if not, one was provided), and the Appointment Card for the visit. An overview of the purpose of the study, proposed benefits and contribution, the safety measures, the right to withdraw and the

protection of their privacy was provided. The proposed measurements were then outlined, using the accessible measurement showcards to guide the description. The researcher then asked if they were happy to participate (irrespective of the written consent secured) and the outcome was recorded in the Results Booklet. Participants were provided with time and space to decide their participation based on full knowledge of the study (verbal and non-verbal cues were assessed by the researcher and acted upon) and any questions asked (e.g. can you explain again, how my waist will be measured?) were answered and demonstrated, if appropriate.

Table 3.9: Review of Written Consent and Agreement with Participants

Template of Instruction Sequence
[Sample – The researcher broke down the key points into sections/short sentences and built understanding from there to suit each individual and the circumstances]
"Thank you for consenting to take part in the pilot study on ageing, and for reaffirming your willingness to participate in the measurement visit at the end of your interview. As you know, I am going to ask you to complete some measurements, such as your height and weight, where possible. The results of this visit will help to improve our knowledge of the measurements and the suitability of the equipment for the national study. The measurement results will also begin to build our understanding of the links between the general build, diet and health of people with intellectual disability aged 40 plus in Ireland. Each measurement is entirely voluntary. You do not have to have any measurements taken if you do not wish but, of course, we very much hope you will agree to all eligible measures, as they are a very important part of this study, and with your help we will become more informed about them."

If a proxy was present, their name was also recorded in the Results Workbook. If there was no proxy present and the participant was happy to take part in the visit, the researcher checked if the participant would like to have someone present, and if necessary this person was sourced before continuing or at the time indicated by the participant. However, if the participant decided to withdraw from this aspect of the study, and reasons were given, the details were recorded, and then they were thanked for taking part in the first two stages of the study. A copy of the *Keeping Well* booklet (DSS 2007) was provided and the measurement visit was ended.

The participant's decision to take part in all, some, or none of the measurements was fully respected. Non-verbal cues were closely monitored during the visit, particularly among those who were unable to express their wishes verbally. The well-being of participants was of paramount importance at all times (see Section 3.10.2). For those taking part, consent/assent was negotiated throughout the visit and supported by the development of a mutual partnership between the participant and the researcher as part of the familiarisation process rolled out.

3.10.1.5 Setting-up and Safety of Equipment

Subsequent to the participant's agreement to take part, the relevant pieces of equipment required for the visit were set up in a systematic way to reflect desired rotation. Efforts were made to promote a smooth transition between measurements for participants and reduce the risk of them becoming disinterested and/or tired. It was also necessary to ensure that the researcher could easily move around the participant and manipulate the equipment without impediment. Although the location of the visit was selected by the participant, the researcher sought where possible to carry out the measurements in a quiet but familiar area within this location; for example, the kitchen of their home or a side-room in the day centre. The type of flooring also guided the selection. Hard flooring was preferred. Carpet flooring was avoided where possible, but if it was the only suitable place available, low-pile carpet was chosen if possible. The type of flooring was recorded for the height and weight measures in the Results Workbook.

Only the equipment required was set up. For safety and to protect participants and others from harm, all of the equipment was placed out of reach until required, and out of the way of others, particularly if the visit was not carried out in a private area. Participants were carefully supported, where needed, to prevent falls when the stadiometer and weighing scales were in use, as participants had to step on and off the piece of equipment. During both the briefing and demonstration stages, the importance of stepping safely on and off both pieces of equipment was emphasised. All measurements were taken on a step-by-step basis, so participants were not rushed. The researcher also carefully explained and monitored the measurement procedures and equipment usage throughout each visit to ensure participants were adequately protected from physical injuries. Further details on other safety precautions taken prior to measuring participants, and during the visit, are detailed in Section 3.10.2.1.

3.10.1.6 Integration of Sensitive Checks in the Set-up of Equipment

During the set-up of equipment, participants were asked if they had eaten or drunk anything in the last 30 minutes and, where appropriate, it was sensitively mentioned that it was a good time for them to use the bathroom facilities if needed. If the participant did not need to use these facilities, the measurement showcards were given to the participants to look through. Even though the researcher was building dialogue with participants from the outset, during this set-up phase, dialogue was intermittent to allow participants time to process the information discussed about the visit and the measurements. A record of both checks was requested in the Results Workbook.

3.10.2 Well-Being and Protection from Harm

Taking anthropometric measurements is a privilege, not a right (Ministry of Health New Zealand 2008). It was the researcher's responsibility to assist participants to feel comfortable about the visit and the measurements being taken. It was also imperative that the right atmosphere was created so the participants felt comfortable asking or indicating their wish to stop measuring at any time. All participants were measured in a way that preserved their dignity and privacy. The measurements were conducted in an open, friendly and simple manner, using the operational protocol and the measurement showcards developed to guide the description of each of the steps involved. Personal space was respected fully (see Appendix 20). The least amount of body contact was made by the researcher when arranging the measuring tape, segmometer and/or landmarking sites. The active role of participants in the measurement process assisted the researcher to reduce the amount of contact needed (e.g. participants assisting the researcher to locate the sites required, where possible).

Great care was taken in choosing terms relating to weight, as the labels 'overweight' and 'obesity' have negative connotations. During the visit, the purpose of the study was emphasised, which was not to interpret the findings but rather learn more about the measurements and the equipment selected. However, the overall importance of healthy lifestyles, such as balanced diets and physical activity, was briefly discussed, and the booklet *Keeping Well* was provided to each participant at the end of the measurement visit (DSS 2007). The intention of the study to advance and generate new knowledge that will produce benefits for participants (i.e. self-learning and increase their awareness of the measurements) and, more generally, for others was emphasised (i.e. improving the measurement process for both the participant and the research being conducted).

3.10.2.1 Measurement Safety Measures

Although the measurements selected do not impose any known physical harm or risk to participants, there were certain precautions that the researcher observed due to the standing positions or movements required for some of the measurements. For example, if the participant seemed unsteady on their feet or tired they were encouraged to be weighed sitting on a chair or to stand holding the horizontal bar of the wheelchair scales for the circumference measurements, where reasonably practical. Otherwise, the relevant measurement was not followed through or attempted. In total, three of the six measurements could be taken in a seated position (ulna length, mid-upper arm circumference and weight) if necessary and if no other restrictions existed. Any adjustments made were recorded in the Results Workbook.

Despite a participant meeting the eligibility criteria set for the measurement, the researcher continually reviewed the safety of the individual to participate in the measurement. For example, if during the briefing or measurement stage participants became weak, confused, unsteady or frustrated, the researcher stopped and assisted the participant to a safe position (e.g. from a standing to sitting position). Once settled, a review of the circumstances was conducted in partnership with the participant and/or with a proxy, where appropriate, and one of the following actions was taken: decide to take a break, skip the specific measure, cease the visit and/or arrange another visit. For all others, during the briefing, the researcher assessed whether the participant understood the directions for the measurement and if after the demonstrations stage it was determined that the participant still did not understand what was required, the measurement was not attempted. Based on judgements made of perceived understanding, the researcher asked the participant (and proxy, where relevant) before each measurement if they understood the measurement instructions and if they felt safe completing it. If the participants responded 'no' to either question and the related reasons, if mentioned, could not be resolved with additional instruction, or clarification where relevant, the measurement was not attempted. Irrespective of the outcome and the actions taken at any stage of the visit, all the related details were recorded in the Results Workbook. Only the measurements that the researcher and participant (and proxy, where relevant) deemed safe to carry out and participants were happy with where attempted.

Of key importance was the review of the Measurement Communication Form (as discussed in Sections 3.8.3 and 3.10.1.1) on the day of the visit. This form enabled the researcher to consider

the participant's age, level of ID, main method of communication, self-rated mobility, and steadiness and eyesight status, and pre-empt access and safety issues that might arise.

3.10.3 Communication Strategy and Presence of Third Party

Clear, open and accessible communication that is age appropriate between the researcher and participant (and proxy where relevant) was critically important to the implementation of the study's design. Listening to and observing non-verbal cues were equally important priorities. The allocation of sufficient time for communication exchanges, so participants did not feel rushed, was essential. The researcher assumed responsibility for effective communication and maximising the conditions (e.g. safe and comfortable environment) for optimal quality of exchanges. From the outset, the review of the Measurement Communication Form and the responses given to the communication-related questions developed were critical, and guided the methods used to initially engage with participants. From there, the methods of communication were adapted as planned in the operational protocol developed and to the needs of each participant. The integration of the familiarisation steps and the methods selected from the Cone of Experience model (discussed in Section 3.6.2) assisted this process.

Respect for the participant was conveyed at all times through the researcher's verbal communication (e.g. tone, content, pace), actions (e.g. avoidance of interpreting, finishing sentences) and body language (e.g. physical expression). Participants were invited to let the researcher know when they did not understand them. The participant's right to decide whether they wished to take part in all, some or any of the measurements was established and respected, irrespective of whether it was expressed verbally and/or through non-verbal cues. If needed, the participant's right to self-determination, irrespective of their level of intellectual disability (ID), was sensitively communicated to the third party present. Any communication-related difficulties met or related experiences were noted in the Results Workbook. Further details on the communication guidelines developed for the visit are detailed in Appendix 29.

3.10.4 Eligibility, Non-Eligibility and Practice Considerations

Aside from the inclusion and exclusion criteria discussed earlier for this study and each of the measurements, supplemental guidelines were developed to ensure the process was fully transparent and implemented consistently across the study (see Appendix 30).

3.10.5 Evaluation Questions on the Process

After each of the second-round measurements (or the first round, if the second was not completed), the researcher completed the evaluation questions in the Results Workbook on any difficulties experienced with the equipment and any other related information about the measurement that needed to be known (see Appendix 21). During this time, participants were preparing for the next measurement and/or for the end of the visit. Once these evaluation questions and the Measurement Record Card (as discussed in Section 3.8.10) had been completed, the researcher introduced, discussed and completed the final questions with participants. The final questions evaluated the usefulness of the Appointment Card and the Measurement Information Booklet. All other feedback given by participants (and proxy where relevant) was recorded in the open space provided in the Results Workbook. Before proceeding any further, each response to the dichotomous questions asked, and any feedback given, by participants (and proxy where relevant) was reflected back to the respondent, so that the researcher could confirm if their response/feedback had been interpreted correctly. The identity of the respondent to the questions and/or feedback was recorded (participant and/or proxy). Lastly, the researcher evaluated the usefulness of the measurement showcards and recorded any other information, feedback and/or reflections from the visit in the open space at the end of the workbook – i.e. details on the effectiveness of the implementation of the operational procedures; the practicality of the materials; the briefing, demonstration and debriefing process; the status of proxy support; and the overall measurement experience.

3.10.6 Position of the Development Stage within the Research Design

Throughout the development stage, there was ongoing evaluation to ensure all the factors from the design stage were addressed. This process also ensured the continuous assessment of the relevance and improvement of the study design and development of any additional guidelines needed to support the implementation stage. The activities of the development stage reflected the influences of both the positivism and post-positivism paradigm positions. However, while the instruction procedures developed were mainly to support the collection of the quantitative data required, there were influences of qualitative components, which sought to extract details of the associated experiences and meaning beyond quantifiable facts.

3.11 Data Collection

Implementation Stage of ADDIE

3.11.1 Timeline of Data-Collection Phases

The data for this exploratory study was broken into two collection phases. The first phase of the measurement visits was undertaken over a four-month period from 21st July 2009 to 23rd November 2009. The second phase was undertaken over a two-month period from 1st August 2010 to 7th October 2010. The measurement visits were scheduled at times and places most suitable for participants (e.g. after work, when they returned from holidays). Where possible, the researcher tried to visit participants in the same place on the same day or week, to improve cost and time efficiencies yet maintain the flexibility offered to participants as much as reasonably practicable. In total the data-collection period for the measurement visits was six months, which was split over two consecutive years. At the end of each data-collection day, all the completed Anthropometric Measurement Results Workbooks were transferred into the locked filing cabinet as per the study's protocol (see Section 3.13.6 for further details).

3.11.2 Position of the Implementation Stage within the Research Design

Throughout the implementation stage, there was ongoing evaluation to ensure all the factors from the development stage were implemented and, if not, the reasons were recorded in the Results Workbook. Unforeseen items for consideration were also recorded and addressed, where appropriate. The design of the Results Workbook facilitated the review of the measurement standards, equipment, accessible materials, and the experience itself. The activities of the implementation stage reflected the influences of both the positivism and post-positivism paradigm positions. Although the quantitative influences were the most dominant, towards the end of the visit the influences of the qualitative components became evident, as indirectly noted in Section 3.10.5 (i.e. the open space in the Results Workbook for feedback).

3.12 Data Analysis

Evaluation Stage of ADDIE

3.12.1 Formative and Summative Evaluation Process

The final stage of ADDIE is the evaluation, consisting of two parts, formative and summative. Formative evaluation was present in each stage of ADDIE to ensure it accomplished what it was supposed to and gathered the necessary information to feed into the summative evaluation. Of critical importance to this summative evaluation was the development and use of the

Anthropometric Measurement Results Workbook in the implementation stage of this study, as it captured the results of the formative evaluation completed. It gathered information on the measurement process from the start to the end of each visit and was used to establish whether the operational protocol had been implemented as planned. It also sought to capture any difficulties, unexpected considerations needed or challenges that emerged, and the details of any adjustments made to ensure the successful implementation of the operational protocol where possible. All the information collected was used to conduct the summative evaluation at the end of the study, which consisted of data analysis and statistical tests. The results were used to determine the learning outcomes of conducting the selected anthropometric measurements within the design framework developed as part of the pilot for IDS-TILDA. However, given the small sample size, some of the conclusions drawn may need to be interpreted cautiously (i.e. with a consideration of the assumptions and inferences), and where necessary, this will be broadly noted in the results chapter (see Chapter 4). The patterns and frequencies reported are not representative of the total population with intellectual disability.

3.12.2 Data Verification and Cleaning

All measurement data was recorded on pre-coded, paper-based forms (see Appendix 21) and inputted into the database developed using the Statistical Package for the Social Sciences (SPSS) Version 18. The SPSS database developed captured all the information collected during the anthropometric measurement visit. All primary data was stored in a locked filing cabinet with access only to the researcher. Prior to data analysis, 10% of the electronic data was compared to the original data source to establish the accuracy of the data entered. No errors were found in the measurement data entered from the original source. However, a few random blank cells (less than 0.03%) were found which should have been coded as legitimate skips '0' during the data transformation stage but were missed. In response, the random blank cells were transformed and coded as legitimate skips '0'. No other errors were found in the anthropometric dataset.

3.12.2.1 Computation of Mean Values

Notably, in the Results Workbook, up to three results may be recorded for each measurement but only the two closest valid readings were used to calculate the mean value and/or to compare the differences between the first and second readings (see Section 3.12.2.4, case-matched valid readings). In some instances, it was necessary to round the mean value to the nearest 0.1cm and, where necessary, rounding was taken to the nearest even digit to reduce systematic over-reporting (Armitage & Berry 1994). For example, a mean value of 72.25cm

would be rounded to 72.2cm while a mean value of 72.35cm would be rounded to 72.4cm. Importantly, if the reading was coded as invalid, the cell with the readings was re-coded '888', signifying not applicable. If the measurement was skipped, the cell was coded '0', signifying a legitimate skipped, as the measurement was not attempted or refused. In terms of calculating the mean reading value per case, if two valid readings (closest two) did not exist, the cell was coded '888', signifying not applicable, or if one valid reading existed, the cell was coded '999', signifying missing, as the mean could not be calculated. Similarly, if the measurement was skipped the cell was coded '0', signifying a legitimate skip. Lastly, in order to capture whether three measurements had been taken, a separate variable was created in the dataset, to extract the status of the third measurement (e.g. response options provided: yes, no, not applicable).

3.12.2.2 Use of Malnutrition Universal Screening Tool (MUST) and Rounding Values

The MUST equations were used to estimate height (BAPEN 2003) from the mean left ulna length measurement values and compared against the height measured values, where possible. Due to the design of the MUST table (see Appendix 31, Table 1), each related mean ulna length value (valid cases only) was rounded to the nearest 0.5cm (half or whole number) for this tool (and the related tests). On the examination of the efficacy of MUST to estimate the Body Mass Index category (see Appendix 31, Table 2) from the mean mid-upper arm circumstance values, no rounding was required.

3.12.2.3 Computation of Ratio Value

A ratio was calculated and formed separate variable in the dataset: body mass index (BMI) score. BMI is based on the ratio of weight (in kg) to height (in meters) squared, using the valid means of each value (case matched). The International BMI classification system (see Table 3.10) of the World Health Organization (2000a) was used to classify BMI scores.

Table 3.10: Classification of Adult Weight Status according to BMI

Classification	BMI Score (kg/m²)
Underweight	< 18.50
Normal Range	18.50 – 24.99
Overweight	25.00 – 29.99
Obesity	≥30.00
Obese Class I	30.00 – 34.99
Obese Class II	35.00 to 39.99
Obese Class III	≥40.00

3.12.2.4 Case-Matching Valid Readings

For tests or explorations that required two variables of interest, only the cases that had both variables and were valid were used (e.g. cases with measured and self-report weight data).

3.12.2.5 Rounding Percentages

Most of the percentages were rounded but a few may not add up to 100% (may add up to 99% or 101%); while in other places the details will not add up to 100% due to multiple responses. Decimals less than 0.5 were rounded down and decimals equal to or more than 0.5 were rounded up.

3.12.2.6 Supplemental Datasets (Stage One and Stage Two of IDS-TILDA Studies)

Aside from the data collected from the measurement visits (Stage Three), there were important contextual covariates of significance to this study from Stage One and Two of the IDS-TILDA studies[14]. Selected data from both the Pre-Interview Questionnaire (Stage One) and Main Interview (Stage Two) of the participants involved in the Measurement Visit (Stage Three) was extracted and merged into a new secured data file. The broad themes of questions extracted and examined were: basic demographics, self-reported height and weight, general health, lifestyle and nutritional status, and personal choices about food selection. Details of the specific questions from both data-collection sources are listed in Appendix 32. The examination of the contextual data selected was of critical importance to building a more complete picture of the sample, and allowing the exploration of links between variables.

[14] IDS-TILDA Pilot Study and one site from the National IDS-TILDA Study

3.12.2.7 Transformations of Self-Report Height and Weight

In the Pre-Interview Questionnaire (PIQ), weight and height if known was reported in a variety of formats (e.g. height in metres, inches, feet or centimetres). For the purpose of data entry, all raw height and weight data was converted to metres and kilograms respectively. To reduce the risk of conversion errors, the personnel cleaning the PIQ dataset were provided with a conversion calculator to check all the calculations for Sites 1 to 3. The error rate found was 10%. For the fourth site, where multiple interviewers were used, the researcher developed an automated conversion table for height and weight in an Excel document (see Appendix 33). Irrespective of how height and/or weight were reported, interviewers would be able to convert the raw data into the preferred format. The conversion table was locked to reduce the risk of formulas being changed or deleted. No errors were found. From all the converted data, the BMI scores were calculated where possible (e.g. presence of both height and weight data), using the formula: weight (kg) / [height (m)]^2. All the conversions were re-rechecked by the researcher. Four of the 51 cases had score errors (8%). Although all four BMI scores changed as a result, only one score changed the related cut-off points, which are used to define weight status (e.g. score changed from overweight to obese).

The researcher had no access to or knowledge of the self-report height and weight data of participants until the analysis stage of this study; thus there was no risk of bias concerning the anticipated values of both variables when measured.

3.12.2.8 Transformations of Levels of Intellectual Disability

In the PIQ, respondents were provided with six response options to categorise their level of ID: not verified; mild; moderate; severe; profound; and don't know. Each category was included in the analysis, including those classified as 'not verified' or 'don't know', as each participant in the study has an ID (requirement for registering on the sampling frame used). Participants in the 'not verified' group have not had their level of ID confirmed and those classified as 'don't know' either did not know their level of ID or it was not given by the participant and/or proxy at the time of the PIQ completion. For the purposes of this study, the contribution of those in both the 'not verified' and 'don't know' category are of no less importance than those in the other four categories. However, there is a caveat concerning the use of both categories in the quantitative analysis phase (see Section 3.12.3). For ease of reading, the category 'not verified' is referred to as 'unverified' and 'don't know' is referred to as 'unknown' from here on. Also, for some of the

analysis, the six categories on levels of ID are regrouped into three main categories: mild and moderate; severe and profound; and unverified and unknown.

3.12.3 Quantitative Analysis

Descriptive results for means, standard deviations and frequencies were used and organised into tabular and graph forms, where appropriate. Means and standard deviations were rounded to two decimal places. Certain data was examined against gender, age, levels of ID, and other categories of interest. However, due to low numbers, the influence of those with unverified or unknown levels of ID (i.e. the 'don't know' category) and those aged 60 years and over was not always examined (not normally distributed). Where this applies, a short note will be provided. The normality of the distribution for each of the measurements was examined by Kolmogotov-Smirnov and Shapiro-Wilk Tests (n=<50), histograms and Q-Q plots, and, unless otherwise stated, the data was normally distributed. Only the cases that had two valid readings per measurement (e.g. height) were included in the statistical analysis.

3.12.3.1 Operational Feasibility

To gauge the operational feasibility of conducting the selected anthropometric measurements within a random sample of people with ID aged 40 years and over, the percentage of participants eligible for each measurement was calculated. The total number of participants eligible for each measurement was divided by the total number of participants. See Section 3.10.4 for further eligibility details and Appendix 7 for the specific eligible criteria for each measure.

3.12.3.1.1 Measured Feasibility among Eligible Participants

Despite initial eligibility, some participants were unable to complete the measurement or it was unsafe to do so. To determine the feasibility of conducting each measurement among elgible participants, the percentage of participants measured was calculated. The total number of participants measured was divided by the total number of participants eligible for each measurement. Of those measured with case-matched readings, the validity and reliability of the measurement results were then assessed for each measurement.

3.12.3.1.2 Feasibility of Valid Measurement Obtainment

The feasibility of obtaining valid measurements was assessed in two ways. First, based on the 95% success rate set within a similar study (Waninge *et al.* 2009); for each measurement the

number of successful measurements (valid readings) was compared with the total number of measurements, using the Binomial Test. Secondly, based on the difficulties reported in the literature on measuring height in an older population, and the validity concerns and challenges of measuring waist circumference over clothing that were expressed by personnel contacted during the analysis stage of this study, the researcher set an expected success rate below 95% for both measurements, and a greater than or equal to 95% rate for all other measurements. The actual feasibility percentage (number of successful measurements [valid readings] by the total number of measurements) was then compared to the percentage expected, as noted above.

3.12.3.2 Assessing the Reliability of Anthropometric Measurements

To assess the reliability of anthropometric measurements in the dataset, the means and standard deviations of each measurement (first and second readings) were calculated (valid readings) and statistical inferences within the same set of measurements were made through paired t-test. The associations among the first and second measurement readings were also analysed by the Pearson's correlation coefficients (r) at a 0.05 significance level. The correlation coefficient values closest to 1.0 demonstrate a stronger positive linear relationship between the data examined. Chan (2003) suggests that values from 0.8 upward indicate a very strong linear relationship, while a value less than 0.3 suggests a poor linear relationship. The relative retest reliability of each measurement was determined by the intra-class correlation coefficient (ICC). The 95% confidence intervals for the ICCs were calculated. The values for the reliability coefficient ranged from 0 to 1.0. A coefficient below 0 indicates 'no reliability', >0 to <0.2 'slight reliability', 0.2 to <0.4 'fair', 0.4 to <0.6 'moderate', 0.6 to <0.8 'substantial' and 0.8 to 1.0 'almost perfect reliability' (Bland & Altman 1986). The systematic error (the mean of difference scores of retest and test) was checked by a paired t-test with the significance level set at 0.05. The Technical Error of Measurement, an accuracy index that represents the measurement quality and control dimensions, was also assessed in this study.

3.12.3.2.1 Technical Error of Measurement (TEM)

Technical Error of Measurement (TEM) is the method used and adopted by anthropometrists accredited by the International Society for the Advancement of Kinanthropometry (ISAK). The TEM index allows examiners to verify the degree of accuracy when performing and repeating measurements. The lower the relative TEM obtained (%TEM), the better the reliability and accuracy of performing the measurement. The accepted range of relative TEM for Level 2 ISAK

anthropometrists is ≤1.0%. For each measurement, TEM, %TEM and the coefficient of reliability (R) were calculated. R represents the proportion of between-subject variance that is free from measurement error (e.g. R = 0.90 means that the measurement is 90% error-free). The R ranges between '0' and '1'; the nearer the value is to '1' the better is its reliability.

The formula for TEM calculation was used:

$$\mathbf{TEM = \sqrt{(\Sigma d^2)/2n}}$$

where '$\sum d^2$' = summation of deviations raised to the second power and 'n' = number of participants measured.

To covert the TEM, also known as the absolute TEM, to a relative TEM (%TEM), the following equation was used:

$$\mathbf{\%TEM = (TEM/mean) \times 100}$$

The coefficient of reliability (R) was calculated by:

$$\mathbf{R = 1-(TEM^2/SD^2)}$$

where 'mean' refers to the measurement's average and 'SD' refers to the standard deviation for that measurement. R values > 0.95 were sought (Ulijaszek & Lourie 1994), meaning greater than 95% of the measurement is error-free (high degree of measurement precision). The values were rounded to four decimal places.

3.12.3.3 Statistical Tests Examining Relationships and Differences between Variables

The following statistical tests were used to analyse the data following standard test procedures: Pearson's Product-Moment Correlation for the strength and direction of associations; paired t-tests to assess the significant differences between means; independent t-test to test the significance of the difference between the mean of two independent samples and linear regression to measure to what extent there is a linear relationship between two variables. Eta-squared was used to calculate the effect size and determine the significance of the paired t-test results.

The formula used was calculated by:

$$\mathbf{Eta^2 = t^2/t^2 + df}$$

and the value was rounded to two decimal places.

Separately, to account for multiple comparisons made on the height-related variables (i.e. estimated, measured and self-report) using paired t-tests; the Bonferroni Correction was applied to a critical P value of 0.05 to obtain a new criterion. The Bonferroni Correction sets the significance cut-off at α/n. If the unadjusted p-value was less than the Bonferroni-corrected target alpha, then the null hypothesis was rejected. If the unadjusted p-value was greater than the Bonferroni-corrected target alpha, then the null hypothesis was not rejected.

3.12.3.3.1 Statistical Differences

Statistical differences detailed in the results chapter are shown as being significant, at a 95% confidence interval ($p<0.05$). The terms 'significant difference' and 'statistically significant' are used interchangeably. Instances where the differences are described as 'not statistically significant' or 'not significant' indicate $p>0.05$ and the null hypothesis is accepted. An alpha level of 0.05 was used for all statistical tests, and the above interpretation was guided by the School of Computer Science and Statistics Base Module in Trinity College Dublin (TCD 2011, p. 9). Confidence intervals were rounded to four decimal places.

3.12.4 Qualitative Analysis

The qualitative data analysed in this study was compared to the overall quantitative findings to test the authenticity of the results and experiences. A thematic analysis was conducted of the observable data reported in the Anthropometric Measurement Results Workbooks collated. Importantly, both datasets were analysed separately and neither compared until both analyses were complete. On completion, for example, the recorded observations (qualitative data) on the problems experienced with measuring equipment were compared to percentage of cases that were quantitatively categorised as experiencing problems with measuring equipment.

3.12.4.1 Constant Comparative Method

The constant comparative (CC) method was adopted to conduct the analysis according to Miles and Huberman (1994) and Maykut and Morehouse (1994) who draw on the work of Glaser and Strauss (1967) and Lincoln and Guba (1985). The analysis sought to "find patterns within the

words and present those patterns for others to inspect while at the same time staying as close to" the measurement visit "as the participants originally experienced it" (Maykut & Morehouse 1994, p. 18). The data was not grouped into pre-defined categories but rather leading categories of meaning and relationships between them were derived from the data itself through the process of inductive reasoning. The CC method allowed the researcher to access and analyse the perspectives reported, and explain the processes under study, which ultimately complements and provides a greater insight into the quantitative data.

3.12.4.2 Overview of Process Mapping

The constant comparative method involves breaking down the data into discrete 'incidents' (Glaser & Strauss 1967) or 'units' (Lincoln & Guba 1985) and coding them into categories. Broadly, the categories arising from this method fall into one of two overarching themes: (1) those that derive from the participants, and (2) those that the researcher identifies as significant to the study. The aim of the first overarching theme was to reconstruct the categories used by participants to conceptualise their experiences, while the latter sought to assist the researcher in developing theoretical insights into the processes under study. Hence the process of constant comparison stimulates thought that leads to both descriptive and explanatory categories (Lincoln & Guba 1985). As a result, during the analytical process, the categories undergo content and definition changes as the 'incidents' or 'units' are compared and categorised. Equally, as the researcher's understanding of the details of the categories and the relationships between them developed, the categories became more refined over time.

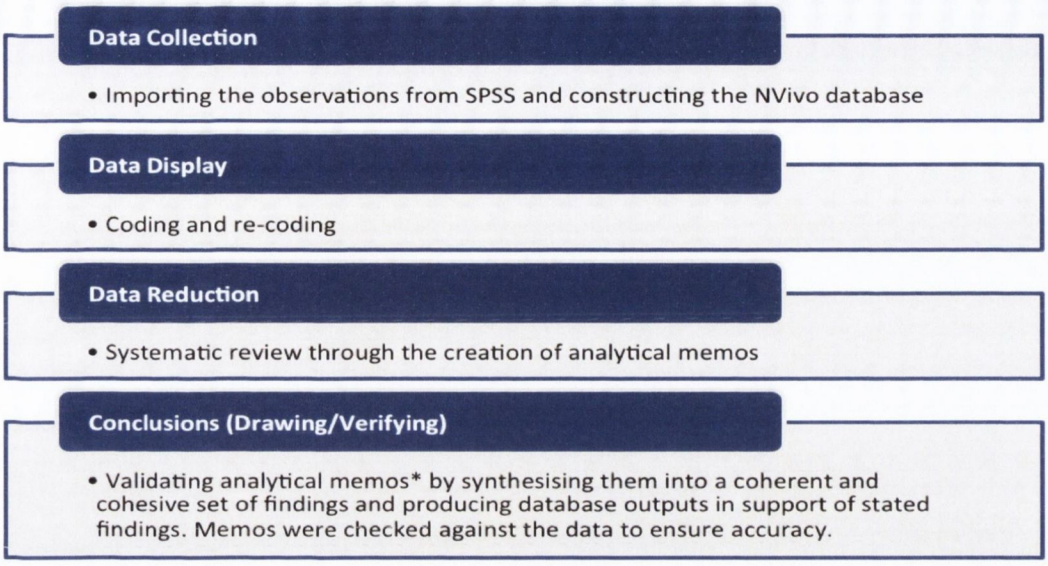
3.12.4.3 Data Analysis Software

The qualitative analysis tool used was NVivo 10 Research Software Package.

3.12.4.4 Guiding Framework for Qualitative Analysis

The guiding framework used to complete the data analysis was Miles and Huberman (1994). It consists of four main steps: data collection, data display, data reduction, and conclusions. See Figure 3.14 for details of the main activities associated with each of these steps. Details of the key elements contained in the analytical memos developed are given below Figure 3.14.

Figure 3.14: Guiding Framework for Qualitative Data Analysis



*The analytical memos contained five key elements:

- The content of the cluster of codes on which it was reporting.
- The numbers where relevant – levels of coding, used to identify exceptional cases as well as shared experiences.
- Placement of the code(s) on the storyboard – considered as the relatedness of codes to each other and their importance to addressing the research question.
- Consideration of background information recorded against participants and any patterns in relation to their profiles (cross-referenced against the table).
- Consideration of the primary sources and relationships with the literature as well as gaps in the literature, where relevant.

3.12.4.5 Displaying the Qualitative Results

Tables were used to show the list of categories to emerge from the analysis. The themes of the categories were ranked by frequency distribution, from most to least frequent. The themes ranked least frequent are no less important than those ranked most frequent. All categories, irrespective of their placement, contribute equally to our overall understanding of the phenomena of interest. Unlike with the quantitative data, the actual frequency is not reported in the tables, as the frequency was used to guide the ranking process only. The purpose of the tables is to show the overall categories/themes for each relevant section before providing insights into the related details. Next to each quotation used, a code number was included to anonymously represent the identity of the participant and affirm validity. All gender-specific

pronouns were removed from quotes used to further protect the anonymity of participants (see Section 3.13.6 for further details). In the analysis stage of ADDIE, quotations were also included but, at the end of each, the type of personnel involved was provided in brackets as opposed to the code number assigned to them.

3.12.5 Position of the Evaluation Stage within the Research Design

Although the evaluation stage is theoretically the final stage of the ADDIE model, formative evaluations were part of each stage. In the analysis stage, the formative methods used included: a detailed literature review, expert reviews of the proposed study, one-to-one consultations with experts (e.g. email, telephone, site visit) and a small group session with the target audience. At the end of each method, a record analysis of the findings was completed, which informed decisions about how to improve the study and/or any further actions needed.

Throughout the ADDIE stages, the researcher was critically reflective, to ensure all components outlined were addressed and any new ideas that emerged were considered and acted upon, where appropriate. In the design and development stage of ADDIE, the central tenet was the ongoing review of the information gathered and key learning from each preceding stage, as well as the identification of any gaps or errors in the instructional development process. Small group sessions with the target audience were held to review the accessible materials developed before the field test. All of the data and information gathered during the first three stages was used to improve the effectiveness of the instructions and materials.

Critical to the implementation stage (field test) was the use of the Results Workbook, as it captured not only the measurement findings but also in-depth information on the process and contextual factors that facilitated or hindered the successful implementation of the instructional procedures. All related experiences and observations were recorded. The findings from all of these formative evaluations were fundamental to the summative evaluation completed at the end of the study. The evaluation stage sought to assess the overall effectiveness of the instructions, the measurement results and process, and related experiences. The findings reflected the influences of both the positivism and post-positivism paradigm positions as set out in the study design. The former paradigm represented the main influence of the evaluation conducted (e.g. quantifiable data) but the latter provided a deeper understanding of contextual variables and explanations of how and why the study outcomes were or were not achieved (see Chapter 4 for the results).

3.13 Ethical Considerations and Protections

All research activity associated with this study was carried out in accordance with the regulations of the University of Dublin, Trinity College Guidelines for the Conduct of Research Studies (TCD 2009). Key ethical principles guided the considerations and actions taken by the researcher from the inception of the study through to the end of the research process. The guiding principles were: justice; autonomy; informed consent; privacy and confidentiality; freedom from harm, and the anticipated benefits of this research study. The safe, respectful inclusion of people with ID and protection of their right to decide whether or not they wished to take part in the study were deemed critically important. In support of this position, the researcher adopted a person-centred perspective to ensure the interests of the participants remained central to the study at all times. All efforts were made to plan and respond to the diversity of abilities, levels of understanding, and potential support needs of the participants.

3.13.1 Ethical Review and Approval Process

Ethical approval for the IDS-TILDA studies (pilot and national study), which included the measurement visit (i.e. for the three IDS-TILDA pilot sites and one site in the national study only), was first granted (see Appendix 4) by the Faculty of Health Sciences (FHS) Research Ethics Committee in TCD. Local ethical approval was then sought and secured from the four participating sites. Details of the measurements and copies of related accessible information to be released to potential participants (i.e. Measurement Information Booklet, Appointment Card and Record Card) were supplied to each committee as part of the ethics applications submitted. No revisions were requested by any of the five ethics committees (TCD plus 4 sites). A copy of the letter outlining the approval granted by TCD was included in the site applications to the four participating sites, and to the National Intellectual Disability Database (NIDD) committee as part of the application to use the NIDD datasets as the sampling frame. Finally, after ethical approval was secured from each of the four sites, a letter of support from each site was requested, obtained and included in the invitation packs issued to participants (as discussed in Section 3.8.2.1). Critically, this letter sought to reaffirm the right of the participant to determine whether or not they wished to take part in the study, and, irrespective of the decision made, it stated that a decision not to take part would not affect the current or future services or supports offered. A similar message was also included in the study materials issued.

3.13.2 Justice and Inclusiveness

The participants' right to fair and equitable treatment both in the selection and participation in the study was respected and acted upon. The distribution of the present and future benefits of

the study, and the burdens of research (e.g. time commitment) were shared equally. In practice, all persons with ID aged 40 years and over, registered on the NIDD within the four sites, had an equal chance of being selected to take part in the study. No other selection criterion was applied, which ensured the necessary diversity within the population group (e.g. different levels of ID). Once the eligibility criteria for the study, the measurement visit, and each measurement had been met, with the participant's agreement the measurements were taken. The researcher took steps to ensure the inclusiveness of all levels of ID, not only in terms of sample selection in the design phase, but also in the recruitment and implementation stages by using various methods (e.g. pictures, text) to engage participants with varying levels of ability (as discussed in Sections 3.7 and 3.10.3).

Throughout the measurement visit, a system of process consent was used (see Section 3.13.5) with all participants (e.g. by obtaining assent and respecting dissent). However, its use was particularly important among those who required third-party support to complete the consent form as they were unable to sign or mark the form themselves. Necessary checks were integrated into the study design to ensure that all participants were happy to take part and their rights were protected at all times. The dignity of participants was also respected throughout the research process. Finally, in relation to both justice and inclusiveness within the broader context, national surveys – such as the Survey of Lifestyle, Attitudes and Nutrition (*SLÁN*) – have not investigated direct[15] anthropometry in people with intellectual disability (ID), either exclusively (as a subsample alongside the main study) or inclusive of sufficient numbers to be representative of this population group, despite the need for such information. This study is the first step towards addressing this gap and will provide future direction on the inclusion of anthropometry assessment with people with ID in research studies, such as IDS-TILDA, and other relevant national and regional surveys.

3.13.3 Autonomy and Rights

Promoting the autonomy and rights of the participant to make their own decision about whether or not to take part in the study, free of coercion and without any negative consequence, was one of the guiding principles in the study. To promote both, the invitation packs were sent directly to the person with ID selected. The right of the individual to determine their own will and preference was outlined in the information material issued. All materials were accessible so as to maximise understanding. As discussed earlier in this chapter, all the accessible materials were reviewed for accessibility (see Section 3.8.1).

[15] Reminder: Use of the term 'direct' in this context refers to measured anthropometric parameters such as height, weight, etc.

For those who were unable to read or fully comprehend the materials, support workers/family members were requested to discuss the study with the participant. In all cases, irrespective of the participant's level of ID or method of consent, the researcher acknowledged at the start of the measurement visit the right of the participant to take part in all, some or none of the measurements (and withdraw from the visit at any stage), and the decision made by them (verbally or non-verbally) was fully respected. Specific instructions to guide third-party support were developed and integrated into the operational protocol. In particular, on the day of the measurement visit, despite the presence of proxies (where applicable), the importance of the participant remaining central at all times and of their rights being protected was emphasised.

As noted earlier, process consent was used throughout each stage of the study irrespective of written consent/agreement received. Using a mixture of verbal, visual and text aids, the researcher sought to ensure that participants understood the purpose of the study, any potential risks, benefits to themselves and others in the future, their right to refuse or withdraw at any stage, and their rights to privacy and confidentiality. An ongoing review of their understanding of these factors and the procedures involved for each eligible measurement was undertaken by the researcher. Ensuring voluntary consent/assent (e.g. review of verbal and non-verbal cues), minimising the potential of any risk of harm (e.g. correct use of equipment) or burdens, and respecting participants' dissent (i.e. verbal or non-verbal cues indicating their wish not to take part in all or some of the measurements), were key considerations throughout the study.

3.13.4 Informed Consent

Before the study could commence, the participant and/or proxy (support worker and/or family member) where relevant must authorise his/her participation in the research study, by return of the consent and/or agreement forms issued. The process of providing the necessary information, obtaining consent/agreement and re-negotiating the participant's agreement thereafter (e.g. at start of the measurement visit and at each measurement using the 'process consent' method) is discussed from Section 3.13.4.1 to 3.13.5. Ensuring that all the relevant information was provided to participants in an accessible format, so they could reach a truly informed decision about whether or not to participate in the study and what their participation involved, was a vital part of the research process. Necessary checks were integrated into the operational protocol to ensure informed consent (and assent [i.e. participants agreement], if unable to give informed consent) was given freely, without coercion, and the choice to participate was voluntary, while the right to withdraw without negative consequence was

clearly communicated. An awareness of verbal and non-verbal cues from participants indicating their wish or reluctance to be involved in the study was paramount throughout the measurement visit.

3.13.4.1 Disclosure and Comprehension

Through each invitation pack issued, participants (and families/guardians) were informed of the purpose of the research study (including the measurement visit), the procedures involved, the expected benefits, the lack of any foreseeable risks, the length of time the measurement was expected to take, the measures taken to ensure confidentiality and the anonymity of participants, and the contact details of personnel to contact with questions. For the measurement visit, a more detailed but accessible Measurement Information Booklet was provided at the end of the interview. Although all the materials issued for participants were accessible, if additional support was needed, guidelines were included in the materials that were directed to the families/guardians.

3.13.4.2 Return of Consent/Agreement Forms

Those selected who were interested in taking part in the IDS-TILDA studies[16] and able to consent independently were requested to return their consent form directly to the study team in the self-addressed envelope provided. However, it was acknowledged that some people might not be able to give written consent (signing their name or marking the form) but would like to take part in the study, using self-expression methods and/or indicating this through a family member/support worker acting on the will and preferences of the person. In such situations, the materials issued (and the study team if contacted) advised that someone who knew the person well (i.e. family member/support worker) should discuss the study materials with the person selected. If interested, the family member/support worker should then complete and return the agreement form to the study team in the self-addressed envelope provided. Guidelines on returning the consent/agreement forms were outlined in the information packs. Participants were also informed that they could have the full or partial support of a family member, support worker or another person of their choosing during the study if needed. The contact details of the study team (plus the researcher) were provided in all of the materials issued.

[16] IDS-TILDA Pilot Study and one site from the National IDS-TILDA Study

Once a consent/agreement form was returned, an individual identification number was assigned to the participant, and the interviewer allocated to that site placed a thank-you call to the contact person detailed on the form (e.g. participant/family). The identification number was used on all forms (including the measurement visit forms) and communications between the interviewers and the researcher to protect the person's anonymity. Details of all the measures taken to protect the privacy and confidentiality of the participants in the study are provided in Section 3.13.6.

3.13.4.3 Written Consent/Agreement to Measurement Visit

As the measurement visit formed an integral part of the pilot study and the single site selected from the national IDS-TILDA study, all the relevant materials in the invitation pack (e.g. accessible information booklet, consent/agreement form) issued to the selected sample had brief but key details of the measurements sought. Interested participants were not only consenting or agreeing to complete the interview; they were also agreeing to have some measurements taken. However, despite the securement of written consent/agreement and the target to measure all the participants in the IDS-TILDA studies, interviewers were instructed to reintroduce 'the measurement visit' at the end of the interview stage. Essentially, interviewers outlined the importance of the measurement visit and provided the accessible Measurement Information Booklet (see Appendix 25), which gave more detailed information on each measurement proposed. Interviewers gave a brief overview of the booklet, which included: type of measurements; how long the visit would take; who would take the measurements; no foreseeable risks of harm or discomfort; the results; and the right to withdraw at any stage. The intended outcome of the briefing was to reaffirm the participant's willingness, and/or proxy agreement to support the participant (proxy-only interviews), to have some measurements taken, where possible. Details of the specific instructions/guidelines given to interviewers by the researcher as part of their training programme are outlined in Appendix 16.

3.13.5 Process Consent, Voluntariness and Withdrawal

Throughout the study, the concept and practice of process consent was applied. The researcher continually renegotiated verbal/expressed consent to participate, irrespective of written consent/agreement received, to ensure the participant (and proxy, where relevant) played a collaborative role in the decision-making process regarding their ongoing participation (Polit & Beck 2008). To empower participants (and proxies, where relevant) to make such decisions, it was imperative that they be kept informed at all stages of the data-collection process, including the measurement visit. The Economic and Social Research Council (ESRC) Framework for

Research Ethics (ESRC 2010) in the UK suggests that 'process consent' is especially important in a research design which involves more than one point of contact with the participant, as in this study.

The participant's capacity to make decisions for themselves about the measurement visit and each measurement was always assumed. Clear accessible communication (see Section 3.10.3) and the use of alternative forms of communication by the researcher, as well as observation of and respect for non-verbal cues from participants (e.g. body language [facial expression, eye contact, gestures and posture], emotional and behavioural responses) were critical to the 'process consent' method (i.e. obtaining assent and respecting dissent). The researcher also sought to create a relaxed environment for participants, so they felt comfortable asking questions and to freely make the decision to take part or withdraw should they choose to do so, irrespective of who completed the formal consent/agreement form. Whether the participant completed the consent form and/or an agreement form was completed on their behalf, it was acknowledged that they might not be able to anticipate what the measurement visit entailed until the visit itself, so participants were reminded on the day of their right to withdraw at any stage. Section 3.10.1.4 detailed the consent checks developed for the start of measurement visits and were followed through before commencing any measurements.

3.13.6 Confidentiality and Anonymity

Two standards were applied to protect the privacy of participants: confidentiality and anonymity. Both were noted in the invitation materials issued and explained in person to the participant (and proxy where relevant) at the beginning of the measurement visit, using terms they understood. The researcher verified that they understood both standards. The participant's confidentiality is protected in accordance with the Data Protection Acts (Government of Ireland 1988, 2003). Strict procedures were developed and maintained to protect the participant's identity and data. One of the key procedures was the use of the PIN number generated for each participant at the point of entry into the IDS-TILDA studies in order to reversibly anonymise the data on all records. Neither the participants' name nor contact details were recorded in the Anthropometric Measurement Results Workbook, which not only protected their identity but also ensured they could not be identified on the basis of the data.

All completed workbooks were stored securely in a locked filing cabinet with restricted access. Encryption technology was used so that electronic data was kept safe and the files were protected by an encryption code to maintain privacy. Access to the locked filing cabinet and the

computer was restricted to the researcher. Participants (and proxies, where relevant) were informed that the data would be reported in group form only and no identifying features of participants, services or others would appear. Unique anonymised numbers were inserted beside the qualitative quotes reported, to replace the allocated PINs. All gender-specific pronouns were removed from quotes used in order to protect anonymity further and were replaced with gender-neutral pronouns in brackets such as 'their', 'they' and 'them'.

3.14 Conclusion

This chapter has presented a detailed account of the research philosophy, strategy and methodology underlying and guiding the execution of this study. The level of detail provided is reflective of the need for rigorous study design and standards, and transparent reporting, in anthropometry research involving people with intellectual disability. The two overarching research paradigms (positivism and post-positivism) applied in this study reflect the epistemological position taken by the researcher. A mixed-methods approach was taken; both quantitative and qualitative techniques were used but the quantitative method was most dominant. These methods were conceptually guided by two theories, the measurement theory and the familiarisation theory, and the Cone of Experience model, and all three were incorporated into the ADDIE framework for instructional design. In the following chapter, Chapter 4, details of the research findings are presented.

Chapter 4: Results of Analysis

4.1 Introduction

This chapter presents the results of the statistical and data analysis for the data collected by using mixed methods. The results are divided into three phases[17]. *Phase 1* presents the response rate and key demographic, health and lifestyle data of the sample population. *Phase 2,* broken into three sections, presents details of (a) the results of the anthropometric measurements, (b) the process findings on completing the measurements, and (c) the process findings on the experience of using the project materials. *Phase 3* presents the results of the hypotheses tested based on the valid measurement readings reported in Phase 2. A summary of the main findings follows each hypothesis.

4.2 Phase 1: Response Rate, Baseline Demographic, Health and Lifestyle Data

4.2.1 Response Rate and Consent/Agreement Status

A summary of the response rate and the status of the consent/agreement forms returned is presented below.

4.2.1.1 Response Rate on Day of Measurement Visit

A total of 77 participants aged 40 years and over took part in the measurement \ representing 95% of those who had reaffirmed their interest at the interview stage of the IDS-TILDA studies[18] (n=81). On the day of the measurement visit, four of the 81 participants who reaffirmed their interest at the interview stage were withdrawn. The reasons for their withdrawal were: change of mind (n=3), with one participant communicating this verbally and the two others communicating it through behaviour (e.g. looking into the room where the equipment was located and walking away), and ill health (n=1). See Table 4.1 for a summary of the recruitment process results (and Appendices 5 and 6 for further details on the process).

[17] Reminder: Due to rounding, some totals may add to 99% or 101%

[18] IDS-TILDA Pilot Study and one site from the National IDS-TILDA Study

Table 4.1: Summary of the Recruitment Process

		Site 1	Site 2	Site 3	Site 4*	Total
Response Rate to IDS-TILDA Pilot Study & One Site from the National Study						
Recruitment Stage	No. of People Invited	80	20	60	28	188
	No. of Consents/ Agreements Received	18	18	30	21	87
	%	23%	90%	50%	75%	46%
Rate of Reaffirmed Consents/ Agreements to Measurement Visit						
Interview Stage	No. of Reaffirmed Consents/Agreements	15	15	30	21	81
	%	83%	83%	100%	100%	93%
Final Response Rate to Measurement Visit (Exploratory Study)						
Measurement Stage	No. of People Measured	14	15	28	20	77
	%	93%	100%	93%	95%	95%
*Site 4 is part of the national IDS-TILDA study						

4.2.1.2 Status of the Consent and Agreement Forms Received

On review of the consent/agreement forms received from those actively involved in the IDS-TILDA studies and associated with the measurement visit (*n*=77), the majority, 97% (*n*=75), of participants, received some level of support in completing the consent form process. Only 6% (*n*=5) self-consented and, of these, three participants (4%) also returned the family/guardian agreement form. Table 4.2 shows a summary of the consent and agreement status.

Table 4.2: Summary of Consent and Agreement Status

Consent and Agreement Status	n	%
Self-consent only	2	3
Self-consent plus family/guardian agreement form	3	4
Self-consent form completed in partnership with support worker	30*	39
Consent form: agreement section signed by support worker only	26**	34
Family/guardian agreement form signed by family or guardian only	16	21

**n*=24 and ***n*=19 also returned a family/guardian agreement form

4.2.2 General Demographic Characteristics of the Participants

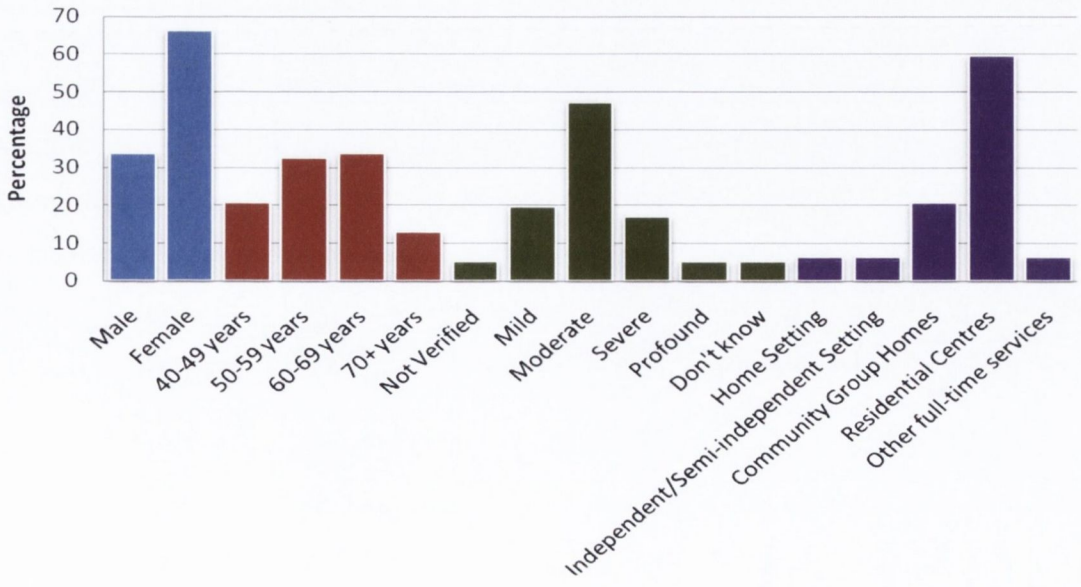
Key data on the demographic characteristics of the participants (n=77) was selected from the Pre-Interview Questionnaire (PIQ) and the face-to-face interview databanks (see Appendix 32 for further details) of the IDS-TILDA studies to provide a contextual profile of the participants.

a) Gender, Age and Marital Status

Of the 77 participants, 34% (n=26) were male and 66% (n=51) female. Fewer men than women took part. As discussed in Chapter 3, Section 3.7.1.3, the invited sample had 20% fewer males and 20% more females in proportion to the total of those aged 40 years and over registered on the National Intellectual Disability Database (NIDD). The mean age of the participants was 59 years (range 43-94 years). There was no significant difference between genders, with the mean age of males at 57 years (SD=10) and at 60 for females (SD=10). Twenty-one percent (n=16) of all participants were aged between 40 and 49 years, 32% (n=25) were aged between 50 and 59, 34% (n=26) were aged 60-69, and 13% (n=10) were aged 70 and over. All age groups over 40 years were represented, with 40-59 year-olds accounting for 66% (n=51) of the sample. Within this sample group, one of the males was separated (1.3%) and one of the females was living with a partner (1.3%); the rest of the participants classified themselves as single (97.4%).

See Figure 4.1 for the gender and age distribution of the participants, as well as other characteristics.

Figure 4.1: Demographic Characteristics of Participants



b) Level and Cause of Intellectual Disability

All levels of intellectual disability (ID) were represented in the study (see Figure 4.1). A total of 5.2% of participants (n=4) reported their level of ID as not verified, while 19.5% (n=15) reported it as mild, 46.8% (n=36) as moderate, 16.9% (n=13) as severe, and 5.2% (n=4) as profound. A total of 5.2% (n=4) did not know their level of ID and one participant (1.3%) did not wish to complete this question on the Pre-Interview Questionnaire (PIQ) issued (also classified as 'don't know' for the purpose of this report). On review of the nine cases (11.7%) with no specified level of ID reported against the data on the measurement experience (levels of interaction and participation in the process) and the level of functioning as it relates to Activities of Daily Living (ADL) and Instrumental ADL reported in the interview, the researcher tentatively suggests that six of the participants are likely to be in the mild and moderate range of ID and three to fall within the severe and profound range. In terms of the causes of the ID, 13% (n=10) reported the cause of their ID to be Down syndrome; 58% (n=45) reported the cause to be unknown, while 12% (n=9) reported a range of other causes, such as cerebral palsy, birth complications, phenylketonuria, and meningitis. A total of 16% (n=12) did not know the cause of their ID and one participant (1%) did not complete this question on the PIQ.

c) Level of Educational Attainment and Residential Status

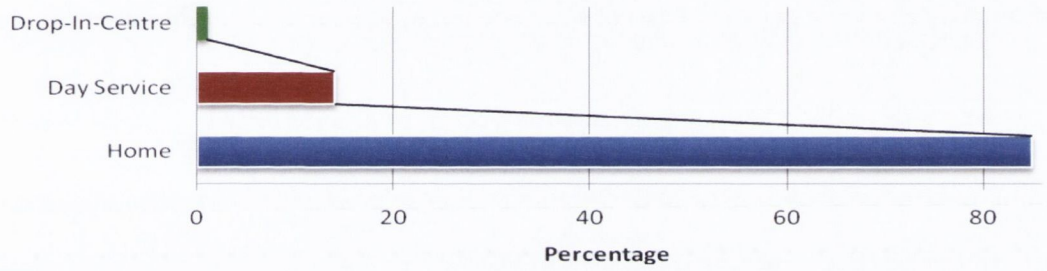
A total of 44% (n=34) of participants reported having no or only some primary-level education, with a further 21% (n=16) unsure about the level of education completed. Only 22% (n=17) had completed primary-level education and 13% (n=10) had attended special schools for the equivalent primary and secondary years of education. The majority, 86% (n=66), of participants reported that they had not participated in a course or attended any training in the last year. As can be seen in Figure 4.1, the main types of residential circumstances were represented in the study, but the majority, 61% (n=47), reported living in residential centres, which was not unexpected given the sites selected. Five participants (6%) reported living independently or semi-independently, 5% (n=4) living with family/relatives, 22% (n=17) living in community group homes. While the remaining 5% (n=4) had different living circumstances, including living with sister and partner (n=1), with a non-disabled person (n=1), and combined residential/community living provision with individualized home arrangements (n=2).

i) Selected Locations for the Measurement Visits

The majority of participants (84%; n=65) chose to have the measurements taken in their home. A total of 14% (n=11) chose to have them taken at their day service and one participant (1%) decided to have them taken at their local drop-in-centre. See Figure 4.2 for the chosen locations selected by the participants for the measurement visit. Notably, 26% (n=20) of participants were

provided the opportunity to have the measurements taken at a central onsite location (i.e. day centre) to mirror a 'clinic-style set-up'. Only six agreed and, of these, just four appointments took place at this location. On the day of the measurement visit, two participants changed their minds and chose to have the measurements taken in their home, along with the other 14 participants who opted for home visits. More localised 'clinic-style set-ups' (e.g. in homes) were often feasible when more than one participant was involved. The benefits, such as the smooth transition between appointments and reduced set-up time of equipment, were noted and will be discussed as part of the findings presented in Phase 2.

Figure 4.2: Selected Locations for the Measurement Visits



4.2.3 Mobility and Sensory Status

Mobility and sensory status (vision and hearing) were two important factors considered in the preparation and implementation of the operational protocol for the measurement visit with each participant. Although the key information required was detailed on the Measurement Communication Forms received from interviewers (see Appendix 17), for the report of details presented below the data was selected from the face-to-face interview databank (see Appendix 32). A summary of the overall mobility and sensory status is presented below.

a) Wheelchair Use Status

On the day of the measurement visit, 19 participants (25%) were active wheelchair-users, two more than had been recorded and reported by interviewers (n=17). The majority, 63% (n=12), of the wheelchair-users had a severe or profound ID, which represents 71% of the total population of people with severe or profound ID (n=17) that took part in this study. The remaining 37% (n=7) had a moderate (n=5), mild (n=1) or an unverified (n=1) level of ID.

b) Steadiness Walking, Standing and Getting Up from a Chair

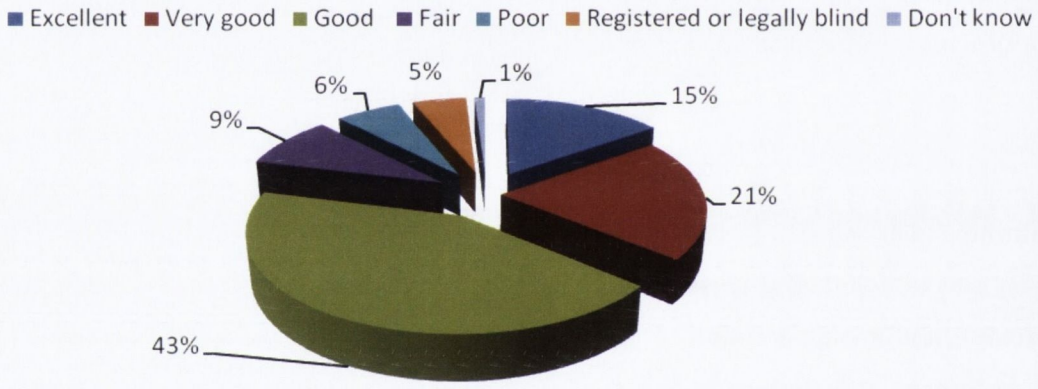
The majority of participants reported being very steady walking (60%; n=46), standing (68%; n=52) and getting up from a chair (61%; n=47). Only 3% (n=2) of participants reported being

very unsteady when walking and none reported this status for either of the other two parameters. However, across the board, a few participants did report that they were either slightly unsteady or slightly steady when walking (12%; *n*=9 vs. 5%; *n*=4), standing (8%; *n*=6 vs. 4%; *n*=3), and getting up from a chair (14%; *n*=11 vs. 6%; *n*=5). The outstanding 21% (*n*=16) reported that none of the questions was applicable to them at the time of the interview.

c) Eyesight and Hearing Status

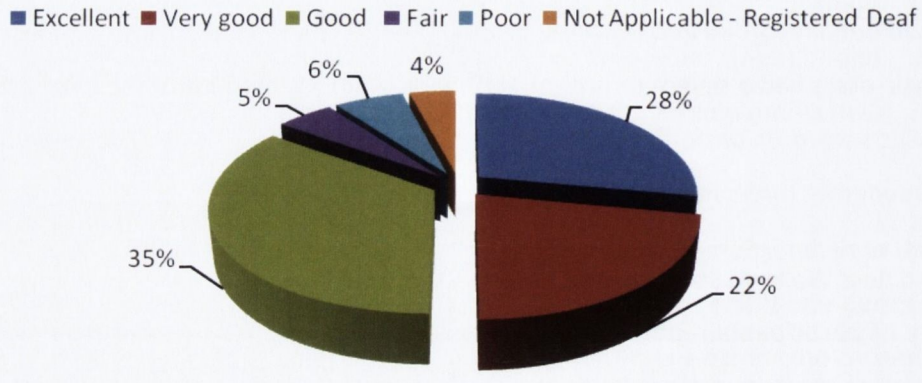
Overall, both vision and hearing were rated positively: 92% (*n*=71) reported having no problems seeing things up close; for example, reading ordinary newspaper print or looking at photographs (see Figure 4.3). Only 5% (*n*=4) were registered or legally blind, but two of these participants did have some sight, which was assisted by the use of glasses.

Figure 4.3: Eyesight Condition



Similar to eyesight, the majority of participants, 90% (*n*=69), rated their hearing between the spectrum of excellent to fair, see Figure 4.4. Only 4% (*n*=3) were classified as registered deaf.

Figure 4.4: Hearing Condition



4.2.4 General Health and Wellbeing Characteristics of Participants

Selected data on the general health and wellbeing of participants is reported below. This data was either reported in the PIQ or came from the face-to-face interview (see Appendix 32). The findings provided should be interpreted with caution, given the small sample size. The purpose is to provide a contextual understanding of the general health and wellbeing of participants.

4.2.4.1 Physical and Mental Health Status

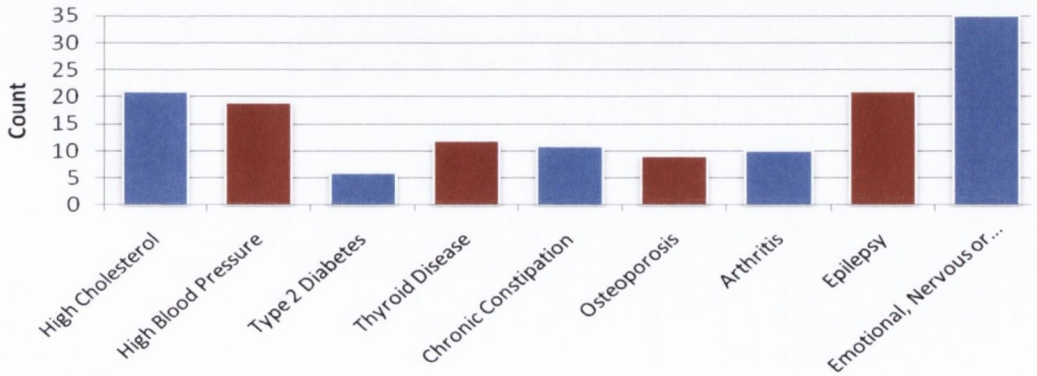
a) Self-Rated Health

Self-rated or proxy-rated health of participants was very positive: 84% (n=65) selected the options of excellent (19%; n=15), very good (19%; n=15) or good (45%; n=35), while 12% (n=9) rated their health as fair, and only 4% (n=3) rated it as poor.

b) Physical and Mental Health Conditions

On review of the status of the physical and mental health conditions reported (see Appendix 32 for a list of the conditions reviewed), nine conditions were rated with greater frequency (≥ 5 cases). Of these, the four most frequently rated were: high cholesterol (27%; n=21); high blood pressure (BP) (25%; n=19); epilepsy (27%; n=21); and emotional, nervous or psychiatric condition (45%; n=35) – see Figure 4.5. Among those that reported having high BP, the mean age of onset was 55 years, where known (n=10; range 46–67). While, the mean age of onset of high cholesterol is unknown, as this data was not requested from participants. Of those diagnosed with diabetes (8%, n=6), all had Type 2 diabetes, with a mean age of onset at 50 years, where known (n=4; range 40-58). Levels of reported screening among the participants within the last two years was high for cholesterol (83%; n=64) and blood pressure (94%; n=72). Testing of blood glucose (71%; n=55) and thyroid function (70%; n=54) was slightly lower.

Figure 4.5: Selected Physical and Mental Health Conditions



c) Medication Usage

A total of 84% (*n*=65) of participants reported taking one or more medications. A medication was defined as any "prescription and non-prescription medications, over-the-counter medicines, vitamins, herbal and/or alternative medicines"; 9% (*n*=7) reported taking no medications and 6% (*n*=5) did not know if they took any medication.

4.2.4.2 Behavioural Health Status

a) Smoking, Alcohol and Physical Activity

Levels of current smoking were low (13%; *n*=10), while 43% (*n*=33) reported that they had taken an alcoholic drink in the last six months. The majority, 73% (*n*=24), reported frequency of alcohol consumption to be once or twice a month (*n*=12) or less than a month (*n*=12) within that specified timeframe. On review of the physical activity levels, the majority of participants reported that they hardly ever or never engaged in vigorous (90%; *n*=69) or moderately energetic activity (66%; *n*=51), but did engage in mildly energetic physical activity (70%; *n*=54) more than once a week, which may or may not have caused minimal sweating and/or mild increase in breathing or heart-rate. Sixteen percent (*n*=12) reported that they hardly ever or never engaged in exercise at any level. On review of who decides how their free time is spent, 52% (*n*=40) reported it to be their own decision, for 21% (*n*=16) it was a supported choice, while for the remaining 27% (*n*=21) the choice was determined by a relative (*n*=2) or support staff (*n*=19).

b) Nutritional Health Status

Self-rated or proxy appraisal of the healthfulness of the individual's overall diet was very positive, with 94% (*n*=72) selecting the options excellent (*n*=11), very good (*n*=27) or good (*n*=34). Four percent (*n*=3) rated their diet as fair and slightly less, 3% (*n*=2), as poor. With respect to daily food choices, 84% (*n*=65) reported that they did not consume five or more portions of fruit and vegetables a day; just over half reported that they ate only one portion of fruit a day (55%; *n*=42) and one portion of vegetables a day (53%; *n*=41). Snacks were reported to be consumed daily by 77% (*n*=59) of participants.

c) Self-Report Body Mass Index (BMI)

On calculation of the participants' Body Mass Index (kg/m2) based on self-reported height and weight data (*n*=51; 66% of the sample), 2% (*n*=1) were classified as underweight, 33% (*n*=17) fell within the normal weight range, 31% (*n*=16) were overweight, and 33% (*n*=17) were obese. Yet, 64% (*n*=49) perceived themselves (or participant) to be about the right weight, 29% (*n*=22) to be overweight, 6% (*n*=5) to be underweight, and 1% (*n*=1) provided an unclear response. The

influences of key covariates (e.g. age, gender) on self-report BMI are not reported due to small sample size. For the remaining 34% (n=26) of the sample, BMI could not be calculated due to self-reported height and/or weight data not being reported by participants.

Missing BMI Data: Of the 26 participants (34% of total sample) for whom BMI could not be calculated, the most common item missing was height at 88% (n=23) compared to weight at 35% (n=9). Within this group (n=26), 73% (n=19) were women and 27% (n=7) were male; 69% (n=18) had a mild or moderate level of ID, 19% (n=5) had a severe or profound ID, and the remaining 12% (n=3) had either an unverified or unknown level of ID. Over half (58%; n=15) of those with missing height and/or weight data were aged 60 years and over.

This completes Phase 1 of the report.

4.3 Phase 2: Feasibility and Measurement Status Data

4.3.1 Logistical Operational Matters and Briefing Checks

The return of the Measurement Communication Forms, the success of the interviewer training, the procedures for reaffirming consent/assent and briefing checks are presented below.

a) Measurement Communication Forms and Interviewer Training

With the exception of 10% (n=8), all of the Measurement Communication Forms were returned shortly, typically one or two days, after each interview was completed, as recommended. For the 10% outstanding, the researcher followed up on the return of the forms with the specific interviewers and all were submitted without delay. The operational protocol developed for interviewers and the practical guidance given during their training programme was deemed successful. No amendments were necessary and no changes are recommended to either component. Critical to this success was the development of both good working relationships and open communication between the researcher and each interviewer.

b) Procedures for Reaffirming Consent/Assent to Participate and Briefing Checks

No problems were encountered with the procedures developed to reaffirm the participant's willingness to take part or their withdrawal from the measurement visit. No changes were made or are recommended to the operational protocol. All the checks and briefings listed in the preparation phase of the Results Workbook were successfully completed and were deemed to be appropriately placed at the beginning of the visit. Similarly, no amendments were made and no changes are recommended. All measurements were taken at least one hour after the participant's last food or drink intake and after voiding, where appropriate.

4.3.2 Feasibility of Conducting Anthropometric Measurements

The main feasibility results will be presented in three ways. First, the results of operational feasibility will be outlined, followed by the feasibility of the measurements among eligible participants, and then the feasibility of valid measurement obtainment. Finally, the results of measured feasibility will be compared to the expected figure preset by the researcher.

a) Operational Feasibility of Anthropometric Measurements

Application of the inclusion criteria for three of the six measurements resulted in nearly 100% of the participants being eligible for ulna length, mid-upper arm circumference (MUAC), and weight measurements. For the remaining three measurements – standing height, waist circumference (WC) over clothing and hip circumference (HC) – more than two-thirds of the

participants were eligible (≥68%). For the WC measurement on bare skin, just under half of participants were eligible (49%; *n*=38). See Table 4.3 for a breakdown of the percentage of participants eligible for each measurement. Although the reasons for non-eligibility for each relevant measurement are outlined in the individual measurement status reports (e.g. see Height, Section 4.3.3.1), one of the main contributing factors to the lower eligibility in the measurements identified above was 25% (*n*=19) of participants being wheelchair-users (i.e. all three measurements required the participant to be in a standing position).

Table 4.3: Operational Feasibility

	No. Eligible for Measurement (*n*=77)	% Eligible for Measurement
Standing Height	55	71
Ulna Length Left	77	100
Ulna Length Right	77	100
Mid-Upper Arm Circumference	75	97
Weight	77	100
Waist Circumference – Clothing	52	68
Waist Circumference – Bare Skin	38	49
Hip Circumference	52	68

b) Feasibility of Measurements among Eligible Participants

Despite the initial eligibility established for each measurement, the percentage of participants measured varied slightly in four of the measurements; see Table 4.4. The reduced percentages resulted from the measurements either being attempted but not obtained or refused by the participant. Most notable was MUAC, where only 73% (*n*=55) of eligible participants were measured. The main contributing factor was unsuitable clothing (*n*=18), which resulted in the measurement being attempted but not obtained (e.g. clothing-restricted view of the acromion bone). The reasons for measurement attempts but non-obtainment and/or refusals are outlined in the measurement status reports for each measurement, where this status applied (e.g. see Height, Section 4.3.3.1 [f] to [h]).

Table 4.4: Feasibility of Measurements among Eligible Participants

	No. of Eligible Participants	No. of Participants Measured	% Feasibility among Eligible Participants
Standing Height	55	49	89
Ulna Length Left	77	76	99
Ulna Length Right	77	77	100
Mid-Upper Arm Circumference	75	55	73
Weight	77	76	99
Waist Circumference – Clothing	52	45	87
Waist Circumference – Bare Skin	38	37	97
Hip Circumference	52	51	98

c) Feasibility of Valid Measurement Obtainment

The feasibility of valid measurement obtainment among eligible participants was examined in two ways. Only the participants who had two valid readings for each measurement examined were included in the analysis. A more detailed breakdown of the validity status is presented in each measurement report (for example, see Section 4.3.3.1 [c] and [e]).

At the outset, a series of binominal tests were carried out on each of the anthropometric measurements to evaluate if the number of successful measurements was significantly different from the feasibility figure of 95%. This feasibility figure was set by another study, which tested anthropometric measurements in a sample of people with severe and sensory disabilities (Waninge *et al.* 2009). See below the list of hypotheses tested. The results of the hypotheses tested are presented in Table 4.5 and are interpreted directly beneath.

d) Feasibility Hypotheses

(1) *H1:* ***Standing height*** *will not meet the criteria of 95% feasibility. H0:* ***Standing height*** *will meet the criteria of 95% or higher feasibility.* **(2)** *H1:* ***Left ulna length*** *will not meet the criteria of 95% feasibility. H0:* ***Left ulna length*** *will meet the criteria of 95% or higher feasibility.* **(3)** *H1:* ***Right ulna length*** *will not meet the criteria of 95% feasibility. H0:* ***Right ulna length*** *will meet the criteria of 95% or higher feasibility.* **(4)** *H1:* ***Mid-Upper Arm Circumference (MUAC)*** *will not meet the criteria of 95% feasibility. H0:* ***MUAC*** *will meet the criteria of 95% or higher feasibility.* **(5)** *H1:* ***Weight*** *will not meet the criteria of 95% feasibility. H0:* ***Weight*** *will meet the criteria of 95% or higher feasibility.* **(6)** *H1:* ***Waist Circumference (WC)*** *over clothing will not meet the criteria of 95% feasibility. H0:* ***WC*** *over clothing will meet the criteria of 95% or higher feasibility.*

(7) *H1:* ***WC*** *bare skin will not meet the criteria of 95% feasibility. H0:* ***WC*** *bare skin will meet the criteria of 95% or higher feasibility.* **(8)** *H1:* ***Hip Circumference (HC)*** *will not meet the criteria of 95% feasibility. H0:* ***HC*** *will meet the criteria of 95% or higher feasibility.*

Table 4.5: Feasibility of Valid Measurement Obtainment

	Measurements		Measured Feasibility		Binominal Test	
	Total No. of Measurements	*Total No. of Valid Measurements*	*% Measured Feasibility****	*% Expected Feasibility*	*P value*	*Significance Level*
Standing Height	49	34	69	<95	<.001	.05
Ulna Length Left	76	75	99	≥95	.101	.05
Ulna Length Right	77	75	97	≥95	.253	.05
MUAC*	55	53	96	≥95	.477	.05
Weight	76	74	97	≥95	.261	.05
WC – Clothing**	45	33	73	<95	<.001	.05
WC – Bare Skin**	37	30	81	≥95	.002	.05
Hip Circumference	51	49	96	≥95	.527	.05

*Mid-Upper Arm Circumference ** Waist Circumference ***Average=88.5%

i) Results for Hypotheses 2, 3, 4, 5 and 8

The results indicate that there is no statistically significant difference in feasibility for ulna length left (p=.101) or right (p=.253), MUAC (p=.477), weight (p=.261) and HC (p=.527) to the feasibility criteria set in the Waninge *et al.* (2009) study. In other words, the proportions of the measurements specified do not significantly differ from the hypothesized feasibility value of 95% set for anthropometric measurements by Waninge *et al.* (2009). We therefore fail to reject the null hypothesis in each case specified above, and conclude that the criterion of 95% feasibility was supported for these measures. See Table 4.5 for an overview of the findings.

ii) Results for Hypotheses 1, 6 and 7

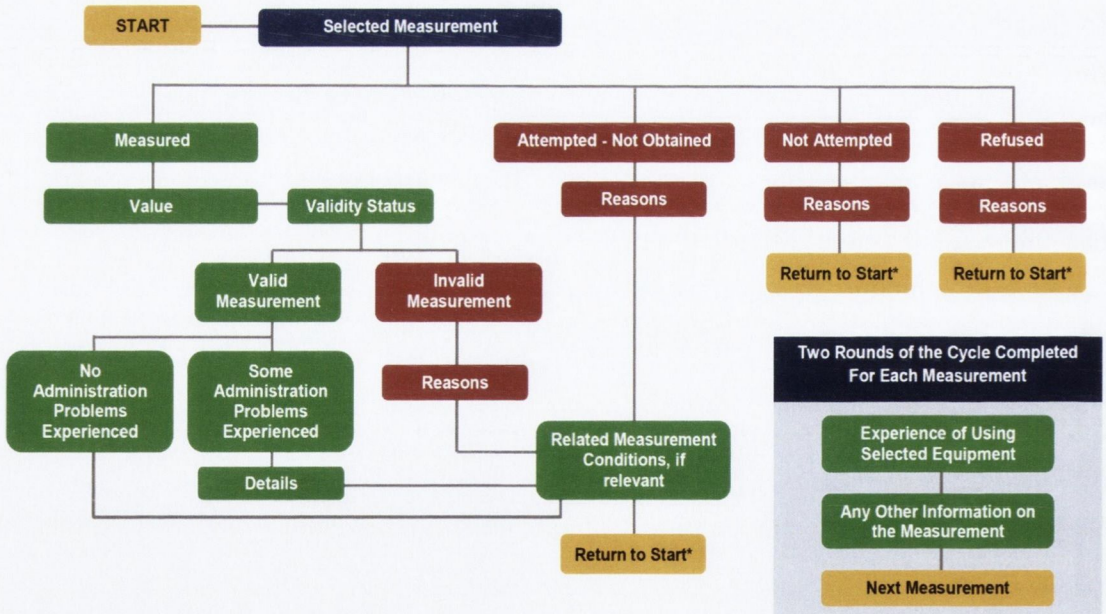
In contrast, the results for height (p=<.001) and WC over clothing (p=<.001) and on bare skin (p=.002) were significantly different from the hypothesized value of 95%. The percentage difference ranged from 14% to 26%. Height had the largest difference from the feasibility criteria being tested, at 26%, followed by WC over clothing at 22%, and the WC on bare skin at 14%. We therefore reject the null hypothesis for standing height, and WC over clothing and on bare skin in favour of the alternative.

After the series of binomial tests were completed, the rates of measured feasibility were compared to expected feasibility rates. The percentage of successful measurements was compared to an expected feasibility rate preset by the researcher which was either less, greater than or equal to 95%, depending on the type of measurement. The expected feasibility rate set for each anthropometric measurement is presented in Table 4.5. All measurements except for WC on bare skin (81%) met the feasibility expected (see Table 4.5).

4.3.3 Measurement Reports on the Anthropometric Measurements

The practical implementation and acceptability of each anthropometric measurement selected for the measurement visit will be reported individually. The report structure is based on the Anthropometric Measurement Results Workbook developed (see Appendix 21). Each report will contain: the measurement status and related outcomes; the validity of the results; details of any difficulties encountered with the equipment, and all other information relevant to the measurement visit. Finally, an evaluation of the accessible appointment card, information booklet and measurement showcards, and the researcher's reflections on the visit, will be presented. See Figure 4.6 for a visual representation of the general reporting cycle followed.

Figure 4.6: General Outline of the Measurement Reporting Cycle



* Complete two rounds of this reporting cycle for each measurement, where possible.
Note: Participants may be catergorised differently each round.

4.3.3.1 Standing Height Measurement Report

a) Height Measurement Status

A total of 55 participants (71%) attempted the height measurement. Forty-nine participants (64%) had the first measurement reading taken and 45 participants completed the second measurement reading (58%). Six participants (8%) attempted the first measurement, but it was not obtained. See Section (f) for the reasons for non-obtainment of measurements. For 22 participants (29%) on the first round and 31 (40%) on the second round, the measurement was not attempted. See Section (g) for the reasons for not attempting this measurement. None of the participants eligible for this measure refused on the first reading, and one participant (1%) refused on the second reading. The reason for this refusal is discussed in Section (h).

See Table 4.6 for a breakdown of the height measurement status findings. Nine of the 55 participants (16%) who attempted or completed the measurement required a third measurement, as the first or second reading may have been invalid and/or the difference between the first and second reading was greater than 0.5cm. The majority of the measurements (*n*=49) were conducted in either the morning (*n*=18; 37%; 9.00-11.59am) or mid to late afternoon (*n*=17; 35%; 3.00-5.59pm). The remaining 18% (*n*=9) were taken early afternoon (12.00-2.59pm) and the least were taken in the evening after 6pm (*n*=5; 10%).

Table 4.6: Height Measurement Status

	1st Measurement		2nd Measurement*	
	n (*n*=77)	%	n (*n*=77)	%
Height Measured	49	64	45*	58
Height Attempted Not Obtained	6	8	0	0
Height Not Attempted	22	29	31	40
Height Refused	0	0	1	1

*92% (*n*=45) had duplicate measurements

b) Validity of Height Measurements

Separately, 69% (*n*=34) of the first series of height measurements were valid and 76% (*n*=34) of the second series of measurements were valid[19]. Based on case matching of the valid readings in each series, the overall validity of the height measurement was 69%. However, of the 69% (*n*=34) of measurements that were valid in the first series, 27% (*n*=13) experienced some

[19] Criteria for validity: All standards were fulfilled and (a) no problems were experienced, or (b) some administration problems were experienced that required more attention or adjustment.

administration problems and similarly, this validity status applied to 31% (n=14) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (c). Concerning invalid measurements, the rate in the first series was 31% (n=15) and 24% (n=11) in the second series; the associated reasons for invalidity are discussed in Section (e). See Table 4.7 for a breakdown of the validity results.

Table 4.7: Validity of Height Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	49	64	45	58
No. of Valid Readings	34**	69	34**	76
No Problems with O.P.* Experienced	21	43	20	44
Some Administration Problems Experienced	13	27	14	31
No. of Invalid Readings	15	31	11	24

*Operational Protocol ** 62% (n=21) were aged 40-59 and 38% (n=13) were aged 60+

c) Height Problems Experienced – Valid Measurements

The themes that emerged from the qualitative responses recorded were coded into the categories set out in Table 4.8 (n=14). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent[20]). Despite these measurement considerations, valid readings were obtained. Insights into the details of the more frequent categories (Table 4.8) are presented in Appendix 34 (see Section 1a), except for the category *"problems with equipment"*, which will be discussed in Section (i). The findings presented provide future researchers with further insights into the practice of measuring height and what should be taken into consideration.

[20] Reminder: The themes ranked least frequent are no less important than those ranked most frequent. All categories, irrespective of their placement, contribute equally to our overall understanding of the phenomena of interest.

Table 4.8: Height Problems Experienced, Valid Measurements

Description of Problems Experienced - Valid Measurements	
Problems with equipment	
Heels not at back of baseplate, but were close	
Leaning slightly	
Very tall, needed a stool	
Poor understanding, more support required	
Head slightly titled	Joint Position
Not exactly in Frankfort Plane position, but very close	
Negotiation with participant	
Very slight slope on floor (remained within the limits set)	

d) Conditions of the Measurement Environment

A total of 88% (*n*=43) of measurements were taken on linoleum/tile/wood flooring and 12% (*n*=6) on low-pile carpet. The majority of measurements, 33% (*n*=16), were taken in the living/relaxation room, followed by 24% (*n*=12) in the kitchen/dining room, 20% (*n*=10) in the clinic room/classroom, 18% (*n*=9) in the visitors room, and 4% (*n*=2) in the bedroom.

e) Invalid Height Measurements

Fifteen participants (31%) in the first series and 11 (24%) in the second series had invalid height measurements. The main reason for this in the first and second series was the participant's stance – either leaning forward and/or to the right, or their back not being straight. The second and third highest reasons in the first series, but significantly lower than the main reasons, were, respectively, participants trying but not fully understanding the procedures, and their head not being positioned in the Frankfort plane. Both of these reasons also featured in the list of the reasons for invalid measurements in the second series, but were not as frequent. Less frequent reasons in both the first and second series included the participant's legs not being straight, not standing still, and a lack of space to carry out the measurement. See Table 4.9 for a breakdown of the main reasons and frequency of the invalid height measurements obtained.

Table 4.9: Reasons for Invalid Height Measurements

	1st Measurement		2nd Measurement	
	n (*n*=15*)	%	n (*n*=11**)	%
Leaning (forward or right) or back not straight	12	80	8	73
Tried but did not fully understand	7	47	4	36
Head not in the Frankfort position	7	47	4	36
Did not stretch to fullest	6	40	3	27
Heels not close and/or close to back	6	40	6	55
Not positioned adequately on stadiometer	4	27	4	36
Legs not straight	3	20	2	18
Did not stand still	1	7	1	9
Environment not ideal (lack of space)	1	7	1	9
Other reason or comments	4	27	3	27

*53% (*n*=8) were aged 40-59 and 47% (*n*=7) were aged 60+. **55% (*n*=6) were aged 40-59 and 45% (*n*=5) were aged 60+.

Also, of particular note, in the case of three of the four participants who were not positioned adequately on the stadiometer in the first and second series, it was recorded that their *"weight distribution (body shape) was a significant contributing factor to the measurement being invalid" [1; 14; 66].* One of the other reasons noted for the invalid measurement in the first series, which is not specified in the table, was the participant stepping off the stadiometer before the final checks were completed. Other comments noted in both the first and second series are detailed below and relate to the equipment and the role it played in this measurement outcome.

> *Old Model: "Participant very conscious of the side rims when stepping onto the stadiometer (took their time as advised) – no need for side rims." [13]*
>
> *New Model: "Colour of the baseplate did not assist the securement of the correct position – too similar to the colour of the flooring." [66]*

f) Height Measurements Attempted – Not Obtained

Six participants (8%) attempted the height measurement in the first series but it was not obtained. None of the participants had this measurement status in the second series. The main reason for not obtaining the measurement in the first series was the participant's stance, not standing upright or being too stooped, followed by legs not being straight and being unsteady

on their feet. See Table 4.10 for a breakdown of the frequencies. An example of one of the related observations recorded against this measurements status was:

> *"After the briefing and demonstration stage for height measurement it became clear that the participant's gait was poor (walking towards the stadiometer). Although the measurement was initially attempted, it was sensitively ceased and the reason for ceasing the measurement was simply examined to [them]. I then suggested skipping to the next measurement, they were happy to do so. I reminded [them] that we can estimate their height from their ulna length." [65]*

Table 4.10: Reasons for Height Attempted – Not Obtained

	1st Measurement	
	n (*n*=6)	%
Could not stand upright/too stooped	5	83
Legs not straight	3	50
Unsteady on feet	2	33

Another observation, made on two occasions as part of the measurements attempted, was that the headplate on the new stadiometer appeared smaller than on the older model, even though the participant's stance did not enable the measurement to be completed. For one of these participants, this seemed particularly evident due to increased weight around the hip circumference area, which moved their position further out from the back of the baseplate.

g) Height Measurements Not Attempted

For 22 participants (29%) in the first series and 31 participants (40%) in the second series, height measurement was not attempted. The main reason for this in both series was due to the participants being wheelchair-users. The other reasons were significantly smaller in proportion to the main reason, but the numbers did increase slightly in the second series of measurement, as can be seen in Table 4.11, particularly with participants who could not stand upright or were too stopped.

Table 4.11: Reasons for Height Not Attempted

	1st Measurement		2nd Measurement	
	n (*n*=22)	%	n (*n*=31)	%
Wheelchair-user	19	86	19	61
Unsteady on feet	2	9	3	10
Anthropometrist felt it would not be safe	1	5	2	6
Did not understand the procedure	1	5	3	10
Could not stand upright/too stooped	1	5	5	16
Other reasons	0	0	2	6

Finally, in the second series, two other reasons for non-attempt with two participants were that one was also unable to straighten their legs as well as stand upright, while the other leaned slightly forward and the distribution of weight around their abdominal and hip area did not allow them to maximize their stance on the stadiometer in the first series of measurements (headplate on the new model seemed shorter). In the latter case, the warm weather on the day of the measurement did not assist either, but this might not have changed the outcome.

h) Height Measurements Refused

None of the eligible participants refused the first height measurement. Only one participant (1%) refused in the second series of measurement; no reason was given, just said "*no*" *[25]*.

i) Problems with Equipment – Height Measurement

Based on the total number of participants who attempted to have or had their height measured (*n*=55), 91% of participants (*n*=50) were observed having some problems with the stadiometer. Of these, 34 of the 38 participants (89%) experiencing problems with the stadiometer used the old model and 16 of the 17 participants (94%) used the new model. The qualitative responses as recorded were coded into the following categories, as set out in Table 4.12. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). While the stadiometers alone did not prevent or invalidate any height measurements, some difficulties were observed during the measurements process, but all were easy to surmount with more time, breakdown of instruction, and support. Insights into the details of the categories (Table 4.12) are presented in Appendix 34 (see Section 1b). The findings presented provide useful insights into the practical application of the equipment in the field, as well as some considerations for future use and research.

Table 4.12: Description of Equipment Problems – Height Measurement

Description of Equipment Problems
Side-rim restrictions (old model)
Baseplate too small (old model)
Removal of footprints, and colour of baseplate (new model)
Nervousness of participants (old and new model)
Headplate (old and new model)

A summary of the key details relating to the equipment problems is presented below.

i) Summary Description of Equipment Problems

In the old model, the side rims and small baseplate affected the ease of using this piece of equipment in practice, and, in many cases, participants appeared nervous while getting on, and less so getting off, the device. This problem created a greater reliance on the researcher and/or proxy having to support the participant in some cases, more often than would otherwise have been the case. While the new model did address both of these issues, the colour of the device was changed and the footprints were removed, which resulted in participants also being cautious using this updated device. The change in colour, which was often similar to the colour of flooring, meant that participants had to negotiate the placement of their feet (similar to action taken by those using the old device but due to the side rims) and needed more time and support to adjust their feet, given the absence of reference points (e.g. footprints). Both observations increased the dependency on others to assist with stepping on and adjusting their feet on the device. However the transition on (with support, where needed) and off the device was much better than with the old model. Lastly, the headplate on the new model was notably smaller, and further use may show that it does not take account of the different body shapes (increased weight in abdominal and hip area) and stances of an older population group.

j) Any Other Information – Height Measurement

In 45% (n=25) of the cases measured (n=55), additional comments were noted under the 'any other information' question. The qualitative responses as recorded to the open-ended question on height were coded into categories (see Table 4.13). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). Insights into the details of the more frequent categories (Table 4.13) are presented in Appendix 34 (see Section 1c), except for the category *"type of guidance from proxy"*, which will be discussed separately in

Section j(*ii*). While none of the issues affected completion of the measurement, the findings presented provide further insight into the measurement experience and highlight some considerations for future use and research.

Table 4.13: Description of Any Other Information – Height Measurement

Description of Any Other Information	
Extra guidance and support from researcher needed	
Type of guidance from proxy	
Time of measurement	
Space as a concern	
Distractions disrupting measurement	Joint Position
Checking floor levels	
Long trousers as a barrier	
Weight distribution influencing position	

i) Status of Proxy Support

Of all the participants who attempted the height measurement (*n*=55), 32 (58%) had a proxy present, with 29% (*n*=16) providing active support and 29% (*n*=16) present only. The remaining 23 participants (42%) did not have or wish to have a proxy present for this measurement.

ii) Nature of Proxy Support

The nature of the support captured in the qualitative observational recordings fell into four discrete types of support (assistance, checks, instruction, and full assistance) set out in Table 4.14. The types of support were ordered using the patterns of frequencies recorded (ranked from most to least frequent).

Table 4.14: Nature of Proxy Support – Height Measurement

Description of Proxy Support
Assisting the participant onto the stadiometer
Assisting with checks required
Instructing the participant as needed
Full assistance with measurement

Most support provided by proxies in this measurement involved assisting the participant onto the stadiometer or offering general assistance with checks. Some participants received instructions from the proxy but this level of support was quite limited.

> *"Side rim was a barrier but added caution needed as the participant did not fully understand all of the instructions. Mum assisted the participant once they walked over to the stadiometer (e.g. stepping onto the stadiometer and position needed). Once complete, the participant stepped off no problem and returned to seat." [31]*

A very small number of cases needed full assistance with the measurement.

iii) Summary Description of Any Other Information

In a substantial number of cases, extra guidance and support was required and provided by the researcher (mainly related to the participant's stepping onto the stadiometer) but few participants' required full assistance with the measurement. In some cases, as expected, it was noted that the time of day height measurements are taken might affect outcomes. The height of the participant relative to the researcher was noted as causing some difficulty. Physical space and the standing positions of participants created difficulty with this measurement. The nature of proxy support provided in this measurement was assisting the participant onto the stadiometer or offering general assistance with checks. Some participants did receive instructions from the proxy but this level of support was quite limited. Almost all proxy support in this category involved assisting with measurements and mostly assisting participants with getting on and off the baseplate, particularly with the older model due to the side rims.

4.3.3.2 Ulna Length Measurement Report

a) Ulna Length Measurement Status

All 77 participants (100%) attempted the ulna length measurement, which consisted of both the left and right arm. Seventy-six participants (99%) had the first and second series of measurement readings taken. One participant (1%) attempted the left ulna length measurement but it was not obtained in the first series and neither arm was measured in the second series of readings. See Section (h) for the reasons for the non-obtainment and non-attempt with this participant, and Table 4.15 for a breakdown of the ulna length measurement status findings. Two of the 77 participants (3%) who attempted or completed the ulna length measurements required a third measurement as the first or second reading may have been invalid and/or the difference between the first and second reading was greater than 0.5cm.

Table 4.15: Ulna Length Measurement Status

	1st Measurement				2nd Measurement*			
	Left (*n*=77)		Right (*n*=77)		Left (*n*=77)		Right (*n*=77)	
	n	%	n	%	n	%	n	%
Ulna Length Measured	76	99	77	100	76*	99	76*	99
Ulna Length Attempted Not Obtained	1	1	0	0	0	0	0	0
Ulna Length Not Attempted	0	0	0	0	1	1	1	1
Ulna Length Refused	0	0	0	0	0	0	0	0

* 100% (*n*=76) on the left and 99% (*n*=76) on the right had duplicate measurements.

b) Position of Participants for Ulna Length Measurements

The majority of participants ($\bar{x}$=63.5%) for the first and second left and right ulna length measurements were in a seated position, followed by standing ($\bar{x}$=33.5%), and the fewest were in a lying position ($\bar{x}$=3.25%). See Table 4.16 for a breakdown of the positions for each ulna length.

Table 4.16: Position of Participants for Ulna Length Measurements

	1st Measurement				2nd Measurement			
	Left		Right		Left		Right	
	n (*n*=76)	%	n (*n*=77)	%	n (*n*=76)	%	n (*n*=76)	%
Standing	24	32	26	34	26	34	26	34
Sitting	50*16	66	48*16	62	48*16	63	48*16	63
Lying Down	2*2	3	3*3	4	2*2	3	2*2	3

*=Number of wheelchair-users

c) Position of Arms for Ulna Length Measurements

The majority of participants ($\bar{x}$=87%) for the first and second left and right ulna length measurements held their arms diagonally across their chest, followed by their arm positioned across their stomach ($\bar{x}$=11.25%); the fewest rested their arm on a table or arm of chair ($\bar{x}$ =1.75%). See Table 4.17 for a breakdown of the arm positions for each ulna length side.

Table 4.17: Position of Participant's Arm for Ulna Length Measurements

	1st Measurement				2nd Measurement			
	Left		Right		Left		Right	
	n (*n*=76)	%	n (*n*=77)	%	n (*n*=76)	%	n (*n*=76)	%
Diagonal across the Chest	66*12	87	66*12	86	67*13	88	66*12	87
Across Stomach	7*4	9	11*7	14	7*4	9	10*6	13
Resting on Table/Arm of Chair	3*2	4	0	0	2*1	3	0	0

*=Number of wheelchair-users

d) Validity of Left Ulna Length Measurements

Separately, 99% of the first (*n*=75) and second (*n*=75) series of left ulna length measurements were valid[21]. Based on case matching of the valid readings in each series, the overall validity of the left ulna length measurement was 99%. However, of the 99% (*n*=75) of measurements that were valid in the first series, 32% (*n*=24) experienced some administration problems; similarly, this validity status applied to 30% (*n*=23) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (f). For invalid measurements, the rate in both the first and second series was 1% (*n*=1). The associated reasons for invalidity are discussed in Section (g). See Table 4.18 for a full breakdown of the validity results of the left ulna length measurements.

Table 4.18: Validity of Left Ulna Length Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	76	99	76	99
No. of Valid Readings	75	99	75	99
No Problems with O.P.* Experienced	51	67	52	68
Some Administration Problems Experienced	24	32	23	30
No. of Invalid Readings	1	1	1	1

*Operational Protocol

e) Validity of Right Ulna Length Measurements

Separately, 99% of the first (*n*=76) and second (*n*=75) series of right ulna length measurements were valid. Based on case matching of the valid readings in each series, the overall validity of

[21] Criteria for validity: All standards were fulfilled and (a) no problems were experienced, or (b) some administration problems were experienced that required more attention or adjustment.

the right ulna length measurement was 97%. However, of the 99% (n=76) of measurements that were valid in the first series, 31% (n=24) experienced some administration problems. Similarly, this validity status applied to 33% (n=25) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (f). For invalid measurements, the rate in both the first and second series was 1% (n=1). The associated reasons for invalidity are discussed in Section (g). See Table 4.19 for a full breakdown of the validity results of the right ulna length measurements.

Table 4.19: Validity of Right Ulna Length Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	77	100	76	99
No. of Valid Readings	76	99	75	99
No Problems with O.P.* Experienced	52	68	50	66
Some Administration Problems Experienced	24	31	25	33
No. of Invalid Readings	1	1	1	1

*Operational Protocol

f) Ulna Length Problems Experienced – Valid Measurements

The themes to emerge from the qualitative responses on the left and right ulna length measurements recorded were coded and all but three observations (left and right ulna length) were the same. One of the observations on the left side, coded as the *"proxy as a barrier"*, related to the non-supportive comments they made during the measurements on the left side. The other two observations on the right side were coded under the theme *"position of participant's arm as a barrier"*, where restrictive movement or position required more time to take the measurement. The remaining qualitative responses of the problems experienced applied to both sides and were coded into the categories set out in Table 4.20 (n=25). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). Despite these measurement considerations, valid readings were obtained. Insights into the details of the more frequent categories (Table 4.20) are presented in Appendix 34 (see Section 2a). The findings presented provide future researchers with further insights into the practice of measuring ulna length and what should be taken into consideration.

Table 4.20: Ulna Length Problems Experienced, Valid Measurements

Description of Problems Experienced – Valid Measurements
Styloid process difficult to locate
Arm movement hampered timing of reading
Wheelchair and seated position delayed reading
Participant did not fully understand instructions
Breathing pattern affected timing of reading

g) Invalid Ulna Length Measurements

Similarly, the reasons for the single invalid measurement (1%) on the first and second readings for both the right and left ulna lengths were due to the participant being unable to remain still, and, although the measurement was attempted, they did not fully understand the procedures.

h) Ulna Length Measurements Attempted – Not Obtained and Not Attempted

Only one participant (1%) during the first left ulna length measurement had the measurement attempted but not obtained, as they did not fully understand the procedures. During the second series, measurement of the left and right ulna lengths was not attempted with this participant (1%) as they did not fully understand the procedure and showed anxiety.

i) Ulna Length Measurements Refused

None of the participants refused the left or right ulna length measurements.

j) Problems with Equipment – Ulna Length Measurement

Based on the total number of participants who attempted or had their ulna lengths measured (n=77), 42% of participants (n=32) were observed having problems with the segmometer. The majority of the participants (84%; n=27) experiencing problems with the segmometer had the measurement taken in a seated position (16 of whom were wheelchair-users), while 9% were in a lying position (n=3; all of whom were wheelchair-users) and 6% (n=2) were standing. The remaining 58% (n=45) encountered no problems with the equipment selected, with 53% (n=24) of participants measured while standing and 47% (n=21) measured in a seated position. The qualitative responses as recorded were coded into the categories as set out in Table 4.21. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). While the segmometer did not prevent or invalidate any ulna length measurements, some difficulties were observed during the measurement process, but all were surmounted

with more time, guidance and support. Insights into the details of the categories (Table 2.21) are presented in Appendix 34 (Section 2b). The findings presented provide useful insights into the practical application of the equipment in the field, as well as some considerations for future use.

Table 4.21: Description of Equipment Problems – Ulna Length Measurement

Description of Equipment Problems
Segmometer too long
Restricted space – poor performance
Wheelchair restrictions – poor performance

A summary of the key details relating to the equipment problems is presented below.

i) Summary Description of Equipment Problems

Just under half of the participants were observed having problems with the segmometer. The most cited difficulty was that the segmometer was too long; the majority were in a seated position and the remaining few in a lying or standing position for this measurement. There were many cases where physical space or the participant's position in a wheelchair or lying down resulted in repeated observations that the segmometer's length was an impediment to taking the measurement with ease and minimal adjustments. No problems with the current length were experienced by the majority of those who stood for the measurement or by those in a seated position where they were able to make the adjustments required.

k) Any Other Information – Ulna Length Measurement

In 56% (*n*=43) of the cases measured (*n*=77), additional comments were noted under the 'any other information' question. The qualitative responses as recorded to the open-ended question on ulna length were coded into categories (see Table 4.22). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). While none of the issues affected completion of the measurement, the findings presented provide further insight into the measurement experience and highlight some considerations for future use. Insights into the details of the categories (Table 4.22) are presented in Appendix 34 (see Section 2c), except for the category *"type of guidance from proxy"*, which is discussed separately in Section k(*ii*).

Table 4.22: Description of Any Other Information – Ulna Length Measurement

Description of Any Other Information	
Participant adjusted position	Joint Position
Type of guidance from proxy	
No obstruction with seating	
Extra guidance from researcher needed	
Arm-rests cause restrictions	

i) Status of Proxy Support

Of all the participants who attempted the ulna length measurements (n=77), 50 (65%) had a proxy present; 21% (n=16) of these provided active support and 44% (n=34) were present only. The remaining 27 (35%) did not have or wish to have a proxy present for this measurement.

ii) Nature of Proxy Support

The nature of the support captured in the qualitative observational recordings fell into four discrete types of support (positioning of arm(s), full assistance, interaction, and negative support) set out in Table 4.23. The types of support were ordered using the patterns of frequencies recorded (ranked from most to least frequent).

Table 4.23 Nature of Proxy Support – Ulna Length Measurement

Description of Proxy Support
Positioning of participant's arm(s)
Full assistance with measurement
Chatting to participant to distract attention
Negative impact of support

Most of the support provided by the proxy in this measurement was concerned with assisting the participant with the selection of the correct arm and its positioning for the measurement. For some participants this support was needed for both the left and right arms and at each reading; for others it was the first arm only or the first round of readings only. Others, but not many, required full assistance (n=5), and a few participants required more interaction from the proxy to distract from the measurement. The negative influence (albeit inadvertent) of the presence of proxies during this measurement on two different visits was also recorded:

"With some guidance (additional to briefing and demonstration) the participant was able to do the 1st set of measures independently – no proxy present, however on their return the participant did not respond as they had done and looked to the proxy for full assistance, even though positive appraisal was re-emphasized – did not change the situation. The participant was also slightly distracted by staff going off duty." [71]

"After the first set of measures the proxy left for a few moments and I decided to take the second set of measurements directly afterwards with the participant's permission, so as to maximize the positive response at the end of the first set. At the start the proxy had stated 'I don't think [they] will do this twice' and I believe if there hadn't been so many uses of 'won't, wouldn't' etc by the proxy I could have implemented the standard approach with the measurements procedures and it would have been potentially possible for the participant to hold [their] arm in the preferred position." [55]

iii) Summary Description of Any Other Information

There were no reported obstructions with seating; participants were able to adjust their position in most cases, except where arm-rests on the chair caused restrictions. In some cases a little extra support from the researcher was required. In a number of cases, people with severe[22] intellectual disability were able to complete the measure independently with a little extra support. Where proxy support was required, the nature of that support was assisting with the measurement, usually helping in the positioning of arms, and occasionally chatting with the participant to distract their attention during the process. The negative influence of the presence of proxies (though there were few) during the measurement was noted.

4.3.3.3 Mid-Upper Arm Circumference (MUAC) Measurement Report

a) MUAC Measurement Status

A total of 75 participants (97%) attempted the mid-upper arm circumference (MUAC) measurement. Fifty-five (71%) had the first measurement reading taken and 54 completed the second measurement reading (70%). Twenty participants (26%) attempted the first and second measurement but it was not obtained. See Section (g) for the reasons for the non-obtainment of the measurements. For two participants (3%) in the first and second series (3%), the measurement was not attempted. See Section (h) for the reason for not attempting the measurement. None of the participants eligible for the measurement refused in the first series and two (3%) refused in the second. The reasons for the refusals are discussed in Section (i). See Table 4.24 for a breakdown of the MUAC measurement status findings. Only one of the 75 participants (1%) who attempted or completed the measurement required a third

[22] Reminder: Categorised according to ICD-10 on the National Intellectual Disability Database

measurement, as the first or second reading may have been invalid and/or the difference between the first and second reading was greater than 0.5cm.

Table 4.24: Mid-Upper Arm Circumference (MUAC) Measurement Status

	1st Measurement		2nd Measurement*	
	n (*n*=77)	%	n (*n*=77)	%
MUAC Measured	55	71	54*	70
MUAC Attempted Not Obtained	20	26	19	25
MUAC Not Attempted	2	3	2	3
MUAC Refused	0	0	2	3

* 98% (*n*=54) had duplicate measurements

b) Position of Participants for MUAC Measurements

Just over half of the participants in the first and second series of measurements stood for the measurement ($\bar{x}$=51.5%), followed closely by seated position ($\bar{x}$=46.5%), while the fewest were lying down ($\bar{x}$=2%). See Table 4.25 for the breakdown of the position for each measure.

Table 4.25: Position of Participants for MUAC Measurements

	1st Measurement		2nd Measurement	
	n (*n*=55)	%	n (*n*=54)	%
Standing	28	51	28	52
Sitting	26*10	47	25*10	46
Lying Down	1*1	2	1*1	2

*=Number of wheelchair-users

c) Selected Arm for MUAC Measurements

Of the participants measured (*n*=55), 95% (*n*=52) had the measurements taken on the left arm and 5% (*n*=3) had the measurement taken on the right arm as the left was not suitable.

d) Validity of MUAC Measurements

Separately, 98% of the first (*n*=54) and second (*n*=53) series of MUAC measurements were valid[23]. Based on case matching of the valid readings in each series, the overall validity of the MUAC measurement was 96%. However, of the 98% (*n*=54) of measurements that were valid in

[23] Criteria for validity: All standards were fulfilled and (a) no problems were experienced, or (b) some administration problems were experienced that required more attention or adjustment.

the first series, 29% (n=16) experienced some administration problems. Similarly, this validity status applied to 24% (n=13) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (e). For invalid measurements, the rate in both the first and second series was 2% (n=1); the associated reasons for invalidity are discussed in Section (f). See Table 4.26 for a breakdown of the validity results.

Table 4.26: Validity of MUAC Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	55	71	54	70
No. of Valid Readings	54	98	53	98
No Problems with O.P.* Experienced	38	69	40	74
Some Administration Problems Experienced	16	29	13	24
No. of Invalid Readings	1	2	1	2

*Operational Protocol

e) MUAC Problems Experienced – Valid Measurements

The themes to emerge from the qualitative responses recorded were coded into the categories set out in Table 4.27 (n=16). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). Despite these measurement considerations, valid readings were obtained. Insights into the details of the more frequent categories (Table 4.27) are presented in Appendix 34 (see Section 3a), except for the category *"segmometer too long"*, which is discussed in Section (j). The findings presented provide future researchers with further insights into the practice of measuring MUAC and what should be taken into consideration.

Table 4.27: MUAC Problems Experienced, Valid Measurements

Description of Problems Experienced – Valid Measurements	
Arm movement hampered reading	
Wheelchair position delayed reading	Joint Position
Negotiating with participant	
Segmometer too long	
Clothing hampered process	Joint Position
Limited space as a barrier	
Proxy as a barrier	
Did not fully understand the instructions	

f) Invalid MUAC Measurements

The reason for the single invalid measurement on the first and second series of readings was the same: the participant not wearing suitable clothing for the measurement.

g) MUAC Measurements Attempted – Not Obtained

The main reason for the attempt but non-obtainment of the MUAC measurement among eligible participants (*n*=75) in the first and second series of readings was the participants (*n*=18; 24%) wearing unsuitable clothing (e.g. restrictive clothing – unable to see the location of the *acromion* bone for landmarking and clothing was covering or on the midpoint), while one of these participants was also unable to stand still for the measurement (see Table 4.28). For other participants in the first round of readings (*n*=2), one did not like the tape measure on their arm; for another, it was not possible in the first and second round (*n*=1) to measure the length of their arm with the segmometer due to their position in bed. It was possible to measure with the tape but this deviated from the protocol, so the reading was not included in the analysis. A shorter segmometer might have made this measure possible (and valid).

Table 4.28: MUAC Measurement Attempted – Not Obtained

	1st Measurement		2nd Measurement	
	n (*n*=20)	%	n (*n*=19)	%
Unsuitable clothing	18*6	90	18*6	95
Did not remain still	1	5	1	5
Other reason	2	10	1	5

*=Number of wheelchair-users

On review of the codes in this category and cross-referencing with the measured and estimated BMI scores using standing height and ulna length respectively together with measured weight, only three participants in the first and second series did not have either BMI scores.

h) MUAC Measurements Not Attempted

The reasons for the non-attempt of this measurement with two participants (3%) were the same for the first and second series of measurements. One participant did not understand the procedure and was anxious about the measurement, so it was not attempted. The second participant was wearing unsuitable clothing on the day of the measurement visit; had suitable clothing been worn, a valid measurement could have been achieved.

i) MUAC Measurements Refused

None of the eligible participants (n=75) refused during the first series of measurements. Two participants (3%) refused in the second series; one did not like the measurement (i.e. the measuring tape being placed around his arm) and the other was not interested. For the participant who was not interested, the qualitative response recorded and reported below gives an insight into the visit:

> *"... felt the negative comments from the proxy (albeit inadvertent) did not help but maybe the participant was tired of the measurements – difficult to know. [They] had responded positively when the proxy's comments could be deflected, where relevant." [55]*

j) Problems with Equipment – MUAC Measurement

Based on the total number of participants who attempted or had their MUAC measured (n=75), 29% (n=22) were observed having problems with the equipment (segmometer only). No problems were encountered with the measuring tape except with one participant who did not like the tape placed around their arm in the second series of measurements, and refused the measurement (1%). The majority of the participants (77%; n=17) experiencing problems with the equipment were wheelchair-users; all of these had the measurement attempted or taken in a seated position, except for two participants who were in a lying position. The remaining five participants (23%) were seated for the measurement. A total of 71% (n=53) encountered no problems with the equipment selected, with 62% (n=33) of participants who attempted the measurement in a standing position, and 38% (n=20) in a seated position and able to make any necessary adjustments.

The qualitative responses as recorded were coded into the categories set out in Table 4.29. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). While the segmometer did not prevent (except in one case but it was not the only contributing factor, as a shorter segmometer might not have worked either due to their position in bed) or invalidate any MUAC measurements, some difficulties were observed during the measurements process, but all were surmounted with more time, guidance and support. Insights into the details of the categories (Table 4.29) are presented in Appendix 34 (see Section 3b). The findings presented provide useful insights into the practical application of the equipment, as well as considerations for future use.

Table 4.29: Description of Equipment Problems - MUAC Measurement

Description of Equipment Problems
Segmometer too long
Problems with wheelchair or seated position (segmometer length)
Problems with lying position if unable to adjust (segmometer length)

A summary of the key details relating to the equipment problems is presented below.

i) Summary Description of Equipment Problems

No problems were observed with the measuring tape except with one participant who decided that they did not like the tape around their arm in the second series of measurements. Just over a quarter of participants were observed having problems with the segmometer. Similarly to the ulna length measurement, the most cited difficulty was that the segmometer was too long. The majority were in a seated position for the measurement and the fewest in a lying position. Of those seated, just over three-quarters were in a wheelchair and there was often insufficient room to adjust and/or to accommodate the segmometer, which proved too long in many instances. Although the lying position was only encountered twice, difficulties were recorded with this position and the equipment, particularly for one of the participants who was unable to make the adjustments needed (measurement attempted but not obtained).

k) Any Other Information – MUAC Measurement

In 60% (n=45) of the cases where the MUAC was measured or measurement was attempted (n=75), additional comments were noted under the 'any other information' question. The qualitative responses as recorded to the open-ended question on MUAC were coded into categories (see Table 4.30). The themes were ordered using the patterns of frequencies

recorded (ranked from most to least frequent). While all but the first category had no impact on completing the measurement, the findings presented provide further insight into the measurement experience and highlight some considerations for future use. The first category, 'clothing', significantly affected the success of completing this measurement. Had suitable clothing been worn, the total number of measurements completed would most likely have increased. Insights into the details of the more frequent categories (Table 4.30) are presented in Appendix 34 (Section 3c), except for the category *"type of guidance from proxy"*, which will be discussed separately in Section k(*ii*).

Table 4.30: Description of Any Other Information – MUAC Measurement

Description of Any Other Information	
Clothing as a factor	
Participant adjusted for segmometer	
Type of guidance from proxy	
Participant's position as a factor	
Participant's weight as a factor	
Extra guidance needed from researcher	Joint Position
Administration as a factor	

i) Status of Proxy Support

Of all the participants who attempted the MUAC measurement (*n*=75), 49 (65%) had a proxy present, with 17% (*n*=13) of these providing active support and 48% (*n*=36) present only. The remaining 26 cases (35%) did not have or wish to have a proxy present for the measurement.

ii) Nature of Proxy Support

The nature of the support captured in the qualitative observational recordings fell into five discrete types of support (positioning of arms, interaction, general support, full assistance, and negative support) as set out in Table 4.31. The types of support were ordered using the patterns of frequencies recorded (ranked from most to least frequent).

Table 4.31 Nature of Proxy Support – MUAC Measurement

Description of Proxy Support	
Positioning of participant's arms	Joint Position
Emotional support	
General support with measurement	
Full assistance with the measurement	
Negative impact of support	

Most observations under 'nature of support from proxy' related to supporting the position of the participant's arm and general support, such as holding the participant's sleeve up to assist with the first part of the measurement, and the provision of emotional support by the proxy and researcher.

> *"We sang for most of this measurement. Participant said [they] did not like the 3rd MUAC measurement after the tape was released, which was probably due to me [the researcher] not singing at the end of the measure while taking the reading – participant preferred everyone singing and a high level of interaction was needed throughout. Proxy stood beside participant singing too." [24]*

In very few cases, the observations noted that full assistance was needed (n=2). There was also one incident of negative (albeit inadvertent) support from the proxy:

> *"Participant adjusted [their] position in the chair for the measurement. Negative/disempowering comments were a significant influencing factor in [their] disinterest in the second measure –proxy was not conscious of the potential impact, and positive deflection was not always successful." [55]*

iii) Summary Description of Any Other Information

The most cited observation concerned the participant's clothing being unsuitable for the measurement, which resulted in a source of difficulty but mostly in a barrier to completing a valid measurement. As with previous measurements (ulna length), there were many positive observations of the participant adjusting position for the segmometer. However, there was a similar level of recordings of the participant's position as a factor that impeded but did not prevent a valid measurement. There were also observations recorded noting that, where the participant was thin or slender, the acromion bone was easy to locate. This suggests that, although there were no incidences of too much weight being recorded as a factor, this might be a problem if the participant was heavy. The small number of other observations concerned physical space, the participant needing further guidance, and an administration issue (where

the appointment card did not arrive, resulting in the participant not getting the final reminder about wearing short sleeves). Most observations concerning the nature of proxy support related to supporting the position of the participant's arm and helping with the measurement, but very few cases required full assistance. The provision of emotional support by the proxy and researcher was also recorded, and one incident of negative support from the proxy.

4.3.3.4 Weight Measurement Report

a) Weight Measurement Status

A total of 77 participants (100%) attempted the weight measurement. Seventy-six (99%) had the first measurement reading taken and 74 completed the second reading (96%). One participant (1%) attempted the first, but it was not obtained. See Section (f) for the reasons for non-obtainment of the measurements. For two participants (3%) in the second series, the measurement was not attempted; see Section (g) for the reasons. None of the participants eligible for this measurement refused in the first series while one participant (1%) refused in the second series; the reason for this refusal is discussed in Section (h).

Table 4.32 shows a breakdown of the weight measurement status findings. Four of the 77 participants (5%) who attempted or completed the measurement required a third measurement as the first or second reading may have been invalid and/or the difference between the first and second reading was greater than 0.5kg. Most of the weight measurements (*n*=76) were conducted in either the morning (*n*=27; 36%; 9.00-11.59am) or mid to late afternoon (*n*=24; 32%; 3.00-5.59pm). The remaining 25% (*n*=19) were taken in the early afternoon (12.00-2.59pm) and the fewest in the evening after 6pm (*n*=6; 8%).

Table 4.32: Weight Measurement Status

	1st Measurement		2nd Measurement*	
	n (*n*=77)	%	n (*n*=77)	%
Weight Measured	76	99	74*	96
Weight Attempted Not Obtained	1	1	0	0
Weight Not Attempted	0	0	2	3
Weight Refused	0	0	1	1

*97% (*n*=74) had duplicate measurements

b) Position of Participants for Weight Measurements

The majority of the participants measured (n=76) for the first and second measurement were in a standing position ($\bar{x}$=74%), followed by a seated position ($\bar{x}$=26%), of whom 19 (95%) were wheelchair-users in the first series of measurements and 18 (95%) in the second series. See Table 4.33 for a breakdown of the positions for the first and second weight measurements.

Table 4.33: Position of Participants for Weight Measurements

	1st Measurement		2nd Measurement	
	n (n=76)	%	n (n=74)	%
Standing	56	74	55	74
Sitting	20*	26	19**	26

*n=19 wheelchair-users **n=18 wheelchair-users

c) Validity of Weight Measurements

Separately, 99% of the first (n=75) and 100% (n=74) of the second series of weight measurements were valid[24]. Based on case matching of the valid readings in each series, the overall validity of the weight measurement was 97%. However, of the 99% (n=75) of measurements that were valid in the first series, 16% (n=12) experienced some administration problems. Similarly, this validity status applied to 15% (n=11) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (d). For invalid measurements, the rate in the first series was 1% (n=1); the associated reasons for this invalidity are discussed in Section (e). None of measurements in the second series was invalid. See Table 4.34 for a full breakdown of the validity results.

Table 4.34: Validity of Weight Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	76	99	74	96
No. of Valid Readings	75	99	74	100
No Problems with O.P.* Experienced	63	83	63	85
Some Administration Problems Experienced	12	16	11	15
No. of Invalid Readings	1	1	0	0

*Operational Protocol

[24] Criteria for validity: All standards were fulfilled and (a) no problems were experienced, or (b) some administration problems were experienced that required more attention or adjustment.

d) Weight Problems Experienced – Valid Measurements

The themes to emerge from the qualitative responses recorded were coded into the categories set out in Table 4.35 (n=12). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent[25]). Despite these measurement considerations, valid readings were obtained. Insights into the details of the more frequent categories (Table 4.35) are presented in Appendix 34 (see Section 4a), except for the category *"limited space for wheelchair scale"*, which is discussed in Section (i). The findings provide future researchers with further insights into the practice of measuring weight and what should be taken into consideration.

Table 4.35: Weight Problems Experienced, Valid Measurements

Description of Problems Experienced – Valid Measurements	
Limited space for wheelchair scale	
Negotiation with participant	
Kept shoes / jumper on during measurement	
Looked down or moved feet	
Very slight slope on floor (remained within the limits set)	Joint Position
Measurements taken consecutively	

e) Invalid Weight Measurements

The reason for the single invalid measurement on the first series of measurements was the participant leaning on the proxy for support, which affected the reading. The qualitative response from this case was:

> *"Although the participant was not a wheelchair-user, the use of the wheelchair scale may have [led] to a valid reading but the set-up in the room was not possible. This case represents a good example of one of the benefits of a clinic set-up i.e. where all the equipment would be set up with the props needed to assist and maximize the potential of visits." [35]*

f) Weight Measurements Attempted – Not Obtained

The reason for the single weight measurement that was attempted but not obtained in the first series was the participant being distracted in their environment and losing interest in the measurement. The qualitative response from this case was:

[25] Reminder: The themes ranked least frequent are no less important than those ranked most frequent. All categories, irrespective of their placement, contribute equally to our overall understanding of the phenomena of interest.

"Participant saw the support staff bringing out tea and biscuits when [they] were half way to the flat scale and turned back and sat down for tea – lost interest in this measurement." [48]

Following the disruption, the researcher was unable to successfully re-engage the participant on this measurement, so the next measure was discussed, demonstrated and undertaken.

g) Weight Measurements Not Attempted

Two of the reasons for the non-attempt of this measurement with two participants (3%) in the second series of measurement were the same. The researcher felt it would not be safe, and the participant did not understand the procedure. One of the participants seemed tired by the second round of measurements and not steady on their feet. The other participant shook the bar on the wheelchair scale a few seconds after the first reading and continued, which meant the monitor would not remain still; this was likely to continue, so it was deemed to be the participant's way of expressing their wish to cease measurements.

h) Weight Measurements Refused

None of the eligible participants (n=77) refused during the first series of measurements. One participant (1%) refused in the second series, but no reason was given. The qualitative response recorded gives an insight into the visit:

"Participant lost interest in this measurement after the first attempt earlier [staff brought tea and biscuits into the room for all the service users] and did not want to take part in the second measure – non verbal cues. Room was not suitable; a lot of distractions but [they] opted to have the measurements taken in the living room." [48]

i) Problems with Equipment – Weight Measurement

Based on the total number of participants who attempted or had their weight measured (n=77), 14% (n=11) of the records had reported problems with the equipment, mainly relating to the wheelchair scale (n=10). Notably, 21 other participants used the wheelchair scale, but it had already been set up for use. The wheelchair scale was not required or set up in any offsite community or family homes, but was used at onsite service settings (i.e. units, houses and a day centre). The qualitative responses as recorded were coded into the categories set out in Table 4.36. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). While the scales (wheelchair and flat scales) did not prevent or invalidate (except for one case; the flat scale proved unsuitable for the participant) any of the weight measurements, some difficulties were observed in the set-up stage and during the measurement process. Even though the difficulties were surmounted with more time (except in

one case, as the flat scale could not be replaced with the wheelchair scale due to physical space), the transfer of the wheelchair scale to the specified location was not easy and very physically demanding on the researcher. Insights into the details of the more frequent categories (Table 4.36) are presented in Appendix 34 (see Section 4b). The findings provide useful insights into the practical application of the equipment, as well as considerations for future use.

Table 4.36: Description of Equipment Problems – Weight Measurement

Description of Equipment Problems	
Logistics as a factor with wheelchair scale	
Space as a factor with wheelchair scale	
Errors with wheelchair scale	
Uncomfortable on flat scale	Joint Position
Participant walking and standing abilities as a factor	

i) Summary Description of Equipment Problems

The single biggest recorded difficulty with equipment in the weight category was with the logistics of moving the wheelchair scale from a vehicle to the participant's home / specified location by oneself and often into confined spaces. Despite these logistical difficulties, it was observed that the wheelchair scale was more comfortable for the participant and definitely a preferred option, especially if the scale was already in situ. Physical space was recorded as problematic in many observations, when using the wheelchair scale, with a need to move furniture to set up the wheelchair scale in a participant's home / specified location. Other observations, although very few, related to a technical issue with the wheelchair scale, which was resolved, and the participant's reported ability to stand and walk being inconsistent with the interviewer's notes on the Measurement Communication Form, which led to the wrong scale being initially set up; this was also resolved except in one case where the location of the plug for the wheelchair scale was not suitable.

j) Any Other Information – Weight Measurement

In 56% (n=43) of the cases where weight was measured and/or attempted (n=77), additional comments were noted under the 'any other information' question. The qualitative responses recorded to the open-ended question on weight were coded into categories (see Table 4.37). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). While none of the issues affected completion of the measurement, the findings

presented provide further insight into the measurement experience and highlight some considerations for future use. Insights into the details of the more frequent categories (Table 4.37) are presented in Appendix 34 (see Section 4c), except for the category *"type of guidance from proxy"*, which is discussed in Section j(*ii*).

Table 4.37: Description of Any Other Information – Weight Measurement

Description of Any Other Information	
Type of guidance from proxy	
Wheelchair scale already set up by researcher	
Weight of wheelchair or seat	
Researcher supporting the participant onto the scales	
Participant shoes as a factor	
Medical observations	Joint Position
Floor levels as a factor	

i) Status of Proxy Support

Of all the participants who attempted the weight measurement (*n*=77), 50 (65%) had a proxy present, with 31% (*n*=24) of these providing active support and 34% (*n*=26) present only. The remaining 27 participants (35%) did not have or wish to have a proxy present for this measurement.

ii) Nature of Proxy Support

The nature of the support captured in the qualitative observational recordings fell into five discrete types (assisting the participant on and off the scales [wheelchair and flat scales], assisting the participant on or off the scales, standing beside the participant, providing guidance only, and full assistance), as set out in Table 4.38. The types of support were ordered using the patterns of frequencies recorded (ranked from most to least frequent).

Table 4.38: Nature of Proxy Support – Weight Measurement

Description of Proxy Support	
Supporting the participant on and off the scales (wheelchair and flat scales)	
Supporting the participant on or off the scales (wheelchair and flat scales)	
Standing beside the participant during the measurement	
Guidance only provided	Joint Position
Full assistance with measurement	

The most cited type of support was supporting the participant on and off the scales (wheelchair and flat scales). A total of 67% (n=12) of participants (n=18) requiring this type of support were wheelchair-users. In a few cases, participants required support getting on or off the scales'. The provision of emotional support was also recorded a few times:

"Proxy and I stood beside [them] for reassurance during this measurement." [25]

The type of support least given or required was general guidance (n=1) and full assistance with the measurement (n=1).

iii) Summary Description of Any Other Information

The most consistent and frequently recorded observation was the provision of assistance given to the participant moving on and off the scales (wheelchair and flat scales) by the proxy and, with less frequency, the researcher. The nature of proxy support was almost exclusively restricted to moving the participant on and/or off the scales. The type of proxy support least recorded was the provision of emotional support and guidance only. Only one participant required the full assistance of the proxy (which led to an invalid measurement). A high number of observations were also recorded on the use and benefits of the wheelchair scale for all participants when it was already set up. The weights of wheelchairs were calculated in one of three ways: by weighing the wheelchair before or after use (the same strategy was applied for seats used); the weight was taken from records by proxies, or the weight was taken from the manufacturer's stamp. In cases where the participants wanted to keep their shoes on during the measurement, it was noted that a protocol to weigh the shoes separately should be in place; this process was followed in these instances. The importance of checking levels of flooring, as outlined in the protocol, was noted. Medical-related observations were also made during the measurement process.

4.3.3.5 Waist Circumference (WC) Measurement (Single Layer of Clothing) Report

a) WC Measurement Status

A total of 52 participants (68%) attempted the waist circumference measurement. Forty-five (58%) had the first measurement reading taken and 44 completed the second reading (57%). Seven participants (9%) attempted the first and two (3%) the second measurement, but it was not obtained. See Section (g) for the reasons for non-obtainment of the measurements. For 25 participants (32%) in the first series and 31 (40%) in the second series, the measurement was not attempted. See Section (h) for the reasons for not attempting this measurement. None of the participants eligible for this measurement refused in the first or second series of measurements. See Table 4.39 for a breakdown of the waist circumference measurement status findings.

Five of the 52 participants (10%) who attempted or completed the measurement required a third measurement as the first or second reading may have been invalid and/or the difference between the first and second reading was greater than 0.5cm.

Table 4.39: Waist Circumference (WC) Measurement Status

	1st Measurement		2nd Measurement*	
	n (*n*=77)	%	n (*n*=77)	%
WC Measured	45	58	44*	57
WC Attempted Not Obtained	7	9	2	3
WC Not Attempted	25	32	31	40
WC Refused	0	0	0	0

* 98% (*n*=44) had duplicate measurements

b) Side and Position of the Participants for WC Measurements

Of those measured (*n*=45), the majority of participants (*n*=41; 91%) had the measurement taken on the right side of the body while standing, which was the preferred option. The remaining 9% (*n*=4) had the measurement taken on the left side, in a standing position. The left side was selected for these participants mainly due to their stance and the unsuitability of the right side.

c) Thickness of the Single Layer of Clothing

Based on all measurements taken (*n*=45), the mean thickness of the participants' single layer of clothing was 0.527mm (range 0.2mm to 1.4mm). Removing the invalid cases (*n*=12), the mean thickness of their single layer of clothing was 0.458mm (*n*=33; range 0.2mm to 1.0mm).

d) Validity of WC Measurements

Separately, 73% of the first (n=33) and 75% (n=33) of the second series of waist circumference (WC) measurements were valid[26]. Based on case matching of the valid readings in each series, the overall validity of the WC measurement was 73%. However, of the 73% (n=33) of measurements that were valid in the first series, 36% (n=16) experienced some administration problems. Similarly, this validity status applied to 36% (n=16) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (e). For invalid measurements, the rate in the first and second series was 27% (n=12) and 25% (n=11) respectively. The associated reasons for invalidity are discussed in Section (f). See Table 4.40 for a breakdown of the validity results.

Table 4.40: Validity of WC Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	45	58	44	57
No. of Valid Readings	33	73	33	75
No Problems with O.P.* Experienced	17	38	17	39
Some Administration Problems Experienced	16	36	16	36
No. of Invalid Readings	12	27	11	25

*Operational Protocol

e) WC Problems Experienced – Valid Measurements

The themes to emerge from the qualitative responses recorded were coded into the categories set out in Table 4.41 (n=16). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). Despite these measurement considerations, valid readings were obtained. Insights into the details of the more frequent categories (Table 4.41) are presented in Appendix 34 (see Section 5a). The findings provide future researchers with further insights into the practice of measuring WC and what should be taken into consideration.

[26] Criteria for validity: All standards were fulfilled and (a) no problems were experienced, or (b) some administration problems were experienced that required more attention or adjustment.

Table 4.41: WC Problems Experienced, Valid Measurements

Description of Problems Experienced – Valid Measurements	
Clothing hampered process	
Movement hampered reading	Joint Position
Difficulty locating iliac crest	
Participant's position as a factor	
Breathing pattern impeded process	
Limited space as a factor	

f) Invalid WC Measurements

The main contributing factor to the invalid measurements in the first and second series was unsuitable clothing; in particular, polyester clothing caused the tape to slide off the landmark and the thickness of non-polyester clothing made it difficult to palpate the edge of the iliac crest (mean thickness 0.717mm; range of thickness 0.4mm to 1.4mm). The next most frequent reason for invalid measurements in the first series was the movement of participants, which either reflected them being curious about the measurement and looking down at the tape measure, and/or not standing still. An example of a situation where the surrounding circumstances did not assist the participant and/or measurement process is recorded below.

> *"... looking down at what I was doing and the methods of distraction/engagement were not working (proxy also asked how many more measurements are there?). At the beginning of the measure, the proxy repeated the non-supportive comments 'xx wouldn't like' etc even though the participant seemed engaged during the briefing and demonstration – I said let's see what (the participant) would like to do." [32]*

Both of these reasons were also apparent in the second series of measurements but to a lesser extent. The other reasons of similar frequency that contributed to invalid measurements in the first and second series included: arms not being in the correct position; participant trying but not fully understanding the measurement; being unable to locate the specific edge of the iliac crest; holding their breath, and posture difficulty (leaned forward). See Table 4.42 for a breakdown of the type and frequency of invalid reason(s) for this measurement.

Table 4.42: Invalid Waist Circumference Measurements

	1st Measurement		2nd Measurement	
	n (*n*=12)	%	n (*n*=11)	%
Unsuitable clothing	7	58	7	64
Looking down at tape	3	25	2	18
Did not stand still	3	25	2	18
Arms not in correct position	2	17	2	18
Tried but did not understand	2	17	2	18
Unable to locate edge of iliac crest	2	17	2	18
Held breath	1	8	1	9
Posture difficulty (leaned forward)	1	8	1	9

g) WC Measurements Attempted – Not Obtained

The reasons for the attempts but non-obtainment (*n*=7; 9%) in the first series of measurements are classified under three themes: unable to locate the iliac crest, double layer of clothing, and loss of interest. The majority of the cases (*n*=4) were classified under the first theme, and the reasons were: unsuitable clothing, body weight distribution in the abdominal area, and two participants leaning slightly forward. Although one of the participants who leaned forward was able to locate their iliac crest during the demonstration stage, it was not possible to locate it at the time of measurement. Under the theme 'double layer of clothing', two participants (*n*=2) wore two layers of clothing and did not wish to have the measurement taken over a single layer only, so that a valid reading could be taken. Lastly, one participant (*n*=1) lost interest after they located the approximate area (reason unknown); although they did not wish to continue, they were happy to move on to the next measure. In the second series of measurements (*n*=2; 3%), the reason for the attempts but non-obtainment was due to clothing attire; both participants, wearing two layers of clothing, did not wish to hold up or take off the second item, which was a jumper in one case and a waistcoat in the other case.

h) WC Measurements Not Attempted

The main reason for the non-attempt of the waist circumference measurement in the first (*n*=25; 32%) and second series (*n*=31; 40%) of measurements was due to 19 participants being wheelchair-users. Less frequently coded reasons included the participant not being able to stand comfortably, poor gait or posture (leaning forward), unsuitable clothing, and emotive

responses. Under the theme 'unsuitable clothing', it was noted that one of the participants wore suspenders with clothing underneath, and that *"the avoidance of wearing suspenders needs to be included beside belts on the appointment card" [72]* for measurement visits in the future. Only one of the eligible participants did not understand the procedures and measurement was not attempted. By the end of the second series of measurements, one participant was tired, and another two were disengaged; one was anxious to get finished in time for lunch and the other seemed to have had enough and was not supported by the proxy. The corresponding qualitative observation was:

> *"Similar comments made by proxy, said [they] would not take off [their] jacket again, even though [they] had taken it off previously when requested. The 2nd measurement was not attempted as the participant had disengaged in the process – had put [their] jacket back on and moved away. The proxy's comments did not provide the most optimal conditions for the visit. I'm not sure the proxy even noted how negative the comments were even when they were deflected and converted to positive comments." [55]*

Finally, one of the participants did not like the measurement and wanted to skip it, so it was not attempted, but was happy to continue and complete the remaining measurement. See Table 4.43 for a breakdown of the type and frequency of the reasons for the non-attempts.

Table 4.43: Reasons for Non-Attempt of the WC Measurement

	1st Measurement		2nd Measurement	
	n (*n*=25)	%	n (*n*=31)	%
Wheelchair-user	19	76	19	61
Not able to stand comfortably or steadily	2	8	2	6
Poor gait or posture (leaning forward)	2	8	3	10
Unsuitable clothing	2	8	3	10
Did not understand the procedures	1	4	1	3
Tired, disengaged or anxious to get finished	0	0	3	10
Did not like the measurement	0	0	1	3

i) WC Measurements Refused

None of the eligible participants (*n*=52) refused the WC measurement during the first or second series of measurements.

j) Problems with Equipment – WC Measurement

Based on the total number of participants who attempted or had their WC measured (n=52), none experienced any problems with the measuring tape selected.

k) Any Other Information – WC Measurement

In 81% (n=42) of the cases where WC was measured and/or attempted (n=52), additional comments were noted under the 'any other information' question. The qualitative responses as recorded to the open-ended question on WC were coded into the categories set out in Table 4.44. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). All but the first category had no impact on completing the measurement. Insights into the details of the more frequent categories (Table 4.44) are presented in Appendix 34 (see Section 5b), except for the category *"type of guidance from proxy"*, which will be discussed in Section k(*ii*). The findings presented provide further insight into the measurement experience and highlight some considerations for future use. The first category, 'clothing', significantly affected the success of completing this measurement. Had suitable clothing been worn, the number of valid measurements would most likely have increased.

Table 4.44: Description of Any Other Information – WC Measurement

Description of Any Other Information
Clothing as a factor
Type of guidance from proxy
Sensitivity with participant
Additional support from researcher

i) Status of Proxy Support

Of all the participants who attempted the WC measurement (n=52), 31 (60%) had a proxy present, with 13% (n=7) of these providing active support and 46% (n=24) present only. The remaining 21 participants (40%) did not have or wish to have a proxy present for this measurement.

ii) Nature of Proxy Support

The level of support given by or required from proxies for this measure was very small. The nature of the support captured in the qualitative observational recordings fell into four discrete types of support (general support, interaction, emotional support, and negative support) as set

out in Table 4.45. The types of support were ordered using the patterns of frequencies recorded (ranked from most to least frequent).

Table 4.45 Nature of Proxy Support – WC Measurement

Description of Proxy Support	
General support with measurement	
Provided distraction	Joint Position
Emotional support	
Negative support	

General support – such as standing beside the participant, holding the second layer of clothing up, and assisting with the placement of the tape measure – was the main type of support provided. This was followed closely by the provision of emotional support (holding the participant's hands) and interacting with participants, so as to distract them from looking down at the tape measure during the measurement. One incident of negative (albeit inadvertent) support from a proxy involved negative/disempowering comments (for example, the participant *"will not take off their jacket"*), which did not provide optimal conditions for the measurement process or the delivery approach developed to empower participants.

iii) Summary Description of Any Other Information

The most cited observation concerned the participant's clothing being unsuitable for the measurement, which resulted in either a source of difficulty or a barrier to completing a valid measurement. The level of proxy support required for this measurement was limited; its nature was mainly general assistive support (e.g. holding up second layer of clothing), followed by interaction with the participant in the form of emotional support (e.g. holding hands during the measurement) and distraction (e.g. chatting) from looking down at the tape measure. Consistent with other measurements, one participant had inadvertently negative support from the proxy who stated that the participant would not complete the action required. The importance of managing the measurement sensitively and of including this sensitivity reminder, not only in the operational protocol, where this is currently stated, but also in training was noted. The level of extra support needed from the researcher was very limited.

4.3.3.6 Waist Circumference (WC) Measurement (Bare Skin) Report

a) WC Measurement on Bare Skin Status

Towards the end of the measurement visit, a total of 37 participants (48%) attempted the waist circumference measurement on bare skin. All of these participants (100%; *n*=37) also completed this measurement over a single layer of clothing. Thirty-seven participants had the first measurement reading taken (48%) and 33 completed the second reading (43%). For 39 participants (51%) in the first series and 44 (57%) in the second series, the measurement was not attempted. See Section (d) for the reasons for not attempting this measurement. One of the participants (1%) eligible for the measurement refused in the first series but none refused in the second series; see Section (e) for the reason for the sole refusal.

A breakdown of the waist circumference measurement status findings on bare skin is presented in Table 4.46. None of the participants required a third measurement to be taken. Ninety-five percent (*n*=35) had the measurement taken on the right side (iliac crest) standing and 5% (*n*=2) had it taken on the left side due to their stance and leaning slightly to the right.

Table 4.46: Waist Circumference (WC) Measurement Status on Bare Skin

	1st Measurement		2nd Measurement	
	n (*n*=77)	%	n (*n*=77)	%
WC Measured	37	48	33*	43
WC Attempted Not Obtained	0	0	0	0
WC Not Attempted	39	51	44	57
WC Refused	1	1	0	0

*89% (*n*=33) had duplicate measurements.

b) Validity of WC Measurements on Bare Skin

Separately, 84% of the first (*n*=31) and 91% of the second (*n*=30) waist circumference measurements on bare skin were valid. Based on case matching of the valid readings in each series, the overall validity of the WC measurements on bare skin was 81%. For invalid measurements, the rate in the first and second series was 16% (*n*=6) and 9% (*n*=3) respectively; the associated reasons for invalidity are discussed in Section (c).

c) Invalid WC Measurements on Bare Skin

The main contributing factor to the invalid measurements in the first (n=2) and second (n=2) series was the measuring tape sticking to the participant's skin. For one participant, the warm weather greatly increased the temperature inside their home; another participant had several layers of clothing on, which increased their body temperature. In the qualitative observations recorded, the following was noted: *"need to add a note of caution into the operational protocol for future reference on the impact of hot weather* [and body temperature due to extra layers of clothing] *on such measurement on bare skin" [38].* Another invalid measurement in the first (n=1) and second (n=1) series was due to posture and the participant not standing straight, which pushed further tissue down into the abdominal area. The remaining reasons for invalid measurements in the first series were of singular occurrence, and include: moving arms and not standing still (n=1), holding breath and not exhaling fully (n=1), and looking down at the tape measure during the measurement (n=1).

d) WC Measurements Not Attempted on Bare Skin

The main reason for the non-attempt of the WC measurement in the first (n=39; 51%) and second (n=44; 57%) series was due to participants being wheelchair-users (n=19). The second and third reasons were the participant being disengaged, tired and/or anxious to get finished, as this measurement was towards the end of the visit (first series n=7; second series n=8), and their posture not being ideal for the measurement (n=5). The fourth most commonly coded reasons were of equal frequency: the proxy not being visible or available to assist with the measurement (n=4), and the participant not wearing suitable clothing (n=4). Less frequently coded reasons (ranging from n=2 to n=1) varied from unsuitable location to carry out this measurement on bare skin to the participant moving their arms and not standing still in the first attempt, and being likely to continue to do so. See Table 4.47 for a full breakdown of the type and frequency of the reasons for the non-attempts.

Table 4.47: Reasons for Non-Attempt of the WC Measurement on Bare Skin

	1st Measurement		2nd Measurement	
	n (*n*=39)	%	n (*n*=44)	%
Wheelchair-user	19	49	19	43
Tired, disengaged or anxious to get finished	7	18	8	18
Poor posture (leaning forward)	5	13	5	11
Proxy not visible or available	4	10	4	9
Unsuitable clothing	4	10	4	9
Unsuitable location	2	5	2	5
Did not understand the procedures	2	5	2	5
Unable to locate iliac crest over single layer of clothing (weight distribution)	2	5	2	5
Not able to stand comfortably	1	3	1	2
Did not like the measurement	1	3	1	2
Moving arms – not standing still	0	0	1	2
Holding breath – not exhaling fully	0	0	1	2
Looking down at the measurement	0	0	1	2

e) WC Measurements on Bare Skin Refused

One eligible participant refused the WC measurement on bare skin in the first series, as they did not wish to have this or any other measurements taken at the end of the visit.

f) Presence and Support of Proxy for WC Measurements on Bare Skin

All eligible participants who attempted or completed the WC measurement on bare skin had a proxy present with the participant's permission, which was required as part of the eligibility criteria for this measurement (*n*=37; 100%). All the proxies assisted by holding the participant's single layer of clothing to the level of the participant's navel for the duration of the measurement. Five percent (*n*=2) also kept the participant's focus straight ahead and interacted with the participants to distract them from holding their breath (not exhaling fully) for the measurement. Another proxy stood to the right of the participant for support as they leaned slightly to the right (*n*=1; 3%). Lastly, in one case, the timing of the proxy's interaction with the researcher during the measurement proved distracting; despite the researcher's efforts to try to deflect their interaction until the measurement reading had been taken and recorded. The observation recorded was:

"During the measurement [proxy joined for this measure only], the proxy kept chatting which made it more difficult to concentrate on breathing patterns of the participant – proxy very interested in the significance of weight around the abdominal area in general." [33]

It was noted that in a small number of cases the bare skin measurement was not possible due to the proxy not being visible or available at the time of measurement:

"Proxy was not present or nearby, so we did not carry out the measurement on bare skin, over clothing only – participant happy with this. The measure was mentioned at the start of the visit and to be discussed in more detail, if it was possible to take." [5]

4.3.3.7 Hip Circumference (HC) Measurement Report

a) HC Measurement Status

A total of 52 participants (68%) attempted the hip circumference measurement. Fifty-one (66%) had the first measurement reading taken and 50 completed the second reading (65%). One participant (1%) attempted the first measurement but it was not obtained. See Section (f) for the reasons for non-obtainment of the measurement. For 25 participants (32%) in the first series and 27 (35%) in the second series, the measurement was not attempted. See Section (g) for the reasons for not attempting this measurement. None of the participants eligible for this measurement refused in the first or second series of measurements. See Table 4.48 for a breakdown of the hip circumference measurement status findings. Of the 52 participants who attempted or completed the measurement, only one (2%) required a third measurement as the first or second reading may have been invalid and/or the difference between the first and second reading was greater than 0.5cm.

Table 4.48: Hip Circumference (HC) Measurement Status

	1st Measurement		2nd Measurement*	
	n (*n*=77)	%	n (*n*=77)	%
HC Measured	51	66	50*	65
HC Attempted Not Obtained	1	1	0	0
HC Not Attempted	25	32	27	35
HC Refused	0	0	0	0

* 98% (*n*=50) had duplicate measurements

b) Side and Position of Participants for HC Measurements

Of those measured (n=51), the majority of participants (n=49; 96%) had the measurement taken on the right side of the body standing, which was the preferred option. The remaining 4% (n=2) had the measurement taken on the left side in a standing position. The left side was selected for these participants mainly due to their stance and the unsuitability of the right side.

c) Validity of HC Measurements

Separately, 98% of the first (n=50) and second (n=49) series of HC measurements were valid[27]. Based on case matching of the valid readings in each series, the overall validity of the HC measurement was 96%. However, of the 98% (n=50) of measurements that were valid in the first series, 10% (n=5) experienced some administration problems. This validity status applied to 8% (n=4) of the measurements in the second series. An overview of the administration problems experienced is presented in Section (d). For invalid measurements, the rate in both the first and second series was 2% (n=1); the associated reasons for invalidity are discussed in Section (e). See Table 4.49 for a breakdown of the validity results.

Table 4.49: Validity of HC Measurements

	1st Measurement		2nd Measurement	
	n	%	n	%
No. of Measurements	51	66	50	65
No. of Valid Readings	50	98	49	98
No Problems with O.P.* Experienced	45	88	45	90
Some Administration Problems Experienced	5	10	4	8
No. of Invalid Readings	1	2	1	2

*Operational Protocol

d) HC Problems Experienced – Valid Measurements

The themes to emerge from the qualitative responses recorded were coded into the categories set out in Table 4.50 (n=5). The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent[28]). Despite these measurement considerations, valid readings were obtained. There were very few recorded observations under this category. Insights into the details of the categories (Table 4.50) are presented in Appendix 34 (see Section

[27] Criteria for validity: All standards were fulfilled and (a) no problems were experienced, or (b) some administration problems were experienced that required more attention or adjustment.

[28] Reminder: The themes ranked least frequent are no less important than those ranked most frequent. All categories, irrespective of their placement, contribute equally to our overall understanding of the phenomena of interest.

6a). The findings provide future researchers with further insights into the practice of measuring HC and what should be taken into consideration.

Table 4.50: HC Problems Experienced, Valid Measurements

<table>
<tr><th colspan="2">Description of Problems Experienced – Valid Measurements</th></tr>
<tr><td colspan="2">Negotiation with participant</td></tr>
<tr><td>Weight distribution</td><td rowspan="2">Joint Position</td></tr>
<tr><td>Leaned to the right</td></tr>
<tr><td colspan="2">Clothing as a factor</td></tr>
<tr><td colspan="2">Moved slightly</td></tr>
</table>

e) Invalid HC Measurements

The reason for the invalid measurement in the first and second series was due to unsuitable clothing:

> *"... the end of [their] waist coat fell into the measurement point and the participant did not want to adjust it, so the measure was taken over part of it, increasing the reading." [14]*

f) HC Measurement Attempted – Not Obtained

The reasons for the attempt but non-obtainment (n=1; 1%) in the first series of measurement was due to the participant not liking this measure, which was demonstrated through their body language; the specific reason was unknown and measurement was skipped.

g) HC Measurements Not Attempted

The main reason for non-attempt of the HC measurement in the first (n=25; 32%) and second (n=27; 35%) series was due to 19 participants being wheelchair-users. Less frequently coded reasons included poor gait or posture (leaning forward), not being able to stand comfortably or steadily, not understanding the procedures, wearing unsuitable clothing, and getting tired due to the warm weather, losing interest in the visit, and not liking this measurement (second series). The qualitative observation recorded about the participant getting tired noted:

> *"... participant was starting to get tired due to the warm temperature outside and inside, as a result they were also leaning more forward compared to stance at the beginning of the visit." [60].*

See Table 4.51 for the reasons for non-attempts of this measurement.

Table 4.51: Reasons for Non-Attempt of the HC Measurements

	1st Measurement		2nd Measurement	
	n (*n*=25)	%	n (*n*=27)	%
Wheelchair-user	19	76	19	70
Poor gait or posture (leaning forward)	3	12	3	11
Not able to stand comfortably or steady	1	4	2	7
Unsuitable clothing	1	4	1	4
Did not understand the procedures	1	4	1	4
Tired due to heat or disengaged	1	4	2	7
Did not like the measure – reason unknown	0	0	1	4

h) HC Measurements Refused

None of the eligible participants (*n*=52) refused the HC measurement during the first or second series of the measurement.

i) Problems with Equipment – HC Measurement

Based on the total number of participants who attempted or had their HC measured (*n*=52), none experienced any problems with the measuring tape selected.

j) Any Other Information – HC Measurement

In 4% (*n*=2) of the cases where HC was measured and/or attempted (*n*=52), additional comments were noted under the 'any other information' question. All of the qualitative responses related to the support given by proxies to participants; see Section j(*i*).

i) Status and Nature of Proxy Support

Of all the participants who attempted the HC measurement (*n*=52), 31 (60%) had a proxy present, with 4% (*n*=2) of these providing active support (i.e. adjusting clothing and standing beside the participant) and 56% (*n*=29) present only. The remaining 21 participants (40%) did not have or wish to have a proxy present for this measurement. The nature of proxy support was: adjusting clothing slightly to ensure a valid measurement could be obtained, and standing beside the participant for support as they leaned slightly to the right, while the measurement was being taken on the left side.

ii) Summary Description of Any Other Information

There were very few recorded observations against this category. The level of support required for this measurement was minimal; proxy support consisted of adjusting clothing and standing beside the participant for support.

4.3.3.8 Participants with Down Syndrome and Measurement Findings

In the cases (n=10) involving participants with Down syndrome (DS), there was only one finding that was notably prevalent (n=5). However, this finding was not unique to this sub-group, as it applied also to other participants with intellectual disability. The finding relates to the styloid process (ulna length measurement completed) – see Appendix 34, Section 2a.

4.3.3.9 Overall Status of Proxy Presence for Measurement Visit

The status and nature of the support proxies provided to participants as part of the measurement visit are detailed within each of the six measurement reports. An overview of the overall presence of proxies during the visit was also analysed, and is detailed in Section (i).

i) Status of Proxy Presence during the Measurement Visit

Over half of the participants (n=40; 52%) had a proxy present for all or nearly the entire visit. Eighteen percent (n=14) only had a proxy present for the waist circumference measurement on bare skin and 17% (n=13) had no proxy present, but for 13% (n=10) of these, one was available if needed. See Table 4.52 for a breakdown of the status of proxies during the visits.

Table 4.52: Status of Proxy Presence during the Measurement Visit

Types of Proxy Status	n (n=77)	%
Present for all or nearly the entire visit	40	52
Present for 1st series of measurements only	1	1
Present at the beginning and/or end of visit	6	8
Present intermittently	3	4
Present for waist circumference measurement – bare skin only	14	18
No one present but available if needed	10	13
No one present or available	3	4

ii) Overview of Proxy Presence and Support for Each Measurement

Concerning the role of the proxies present at each of the measurements, the majority were present only, as no active support was needed by participants (see Table 4.53), except for the waist circumference measurement on bare skin, as active support was one of the inclusion criteria for this measurement. Of those who provided active support, only 11 participants required full assistance, which was split across four of the measurements. Five participants needed full assistance with the ulna length measurement, three with the height, two with the mid-upper arm circumference (MUAC) measurement, and one with the weight measurement. For all others, the active support needed was minimal (but no less important); and it ranged from assisting with the position needed for the measurement (e.g. assisting the participant on and/or off the wheelchair scale, guiding the position of their arm, feet or head), to provision of emotional support and/or guidance only. A detailed overview of the type of support given is presented within each measurement report.

Table 4.53: Summary of Proxy Presence and Support for Each Measurement

			Role of Proxy			
	Proxy Present		Active Support		Present Only	
	n	%	n	%	n	%
Standing Height	32	58	16	29	16	29
Ulna Length	50	65	16	21	34	44
MUAC*	49	65	13	17	36	48
Weight	50	65	24	31	26	34
WC** – Clothing	31	60	7	13	24	46
WC** – Bare Skin	37	100	37	100	0	0
Hip Circumference	31	60	2	4	29	56

*Mid-Upper Arm Circumference ** Waist Circumference

4.3.3.10 Summary of Duplicate Measurements Status

Across all the measurements and all of those measured, the mean rate of duplicate measurements achieved was 96% (range 89 to 100). The measurement with the lowest rate (89%) was waist circumference (WC) on bare skin and the highest-rated (100%) was left ulna length, followed closely by right ulna length (99%), WC over clothing (98%), hip circumference (98%), MUAC (98%) and weight (97%). Height (92%) was next to the lowest-rated. Overall, the

rate of duplicate measurements achieved was very high. Duplicate measurements are feasible in this sample population.

4.3.3.11 Accessible Measurement Materials and Measurement Experience

a) Evaluation of the Measurement Materials and Measurement Experience

As noted in Chapter 3, Section 3.10.5, the final sections of the Anthropometric Measurement Results Workbook (see Appendix 21) comprised evaluation questions on the accessible materials developed and used as part of the measurement visit, and concluded with an open-ended question on the experience. The overall findings from each question will be presented.

b) Usefulness of the Accessible Measurement Appointment Card

Of those asked (*n*=75), 88% of the participants (*n*=66) felt that the appointment card was useful; 29 of these participants (39%) answered the question themselves, 12 (16%) were joint participant and proxy responses, and in 25 cases (33%) proxies answered on behalf of the participant. One participant gave an unclear response (1%; *n*=1), while the remaining 11% (*n*=8) of responses were coded as not applicable, as the participant and/or proxy did not see and/or receive the appointment card in the post. The qualitative responses as recorded for *"not applicable"* were coded into the four categories outlined in Table 4.54.

Table 4.54: Not Applicable – Usefulness of the Accessible Measurement Appointment Card

Measurement Appointment Card	n (*n*=8)	%
Participant did not see the card	3	38
Card never arrived in the post (participant and proxy)	2	25
Proxy never saw the card but all the information was in the diary	2	25
Family did not see the card – staff had filed the card	1	13

Two participants (3%) were not asked to evaluate the usefulness of the appointment card, as the card had not been issued before the measurement visit. At the interview, one of the participants decided not to take part in the measurement visit, but, after seeing another participant in their house taking part in the final stage of the study, changed their mind and wanted to take part too. For the other participant, the proxy had yet to complete the associated interview but was supporting two others participants with the measurement visit. With the participant's assent, all three visits were completed the same day.

c) Usefulness of the Accessible Measurement Information Booklet

Of those asked (*n*=75), 91% of the participants (*n*=68) felt that the information booklet was useful; 33 of these participants (44%) answered the question themselves, 11 (15%) were joint participant and proxy responses, and 24 proxies (32%) answered on behalf of participants. One participant gave an unclear response (1%; *n*=1). The remaining 8% (*n*=6) responses were coded as not applicable, as they did not see and/or receive the booklet. The qualitative responses as recorded for *"not applicable"* were coded into the four categories outlined in Table 4.55.

Table 4.55: Not Applicable – Usefulness of the Accessible Measurement Information Booklet

Measurement Information Booklet	n (*n*=6)	%
Participant did not see the booklet	2	33
Family or proxy did not see the booklet	2	33
Booklet received but neither participant or proxy saw it	1	17
Booklet never received from the interviewer (proxy)	1	17

Lastly, two participants (3%) were not asked to evaluate the usefulness of the measurement information booklet, as (a) the interviewers had not issued this booklet as one participant did not want to take part in the measurement visit at the time of interview and (b) the interview had yet to be completed. A copy of the accessible booklet was given to each participant and a brief overview of the content was provided at the beginning of the visit.

d) Any Other Information – Accessible Measurement Appointment Card and Information Booklet

An open-ended question for any other information/feedback followed the two evaluation questions on the usefulness of the measurement appointment card and information booklet. The qualitative responses as recorded were coded into the categories set out in Table 4.56. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent[29]). The findings provide future researchers with further insights into the use of an accessible measurement appointment card and information booklet in practice.

[29] Reminder: The themes ranked least frequent are no less important than those ranked most frequent. All categories, irrespective of their placement, contribute equally to our overall understanding of the phenomena of interest.

Table 4.56: Any Other Information (AOI) – Accessible Measurement Appointment Card and Information Booklet

Description of Any Other Information	
(Participant) Positive engagement – good understanding	
Researcher unsure if the visit had been discussed with participant beforehand	
(Participant) Photo ID and illustrations helpful	
(Proxy) Both materials are useful for staff	
(Participant) Did not see appointment card	
(Participant) Did not see information booklet	
(Participant) Poor understanding of evaluation questions	
(Proxy) Did not see appointment card	Joint Position
(Proxy) Did not see information booklet	

Insights into the details of the more frequent categories are given below.

i) Participant Positive Engagement – Good Understanding

In many instances, the qualitative observational data recorded positive engagement and good understanding by the participant:

> *"Participant had the appointment card with [them], said [they] liked the photo and knew who was coming. Met participant outside and said 'hello Janet' and introduced [self]. [They] felt the card and booklet were clear and easy to understand. Good example of the benefits of staged communication, empowering participants in the process." [4]*

> *"Participant had appointment card with [them] and said that [they] liked it, provided all the information needed about the visit and with the picture [they] knew who to expect. [They] also said the information booklet was clear and knew overall what was going to be involved before the visit." [73]*

ii) Participant and Proxy – Uncertainty of Discussion before Measurement Visit

There were a significant number of observations where it was unclear if any discussion by the proxy or staff had taken place with the participant about the measurements prior to the visit, using the appointment card or the information booklet issued at the end of the interview.

> *"Participant and proxy said that appointment card was received but they didn't see it, all information from it was written in the diary. Also, the participant and proxy said neither of them [had] seen the information booklet (copy left)." [6]*

[Proxy did not see the information booklet] "A copy of the information booklet was left with the participant and proxy. I am unsure if anyone went through the booklet with the participant before the visit, if received." [Researcher] [23]

On review of the codes in this category and cross-referenced with quantitative information (n=29), over half of cases involved had a severe or profound range of intellectual disability (ID) (55%; n=16). This figure (55%) represents all of the participants taking part in the study in those ranges except for one participant who had severe ID but had not completed the interview before the home visit and was therefore not asked these evaluation questions. The remaining cases represented nine participants in the moderate range (31%), one in the mild range (3%), and two with unverified (7%) and one with unknown (3%) levels of ID.

iii) Participant – Photo ID and Illustrations Helpful (Appointment Card)

There were many recorded observations where the participant, proxies and staff found the photo ID of the researcher useful for security reasons, especially for reassuring the participant and preparing them for the visit.

"Participant found the card very useful and knew who I was from the card (photo) and that it was safe to let me in. Even though [they] cannot read, the participant said the pictures (i.e. illustrations) were useful and was able to get the key messages. [They] also said [they] enjoyed the visit and measurements, first time to be included in a study." [71]

"Proxy said the appointment cards are very useful as it has reminders for staff as well. Participant said [they] liked the appointment card with the picture and knew who was coming, and liked the materials too." [30]

"Participant said [they] really liked appointment card. Proxy also added the inclusion of picture is great for security purposes and the card was informative. [45]

iv) Materials Useful for Proxy and Staff

There were a significant number of observations where the proxy and/or staff commented positively on the usefulness of the appointment card and information booklet for informing them of the impending visit and its purpose:

"Proxy said the appointment card and information booklet were clear and useful for staff to refer to if they were unaware of the study." [34]

"Spoke to proxy after the visit was complete at nurse's station. Proxy said the appointment card was a good reminder of the visit and who to expect. Information booklet was clear and user friendly." [48]

"Participant and proxy liked the appointment card (on table) and said they knew who was coming. Information booklet gave them an idea of the visit and what was going to happen. They said both items were clear and easy to follow." [66]

v) Participant Did Not See the Measurement Appointment Card

There were some recorded cases where the participant self-reported that they did not see the appointment card, although it had arrived as the information was detailed in the staff diary, and, for two others, it did not arrive in the post and/or got delayed at the central sorting office:

"Participant liked the booklet and the pictures (illustrations), said it was clear and easy to understand. However, the participant said that appointment card did not arrive in the post yet and had [they] seen the reminder about clothing [they] would have worn the right top (echoed by proxy)." [40]

"On initial briefing checks, the participant said [they] did not see either pieces (card or booklet). Office copies were shown but they were not familiar. A copy of each was given to the participant for [their] information and [they] thanked me for the materials." [63]

vi) Participant Did Not See the Measurement Information Booklet

There were slightly fewer observations recorded where the participant self-reported that they had not seen the booklet, compared to the appointment card, prior to the visit.

"Participant said [they] didn't see the appointment card or the information booklet." [69]

"Participant said [they] had not seen the information booklet." [6]

vii) Participant – Poor Understanding of Evaluation Questions

There were a small number of cases recorded where the researcher felt the participant did not understand fully or in part the evaluation questions, even with adapted wording and reference materials. Three of the four participants had a moderate level of intellectual disability.

"Unsure whether the participant fully understood the questions, adapted the wording but I am still not 100% sure of their complete understanding. [They] did respond positively to both items when copies were shown." [65]

"Not sure if the participant fully understood the questions (used adapted wording and showed both items), the participant smiled and made gestures which one could perceive as [them] communicating [their] like of the materials." [77]

viii) Proxy Did Not See the Measurement Appointment Card

There were fewer observations recorded where the proxy reported that they did not see the appointment card, although the details were in the diary, and in one case it hadn't arrived in the post:

"Proxy said [they] did not receive the appointment card in the post or the information booklet at the end of the interview." [26]

"Proxy said [they] didn't see the appointment card but information about the visit was in diary, so it was received but were not sure where it was filed." [23]

ix) Proxy Did Not See the Measurement Information Booklet

Of equal proportion to the previous observation, there were fewer incidents of the proxy not seeing or receiving the information booklet.

"... proxy did not see the information booklet. A copy of the information booklet was left with the participant and proxy." [Researcher] [23]

"Proxy said [they] did not receive the information booklet at the end of the interview." [31]

x) Summary Description of Any Other Information

There were many instances where the qualitative observational data recorded positive engagement and good understanding by the participant of the evaluation questions. There were a significant number of observations where the researcher was unsure whether or not the proxy had discussed the measurement visit with the participant beforehand (over half of these observations related to cases of severe or profound intellectual disability). There were many recorded observations where the participant, proxies and support staff found the photo ID on the measurement appointment card useful for security reasons, especially for reassuring the participant and preparing them for the visit. There were a significant number of observations where the proxy and/or staff commented positively on the usefulness of the appointment card and the information booklet for informing them of the impending visit and its purpose. There were some observations recorded where the participant and/or proxy had not seen or (in fewer incidences) received the appointment card or booklet. In a very small number of cases, where three of the four participants had a moderate level of intellectual disability, the researcher felt they did not understand fully or in part the evaluation questions being asked, even with the use of adapted wording and the accessible reference materials.

e) Evaluation of the Accessible Measurement Showcards Use

The measurement showcards were used in 95% (n=73) of the visits and were deemed useful by the researcher and were positively received. For three participants (4%), the usefulness was unclear, as it was difficult to determine how much one of the participants understood based on non-verbal communications solely; another had a visual impairment and the researcher was unsure if they could see the images, and the final participant showed no interest in the

measurement showcards. There was only one visit where the showcards were not deemed useful (1%), as the participant had a visual impairment and was unable to see the cards.

f) Any Other Information – Feedback, Observations or Reflections

At the end of the Anthropometric Measurement Results Workbook, there was an open-ended section for the researcher to detail any other feedback and/or reflections on the components of the visit; for example, the participant's response to the briefings and demonstration stage of the measurements. This section was completed on all forms in different degrees of detail, and included mostly information not previously coded under other categories. The qualitative responses as recorded were coded into the categories set out in Table 4.57. The themes were ordered using the patterns of frequencies recorded (ranked from most to least frequent). The findings provide future researchers with further insights into the measurement visit, particularly the response to the familiarisation steps included within the study design.

Table 4.57: AOI – Feedback, Observations or Reflections from the Measurement Visit

Description of Any Other Information	
Briefings and demonstrations worked well	
Participant – understood and communicated	
Proxy and staff – fully engaged	Joint Position
Participant – level of understanding and modes of communication	
Participant enjoyed the visit	
Proxy distant support enabled focus on participant	Joint Position
Importance of sensitivity	
Negotiating with proxy	

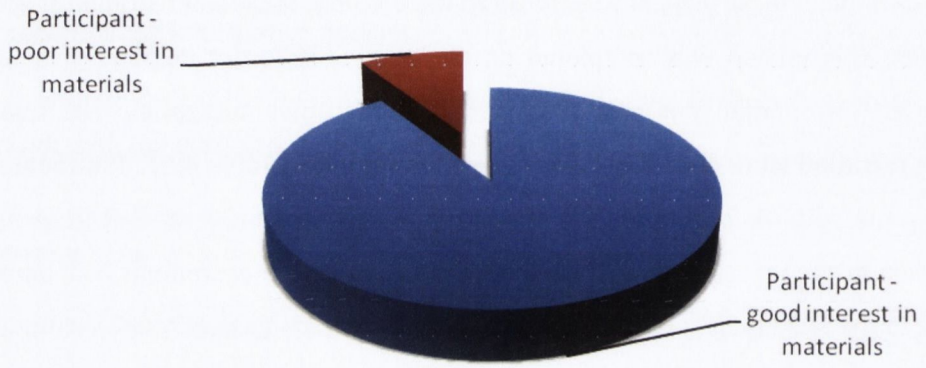
Insights into the contextual details of the categories are given below (see Appendix 35 for details of the analytical memos against each of the categories listed).

i) Briefings and Demonstrations Worked Well

The single most cited observation was that briefings and demonstrations worked well and were well received irrespective of the participant's level of intellectual disability. It was also noted when the participant showed a keen level of interest in the materials or where a particularly poor level of interest was displayed. Figure 4.7 shows that the incidence of a poor level of interest was relatively very small. In the main, the materials refer to the showcards used during

the visit (briefing stage before each measurement), the accessible booklet *Keeping Well* (DSS 2007) and the accessible Measurement Information Record Card, which details the measurement results (both were given to the participant towards the end of the visit).

Figure 4.7: Participants' Level of Interest in the Materials



To build on the success of the materials, it was noted that, if there were sufficient resources for future application, all the illustrations should be replaced with photographs depicting the same messages and the subject models should be people with intellectual disability.

ii) Participant Understood and Communicated

Similarly there were high levels of observational data recorded of participants demonstrating a clear understanding and communicating that understanding during the measurement process.

iii) Proxy and Staff Fully Engaged

Proxies and staff were noted as being generally helpful and fully engaged in the processes.

iv) Participant – Level of Understanding and Modes of Communication

There were several instances, mainly involving participants with severe and profound ID, where their level of understanding of the adapted briefings and demonstrations was unclear, but non-verbal communication, such as gestures, were used by many of these participants. This assisted in the assessment of support needed during the measurement and, most importantly, the assessment of their assent to participate in each eligible measure.

v) Participant Enjoyed the Visit

It was regularly noted in the qualitative observations if the participant particularly enjoyed the visit.

vi) Proxy Distant Support Enabled Focus on Participant

It was noted that, where the proxy limited support to stepping in and out where required and, when present in part or fully, stayed in the background when not needed, it greatly assisted the researcher to focus on the participant, and was noted as very beneficial to the process.

vii) Importance of Sensitivity

The importance of sensitivity (e.g. locating specific landmarks) towards the participant was noted in several observations under the feedback section of the qualitative observations.

viii) Negotiating with Proxy

In a very small number of exceptional cases, it was noted that it was necessary to negotiate with the proxy in order to successfully complete the measurement process.

ix) Summary Description of Any Other Information

The single most cited observation was that the briefing and demonstrations worked well and were well received. It was noted when the participant showed a keen level of interest in the materials or where a particularly poor level of interest was displayed. The incidence of poor levels of interest was very small relative to the others. Similar high levels of recordings were made indicating that the participant had demonstrated clear understanding and had communicated that understanding during the measurements. Proxies were noted as generally helpful and fully engaged in the process, but in a few exceptional cases, it was necessary to negotiate with the proxy in order to satisfactorily complete the process. A spotter/recorder might have been useful to record the measurement results when there were additional environmental stimuli to manage. It was noted that where the proxy limited support to stepping in and out where required, and staying in the background when not needed either when present in full or in part, this greatly assisted the researcher to focus on the participant, and was very beneficial to the process. There were several instances, mainly involving participants with severe and profound ID, where their level of understanding was unclear, but many of these individuals used non-verbal cues, such as gestures. It was regularly noted in the qualitative observations that the participant particularly enjoyed the visit. Finally, the importance of sensitivity towards the participant was also noted in several observations.

g) Anthropometric Measurement Results Workbook – Status of Completion

All the workbooks were completed in full. The process of manually completing the workbooks and transferring the information to the corresponding Statistical Package for the Social Sciences (SPSS) database developed after each measurement visit was very time-consuming, as it

involved recording the data twice as opposed to once if a mobile devise was used (a personal digital assistant improves speed and transfers data directly into the SPSS database).

h) Inclusion and Exclusion Criteria for Each Measurement

No revisions to the inclusion criteria for the uptake of the measurement visit or any of the measurements were made or proposed. Regarding the exclusion criteria, only one amendment was identified and was acted upon in this study; this was the exclusion of a participant from the waist circumference measurements due to them wearing suspenders.

This completes Phase 2 of the report.

4.4 Phase 3: Reliability and Hypotheses

4.4.1 Evaluation of the Reliability of Anthropometric Measurements

An evaluation of the reliability of the valid anthropometric measurements taken and the rates of intra-evaluator technical error of measurement for each measure is presented below.

a) Reliability Hypotheses

(1) *H1: There will be a significant difference between the mean of the first and second* ***standing height*** *measurements. HO: There will be no significant difference between the mean of the first and second* ***standing height*** *measurements.* **(2)** *H1: There will be a significant difference between the mean of the first and second* ***left ulna length*** *measurements. HO: There will be no significant difference between the mean of the first and second* ***left ulna length*** *measurements.* **(3)** *H1: There will be a significant difference between the mean of the first and second* ***right ulna length*** *measurements. HO: There will be no significant difference between the mean of the first and second* ***right ulna length*** *measurements.* **(4)** *H1: There will be a significant difference between the mean of the first and second* ***mid-upper arm circumference (MUAC)*** *measurements. HO: There will be no significant difference between the mean of the first and second* ***MUAC*** *measurements.* **(5)** *H1: There will be a significant difference between the mean of the first and second* ***weight*** *measurements. HO: There will be no significant difference between the mean of the first and second* ***weight*** *measurements.* **(6)** *H1: There will be a significant difference between the mean of the first and second* ***waist circumference (WC)*** *measurements over clothing. HO: There will be no significant difference between the mean of the first and second* ***WC*** *measurements over clothing.* **(7)** *H1: There will be a significant difference between the mean of the first and second* ***WC*** *measurements on* ***bare skin****. HO: There will be no significant difference between the mean of the first and second* ***WC*** *measurements on* ***bare skin****.* **(8)** *H1: There will be a significant difference between the mean of the first and second* ***hip circumference (HC)*** *measurements. HO: There will be no significant difference between the mean of the first and second* ***HC*** *measurements.*

Based on case matching of the valid readings in each series, Table 4.58 summarises the mean and standard deviations of the first and second measurements of height, ulna lengths, MUAC, weight, WC and HC, the results of the paired t-tests, Intraclass Coefficient and the Pearson's correlation coefficient tests. The results of all the t-tests suggest that there are no significant differences between the first and second measurements (see Table 4.59). The mean differences were checked, and a p-value > 0.05 indicated no significant differences in the measurements. The largest mean difference (SD) was 0.5cm (0.04) for the WC measurement taken over a single

layer of clothing. All of the variables nearly correlated perfectly. The intraclass correlation coefficient of the variables was 0.998 or above, with the upper and lower confidence intervals ranging from 0.997 to 1.00, which represents almost perfect reliability.

Table 4.58: Reliability of Anthropometric Measurements

	Paired t-test			Intraclass Coefficient				Test Retest	
	Mean 1 (SD)	Mean 2 (SD)	*P* value	ICC	CI Lower	CI Upper	*P* value	Pearson value (r)	*P* value
Height cm (*n*=34)	158.99 (11.60)	158.97 (11.62)	.518	1.000	1.000	1.000	<.001	1.000	<.001
Ulna Left cm (*n*=75)	24.36 (1.92)	24.37 (1.90)	.440	.999	.998	.999	<.001	.999	<.001
Ulna Right cm (*n*=75)	24.44 (1.86)	24.45 (1.85)	.262	.998	.997	.999	<.001	.998	<.001
MUAC cm (*n*=53)	30.63 (4.78)	30.61 (4.77)	.278	1.000	.999	1.000	<.001	1.000	<.001
Weight kg (*n*=74)	69.04 (17.51)	69.04 (17.51)	.288	1.000	1.000	1.000	<.001	1.000	<.001
WC Clothing cm (*n*=33)	97.20 (13.95)	97.25 (13.99)	.160	1.000	1.000	1.000	<.001	1.000	<.001
WC Bare cm (*n*=30)	97.41 (13.02)	97.42 (13.04)	.712	1.000	1.000	1.000	<.001	1.000	<.001
HC cm (*n*=49)	104.68 (11.20)	104.66 (11.15)	.434	1.000	1.000	1.000	<.001	1.000	<.001

Abbreviations: MUAC – Mid-upper arm circumference; WC – Waist Circumference; HC- Hip Circumference

For each of the hypotheses, we fail to reject the null hypothesis, as there are no significant differences between the means of the two variables in any of the parameters tested. Additionally, the correlations between the first and second measures were all very high, which collectively suggests that the conditions under which the testing was conducted in all locations (e.g. home) were reproducible. See Table 4.59 for a breakdown of the significance of t-tests.

Table 4.59: Significance of t-tests

Significance of t-tests	
Standing Height cm	Non-significant $t(33) = .653$, $p > .05$ ($p=.518$)
Ulna Length Left cm	Non-significant $t(74) = -.776$, $p > .05$ ($p=.440$)
Ulna Length Right cm	Non-significant $t(74) = -1.131$, $p > .05$ ($p=.262$)
MUAC cm	Non-significant $t(52) = 1.097$, $p > .05$ ($p=.278$)
Weight kg	Non-significant $t(73) = -1.070$, $p > .05$ ($p=.288$)
WC Clothing cm	Non-significant $t(32) = -1.437$, $p > .05$($p=.160$)
WC Bare cm	Non-significant $t(29) = -.372$, $p > .05$ ($p=.712$)
HC cm	Non-significant $t(48) = .789$, $p > .05$ ($p=.434$)

b) Intra-evaluator Technical Error of Measurement (TEM)

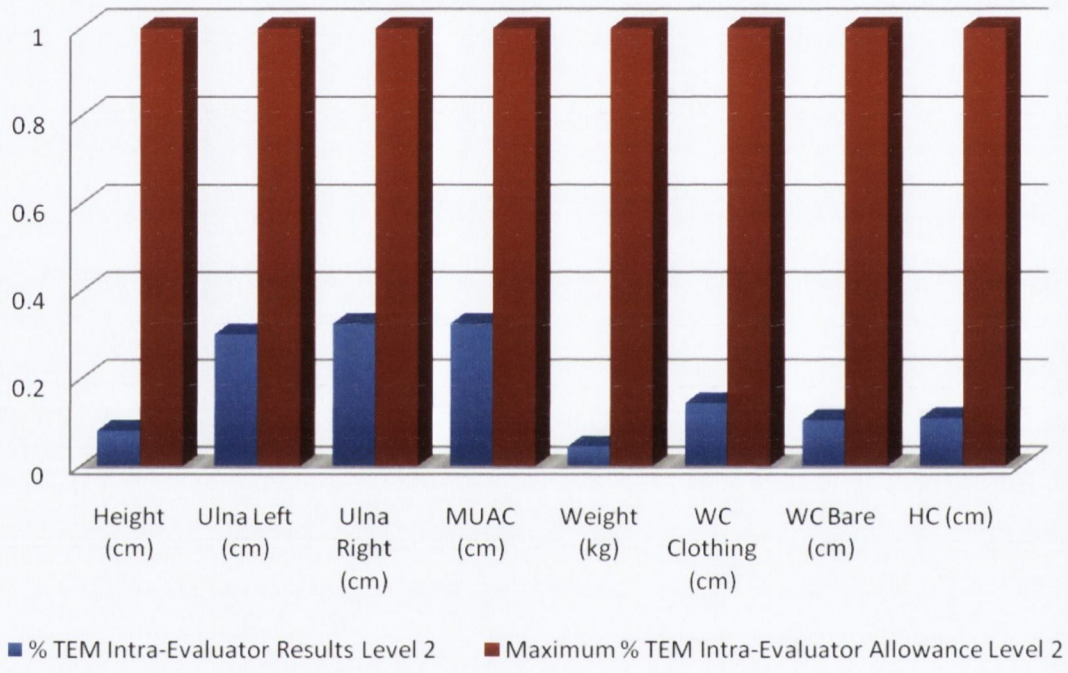
From this replicate data, three precision estimates were calculated: the technical error of measurement (TEM), the relative technical error of measurement (%TEM), and the coefficient of reliability (R). For all the measurements, all three estimates yielded a very high degree of precision (TEM < 1 cm or 1kg, %TEM < 1%, and $R \geq 0.99$); see Table 4.60. These results suggest that the measurements are sufficiently precise for anthropometric research application.

Table 4.60: Technical Error of Measurement (TEM)

	TEM	% TEM	Classification of % TEM	R
Standing Height cm	.128909	.081088	Acceptable (<1.0%)	.9999
Ulna Length Left cm	.073485	.301653	Acceptable (<1.0%)	.9985
Ulna Length Right cm	.079582	.325579	Acceptable (<1.0%)	.9982
MUAC cm	.097613	.318790	Acceptable (<1.0%)	.9996
Weight kg	.030756	.044550	Acceptable (<1.0%)	1.0000
WC Clothing cm	.139262	.143234	Acceptable (<1.0%)	1.0000
WC Bare cm	.102470	.105189	Acceptable (<1.0%)	.9999
HC cm	.114731	.109610	Acceptable (<1.0%)	.9999

Review of the precision and TEM results showed that all were within the acceptable TEM limits for a Level 2 accredited anthropometrist defined by the International Society for the Advancement of Kinanthropometry, which is the accreditation level held by the researcher. All measurers were within the tolerance limits, as shown in Figure 4.8. A limit of TEM ≤1.0% was applied when determining the practical significance of this error at each site (e.g. height, weight). In terms of the R values, all were above the 0.95 sought (R >0.95) (see Table 4.60).

Figure 4.8: Anthropometric Measurement Results ISAK % TEM Level 2



c) Summary of the Reliability of Anthropometric Measurements Performed

No significant differences were found between the first and second measurements in any of the anthropometric parameters tested. All the correlations between the first and second measurements were also very high. All three precision estimates yielded a very high degree of precision and the entire measurements fell within the acceptable TEM limits of a Level 2 accredited anthropometrist, which is the standard the researcher aimed to achieve if possible.

4.4.2 Anthropometric Measurements Hypotheses

A range of hypotheses that were tested on valid anthropometric measurements collected will now be presented for the purpose of forming recommendations and suggestions for future work in this area. Although the findings should be interpreted with caution due to the small

sample, along with the results presented in Phase 2 they provide the further direction sought to inform the inclusion of measured anthropometric parameters in the IDS-TILDA study.

4.4.2.1 Evaluation of the Left and Right Ulna Length Measurements MUST Values

a) Comparison of the Left and Right Ulna Length Malnutrition Universal Screening Tool (MUST) values

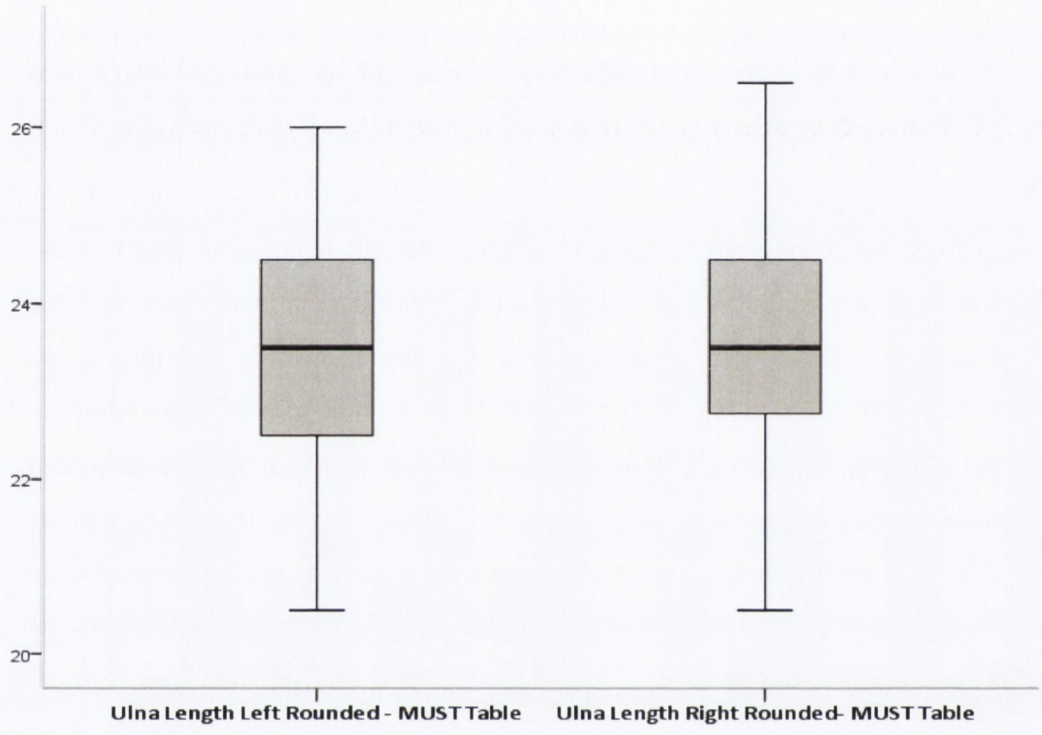
Hypothesis: *H1: There will be a significant difference between the left and right ulna length MUST values. HO: There will be no significant difference between the left and right ulna length MUST values.*

A paired sample t-test was conducted to evaluate whether the left ulna length MUST values differed from the right ulna length MUST values. Results indicated that the mean left ulna length MUST value ($\bar{x}$ = 24.37, *SD* = 1.93) was significantly different from the right ulna length MUST value ($\bar{x}$ = 24.48, *SD* = 1.88), $t(73) = -2.160$, $p < .05$. The magnitude of the mean difference between the left and the right MUST value was medium (eta squared 0.06), with a 95% confidence interval (CI) for the mean difference between -.2208 and -.0089. The null hypothesis is rejected (p=.034) and we conclude that the alternative is true at the pre-determined CI of 95%. The test has provided evidence that the left ulna length MUST value is slightly less than the right in this sample population.

On review of the gender influences, when only males were selected, the mean for the left side ($\bar{x}$ = 25.77, *SD* = 1.96) was not significantly different from the right ulna MUST value ($\bar{x}$ = 25.87, *SD* = 1.81), $t(25) = -.895$, $p > .05$ (p=.380). The effect size was small (eta squared 0.03), with a 95% CI for the mean difference between -.3175 and .1252. For females, the results indicate that the mean for the left side ($\bar{x}$ = 23.60, *SD* = 1.44) was significantly different from the right ulna MUST value ($\bar{x}$ = 23.73, *SD* = 1.45), $t(47) = -2.133$, $p < .05$ (p=.038). The magnitude of the mean difference between the sides was medium (eta squared 0.09), with a 95% CI for the mean difference between -.2429 and -.0071 (see Figure 4.9). In order to compare the left and right ulna length MUST values in males and females, a series of independent t-tests were conducted. A significant difference in the left ulna length MUST values for males ($\bar{x}$ = 25.77, *SD* = 1.96) and females ($\bar{x}$ = 23.60, *SD* = 1.44) was found: $t(72) = 5.436$, $p < .05$ (p=<.001). Similarly, there was a significant difference found in the right ulna length MUST values for males ($\bar{x}$ = 25.87, *SD* = 1.81) and females ($\bar{x}$ = 23.73, *SD* = 1.45): $t(72) = 5.537$; $p < .05$ (p=<.001). Gender differences in ulna lengths MUST values were found to be significant (p <.05), with mean left and right ulna length MUST values of males larger than those of females. The effect size was large for both the left and right ulna lengths MUST values (eta squared 0.29 and 0.30 respectively), with 95% CI for the

mean difference for the left ulna length MUST value between 1.3712 and 2.9590 and the right ulna length MUST value between 1.3671 and 2.9053.

Figure 4.9: Mean Difference of Female Left and Right Ulna Length MUST Values



On review of ulna length MUST values in terms of the influence of age, the results of the participants aged 40-59 indicate that the mean for the left ulna length MUST value ($\bar{x}$ = 24.55, *SD* = 2.13) was not significantly different from the right ulna length MUST value ($\bar{x}$ = 24.64, *SD* = 2.06), *t*(38) = -1.000, *p* > .05 (*p*=.324). The effect size was small (eta squared 0.03), with a 95% CI for the mean difference between -.2714 and .0919. Similarly, the results of the participants aged 60 years and over indicate that the mean for the left ulna MUST value ($\bar{x}$ = 24.16, *SD* = 1.68) was significantly different from the right ulna MUST value ($\bar{x}$ = 24.30, *SD* = 1.66), *t*(34) = -2.719, *p* < .05 (*p*=.010). The effect size was large (eta squared 0.18), with a 95% CI for the mean difference between -.2496 and -.0361.

b) Summary of the Left and Right Ulna Length MUST Values

A statistically significant difference between the left and right ulna lengths MUST values was found. However, the left ulna length MUST value was only slightly smaller than the right ulna length MUST value. Overall, males had larger ulna lengths MUST values (left and right) than females. No significant difference was found between the ulna lengths MUST values (left and

right) of males. There was a difference in females, but the differences between the sides were small. For those aged 40-59 years, there was no significant difference found between the left and right ulna length MUST values. There was a difference in those aged 60 years and over, but the differences were small.

4.4.2.2 Evaluation of Left Ulna Length MUST Value and Measured Height and MUST Estimated Height

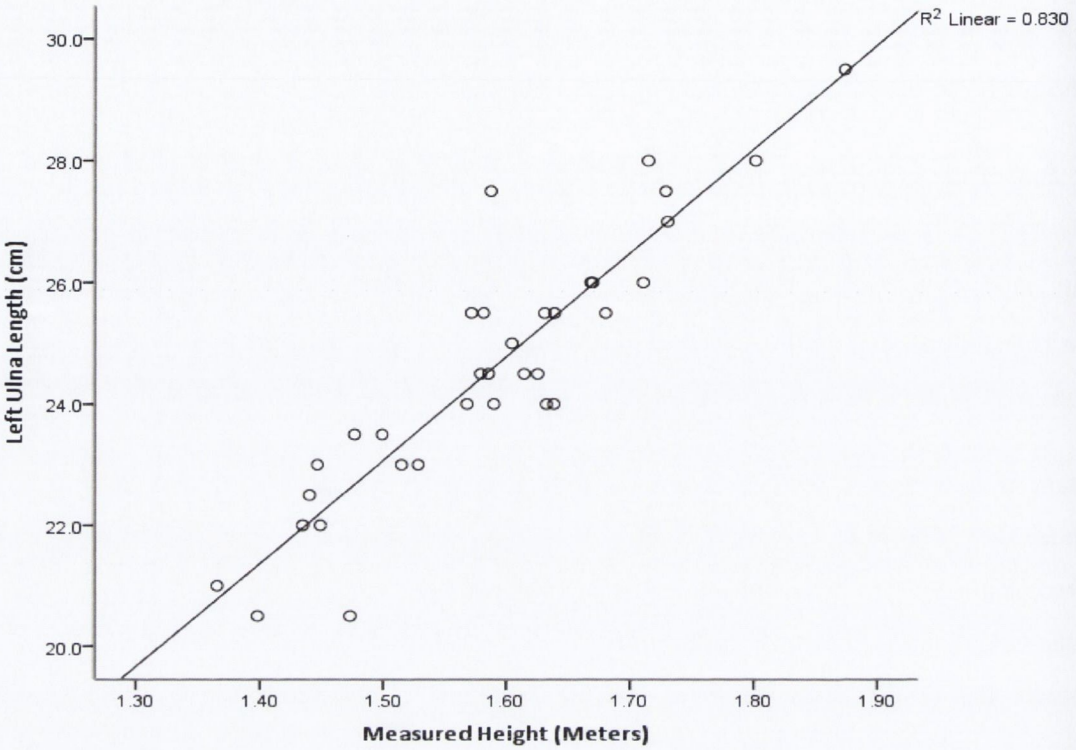
An evaluation of the relationship between left ulna length MUST value and measured height, and the correlation between MUST estimated height (based on left ulna length MUST values) and measured height is presented below.

a) Relationship between Left Ulna Length MUST Value and Measured Height

Hypothesis: *H1: There will be a relationship between the left ulna length MUST value and measured height. HO: There will be no relationship between the left ulna length MUST value and measured height.*

To evaluate the prediction of measured height from the ulna length MUST value, a linear regression analysis was conducted. The results show the relationship was significant (F (1, 32) = 156.052, $p < .05$. Both variables are linearly related such that as ulna length MUST value increases so does measured height (see Figure 4.10 scatterplot, positive relationship). The 95% confidence interval (CI) for the slope, .041 to .057, does not contain the value of zero, and therefore overall ulna length MUST value is related to overall measured height. Approximately 83% of the variance of the measured height was accounted for by its relationship with ulna length MUST value. The null hypothesis is rejected (p=<.001) and we conclude that the alternative is true at the pre-determined CI of 95%.

Figure 4.10: Left Ulna Length MUST Value and Measured Height



b) Relationship between MUST Estimated Height and Measured Height

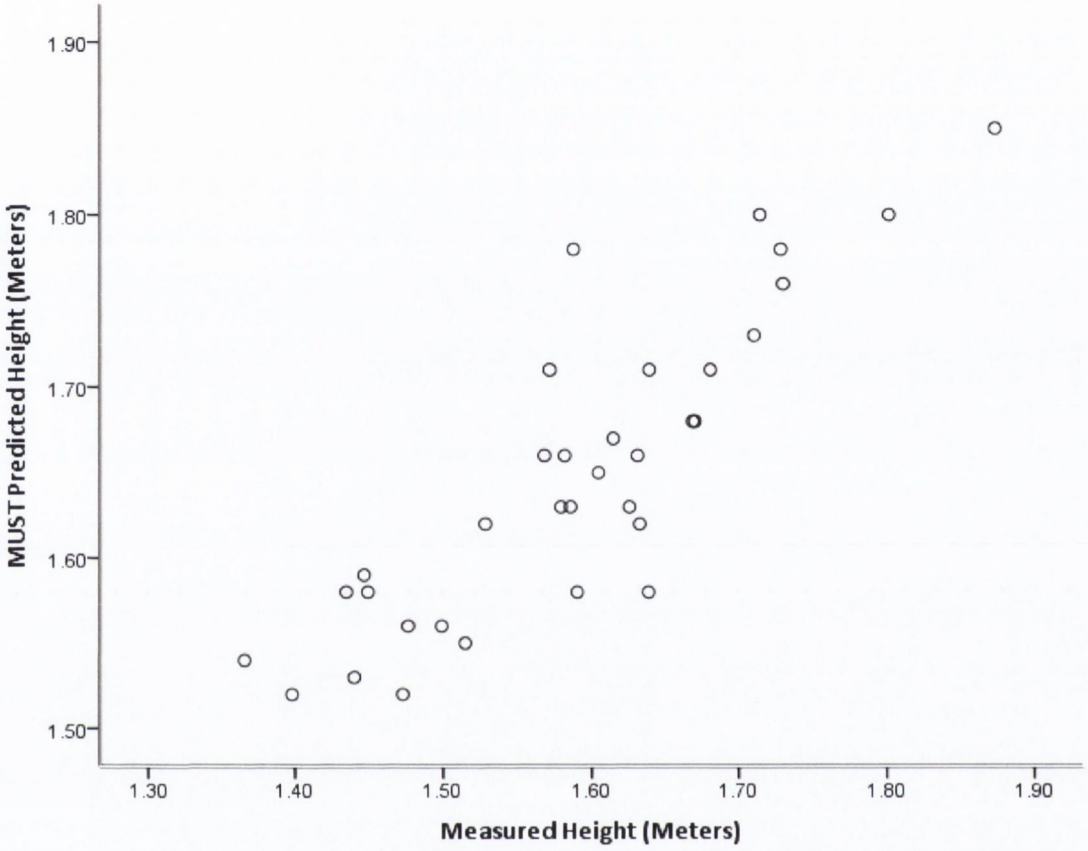
Hypothesis: *H1: There will be a relationship between MUST estimated height and measured height. HO: There will be no relationship between MUST estimated height and measured height.*

Correlation coefficients were computed among the population that had valid height and left ulna length (UL) measurements. Left UL measurements were converted (see Section 3.12.2.2) to estimated height values based on the MUST tables (see Appendix 31). The results of the correlation analyses show that the correlation was significant $r(34) = .869$, $p < .05$. In general, as the MUST estimated height increases, measured height increases as well (see Figure 4.11 scatterplot, positive relationship). The null hypothesis is rejected (p=<.001) and we conclude that the alternative is true at the pre-determined CI of 95%.

In terms of gender, correlation coefficients were computed and the results of the correlation analyses for males ($r(16) = .902$, $p < .05$ [p=<.001]) and females ($r(18) = .834$, $p < .05$ [p=< .001]) were significant. As MUST estimated height increases, measured height increases as well. Similarly, the correlation coefficient results of both age groups were significant. For the 40-59 age group, the results were $r(21) = .925$, $p < .05$ (p=<.001). Although the results for those aged 60 years and over were significant $r(13) = .795$, $p < .05$ (p=.001), the distributions for MUST estimated height and measured height in this latter age group were not normally distributed, so

the findings need to be interpreted with caution as a larger sample of those aged 60 years and over is required.

Figure 4.11: MUST Estimated Height and Measured Height



c) Summary of Left Ulna Length MUST Value, Measured Height and MUST Estimated Height

A statistically significant relationship between left ulna length MUST values and measured height was found, which suggests that left ulna length MUST values can be used to predict height. Using MUST to calculate estimated height from the left ulna length MUST values, the findings resulted in the MUST estimated height being positively correlated with measured height. The same outcome was found for both genders and age groups (40-59 and 60 years and over). Collectively, the findings suggest that MUST equations can be used to predict height using ulna length MUST values in this sample group, similar to the general population.

4.4.2.3 Evaluation of MUST Estimated, Measured and Self-Report Heights

An evaluation of MUST estimated height (based on left ulna length MUST values) compared to measured height and self-report height is presented below. The relationships between these

variables will also be examined and the closest value to each variable will be presented. Lastly, an evaluation of MUST estimated height and self-report height among wheelchair-users only will be presented.

a) MUST Estimated Height and Measured Height

Hypothesis: *H1: There will be a difference between MUST estimated height and measured height. HO: There will be no difference between MUST estimated height and measured height.*

A paired sample *t*-test was conducted to evaluate whether a difference exists between MUST estimated height and measured height. The results indicated that the mean for MUST estimated height ($\bar{x}$ = 1.66, *SD* = .10) was significantly greater than the mean for height measured ($\bar{x}$ = 1.59, *SD* = .13), $t(24) = 6.051$, $p < .05$. The mean increase in height by left ulna length was 0.07, with a 95% confidence interval (CI) for the mean difference between the two ratings, ranging from .0454 to .0924. The eta squared statistic (.60) indicated a large effect size. The null hypothesis is rejected (p=<.001) and we conclude that the alternative is true at the pre-determined CI of 95%. Separately, a Bonferroni correction was also applied (see Section [e]).

Gender does not adjust the above outcome, as the mean MUST estimated height for males ($\bar{x}$ = 1.71, *SD* = .09) and females ($\bar{x}$ = 1.59, *SD* = .06) was significantly greater than the mean for height measured for males ($\bar{x}$ = 1.64, *SD* = .13), $t(12) = 4.298$, $p <$ .05 (p=.001*)* and females ($\bar{x}$ = 1.53, *SD* = .10), $t(11) = 4.104$, $p < .05$ (p=.002). The effect size for both genders was large (eta squared .61 for males and .60 for females); the 95% CI for the mean difference between the two ratings for males was .0357 to .1090 and for females it was .0302 to .1002. Similarly, for those aged 40-59 years, the mean for MUST estimated height ($\bar{x}$ = 1.66, *SD* = .09) was significantly greater than the mean for height measured ($\bar{x}$ = 1.59, *SD* = .13), $t(16) = 5.216$, $p < .05$ (p=<.001). The 95% CI for the mean difference between the two ratings was .0402 to .0952. An analysis was not completed on the 60 years+ age group as the distributions do not resemble a normal distribution, n=8.

b) MUST Estimated Height and Self-Report Height

Hypothesis: *H1: There will be a difference between MUST estimated height and self-report height. HO: There will be no difference between MUST estimated height and self-report height.*

A paired sample t-test was conducted to evaluate whether a difference exists between MUST estimated height and self-report height. The results indicated that the mean for MUST estimated height ($\bar{x}$ = 1.66, *SD* = .10) was significantly greater than the mean for self-report height ($\bar{x}$ = 1.61, *SD* = .14), $t(24) = 3.301$, $p < .05$. The mean increase in height by left ulna length

was 0.05, with a 95% CI for the mean difference between the two ratings, ranging from .0183 to .0791. The eta squared statistic (.31) indicated a large effect size. The null hypothesis is rejected (p=.003) and we conclude that the alternative is true at the pre-determined CI of 95%. Similarly, a Bonferroni correction was also applied (see Section [e]).

In terms of gender, the mean of the MUST estimated height for males ($\bar{x}$ = 1.71, SD = .09) was also significantly greater than the mean for self-report height ($\bar{x}$ = 1.66, SD = .14), $t(12) = 2.387$, $p < .05$ (p=.034). The eta squared statistic (.32) indicated a large effect size, with a 95% CI for the mean difference between the two ratings, .0045 to .0984. However, for females the mean of the MUST estimated height ($\bar{x}$ = 1.59, SD = .06) was not significantly greater than the mean for self-report height ($\bar{x}$ = 1.55, SD = .12), $t(11) = 2.183$, $p > .05$) but the p value (p=.052) was approaching a significant level. The eta squared statistic (.28) indicated a large effect size, and the 95% CI for the mean difference between the two ratings was -.0003 to .0917.

Similarly, the paired sample t-test indicated that, for those aged 40-59 years, the mean for MUST estimated height ($\bar{x}$ = 1.66, SD = .09) was significantly greater than the mean for self-report height ($\bar{x}$ = 1.59, SD = .13), $t(16) = 4.792$, $p < .05$ (p=<.001). The 95% CI for the mean difference between the two ratings was .0360 to .0930. The eta squared statistic (.59) indicated a large effect size. An analysis was not completed on the 60+ year age group as the distributions do not resemble a normal distribution, n=8.

c) Relationships between MUST Estimated, Measured and Self-Report Heights

A series of Pearson product-moment correlation tests were also conducted on the variables, MUST estimated height, measured height and self-report height. Although strong positive correlations were found across all the tests (see Table 4.61), each had a stronger relationship with one of the two variables examined. The results of MUST estimated height show that measured height ($r(25) = .911$, $p <$. 05 [p=<.001]) had the strongest positive correlation. The strongest positive correlation to measured height was self-report height ($r(25) = .930$, $p < .05$ [p=<.001]) and finally, to self-report height, it was measured height ($r(25) = .930$, $p < .05$ [p=< .001]). The weakest of the positive correlations was, reciprocally, self-report height and MUST estimated height ($r(25) = .857$, $p < .05$ [p=<.001]).

Table 4.61: Relationships between MUST Estimated, Measured and Self-Report Heights

	MUST Est. Height			Measured Height			Self-Report Height		
	r	p<	n	R	p<	n	R	p<	n
MUST Estimated Height				.911	.001	25	.857	.001	25
Measured Height	.911	.001	25				.930	.001	25
Self-Report Height	.857	.001	25	.930	.001	25			

However, it is important to note that this sample group (n=25) mainly represents people with mild and moderate intellectual disability (84%; n=21) and those aged between 40 and 59 years (68%; n=17). There was an under-representation of people with severe and profound intellectual disability and of those aged 60 years and over. Despite these limitations, the gender split in this sample group was almost even, with males at 52% (n=13) and females at 48% (n=12).

i) Case Matching Pairs Only of Height-Related Variables

Interestingly, on exploration of the same height variables but case-matched in pairs as opposed to matching all three variables, the sample size increased for two pairing reciprocally, MUST estimated height and measured height (Pair 1) and MUST estimated height and self-report height (Pair 2) (see Table 4.62), but the strength of the positive correlations only decreased slightly. Although a similar breakdown of the characteristics of the sample existed for the MUST estimated height and measured height, as mentioned above, the increased sample in the other group – MUST estimated height and self-report height – resulted in more people with severe and profound ID (n=2; 8% to n=11; 21%) and those aged 60 years and over (n=8; 32% to n=22; 42%) being represented, but the positive correlation remained the same.

Table 4.62: Case Matching Pairs Only – Height-Related Variables

	MUST Est. Height			Measured Height			Self-Report Height		
	r	p<	n	R	p<	n	R	p<	n
MUST Estimated Height				.869	.001	34	.842	.001	53
Measured Height	.869	.001	34				.930	.001	25
Self-Report Height	.842	.001	53	.930	.001	25			

d) Wheelchair-Users Only – MUST Estimated Height and Self-Report Height Values

Hypothesis: *H1: There will be a difference between MUST estimated height and self-report height among wheelchair-users. HO: There will be no difference between MUST estimated height and self-report height among wheelchair-users.*

A paired sample t-test was conducted to evaluate whether a difference exists between MUST estimated height and self-report height among wheelchair-users. The results indicated that the mean for MUST estimated height ($\bar{x}$ = 1.61, *SD* = .09) was not significantly different from the mean for self-report ($\bar{x}$ = 1.59, *SD* = .13), $t(11) = 1.253$, $p > .05$. The mean increase in height by left ulna length was 0.02 (eta squared 0.12; large effect size), with a 95% confidence interval for the mean difference between the two ratings, ranging from -.0163 to .0595. We fail to reject the null hypothesis (p=.236) and conclude that there is not enough evidence to state that the alternative is true. Correlation coefficient was also computed; the analysis showed that the correlation between MUST estimated height and self-report height was significant – $r(12)$ = .912, $p < .05$ (p=<.001) – among this sample of participants who were wheelchair-users (positive relationship). Due to low numbers, an analysis of age or gender influences was not done in either test. The findings should be interpreted cautiously because of the small sample.

e) Post-Hoc Adjustments (Multiple Testing on Height-Related Variables)

Adjusting for the probability that the results of the multiple paired t-tests conducted were due to chance, Bonferroni correction (post-hoc control) was applied to the alphas of the three height variables tested (MUST estimated height, measured height, and self-report height). After applying a Bonferroni correction (with adjusted p value = .0167), the outcome of all three pairs remained the same. MUST estimated height remained significantly greater than both measured height (p=<.001, see Section 4.4.2.3 [a]) and self-report height (p=.003, see Section 4.4.2.3 [b]); and measured height remained not significantly different to self-report height (p=.056, see Section 4.4.2.4 [a]).

f) Summary Evaluation of MUST Estimated, Measured and Self-Report Height Values

Although small, significantly greater mean differences between MUST estimated height and measured height (Pair 1; mean difference was .07cm by MUST estimated height), and MUST estimated height and self-report height (Pair 2; mean difference was .05cm by MUST estimated height) were found. In Pair 1, neither gender nor age influenced this position. However, while the position on age in Pair 2 was the same as for Pair 1, the gender position was different for women only, with no significant mean difference found between the variables, although the difference was approaching statistical significance.

Concerning the relationships between MUST estimated height, measured height and self-report height, strong positive correlations were universally found across the matrix of tests completed. The closest correlation to measured height was self-report height and, reciprocally, the closest correlation to self-report height was measured height. The closest correlation to MUST estimated height was measured height. The weakest of the positive correlations was MUST estimated height and self-report height, and the same was found for self-report height. Among the wheelchair-users, no significant difference between the MUST estimated height and self-report height was found. A strong positive relationship exists between the two variables.

4.4.2.4 Evaluation of Measured and Self-Report Height, Weight and Body Mass Index (BMI)

An evaluation of measured and self-report height, weight and body mass index (BMI) values is presented below.

a) Difference between Measured Height and Self-Report Height

Hypothesis: *H1: There will be a difference between measured height and self-report height. HO: There will be no difference between measured height and self-report height.*

A paired sample t-test was conducted to evaluate whether a difference exists between measured height and self-report height. The results indicated that the mean for measured height ($\bar{x}$ = 1.59, *SD* = .13) was not significantly different from the mean for self-report height ($\bar{x}$ = 1.61, *SD* = .14), $t(24) = -2.010$, $p > .05$). The 95% confidence interval (CI) for the mean difference between the two ratings was -.0410 to .0006. The eta squared statistic (.14) indicated a large effect size. We fail to reject the null hypothesis (p=.056) and conclude that there is not enough evidence to state that the alternative is true, but it was close to significant. As with the other height variables discussed, a Bonferroni correction was applied (see Section 4.4.2.3 [e]).

In terms of gender, the mean of measured height for males ($\bar{x}$ = 1.64, *SD* = .13) and females ($\bar{x}$ = 1.53, *SD* = .10) was not significantly greater than the means for self-report height for males ($\bar{x}$ = 1.66, *SD* = .14), $t(12) = -1.177$, $p > .05$ (p=.262); 95% CI = -.0594 to .0178) or females ($\bar{x}$ = 1.55, *SD* = .12), $t(11) = -2.068$, $p > .05$ (p=.063); 95% CI = -.0403 to .0013). The effect size for both genders was large (eta squared .10 for males and .28 for females). Similarly, the paired sample t-test was conducted on the 40-59 year age group to evaluate whether a difference exists between measured height and self-report height. The results indicated that the mean for measured height ($\bar{x}$ = 1.59, *SD* = .13) was not significantly different from the mean for self-report height in this age group ($\bar{x}$ = 1.59, *SD* = .13), $t(16) = -.355$, $p > .05$ (p=.727). The 95% CI for the mean difference between the two ratings was -.0223 to .0159. The eta squared statistic (.01)

indicated a small effect size. An analysis was not completed on the 60+ age group as the distributions do not resemble a normal distribution, n=8. See Table 4.63 for a summary of the overall measured and self-report height findings.

i) Relationship between Measured and Self-Report Height

To evaluate the relationship between measured height and self-report height, a Pearson product-moment correlation was conducted. The results of the correlation analyses show that the correlation was significant: $r(25) = .930$, $p < .05$ (p=<.001). The strength of the association between measured height and self-report height is high (strong positive correlation).

b) Difference between Measured Weight and Self-Report Weight

Hypothesis: *H1: There will be a difference between measured weight and self-report weight. HO: There will be no difference between measured weight and self-report weight.*

A paired sample t-test was conducted to evaluate whether a difference exists between measured weight and self-report weight. The results indicated that the mean for measured weight ($\bar{x}$ = 69.58, *SD* = 17.86) was not significantly different from the mean for self-report weight ($\bar{x}$ = 69.65, *SD* = 17.94), $t(64) = -.168$, $p > .05$. The 95% CI for the mean difference between the two ratings was -.9366 to .7916. The eta squared statistic (<.001) indicated a small effect. We fail to reject the null hypothesis (p=.867) and conclude that there is not enough evidence to state that the alternative is true.

In terms of gender, the mean of measured weight for males ($\bar{x}$ = 76.31, *SD* = 17.41) and females ($\bar{x}$ = 66.59, *SD* = 17.42) was not significantly greater than the means for self-report weight for males ($\bar{x}$ = 76.56, *SD* = 17.55), $t(19) = -.326$, $p > .05$ (p=.748); 95% CI = -1.8932 to 1.3828) or females ($\bar{x}$ = 66.58, *SD* = 17.42), $t(44) = -.017$, $p > .05$ (p=.987); 95% CI = -1.0483 to 1.0656). The effect size for both genders was small (eta squared <.01 for males and <.01 for females).

Similarly, the paired sample t-test was conducted on the 40-59 year and 60+ age groups to evaluate whether a difference exists between measured weight and self-report weight. For those aged 40-59, the results indicated that the mean for measured weight ($\bar{x}$ = 72.39, *SD* = 20.36) was not significantly different from the mean for self-report weight in this age group ($\bar{x}$ = 72.40, *SD* = 20.32), $t(32) = -.013$, $p > .05$ (p=.990). The 95% CI for the mean difference between the two ratings was -.8346 to .8241. For those aged 60+, the results indicated that the mean for measured weight ($\bar{x}$ = 66.67, *SD* = 14.61) was not significantly different from the mean for self-report weight in this age group ($\bar{x}$ = 66.81, *SD* = 14.89), $t(31) = -.182$, $p > .05$ (p=.857). The 95% CI

for the mean difference between the two ratings was -1.7319 to 1.4482. The effect size for both age groups was small (eta squared <.001 and .001 for those aged 40-59 and aged 60+ respectively). See Table 4.63 for a summary of the overall measured and self-report weight findings.

i) Relationship between Measured and Self-Report Weight

To evaluate the relationship between measured weight and self-report weight, a Pearson product-moment correlation was conducted. The results of the correlation analyses show that the correlation was significant $r(65) = .981$, $p < .05$ (p=<.001). The strength of the association between measured weight and self-report weight is very high (strong positive correlation).

c) Identity of the Reporter of Self-Report Height and Weight

Self-report height (n=54) and weight (n=68) values were reported in the Pre-Interview Questionnaire (PIQ); 100% of the participants were supported by a third party (e.g. support worker) in part or full completion of the PIQ. However, it is not known if the participant and/or the proxy reported the height and weight values and if they were reported from memory, estimated, taken from records, or measured prior to reporting on the PIQ form.

d) Measured BMI and Self-Report BMI

Hypothesis: *H1: There will be a difference between measured BMI and self-report BMI. HO: There will be no difference between measured BMI and self-report BMI.*

A paired sample t-test was conducted to evaluate whether a difference exists between measured BMI and self-report BMI. The results indicated that the mean for measured BMI ($\bar{x}$ = 30.08, SD = 6.06) was significantly different from the mean for self-report BMI ($\bar{x}$ = 29.11, SD = 6.65), $t(22) = 2.271$, $p < .05$. The 95% CI for the mean difference between the two ratings was .0838 to 1.849. The eta squared statistic (.19) indicated a large effect. Although the mean difference between the values is very small (.97), it is very significant, as the mean for measured BMI ($\bar{x}$ = 30.08) falls into the obese category, while the mean for self-report BMI ($\bar{x}$ = 29.11) falls into the overweight category, as defined by the international classification of underweight, overweight and obesity according to BMI in adults (WHO 2000a). Small differences in BMI scores can influence the overall BMI classification. The null hypothesis is rejected (p=.033) and we conclude that the alternative hypothesis is true.

In terms of gender, the mean of measured BMI for males ($\bar{x}$ = 28.67, SD = 5.56) and females ($\bar{x}$ = 31.61, SD = 6.46) was not significantly greater than the means for self-report BMI for males ($\bar{x}$ = 27.74, SD = 5.43), $t(11) = 1.445$, $p > .05$ (p=.176); 95% CI = -.4893 to 2.3581 and females ($\bar{x}$ =

30.61, *SD* = 7.75), *t*(10) = 1.741, *p* > .05 (*p*=.112); 95% CI = -.2804 to 2.2829. Similarly, a paired sample t-test was conducted on the 40-59 year age group to evaluate whether a difference exists between measured BMI and self-report BMI. The results indicated that the mean for measured BMI ($\bar{x}$ = 30.93, *SD* = 6.39) was not significantly different from the mean for self-report BMI in this age group ($\bar{x}$ = 30.92, *SD* = 6.73), *t*(15) = .039, *p* > .05 (*p*=.969). The 95% confidence interval for the mean difference between the two ratings was -.7510 to .7793. An analysis was not completed on the 60+ age group as the distributions do not resemble a normal distribution, *n*=7.

See Table 4.63 for a summary of the overall measured and self-report BMI findings.

i) Case Matching Pairs Only – Measured and Self-Report BMI

Based on case matching of the variables, measured and self-report BMI categorisations (*n*=23), the cross-tabulation revealed that 50% (*n*=5) of those with a measured BMI categorisation of overweight (*n*=10) were positioned in the normal BMI range by their self-report values, while 20% (*n*=2) of those with a measured BMI categorisation of obesity (*n*=10) were positioned in the overweight category by their self-report values. One participant with a measured BMI in the normal range (*n*=3) was positioned in the overweight category by their self-report values. In total, 35% (*n*=8) of this sub-sample (*n*=23) did not have the same measured and self-report BMI ranges; self-reported BMI scores tended to underestimate (*n*=7) measured BMI scores.

Table 4.63: Difference between Measured and Self-Report Values of Height, Weight and BMI Scores

	n	Measured	Self-Report	*p*	95% Confidence Interval	Measured – Self-Report
Mean Height						
Both Sexes	25	1.59	1.61	.056	-.0410 to .0006	-.02
Males	13	1.64	1.66	.262	-.0594 to .0178	-.02
Females	12	1.53	1.55	.063	-.0403 to .0013	-.02
Age group						
40 – 59	17	1.59	1.59	.727	-.0223 to .0159	0
60 +	Insufficient numbers (*n*=8) to report (data not normally distributed)					
Mean Weight						
Both Sexes	65	69.58	69.65	.867	-.9366 to .7916	-.07
Male	20	76.31	76.56	.748	-1.8932 to 1.3828	-.25
Female	45	66.59	66.58	.987	-1.0483 to 1.0656	.01
Age group						
40 – 59	33	72.39	72.40	.990	-.8346 to .8241	-.01
60 +	32	66.67	66.81	.857	-1.7319 to 1.4482	-.14
Mean BMI Score						
Both Sexes	23	30.08	29.11	.033	.0838 to 1.849	.97
Male	12	28.67	27.74	.176	-.4893 to 2.3581	.93
Female	11	31.61	30.61	.112	-.2804 to 2.2829	1.0
Age group						
40 – 59	16	30.93	30.92	.969	-.7510 to .7793	.01
60 +	Insufficient numbers (*n*=7) to report (data not normally distributed)					

e) Weight Status and Risk of Developing Co-Morbidities using BMI Scores

Based on the measured and self-report BMI scores (*n*=23; case matched), the weight status and risk of participants developing co-morbidities has been estimated using the World Health Organization categorisations (WHO 2000a) – see Table 4.64. According to measured BMI scores, 87% (*n*=20) of participants were overweight or obese compared to 70% (*n*=16) using the self-report scores. A total of 87% (*n*=20) of participants measured were classified as having increased to severe risk of developing co-morbidities for BMI 25.00 to 39.99. Based on their self-report BMI scores, 70% (*n*=16) were classified as having increased to very severe risk of

developing co-morbidities for BMI 25.00 to ≥40.00. There is a 17% (*n*=4) difference between the case-matched groups (measured and self-report BMI scores) and their risk of co-morbidities (increased to very severe categories only; BMI 25.00 to ≥40.00).

Table 4.64: Weight Status and Risk of Developing Co-Morbidities using BMI Scores

	Measured		Self -Report		
BMI Classifications (*n*=23)	**n**	**%**	**n**	**%**	**Risk of Co-morbidities**
Underweight ≤ 18.49	-	-	-	-	**Low (but other clinical problems increased)**
Normal Range 18.50 - 24.99	3	13.0	7	30.4	**Average**
Overweight 25.00 - 29.99	10	43.5	8	34.8	**Increased**
Obesity Class I 30.00 - 34.99	4	17.4	4	17.4	**Moderately**
Obesity Class II 35.00 – 39.99	6	26.1	2	8.7	**Severe**
Obesity Class III ≥ 40.00	-	-	2	8.7	**Very Severe**

f) Summary of Measured and Self-Report Height, Weight and BMI

Neither measured height nor weight was statistically different from the self-report values in this sample population. Nor were they influenced by gender or age (except that, for height, the influence of those aged 60 and over was not tested due to the low numbers involved). A strong positive correlation between measured and self-report height and weight was found. Despite such findings, there was a statistically significant difference found between measured and self-report BMI scores. Even though the mean difference between the values was small, the implications are very significant. The mean for measured BMI score falls into the obese category, while the mean for self-report BMI score falls into the overweight category. Based on case matching, just over one-third of cases were not classified in the same BMI categories, when measured BMI categorisations were compared directly to self-report categorisations. Of note, all of the participants who reported their height and weight values in the Pre-Interview Questionnaire had some level of assistance from a third party in completing this form. The level and type of assistance received with these questions (height and/or weight) is unknown.

Lastly, using measured BMI scores, the percentage at increased or greater risk of developing co-morbidities was higher than the percentage classified using their self-report BMI scores (87% vs. 70%). Irrespective of the difference, the predicted risk of developing co-morbidities was high whether using their measured BMI scores or self-report BMI scores (case-matched).

4.4.2.5 Evaluation of BMI Scores Measured, Self-Report and Ulna Estimated

Based on case matching of the variables, measured, self-report and ulna estimated BMI scores (n=23), the cross-tabulation revealed that the mean ulna estimated BMI score was lower ($\bar{x}$ =27.71, SD = 5.98) than both the measured ($\bar{x}$ =30.08, SD = 6.06) and self-report ($\bar{x}$ =29.11, SD = 6.65) BMI scores reported. In terms of the resulting BMI classifications from the respective BMI scores, the ulna estimated classifications were more closely aligned to the self-report classifications (see Table 4.64) than the measured, with 61% overweight (n=7) or obese (n=7), 35% (n=8) in the normal range, and one participant classified as underweight (4%). A series of Pearson product-moment correlation tests were run to determine the relationships between the three variables and to identify which two had the strongest correlation (n=23). Ulna estimated BMI scores were based on left ulna length scores and measured weight.

a) BMI Score Measured vs. BMI Scores Self-Report and Ulna Estimated

A strong positive correlation between BMI score measured and BMI score self-report ($r(23)$ = .953, p < .05 [p=<.001]), and BMI score ulna estimated (r(23) = .929, p < .05 [p=<.001]) was found. Both results were statistically significant. However, the closest correlation value to BMI score measured was the BMI score self-report ($r^{2=}$.907).

b) BMI Score Self-Report vs. BMI Scores Measured and Ulna Estimated

A strong positive correlation between BMI score self-report and BMI score measured (r(23) = .953, p < .05 [p=<.001]), and BMI score ulna estimated (r(23) =.900, p < .05 [p=<.001]) was found. Both results were statistically significant. However, the closest correlation value to BMI score self-report was the BMI score measured ($r^{2=}$.907).

c) BMI Scores Ulna Estimated vs. BMI Scores Measured and Self-Report

A strong positive correlation between BMI score ulna estimated and BMI score measured (r(23) = .929, p < .05 [p=<.001]), and self-report BMI score (r(23) = .900, p < .05 [p=<.001]) was found. Both results were statistically significant. However, the closest correlation value to BMI score ulna estimated was the measured BMI score ($r^{2=}$.864).

d) Summary of BMI Scores Measured, Self-Report and Ulna Estimated

Based on the mean BMI scores, measured BMI had the highest score, closely followed by the self-report BMI, while ulna estimated BMI had the lowest score. Using the BMI scores, the ulna estimated BMI classifications were more closely aligned to the self-report BMI classifications than the measured. All three variables – BMI scores measured, self-report and ulna estimated – had strong positive correlations and all the findings were statistically significant. However, of all

the correlations and co-efficient of determinations, the BMI measured score and BMI self-report score had, interchangeably, the strongest positive correlation. This was followed by a slightly weaker but strong positive correlation between BMI ulna estimated score and BMI measured score. The weakest of the positive correlations was conversely between BMI ulna estimated score and BMI self-report score.

4.4.2.6 Evaluation of BMI Measured to Mid-Upper Arm Circumference (MUAC)

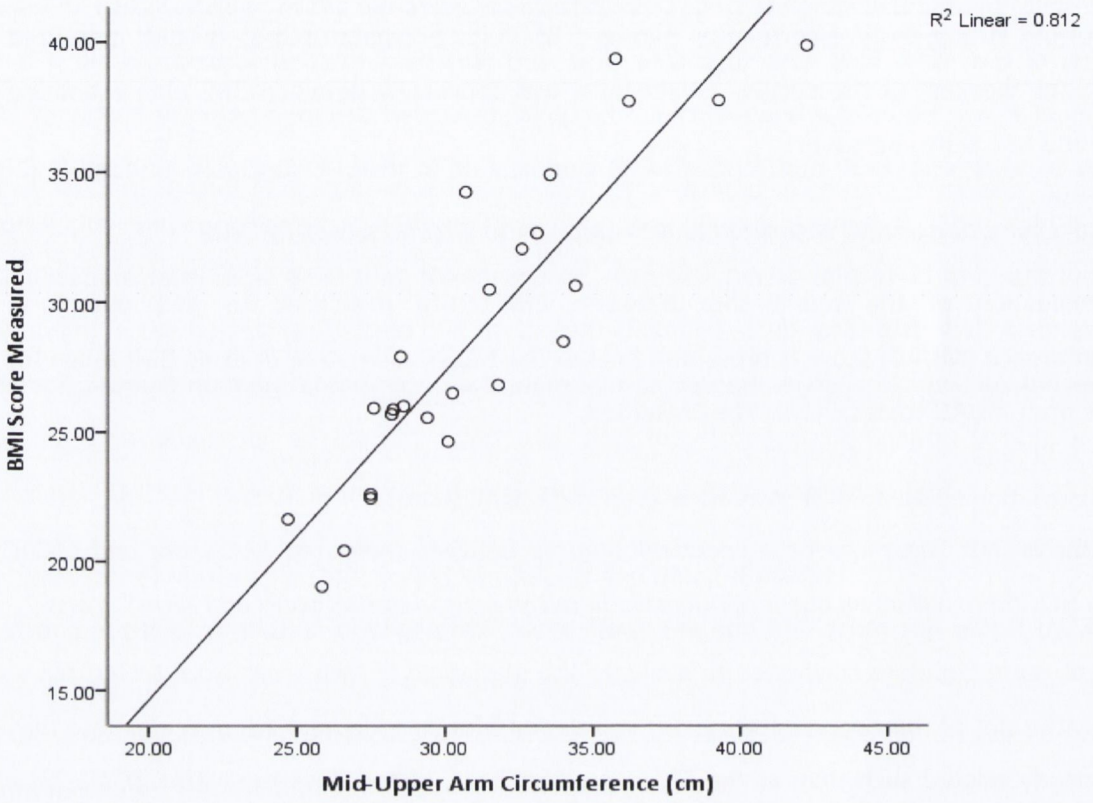
An evaluation of the relationship between BMI score measured to mid-upper arm circumference (MUAC) score is presented below. The MUST estimation of likely BMI range for adults from MUAC scores will also be presented.

a) Association between BMI Score Measured and MUAC Score

Hypothesis: *H1: There will be a linear relationship between measured BMI score and MUAC score. HO: There will be no linear relationship between measured BMI score and MUAC score.*

A linear regression was conducted to evaluate the prediction of BMI score from MUAC score. The scatterplot of the two variables (positive relationship) (see Figure 4.12) indicates that they are linearly related such that, as the BMI score increases, so too does the MUAC (F (1, 23) = 99.526, $p < .05$. The 95% confidence interval (CI) for the slope, 1.008 to 1.536, does not contain the value of zero, and therefore the overall MUAC score is significantly related to the BMI score. The Pearson correlation between MUAC score and BMI score was .901. Approximately 81% (r^2 = .812) of the variance of the BMI score was accounted for by its relationship with the MUAC score. The null hypothesis is rejected (p=<.001) and we conclude that the alternative is true at the pre-determined CI of 95%. The influences of gender and age on the findings were explored but are not reported, as the numbers were low and the values are not perfectly normally distributed.

Figure 4.12: Association between BMI Score Measured and MUAC



b) MUST Estimation of BMI Range vs. BMI Measured Score

On review of the MUST (Malnutrition Universal Screening Tool, 2003) predictions of the likely range of BMI for adults in the general population from MUAC scores (*n*=25), 88% (*n*=22) of the MUAC scores in this sample population were estimated in the correct BMI ranges when compared to BMI measured scores. The remaining 12% (*n*=3) were estimated incorrectly when compared to the BMI measured scores. Of those in the correct range, 36% (*n*=8) were correctly identified to be in the MUST obese category when compared to the measured BMI scores. The remaining 64% (*n*=14) fell between the two MUST risk categories and represents those falling in the normal to overweight BMI categories. On review of the measured BMI scores for this 64% (*n*=14), 8 participants were classified as overweight and 6 fell within the normal BMI range, which supports the MUST classification system. Using MUST estimation alone, the percentages of those in either the normal or the overweight BMI categories would be unknown; instead they would be grouped in the in-between MUST category (i.e. MUAC is ≥ 23.5 and <32.0cm; BMI is likely to be ≥ 20 and <30 kg/m^2).

On review of the measured BMI scores of those predictions misclassified (12%; n=3), two of the cases were classified as obese (BMI measured) but fell into the in-between category in MUST estimations based on their MUAC score. However, both cases were close to the correct MUST estimation category required; one MUAC was 0.5cm less than the value needed and the other 1.3cm less. The other participant was classified as overweight (BMI measured) but fell into the obese MUST estimation category. Similarly, if the participant's measured BMI score were 1.5 points higher, the MUST estimation would have been correct (obese).

c) Summary of BMI Measured and MUAC

Measured BMI score was linearly related to the MUAC score (positive relationship). The influences of gender and age on the findings were not reported due to low numbers and the values not being perfectly normally distributed. On review of the MUST estimations of likely range of BMI for adults in the general population from MUAC scores, the majority of MUAC scores in this sample population (88%) were estimated in the correct BMI ranges and those misclassified were not far off the correct predictions.

4.4.2.7 Evaluation of WC Measurement over Clothing and on Bare Skin

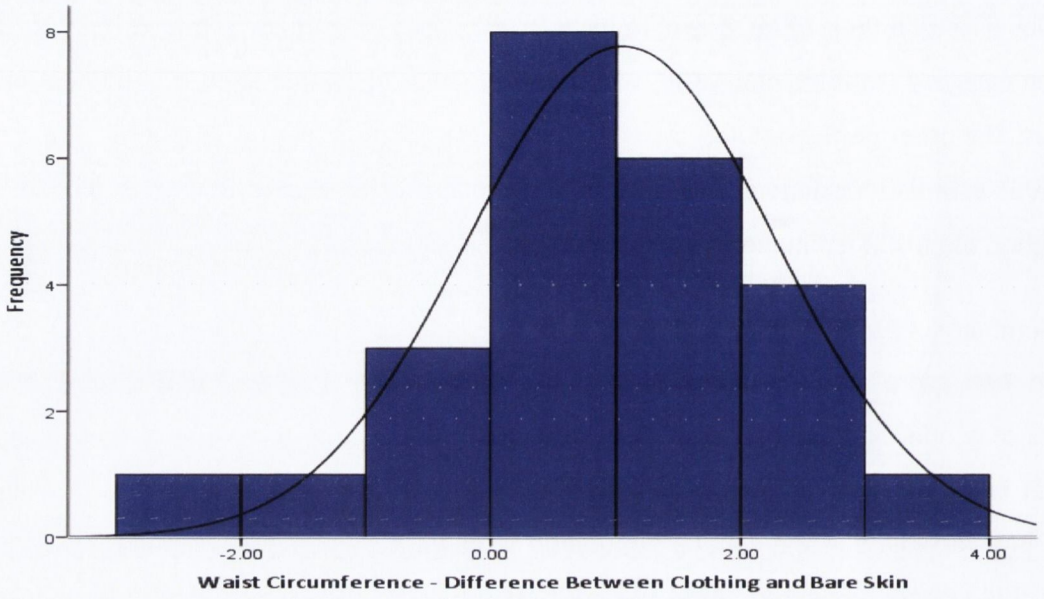
An evaluation of the difference between WC measurements taken over clothing and on bare skin is presented below. Also, the reported clothing effect of .5cm in other research studies in the general population will be examined, along with whether clothing thickness predicts the difference between measurements taken over clothing and bare skin.

a) WC Measurement over Clothing and on Bare Skin

Hypothesis: *H1: WC measurement over clothing will be significantly greater than WC taken on bare skin. HO: WC measurement over clothing will not be significantly greater than WC taken on bare skin.*

A one-tailed paired sample t-test was conducted to evaluate whether WC measurement was significantly larger with a single layer of clothing than with bare skin. The results indicate that the mean for WC with clothing ($\bar{x}$ = 98.01, SD = 14.52) was significantly greater than the mean for WC without clothing ($\bar{x}$ = 97.06, SD = 14.28), $t(23) = 3.576$, $p < .05$. The mean difference was 0.96cm (see Figure 4.13), with a 95% confidence interval (CI) ranging from .4040 to 1.5113. The eta statistic (.36) indicated a large effect. The null hypothesis is rejected (p=.001) and we conclude that the alternative hypothesis is true at the pre-determined CI of 95%.

Figure 4.13: Difference between WC Measurement over Clothing and Bare Skin



b) WC over Clothing minus the Clothing Effect

Hypothesis: *H1: There will be a difference between WC measurement over clothing minus the clothing effect of .5cm and WC taken on bare skin. HO: There will be no difference between WC measurement over clothing minus the clothing effect of .5cm and WC taken on bare skin.*

A second paired sample t-test was conducted to evaluate whether there would be a difference between WC over clothing minus the reported clothing effect and WC taken on bare skin. The individual values of the variable, WC with clothing, has .5cm subtracted from it to be consistent with the other studies which report this value to be the effect of clothing on this measurement. The results indicate that the mean for WC with clothing minus the reported clothing effect of .5cm ($\bar{x}$ = 97.51, *SD* = 14.52) was not significantly different from the mean for WC without clothing ($\bar{x}$ = 97.06, *SD* = 14.28), $t(23) = 1.710$ $p > .05$. The mean difference was .46cm, with a 95% CI ranging from -.0960 to 1.0127. The eta statistic (.11) indicated a large effect. We fail to reject the null hypothesis (p =.101) and conclude that there is not enough evidence to state the alternative hypothesis is true at the pre-determined CI of 95%. Although the findings were not statistically significant, a difference still exists between measurements with clothes and without, even when the .5cm is subtracted from the WC measurement results with clothing. While .5cm may account for the clothing, the outstanding mean difference of .46cm, rounded to .5cm, may be explained by landmarking error on the placement of the measuring tape at the site. Unlike the WC taken on bare skin, it is not possible to exactly verify the landmark site when placing the

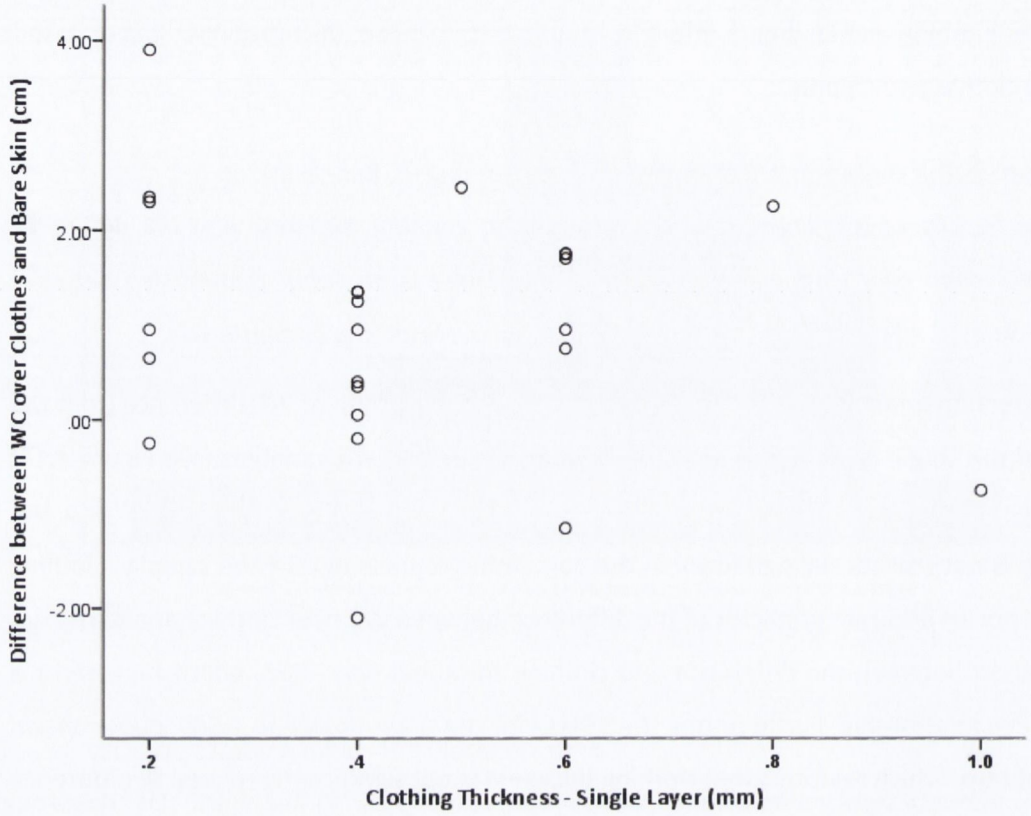
measuring tape over clothing, as no marking is made on the clothing (unlike the small line made directly on the skin for the WC measurement on bare skin). It therefore may be more accurate to report the clothing and landmark effect in adults at 1cm (mean .96cm rounded) as opposed to the .5cm clothing effect only.

c) Clothing Thickness and WC Differences (over Clothing vs. Bare Skin)

Hypothesis: *H1: There is a linear relationship between clothing thickness and the difference between WC taken over clothing and bare skin. HO: There is no linear relationship between clothing thickness and the difference between WC taken over clothing and bare skin.*

A linear regression analysis was conducted to evaluate the prediction of WC difference from the thickness of the single layer of clothing. The scatterplot for the two variables (see Figure 4.14) indicates that the two variables are not linearly related (F (1, 22) = .849, p > .05) and the relationship is not statistically significant in the population represented by the sample. Clothing thickness is not an accurate predictor of the difference between WC over clothing and bare skin. The correlation between the difference and clothing thickness was -.193, which represents a weak negative relationship. Furthermore, the 95% CI for the slope, -4.028 to 1.549, does contain the value of zero, which reaffirms that clothing thickness is not significantly related to difference between WC taken over clothing and bare skin. We fail to reject the null hypothesis (p=.367) and conclude that there is not enough evidence to state that the alternative is true at the pre-determined CI of 95%. In view of the previous findings in Section 4.4.2.7 [b] and the above finding that clothing thickness does not predict (mean thickness .446mm rounded to .4mm) the degree of difference between the WC over clothing and bare skin, it would suggest that the .5cm clothing effect reported in other studies is only one of two factors that needs to be considered, the second being the related contribution of landmarking error.

Figure 4.14: Clothing Thickness and WC Differences



d) Summary of WC Measurement over Clothing and on Bare Skin

The WC over clothing (single layer) was significantly greater than WC measurement taken on bare skin. On subtraction of .5cm from the WC measurements over clothing, the clothing effect reported in the literature, no statistically significant difference was found between the measurements taken over clothing and those on bare skin. However, there was an outstanding difference of .46cm, which rounded equals .5cm. The mean thickness of clothing (single layer) was .4mm (rounded). Clothing thickness was not an accurate predictor of the difference between WC over clothing and bare skin. The findings suggest that clothing is only one of the contributing factors to the difference in results, and that landmarking error due to clothing (i.e. tester is unable to verify the exact landmarking site) also needs to be considered.

4.5 Conclusion

This chapter was divided into three parts. Phase 1 described the key demographic, health and lifestyle data of the sample population. Phase 2 provided a detailed description of the anthropometric measurement results, the measurement process, and the process findings on the experience of using the project materials. Phase 3 presented the results of the hypotheses tested based on the valid measurement readings reported in Phase 2. The next chapter will

examine and compare the study's main findings with relevant findings from other published work, and explore how this study contributes to a better understanding of anthropometry assessment in this population group. Possible areas for further research will also be identified.

Chapter 5: Discussion

5.1 Introduction

Despite the level of international research on overweight and obesity in people with ID, there is a lack of comparable measured anthropometric data. During the last decade, especially, several researchers have raised the need for standardisation in this field of research. For example, Rimmer *et al.* (2010, p. 9) have highlighted the need "to establish appropriate methodology and equipment for the accurate measurements of body composition in selected disability groups". A year earlier, Humphries *et al.* (2009) confirmed the need for improvements in the research methodology and design of nutrition research on people with ID, and strongly suggested that researchers must define the best standards and techniques to use with this population and seek to achieve consensus on these standards. Concurrently, Verstraelen *et al.* (2009, p. 311) further reaffirmed the need for more research "on the limitations of the measuring methods and the gold standard", and stated that the "question remains as to how best to measure weight status in people with intellectual disability". While over ten years ago, the need to develop norms for anthropometric measurements that are standardised on persons with ID was identified, but remains unmet (Aldridge *et al.* 2000).

As part of the pilot for the national IDS-TILDA study, using a mixed-methods approach that combined two theories, measurement and familiarisation, and one model, Cone of Experience, within the conceptual framework of the ADDIE model, the operationalisation of standardised anthropometric procedures (using generic reference methods) was tested, as well as strategies designed to promote greater participation and familiarisation of the measurements among adults with ID, beyond the act of measurement alone. This exploratory study sought to determine the feasibility, validity and reliability of performing anthropometric measurements on people with intellectual disability (ID) aged 40 years and over, and develop an evidenced based research field tool to guide the baseline assessment of anthropometry in adults with ID. This chapter discusses the main findings (presented in Chapter 4) of the study as they relate and contribute to the literature. The context of the discussion is mainly framed on the central themes of the rapid research field tool developed (see Figure 5.1) from key learnings of this study.

5.2 Summary of Key Findings

High-quality measured anthropometric data can be collected in adults with ID in field research. The anthropometry module developed proved to be highly feasible to deliver as part of the IDS-

TILDA study and was acceptable to people with varying abilities. Overall, high rates of valid and reliable anthropometric measurements were achieved, using generic reference methods (with very minor standardised adjustments to widen reach to all).

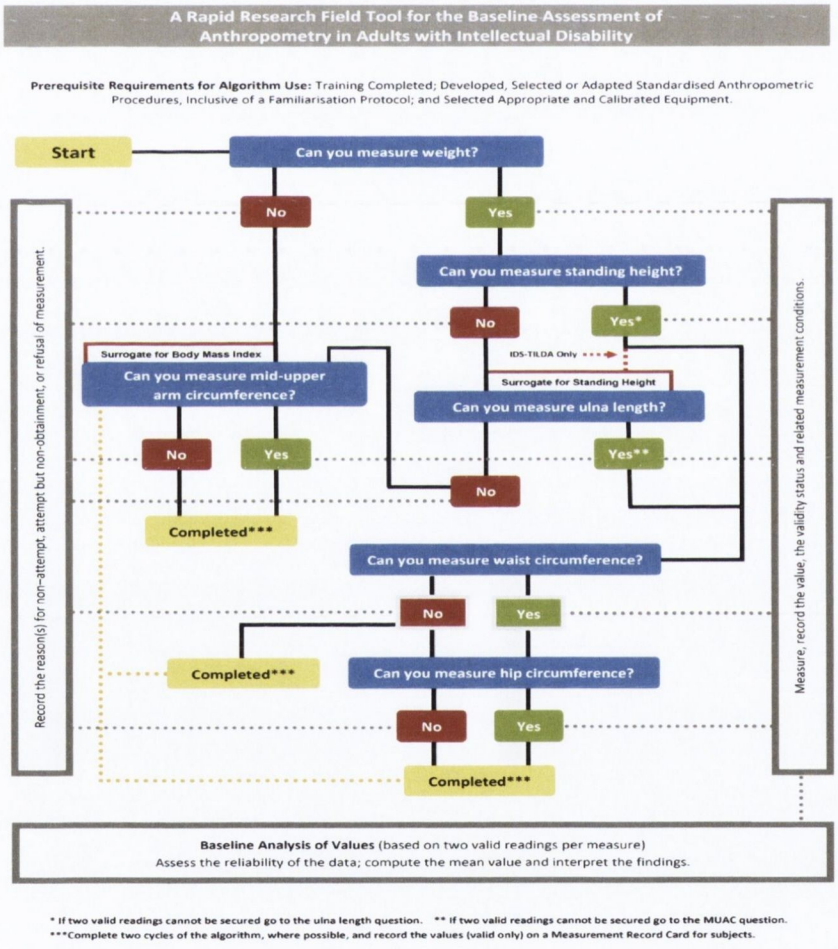
The study has shown the importance of securing accredited training from certified trainers, the use of standardised procedures with an integrated familiarisation protocol, and the selection of appropriate and calibrated equipment. The importance of reporting the validity status of each parameter measured against predefined validity criteria, the undertaking of duplicate measurement readings to allow intra- and inter-observer reliability to be assessed, and the quantification of the non-measurement outcomes, was demonstrated. The need to include surrogate measurement options as standard practice in anthropometry studies seeking to measure standing height and weight in people with ID was confirmed. The utility of both the surrogates tested in this study, the ulna length, as an estimate for standing height, and mid-upper arm circumference (MUAC), as an estimate of BMI category, was confirmed. However, further research is required. No anthropometric measurement is without limitations.

The validity and reliability of the surrogates tested was high and both were accessible to, and acceptable by, all the people with ID. The value of measuring MUAC in all adults with ID was also noted, along with the need to examine the rate of height loss in this population. The selected waist circumference (WC) site, the iliac crest, was acceptable to people with ID over a single layer of clothing and on bare skin. A higher rate of valid WC measurements on bare skin was obtained, but slightly more agreed to the WC measurement over clothing. The importance of light clothing (≤1.0mm) was noted, particularly if participants are not eligible to have the measurement taken on bare skin. The effect of clothing on the measurement result revealed that clothing is only one of the two factors that needs to be considered, the other being landmarking error. A correction of -1.0cm for the clothing effect and landmarking error is proposed, when it is taken at the iliac crest site over a single layer of clothing. The study also revealed the importance of establishing the identity of the reporter and the source of self-report height and weight data, particularly when more than one reporter is involved in the data collection (e.g. the person with ID and their family member).

More than was expected, the study revealed the important contribution of familiarisation (and the associated accessible materials developed) in anthropometry research for both the participant and the research being conducted. The potential to replicate the familiarisation protocol developed beyond anthropometry research to other types of physical tests or

examinations for people with ID was noted. Lastly, all the selected equipment except for the wheelchair scale proved in the field research to be feasible (portable and practical), accessible and acceptable to people with ID. Use of the wheelchair scale is suitable only for 'clinic-style set-ups'. Slight design improvements were identified for two of the selected pieces of equipment, the Segmometer 4 and the Seca 217 height measure, but both can be used in the current design with extra time allotted. Collectively, the results confirm the feasibility of this new approach to anthropometric assessments in adults with ID, which can be successfully replicated in the IDS-TILDA study and by others in both the research and practice field.

Figure 5.1: Rapid Research Field Tool Developed for Baseline Assessment of Anthropometry



5.3 Anthropometry Training

Anthropometry involves the measurement of human body dimensions. It offers many benefits; it is low cost, non-invasive and easy to perform, and the equipment is portable, but anthropometric techniques can be problematic due to their vulnerability to measurement

errors and lack of reliability (Sicotte *et al.* 2010). According to Mulholland and Rolland (2012, p. 46) "in skilled hands, anthropometry can be highly reproducible and the most useful field method for assessing body composition". However, due to its many benefits, many investigators underestimate the skill required. Although the use of direct[30] anthropometric measurements in research studies with people with ID continues to increase worldwide, anthropometry training is little considered and, where reported, lacks specific details – for example, on theoretical issues such as standards and on practical components, assessment methods, duration of training, trainers' skills and expertise, and reliability measures. A recent scoping review, from 1990 to the present, by Casey (2013, p. 1) found that the "current research literature contains too few well-conducted studies to determine the precision and validity of body composition measures on people with ID". The current study, although small, represents the first step towards developing an evidence-based framework (see Figure 5.1) on the key methodological components, inclusive of training, that need to be considered by researchers conducting anthropometry assessments with people with ID. Anthropometry training should be one of the first considerations of those seeking to undertake direct anthropometric measurements with this population group for research purposes.

Collectively, the lack of transparency on training in the literature (as discussed in Section 2.5.4), the absence of any reference to national or international certified anthropometry training programmes, and the emergence of the same finding – concerning the absence of standardised training – among all but one of the researchers and clinicians consulted (see Appendix 3, Theme 3), led the researcher to source structured training delivered by certified trainers. Since the initiation of this study, the lack of transparency on training has continued to be observed (Verstraelen *et al.* 2009, Temple *et al.* 2010, Melville *et al.* 2011, Soler Marin & Xandri Graupera 2011, Thomas & Kerr 2011, Tsai *et al.* 2011, Mitchell *et al.* 2013) and although, more than previously reported have referred to 'training' or measurements being conducted by 'trained' personnel, the associated training details provided (as discussed in Section 2.5.4) continues to be limited (Waninge *et al.* 2009, 2010, de Winter *et al.* 2012, Temple *et al.* 2013).

Although the researcher (an experienced intellectual disability nurse) had knowledge of basic body measurements, such as height and weight, she was convinced that perceived skills and expertise in anthropometry cannot be assured for research purposes without specific training and assessment of all three components, irrespective of how easy the measurements are

[30] Reminder: Use of the term 'direct' in this context refers to measured anthropometric parameters such as height, weight, etc.

perceived to be. Hinojosa *et al.* (2000, p. CE-1) state that "as members of a profession, we are expected to demonstrate professional behaviour and conduct and to assure society that we are competent". Yet "the process of maintaining competence is ongoing and developmental" (Youngstrom 1998, p. 717), and includes (but is not limited to) the understanding of new knowledge and further development of technical skills. An evaluation, though small, of three anthropometrists revealed that the shorter the experience and previous (or insufficient) training of testers, the more errors were made during the measurements, resulting in poor precision and accuracy, particularly in girths and skinfolds (Bagni *et al.* 2009). For instance, if we consider the mid-upper arm circumference measurement, despite it being a relatively easy measure, small errors such as incorrect location of one or any of the landmarks, inaccurate positioning of the arm or the tape measure at the midpoint site, or insufficient tension placed to hold the tape at the designated landmark without indenting the skin, can each or collectively lead to erroneous interpretations (de Almeida *et al.* 2003) – without specific training. Although other key components, such as the use of standardised procedures and calibrated equipment, are also required to reduce the risk of measurement errors, anthropometry training is the key building block needed by those wishing to measure anthropometric parameters in research. However, the receipt of training in itself is not sufficient to ensure accuracy; the knowledge and skills of learners must be assessed against strict criteria, and only those that meet the required standards of the course should be accredited.

Critically, ISAK (International Society for the Advancement of Kinanthropometry) provided the necessary professional training to assess, plan, implement and evaluate the form, shape, proportionality and body composition of subjects. Although the course was not specifically designed for professionals assessing people with ID, the measurement standards, techniques and applications are universally applicable, irrespective of the target population group. Slight adjustments, as noted in the methodology chapter, were made to widen the reach and use with people with ID in a field study, but all the same measurement principles (e.g. use of standardised procedures, assessment of technical error of measurement), techniques (e.g. how to landmark a skeletal point) and considerations (e.g. calibrations, equipment manipulation) learned were applied in practice.

The ISAK training was delivered by certified trainers who are reassessed every four years against strict (and transparent) criteria and are required to provide evidence of ongoing involvement in teaching and examining of ISAK courses (Stewart & Sutton 2012). Such rigorous and transparent training standards and exam-based certification (competency-based, including target inter- and

intra-tester technical error of measurement criteria) offered the quality assurance needed and ensured confidence in the skills, knowledge and competence obtained. Although this study is small, the high standard of training obtained maximised the quality of the results the study produced. Based on all the findings, it is clear that the importance of anthropometry training in research cannot be underestimated. In this study, the ISAK training scheme guided the researcher through the research process. In particular, it directed the researcher on the primary considerations needed, such as the subject, the data-collection process and the equipment (selection, care and use), followed through to the measurement standards and methods for assessing the validity and reliability of the results. The thoroughness of ISAK highlights the need for appropriate consideration to be given to the quality and quantity of training undertaken by researchers in the field, including that of trainers. Such guidance and direction is absent in the ID literature, which has led to the lack of related details in this field. For example, in one of the more recent studies, Moss (2009) reported that skinfolds were measured by an accredited Level 2 anthropometrist, but did not specify, if they or someone else conducted the other anthropometric parameters assessed.

While the completion of ISAK training (Level 1) by all future examiners (i.e. researchers) may not be attainable in the IDS-TILDA study or other epidemiological studies involving direct anthropometry assessment, it serves as a good benchmark for training standards. If ISAK training cannot be completed by researchers, then the methodological details of more localised training – i.e. content, duration, assessment methods (including intra- and inter-technical error of measurement criteria), and how trainers are assessed, etc – needs be clearly outlined in research reports, so that the quality of training and the data collected can be assessed. However, examiners, as recommended by Geeta *et al.* (2009, p. 1,018), "should be trained and later assessed by qualified anthropometrists against some predetermined target training values". Equally, all personnel involved in directly measuring anthropometric parameters for research purposes, irrespective of their professional background, should receive training, as new techniques, knowledge and equipment are continually being developed. To maintain high standards in field research, regular monitoring (e.g. intermittent checks using repeated measurements on the same subjects, with their permission) and refresher training may be required depending on the study design. For example, intermittent checks would be required in large studies, such as the IDS-TILDA study, where anthropometry data is being collected on a large sample over several consecutive months. It has been reported that "the availability of an 'expert' in anthropometry may be crucial not only during the training process but also during data-collection supervision" (Sicotte *et al.* 2010, p. 7), particularly in large studies. Kaaks *et al.*

(1994) suggested that, by comparing data gathered to that of a gold standard, it could be possible to calibrate for the bias due to errors, and also identify and resolve any related concerns. Anthropometry is highly objective and reliable in the hands of trained anthropometrists (Krishan 2007).

5.4 Standardised Anthropometric Measurement Procedures and Reporting

To accurately assess the feasibility, validity and reliability of direct anthropometric measurements of adults with ID, in this study, the application of, and adherence to standardised anthropometric measurement procedures, guided by generic reference methods, was critically important. The pooled findings from the literature review (see Section 2.5.2) and the consultations completed (see Section 3.5.1) at the methodological stage confirm that there is a lack methodological transparency and reported use of reference methods (Frisancho 1984, Lohman *et al.* 1988, WHO 1995, Marfell-Jones *et al.* 2006) in this research field. Since the initiation of this study, there has been a slow increase in the number of ID studies quoting either a reference method or a specific protocol for all (or implied for all) of the measurements examined (e.g. Moss 2009, Waninge *et al.* 2009, Soler Marin & Xandri Graupera 2011, Tsai *et al.* 2011, Temple *et al.* 2013), but it is by no means standard practice in research.

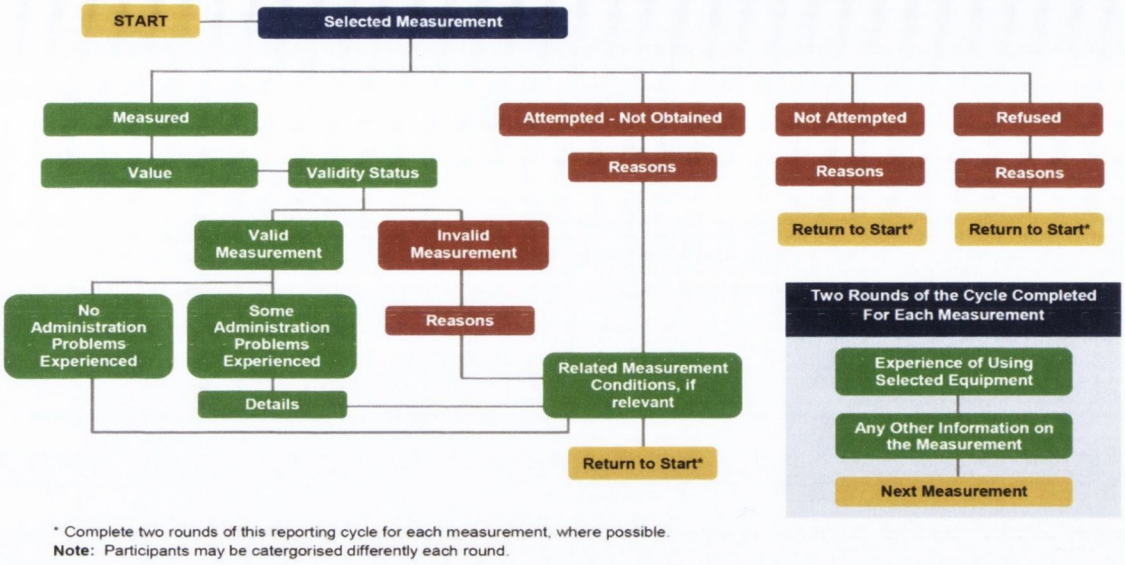
This methodological status is a matter of concern, particularly as standardised procedures are essential in order to maximise the validity and reliability of anthropometric data collected in this population, but also to allow for direct comparisons to be made between studies and population groups, and to permit the pooling of results from different studies. An example of the type of differences and lack of detail found in the ID literature is reflected in the following two studies: Melville *et al.* (2008) and de Winter *et al.* (2012), which involved 945 adults with ID in the physical assessments undertaken. Focusing only on the height parameter and the method reported in both studies, neither mentioned, at a minimum, the position required of the participant's head or upper and lower part of the body. In de Winter *et al.* the researchers stated that "height was measured using a Seca stadiometer, type 214, with the participant standing, wearing no shoes" (p. 400); in Melville *et al.* it "was measured without footwear using a portable stadiometer" (p. 427). This lack of detail (i.e. criterion requirements) raises the question (for many related studies in the ID field) of how the validity of the measurements was assessed or what standards it was measured against to be classified as 'valid'.

Relatively small biases in the measurement process can result in the misclassification of groups or population trends; for example, a difference of one decimal point (e.g. 29.9 and 30.0) on the

Body Mass Index Classification Scale can mean the difference between someone being categorised in either the overweight or obese category. Such measurement errors not only affect the quality of the data collected, but also the relationships and differences among variables uncovered or examined within the population and with respect to other population groups. This raises questions such as: is the difference a true difference, or is the difference a result of errors caused by the data collector (i.e. trained or not trained), equipment (i.e. not calibrated) or protocol variability, if used. Perissinotto *et al.* (2002) confirmed that the use of non-standardised methods and insufficient sample sizes make it difficult to compare reference values for clinical and epidemiological purposes. Although it is clear that adherence to recommended procedures will reduce bias in measurement (WHO MGRS 2006), the reporting of such practices among investigators in ID research is very limited. This lack of standardisation has been a major factor confounding comparisons between and within ID studies, as well as meta-analyses.

In the literature, there was no evidence found indicating that standardised anthropometric procedures (i.e. reference methods) cannot be successfully used with or without adaptations (if needed) in this population group. While each anthropometric study in this field seeks to make independent contributions to knowledge, the measurement principles and procedures that permit comparability among studies should for the most part be the same. The use and reporting of standardised methods will fundamentally improve the quality of anthropometry studies on people with ID. The feasibility, validity and reliability findings from this study clearly show that standardised anthropometric procedures based on generic reference methods, with some minor adaptations, can be successfully operationalised in field research with this population group. To substantiate this position, the use of the reporting cycle developed for the study was critically important (see Figure 5.2), as it facilitated the quantification of the measurement status from each measurement, which is absent in the literature. Access to quantified data on the validity status, measurement attempts, non-obtainments, non-attempts and refusals – including the reasons if known – provides a more comprehensive picture on the status of anthropometric measurements in this population group. Access to this information also provides the opportunity to learn what actions are needed to reduce or avoid, where possible, invalid, incomplete or non-attempted measurements in the future. Not dissimilarly, although not as specific and transparent as this study, the Wallace and Schluter (2008) enquiry into cardiovascular risk factors and adults with ID specified if a particular risk factor had not been assessed, and an attempt was made to establish the reason for the omission and record the details in the audit, which is an important step in the assessment process.

Figure 5.2: General Outline of the Measurement Reporting Cycle



* Complete two rounds of this reporting cycle for each measurement, where possible.
Note: Participants may be catergorised differently each round.

Critical to the success of the operationalisation of the standardised procedures developed and used in this study was the accredited anthropometry training completed. While the positive response received from participants to the standardised procedures employed was aided by the integration of a familiarisation protocol into the study design (see Section 5.10 for further details). The inclusion and testing of surrogate measurements for standing height and BMI, for future use in the IDS-TILDA study, also maximised the participation of participants. The minor but standardised adaptations made to the measurement procedures, and the selection and use of appropriate equipment (see Section 5.12), also widened the reach to participants. The identification, consideration and planning of other key influential factors (see Section 5.11), such as communication access, allocation of sufficient time, and the setting, also played a significant role in the positive results achieved in this study. Together, all of the efforts made to build on and improve anthropometry research in people with ID align with the Rimmer *et al.* (2010, p. 9) recommendation for the "establishment of appropriate methodology and equipment for the accurate measurement of body composition in select disability groups". Importantly, this study demonstrates that generic reference methods can be successfully used in this population group when some reasonable adjustments are made.

5.5 Operational Feasibility in Field Research

The operational feasibility, based on those eligible for the measurements, in this study is believed to reflect the varying needs and abilities of this population group. The findings highlight the importance for surrogate measurements – such as those tested in this study: ulna

length for standing height, and mid-upper arm circumference for BMI – to meet the differing needs of the population. Nearly all of the participants were eligible for weight, ulna length and mid-upper arm circumference measurements. Importantly, all three of these measurements could be taken in a standing (preferred option) or sitting position, which widened the reach to all participants with varying levels of abilities. However, the numbers eligible for the weight measurement would have been decreased by at least a quarter if the wheelchair scale had not been available, as a quarter of the sample were wheelchair-users. Others also used this scale (standing or sitting in a chair), where feasible, if they were unsteady on their feet, or if it was already set up, as it provided users with a wider platform to adjust their position for the measurement. As the population ages, the need for accessible equipment such as a wheelchair scale, and alternative methods to conduct measurements such as surrogates for standing height and BMI, in both the research and practice field is going to increase for all members of society. Both the practical application and portability of the equipment used for all three measurements, particularly the wheelchair scale, were examined closely to offer future guidance on its use in field research, mainly home-based visits (see Section 5.12).

For the remaining three measurements – height, waist (over clothing) and hip circumferences – just over two-thirds of participants were eligible for the measurements, and just under half were eligible for the waist circumference (WC) measurement on bare skin. However, as all of these measurements require participants to be in a standing position, which precludes wheelchair-users, this lower operational feasibility figure was not unexpected. If the wheelchair-users are excluded from the equation, the operational feasibility for height, waist (over clothing) and hip circumferences was very good. Of note, the operational feasibility figures on waist and hip circumference may increase in the future, when only the minimally required measurements are conducted in the IDS-TILDA study, particularly in the case of the WC measurement on bare skin. In a very small number of cases, but no less important, the effects of fatigue influenced the reasons for the non-operationalisation status towards the end of the measurement visit. However, based on the key learning on the utility of the surrogate measurements selected and the effect of clothing on the WC measurement in this study, only those that require surrogates will be advised to complete (with the exception of one recommendation on MUAC, outlined in Section 5.7.2), which will result in fewer measurements, reduce the risks of fatigue on participants, and maximise their uptake and performance on the key parameters of interest. However, the main influencing factor that lowered operational feasibility across these measurements was the number of wheelchair-users.

With regards to the WC measurement on bare skin, the number of those eligible may increase, at least to the levels of WC over clothing, as several of the reasons for non-eligibility are potentially adjustable factors that might not have been as significant if the participants had only been required to complete the basic set of measurements, as will be conducted in the IDS-TILDA study. However, for the purpose of this study, all the measurements were examined among those eligible, so that the surrogate measures and the effect of clothing on WC measurement could be examined closely. In order to allow the eligible participants more time to get to know and feel comfortable with the researcher, and to avoid the risk of compromising the securement of the other measurements (e.g. due to fatigue, disinterest), the WC measurement on bare skin was purposively placed at the end of the visit. However, at this stage several of the participants were tired, disengaged or anxious to get finished, which contributed in part to the reduced operational feasibility figure reported. Although this finding was not unexpected, it demonstrates in this context the potential influence of fatigue on uptake levels. Bird (2008, p. 3) asserted that, in "conducting a series of tests or measurements, the sequence in which they are performed can be important, as fatigue from one test can affect the results of another test". As demonstrated in this study, the sequencing of the measurements was critical, particularly in terms of operational feasibility, so as to ensure that the key parameters of interest were not compromised. It is imperative that studies include a clear rationale for each measurement selected, how the findings will be used and who will benefit, and that the sequence of the measurements to be performed has been considered with a view to reduce the effects of fatigue on the uptake levels and/or the performance effort. Overall, the operational feasibility figure achieved confirms the need for and importance of the rapid research field tool developed from the results of this study, to offer guidance on the decision-making process in the selection and sequencing of the most suitable measurements for the baseline assessment of key anthropometry parameters in adults with ID for field research purposes (see Figure 5.1).

5.5.1 Measured Feasibility among Eligible Participants

Despite the participants' initial eligibility for the measurement, the percentage of those measured varied slightly in two of the measurements: height and WC over clothing, and, more particularly, in the mid-upper arm circumference (MUAC) measurement. The reduced figures resulted from measurements being attempted but not obtained or refused. On examining standing height, none of the reasons reported were unexpected. Standing height measurements in older people can be difficult to obtain because of an inability to stand straight or steadily due to pain, weakness, disability, or spinal deformities such as kyphosis or scoliosis, or due to osteoporosis (Hirani & Mindell 2008, Erwin 2012) and are not always practical (Auyeung *et al.*

2009). At present, there are no guidelines regarding the degree of spinal curvature that would invalidate the measurement of height, but there are obviously individuals whose height should not be measured because of kyphosis or other postural problems (WHO 1995). At the outset, it may not always be clear if it will be possible to measure standing height; as found in this study, only as the researcher moved through the briefing, demonstration and/or attempting stage did it become clear that this would not be possible for some participants. Several studies have noted that height measurements of people with ID can sometimes be difficult (Bell & Bhate 1992, Marshall *et al.* 2003, Fender *et al.* 2007, Melville *et al.* 2008, Wallace & Schluter 2008, Verstraelen *et al.* 2009), yet no surrogate measurement was included in these studies or other studies measuring height in this population, as back-up, if required (Frey & Rimmer 1995, Prasher 1995, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Braunschweig *et al.* 2004, Moore *et al.* 2004, Melville *et al.* 2005, Chapman *et al.* 2005, Draheim *et al.* 2007, Stanish & Draheim 2007, Fender *et al.* 2007, Bhaumik *et al.* 2008, Starr & Marsden 2008, Temple *et al.* 2010, Thomas & Kerr 2011, Tsai *et al.* 2011, Soler Marin & Xandri Graupera 2011, Temple *et al.* 2013). However, based on what is known about the difficulties of measuring height in older people, from the generic literature, the loss of height that occurs with ageing due to the thinning of the discs of the spinal column and diminution in the height of the vertebrae (Milne & Williamson 1983, Cline *et al.* 1989), and the reported difficulties experienced by some people with ID with the height measurement, combined with the likelihood for such difficulties to increase as this population ages with increased life expectancy (Coppus 2013), it is important to include a surrogate option for when standing height cannot be obtained or accurately measured.

The use of surrogate measurements with different body segments (i.e. ulna, knee height, arm span and demi-span) to estimate standing height in the older population has been reported widely in the generic literature for many years (Mitchell & Lipschitz 1982, Chumlea *et al.* 1985, Haboubi *et al.* 1990, Cockram & Baumgartner 1990, Kwok & Whitelaw 1991, Bannerman *et al.* 1997, Hickson & Frost 2003, Ritz 2004, Weinbrenner *et al.* 2006, Prasad *et al.* 2012). A similar response needs to be available to people with ID more widely in research studies, so that the data is as comprehensive as possible. From a practice perspective, Welch and Craggs (2010, p. 36) similarly highlighted the importance of practitioners having "an understanding of the different techniques which allow the application of a BMI assessment to be adaptable [such as the use of alternative measurements for standing height] and flexible enough to accommodate the diverse needs of client groups", including people with ID.

In this study, ulna length was selected as the surrogate measure of choice, as it is known to be generally easy and quick to perform, even with people who are bed-bound or chair-bound (Elia 2003). It was confirmed that easily identifiable surface landmarks not only make the measurement possible with people with compromised postures (Mondal *et al.* 2012), the accessibility of the landmarks – i.e. olecranon process (point of elbow) and styloid process (prominent bone in the wrist) – also means that participants, regardless of their level of ID, may be able to assist with locating the two landmark sites in the lead-up to the actual measurement. For the purposes of this study, ulna length was measured among all eligible participants, so that its suitability as a surrogate height measure could be examined. The continuity of the feasibility figures from the operational stage to measurement stage were excellent, similar to the weight measurement, but, as noted earlier, this was particularly aided by the access to, and use of, the wheelchair scale. Unfortunately, the same level of transfer figures between the stages was not achieved for the MUAC measurement, which was also tested among all eligible participants for the purposes of examining its potential as a surrogate for BMI when either weight and/or standing height (or ulna length) cannot be measured.

The review of the reasons for the unexpected drop in the number of participants measured for MUAC revealed the main contributing factor to be unsuitable clothing, the incidence of which may be greatly reduced in the future. For these participants, the upper clothing was found to be too restrictive and did not allow the researcher to see the location of the acromion bone, and the garment was either covering or on the midpoint site. Had suitable clothing been worn (e.g. a t-shirt or shirt that was not restrictive at the top of the arm), the percentage of those measured would not have decreased from the operational feasibility stage. Although participants (and proxies) were advised at the appointment stage on suitable clothing required for the measurement visit and a written and illustrative reminder was included on the appointment card issued (see Appendix 24), two amendments to the card are proposed for the IDS-TILDA study. First, it is advised that the layout of the text on t-shirts/shirts be separated from the point on trousers/skirts (this amendment may also benefit the WC measurement over clothing, as its measured feasibility dropped slightly due to unsuitable clothing); secondly, the text should be revised to read "wear a short-sleeve t-shirt or shirt that can be rolled up to your shoulder". On booking appointments, it is advised that extra emphasis be placed on the importance of participants, particularly wheelchair-users, being able to roll up their t-shirt/shirt to their shoulder. While the overall dependence on this measure for an estimated BMI was low in this sample, as BMI could be calculated from the measured values secured on weight and height (or ulna length), if the wheelchair scale had not been available or suitable for the selected location

of the visit, the dependence levels on this measure would have increased significantly. Thus the importance of suitable clothing for the measurement visit cannot be underestimated in the IDS-TILDA study, not only because it involves a much larger sample but, as the study population ages, it may become more dependent on the MUAC measurement if the wheelchair scale is not a feasible option or standing height or ulna length cannot be measured. Overall, across all of the measurements tested, the measured feasibility among the eligible participants was very good, except for the mid-upper arm circumference, where just over a quarter of those eligible could not be measured due to unsuitable clothing, but this is an adjustable factor that can be reduced in the future with the modifications suggested.

5.6 Validity and Reliability of Measurement Data

Key to the operationalisation of the standardised procedures to maximise the validity and reliability of results achieved proved to be trained personnel (as discussed in Section 5.3) and the selection of appropriate and calibrated equipment (see Section 5.12). Importantly, three other concepts, often absent from the methods reported in the literature, formed key components of the standardised procedures developed and used in this study. These included: (a) the criteria set for assessing the validity of readings, (b) the use of duplicate measurements to assess the reliability of readings, and (c) the inclusion of a familiarisation strategy to reduce any potential measurement difficulties and/or barriers. Interestingly, in the generic literature, Jamaiyah *et al.* (2010) reported that, despite the importance of accurate and reliable anthropometric measurements, there are relatively few papers (Johnson *et al.* 2009), addressing the reliability and validity of these assessments. The importance of the validity and reliability of measurements, and the need to address both concepts, is therefore universally applicable; this study is the first attempt known to systemically address both concepts.

5.6.1 Measurements Readings: Assessment of Validity and Reliability

Both the interpretation of anthropometric data and the determination of the impact of the findings depend on the validity and reliability of the measurement findings, and neither should be assumed in research publications. A review of the methodologies of studies in this field concerning people with ID showed very limited or, more often, no details on how the validity or reliability of the selected measurements was assessed. For example, researchers in a large study (Temple *et al.* 2013) reported that its major strengths were the size and diversity of the sample and that BMI was measured directly rather than relying on self or proxy reports of BMI, yet no details on the validity and reliability of the measurement readings were discussed. In another study (Verstraelen *et al.* 2009), focusing solely on the weight, height and waist circumference

measurements taken, very limited details on the standards applied were provided, and, although all the measurements were obtained, the limitations noted in their discussion leads one to query the validity and reliability of the findings:

> *"It sometimes was difficult to take measurements, because some people were not able to stand straight up to measure their height and the waist circumferences, and not everyone was able to lie in a correct position. However, despite these shortcomings there were no indications that the results were substantially influenced by these factors." (Verstraelen et al. 2009, p. 311)*

However, without specific details on the standards applied, the validity criteria set and duplicate measurements taken, how can one be sure that the results were not substantially influenced? The lack of such details in studies prompts one to question the quality of data, before even considering any other potential internal and/or external threats to the validity and reliability of measurements.

5.6.2 Classification of Validity Status

On review of the literature, no studies were found specifying a universal criterion for determining the validity of anthropometric measurements. Considering the lack of details often provided on the standards applied, this is not surprising. It appears that validity is being implied by virtue of the measurement results being reported, or, in other cases, it is indirectly implied. For example, in the Waninge *et al.* (2009, p. 381) study, for two of the measurements, height and weight, the researchers stated that "when the participant was standing correctly, we determined body length"; even more indirectly, "when a participant was unable to stand independently, without moving, the participant was weighed in a wheelchair chair", implying that the lack of movement determined the validity of the measurement. As part of their discussion on the findings, the researchers do state that "the measurement process must follow the protocol", but a more explicit statement on validity is required earlier. A short, universal criterion statement on the classification of validity status, such as "a measurement reading is determined valid when all the standards are fulfilled", should be included as part of the standard procedures operationalised, as successfully demonstrated in this study, and be detailed in the methodological section of any related research published in this field. Its use will not only confirm the status of the results reported, but also direct and require researchers to consider and specify what standards or reference methods each measurement is being judged against. At the data-collection stage, it will also require researchers to consider if all the standards specified have been met to classify the reading as valid. Once established, the reliability of the data can then be examined. Of equal importance is the capturing of the rate of

invalid measurements that occur and gaining an insight into the main reasons contributing to this status (see Figure 5.2). This information will also guide researchers in the field about future considerations that may be required. Central to the validity process is the use of a clear and transparent reporting form to capture the data required. Due to restricted resources, a paper-based form was used in this study; although it met requirements, the speed of transcribing and transferring data could have been improved if a personal digital assistant (PDA) mobile device had been used instead. It is recommended, resources permitting, that IDS-TILDA use a PDA to record the health assessment data similar to The Irish Longitudinal Study on Ageing (TILDA) to improve the efficiency of data recording.

5.6.3 Validity Status of Measurements Achieved

The overall validity of the measurements was very good (88.5%), reflecting the degree to which the participants fulfilled all of the measurement standards set for each respective measurement. A key factor to achieving this outcome may be attributed to the familiarisation steps taken (see Section 5.10) in this study. However, the role and contribution of the other methodological components previously mentioned, such as the completion of accredited training, the use of standardised procedures and the selection of appropriate and calibrated equipment, along with other key influential factors – for example, time allocation (see Section 5.11), cannot be underestimated. All of these factors are inextricably linked and collectively aided the validity status achieved. The results show that nearly all of the participants had valid ulna lengths (left/right), MUAC, weight, and hip circumference measurements. Comparing the rate of validity to a similar study in this population which set the benchmark of validity as sufficient when 95% of the measurements were successful (Waninge *et al.* 2009), all four measurements had validity levels of greater than 95%. Although Waninge *et al.* did not examine ulna length, they did examine tibia length as a surrogate for standing height; similarly to this study, the surrogate achieved a validity rate of at least 95%. Interestingly, the weight measurement rate in both studies was 95% or greater, which may be linked to the use of a wheelchair scale. However, access to this scale was different in both studies; all participants had access to the scale in the Waninge *et al.* study as it remained stationed at one location, whereas access to the wheelchair scale in this study was generally restricted according to need unless it was already set up, as assessments were mainly home-based.

The validity findings in this study strongly confirm the utility and acceptance of the ulna length and MUAC measurements among participants as a potential surrogate for standing height and BMI, respectively, where required. Both ulna length (BAPEN 2003, Auyeung *et al.* 2009, Lai *et al.*

2010, Barbosa *et al.* 2012, Madden *et al.* 2012, Mondal *et al.* 2012, Prasad *et al.* 2012) and MUAC (Frisancho 1984, James *et al.* 1994, Baumgartner *et al.* 1995, Bannerman *et al.* 1997, Miller *et al.* 2002, BAPEN 2003, Corish & Kennedy 2003, Sanchez-Garcia *et al.* 2007, Haboubi *et al.* 2010, Wijnhoven *et al.* 2013) measures are widely used in the generic research and practice field, as surrogates and/or supplementary measurements. However, despite the high rate of valid results secured across all four of these measurements, some important observations were noted with two of the three pieces of equipment used (see Section 5.12). Although none of the observations affected the validity status achieved for the associated measurements (weight, ulna length or MUAC), they do highlight some practical considerations that need to be explored further by future testers, as no evidence was previously found on the use of the segmometer with older adults with ID in a seated position or the use of a wheelchair scale in a field of research studies that mainly conducted home-based assessments (see Section 5.12).

In contrast, standing height and waist circumference (WC) measurements over clothing (single layer of light clothing) and bare skin had lower levels of validity. All measurements were under the 95% benchmark tested, particularly standing height. Neither height nor WC over clothing came close to the validity figures (about 25% lower) achieved for the same measurements in Waninge *et al.* (2009) study (≥95%). In the examination of waist circumference, it was expected that the measurement over clothing would likely be under the 95% benchmark tested against, due to the potential influence of clothing; however, the lower validity figure on bare skin was not expected as the landmark site is visible to the tester. Review of the associated reasons for the invalid measurements indicates that both figures may be adjusted positively. The main contributing factor to invalid WC readings over clothing was the unsuitable single layer of clothing; in particular, polyester clothing caused the tape to slide off the landmark site, and the thickness of non-polyester clothing made it difficult to palpate the edge of the iliac crest. Both factors added more to the measurement process, which potentially caused other factors that may not have otherwise arisen (e.g. looking down at time, not standing still). Similar difficulties associated with clothing, such as the tape slipping and locating the exact measuring site, were reported in a study examining the effect of clothing on WC in the general population (Wills & Bhopal 2010). In future, a short simplified request to avoid polyester clothing and to wear light clothing needs to be included in the accessible Measurement Information Booklet issued, and the word 'light' needs to be added to the text already included on clothing in the accessible Appointment Card developed.

Given the potential influence of clothing on this measurement, a validity target of greater than or equal to 85% is deemed more suitable, which is 10% less than in the Waninge *et al.* study. An important comparative difference between the two studies was the type of clothing worn. In the Waninge *et al.* study the participants wore swimming clothes for the assessment, which is not deemed suitable for this type of study, for its method of data collection (e.g. location of the visit selected by participants), and for the cross-section of age groups involved in the IDS-TILDA study. Review of the reasons for the lower than expected validity figure for the WC measurements on bare skin (<95%) indicated that the main ones were potentially linked to its placement towards the end of the visit and the related effects of fatigue on the participant (e.g. more distracted, increased movement, not standing straight), which have been discussed earlier in terms of the reduced operational and measurement feasibility findings. The other reason for invalid measurements, although it applied to only two cases, was the tape sticking to clammy skin. Wills and Bhopal (2010) reported the same problem with this measurement on bare skin. Notably, the validity figure for WC on bare skin was greater than that achieved for the same measurement taken over a single layer of light clothing.

Leading health authorities (e.g. WHO 1995, NIH 2000), organisations (e.g. International Chair on Cardiometabolic Risk 2007, American College of Sports Science 2013), reference methods (e.g. Lohman *et al.* 1988, Norton & Olds 1996, Marfell-Jones *et al.* 2006) and large internationally recognised studies or programmes (e.g. Westat Inc. 1988, Balkau *et al.* 2007, WHO 2008, Tolonen 2013) recommend that WC should be taken on bare skin so that each, or the single landmark depending on the method used (e.g. iliac crest, midpoint), can be marked and the position of the tape verified. Although this recommendation is supported (and is the preferred method) by the higher level of validity results achieved in this study compared to the results over clothing, it is acknowledged that it will not always be practical or possible to take this measurement on bare skin. Aside from the standard inclusion and exclusion criteria set for the WC measurement, it is advised that a third party (e.g. family member, proxy) be present for this measurement on bare skin with the participant's permission, when the researcher is the only data collector present, as demonstrated in this study. Otherwise, this measurement should be taken over a single layer of light clothing (see Section 5.8). Either way, it is imperative that the researchers specify whether the measurements are taken over clothing (including the associated details of how 'clothing' is defined, as demonstrated in this study) and/or on bare skin. Many studies in both the ID (Braunschweig *et al.* 2004, Moore *et al.* 2004, Fender *et al.* 2007, Stanish & Draheim 2007, Verstraelen *et al.* 2009, Elinder *et al.* 2010, Waninge *et al.* 2010, Soler Marin & Xandri Graupera 2011, Mitchell *et al.* 2013) and generic literature (Baumgartner

et al. 1995, Hughes *et al.* 2004, Martins dos Santos & Sichieri 2005, Sanchez-Garcia *et al.* 2007, Hirani & Mindell 2008, Heim *et al.* 2010, Czernichow *et al.* 2011, Gomez-Ambrosi *et al.* 2012, Stewart-Knox *et al.* 2012) do not explicitly report on this factor in their methodology, which has implications for direct comparisons between studies and interpretation of the findings. Further details on the effect of clothing on the WC measurement and the associated recommendations are given in Section 5.8. On bare skin or over clothing, the selected WC site (the iliac crest), a fixed skeletal landmark, was acceptable to participants and they were able to assist with its approximate location as part of the demonstration stage of the study. Up until now, the reported use of this site is very limited in ID research (e.g. Kelly *et al.* 1986).

Lastly, across all the measurements conducted in this study, standing height represented the lowest validity achieved, which further confirms the need for a surrogate height measure to be included and used, as required, in studies that set out to measure standing height but cannot secure valid readings. The validity figure achieved (69%) does not correspond closely with Waninge *et al.* (2009), which secured at least 95% validity for the standing height measurements. However, their finding may have been aided by the fact that participants were asked to lie in a supine position or on one side with stretched legs for body length, if they were unable to stand against the wall properly. A similar request was also made in the Lea (2009) study, where required. However, in the current study, such a request would not have been logistically feasible or practical for the same reasons outlined earlier (e.g. test setting, age spread of the population) and because nearly half of those with invalid height measurements in this study were aged 60 years and over. On review of the validity results of the standing height measurements in a much larger study (3,346 participants) on adults aged 65 years and over in the general population (Hirani & Mindell 2008), lower validity levels were also reported, with 82% of the sample having a valid height measurement and 71.8% a valid demi-span measurement (surrogate for standing height). Interestingly, if we solely focus on the weighting of the percentages, as the sample sizes of the studies were starkly different, the opposite weighting was found in this study across the age groups (40+ years); and the percentage of valid ulna length measurements (surrogate for standing height) significantly outweighed the proportion of valid standing height measurements achieved. The validity figure achieved in the current study (69%) falls more in line with the figure achieved (62.8%) in a study involving elderly persons who were frail and housebound (Ewart *et al.* 2001), but, again, the rate of valid surrogate height measurements in this study (98%) was greater than Ewart *et al.* achieved (86.2%).

It is widely accepted that obtaining accurate measurements in some older adults and elderly subjects can be difficult (Hickson & Frost 2003, Shahar & Pooy 2003), if not impossible (Weinbrenner *et al.* 2006). A review of the reasons for the invalid height measurements showed that the majority reflected the commonly reported difficulty of standing straight among people with ID (Bell & Bhate 1992, Melville *et al.* 2008, Verstraelen *et al.* 2009) and the general population (Hirani & Mindell 2008, Erwin 2012). Collectively, the findings concur with those reported in the general population, which indicate that, as people with ID get older, standing height measurements may be more difficult for some individuals. Most notably, of all the anthropometric parameters tested, standing height required the most time, as several standard checks had to be completed at one time to determine the validity of the measurement. However, the measurement process was greatly aided by the familiarisation steps included in the design of the study (see Section 5.10), which sought to increase the participant's awareness of the checks involved. Waninge *et al.* (2009, p. 384) reported that the "process of measuring height can be very difficult for the tester because it is often hard for a subject to stand still for a few seconds in the correct position". It is expected that this study would have found the same had additional time not been spent in familiarising subjects with the steps involved and had the validity checks not been completed without delay.

Due to the risk of errors associated with standing height measurements, the importance of trained testers, use of strict criteria, duplicate measurements, and the integration of familiarisation steps into the measurement process to enable the subjects to produce maximal efforts cannot be overestimated. Although the rate of valid measurements could be increased if the criteria were not as restrictive, adjustments are not recommended. Given what is known about the effects of ageing on height (Sorkin *et al.* 1999), the increased risk of inaccuracies in obtaining measurements in older people and the possibility that measurements might not reflect maximal attained height (Milne & Williamson 1983, Cline *et al.* 1989) due to degenerative changes in the vertebrae (i.e. compression of spinal discs), the use of strict criteria is critical. Despite the lower validity figure for this measurement, standing height is a feasible measurement for segments of the adult ID population. However, as people age differently, and have different body compositions, eligibility among ambulatory subjects cannot be determined by age. It needs to be determined on an individual basis. It is therefore recommended that subjects who fulfil the eligibility criteria be offered the opportunity to attempt the standing height measurement under the conditions mentioned above (trained testers, strict criteria, familiarisation steps) to maximise the possibility of securing valid readings. However, if valid readings cannot be secured (in duplicate), testers should use the same surrogate height

measurement offered to subjects who do not meet the eligibility criteria from the outset. Unlike vertebral height (Sorkin *et al.* 1999), long bones, such as the ulna length, are reported to change less with ageing (Mitchell & Lipschitz 1982), which was part of the reasoning behind the selection of this particular surrogate measure for height. Further details on the relationship of ulna length to standing height in this study sample are given in Section 5.7.1. Finally, despite the securement of the valid standing height readings, some routine observations were noted during the measurement process, such as the position of the participant's heels on the stadiometer due to weight distribution and the need to have access to a stool when participants are tall, but none affected the validity of the measurements obtained. However, one practical observation that was not expected and needs to be considered and explored further by future testers relates to the stadiometers selected and used. No evidence was previously found on the experience of using either stadiometers in practice with older adults with ID (see Section 5.12).

5.6.4 Related Measurement Conditions

Although the use of standardised procedures is designed to maximise the validity and reliability of measurements, several related measurement factors need to be recorded, analysed (where relevant) and reported. Such baseline factors include the time of day the measurements were taken (height and weight only); position (standing, sitting or lying) during the measurement (weight, ulna length and MUAC only); position of the participant's arm (ulna length only); the side (left or right) of the body the measurement was taken on (ulna length, MUAC, WC and HC only), and type of floor surface (height and weight only). The importance of capturing and broadly reporting this data has not been reported in the ID literature, and needs to be captured as standard practice, as demonstrated in this study. The data is not only important for comparisons with other studies, but, more critically, for the examination of changes over time within a sample, as in the IDS-TILDA study. Access to this information will enable researchers to determine if differences or changes in the data are associated with different baseline factors (e.g. height taken in the morning at the first time-point and in the evening at the second time-point). In repeated-measure design studies, like IDS-TILDA, it is critical that the same measurement methods (e.g. right arm selected each time) be used in for any one individual, where possible, to monitor changes effectively.

5.6.5 Classification of Precision and Reliability Status

Evidence of observer measurement reliability (tester's precision) being assessed in anthropometry studies in this population was very limited (Stevenson *et al.* 2006, Waninge *et al.* 2009, 2010), even though measurement reliability is a direct indicator of measurement quality

(WHO MGRS 2006). A few studies have reported taking duplicate measurements (or it is implied by virtue of the reference method used) in this population group, but did not report their measurement precision (Stanish & Draheim 2007, Moss 2009, Melville *et al.* 2011) or include future intentions to report (Mitchell *et al.* 2013). Poor measurement precision can have serious consequences for individuals and the population; for example, it can lead to the misrepresentation of BMI estimates, and the underestimation (and overestimation) of correlations to other variables (Rosner & Willett 1988). Similar to validity status, it appears that there is a culture of assuming that measurements are reliable by virtue of the measurement results being reported, yet all 'indirect' anthropometry methods, such as those used in this study (i.e. of mass, lengths and girths), are subject to variability (e.g. diurnal effect on height) and precision error. As the values are not fixed and given the potential influences on measurements (e.g. intrinsic and extrinsic factors, such as biological variation, posture, movement, incorrect use of equipment, tester skill, poor description of standards, unsuitable setting – flooring and/or limited space) and uses of anthropometry data (e.g. to inform national prevalence estimates on obesity), reducing precision errors are vital. Assessing precision is even more vital in studies involving an older population, as in IDS-TILDA, as the ageing process involves physiological and nutritional changes that are manifested by height and weight loss (Dey *et al.* 1999), muscular mass loss, fat increase and the redistribution of adipose tissue, with fat accumulation in the trunk and visceral areas (Steen 1988, Schwartz 1998), which could make measurements more difficult. Gomez-Cabello *et al.* (2012) concurred that an older population may be more susceptible to error than younger populations.

In the ID literature, there was no evidence found to suggest why observer precision is not being investigated or why duplicate measurements are not completed as standard practice. Although evidence does exist on the difficulties and barriers encountered by some people with ID with different anthropometry measurements (e.g. Bell & Bhate 1992, Marshall *et al.* 2003, Wallace & Schluter 2008, Waninge *et al.* 2009, Verstraelen *et al.* 2009), none of the reasons reported was associated with attempts to complete duplicate measurements. Based on the findings from this study, the practice of duplicate measurements is feasible (mean rate was 96%) and acceptable to people with ID; the researcher believes that this was aided by the familiarisation procedures integrated into the design of the study (see Section 5.10). To improve the quality of anthropometry data collected in this population, the precision of the measurements needs to be reported. Measurements need to be repeated in sets to reduce bias (i.e. conduct all measurements in sequence and then repeat the same measurements) and all associated details need to be reported clearly in all related publications. Based on duplicate measurement

readings, studies should report the most commonly used measures of precision in anthropometry research, which are: technical error of measurement (TEM) and coefficient of reliability (R) (Arroyo *et al.* 2010), and intraclass correlation co-efficient (ICC). TEM, also known as absolute TEM, should be converted to a relative TEM (%TEM) to simplify the comparison of TEMs collected on different variables (Ulijaszek & Kerr 1999) and across studies. Use of the same measures in ID research, particularly in the IDS-TILDA study, will allow investigators to verify the degree of accuracy of testers when performing and repeating anthropometric measurements (intra-evaluator) collected, and facilitates the comparison of their measurements with those from other testers (inter-evaluator) at different data-collection time-points. Perini *et al.* (2005) have suggested that periodic evaluation of TEMs controls and minimises intra- and inter-examiner variations among testers. Inclusion of TEM checks during the data-collection process, particularly in a study like IDS-TILDA, or where testers have limited experience, will strengthen its quality control. However, investigators need to first set and report the margin of error accepted for the selected measurements (i.e. mass, lengths, girths, skinfolds and breaths) as part of the methodology, as demonstrated and outlined in this study's methodology (see Section 3.8.6.1).

5.6.6 Precision and Reliability Status of Measurements Achieved

All the results from this study show a high degree of precision and reliability of the measurement methods and operational protocol used with people with ID aged 40 years and over in field research. No significant differences were found between the means of the first and second readings in any of the parameters investigated. The intra-examiner variability of the measurements was within the accepted limits for an ISAK Level 2 anthropometrist. The results indicate that the human error for measurements in this study was small; all were below the acceptable 1% mark set (i.e. technical errors of measurements were minimal). There is no reason why intra- and inter-examiner variability of all testers cannot be determined in anthropometry research with this population group. Determination of the variability within and between testers is vital. Access to data on the precision and reliability of measurements will not only raise standards of anthropometry research in people with ID (and the estimates of body composition), but the data, as mentioned previously, can also be used as a quality-control measure to monitor testers performing the measurements. Unfortunately, the ability to compare the study's findings directly with other research concerning this population group was restricted to two studies (Waninge *et al.* 2009, 2010) and, even within these two, there were comparative restrictions as not all the measurements were the same and the necessary details were not provided. The number of participants and testers and the measurement protocols and

equipment employed also varied from this study. Despite these limitations, the findings do provide some initial comparative insights into the reliability of three anthropometric measurements with other adults with ID. The reliability findings from the Stevenson *et al.* (2006) study in this population were not compared even though TEMs scores were reported, as the age range of participants was not equivalent, as it involved children. Since TEM is age-dependent and related to the anthropometric characteristics of the group or population under investigation (Ulijaszek & Kerr 1999), comparison of the study's findings to the general population was also limited.

Notwithstanding the limitations concerning direct comparisons in ID research, the reliability of the height, weight and waist circumference measurements obtained in this study was comparable to the reliability findings reported on the same measurements in the Waninge *et al.* (2009) study. Similarly, there were no significant differences between the first and second measurements found, and the ICCs of all three parameters were .97 or above. Only one of the %TEM scores, weight, could be compared to this study, as the researchers did not report the TEMs for the other two measurements. Although %TEMs for weight were both well below the limits set (1% TEM) in this study, the Waninge *et al.* %TEM was much smaller (0.04455 vs. 0.0008 respectively). In the second study (Waninge *et al.* 2010), which focused solely on waist circumference (WC) measurements, there was similarly no significant difference between the first and second measurements, and the ICC findings were comparable too. The Waninge *et al.* ICC was .98; in the current study, the ICC was 1.00 over clothing and .999 on bare skin. In both the Waninge *et al.* studies, it is unclear if the WC measurements were taken over clothing or on bare skin. However, this finding is not uncommon in ID or generic research; as noted previously, this measurement factor should be clearly specified in the methodologies reported by researchers, so that an accurate evaluation of the data can be completed.

Broadly, in terms of the general population, the %TEM and *R* of three measurements (height, waist and hip circumference) from a pilot study conducted with an elderly population for a multi-site study in Spain (Gomez-Cabello *et al.* 2012) revealed similar results to this study. In three of the five sites involved, the %TEM for height was greater or equal to (0.10; 0.13; 0.08) that achieved in this study (.08108). The remaining two sites had a lower %TEM than this study (.06; .02). On review of the reliability (*R*) scores for height, all five sites' *R* were ≥.99, which compares well to this study (*R*=.9999). For the waist and hip circumferences measurements, the %TEMs across all five sites were greater than the %TEMs in this study, meaning the level of variability was less than that found in the Gomez-Cabello *et al.* study. However, all but one of

the five sites was still under the 1% TEM threshold limit set for this study. The findings from Gomez-Cabello *et al.* suggested a greater intra-examiner variance for the circumferences measurements compared to standing height, which is not dissimilar to this study's findings, but the variance was closer to the lower end of 1% (e.g. between .081088 and .143234), whereas the height and circumferences in Gomez-Cabello *et al.* were more at the opposing ends of 1% (e.g. between .02 and .88, excluding the one site that exceeded 1% on the WC measurement; %TEM 1.05). Similar to height, the reliability of the *R* scores for waist and hip circumferences across all five sites (R=≥.98) compared well (current study: WC over clothing *R*=1.000 and on bare skin *R*=.9999, and hip circumference *R*=.9999). Separately, in the MUST nutritional screening report (Elia 2003), the intra-observer %TEM results from a small study were given on four measures (height, weight, ulna length and MUAC), and all compared favourably to the results of this study. The %TEM results of height (Elia=0.07; current study CS=0.08), weight (Elia=0.22; CS=0.04), ulna length (Elia=0.39; CS=0.30) and MUAC (Elia=0.35; CS=0.31) mostly fell slightly below those reported by Elia (2003, p. 79).

Compared to other studies involving adults in the general population, a similarly high degree of intra-examiner reliability ($R \geq .96$) was found for waist and hip circumference measurements (Ferrario *et al.* 1995, Nordhamn *et al.* 2000, Geeta *et al.* 2009 [waist only]), mid-upper arm circumference ($R \geq .98$) (Wijnhoven *et al.* 2013), and height and weight measurements ($R \geq .98$) (Marks *et al.* 1989, Sonnenschein *et al.* 1993 [height only], Nordhamn *et al.* 2000, Geeta *et al.* 2009). It has been suggested that weight and height are less vulnerable to imprecision (Klipstein-Grobusch *et al.* 1997, Sicotte *et al.* 2010) compared to that of circumferences and skinfolds (Ulijaszek & Kerr 1999). Review of the findings in the current study indicates that the pattern of variance was similar to the general population. However, given the physiological changes associated with ageing, it is unknown if this pattern will be replicated in a larger sample of people with ID. Future studies in this field will offer further insight into the patterns of variance within and between the populations.

Importantly, the high degree of precision and reliability achieved across all the measurements tested is attributed to several factors, in particular, the accredited training completed, the use of standardised procedures, the selection of appropriate and calibrated equipment, the securement of optimal performance measurement circumstances (see Section 5.11) where possible, and the integration and use of the familiarisation steps in the measurement process (see Section 5.10).

5.7 Surrogate Measurements

Based on matched valid and reliable measurements secured (the same applies to Sections 5.8 & 5.9), two key areas were examined further: ulna length and mid-upper arm circumference, to expand on the findings already presented and to form recommendations for future research practice.

5.7.1 Ulna Length: Surrogate for Standing Height

On the examination of the statistical relationship of ulna length to standing height measurements, the findings further confirm its suitability as a surrogate measure in this population when standing height cannot be measured or valid readings (in duplicate) cannot be secured. A statistically significant positive relationship was found between measured height and left ulna length MUST values, which confirms that ulna length can be used to estimate height in this population group. Comparatively, ulna length has also been shown to be an accurate and reliable means of estimating the height of an individual in the general population (Badkur & Nath 1990, Mall *et al.* 2001, Elia 2003, Auyeung *et al.* 2009, Ilayperuma *et al.* 2010, Barbosa *et al.* 2012, Prasad *et al.* 2012, Mondal *et al.* 2012). Unfortunately, no direct comparisons can be made to adults with ID, as no research studies were found examining this surrogate measure. The use of surrogate height measurements in adults with ID is minimal, and is limited to tibia length (Waninge *et al.* 2009) and knee height (de Winter *et al.* 2012). Not surprisingly, Rimmer *et al.* (2010, p. 11) asserted that "the use of segmental measures needs to be better understood to establish a more accurate estimation of height in individuals who cannot maintain an erect posture". However, similarly to the general population, ulna length was found to be easy to use (see Section 5.12 on observations noted relating to the equipment piece), and the surface landmarks were easily identifiable (Barbosa *et al.* 2012, Prasad *et al.* 2012) In the current study, the styloid process (one of the landmarks) was not found immediately in some subjects who were overweight or obese (i.e. due to thickness of the soft tissue overlying and around the bony landmark). However, with a little more time, the landmark was located as required.

The positively correlated relationship found between measured height and the Malnutrition Universal Screening Tool (MUST) estimated height (calculated with the MUST based on left ulna length scores) confirms that MUST equations by gender and age can be used to estimate height in adults with ID similar to the general population (Elia 2003, Madden *et al.* 2012). MUST recommends, the use of left ulna length, if possible, which proved feasible in all but one case where the person did not wish to undertake the measurement on that side. However, both the left and right ulna lengths were measured in this study to examine whether a significant

difference exists, so as to offer guidance on whether the right ulna length is a suitable alternative for future use, if the left is not possible. Although the results found a significant difference between the left and right ulna length MUST values, it was small and is not practically significant (this small difference may also have occurred because of rounding).

In terms gender, the results found no significant difference between the left and right ulna length MUST values in males; although a significant difference was found in females, the difference between the sides was small. For those aged 40-59 years, no significant difference was found between the sides, but a significant difference, although small, was found in those aged 60 years and over. Based on all of the findings, it is recommended that ulna length should be measured on the left side for the use of MUST, similar to the general population, and if it is not possible, the measurement can be taken on the right side. The small differences noted between the left and right ulna length MUST values in both genders combined, in females, and among those aged 60 years and over are not seen to be practically significant, particularly as the proportional use of the right side will likely be very small. However, it is important that the side measured (left or right) is be recorded by testers, as well as the position of the participant for the measurement and the position of their arm, as previously noted (see Section 5.6.4).

Uniquely, this study measured ulna length using a segmometer, which in principle is similar to a bone caliper that has been used and reported by some in the generic literature (Hogan 1999, Hickson & Frost 2003, Shahar & Pooy 2003, Marais *et al.* 2007, Cereda *et al.* 2010, Ilayperuma *et al.* 2010, Prasad *et al.* 2012). However, traditionally and up to the present day, many surrogate height measurements based on segmental bone lengths (e.g. tibia, fibula, ulna) are measured using a measuring tape in both the general population (Bannerman *et al.* 1997, Auyeung *et al.* 2009, Barbosa *et al.* 2012, Madden *et al.* 2012, Mondal *et al.* 2012) and among adult people with ID (Waninge *et al.* 2009, de Winter *et al.* 2012). However, advances in anthropometry equipment, gained through the accredited training completed, led the researcher to select the segmometer. The segmometer "measures the point-to-point distance over a curved surface, which avoids the error introduced by measuring at the skin surface" (Mulholland & Rolland 2012, p. 43), and curvature if a tape is used (Winter *et al.* 2006), and supports the attainment of the most accurate measure, setting a new standard of precision (Rosscraft 2013). The segmometer is commonly used in the research field of sports science (Slater *et al.* 2005, Winter *et al.* 2006, Weidauer *et al.* 2012) but it also used in other areas of research, such as measuring surface lengths for cardiovascular research (Sugawara *et al.* 2010). All future studies, including IDS-TILDA, should use a segmometer to measure the long axis of the ulna bone and any other

limb lengths, where possible. Some observations were noted in its use when participants were seated; see Section 5.12 for details. None of the issues observed prevented any measurement, but more time was required to make the adjustments needed. The use of the segmometer was received positively by participants.

5.7.1.1 Suitability of Standing Height in Middle-Aged to the Oldest Old

Height is one of the two components used to calculate body mass index (BMI), an indicator of weight classification, nutritional status and health risk (Chapman *et al.* 1996, Payette *et al.* 1999, Flegal *et al.* 2007). However, it is reported that inaccurate standing height determination and/or the effects of ageing on height (e.g. some degree of shrinkage or vertebral collapse) may lead to BMI misclassification (Sorkin *et al.* 1999), with BMI tending to be artificially inflated through, for example, underestimating the prevalence of underweight and overestimating the prevalence of overweight and obesity (Miller *et al.* 2002, Vasconcelos *et al.* 2010). It is estimated that loss of height begins at around 30 years of age, leading to a loss of approximately 1cm per decade until the age of 70, with a loss of .5cm per year thereafter (Zamboni *et al.* 2005). This raises the question: should a validated surrogate for standing height be used to calculate BMI? – particularly if we consider that the BMI equation was developed and based on maximal attained height. Interestingly, the mean height in the current study was greatest using the surrogate, ulna length, compared to measured and self-reported height.

Although various surrogate methods (e.g. ulna length, knee height, tibia length) have been developed and are used to estimate height in the general population, and to a much lesser extent with people with ID, when standing height is not possible, there has been no universal shift towards replacing standing height with a surrogate method for older adults and/or the elderly in research studies. Standing height continues to be the most widely collected and quoted statistic for BMI in older adults and elderly populations, where feasible (Sette *et al.* 1991, WHO 1995, Rea *et al.* 1997, Finch *et al.* 1998, Dey *et al.* 1999, Chiu *et al.* 2000, Haftenberger *et al.* 2002, Miller *et al.* 2002, Barreto *et al.* 2003, Keller & Ostbye 2005, Martins dos Santos & Sichieri 2005, Jones *et al.* 2011, Kvamme *et al.* 2012, Drumond Andrade *et al.* 2013). Future research in this field may provide the direction needed on whether surrogates should only be used in the absence of being able to attain accurate height measurements or as a measure of choice in research involving older adults (middle-aged to the oldest old). However, until such time, it is advised that the former recommendations made on the application of strict criteria for standing height and the use of a surrogate height measurement, ulna length, should be applied in research studies. However, due to limitations of the self-report data in this study,

which will be discussed later in this chapter (Section 5.9), the measurement of both standing height and ulna length among all eligible subjects is being recommended for the IDS-TILDA study, so that the determination of the relationship between both variables to self-report height can be evaluated in a large representative sample of people with ID.

5.7.2 Mid-Upper Arm Circumference: Surrogate for Body Mass Index

In field research, circumstances may arise where weight and/or height (or surrogate height measure) measurements cannot be obtained or valid readings secured to calculate measured body mass index (BMI), so access to a surrogate measurement is required to provide an estimate of BMI. The results of this study confirm that BMI scores closely correlate to mid-upper arm circumference (MUAC) scores, and show that, for field research purposes, BMI can be approximated from MUAC where required. This is particularly valuable when self-report height and weight values are not available. The close relationship found between the two parameters concurs with the findings with older adults (mainly middle-aged and elderly) in the general population (James *et al.* 1994, Finch *et al.* 1998, Powell-Tuck & Hennessy 2003, Elia 2003, Jayne *et al.* 2011, Lithander *et al.* 2011, Ngoh *et al.* 2011, Blankson & Hall 2012). Unfortunately, no comparative studies were found testing the surrogate validity of these parameters with adults with ID. Although the fact that BMI and MUAC were highly correlated with each other is significant, the findings did show that 19% of the variation was unexplained. On review of the accuracy of the Malnutrition Universal Screening Tool (MUST) to estimate BMI ranges based on the MUAC scores, the majority (88%) of MUAC scores in this sample population were estimated in the correct ranges and those misclassified were not far off the correct BMI estimations. Collectively, the findings support the use of MUAC as a surrogate for measured BMI, where required, and the use of MUST to provide an estimate of BMI. However, some caution needs to be applied, as MUAC was not sensitive enough to correlate perfectly to measured BMI; nor was MUST sensitive enough to classify all the cases correctly according to the measured BMI.

Many anthropometry-related studies specifically with or involving older adults in the general population have included MUAC as a separate indicator of nutritional health along with the use of BMI (Bannerman *et al.* 1997, Finch *et al.* 1998, Rahman *et al.* 1998, Corish & Kennedy 2003, Hughes *et al.* 2004, Faruque *et al.* 2006, Sanchez-Garcia *et al.* 2007, Harris *et al.* 2008, Wijnhoven *et al.* 2010). Significantly fewer studies have included MUAC with adults with ID (e.g. Soler Martin & Xandri Graupera 2011, Tsai *et al.* 2011). Ageing is associated with changes in body composition, with a substantial reduction in fat-free mass and muscle mass and an increase in visceral fat (Baumgartner *et al.* 1995, Gallagher *et al.* 2000, Harris 2002), but body

weight can remain unchanged. The redistribution of mass can occur even when there are no significant changes in BMI (Ding *et al.* 2007), which highlights the importance of using other indicators to complement BMI. Similarly, no change in BMI could be masking a loss in weight if height has fallen, which would mean we are likely overestimating obesity and underestimating under-nutrition in the elderly (Han *et al.* 2011) and in all older adults (40+ years).

It is proposed that MUAC may be a more sensitive indicator for loss of muscle mass and be a better indicator of peripheral muscle and subcutaneous tissue wasting than BMI (James *et al.* 1994). However, both indicators (BMI and MUAC) are recommended as part of anthropometry assessment criteria on older adults (WHO 1995). It is reported that MUAC is useful for both screening acute adult under-nutrition and for estimating prevalence of under-nutrition at a population level (Collins *et al.* 2000), and in younger populations, it has been used along with BMI to assess obesity risk (Mazicioglu *et al.* 2010). The composite use of waist circumference and MUAC has thus been recommended in clinical practice to assess mortality risk among the elderly, as advanced age has been associated with significantly increased mortality risk (Wannamethee *et al.* 2007). In an older population, it is reported that under-nutrition rather than over-nutrition is the main cause for concern, since its relation to morbidity and mortality is stronger than that of obesity (Elia 2003). Several studies have shown that elderly people who are underweight are at higher risk of acute illness and death (Kushner 1993, Seidell *et al.* 1996, Beck *et al.* 1999). For people with ID, this elevated risk may occur at even an earlier age according to the findings of a recent investigation examining the unexpected deaths of people with a learning disability in the UK (Heslop *et al.* 2013). The confidential inquiry found that those who were underweight had a lower median age at death (57.5 years) than those who were of optimal weight (69.5 years), overweight (65 years) and obese (62 years) (Heslop *et al.* 2013). MUAC is reported to be a helpful indicator of malnutrition in those who are ill and has been shown to be an independent predictor of mortality in elders living in long-term care institutions (Allard *et al.* 2004). Conversely, there is also evidence to suggest that both underweight and obesity generally imply greater increase of relative risks for all causes of mortality (Ringback Weitoft *et al.* 2008). Malnutrition, at either end of the weight spectrum (i.e. underweight or obesity), is one of the greatest threats to the health, well-being and autonomy of older adults (Sahyoun *et al.* 2004). People with ID are reported to be at increased risk of both under- and over-nutrition (Tsai *et al.* 2011).

Similarly to the general adult and elderly population (Jenkins 2004, Kennedy *et al.* 2004, Villareal *et al.* 2005, Popkin 2006, Andreyeva *et al.* 2007, Jenkins *et al.* 2007), the prevalence of obesity

among adults with ID is continuing to grow (Rimmer & Yamaki 2006). Recent self-report BMI figures of people aged 40 years and over with ID in Ireland revealed that 61% fell into the overweight (30%) or obese (31%) category (McCarron *et al.* 2011). These figures are not starkly different from those for the general population, with 78% of older Irish adults overweight (44%) or obese (34%) (Cronin *et al.* 2011). However, the latter figures are based on objective measurements. If similar measurements are completed in the next wave of IDS-TILDA, the prevalence figures for overweight and obesity may be found to be higher in older Irish adults with ID. A recent study examining obesity reported that adults with ID, in general, have a higher risk of developing obesity, and women have a high risk of developing morbid obesity (Hsieh *et al.* 2013). Although proportionally less than the rate of obesity, Gates and Barr (2009, p. 164) have reported that "the prevalence of being underweight increases with the severity of the ID". According to Bhaumik *et al.* (2008, p. 288), a wide range of estimates has been reported for nutritional status in the whole ID population, "from 2% to 35% for obesity and 5% to 43% for significant underweight (Gravestock 2000, Emerson 2005, Yamaki 2005)". In the Bhaumik *et al.* (2008) population-based prevalence study, 18.6% of the study population were reported to be underweight and 48.7% to be overweight (28%) or obese (20.7%). As life expectancy continues to increase, so too does the risk of malnutrition. The universal inclusion of MUAC as part of the anthropometric indicators examined in the IDS-TILDA and other studies (and not just as a surrogate measure for BMI), will allow the validity and usefulness of the MUAC measurement to the assessment of nutritional status at a population-based level to be determined. It will also facilitate the examination of the associations between MUAC, BMI and health status. However, to reduce the risk of compromising the securement of any other measurements among those people who do not require MUAC as a surrogate for BMI, it is advised that MUAC be placed at the end of the measurement cycle (see Figure 5.1).

5.8 Waist Circumference Measurement over Clothing

Across the literature, there is a lack of research on the effect of clothing on the waist circumference (WC) measurement results. Taking WC over clothing, even a single layer, greatly increases the risk of inaccurate measurements, as the measuring site is not visible, nor can it be landmarked. Several factors can contribute to error in girth measurements, but one of the most significant is error in locating the correct measurement site (Daniell *et al.* 2010). At the outset of this study, there was no evidence found examining the 'clothing effect' on adults with or without ID, which was surprising – particularly so as several of the 'ageing' studies, such as TILDA, ELSA and HRS, and other, 'non-ageing' studies in both the ID and generic literature (Taylor *et al.* 1998, Cotugna & Vickery 2003), take this measurement over clothing but do not

address the effect of clothing on the results or universally define the clothing requirements for this measurement (e.g. single layer of light clothing – HRS only). The same applied across many of the studies in the ID and generic literature noted earlier, which failed to specify whether the measurements were taken over clothing and/or on bare skin. Even though one study (Haftenberger *et al.* 2002) involving adults in the general population reported the use of the correction factor of -2.0cm for WC taken at the natural waist or the midpoint site, based on an earlier multi-centre study, no further related details were found on how this figure was determined. However, the commonly quoted study by McCarthy *et al.* (2003), which involved young people, reported the 'clothing effect' to be .5cm measured at the midpoint site. On the basis that WC may be taken over a single layer of light clothing (as defined in the methodology chapter), if the eligibility criteria for the measurement on bare skin are not fulfilled by participants in the IDS-TILDA study, it was critically important that the effect of clothing be examined. The findings to emerge have applicability beyond IDS-TILDA.

Not surprisingly, WC over clothing (single layer of light clothing) was significantly larger than WC on bare skin, with a mean difference of .96cm at the iliac crest site. Compared to McCarthy *et al.* (2003), the mean difference was greater, but less than Haftenberger *et al.* (2002). More recently, Wills and Bhopal (2010) examined the clothing effect in adults and found a mean difference of .5cm, similar to McCarthy *et al.* but 44% of their measurements increased by ≥ .5cm. The difference between the studies may be linked to the different landmark sites used (only the current study used a fixed skeletal site), the age of the population in the McCarthy *et al.* study, and the diverse thickness of the clothing, which was not measured in any of the studies except for the current study. On applying the reported clothing effect of .5cm (McCarthy *et al.* 2003) to this study, the difference between WC over clothing and on bare skin was no longer statistically significant. However, a difference of .46cm, rounded to .5cm, remained, which suggests that the clothing effect is only one of two considerations affecting the measurement result. While .5cm accounts for the clothing effect, the outstanding difference of .5cm is believed to be associated with 'landmarking error'. Although the other studies have not named or examined the potential influence of landmarking error on the measurement results as part of the examination on clothing effect, there is little doubt that it plays a role in the results reported. Unlike the WC on bare skin where the measurement site is marked to ensure proper landmarking, over clothing (even a single layer), it is not possible to absolutely verify that the tape is positioned on the exact site required. The use of a fixed skeletal site (bony landmark), such as the iliac crest, which was successfully used in this study, will assist in reducing (but will not eliminate) the level of landmarking error when taken over clothing compared to non-

skeletal sites. The larger correction figure reported by Haftenberger *et al.* (2002) may be related to the non-skeletal sites (e.g. narrowest waist and midpoint) used to measure WC in the large general adult population studied (aged 50 to 64 years).

As reported in the literature review chapter, there is currently no universally accepted protocol on the site used for WC measurements, and Ross *et al.* (2008) have reported that there is no scientific rationale provided for any of the protocols recommended by leading health authorities (WHO 1995, NIH 2000). Based on the key learning from the current study, the use of a fixed skeletal site is advised in studies, providing the option of taking the measurement over a single layer of light clothing, if required. Ross *et al.* (2008) also reported that the use of bony landmarks will help to ensure reliable and, more importantly, valid measures, while ease of measurement, as confirmed in the current study, would promote adoption by clinicians, researchers and people with ID (i.e. self-measurement) in the future. While Marfell-Jones *et al.* (2006) recommend that the measurement site be the narrowest point of the waist between the lower costal border and the iliac crest, and the World Health Organization (1995) recommends the midpoint, and both on bare skin, neither deals with the influence of clothing on the site, if the measurement is taken over clothing. The selected site, the iliac crest, is recommended by several leading organisations, such as the National Institutes of Health (2000) and the International Chair on Cardiometabolic Risk (2007), and is used in many research studies, such as the NHANES survey (Westat Inc. 1988), which is designed to assess the health and nutritional status of adults and children in the United States. A recent study by Guerra *et al.* (2012) examined 10 WC sites that associated best with abdominal fat mass measured by DEXA (dual-energy X-ray absorptiometry) in older adults and found that WC 2.5cm above the umbilicus was the best site, but that the measurement at the level of the iliac crest gave very close results to this site, and is therefore one of the sites that could be used to measure WC.

To further explore the influence of clothing and whether its thickness can predict the difference between the WC measurement over clothing and on bare skin, the thickness of the single layer of clothing was measured (with no difficulties) in millimetres, using a Holtain Skinfold Caliper. The results show that clothing thickness (single layer) is not an accurate predictor of the difference between WC over clothing and on bare skin. This finding further supports the view that clothing is only one of the contributing factors to the difference in results (over clothing and bare skin) and that landmarking error also needs to be considered. No direct comparisons on clothing thickness can be made, as this variable has not been measured in other WC studies examining the clothing effect. However, several studies examining the clothing effect on blood-

pressure measurements similarly measured the thickness of clothing (sleeved arm) as part of their enquiry (Holleman *et al.* 1993, Kahan *et al.* 2003, Liebl *et al.* 2004, Ma *et al.* 2008). Importantly, the range of clothing thickness among those with valid reading in this study was from .2mm to 1.0mm, with the mean thickness of .4mm, which suggests that eligible participants adhered to the instruction of wearing a light garment. On review of the clothing thickness of those with invalid measurements, the mean was slightly higher at .7mm, with a range from .4mm to 1.4mm. It is recommended that thickness of the single layer of clothing for WC measurements be no greater than 1.0mm, to lessen the risk of contributing to or causing invalid WC measurements. A similar criterion, although for blood pressure, was used in the Liebl *et al.* (2004) study, which excluded subjects with sleeves thicker than 2.0mm. As a result of measuring the thickness of participants' clothing (upper garment) for this measurement in the current study, the researcher was able to verify that the measurement was being taken over a single layer of light clothing (quality check). This requirement proved to be important, as a few wore more than one layer of clothing and, where possible, the relevant adjustments were made. Access to data on clothing thickness when measurements are taken over clothing will be particularly useful in longitudinal research studies, such as IDS-TILDA, as the potential variation and/or influence of clothing thickness on the measurement results can be examined over time.

In research, the WC figures are often categorised against cut-off points, such as those of the National Institutes of Health (NIH 2000), to define the associated disease risk for the population and among specific groups, but the difference of just 1cm has the potential to adjust individuals and populations above or below the thresholds, similar to risks associated with the BMI if measurement errors are made, as discussed earlier. WC figures may also be used to examine associations with cardiometabolic risk factors, to monitor trends, and to evaluate changes over time. However, irrespective of how WC figures are used, it is critically important that the potential for measurement error be reduced. Even though the use of the iliac crest site (i.e. fixed skeletal site), use of a standardised protocol inclusive of the familiarisation steps, the completion of training, and the selection of an appropriate and calibrated tape were all important factors in producing the most accurate results in this study, the risk of measurement error is further increased when measurements are taken over clothing as opposed to bare skin. Based on all the evidence presented, it is recommended that a correction factor of -1.0cm be applied to the iliac crest site in future, to account for the combined result of the clothing effect and the landmarking error in adults that have the WC measurement taken over a single layer of light clothing (≤ 1mm thickness recommended). Although the preferred method for WC is on bare skin, it is recognised that it may be necessary to take the measurement over clothing.

Lastly, the iliac crest site for WC was acceptable to adults with ID both on bare skin and over clothing, as was the measuring of clothing thickness (upper garment only). The researcher believes that this was greatly aided by the familiarisation steps taken and the sequence of measurements followed.

5.9 Self-Reported versus Measured Height and Weight

For practical and fiscal reasons, and similarly to work with the general population, many studies in the ID field use self-reported height and weight values (Fujiura *et al.* 1997, Emerson 2005, Yamaki 2005, McGuire *et al.* 2007) rather than direct measurements to calculate BMI, but the validity of self-report data, particularly in later life, has yet to be established. Similarly to other national ageing studies (e.g. TILDA, ELSA), the IDS-TILDA health assessment module may not be included in each wave of data collection, so an understanding of the accuracy of self-reported height and weight compared to measured values in adults with ID is critical; inaccurate estimates will potentially influence significantly, particularly at national or regional level, the prevalence of BMI classifications, the determination of associations between weight status and morbidity, and the allocation of resources for related health/nutritional planning and targeted interventions (and evaluations). It is important that the level of bias, if any, in this population group and its significance at population-based level be established and reported.

In the general population, the accuracy of BMI derived from self-reported height and weight has been questioned (Flood *et al.* 2000, Gunnell *et al.* 2000, Kuczmarski *et al.* 2001, MacLellan *et al.* 2004, John *et al.* 2006, Basterra-Gortari *et al.* 2007) on the basis that individuals tend to overestimate their height and underestimate their weight (Kuskowska-Wolk *et al.* 1989, Nieto-Garcia *et al.* 1990, Alvarez-Torices 1993, Ziebland *et al.* 1996, Bostrom & Diferichessen 1997, Hill & Roberts 1998, John *et al.* 2006, Faeh *et al.* 2008, Oliveira *et al.* 2009). A large systematic review of the literature by Gorber *et al.* (2007) substantiated the existence of this bias associated with self-reported height and weight data, although the degree of trend varies by gender and the characteristics of the population. Some studies have found that, with the increasing of age, self-report error increases for height (Rowland 1990, Roberts 1995, Bolton-Smith *et al.* 2000, Kuczmarski *et al.* 2001, Sahyoun *et al.* 2008) and/or weight (Rowland 1990, Niedhammer *et al.* 2000, Kuczmarski *et al.* 2001, Lawlor *et al.* 2002) but findings are inconsistent. For example, one longitudinal study reported that only small changes in self-reported height and weight occurred with increasing age (Dahl *et al.* 2010). However, since height declines with age in later life (Giles & Hutchinson 1991), the risk of error increasing is not surprising as people may be unaware of physiological changes in their height and not being

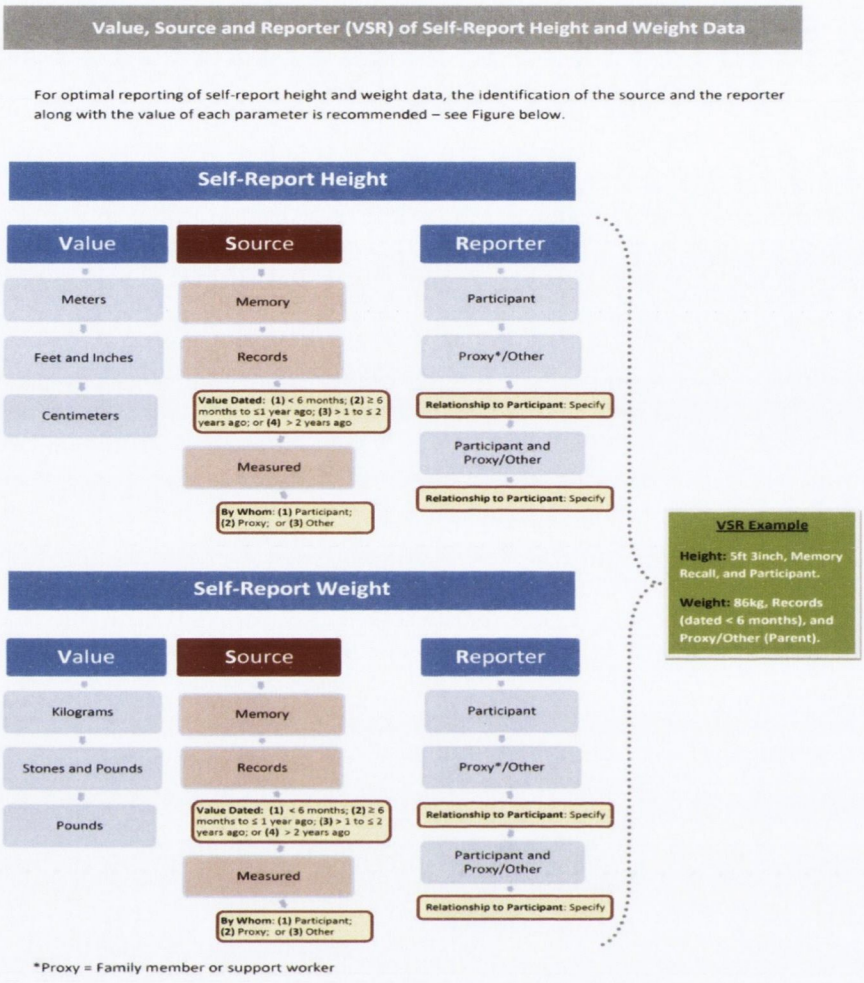
measured on a frequent basis (Ziebland *et al.* 1996) are likely to report their last recalled height. Memory may also influence estimates given, while social desirability may influence the weight provided (Singleton *et al.* 1993, Larson 2000). Despite these findings, several studies have suggested that self-reported values can be used in certain populations (Nieto-Garcia *et al.* 1990, Himes & Story 1992, Zhang *et al.* 1993, Roberts 1995, Hill & Roberts 1998, Nakamura *et al.* 1999, Goodman *et al.* 2000, Spencer *et al.* 2002, Hojgaard *et al.* 2008, Yoong *et al.* 2013) and are often heavily relied upon in population-based surveys.

Overall, the results vary depending on the characteristics of the population (e.g. age, gender), which further highlights the need to determine the status among adults with ID across all age groups and to track any age-related changes in these parameters over time. Similarly to studies in the general population (Jalkanen *et al.* 1987, Rowland 1990, Bostrom & Diderichsen 1997, Hill & Roberts 1998, Vailas & Nitzke 1998, Booth *et al.* 2000, Kuczmarski *et al.* 2001, Avila-Funes *et al.* 2004), the self-report height and weight data was collected and secured prior to its direct measurement, which eliminated the risk of bias. On examination of the data, it proved restrictive (i.e. the depth of analysis that could be completed), but some important design insights were gained for the IDS-TILDA study and others seeking to collect this type of data for research purposes in this population. From the Pre-Interview Questionnaire dataset, it was not possible to establish who had reported the height and weight values (i.e. the participant, proxy/other, or both parties). This is not unique (Aldridge *et al.* 2000, Yamaki 2005), but it does need to be addressed in future studies when more than one reporter is involved in the process (e.g. participant and proxy). In such cases, working from the assumption that the data has been reported by the subject targeted is not sufficient. If proxies report the height and weight data, it should be captured as proxy-report data. However, if both parties are involved in reporting this data, this should be captured and weighted accordingly (and reported). The accuracy of proxy-report data on both variables can also be assessed, which is absent in the ID literature. In the generic literature, the accuracy of proxy-report data on height and weight data is mixed. For example, Reed and Price (1998) have reported similar patterns of bias (as discussed earlier) among individuals in the general population (height overvalued and weight underestimated), while others, such as Paradis *et al.* (2008), found reported values to be highly predictive of measured values.

Aligned with the need to identify the reporter (and for the same reasons), there is a need to establish the source (i.e. memory, records, or measured) of height and weight data reported (see Figure 5.3). Again, this finding is not unique; other studies do not clearly specify this

information (Robertson *et al.* 2000, Emerson 2005, Yen *et al.* 2005, Yamaki 2005, Lennox *et al.* 2006, McGuire *et al.* 2007, Rimmer *et al.* 2010, George *et al.* 2011) or the weighting of each source used is not specified when a mix of sources are reported (Hove 2004, Stancliffe *et al.* 2011). For data accessed from records, several reports do not identify how old the records referenced are (Fujiura *et al.* 1997, Aldridge *et al.* 2000) or provide more specific timeframes on the data (Emerson 2005, Wallace & Schluter 2008, Gale *et al.* 2009). For example, Wallace and Schulter (2008) specified that medical charts were audited from 2002 to 2005 but what year most of the data related to is unknown. To improve on the quality of self-report data gathered and subsequent cross-sectional and longitudinal comparisons, key factors were identified and incorporated into a reference figure developed (see Figure 5.3). Using the reference figure, it is recommended that the IDS-TILDA study incorporate the 'source' and 'reporter' checks beside the questions on participant's height and weight in the questionnaire issued, possibly as 'office use only' items, and that these items be completed with all the other checks undertaken by interviewers before the face-to-face interview begins. In addition, the importance of obtaining height and weight data needs to be emphasised further with interviewers, as the level of missing data also restricted the analysis in this study (i.e. exclusion of those aged 60 years and over due to under-representation). Missing height and weight data is also a common finding in other survey design studies (Emerson 2005, Yen *et al.* 2005, McGuire *et al.* 2007, Wallace & Schluter 2008, Gale *et al.* 2009), but it should be kept to a minimum. Access to the contextual information on the source and the reporter will not only strengthen methodologies in this research field, but also provide a more comprehensive picture of the data, its accuracy and the influence of changes on the data over time.

Figure 5.3: Self-Report Collection Guide for Height and Weight Data



Despite the limitations, the broad analysis of the data in this study initially suggests that there is no difference between measured and self-report height or weight values, and that neither was influenced by gender or age (except that, for height, the influence of those aged 60 years and over was not tested due to missing data). Strong positive correlations were found between the measured and self-report values. If the same findings are found in the representative sample of IDS-TILDA, self-reported height and weight values could be used, with caution, as indicators of weight status when measured data is not collected. However, the accuracy and utility of these self-report values in this population needs to be assessed by the covariates of age, gender, level of ID, the source and the reporter of the data, and the elapsed time. If significant differences emerge, a correction formula to correct the difference between self-report and measured data could be developed. Monitoring the changes and the influence of covariates over time will be critical, particularly as the population ages. It is recommended that measured height and weight values, and self-report values in the absence of measured data, should also be reported as continuous variables in research (not restricted to BMI usage) to increase comparability of

results and our understanding of the relationships of each value to morbidity, and to assess the rate of height loss in persons with ID as they age.

5.9.1 Self-Reported and Measured Body Mass Index

Body mass index (BMI) is based on both height and weight values. Inaccurate values of height and weight either self-reported or measured will lead to biased calculations of BMI, and consequently inaccurate assessment of weight status and the disease and morality risk of a population (Dekkers *et al.* 2008). Given their significance in population studies, biases and errors need to be avoided or, at the very least minimised; if any exist, they should be transparently reported. Similar to the research status reported on the values, height and weight, no evidence was found on the validity of self-reported BMI compared to measured BMI scores in the ID population. However, in the general population, even though the position depends on the characteristics of the population studied, self-reported BMI tended to be underestimated when compared to measured BMI (Kuskowska-Wolk *et al.* 1989, Nieto-Garcia *et al.* 1990, Ziebland *et al.* 1996, Bostrom & Diferichesen 1997, Hill & Roberts 1998, Flood *et al.* 2000, Gunnell *et al.* 2000, Gorber *et al.* 2007, McAdams *et al.* 2007, Elgar & Stewart 2008, Shields *et al.* 2008a, 2008b). Despite the methodological limitations of this study (i.e. unknown reporter of self-report data) and its small sample size, which was compounded by the level of self-report data missing, the same BMI trend was found, even though no significant differences were found between self-reported and measured height and weight values, unlike in most studies of the general population.

Despite the strong positive correlations found between the BMI scores self-reported and measured in this sample population, the implications of the mean difference, although small, between the scores (self-reported and measured) deserve consideration. The mean self-reported BMI score ($\bar{x}$ = 29.11, *SD* = 6.65) fell into the overweight category while the mean measured BMI score ($\bar{x}$ = 30.08, *SD* = 6.06) fell into the obese category (case-matched variables). The standard deviation of both variables was similarly high, which may be in part reflective of the small sample size. The level of variation was slightly less in the measured BMI scores. Overall, self-reported values underestimated the rates of overweight and obesity compared to the measured values (70% [*n*=16] vs. 87% [*n*=20]). Despite the findings in this study not being representative, the data does highlight the very significant impact that small differences between self-report and measured BMI, irrespective of high correlations, can have, when BMI is used as a dichotomised variable. Such differences and the related impact are reported in generic research, where the prevalence of overweight and obesity was underestimated using

self-reported values (Kuczmarksi *et al.* 2001, Faeh *et al.* 2008, Sahyoun *et al.* 2008). For example, misclassification to a lower BMI category has significant potential to inflate the estimates of risk associated with overweight (Shiely *et al.* 2010). It has also been suggested that the use of self-reported data may bias the association of BMI with mortality (Keith *et al.* 2011). It is critical that the IDS-TILDA study determine the morbidity implications of misclassification bias for self-reported BMI data in this population group (with the necessary consideration given to the reporter and source of the related information, as discussed above), and to what extent BMI calculated from self-reported height and weight affects estimates of body-weight status, and also evaluate if the bias is small enough to facilitate its use to monitor trends (i.e. correctly detect changes) in the off-years when direct health assessments are not included in the IDS-TILDA study. It is essential that BMI, an important indicator of population health worldwide (irrespective of its limitations), be based on the most accurate data.

5.9.1.1 Significance of Age and Body Mass Index

Age is an important factor in the use and interpretation of BMI irrespective of whether the data is self-reported or measured, particularly in an older population. In the general population, it has been proposed that self-reported BMI is less reliable in old age (mean error notably larger) than in younger ages due to a lack of awareness of body composition changes such as stature (Rowland 1990, Kuczmarski *et al.* 2001), resulting in underestimated BMI in older populations (Bostrom & Diderichsen 1997, Kuczmarski *et al.* 2001, Faeh *et al.* 2008). Unfortunately, the related status among people with ID is unknown. This needs to be addressed as part of the IDS-TILDA study into the validity of self-reported BMI data compared to measured values. As older people are a very heterogeneous group, the BMI of a 65-year-old cannot be compared to the BMI of an 80-year-old (de Onis & Habicht 1996) or a 40-year-old. It is therefore critical that IDS-TILDA and others stratify BMI categories by age groups (as defined by the WHO Global Database for BMI) and investigate morbidity and mortality risk associated with BMI by age (and gender). By doing so, the IDS-TILDA study will be able to determine if the relationship between BMI and morbidity and mortality risk is the same across all age groups, and potentially identify any adverse functional and/or beneficial effects of overweight and obesity in older adults.

The use and translation of BMI findings into practice by age groups (and gender, level of ID, residential circumstance and rural/urban strata) will potentially help to raise the awareness and knowledge of individuals (or support staff or families) of the associated health risks, which would motivate them to take action, if needed, as the message will be more relatable compared to the translation of broad statistical figures, for example on overweight and obesity, covering

the whole adult population with ID. Although the BMI thresholds defined by WHO (2000) are the most widely used, there is increasing examination and questioning, as part of research enquiries, as to whether the same thresholds apply with the same significance in older adults and the elderly as in a younger population (Campbell *et al.* 1990, WHO 1995, Stevens *et al.* 1998, Seidell & Visscher 2000, Stevens 2000, Elia 2001, Heiat *et al.* 2001, Flegal *et al.* 2005, Janssen & Mark 2007, Hirani & Mindell 2008, Tamakoshi *et al.* 2010). Since BMI is based on maximal attained height, the use of the actual height in older adults or the elderly may lead to BMIs being misclassified. At present, none of the leading international organisations, such as the World Health Organization, have proposed revised thresholds for older adults (60+ years). It remains to be established whether different BMI cut-off points are required from those applied to younger people (Tamakoshi *et al.* 2010). As suggested by Flicker *et al.* (2010), it may now be timely to review the BMI classification for older adults. Until then, the IDS-TILDA study should use the current BMI thresholds with caution in older adults.

5.9.2 Self-Reported Height, Estimated Height and Measured Height

Aligned with the earlier reports on the comparison of estimated height (ulna length) to measured height (see Section 5.7.1), the relationship of both variables to self-report height was also examined. However, given that the 'reporter' of the self-report data is unknown and the level of self-report height data missing, further study is required to give more definitive direction on this topic and the implications of selected height measurement (i.e. measured, surrogate, or self-report) on the calculation for BMI scores and the related classifications. It is recommended that all three variables be examined in the IDS-TILDA study, requiring the ulna length measurement to be taken in all eligible participants and not solely be used as a surrogate for standing height, as required, and be assessed by the same covariates noted in Section 5.10 (e.g. age, gender, level of ID). Despite the limitations, the data initially shows that strong positive correlations exist between all three variables. Very small but significant mean height differences were found. Estimated height had the highest mean value, followed closely by self-report and measured values. The opposite ordering was found for the mean BMI scores and associated classifications. For example, overweight and obesity was rated highest using measured values and lowest using estimated height with measured weight. As noted earlier, the question of whether maximal attained height (while allowing that surrogate measures are reported to decline less with ageing) versus measured height will deliver a more valid BMI has been posed (Roubenoff & Wilson 1993, Hirani & Mindell 2008, Sahyoun *et al.* 2008). Further study on the height variables (with the limitations addressed) in a large representative sample

of people with ID, and the determination of the impact on BMI classification by age and gender, will provide the much-needed evidence on this subject matter in this population group.

5.10 Familiarisation in Anthropometry Research

Task familiarisation has been cited as one of the most important aspects to be addressed and taken into account when planning testing with people with intellectual disability (Pitetti *et al.* 1993, Rintala *et al.* 1995). In 1987, Seidl *et al.* advocated that greater detailing of subject selection, orientation to the test protocol, and administrative difficulties encountered should be specified in all published studies. Since then, the familiarisation concept has, to varying degrees, formed part of many studies investigating physical activity, fitness or intervention, and cardiovascular fitness (Fernhall & Tymeson 1987, Pitetti *et al.* 1992, Rintala *et al.* 1992, Kittredge *et al.* 1994, Temple & Walkley 2003, Rimmer *et al.* 2004, Lahtinen *et al.* 2007, Khalili & Elkins 2009, Moss 2009), and walking and balance tests (Waninge *et al.* 2011a, 2011b). Interestingly, although a number of the physical activity-related studies included different anthropometric measurements as part of their investigation (Temple & Walkley 2003, Lahtinen *et al.* 2007, Moss 2009), the importance and benefits of the familiarisation concept to studies, where anthropometry is the lead focus of enquiry, have been neither directly signalled nor even indirectly implied by researchers until more recently (Soler Marin & Xandri Graupera 2011, Thomas & Kerr 2011). From a practice perspective, Welch and Craggs (2010, p. 31) have stated that "it is essential that every attempt is made to limit any fear and distress that the individual may experience, while striving to make the [measurement] experience a positive one".

Given the difficulties and barriers experienced by some people with ID with different anthropometric measurements reported in research studies (Bell & Bhate 1992, Marshall *et al.* 2003, Wallace & Schluter 2008, Melville *et al.* 2008, Waninge *et al.* 2009, Verstraelen *et al.* 2009, de Winter *et al.* 2012), one would have expected the familiarisation concept to have transferred to this field of research more readily. While all difficulties and barriers cannot be eliminated, every effort should be made by researchers to pre-empt potential influences (e.g. relating to the participant, tester, third-party support, selected measures, measurement protocol, communication access, environment, equipment, time) and plan accordingly. It is clear that many of the difficulties and barriers reported in the literature could be eliminated or minimised by including a familiarisation protocol in the study design. Rintala *et al.* (1995, p. 16) have suggested that, "to obtain an accurate assessment (i.e. valid and reliable results), it is important to develop a familiarisation protocol prior to testing, to eliminate as many of these concerns as possible". Applied to this study, although the researcher believed the use of a

familiarisation protocol would contribute significantly to the accurate assessment of participants (and increase the participation rates), the protocol needed to be used in partnership with standardised measurement procedures and the selection of appropriate and calibrated equipment, and be operationalised by a tester(s) who had completed accredited training in anthropometry assessment. All four requirements set were met in this study.

In the literature and among the views expressed by the researchers and clinicians consulted in the needs analysis of this study, there appears to be an acceptance that physical examinations or tests are often difficult or not always possible in this population or for sub-groups of this population. Despite the credibility of the findings presented in the literature review and the views expressed, there is a clear absence of documented efforts by researchers to maximise the potential of all participants to perform the required tasks of the measurements to the best of their ability (assuming the relative eligibility and safety criteria have been met). The question arises: if a familiarisation protocol had been used in many of the studies that reported difficulties and barriers to screening, would the outcome or the decisions made have been the same? It is imperative that we question what efforts and attempts have been, or need to be made, before, during and after the assessment process, in order to assist all participants, irrespective of their level of ID, to meet the required objectives, where possible. Details of the efforts made, including any specific accommodations (e.g. alternative equipment, surrogate measures, adapted procedures, extra time) and the type of delivery methods used to engage with participants (e.g. visual, text, demonstration) should be outlined by researchers.

Only with this information can more concrete judgements be made on what difficulties and barriers are still faced by people with ID, and can the effectiveness of actions taken be monitored and any further response actions required be identified. As noted previously, it is impossible to pre-empt or eliminate all difficulties and barriers but more can be done to reduce the frequency and types of difficulties and barriers reported. Considering that, for an extended period of time, many people with disabilities do not have their height or weight accurately measured for a variety of reasons (Froehlich-Grobe *et al.* 2012), the resistance shown by some is not surprising. It has also been reported that some people with moderate to severe ID can be anxious or frightened of the type of scale typically used in medical offices as it is not familiar to them (Wilkinson *et al.* 2007). Again, this finding is not unexpected if we consider Zajonc's 'mere exposure theory' (1980) which "indicates that human beings inherently tend to generate favourable affective responses towards things with which they feel familiar" (Sanabria *et al.* 2012, p. 82); people with ID are no different. In anthropometry research, the role of researchers

therefore needs to be viewed as more than just involving the act of measurement alone. Aside from the important task of building, as best possible, the participants' (and proxies' where relevant) awareness, knowledge and understanding of the measurements, the procedures, and the equipment, to generate maximal efforts, the measurement process provides researchers with a critical opportunity to broadly connect how the measurement results reflect the health and nutritional status of citizens, even though individual results may not be interpreted in all studies. Importantly, the use of a familiarisation protocol places participants at the centre of the process and requires researchers to think creatively about how to engage and empower people with all levels of ID to reach their full potential in the measurements process and overcome any difficulties and barriers where at all possible – for example, by getting participants to select the location (home or day/drop-in centre) for the visit, releasing accessible information about the visit in stages, issuing accessible appointment cards with key reminders and using accessible showcards.

5.10.1 Experience of Using Familiarisation in Anthropometry Research

The findings from this study strongly suggest that a familiarisation protocol, using a mix of delivery methods and accessible materials, should be included in all studies investigating anthropometric measurements in field-based research, such as the IDS-TILDA study. Overall, the high level of validity, and excellent reliability, of results achieved was directly linked in part to the familiarisation steps included in the design framework, which were fully operationalised in partnership with the other core methodological components (i.e. training, standardised procedures, selection of appropriate and calibrated equipment). Based on the insights from the rich qualitative feedback received from the participants and the proxies on the familiarisation steps taken before, during, and after the measurement process, it is clear that they had positive effects on the process – specifically, on both the participants and the related measurement results. Together, the quantitative and qualitative findings from this study present strong evidence for the benefits of including a familiarisation protocol in all anthropometry assessments. While the current study had no control group to measure the effect of familiarisation usage against the findings from other studies on the use of pre-defined familiarisation techniques in physical activity-related tests with people with ID (Fernhall & Tymeson 1987, Pitetti *et al.* 1992, Rintala *et al.* 1992, Kittredge *et al.* 1994, Temple & Walkley 2003, Rimmer *et al.* 2004, Lahtinen *et al.* 2007, Khalili & Elkins 2009, Moss 2009, Waninge *et al.* 2011b, Nasuti *et al.* 2013, Nordstrøm *et al.* 2013), it demonstrated that familiarisation led to good participation rates, maximal efforts, and reduced frequency of difficulties and barriers reported. For example, the briefing and practice phase of these studies, as Rintala *et al.* (1995)

described, allowed: (1) "the person being tested to become familiar with the test protocol, the test environment, and the staff performing the test", and (2) "staff to adjust the protocol to ensure the safety of the person tested (i.e. if appropriate, make reasonable adjustments such as using a wheelchair scale with the wider platform as opposed to a flat scale with a standard sized platform) and validity of the test results" (p. 20). In the current study, the briefing, demonstration and practice phase also allowed the participant to become familiar with the equipment and, collectively, this time facilitated the ongoing review of the participant's eligibility for each measurement, and allowed for the participant's level of understanding to be assessed so as to determine whether further guidance and support was required. Critically, the movement from the briefing to the measurement stage was reliant on the fulfilment of the eligibility criteria, the determination of safety, and the securement of the participant's agreement (verbal and non-verbal cues) to continue. Throughout the familiarisation process (and the study), the inclusion and use of 'process consent' was essential.

Interestingly, a recent study by Vis *et al.* (2012) reported that one of its limitations was the lack of a familiarisation protocol for testing, with exercise testing failing for more than half of the participants with ID. As part of this discussion, Vis *et al.* strikingly stated: "as expected most subjects with a severe ID were not able to perform the test due to comorbid physical problems or non-cooperation" and that it was a "relatively simple task which most adults with an ID could understand" (p. 268). On the basis of the amount of research completed in this field (physical fitness tests), it is unclear why a familiarisation protocol was not included along with the necessary adaptations to support the participation of all subjects as far as reasonably practical (i.e. the participant met the eligibility criteria for the test and was deemed safe to complete). It is imperative that researchers do not set out with the view that most people with severe or profound ID, when included in the sample selected, will not be able to perform the required task before the study even commences, or make assumptions about the perceived simplicity of tasks, as 'simplicity' is relative to the individual, irrespective of their level of ID, and the related status may change on the day or over time (i.e. it could be easy for the person today but difficult next week due to internal and/or external factors).

A familiarisation protocol was also surprisingly absent from, or not mentioned in, a large, recent study involving 1,050 older adults with ID, which assessed the feasibility of eight physical fitness tests as part of a wider study on ageing in this population (Hilgenkamp *et al.* 2013). In two of the eight tests, fine adjustments were made. For example, in one of the tests, grip strength, it was noted that "a visual example was provided by squeezing a rubber ball by the test instructor" (p.

36). However, no details were provided on any opportunity given to the participant to learn by experience before the test was conducted. This would not only minimise any learning effects but also assist participants to produce maximal efforts (e.g. practice run of the test procedures and equipment for this or any of the other seven tests). On review of the study's results, one striking finding was that only 24% of participants were successfully measured with the pedometer, yet 72% of the sample was between the borderline and moderate range of ID, and only 10% of the sample, were confirmed wheelchair-users. Based on the evidence from other studies, had a familiarisation protocol been included, it is likely that a higher success rate in this activity would have been achieved (minimising the learning effect and instrumental bias). Noonan and Dean (2000, p. 785) have asserted that, "if time and resources do not permit practice sessions, then the test should not be performed, as the results will not be valid".

Review of the generic literature has shown that the familiarisation concept is similarly applied (with some exceptions such as the two studies just cited – Vis *et al.* and Hilgenkamp *et al.*) and frequently used in sports and exercise science research. For example, many studies on strength testing confirm the importance of familiarisation sessions for the attainment of more accurate results (Ploutz-Snyder & Giamis 2001, Cronin & Henderson 2004, Dias *et al.* 2005) and with excellent retest reliability (Levinger *et al.* 2009, Abdul-Hameed *et al.* 2012, Taylor & Fletcher 2012). Brown and Weir (2001) have suggested that many of the individuals who undergo strength and power testing may have little or no experience performing the strength testing manoeuvres, so the familiarisation process is very important for these subjects, but also for those with experience (Dias *et al.* 2005). It has been reported that novice subjects will likely improve their strength scores on subsequent testing simply due to increased familiarity and comfort with testing (Kroll 1962, Reinking *et al.* 1996). For all subjects, Seo *et al.* (2012) suggested that familiarisation prior to testing (e.g. with grip strength – familiarisation with the tester, procedures and equipment, practice time/trials) is essential for ensuring reliable test results and minimising learning effects or systematic bias (Frontera *et al.* 1993, Hopkins 2000). In the Rimmer *et al.* (2004) study on strength testing in adults with Down syndrome, the same benefits of familiarisation were reported as in the generic literature. Similar findings were found in studies investigating motor performance in persons with Down syndrome, where practice trials, even though it is only one aspect of the familiarisation process, lead to significant changes in motor performance and in indices of motor co-ordination of the subjects tested (Kerr & Blais 1985, Edwards & Elliott 1989, Almeida *et al.* 1994, Latash *et al.* 2002, Smith *et al.* 2007).

Based on all the evidence presented, there is little doubt about the importance and value of familiarisation for physical testing, for both the participant and the research being conducted. This is further reaffirmed by the results of this study. However, merely including the term 'familiarisation' or citing its broad application in a study is not sufficient; researchers need to transparently report (or reference) the familiarisation procedures and activities performed and the related effects. As demonstrated in this study, researchers must begin by considering the needs and abilities of the target group and then plan, implement and evaluate the actions designed to improve participant familiarisation with the measurements, equipment, measurement process and tester. It is also advised that the target group be involved in the design and development of the relevant study components, where possible. In this study, for example, the target group played a key role in design and development of the accessible materials used, which ensured that the materials met the various needs of the intended audience as well as possible. Even though the principle of familiarisation is universal, its application is specific to the topic and the target group; and, since it is a relatively new methodological component in anthropometry research with people with ID, this study was well placed to build on the initial efforts made by two studies in the field; by Soler Marin and Xandri Graupera (2011) and Thomas and Kerr (2011). Neither of these studies provided the blueprint needed to capture the three-phase familiarisation process (before, during, and after) but the related actions specified in both were combined, adapted and used as part of the familiarisation procedures developed: i.e. practice sessions to familiarise subjects with instrumentation, personnel and protocols; touch-and-try of the testing instruments; explaining and demonstrating each test; participants free to do as many as of the tests as they feel comfortable with, and participants offered a copy of their collated results. (Thomas and Kerr 2011 did not specify that the actions taken had been guided or influenced by the familiarisation concept, but the efforts made and reported are closely linked to it.)

Given the infancy of the familiarisation concept in anthropometry research with people with ID, many of the related familiarisation activities and considerations made in this study were more closely aligned to the efforts reported in the Lahtinen *et al.* (2007) study, which included anthropometric measurements as part of its main investigation into physical performance. Interestingly, although Lahtinen *et al.* included all the actions of the other two studies (Soler Marin & Xandri Graupera 2011, Thomas & Kerr 2011), it did not offer participants a copy of their collated results, which was done by Thomas and Kerr (2011). However, absent from both studies but included in Lahtinen *et al.* were references to: the time needed to implement familiarisation activities, the need to plan the order of tests so motivational problems and

fatigue are minimised, rest breaks (test-dependent), the familiarisation of parents or guardians as well as participants with the testing procedures, getting to know the participant, use of accessible language during communications, giving verbal encouragement to maximise efforts, and verbal praise for every test completed or attempt to complete. Collectively, all of the components across the three studies discussed were included with some adaptations as part of the operational protocol developed. However, unique to this study was the development (and direct partnership with the target group) and use of a wide range of accessible materials on or relating to the measurement visit. All the accessible materials, particularly the appointment card, were very positively received by participants (and proxies) and the materials formed a critical part of the familiarisation process. In the future, if resources permit, it is advised that IDS-TILDA replace the illustrations developed with photographs and follow the necessary guidelines to ensure accessibility.

Critical to the success of this study was the staged release of the accessible material and information to participants, as it enabled the researcher to gradually build their awareness and knowledge of the measurement visit and the related process over time (before, during and after the measurement process), using a mix of delivery methods and types of guidance (see Table 5.1). Each stage in the process and every component was important; for example, the final debriefing was no less significant than the initial briefing at the start of the measurement visit. The Cone of Experience model (Dale 1969) proved to be a very useful resource, as it captured the different types of learning experiences selected and helped to define the inductive and deductive strategies, as part of the design of the development stage of the study, to be used to engage with participants. It is recommended that the IDS-TILDA study use the blueprint developed (see Table 5.1) for all physical tests in the future, including anthropometric measurements, as part of its health assessment module. This blueprint could also be used by others seeking to conduct such measurements or other physical tests with this population group. In the latter case, if there is no interview or questionnaire administered as part of the process, the interview stage can be removed and the measurement information booklet listed in it should replace the general information booklet listed in the recruitment stage.

Table 5.1: Blueprint of the Methods, Instructional Materials/Procedures and Guidance

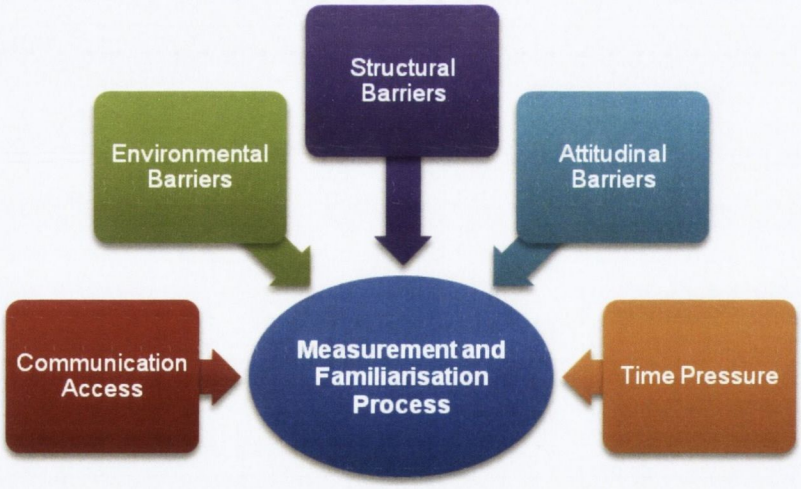
Stages	Type of Methods	Instructional Materials / Procedures	Type of Guidance
Recruitment	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo	• Consent form* • Information booklet* • Guardian agreement form & leaflet	• Text • Visual
Interview	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo	• Briefing by interviewers • Measurement Information Booklet*	• Verbal • Text • Visual
Appointment	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo	• Key reminders via telephone • Appointment card with reminders*	• Verbal • Text • Visual
Measurement	• Text/Verbal Symbols • Pictures/ Visual Symbols • Photo • Demonstrations • Direct Experience	• Researchers ID • Ice-breaker dialogue • Briefings by the researcher • Measurement showcards* • Demonstrations • Get to know the equipment • Practice option • Conduct measurements • Record the results on a record card* • Explain key learning (debriefing)	• Verbal • Text • Visual • Manual

*= Accessible text and illustrations

Notably absent from the studies that used the familiarisation concept with people with ID was the potential impact of other factors on the familiarisation process. Broadly, the potential influences identified by this study were categorised under five main themes (see Figure 5.4 and Section 5.11). Each factor independently, in any combination or collectively, had the potential to significantly affect the successful implementation of the steps outlined in the blueprint developed (Table 5.1). It is therefore imperative that the IDS-TILDA study and others account for these influences and plan accordingly. All the related steps discussed in the methodology chapter (see Section 3.6.3) under these themes were successfully implemented, and contributed to the success of the familiarisation process (and the validity and reliability of the results achieved). Commitment to familiarisation requires time, resources, creative thinking and responsiveness, flexibility, and effective facilitation. It is vital that those who implement the practice operate within a person-centred framework and be transparent about the related activities undertaken, including those in each of the three familiarisation phases (before, during and after). Almost two decades ago, Rintala *et al.* (1995) identified the need for the standardisation of the methods used to prepare people with ID for testing. Although this need was expressed within the context of cardiorespiratory fitness, the same need applies to

anthropometry and all other types of physical testing in this population group. Until now, there has been no universal reference guide developed for anthropometry assessment in persons with ID. This study provides the first critical step towards addressing this deficit; the general principles, as discussed earlier, also have the potential to apply to other physical tests in this population (Table 5.1 and Figure 5.4). The use of familiarisation in this study contributed significantly to the validity and reliability of the results achieved, and the overall positive measurement experience reported across all levels of ID. A measure of its positive contribution is reflected in the very low number of participants, irrespective of their level of ID, who required full support from proxies to complete the measurements. All the steps taken maximised the independent participation of participants as far as possible, and sought to counteract factors (e.g. limited understanding of the measurements and/or the instructions, limited motivation) that may affect the outcomes of the assessment and the experience for the person with ID. It is hoped that familiarisation efforts will also benefit participants in future, as they will be more aware of the measurements and be able to build on the learning gained.

Figure 5.4: Key Influential Factors on Anthropometric Assessment Process



5.10.2 Application of Familiarisation beyond Anthropometry Assessment

In the light of the contribution of familiarisation to the outcomes of this study, the question arises: if familiarisation was included as part of the methodology for all health screening tests, would the uptake and the successful completion of screening increase significantly in this population (i.e. the percentage of valid and reliable measurements)? It is widely reported that people with ID are more likely to have significant health needs that may go unrecognised and untreated because of barriers such as communication difficulties, diagnostics overshadowing,

discrimination or indifference, lack of appropriate equipment and accommodations, lack of flexibility, the requirement for additional time, and lack of sensitivity in the completion of visits and in procedures (Durvasula & Beange 2001, Lindsey 2002, Cumella & Martin 2004, Disability Rights Commission 2006, Barron *et al.* 2008, Michael 2008). In the recent report by Heslop *et al.* (2013), the panel concluded that 42% of the 238 deaths of people with ID investigated in the UK had been premature, with the most common reasons for deaths being assessed as: "delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing needs" (p. 3). McCarron *et al.* (2011, p. 7) have also recently found that "one in three adults with ID in Ireland find it difficult to make themselves understood when speaking with health professionals". Critically, many of these difficulties and barriers would be targeted as part of the familiarisation process. Based on data consistently showing that people with ID receive and participate in fewer routine health screenings for (but not limited to) cholesterol, cervical cancer, breast cancer and other cancers, vision, hearing and blood pressure than the general population (Strauss *et al.* 1999, Stein & Allen 1999, Durvasula & Beange 2001, Lennox *et al.* 2001, Iacono & Sutherland 2006) and what we know about familiarisation, its inclusion would likely have a very positive effect. In Ireland, while the results from Wave 1 of the IDS-TILDA data indicate that access to health checks was high overall, "access to screenings for cancers and access to all screening were lower for people with severe and profound ID" (McCarron *et al.* 2011, p. 107).

Familiarisation could be one of the stepping stones needed to improve the health outcomes for people with ID, as it has the potential to improve access to and use of services for physical testing, while assisting people with ID (and proxies) to become more knowledgeable about their own health and the importance of screening. Although there are cost and resource implications associated with familiarisation (e.g. the development of accessible materials [if not available], the allocation of extra time for screening) that would need to be considered, the long-term benefits would outweigh such implications. An example of successful cross-over is demonstrated in the Walsall Pacesetters project on breast-screening services in the United Kingdom (Social Exclusion Task Force [SETF] 2010), which revised its approach to screening after the low uptake by people with ID. By direct engagement with the target group, it was revealed that the majority had found the initial screening process distressing, which led to future failure to attend (SETF 2010). In response, the service targeted patients with ID with easy-to-read letters and offered 20-minute appointments (rather than the usual six minutes) to allow time for familiarisation with the radiographer as well as providing clear and full explanations. Pre-appointments were also made available and facilitated by a learning disability nurse and

radiographer to discuss the procedures and see the machinery in action. The initial outcomes showed that 40% of women eligible for screening attended, and 33% of these had previously failed to attend (before familiarisation); with advice and support all those eligible attended and continue to do so (DoH UK 2010). The researcher believes that this kind of improvement can be replicated and built upon (e.g. through expansion of accessible materials, such as an appointment card with key reminders, an information booklet, and showcards or DVD on the main screening stages, to be used at the appointment by the tester), be successfully applied to other health screenings, as demonstrated in this study, and assist in reducing health disparities among people with ID.

5.11 Optimal Performance Measurement in Anthropometry Research

Creating the optimal measurement conditions is essential to achieve the desired outcomes for the research (i.e. collection of valid and reliable data) and the participant (i.e. positive measurement experience). As previously noted, reference to the factors (excluding training, standardised procedures and equipment) that may influence the success of the anthropometric measurement (and familiarisation) process is absent in ID research. Uniquely, this study identified and categorised the potential influences under five broad themes (see Figure 5.4). The associated steps taken – such as integration of guidelines on accessible communication, allocation of sufficient time, continuity of proxy support where required, positive reinforcements, etc – were fundamental to the successful operationalisation of the anthropometry assessment process in both home-based and 'clinic-style set-ups', and should be replicated in the IDS-TILDA study (see Section 3.6.3). It is critical that IDS-TILDA (and others) account for the actions taken to reduce the risk of these factors affecting the measurement process. Importantly, the four measurement stages and types of methods, instructional materials/procedures and guidance, outlined in the blueprint developed for this study (see Table 5.1), may be applied to all physical tests in this population. However, where no prior interview or questionnaire is issued, the development of a form similar to the Measurement Communication (MC) form used in this study is essential, and should form part of booking appointments. Access to this information will enable administrators to plan and meet individual needs more effectively (e.g. select suitable equipment), as demonstrated in this study. At minimum, the person's main mode(s) of communication, wheelchair-user status, steadiness in walking and standing, and self-rated eyesight need to be established, where possible. Also during this exchange process, if proxy support is likely to be required, the importance of the selected proxy knowing the person with ID for at least six months, where possible, needs to be stressed. In this study, the steps taken to ensure continuity of proxy support, where required,

was greatly aided by the MC form used. Access to this named proxy enabled the connection already established by interviewers to be further built upon, and the associated procedures developed on the role of proxies in the lead up to and during the measurement visit worked well and kept the central focus on the participant, where support, in part or in full, was required.

5.12 Anthropometry Measuring Equipment

Despite the need for, and importance of, accessible and calibrated equipment to be used to conduct anthropometry measurements in field research, equipment has received the least attention in the literature. Yet equipment (selection, care, use, and maintenance) is as important as the use of standardised measurement procedures and the completion of accredited training. All three factors are essential and are interdependent in order to maximise the validity and reliability of the data produced. However, no studies were found evaluating the utility of the equipment used with adults with ID, either as part of a study on anthropometry assessment, or solely as the topic of enquiry, even though equipment can influence both participation rates and accuracy of data. Review of the selected measurements across other studies with adults with ID shows that many do not provide the brands of equipment used (Bell & Bhate 1992, Lea 1999, Carmeli *et al.* 2003, Cotugna & Vickery 2003, Braunschweig *et al.* 2004, Melville *et al.* 2005, Stanish & Draheim 2007, Maaskant *et al.* 2009, Verstraelen *et al.* 2009, Vis *et al.* 2009, Temple *et al.* 2010) or, where provided, the brand of tape for the circumference measurements was often omitted (Moss 2009, Melville *et al.* 2011, Tsai *et al.* 2011, de Winter *et al.* 2012, Mitchell *et al.* 2013). Similarly, many of these studies did not provide details of calibration checks undertaken on the equipment used for these selected measurements (Braunschweig *et al.* 2004, Fender *et al.* 2007, Stanish & Draheim 2007, Moss 2009, Verstraelen *et al.* 2009, Vis *et al.* 2009, Waninge *et al.* 2009, Temple *et al.* 2010, Mitchell *et al.* 2013 [details of any planned calibration checks]). It is therefore not surprising that the need to "establish appropriate equipment for accurate measurement of body composition in select disability groups" has been identified as an area needing urgent research (Rimmer *et al.* 2010, p. 9).

Accessible measuring equipment is essential in field research. Access to and provision of accessible equipment will not only maximise the participation of persons with ID, which in turn improves the quality of the research undertaken; most importantly, it will make it easier and safer for them to take part. As the population ages, including people with ID, the need and demand for accessible equipment will increase. In the evaluation of the utility of the equipment selected in this study, four of the six pieces of equipment raised important observations in

terms of future use. At the outset of the study, the long-standing, portable Seca Leicester Height Measure was selected. During its use, it became clear that the side rims of the baseplate required participants to place their feet on the baseplate carefully. Several participants also required more guidance than would be needed if the side rims were omitted. Surprisingly, despite its long use in field research and practice, no comparative evidence was found in the literature on the researcher's or practitioner's experience of using this piece of equipment with adults; however, towards the end of the data-collection stage of this study, Seca replaced this Leicester stadiometer with a new 217 model – in which the side rims had been removed. In the testing of the new 217 model, although with a smaller sample of people with ID, similar observations were noted, but the reason was different. Due to the revised colour (grey) of the baseplate on the new model, it often blended with the flooring in sites, which required participants to take extra care stepping on the baseplate. The blue baseplate in the old model was very distinctive, which was particularly helpful to participants with visual impairment. Although the wider baseplate in the new model was helpful, the absence of the 'footprints' feature on the baseplate was a notably missed reference point. The footprints were very useful during the demonstration and practice stage of the familiarisation process and during the actual measurement to guide the positioning of participants' feet. Although it is recommended that the new Seca 217 model be used in future, it would be helpful to both this population group and others, particularly older adults and children, if Seca also produced the baseplate in blue, with the same footprints feature.

Advances in anthropometry equipment led to the development of the Rosscraft Segmometer 4 for segment lengths, combining the precision of calipers and the flexibility of a measuring tape. In this study, the segmometer was used for the ulna length measurement and part of the mid-upper arm circumference measurement. Until now, segment lengths in ID research studies have mainly been taken with a measuring tape, which makes it impossible to avoid following the curvature of the surface of the skin. This limitation has not been addressed. No anthropometry studies were found using this Segmometer 4 with adults with ID. Although no difficulties were observed using the segmometer with participants in a standing position, the length did prove too long for some of the participants in wheelchairs or those sitting in chairs with arm-rests if they were unable to adjust or the space was too restrictive. Even though the current length did not prevent any of the measurements from being taken (with the possible exception of one case where a shorter length may have aided the securement of the measurement in a lying position, but other factors were the dominant reason for non-obtainment), it required more time to complete due to the adjustments needed. While it is recommended that the Segmometer 4 be

used for segment lengths, it would be useful if Rosscraft developed a modified length of 55cm to widen its suitability for all users and ensure ease of use for subjects in a seated or standing position. Access to a shorter segmometer would also improve the flow of measurement efficiency among those in a seated position. To prevent the flexible tape (which forms a central part of the design) from damage, particularly in field research, there is a need for a light carrier box to be developed, to reduce the field risk.

In field research, the measurement of weight as part of the anthropometry assessment process is often restricted to those who are able to stand comfortably on floor scales. For example, the main reason for the inability to check weight in 20% of adults with ID in the study was lack of wheelchair scales for those who were non-ambulatory (Wallace & Schuler 2008). This factor has been reported in several other studies (Marshall *et al.* 2003, Fender *et al.* 2007, Melville *et al.* 2008). As part of this study, the researcher sought to ensure equal access to weight measurements and test the feasibility of the wheelchair scale in field research. However, despite the need to provide access to and provision of accessible equipment for all, the study found the transfer of the wheelchair scale by one person from vehicle to site very difficult due to its weight. Although some consultees in the consultation stage of this study deemed it to be a feasible option, it was not practical or safe for the wheelchair scale to be transferred by one person. Two people are needed. This would not be cost-effective, as all the measurements tested can be taken by one person. It is also important to note that none of the participants living in family homes required this scale, and, given its space requirements, it would not have been possible or practical to use it in most of the homes visited. Once the scales were set up, often at sites where one or more participants lived, it was accessible to all, even those who were not wheelchair-users or required a larger platform to stand for the measurement. Clinic-style set-ups, where possible, proved helpful to the participants as they had the choice to use the wheelchair scale, and also to the researcher, as it maximised the return on the time required to set up this scale. In future, for those who request home-based assessments – that is, based on the experience of this study, most participants – it is advised that, if they require the wheelchair scale, a day (or days) be allocated for weight measurements to be taken at an accessible and agreeable location (e.g. activity centre) that the participant attends, where possible, if they wish to have all the other measurements taken in the home setting. Although access to this scale is not feasible in home settings, unless several participants are being seen and assistance is secured, or a lighter wheelchair scale is sourced, the provision of alternative access via a 'clinic-style set-up' will provide equal access, as far as reasonably practicable.

Except for the wheelchair scale, unless the above requirements are met, all the equipment selected proved feasible (i.e. portable and practical), accessible and acceptable to people with ID in the field research. Improvements can be made to two pieces of equipment selected, as discussed above, but they can be used in their current design with extra time allotted. This study confirms that it is not only important to select the most suitable equipment, but the brands, set-up procedures, calibration checks, care and maintenance of the equipment need to be included in the operational protocol of studies and be transparently reported in research. Collectively, these actions will maximise the validity and reliability of the data collected and improve the quality of the research undertaken. In field research, particularly longitudinal, it is important that the 'wear and tear' of equipment be considered and addressed, as it could affect results. Himes (2009, p. 511) has recommended that the "best quality equipment should be chosen for maximum consistency over time and for reliability among observers taking measurements".

5.13 Conclusion

In this chapter, the main findings from Chapter 4 were discussed in the context of related intellectual disability and generic literature. The similarities and differences of the findings to the literature were highlighted. Many new insights into the assessment of anthropometry in people with ID, such as the important role of familiarisation in the assessment process, were also presented. The discussion was mainly framed on the central themes of the rapid research field tool developed from key learnings of the study. Some practical implications of the findings were discussed and opportunities for future research and/or improvements that could be made were identified. In the next chapter, the conclusions of the study are presented, along with the strengths and limitations of the study, and recommendations for research, education, practice, and policy.

Chapter 6: General Conclusions and Recommendations

6.1 Introduction

Anthropometry is an important tool and an essential component of the assessment of the nutritional status of populations to evaluate their weight status, particularly outside the normal range (e.g. underweight, overweight and obesity), and the associated risks of morbidity and mortality. Access to valid and reliable anthropometric data across all population groups is essential from both a policy and scientific perspective. Such data contributes to the formation of health policies; assists the planning, development and implementation of targeted health prevention and promotion programmes and services to meet the needs identified, and provides evidence to advance our understanding of the relationships between diet, nutrition and health. Yet no national anthropometric data on people with intellectual disability (ID), either as independent investigations or in the context of overall health and nutritional status, is available cross-sectionally or longitudinally in Ireland, or internationally.

This research and surveillance gap urgently needs to be addressed. It is not acceptable that people with ID are excluded from or not represented adequately in mainstream research, particularly given that national and international data monitoring systems are in place to track weight trends in the general population, such as the escalating global epidemic of overweight and obesity. People with ID need to be included in the research and monitoring as much as the general population – if not to a greater extent, due to their frequent under-representation. Given its importance to health, body composition is commonly investigated in epidemiological, clinical and population studies (Moreno *et al.* 2002) in the general population. For instance, in the most recent national *SLÁN* survey of Irish adults aged 18+ years; additional anthropometric measurements were included in two sub-samples of its nationally representative sample (Morgan *et al.* 2008). Irish people with ID need to be afforded their right to be included in national research and surveillance programmes so that their health and dietary status, disease risk and body compositions can be evaluated over time, and the necessary responses need to be taken by both individual citizens and relevant stakeholders. Access to anthropometric data will provide the much-needed picture of over- and under-nutrition in this population group (Humphries *et al.* 2009).

Internationally, the World Health Organization (2013) has affirmed the need to include people with disability in healthcare surveillance, and to conduct more research on the needs, barriers and health outcomes related to this population group. This, coupled with population ageing,

further raises the priority and importance of assessing the nutritional status of all persons, particularly older people, due to its role in ensuring a better health-related quality of life and its association with functional ability (Galanos *et al.* 1994, Manandhar *et al.* 1997, Wells & Dumbrell 2006, Stanner & Denny 2009), such as promoting optimal functioning and capacity.

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is well positioned to begin to address this research disparity and to offer guidance, based on the findings from this study, on how to include anthropometry assessment in future national health-related surveys on people with ID, and to ensure its accessibility to all citizens. Collectively, the evidence, both from the ID literature reviewed and consultations conducted as part of this study, revealed a significant lack of standardisation (e.g. in training, measurement protocols, equipment) similar to the general population due to the multiple anthropometric traditions (Norton & Olds 1996), quality control measures (e.g. assessment of testers, calibration checks, validity and reliability assessment), and direction for the assessment of anthropometry in the ID field to meet the varying abilities of the population. Similarly, no details were found on any proactive measures taken to address the measurement difficulties and barriers frequently reported in the literature (and by several of the researchers and clinicians consulted in the analysis stage of the study). In 2009, Verstraelen *et al.* (2009) reported that the question remains as to how best to measure weight status in people with ID. Four years later, Casey's (2013) scoping review affirmed that there are too few well-conducted studies to enable us to determine the precision and validity of body composition measures.

A summary of the key learnings and contributions of this study to the ID research field within the context of the aims and objectives set out (see Sections 3.1.1 to 3.1.2) will now be outlined, followed by discussion of the strengths and limitations of the study (see Sections 6.4 and 6.5), and recommendations for research, education, practice and policy (see Section 6.6).

6.2 Key Anthropometry Learning and Contribution to ID Research

The key anthropometry learnings of this study and its contributions to the literature are categorised into five broad themes.

6.2.1 Feasibility, Validity and Reliability

This study set out to investigate the feasibility, validity and reliability of performing anthropometric measurements on people with ID aged 40 years and over, as part of the pilot for the national IDS-TILDA study in Ireland (aim 1) and to develop a rapid field tool to guide the

baseline assessment of anthropometry in adults with ID (see Appendix 36, Figure 1), inclusive of measurement standards and an approach that maximised the participants' understanding of the measurement process (aim 2). Both aims were achieved by the fulfilment of the objectives set out. Jointly, the measured feasibility, validity and reliability results confirm and support the inclusion of the selected measurements in the national IDS-TILDA study (objectives 1 to 3). There is no reason why anthropometric measurements cannot be integrated into the health assessment module of IDS-TILDA and other nutritional or health-related surveys involving people with ID. The knowledge gained herein will help to widen the reach of anthropometric assessment to all persons with ID and provide guidance on how to further improve the quality of research produced. The study revealed that it is absolutely critical that surrogate measurement options be included for standing height and body mass index (BMI), when either measured height or both measured height and weight cannot be secured in persons with ID, and this should be done as standard practice. This will ensure that people with ID are not automatically excluded from taking part, and will maximise the possibility of establishing a baseline anthropometry profile on all citizens. As people age, irrespective of having an ID, the need to avail of surrogate options is likely to grow due to the increased difficulty of obtaining valid measured heights in some older adults (e.g. due to kyphosis, mobility problems). The knowledge generated here has the potential for transferability to other population groups.

6.2.2 Surrogate Measurements

Similar to the general population, the findings from this study confirm that surrogate measures tested – ulna length and mid-upper arm circumference (MUAC) – were valid and reliable, and acceptable to people with ID (objectives 4 and 5). The value of measuring MUAC in all adults with ID beyond its use as a surrogate for measured BMI was also identified. Given the limitations of BMI as people age (e.g. it does not consider height loss with ageing, lacks sensitivity), the usefulness of MUAC as an additional criterion of nutritional health status was also highlighted, and it may be particularly useful in identifying those at risk of under-nutrition in that it provides a gauge of fat reserves and muscle mass. However, it should also be used and interpreted with caution, where the upper-arm muscle of participants has been built up to aid mobility. The research also found that MUAC is likely to be of particular value when measured height and weight values cannot be secured and self-reported height and/or weight data is missing.

The validity of the Malnutrition Universal Screening Tool (MUST), for use in the calculation of estimated standing height from ulna length, and the estimated BMI categorisation from MUAC

in this population was also confirmed. However, some caution is needed, as it was not sensitive enough to categorise all MUAC values correctly in the estimated BMI category when compared to measured BMI. This highlights the importance of MUAC also being reported and monitored as a continuous variable when not being used to estimate a BMI category.

6.2.3 Self-Report and Measured Height, Weight and Body Mass Index

Unfortunately, due to the level of self-reported height and weight data missing in an already small study population, the analysis of self-reported data to measured values and subsequent BMI's calculated was restricted (objective 6), but several important findings did emerge. The research revealed the need for questions on self-report height and weight to be expanded to capture the identity of the reporter and source of this information, alongside the values reported. Access to this data will facilitate more comprehensive analysis of its accuracy, and the influence of any reporter or source changes on the values over time, and enhance comparisons with other studies. The self-report collection guide developed in this study (see Appendix 36, Figure 2) for height and weight data will be a useful reference tool for future researchers in designing the related questions in data collection tools. The need for researchers to specify the elapsed time between the self-report (data secured first) and measured data was highlighted. Although the initial insights into self-reported height and weight data compared to measured values showed no significant difference (objective 6), this comparison needs to be studied in a large representative sample both cross-sectionally and over time, and be assessed in terms of key covariates of potential influence (i.e. age, gender, level of ID, reporter, source and elapsed time). If significant differences emerge from this further research, there is potential to develop a correction formula (i.e. to generate more accurate data than by using uncorrected self-reports in the off-years when IDS-TILDA is not conducting health assessments). The significance of reporting height and weight data as continuous variables in research (not restricted to BMI usage) was also highlighted, so the rate of height loss as people with ID age can be determined, and to increase our understanding of the relationship of each value to morbidity.

In terms of BMI, despite the strong positive correlation found between the self-report and measured BMI scores (objective 6); a small but significant mean difference between the scores was also detected. The implication of the difference, revealed the impact that small differences can have on BMI when it is used as a dichotomised variable. BMI data needs to be reported by age (using the stratification of the World Health Organization Global Database), gender, level of ID, residential circumstance, and urban/rural strata. Access to and reporting of this more specific BMI data will not only assist in targeting those at greatest risk, it will deliver messages

that are more likely to resonate with specific subgroups of people with ID and relevant key stakeholders.

6.2.4 Self-Report, Measured and Estimated Heights and BMI Scores

Despite the restricted analysis on self-reported, measured and estimated heights, all three height variables showed strong positive correlations, with small but significant mean height differences found (objective 7). Not surprisingly, estimated height was the highest value and measured height was the lowest, while the opposite effect was found when the variables were used to determine BMI scores (i.e. lowest using estimated height and highest using measured height). Further study is required on these height variables and the effects on BMI classifications in a larger representative sample of adults with ID, such as IDS-TILDA. Of particular note, the research revealed that, as people with ID get older, securing valid height measurement may be more difficult, increasing the need for a surrogate option, as reported for the general population. The research highlighted the critical need to examine and determine the rate of height loss in this population as they age. Jointly, the research findings led the researcher to question whether ulna length, which is reported to change less with ageing, would be a more accurate measure of height than measured or self-report height in all older adults with ID. However, until the related data is collected in a large representative sample of adults with ID and studied over time, the question will remain unanswered in the literature.

6.2.5 Waist Circumference over Clothing and on Bare Skin

The study not only determined the difference between the waist circumference (WC) measurement over clothing and bare skin (objective 8) at the iliac crest site, it also identified the contribution of landmarking error to the difference found. This was unexpected, as it has not been discussed in the related literature. Similar to studies in the general population, the clothing effect of .5cm was found but the remaining difference, rounded to .5cm, was attributed to landmarking error. Even though the iliac crest is a bony landmark, it is not possible to guarantee that the tape was on the exact site required when it was taken over clothing, even a single layer, as no landmark is drawn, unlike WC on bare skin. An adjustment of -1.0cm is proposed to account for both contributing factors at the iliac crest site when WC is taken over clothing (single layer), but WC on bare skin is the preferred option. Uniquely, this study measured the thickness of the clothing the WC measurement was taken over. This should be done as standard practice when WC is taken over clothing. Lastly, the importance of participants wearing suitable clothing for WC (and MUAC) was particularly noted, due to the location of the sites required to conduct each of these measurements.

6.3 Key Methodological Learning and Contribution to ID Research

Based on the findings from the ID literature, a direct focus on the act of measurement alone would have led to opportunities to improve the quality of anthropometric measurements, but focus on the act itself is not sufficient to stimulate the wider change required in anthropometry research. Importantly, the research confirmed that generic reference methods (i.e. measurement procedures), with some minor but standardised adjustments (e.g. inclusion of the seated option for the weight measurement where possible and required) to widen the reach to all, can be operationalised with people with ID. There is no reason why generic reference methods used in the general population cannot be used with people with ID. However, one major and unique difference is the approach needed and taken to operationalise it in practice. The research revealed the criticalness of the familiarisation protocol (including the accessible materials) integrated into the design of this study, not only to the outcomes achieved (quality of data) but, equally important, to the participants and the relevant stakeholders (objective 10). For participants, the creative means of engagement and the staged release of information used to gradually build participants' knowledge and understanding of the selected measurements and the related processes were greatly welcomed by all.

Interestingly, the level of measurement difficulties and barriers encountered by participants was minimal, which is not common according to previous research. Uniquely, the identification and associated planning on the key influential factors in the anthropometric assessment process also helped to maximise the implementation of the measurement and familiarisation procedures developed; for example, ensuring participants' continuity of proxy support from the interview to measurement stage, if required and with their permission where possible. The benefit of replicating the use of familiarisation procedures (similar to this study) in other types of physical testing in this population group was highlighted. All related design tools and reference materials developed could be adapted to the needs of the specific target group and the context of each physical test or examination.

Although familiarisation was critical to the results in this study (e.g. assisting in the attainment of valid and reliable data), the importance of the measurement theory in the design, development, implementation and evaluation stage of the study should not be underestimated. Findings from this study support the importance of not only specifying measurement standards (including the exclusion criteria) and source, but also the validity criteria set, the measurement schedule and process of duplicate readings, and the selection, care and use of equipment, which is frequently absent in ID research. The study confirmed that, with transparent guidelines

and record forms, both the reporting and analysing of the validity and reliability status of measurements can be completed with ease. The validity and reliability status of anthropometric measurements should be reported in ID research, as standard practice.

Similarly, the research showed that it was essential to understand why measurement readings are invalid or were attempted but not obtained, not attempted or refused. With the aid of the measurement reporting cycle developed, researchers can now begin, as demonstrated in this study, to quantify more exactly the measurement status and identify any patterns or circumstances that could be targeted to improve the measurement outcome or increase future participation. Access to and reporting of this contextual information will also assist other researchers planning to undertake the selected measurements (e.g. allocating additional time to measure).

All the equipment selected except for the wheelchair scale was deemed suitable for home visits but this scale can be set up at central locations to facilitate equal access to the weight measurement (objective 9). Additionally, all the equipment used proved acceptable to participants. However, two design changes – a shorter segmometer for use with people in a seated position and a darker baseplate with footprints on the new stadiometer – would make the measurement process more efficient.

Key to the design, development and implementation (maximising the validity and reliability) of anthropometry assessment was the accredited training completed and delivered by certified trainers, giving the quality assurance that is often lacking in related ID studies. Details of the training, the assessment and accreditation process, and the certification status of trainers need to be reported as standard practice in the description of methodologies, so that the quality of the data collected can be assessed, enabling better reliability when comparing these parameters across studies. Based on the level of training and experience of the researcher(s), tolerance limits (acceptable technical error of measurement) between the first and second readings need to be determined before the data is collected, and be specified, as demonstrated in this study, which again is absent in ID research.

Based on all the key learnings from the study, the rapid research field tool developed provides researchers, for the first time, with a reference guide to conduct a baseline assessment of anthropometric measurements in adults with ID. The tool integrates the broad methodological

concepts that need to be addressed by researchers, while providing guidance on the selection of measurements, which can be revised to meet the needs of the particular study.

6.4 Strengths of the Study

This exploratory study has several particular strengths that need to be highlighted. It is the first comprehensive examination of standardisation of anthropometric measurements in persons with ID with varying abilities. To ensure the collection of high-quality data, the rigorous and transparent detail set out in Chapter 3: Methodology not only addressed the limitations of previous studies, it also looked at anthropometry beyond the 'act of measurement' alone by integrating familiarisation procedures and accessible materials into the study design. The use of mixed methods provided a more rigorous approach (breadth and depth for analysis) to measuring anthropometry parameters in this population group than has been previously reported. This approach also enriched the measurement experience for the participant, as clearly demonstrated by the study's findings.

The conceptual framework, the ADDIE model, used in this study ensured that a systematic approach was followed by proceeding through steps that built on each other with a series of input, processes and outputs. The direct engagement with people with ID, families, researchers and clinicians on this topic area in the analysis stage of the study also made clear the need for this research, while the consultation completed with people with ID during the development of the accessible materials ensured the materials were accessible to the target audience. The mix of learning methods used (framed by the Cone of Experience model), the sequence of delivery and the types of guidance used, together with the instructional materials/procedures developed, uniquely built up the participants' familiarisation with the measurements, the visit, and the measurement procedures over time. The linked blueprint developed (see Appendix 36, Figure 3), along with the figures of the key influential factors (see Appendix 36, Figure 4) and the measurement reporting cycle (see Appendix 36, Figure 5) graphically show for the first time in ID research the transparency of the efforts made to look beyond the act of measurement alone (e.g. the integration of creative means of engagement in the protocol to increase participants' awareness, knowledge and understanding of the measurements) while also improving the standardisation and quality of the measurement act itself. Collectively, these components greatly supported the execution of duplicate measurements, which enabled the reliability of the results to be assessed, which is not common practice in related ID research.

Good retention from the interview to the measurement stage and subsequent, active participation in the measurement visit was no doubt aided by the design of the study. The actions taken before the measurement visit and in the lead up to, during and after the measurement process are, except for the act of measurement, notably absent from most studies investigating this topic with people with ID. The inclusion of surrogate measurements and the selection of appropriate equipment to meet the varying abilities of this population group widened the reach and ensured the measurement visit was accessible to all. The transparent and explicit details on the equipment, measurement procedures (including the measurement schedule), data recording, and the quality-control measures taken were also strengths of this study. The high level of international accredited training achieved by the researcher has not been reported in any other anthropometric studies in the ID field, which gives further quality assurance on the methods employed and of the study's findings. The added completion of the anthropometric training delivered to the nurses involved in the pilot health assessments of the Irish longitudinal study on ageing (TILDA) in the general population further strengthened the researcher's knowledge of the similarities and differences between the populations.

All levels of ID, age groups and types of living circumstances were represented in the study, despite its small sample. Crucially, the sample size was appropriate for testing this new methodology and, given its success, can now be rolled out in the national IDS-TILDA study. Both the rapid research field tool for the baseline assessment of anthropometry in adults with ID and the self-report collection guide for height and weight data developed provide future researchers for the first time with reference tools to direct them on the core considerations needed. An added strength of this study is the broad applicability and adaptability of the main concepts to other types of physical testing with people with ID; in particular, the measurement reporting cycle; the blueprint of the methods, instruction materials/procedures and guidance set out; and the figure showing the key influential factors on the assessment process (see Appendix 36). Each of these is presented in a graphical or tabular format (see Appendix 36). Ultimately, the core strength of the study design is that it is easily reproducible and is likely to have applicability beyond the field of ID.

6.5 Limitations of the Study

Due to the nature of this study, an exploratory investigation, limitations are to be expected and acknowledged. In the statistical analysis, the small sample size limited, and in some cases restricted the analysis that could be conducted (e.g. variables of interest by certain age or level

of ID groupings). As noted in Chapter 4, some results presented – in particular, the confidence interval and p-values – need to be interpreted with caution (e.g. the results on those aged 60 years and over, due to the small number involved). Despite the limitation of the small sample size, the study successfully explored, as was intended, a new methodological approach to conducting anthropometric measurements which led to the development of a rapid research field tool for anthropometric measurements. The sample size was sufficient to conduct the required statistical analysis on the feasibility, validity and reliability of the measurement readings, and give necessary direction on the use of selected surrogates' measurements as well as insight into the influence of clothing on the waist circumference measurement. The combined result of the small sample and the level of missing self-report height and weight data restricted analysis of the differences and similarities between self-report, measured and estimated height data, and linked calculations, such as BMI. However, the analysis did reveal the importance of establishing the identity of the reporter and the source of the height and weight data in future studies. Although the findings cannot be considered representative of the total ID population (due to the small sample size), all age groups, levels of ID and living circumstances were represented in the study. In addition, the findings often supported other quantitative studies in the related field in the general population, and also highlighted areas of difference to be explored in the national IDS-TILDA study. However, given the dearth of studies on many of the methodological aspects included in this study's design (e.g. specific measurement standards, validity criteria, reliability assessment), the findings could often not be compared to and validated by those of other ID studies.

Due to restricted resources, the securement of customised photographic images of people with ID as the models for the accessible materials developed was not possible. Every effort was made to source the required images from photobanks but the images required were either not available or did not meet accessibility requirements for use. Instead customised illustrations were developed, but it is advised that IDS-TILDA and other studies in the future should organise or secure, if possible, the matching photographic images for the materials developed in this study. Similarly, due to limited resources, a paper-based form of the Results Workbook was used to record the data collected and then data was transferred to the Statistical Package for Social Sciences (SPSS), adding transcription time that could be avoided if a personal digital assistant (PDA) was used. Once again, where resources allow, it is advised that measurement data be recorded directly onto a PDA device with the SPSS program installed, so that no data needs to be transcribed.

Despite the limitations identified, this study was rigorously conducted. All efforts were made to address the limitations, but some were beyond the scope and control of the researcher, given the exploratory nature of the study.

6.6 Recommendations

Based on the study's findings, the following key recommendations have been identified for research, education, practice, and policy in the field of anthropometry in people with ID.

6.6.1 Key Recommendations for Research

IDS-TILDA: Anthropometry Assessment Module

- Replicate the methodology employed in this study but with the following revisions:
  - **a) Training:** If ISAK Level One training cannot be completed, researchers should at the very least be trained by a certified trainer from a recognised training body. ISAK should be viewed as a good benchmark for training standards. Details of the training – including the content, duration, assessment methods (e.g. inter- and intra-observer technical error of measurement [TEM]), and the status of the trainer's certification – should be reported in the methodology. On successful completion of the training course (and assessment), candidates should be required to measure at least 20 volunteers on the set of measurements selected for the study (in duplicate) and submit the profiles for assessment. If intra-observer TEMs fall within the limits, accreditation should be approved for the specified measures only.

    Based on the level of skill and expertise set for data collection (requirement set at the training stage), the accepted tolerance limits between the first and second readings need to be determined for each measurement and included in the operational protocol before data collection commences. An automated alert on the personal digital assistant (PDA) should be integrated into the reporting system to alert researchers of the third reading required, or highlight the tolerance limits set for each measurement on the paper-based form (as used herein), if a PDA is not used.
  - **b) Accessible materials:** Replace the customised illustrations with customised accessible photographs. Revise the appointment card slightly, by splitting the text on t-shirt/ shirt from trouser/skirt into two bullet points and revise the text to read 'wear a short-sleeve t-shirt or shirt that can be rolled up to your shoulder'.
  - **c) Wheelchair users:** Place extra emphasis on the importance of suitable clothing being worn, based on the revised recommendation noted above on the appointment card.
  - **d) Data record:** Use a PDA device to record the value and all the associated data.

e) **Wheelchair scale:** Set up the access to the wheelchair scale at central locations only.

f) **Measurement selection:** Use the rapid research field tool developed to guide the direction of measurement selection, but adapt to the needs of the participant.

g) **Waist circumference:** Take the measurement on bare skin (preferred method), if a proxy is present or available to assist and with the participant's permission, at the iliac crest. If a proxy is not present or available or if the participant does not wish to have it taken on bare skin, take the reading over one layer of light clothing at the same site. Document the reason(s) why the participant did not wish or it was not possible to take the measurement on bare skin. Before taking the measurement over clothing, measure (and record) the thickness of the clothing, so that a single layer of clothing is verified. It is advised that the thickness of clothing be ≤1.0mm.

h) **Ulna Length:** Measure on the left arm, where possible; if not, on the right arm.

i) **Surrogates:** Measure both ulna length and MUAC in all participants, where possible. (1) Determine the correlation between estimated, measured and self-report heights over time and the implications on BMI classification by age and gender. (2) Evaluate the relationship between MUAC and BMI measured, and health status. (3) Determine the accuracy of MUST to predict BMI category correctly from MUAC.

j) **Standing height:** (1) Monitor and determine the rate of measured height loss by age and gender, and influence on BMI categorisations. (2) Evaluate if estimated height (ulna length) is a more appropriate measure than measured height in all older adults, and determine the BMI implications of each option and mixed use of both in one study.

k) **Pre-Interview Questionnaire (PIQ):** Next to the questions on self-report height and weight, integrate the new reporter and source check (as per the self-report collection guide developed) to be completed by the interviewer as part of the routine checks on the PIQ at the interview stage, or ask participants to complete. Examine the difference between self-report and measured height, weight and BMI by age, gender, level of ID, the reporter and source, and elapsed time.

- Set up quality assurance checks (mix of pre-announced and short notice visits) to be conducted by the certified trainer or anthropometrist, appropriately qualified to monitor and check (with the participant's permission) adherence to measurement procedures and the precision and accuracy of the measurements, and retrain where necessary.
- Present BMI categorical data based on the standard BMI World Health Organization's definitions by age, gender, level of ID, type of residence and urban/rural strata.

- Analyse, monitor and report weight, height and BMI as continuous variables (and transform BMI into a categorical variable, weight status category) and determine the relationship of each value to morbidity.
- Test the use of familiarisation procedures (and similar accessible materials) developed in other types of physical tests or examinations included in the health assessment module.
- Test the use of the measurement reporting cycle developed for reporting the outcomes of other physical tests being conducted, but adapt the associated instructions on completing duplicate measurements, if it is not appropriate for the test (e.g. invasive tests or exams).

Importantly, the recommendations noted above are also applicable and relevant to the wider ID research field on anthropometry assessment in persons with ID. Several other supporting recommendations were made in the discussion of the study's findings (Chapter 5), the key learnings (Section 6.2), and the strengths and limitations of the study (Sections 6.4 to 6.5).

Translation of National or Regional Representative Anthropometric Data on People with ID

- Submit data reports on the key anthropometry findings to the relevant statutory or non-statutory bodies concerned with promoting the health and well-being of the population.
- Develop accessible bulletins and posters for the attention of people with ID and key stakeholders on the BMI and waist circumference findings, by age groups and gender.
- Submit nationally representative BMI measured data to the WHO Global Database on BMI.

6.6.2 Key Recommendations for Education

- Encourage higher education and professional development programmes for healthcare professionals to include, or expand upon, the importance of anthropometric measurements in routine healthcare practice for people with ID, and the role of familiarisation in improving health screening and examinations with this population group.
- Encourage dialogue from multiple perspectives (e.g. researchers, practitioners) on the rapid research field tool developed for the baseline assessment of anthropometry and the application of its broad principles in practice settings, and discuss the adaptability of the accessible anthropometry materials to other physical tests.

6.6.3 Key Recommendations for Practice

- Encourage ID service providers and general practitioners to measure, at a minimum, the height (standing or surrogate; ulna length if required), weight and waist circumference (where possible) of all people with ID on a yearly basis.
    - Highlight the importance of duplicate measurements being taken and recorded, and the mean value being used to monitor changes over time, and of this value being made available, if requested.
- Urge Rosscraft, the designer of the Segmometer 4, to explore the possibility of developing a smaller segmometer (55cm option proposed) to increase accessibility to all.
- Urge Seca, the designer of the new 217 model, to explore the possibility of manufacturing a darker baseplate with the footprints option to improve the ease of measurement for those with visual impairment and others needing reference points.

6.6.4 Key Recommendations for Policy

- The Department of Health and Children (DoHC) and the Health Service Executive should treat the nutritional health of people with ID as a high-priority policy issue in research (as part of all population-based studies and as specifically targeted pieces of research where needed), national health and nutritional policies and programmes.
- The DoHC, the Health Research Board and the National Disability Authority should provide greater resources to support anthropometry research in this population and to develop and roll out accessible health prevention and promotion programmes and services.

6.7 Closing Remarks

Overweight and obesity is a major public health issue, and, combined with population ageing, the identification of people with intellectual disability (ID) at increased risk of health problems due to being overweight or obese (and underweight) needs to be seen as national research priority in Ireland, as it is for the general population. Without valid and reliable national and regional anthropometric data, a key component of nutritional status assessment, on people with ID, not alone can we not establish the prevalence of their weight status, evaluate their body composition changes or track trends over time; we cannot identify those at elevated risk or specifically develop and target health programmes and services at those in most need.

Uniquely, this study confirms that highly rigorous anthropometry and data-collection protocols, based on generic reference methods, can be successfully operationalised with adults with ID in

research. The methodology employed serves as a model for the IDS-TILDA study and others seeking to research anthropometry in this population. The new approach to anthropometry assessment developed will not only maximise the equality of opportunity for all persons with ID – irrespective of their age, gender, level of ID or living circumstances – to take part, but also ensures high-data quality. The major and unexpected finding of the study was the critical contribution of familiarisation theory and its application in the design of the anthropometry assessment process to both the research outcomes and to the participant's, such as reducing any anxiety about the measurements. This study represents a large attempt towards dealing with many of the methodological limitations of previous ID research and seeks to enhance future research on anthropometric values in this population group. The findings have also answered the question raised earlier by Verstraelen *et al.* (2009) on how to best measure the weight status of people with ID. Lastly, this study represents an important milestone towards the goal of ensuring that the right of people with intellectual disability to be included in anthropometric-related surveillance is fulfilled, and that high-quality anthropometric data is collected for them both in Ireland and beyond.

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Appendices

***Note**: In several of the appendices, for practical reasons, it was not possible to present material in the same size or to the same quality as the original.*

Appendix 1 – Supplemental Searches

Intellectual Disability Research Journals
British Journal of Learning Disabilities
Developmental Disabilities Research Reviews
Journal of Applied Research in Intellectual Disabilities
Journal of Developmental and Physical Disabilities
Journal of Intellectual and Developmental Disability
Journal of Intellectual Disabilities
Journal of Intellectual Disability Research
Journal of Learning Disabilities
Journal of Policy and Practice in Intellectual Disabilities
Learning Disabilities Research and Practice
Learning Disability Practice
Research in Developmental Disabilities
The Frontline of Learning Disability

Generic Research Journals
Obesity Research
International Journal of Obesity
Obesity Reviews
The Journal of Nutrition, Health and Aging
European Journal of Clinical Nutrition
International Journal of Obesity and Related Metabolic Disorders
Journal of Public Health Nutrition
Journal of Advanced Nursing

Websites
NHANES - www.cdc.gov/nchs/nhanes.htm
HRS - http://hrsonline.isr.umich.edu
ELSA - www.elsa-project.ac.uk
SHARE – www.share-project.org/
International Chair on Cardiometabolic Risk - www.myhealthywaist.org
MENCAP - www.mencap.org.uk
Department of Health and Children - www.dohc.ie
World Health Organization - www.who.int
Centres for Disease Control and Prevention - www.cdc.gov/Obesity
safefood - www.safefood.eu
Irish Public Health - www.publichealth.ie
National Institute for Health and Care Excellence - www.nice.org.uk
Irish Heart Foundation - www.irishheart.ie
Obesity Hub - http://obesity.thehealthwell.info
Irish Nutrition and Dietetic Institute - www.indi.ie

Electronic Mailing Lists – Regular News Updates / Newsletters (RSS Feeds)
World Obesity Federation
Obesity - a research journal
International Chair on Cardiometabolic Risk
Cardiometabolic Health Congress
International (and European) Association for the Study of Obesity
Institute of Public Health in Ireland (The Health Well)
The Lancet

Appendix 2 – Key Words and Connectors

1) Key Words

"intellectual disability"; "intellectual disabilities"; "learning disability"; "learning disabilities"; "disability"; "anthropometry"; "anthropometric assessment"; "anthropometry measurements" "anthropometric measurements"; "overweight"; "obesity"; "underweight"; "nutritional health"; "nutritional screening"; "nutritional status"; "body composition"; "malnutrition"; "standing height"; "surrogate height measurements"; "ulna length"; "knee height"; "arm-span"; "demi-span"; "weight"; "waist circumference"; "clothing effect"; "waist circumference on bare skin"; "waist circumference over clothing"; "hip circumference"; "mid-upper arm circumference"; "upper arm circumference"; "body mass index"; "self-report"; "measured"; "familiarisation"; "accessible information"; "barriers to health screening"; "measurement difficulties"; "estimating body mass index"; "anthropometry training"; "anthropometric training"; "international society for the advancement of kinanthropometry"; "ISAK"; "measuring equipment"; "segmometer"; "technical error of measurement"; "reliability"; "validity"; "feasibility"; "ageing"; "adults"; "older adults"'; "elderly"; "ageing population"

2) Boolean Connectors

AND, OR and NOT

Appendix 3 – Supplementary Qualitative Data on the Key Items Followed Up

Themes of the Key Items Followed Up (Post Literature Review)	
Theme	**Contextual Details & Analytic Memos**
Waist Circumference (WC) Measuring Sites	One of the most cited items recorded was the identification of the waist circumference (WC) measuring sites used by personnel and/or recommended, as different anatomic sites were reported in the literature and there appeared to be no universally accepted protocol for this measurement. **Excerpts from sites used:** *"Waist circumference was measured at the iliac crest" [Professor – Scientific Director]* *"Waist circumference was measured at the level of the belly button" [Practice Dietician]* *"... measured at the smallest area below the rib cage and above the belly button" [Professor – Nutrition Program]* *"Waist circumference was measured at the midpoint" [Researcher]* *"Waist circumference is taken at the natural narrowing of the waist ... if no natural narrowing then it is taken half way between the top of the iliac crest and the 10th rib" [Anthropometric Trainer]* *"Waist was at the most narrow point, abdomen was at the level of the umbilicus. We did not reference sites because they are pretty common in anthropometric assessment" [Researcher]* **Excerpts from the recommendations made:** *"I would strongly recommend that you use a bony landmark e.g. iliac crest rather than the umbilicus for your measurement site. The rationale for such a decision can be found in a recently comprised review/report written by an expert panel" [Professor – Kinesiology]* *"Recommend the iliac crest as the site for waist circumference measurement" [Professor/Researcher]* *"It is easy to feel the bony landmarks in anyone with BMI under 35. You do not have to mark anything. There is no valid or sensible alternative" [Professor – Human Nutrition]* **Example of a discussion between clinicians in response to questions asked:** ***Professor:*** *"Use the WHO method. There is no reason to do otherwise ... bony landmarks are always identifiable. The umbilicus may reach the ground in very fat people. What would you do then? I would reject a paper which tried to use the umbilicus. The National XX is not a useful source of information on this point and their suggestion is [use of umbilicus], I think unfounded. I will copy this to the Chair of the XX, who will be sympathetic to your concerns, I am sure."*

	Chair's response: *"My understanding is that the United Kingdom way is midpoint between the iliac crest and the lower rib margin at the side, which just so happens usually to be near to the umbilicus. Bony landmarks are certainly not always palpable, hence the US favoured approach of lower tape margin sitting on the iliac crest (I believe). In practice failing all else, measuring at the umbilicus is a perfectly good practice method in any given individual to track changes and monitor improvements in body morphology if bony landmarks are hidden, although there are no cut-offs and the approach is unsuitable epidemiologically speaking."* ***Professor's response:*** *"The tape at the top of the iliac crest is essentially the same as midway between the iliac crest and lowest rib. The gap is only about 1-2 cms. The umbilicus is useless, practical yes but useful no. If the bony landmarks are impalpable you have a patient with colossal obesity, in whom the waist circumference (WC) will not be helpful because it is hoiked down to knee level ... so you don't need to know WC and can record >125cms or whatever your highest sensible measurement is."*
WC – Over Clothing or on Bare Skin	Of equal proportion to the previous observation was the identification of WC measurements being taken over clothing or on bare skin and/or recommended by personnel, as there was no universally accepted position reported in the literature for this measurement. *"We took circumference measure over clothing although we limited it to a thin shirt if possible (i.e. participants removed sweaters, thick belts, if necessary). We elected to do this to increase the comfort of the participants and to reduce the need for a private room. Not ideal but we felt it was most appropriate." [Researcher]* *"We did waist circumference over clothing in [xx] and it was a complete waste of time." [Professor – Human Nutrition]* *"Preferably taken over skin or if required over light clothing, allowing 1cm for clothing." [Practice Dietician]* *"Waist circumference was taken against skin or if preferred over light clothing." [Professor – Kinesiology]* *"... we have collected around 7-8000 measurements all taken over one layer of clothing. We are confident that our measurements are valid and I would disagree with whoever told you that it was a waste of time taking them over clothing. As long as it is only one layer then it shouldn't be a problem. I really think you will be surprised at the little effect one layer has, when you undertake your validation study in adults." [Senior Lecturer]* *"All participants were in lightweight clothing for the measurements." [Researcher]* *"We aimed for bare skin but this was not always possible or appropriate e.g. history of abuse, slightly apprehensive person." [Consultant Psychiatrist]* *"We chose to do the measurement in light clothing because of the nature of the Healthy Athlete screening events: (1) little or no area for privacy (2) sensitivity for athletes and their personal space (3) implementation of a new screening element into Health Promotion (4) light clothing means t-shirt (5) parental concern regarding an individual of opposite sex touching the athlete under the shirt." [Global Clinical Advisor]*

Anthropometry Training	A slightly lower number of records than for the previous observations related to anthropometry training enquiries made with those: a) involved in studies, as details were not reported in the literature, and b) working in the nutrition field. *"I did not go on any formal training course ... but received training on body composition measurements as part of practical's for undergraduate nutrition modules. As far as I aware there are no body composition measurements courses available in Ireland." [Researcher]* *"Interviewers received training (up to a day) from nurses experienced in fieldwork." [Researcher]* *"The researcher was a medical doctor and thus trained in physical examinations." [Researcher]* *"This course is mainly theoretical based and has very limited elements which relate to anthropometry specifically." [Senior Lecturer]* *"We do not offer any training in anthropometric measuring." [Practice Dietician]* *"... regarding anthropometric training, again this doesn't happen as far as I know." [Health Promotion Officer]* *"ISAK anthropometry course is both practical and theoretical and is delivered mainly to sports scientists. It includes topics such as equipment and calibration, anatomy and body composition, and health applications. Successful candidates will gain an international qualification in the accurate measurement of body composition." [Anthropometric Trainer]*
WC Clothing Effect	A substantial number of records related to whether personnel had addressed the effect of clothing on WC measurements, as it was not detailed in the related literature. *"Yes, we deducted 0.5cm from the measure to account for light clothing." [Researcher]* *"In practice, I allow 1cm for measurements taken over clothing." [Practice Dietician]* *"We did not validate waist circumference, all participants were in light clothing. To be honest, I don't think we identified a reference for the clothing effect as it is something that is widely accepted and used in clinical settings and in measurements for research." [Researcher]* *"I have to say I am not aware of what clothing effect there is in adult measurements, only known in children. The best thing to do would be your own validation study." [Senior Lecturer]* *"You pose a good question on the light clothing. We have not done a validation study and do not adjust the measurement. A validation study is a good idea." [Global Clinical Advisor]* *"In the report we will not adjust for individuals who opted to wear light clothing, this may be investigated at a later date." [Researcher]*

	"No, we didn't include a clothing effect, which I can now see was a weakness." [Consultant Psychiatrist] *"Taken that a thin layer has only little impact on the radium of a belly, I feel it quite safe to assume that light clothing does not have a large impact on waist circumference." [Researcher]*
Experience of Measurements in Practice	A significant number of records were related to understanding researchers' and clinicians' experience of conducting measurements in practice with adults with intellectual disability (ID). *"No, we did not devise a booklet on the measurements for participants. We did meet them and their caregiver in advance to discuss the measures to ensure comfort but a manual per se was not written. We did not include those with severe or profound ID. We had no real measurement problems. Height and weight were pretty easy, although standing on a scale involved some balance that was difficult for some." [Researcher]* *"I haven't used the waist/hip ratio measurements. We have used knee height and demi-span measurement and they are not difficult to use ... but having used both I think demi-span is easier. We also have to consider that knee height can be quite stunted in those who are unable to 'weight bear' e.g. those confined to wheelchairs." [Practice Dietician]* *"When assessing adults I routinely carry out weight and height (BMI), as well as waist measurements. For adults who are immobile and unable to stand for supine length, knee height is carried out, but where possible, supine length is the preferred option." [Practice Dietician]* *"The dietetics service in [xx] is grossly inadequate and I continue to lobby for more staff. I am still just using weighing scales (Seca stand on, chair scales or hoists) to measure weight and a stadiometer where possible to measure height. Often these weight and height measurements may not be completely accurate due to poor balance, posture etc. but I find them useful in practice ... I have used ulna length (referring to MUST tables) to estimate the height ... however I generally use a wall mounted or portable (Leicester Height measure) stadiometer or guess by 'eyeballing' if height is not absolutely essential in the client nutritional management. I have not yet measured WHR, MUAC etc in this client group. I had planned to measure waist in a group session but weight and height took so much time that I did not pursue waist measurement too." [Practice Dietician]* *"At present the measurements we would currently use are: weight, using a stand on, wheelchair or hoist scale depending on the physical ability of the person and facilities available where the person is being weighed, and height, using either a stadiometer taken standing and length, using a rollometer, taken lying flat. We have found that generally this population group are uncomfortable with or do not like or are very afraid of invasive measurements, so we avoid any measurements such as skinfolds and even waist/hip ratio. At present we do not use any surrogate measurements for length or height." [Practice Dietician]* *"I am a dietician and teach nutritional assessment, including anthropometry and in this capacity I have become more aware of the problems in measuring height and weight." [Practice Dietician]*

	"I screened 93 adults with intellectual disability who lived in community based homes. This took a long time. I did the measurements myself with the help of a student research aide. I know from experience how difficult it is to obtain correct height and weight. We did skinfolds measures – too many errors that the data was not worth analysing. One group is more compromised than the other – depending on where they live. There are other ways for getting height and weight of individuals who were unable to stand but I felt that these were just too invasive to the individuals." [Director of Dietetics Program/Registered Dietician]
Other Observations	Other observations recorded with less frequency included: the transfer of knowledge gained from the literature review and enquiries made by the researcher to clinicians in practice; with slightly less but equal weighting, the types of measurements undertaken in practice, the type of equipment used, and surrogate measurements (e.g. for standing height, ulna length and for Body Mass Index, mid-upper arm circumference), and, with one less observation, the review of the researcher's PhD study with clinicians, researchers and a family advocate. The least recorded observations, but again with equal weighting, were the nutritional status of adults with ID, whether one or two measurements were or are taken, and the status of accessible materials use as part of measurement practice or research conducted. The influence of all the information obtained on the decisions made will be discussed in Chapter 3, Section 3.5.2.

Appendix 4 – Letter of Ethical Approval

THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

SCHOOL OF MEDICINE
FACULTY OF HEALTH SCIENCES

Trinity College, Dublin 2, Ireland
Tel: +353 1 896 1476
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School Administrator
Email: fmcnamar@tcd.ie

Prof. Mary McCarron
School of Nursing and Midwifery,
Trinity College Dublin,
24 D'Olier Street, Dublin 2

10th July, 2008

Study Title: An Intellectual Disability Supplement to the Irish Longituddinal Study on Ageing (TILDA)

Dear Prof. McCarron,

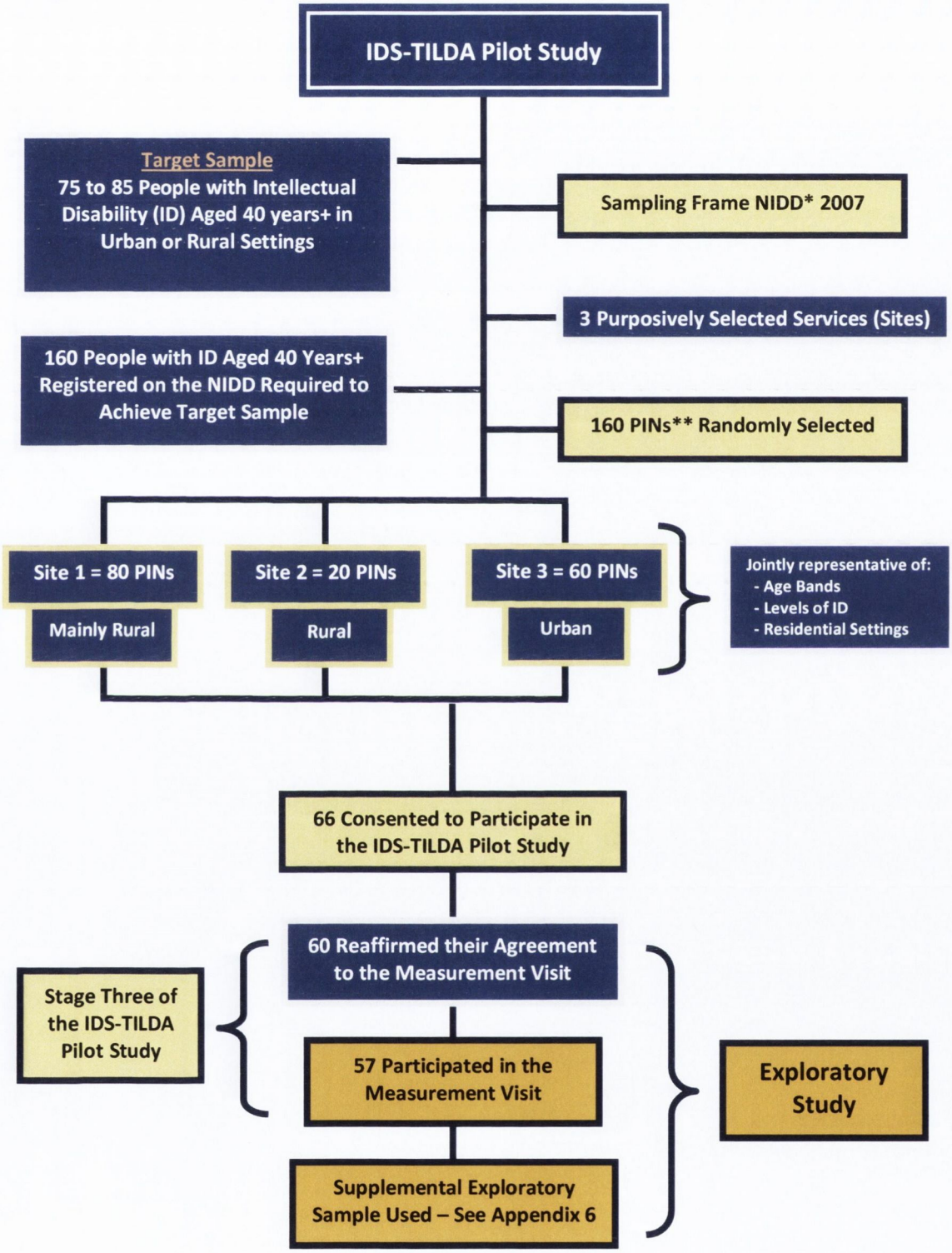
Further to the meeting of the Faculty of Health Sciences Research Ethics Committee on 27th May 2008, I am pleased to inform you that the above project has been approved without further audit.

Yours sincerely,

Dr. Orla Sheils
Chairperson
Faculty of Health Sciences Ethics Committee

Appendix 5 – Exploratory Sample Selection and Recruitment Process

Summary (*n*=160)

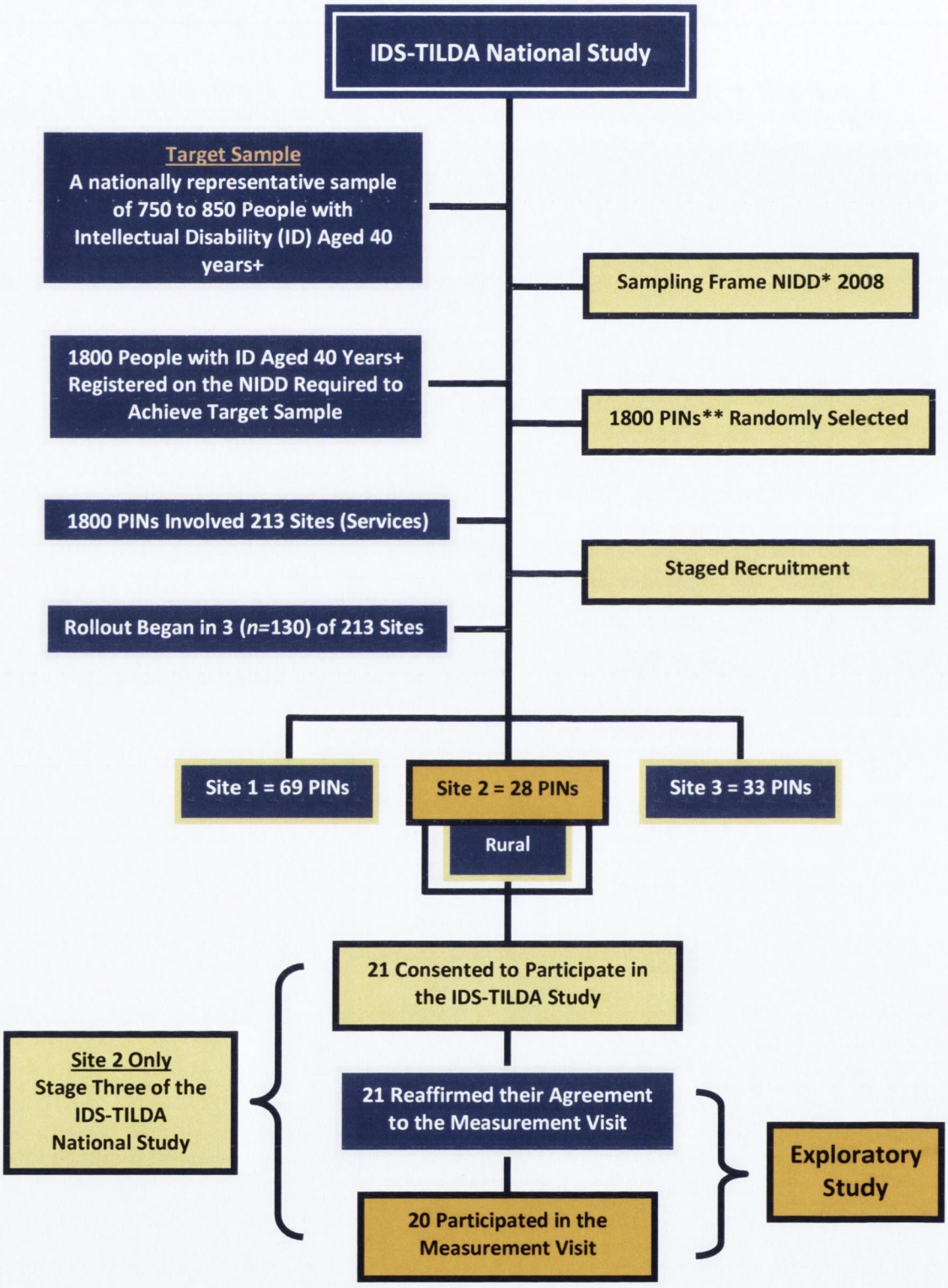


*National Intellectual Disability Database (Kelly *et al.* 2007)

** People with Intellectual Disability Registered on the NIDD

Appendix 6 – Supplemental Sample Selection and Recruitment Process

Summary (*n*=28)



*National Intellectual Disability Database (Kelly *et al.* 2009)

** People with Intellectual Disability Registered on the NIDD

Appendix 7 – Measurement Instructions

(Shortened Version – Reference Only)

Disclaimer: *The instructions detailed in this Appendix* ***should not be viewed or used in isolation*** *of the steps and components described in Chapter 3: Methodology and the linked appendices.*

1. Standing Height Measurement

(a) Purpose

To measure the standing height of all eligible participants, so it can be calculated with weight to determine the participant's body mass index, and be compared to estimated height using ulna length and self-reported height, where possible.

(b) Equipment

The equipment and materials required for this measurement are:

- Seca Leicester Height Measure
- Seca Model 217 Mobile Stadiometer
- Small Spirit Level
- Accessible Height Measurement Showcard
- A4 Landscape of Study Logo (use as a focus point, if needed)
- Medium sterile wipes

Equipment Set-up:

- Ensure all the rods are connected correctly and firmly in place.
- Place the portable stadiometer against a wall to ensure maximum rigidity.
- Place on a hard level surface.
- Avoid a carpeted floor if possible. If the entire household is carpeted, choose the floor with the thinnest and hardest carpet.
- Use a small spirit level to determine the best location (e.g. most level flooring: the range accepted on the spirit level bubble should be centred or at least 75% within the two lines).
- Record the type of flooring in the Results Workbook.
- Ensure the relevant calibration checks were carried out before continuing.

(c) Eligibility

Participants are excluded from the height measurement if they are:

- wheelchair- or chair-bound
- too stooped to obtain a valid measurement
- too unsteady on their feet
- find it painful to stand or stand straight
- express verbally or non-verbally their wish not to have their height measured

and

- if the researcher feels it would not be safe to complete

If any of the above or other reasons apply, select and code the relevant option *"height not attempted"* or *"height refused"* and code the associated reason(s) that apply, in the Results Booklet. Once completed, move on to the next eligible measurement.

(d) Briefing and Demonstration Stage

If the participant is eligible, inform them that you would like to measure their height.

- Provide a brief overview of the height measurement and its purpose, in small segments.
- Use the accessible showcard to guide the description and demonstrate the measurement.
- Encourage the participant to get involved in the briefing and demonstration stage as much as possible (e.g. get them to take a deep breath in, to look up and down).
- Check if the participant (or proxy) has any questions and address each question separately.

If you feel the measurement is safe to conduct and no additional information is needed or concerns arise during the briefing or demonstration stage, ask the participant:

- *"Would you be willing to have your height measured?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or the demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, code the associated reason(s) that apply in the Results Booklet and go to the next eligible measurement.

(e) Preparation Stage

If the participant has agreed to take part, ask them to remove their footwear (excluding socks), any heavy outer clothing (e.g. jumper), headgear (e.g. hat) or to adjust their hairstyle (e.g. buns or ponytails), and remove all objects from their pockets (e.g. coins) in order to obtain a measurement that is as accurate as possible. The removal of excess clothing will also allow you to see the participant's posture more clearly, which is an important validity concern.

(f) Measurement Stage

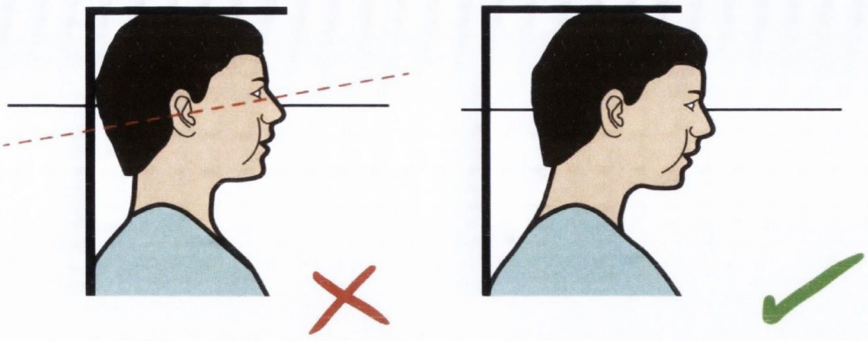
Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate, as needed):

- Stand with his/her back to the measuring rod, facing forward
- Stand as straight as possible, with both feet flat on the baseplate
- Distribute weight evenly on both feet and keep their legs straight
- Place heels together and heels, buttocks and upper part of the back touching the rod
- Relax arms and shoulders, and loosely hang their arms by their sides

Then instruct the participant to (and demonstrate, as needed):

- Look straight ahead at a fixed point (use the study logo card if needed)
- Raise and lower their chin until their head is in the Frankfort plane position (see Figure 1: orbitale is in the same horizontal plane as the tragion), if the alignment is not naturally assumed.

Figure 1



- Take a deep breath in without lifting their heels or moving the position of their head

Immediately, take the following steps (and brief the participant on the relevant steps only):

- Lower the headplate down on the Vertex.
- Apply sufficient pressure to compress the hair.
- Quickly check all the criteria, particularly their heels and Frankfort plane position.
- Take the measurement before the participant exhales.
- Record the value of the reading.
- Raise the headplate enough to avoid any injury.
- Ask the participant to step forward off the stadiometer.
- Assist or guide the participant off the stadiometer, where needed.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in centimeters and millimeters (e.g. 176.6cm)
  If the measurement falls between two millimeters, the nearest even millimeter is recorded. For example, if the figure falls between 176.4cm and 176.5cm, round the figure down (=176.4cm); if it falls between 176.5cm and 176.6cm, round the figure up (=176.6cm).

(h) Recording the Associated Measurement Components

In the Results Workbook, record:

- the time the measurement is taken
- the validity status and details of any related problems
- the type of flooring

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and code the reasons for the non-obtainment in the Results Workbook.

(j) Equipment Check: After 1st Round of Measurement

Wipe the headplate and/or baseplate if required.

(k) Completion of the Measurement Process

On completion of duplicate measurements, check both readings. If they differ by more than 0.5cm, take a third measurement if possible.

Lastly, at the end of the measurement process, record the experience of using the equipment and any other related information in the Results Workbook.

2. Ulna Length Measurement

(a) Purpose

To measure the left and right ulna lengths of all eligible participants, so the similarity and/or difference between the sides can be examined.
The length of the ulna bone will be converted to an estimated height using the MUST tool, and the relationship of estimated height to measured height and self-report height, and its impact on body mass index classification will be examined.

(b) Equipment

The equipment and materials required for this measurement are:

- Rosscraft Segmometer *4*
- Thinline Lufkin Executive Measuring Tape (W606PM)
- Hypoallergenic Skin Marking Pencil
- Accessible Ulna Length Measurement Showcard
- A4 Landscape of Study Logo (use as a focus point, if needed)
- Small sterile wipes

Equipment Set-up:

- Visually check the tape is not kinked. If in doubt, check the tape against the meter stick.
- Ensure the relevant calibration checks were carried out before continuing.

(c) Eligibility

Participants are excluded from the ulna length measurement if:

- they find it painful to place both arms in the required position
- both forearms are amputated or both arms are in plaster
- both forearms have open wounds or rashes at either landmark sites
- clothing is not suitable for locating the landmarks on left and right arm
- they express verbally or non-verbally their wish not to have their ulna length(s) measured
- the researcher feels it would not be safe to complete

If any of the above or other reasons apply, select and code the relevant option *"ulna length not attempted"* or *"ulna length refused"* and code the associated reason(s) that apply, in the Results Booklet. Once complete move on to the next eligible measurement.

(d) Briefing and Demonstration Stage

If the participant is eligible, inform them that you would like to measure the length of their forearms (elbow to wrist on each side).

- Provide a brief overview of the ulna length measurement and its purpose, in small segments.
- Use the accessible showcard to guide the description and demonstrate the measurement.

- Encourage the participant to get involved in the briefing and demonstration stage as much as possible (e.g. get them to point to their wrist and elbow).
- Invite the participant to touch and feel the equipment during the demonstration.
- Check if the participant (or proxy) has any questions, and address each question separately.

If you feel the measurement is safe to conduct and no additional information or concerns arise during the briefing or demonstration stage ask the participant:

- *"Would you be willing to have your ulna [arm] measured?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, code the associated reason(s) that apply in the Results Booklet and go to the next eligible measurement.

(e) Preparation Stage

If the participant has agreed to take part, ask them to remove any upper outer garments such as a cardigan, jacket or jumper where applicable, and adjust the remaining single upper outer garment (e.g. top, shirt), where necessary, so that their forearms are bare. Also ask the participant to remove any jewellery/watch around their wrists.

Remind the participant that you want to locate both their elbow and wrist bone with their support (where possible).

(f) Measurement Stage (same procedure for the left and right ulna length)

Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate as needed):

- Stand for the measurement, if possible – if the participant is unable to stand and/or prefers not to stand, it can be taken in a seated (no arm-rests are preferable) or lying position
- Point to their elbow and wrist bone, if possible
- Place their (left/right) arm and hand flat across their chest with their fingers pointing to the opposite shoulder (position preferred) – if this is not possible, advise them to place their arm across their stomach or rest their arm on the chair or a table horizontally
- Relax their other arm.
- Look straight ahead at a fixed point (use the study logo card if needed).

Once the participant is positioned correctly, take the following steps (and brief the participant on the relevant steps only):

- Locate and landmark the midpoint of the styolid process (prominent bone in the wrist).
- Hold one branch of the segmometer on the site landmarked (midpoint of styolid process) while the other branch is placed on the olecranon process (point of the elbow).
- Check each branch is at the respective landmark.
- Take the reading at the end of a normal expiration.
- Record the value of the reading and the side measured only.
- Remove the landmark.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in centimeters and millimeters (e.g. 26.6cm)
  If the measurement falls between two millimeters, the nearest even millimeter is recorded. For example, if the figure falls between 26.4cm and 26.5cm, round the figure down (=26.4cm); if it falls between 26.5cm and 26.6cm, round the figure up (=26.6cm).

(h) Recording the Associated Measurement Components

In the Results Workbook, record (for each side measured):

- the validity status and details of any related problems
- the position of the participant (e.g. standing)
- the position of their arm for the measurement (e.g. diagonal across chest)

On completion, repeat the measurement stage on the other arm, where possible, with the participant's consent/assent.

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and code the reasons for the non-obtainment in the Results Workbook.

(j) Equipment Check: After 1st Round of Measurement

Wipe the end of each branch on the segmometer if required.

(k) Completion of the Measurement Process

On completion of duplicate measurements of both the left and right side, check both readings per side. If they differ by more than 0.5cm, take a third measurement if possible. Lastly, at the end of the measurement process, record the experience of using the equipment and any other related information in the Results Workbook.

3. Mid-Upper Arm Circumference Measurement

(a) Purpose

To measure the mid-upper arm circumference (MUAC) of all eligible participants, so as to examine the association between MUAC and body mass index.

(b) Equipment

The equipment and materials required for this measurement are:

- Rosscraft Segmometer *4*
- Thinline Lufkin Executive Measuring Tape (W606PM)
- Hypoallergenic Skin Marking Pencil
- Accessible MUAC Measurement Showcard
- A4 Landscape of Study Logo (use as a focus point if needed)
- Small sterile wipes

Equipment Set-up:

- Visually check the tape is not kinked. If in doubt, check the tape against the meter stick.

- Ensure the relevant calibration checks were carried out before continuing.

(c) Eligibility

Participants are excluded from the MUAC measurement if:

- they find it painful to place both arms in the required position
- both arms are amputated or are in plaster
- both upper arms have an open wound or rash at any of the three landmark sites
- clothing is not suitable for locating the landmarks on left and right arm
- they express verbally or non-verbally their wish not to have their MUAC measured
- the researcher feels it would not be safe to complete

If any of the above or other reasons apply, select and code the relevant option *"MUAC not attempted"* or *"MUAC refused"* and code the associated reason(s) that apply in the Results Booklet. Once complete move on to the next eligible measurement.

(d) Briefing and Demonstration Stage

If the participant is eligible, inform them that you would like to measure around their left arm (or right, if left is not feasible).

- Provide a brief overview of the ulna length measurement and its purpose, in small segments.
- Use the accessible showcard to guide the description and demonstrate the measurement.
- Encourage the participant to get involved in the briefing and demonstration stage as much as possible (e.g. get them to point to their shoulder and elbow).
- Invite the participant to touch and feel the equipment during the demonstration.
- Check if the participant (or proxy) has any questions, and address each question separately.

If you feel the measurement is safe to conduct and no additional information is needed or concerns arise during the briefing or demonstration stage, ask the participant:

- *"Would you be willing to have your MUAC (or arm) measured?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, code the associated reason(s) that apply in the Results Booklet and go on to the next eligible measurement.

(e) Preparation Stage

If the participant has agreed to take part, ask them to remove, if they have not already done so, any upper outer garments such as a cardigan, jacket or jumper where applicable, and adjust the remaining single upper outer garment (e.g. top, shirt), so that the top of their arm (left preferably) is bare. If needed, ask them to roll their t-shirt or shirt up to their shoulder if possible.

Remind the participant that you want to locate their shoulder and elbow with their support (where possible) and that a small (removable) line will be drawn between these two points, as shown in the demonstration.

(f) Measurement Stage

Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate as needed):

- Stand for the measurement, if possible – if the participant is unable to stand and/or prefers not to stand, it can be taken in a seated (no arm-rests preferable) or lying position
- Point to their left* shoulder and elbow, if possible
- Relax their shoulders
- Let their arms hang loosely by their sides
- Look straight ahead at a fixed point (use the study logo card if needed)

*If it is not possible to measure the left MUAC, then the right MUAC should be measured and the instructions for the left hand, arm and side should be replaced with right hand, arm and side.

Once the participant is positioned correctly, take the following steps (and brief the participant on the relevant steps only):

Acromiale

- Stand behind and on the left hand side of the participant (or right if required).
- Palpate along the spine of the scapula to the corner of the acromion.
- Apply the straight edge of the pencil to the lateral and superior margin of the acromion to confirm the location of the most lateral part of the border.
- Mark the most lateral aspect with a horizontal line.

Midpoint (Part One)

- Ask the participant to bend their left arm at a 90 degree angle, with the upper arm held parallel to the left side of the body.
- Standing at the side of the participant, place one branch (housing) of the segmometer at the acromion landmark and the other branch at the point of the elbow (olecranon process).
- Check each branch is placed correctly and measure the distance between the two landmarks.
- Identify the midpoint between these two landmarks.
- Place a small mark (horizontal line) at the level of the midpoint using the housing branch of the segmometer (after the earlier demonstration the lead of the skin marking pencil was rubbed across the tip of this branch to assist the marking process).
- Swiftly re-check the distance between the two points to ensure the midpoint site is accurate.

Midpoint (Part Two)

Ask the participant to:

- stand (sit or lie if required) in a relaxed position
- let their arms hang by their sides
- hold their left arm out slightly from their body to allow the tape to be passed around the arm

Then take the following steps:

- Put the tape around the arm and place the tape at the midpoint landmark.

- Measure using the cross-hand technique.
- Make sure the tape is snug (tension constant) but not tight or so that it compresses the skin.
- Check that the tape is horizontal around the arm (not sloping), that it is in continuous contact with the skin, and that the muscle of the arm is not flexed or tightened.
- Record the value of the reading and side measured only.
- Remove the landmark.

Similar to all measurements, each relevant step should be explained to the participants at the level appropriate to their understanding, to ease any anxieties or concerns with this measurement, particularly as it, along with the waist circumference measurement, requires the most contact. It is appreciated that all people have an area around their body known as "personal space" and (as noted in Appendix 20), when this area is invaded they may feel uncomfortable, so extra attention should be paid to the participant's body language during the measurement, to ensure their personal space is not encroached.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in centimeters and millimeters (e.g. 20.3cm)
  If the measurement falls between two millimeters, the nearest even millimeter is recorded. For example, if the figure falls between 20.3cm and 20.4cm, round the figure up (=20.4cm); if it falls between 20.8cm and 20.9cm, round the figure down (=20.8cm).

(h) Recording the Associated Measurement Components

In the Results Workbook, record:

- the validity status and details of any related problems
- the position of participant for the measurement (e.g. standing)

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and code the reasons for the non-obtainment in the Results Workbook.

(j) Equipment Check: After 1st Round of Measurement

Wipe the end of each branch on the segmometer and the tape if required.

(k) Completion of the Measurement Process

On completion of duplicate measurements, check both readings. If they differ by more than 0.5cm, take a third measurement if possible. Lastly, at the end of the measurement process record the experience of using the equipment and any other related information, in the Results Workbook.

4. Weight Measurement

(a) Purpose

To measure the weight of all eligible participants, so that, along with measured, estimated and self-reported height, body mass index can be calculated, and the differences may be compared. Measured weight will also enable the relationship between measured and self-reported weight to be examined, and any systematic biases (e.g. over or under-reporting) to be identified.

(b) Equipment

The equipment and materials required for this measurement are:

- Seca 877 Flat Scales for Mobile Use
- Seca 677 Electronic Wheelchair Scales
- Small Spirit Level
- 5kg M1 Cast Iron Test Weight (leave in car unless needed)
- Accessible Weight Measurement Showcard
- A4 Landscape of Study Logo (use as a focus point, if needed)
- Medium sterile wipes

Equipment Set-up:

- Place the scales (flat and wheelchair) on a hard level surface.
- Avoid a carpeted floor if possible. If the entire household is carpeted, chose the floor with the thinnest and hardest carpet.
- Use a small spirit level to determine the best location (e.g. most level flooring – the range accepted on the spirit level bubble should be centred or at least 75% within the two lines).
- Record the type of flooring in the Results Workbook.
- Check that the scale reads 0.0.
- Ensure the relevant calibration checks were carried out before continuing.

(c) Eligibility

Participants are excluded from the weight measurement if:

- it is thought they will exceed 250kg (39st) on flat scales or 300 (47st) on wheelchair scales
- they express verbally or non-verbally their wish not to have their weight measured
- they are bedbound, frail and/or have casts
- the researcher feels it would not be safe to complete

If any of the above or other reasons apply, select and code the relevant option *"weight not attempted"* or *"weight refused"* and code the associated reason(s) that apply, in the Results Booklet. Once complete move on to the next eligible measurement.

(d) Briefing and Demonstration Stage

If the participant is eligible, inform them that you would like to measure their weight.

- Provide a brief overview of the weight measurement and its purpose, in small segments.

- Use the accessible showcard to guide the description and demonstrate the measurement.
- Encourage the participant to get involved in the briefing and demonstration stage as much as possible (e.g. get them to look straight at a fixed point, such as the study logo).
- Check if the participant (or proxy) has any questions, and address each question separately.

If you feel the measurement is safe to conduct and no additional information is needed or concerns arise during the briefing or demonstration stage, ask the participant:

- *"Would you be willing to have your weight measured?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, code the associated reason(s) that apply in the Results Booklet and go on to the next eligible measurement.

(e) Preparation Stage

If the participant has agreed to take part, ask them to remove, if they have not already done so, their footwear (excluding socks), any heavy outer upper clothing (e.g. jumper) and objects from their pockets (e.g. mobile, coins) in order to obtain a measurement that is as accurate as possible. Participants should be weighed with a single layer of upper and lower light clothing, where possible. Light clothing is defined as follows: t-shirt, shirt or blouse and trousers or skirt.

Remind the participants that you want to get the most accurate measurement and the removal of excess clothing is very important. Demonstrate the influence of excess clothing on the measurement if needed.

Wheelchair Users, Unable to Stand Independently, Unsteady or Tired
If the participant is a wheelchair user or if they are unable to stand independently, are unsteady or tired, they should be weighed sitting, using the wheelchair scale.
If the participant is in a seated position for the measurement, the weight of the chair or wheelchair needs to be obtained, where possible, and both the participant's weight and the weight of the chair or wheelchair needs to be recorded in the Results Workbook.

The weight of the participant needs to be calculated according to the following formula:
Body weight = measured weight–mass of wheelchair/chair.

If the wheelchair scale is not feasible to set up in the selected location, the measurement should be skipped and alternative arrangements be explored (e.g. measure at day service), where appropriate and possible.

(f) Measurement Stage

Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate as needed):

- Stand (or sit depending on the scale) on the centre of the scales when the scale reads 0.0
- Distribute weight evenly on both feet
- Hang their arms loosely by their sides
- Look straight ahead at fixed point (use the study logo card if needed)

- Stand (or sit) without support once they feel secure.

Once the participant is positioned correctly, the following steps are taken (brief the participant on the relevant steps only):

- Ask the participant to stand/sit still – "be like a statue".
- Record the value of the reading, once the numbers stop moving for at least 5 seconds.
- Ask the participant to step/move off the scale.
- Assist or guide the participant off the scale, where needed.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in kilograms to the nearest kilogram (e.g. 65.6kg)
  If the participant is weighed in a seated position, record the value as raw data in the space provided until the weight of the chair/wheelchair is obtained; once secured, subtract the weight from the raw value.

(h) Recording the Associated Measurement Components

In the Results Workbook, record:

- the weight of the chair/wheelchair, where applicable
- the time the measurement is taken
- the validity status and details of any related problems
- the position of the participant for the measurement
- the type of floor surface

For those weighed in a seated position, the chair/wheelchair should either be weighed before they sit in the chair where possible, at the end of the visit, or at a suitable time for the participant.

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and code the reasons for the non-obtainment in the Results Workbook. For example, if the participant moved excessively while on the scales and the display did not remain stable for at least 5 seconds, the result should be coded as *"weight attempted – not obtained"*, as the reading is false.

(j) Equipment Check: After 1st Round of Measurement

Wipe the base of the scale (and handle of the wheelchair scale) if required.

(k) Completion of the Measurement Process

On completion of duplicate measurements, check both readings. If they differ by more than 0.5kg, take a third measurement if possible. Lastly, at the end of the measurement process record the experience of using the equipment and any other related information, in the Results Workbook.

5. Waist Circumference Measurement

(a) Purpose

To measure the waist circumference (WC) of all eligible participants, so the difference between waist circumference taken over clothing and on bare skin can be evaluated.

(b) Equipment

The equipment and materials required for this measurement are:

- Thinline Lufkin Executive Measuring Tape (W606PM)
- Hypoallergenic Skin Marking Pencil
- Accessible Waist Circumference Measurement Showcard
- A4 Landscape of Study Logo (use as a focus point if needed)
- Harpenden Skinfold Caliper
- Small sterile wipes

Equipment Set-up:

- Visually check the tape is not kinked. If in doubt, check the tape against the meter stick.
- Ensure the relevant calibration checks were carried out before continuing.

(c) Eligibility

Participants are excluded from the WC measurement over clothing if they:

- are in a wheelchair
- have a colostomy or ileostomy
- are unable to stand erect comfortably for two minutes
- are too unsteady on their feet
- are too stooped to obtain valid measurement
- are wearing clothing that is not suitable for locating the landmark and it cannot be adjusted
- express verbally or non-verbally their wish not to have their hips measured and
- if the researcher feels it would not be safe to complete

If any of the above or other reasons apply, select and code the relevant option *"WC not attempted"* or *"WC refused"* and code the associated reason(s) that apply, in the Results Booklet. Once complete, move on to the next eligible measurement.

(d) Briefing and Demonstration Stage

If the participant is eligible, inform them that you would like to measure their waist.

- Provide a brief overview of the WC measurement (over a single layer of light clothing).
- Use the accessible showcard to guide the description and demonstrate the measurement.
- Encourage the participant to get involved in the briefing and demonstration stage as much as possible (e.g. get them to feel for their hip bone).
- Invite the participant to touch and feel the equipment during the demonstration, if needed.
- Check if the participant (or proxy) has any questions, and address each question separately.

If you feel the measurement is safe to conduct and no additional information is needed or concerns arise during the briefing or demonstration stage, ask the participant:

- *"Would you be willing to have your waist measured?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, code the associated reason(s) that apply in the Results Booklet and go on to the next eligible measurement.

(e) Preparation Stage

If the participant has agreed to take part, ask them to remove, if they haven't already done so, their footwear (excluding socks), any heavy outer upper garments (e.g. jumper, jacket, cardigan) and belt if worn, where possible, so the measurement is only taken over a single layer of light clothing. Light clothing is defined as follows: t-shirt, shirt or blouse. Tight garments that alter the shape of the body should also be removed, if possible and appropriate.

Remind the participant that you want to get the most accurate measurement and that the removal of excess upper clothing (e.g. jumper) is very important. Demonstrate the influence of excess clothing if needed, using the skinfold caliper, to show the difference in the thickness of different types and layers of clothing.

Also remind the participant that you will be locating their right hip-bone (or left if necessary) with their support (where possible) and will be gently probing around the hip-bone to locate the exact point needed. If the participant did not use the bathroom facilities after the general briefing on the visit, sensitively mention that it is a good time for them to use the bathroom facilities if needed.

(f) Measurement Stage

Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate as needed):

- Stand straight in a relaxed manner (take a deep breath)
- Place feet hip width apart and distribute weight evenly on both feet
- Try and locate their right hip-bone,* where possible, if they are happy to do so – if they are unable to locate it or do not wish to, guide or place their hand in the general location, with their permission
- Fold their right arm across their chest and keep their left arm hanging by their side
- Look straight ahead at the fixed point (use the study logo card if needed)

** If is not possible to measure the right iliac crest, then the left iliac crest should be measured, and instructions for the left and right arm, hand and side should be reversed.*

Once the participant is positioned correctly, the following steps are taken (brief the participant on the relevant steps only):

- Stand behind the participant and use your left hand to stabilise the body by providing resistance on the left side of the pelvis.
- Find the general location of the top of the iliac crest with the palms of the fingers of the right hand and, once located, find the specific edge of the crest by horizontal palpation with the tips of your fingers; once identified,** adjust your stance slightly to the side of the participant (right side).

- Ask the participant to pass the tape around their waist with their left hand, if possible (otherwise loop the tape around the participant's legs and move it up to waist area).
- If the iliac crest falls on the upper garment (single layer of light clothing) and the garment is baggy, it should be folded to avoid it ruffling; if the iliac crest falls on the waistband, adjust clothing with the participant's permission, so that the upper garment is also not included in the reading. The WC measurement should only be taken over one layer of clothing.

*** If the specific edge cannot be located, ask the participant to bend to the right-hand side; position the palms of your fingers at the point of the greatest indentation in their t-shirt/shirt, and ask the participant to straighten. If the iliac crest cannot be located, record "waist circumference – attempted not obtained" in the Results Workbook.*

The strategies used to locate the iliac crest need to be exercised with great sensitivity.

- Hold the stub of the tape and the housing in the right hand while using the left hand to adjust the level of the tape at the site; ensure it is horizontal all the way around.
- Once the tape is level around the body, resume control of the stub in the left hand and use the cross-hand technique at the target site.
- Keep the tape snug but not compressing underlying soft tissue.
- Swiftly check the landmark and if it hasn't moved prepare to take the reading.
- Ensure the participant keeps looking straight ahead (at fixed point if needed).
- Ensure the participant is breathing normally (to avoid them holding their breath, continue talking or use distraction tactics to facilitate the promotion of consecutive natural breaths).
- Take the reading at the end of a normal expiration.
- Record the value of the reading and side measured only.

Similar to all measurements, each relevant step should be explained to the participants at the level appropriate to their understanding, to ease any anxieties or concerns with this measurement, particularly as it, along with MUAC, requires the most contact. It is appreciated that all people have an area around their body known as "personal space"; as noted in Appendix 20, when this area is invaded they may feel uncomfortable, so extra attention should be paid to the participant's body language during this measurement, to ensure their personal space is not encroached.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in centimeters and millimeters (e.g. 106.6cm)
  If the measurement falls between two millimeters, the nearest even millimeter is recorded. For example, if the figure falls between 106.4cm and 106.5cm, round the figure down (=106.4cm); if it falls between 26.5cm and 26.6cm, round the figure up (=106.6cm).

(h) Recording the Associated Measurement Components

In the Results Workbook, record:

- the validity status and details of any related problems

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and code the reasons for the non-obtainment in the Results Workbook.

(j) Completion of the Measurement Process

On completion of duplicate measurements, check both readings; if they differ by more than 0.5cm, take a third measurement if possible. Lastly, at the end of the measurement process record the experience of using the equipment and any other related information, in the Results Workbook.

5a. Waist Circumference Measurement on Bare Skin

Towards the end of the visit (i.e. after the second round of the primary measurements 1 to 6), all eligible participants who completed the WC measurement over clothing and have a proxy or family member present or available within the vicinity, should be briefed on this final measurement.

(a) Purpose

To find out if there is a significant difference between WC measurements taken over a single layer of clothing and those taken directly on bare skin, so we can make any necessary adjustments in the future. The influences of clothing thickness on this measurement will also be assessed.

(b) Equipment

The equipment and materials required are the same as for the WC measurement over clothing, except that the accessible showcard will be replaced with the WC on Bare Skin Showcard.

(c) Eligibility

Participants are excluded from the waist circumference measurement on bare skin if:

- any of the exclusion criteria listed for the WC measurement over clothing apply
- a proxy or family member is not present or available to assist

If any of the above or other reasons apply, insert *"WC bare skin not attempted"* or *"WC on bare skin refused"* in the text box, and specify any associated reason(s) that apply in the Results Booklet.

If WC measurement on bare skin is not completed, ask the participant if they would be willing to have the thickness of their clothing measured (i.e. the garment that the tape was placed over for WC over clothing). Demonstrate the measurement and, with their permission, take two readings (see 5a (j)).

(d) Briefing and Demonstration Stage

The same briefing and demonstration instructions as outlined in WC measurement over clothing apply, except that participants should also be informed that they will be raise their-t-shirt/shirt no higher than their belly button, and, with their permission, the proxy/family member selected by the participant, where possible, will be asked to hold it in the required position.

A short line, similar to the line made for the MUAC, will be made at the iliac crest, so that we know where to place the tape. After the measurement is complete, inform the participant that they will be asked if they would be willing to have the thickness of their clothing measured (and demonstrate if needed).

If you feel the measurement is safe to conduct and no additional information is needed or concerns arise during the briefing or demonstration stage, ask the participant:

- *"Would you be willing to have your waist measured on bare skin?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, outline the reason(s) in the Results Booklet.

(e) Preparation Stage

If the participant has agreed to take part and agrees to the assistance of a proxy/family member, locate the selected person, if not present.

The same general guidelines (e.g. removal of extra upper garments, shoes) outlined for the WC measurement over clothing apply also to this measurement. Once all parties are present, ask the participant to raise their t-shirt/shirt to their belly button and request the proxy/family member to hold the t-shirt/shirt in position until the measurement is completed.

(f) Measurement Stage

Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate as needed) complete each of the steps outlined in the WC measurement over clothing.

Once the participant is positioned correctly, all the steps outlined in the WC measurement over clothing should be followed, except that a small horizontal line will be drawn on the skin at the level of the iliac crest once the specific edge is found, as demonstrated to the participant. WC measurement on bare skin should be measured on the same side as WC measurement taken over clothing.

Once complete, the landmark should be removed. Repeat the measurement procedures, and on completion of the second measurement, remove the landmark again. The procedures for landmarking outlined in Appendix 20 will be followed and each stage will be explained to the participant.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in centimeters and millimeters (e.g. 106.6cm)
  If the measurement falls between two millimeters, the nearest even millimeter is recorded. For example, if the figure falls between 106.4cm and 106.5cm, round the figure down (=106.4cm); if it falls between 26.5cm and 26.6cm, round the figure up (=106.6cm).

(h) Recording the Associated Measurement Components

In the Results Workbook, record:

- the validity status and details of any related problems in the relevant section

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and the reasons for the non-obtainment in the relevant section of the Results Workbook.

(j) Completion of the Measurement Process

On completion of duplicate measurements, check both readings; if they differ by more than 0.5cm, take a third measurement if possible. Lastly, at the end of the measurement process record the experience of using the equipment and any other related information, in the Results Workbook.

After completing the duplicate measurement or if only one round of measurements was secured, ask the participant if they would be willing to have the thickness of the clothing measured (i.e. the clothing that the WC measurement over clothing was taken over). If they agree, take two measurements using the Harpenden skinfold caliper (check that the pointer is positioned at '0'). Record the reading to the nearest millimeter and apply the same rounding rule as discussed above. If a difference between readings is more than 0.2mm, take a third measurement if possible.

6. Hip Circumference Measurement

(a) Purpose

To measure the hip circumference (HC) of all eligible participants, so that waist-hip ratio can be calculated.

(b) Equipment

The equipment and materials required for this measurement are:

- Thinline Lufkin Executive Measuring Tape (W606PM)
- Accessible Hip Circumference Measurement Showcard
- A4 Landscape of Study Logo (use as a focus point if needed)

Equipment Set-up:

- Visually check that the tape is not kinked. If in doubt, check the tape against the meter stick.
- Ensure that the relevant calibration checks were carried out before continuing.

(c) Eligibility

Participants are excluded from the HC measurement if they:

- are in a wheelchair
- have a colostomy or ileostomy
- are unable to stand erect comfortably for two minutes
- are too unsteady on their feet
- are too stooped to obtain valid measurement
- are wearing clothing that is not suitable for locating the required site

- express verbally or non-verbally their wish not to have their hips measured and
- the researcher feels it would not be safe to complete

If any of the above or other reasons apply, select and code the relevant option *"HC not attempted"* or *"HC refused"* and code the associated reason(s) that apply, in the Results Booklet. Once complete, move on to the next eligible measurement, where relevant.

(d) Briefing and Demonstration Stage

If the participant is eligible, inform them that you would like to measure their HC over their trousers/skirt.

- Provide a brief overview of the HC measurement and its purpose, in small segments.
- Use the accessible showcard to guide the description and demonstrate the measurement.
- Encourage the participant to get involved in the briefing and demonstration stage as much as possible (e.g. get them to point to their hips).
- Invite the participant to touch and feel the equipment during the demonstration.
- Check if the participant (proxy) has any questions, and address each question separately.

If you feel the measurement is safe to conduct and no additional information is needed or concerns arise during the briefing or demonstration stage, ask the participant:

- *"Would you be willing to have your HC [or around your hips] measured?"*
  If consent/assent is given, attempt the measurement.
  If the participant is unsure, suggest trying the measurement first. Repeat the briefing and/or demonstration in full or in part, if required.
  If the participant does not wish to take part in this measurement, code the associated reason(s) that apply in the Results Booklet and go on to the next eligible measurement, where applicable.

(e) Preparation Stage

If the participant has agreed to take part, ask them to remove, if they have not already done so, their footwear (excluding socks), any heavy outer upper clothing garments (e.g. jumper) where applicable, and to check if all objects from their pockets (e.g. coins) have been removed, in order to obtain a measurement that is as accurate as possible.

The importance of accurate measurements and potential influence of items in pockets on the reading should be communicated to participants.

If the remaining single upper garment falls onto the buttocks area, ask the participant to adjust their clothing if needed before the measurement, where possible, and/or with their permission fold the item of clothing in line with the top of their trousers or skirt. A demonstration of the clothing adjustment needed should be shown to the participant before proceeding with the measure.

Remind the participant that you will be placing the tape around their hips with their support (where possible).

(f) Measurement Stage

Once the preparation phase is complete and the requirements are met, instruct the participant to (and demonstrate, as needed):

- Stand in a relaxed position (so the gluteal muscles are not contracted)
- Distribute weight evenly, with feet together
- Pass the tape around the left hand side of their body, if possible (if this is not possible, loop the tape around the participant's legs and move it up around their hips from the side)
- Fold their arms across their chest
- Keep looking forward

Once the participant is positioned correctly, the following steps are taken (brief the participant on the relevant steps only):

- Remind the participant they will feel a slight pull on the tape for a few seconds.
- Hold the stub of the tape and the housing in the right hand and use the left hand to adjust the level of the tape at the back to the adjudged level of the greatest posterior protuberance of the buttocks (take several circumferences until the widest point is located).
- Resume control of the stub with the left hand and, using the cross-hand technique, position the tape at the side and check that it is held in a horizontal plane at the target level (the tape should be tight enough so that it does not slip but not tight enough to indent clothing).
- Record the value of the reading and side measured only.

(g) Recording the Measurement Reading

In the Results Workbook, record:

- the value in centimeters and millimeters (e.g. 102.6cm)
  If the measurement falls between two millimeters, the nearest even millimeter is recorded. For example, if the figure falls between 102.4cm and 102.5cm, round the figure down (=102.4cm); if it falls between 102.5cm and 102.6cm, round the figure up (=102.6cm).

(h) Recording the Associated Measurement Components

In the Results Workbook, record:

- the validity status and details of any related problems

(i) Measurement Attempted but Non-Obtained

If the measurement was attempted but not obtained, record this measurement status and code the reasons for the non-obtainment in the Results Workbook.

(j) Completion of the Measurement Process

On completion of duplicate measurements, check both readings. If they differ by more than 0.5cm, take a third measurement if possible. Lastly, at the end of the measurement process record the experience of using the equipment and any other related information in the Results Workbook.

Appendix 8 – Sample Letter of Support

<Organisation Logo/Headed Paper>

Sample Letter

Dear Participant/Family Member,

Please find attached information regarding a new national study recently launched by Professor Mary McCarron at Trinity College Dublin on Ageing in Persons with Intellectual Disability in Ireland.

<Name of Organisation> very much supports this national study and feels it represents a unique opportunity to explore the health, social and environmental circumference of people with intellectual disability as they age, and allow comparisons to be made with the general population.

You/your family member are being invited to participate in this study. The decision about whether to do so or not is entirely your own. Whatever decision you make will in no way affect the current or future services or support offered to you/your family.

The study is voluntary, but it is important that all the people who are selected take part, if at all possible, so that the results give an accurate picture of people with intellectual disabilities lives as they age.
Yours sincerely,

<Signature>

Chief Executive Officer

Appendix 9 – Accessible Letter of Invitation

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
School of Nursing & Midwifery
24 D'Olier Street, Dublin 2.
Tel: + 353 1 896 3186/3187
Fax: + 353 1 896 3001 Email: idstotilda@tcd.ie

24th April 2009



Dear Participant,



We are writing to tell you about a large study we will be carrying out on growing older with intellectual disability in Ireland.



This is a very important study which will involve 800 people with intellectual disability.



It will help us to learn more about what is important to people as they grow older.



We will learn about people's health, work and lifestyles.



But first, we want to make sure that the questions we are going to ask are correct and that people are able to understand them. This is where we need your help.

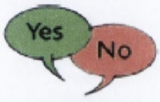


We would like to invite you to take part in a smaller study. We are sending you an information booklet about this study and a consent form.



A consent form is something a person signs which means that they are happy to help and take part.

Please read the information booklet or ask someone to help you to read it. This will help you to understand the study better.



It is your choice to take part in the study.



If you would like to take part, please read and sign the consent form, or ask someone to help you.



We would be delighted if you decided to take part in this study. If you want to ask us any questions then please call us on (01) 8963186 or 8963187.

We look forward to hearing from you.



Yours sincerely,

Prof. Mary McCarron.

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

Appendix 10 – Accessible Information Booklet

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Information booklet



This study is being carried out by Trinity College Dublin.

1. What is this study about?



This study looks at people who are growing older with an intellectual disability in Ireland.



This study will help us to understand what is important to people with intellectual disability as they grow older.



It will help us to learn about the:

- health
- happiness
- and lifestyles

of people as they get older.



It will help the Government to learn about what services people will need as they get older in Ireland.

2

2. Who can take part in this study?



People with intellectual disability aged 40 years and over.

3. Why did we ask you?



We asked you because you are 40 years of age or over, and have an intellectual disability.



We got your name from a national list of people with intellectual disability in Ireland. This list is called the National Intellectual Disability Database.



We picked people from this list at random. This is like picking a name from a hat.

This helps us to make sure we include people from different parts of Ireland.

3

4. What will we ask?



We will ask you questions about:



- your health and well-being



- activities you do everyday



- your friends



- your family

4



- interests and hobbies



- work and retirement



- your home



You will be asked to try and do some things like write your name.



We would also like to measure your:

- height
- weight



and around your:

- arm
- waist
- and hips

5. Who will visit you?



Researchers working on the study from Trinity College Dublin will visit you.

6. Do you have to take part?



No. It is your choice to take part in the study. You can also change your mind and stop taking part at any time.

7. How long will it take?



The interview will take about 90 minutes. However, this will be different for everyone.



If the interview is too long for you we can stop and take a break or come back another day.



The measurements will take about 15 minutes.

8. Are there any risks involved?



We do not know of any risks involved in this study.

9. Will anyone else know what you tell us?



No. We will keep all your personal information private. You will not be named in any reports.

10. What should you do next if you decide to take part?



If you decide to take part in the study, you will need to read and sign the consent form we have sent you.

This form asks you for your name and contact details.

This form also tells us that you know what the study is about and that you want to take part.



Please write on the form the best time of day to contact you.



Please return the form in the envelope we gave you.

We will contact you to see when it suits for us to come and visit you.

11. Is there anything else you need to think about?



Yes. You need to think about:

- where and when we can meet for the interview
- If you want to bring someone with you to the interview

12. Who do you contact if you have any questions?



If you need more information or if you have any questions, please contact one of the people below.



Professor Mary McCarron
Principal Investigator
Phone: 01–8963186 or 01–8963187
Email: mccarrmy@tcd.ie



Janet Swinburne
Project Manager/PhD student
Phone: 01–8963186 or 01–8963187
Email: swinburj@tcd.ie

Or write to us at:



Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College,
School of Nursing & Midwifery,
24 D'Olier Street, Dublin 2.

Email: idstotilda@tcd.ie

Appendix 11 – Accessible Consent Form

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

Consent form

Please read the information below and sign this consent form if you wish to take part in this study.

I agree with the following statements:

	Please tick
I have gone through the information about this study	☐
I knew who to contact if I had any questions.	☐
Any questions that I might have had were answered.	☐
I know that it is my choice to take part in this study.	☐
I understand that I will be asked questions about my: • life • health • work • friends and things I like to do.	☐
I understand that I do not have to answer questions I don't feel happy with.	☐
As part of the study, I know that I will be asked to try and do some things such as write my name.	☐
I understand that I will be asked to have some measurements taken such as my height and weight.	☐
I understand that I can stop taking part in this study when I want to. I do not have to give a reason.	☐
I understand that all information I give during this study will be kept safe and private. I will not be named in any reports.	☐
I understand that there are no known risks with this study.	☐
I am happy to take part in this study.	☐

1

Your consent

Your name: _____ Your phone number: _____

Your address:
_____
_____
_____
_____
_____

When is the best time to contact you? (Please tick)

- Morning time ☐
- Afternoon time ☐
- Evening time ☐

Please sign your name: _____ Date: _____

The person supporting you

I have supported the person named above to fill out this form. I believe they understand the information and have freely agreed to take part in this study.

Print name: _____

Relationship to the person named above: _____

Phone number: _____

Signature: _____ Date: _____

Please return this consent form in the envelope provided.

Intellectual Disability Supplement to TILDA, The University of Dublin, Trinity College, School of Nursing & Midwifery, 24 D'Olier Street, Dublin 2
Tel: +353 1 8963186/8963187 Fax: +353 1 8693001 Email: idstotilda@tcd.ie

3

Appendix 12 – Briefing Letter for Families / Guardians

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
School of Nursing & Midwifery
24 D'Olier Street, Dublin 2.
Tel: + 353 1 896 3186/3187
Fax: + 353 1 896 3001 Email: idstotilda@tcd.ie

24th April 2009

Dear family member/guardian,

The Intellectual Disability Supplement to TILDA is the most comprehensive study on ageing in persons with intellectual disability ever to be undertaken in Ireland. For the first time, there is a large and growing population of older people with intellectual disability in Ireland and elsewhere. Although this is an incredible success, we know little about the ageing of this population group.

This study will explore the health, lifestyles, living circumstances and quality of life for about 800 people with intellectual disability as they grow older. It will also see how their circumstances change over a 10-year period. The study is being carried out by Trinity College Dublin and is part of a major Irish longitudinal study on ageing (TILDA) in the general population, which is led by Professor Rose Anne Kenny.

We have chosen your family member/person with intellectual disability to take part in the first stage of this study, which is the pilot study. The pilot stage is essential as it will allow us to make sure we carry out the larger study efficiently. This stage is voluntary, however it is a very important study and we will get better information if we have a large number of people taking part.

Please find attached an information leaflet about the study and what it involves. If your family member/person with intellectual disability decides to take part in this study, an interviewer with a lot of experience of working with people with intellectual disability will arrange a suitable time to conduct the interview with them. We hope you agree to your family member/person with intellectual disability taking part in this study. If so, please sign the attached agreement form and return it in the stamped addressed envelope enclosed. If you have any questions, please do not hesitate to contact me or a member of the research team on 01-896 3186/3187.

Yours sincerely,

Prof. Mary McCarron

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA

Appendix 13 – Information Leaflet

* Reduced quality – not scaled to actual size of original (DL Folded Leaflet) *

Outside

Trinity College Dublin

Is the study confidential?
Yes. We will treat all the information from the study as strictly confidential and we will not publish the name of the person with intellectual disability or pass it on to anyone outside of the research team. The Faculty of Health Sciences Research Ethics Committee, of Trinity College, Dublin, has approved this study after ensuring that proper safeguards are in place.

Who is involved in the study?
This study has been set up by people who have a lot of experience of working with people with intellectual disability.

The advisory team consists of:

- Family Members
- Researchers
- Nurses
- Physicians
- Psychologists
- Psychiatrists
- Service Providers

People with intellectual disability also play an important role in our advisory team through participation in consultative workshops. These workshops will be ongoing with groups throughout the country as the study progresses.

Where can I get more information?
If you have any questions, or if you want more information about the study, please do not hesitate to call or email one of the contacts listed below.

Professor Mary McCarron
Principal Investigator
Phone: 01- 896 3186/3187
Email: mccarrm@tcd.ie

Ms Janet Swinburne
Project Manager / PhD Student
Phone: 01- 896 3186/3187
Email: swinburj@tcd.ie

Or write to:

Intellectual Disability Supplement to TILDA,
The University of Dublin, Trinity College,
School of Nursing & Midwifery,
24 D'Olier Street,
Dublin 2.

Fax: 01- 8963001
Email: idstotilda@tcd.ie

The Intellectual Disability Supplement to TILDA is funded by the Health Research Board.

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS to TILDA)

Pilot Study



Trinity College Dublin

Inside

Trinity College Dublin

What is the study about?
The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS to TILDA) is the most important study on ageing ever undertaken in Ireland.

It will look at the health, lifestyles and quality of life of about 800 people with intellectual disability as they grow older. It will also observe how their circumstances change over a 10-year period.

The information will be used to develop suitable health and social services that will benefit all people with intellectual disability as they age in Ireland.

We are inviting people with intellectual disability to take part in the **pilot** stage of this study which we are carrying out to make sure we include everything that is important to them in our main study.

How are participants selected for the pilot study?
People who are registered on the National Intellectual Disability Database (NIDD) and are aged over 40 years may be selected to take part in the study. The sample will be randomly selected from this database.

Does the person with intellectual disability that is selected have to take part?
No. Taking part is voluntary. However, this is a very important study and the information we collect will be better if we have a large number of people taking part. We are inviting men and women aged 40 years and older with an intellectual disability to take part. The person with intellectual disability selected can decide to withdraw from the study at any time.

What if the person with intellectual disability does not take part?
If the person with intellectual disability does not take part or later decides to withdraw, then their decision will in no way affect the current or future services or supports offered to them.

What does the study involve?
A researcher with experience of working with people with intellectual disability will visit the person with intellectual disability and ask questions about their health, lifestyle, living circumstances and quality of life.

We understand that some people may not be able to give this information on their own and may need support. If this is the case then the person with intellectual disability may ask someone (for example, a family member, guardian or key worker) to support them in giving this information.

We will also ask the person with intellectual disability to try and carry out some tasks such as:

- brushing their hair
- writing their name
- naming some colours

The interview will take about 90 minutes. However, this will be different for each person.

At the end of the interview we will arrange a suitable time to take some important physical measurements such as height and weight. We will use these results to find out much more about the health of people with intellectual disability than we could by just asking questions about diet and lifestyles alone. The measurements will take about 15 minutes.

Are there any risks involved?
There are no known risks involved in this study. We will explain each stage of the study to the person with intellectual disability using suitable information booklets and show cards.

At all times, the well-being of the person with intellectual disability will take priority over the research activities. If the person with intellectual disability tells us or indicates that they do not want to take part, or if they decide to withdraw, we will fully respect their decision.

Appendix 14 – Agreement Form

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
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Intellectual Disability Supplement to TILDA

Agreement Form for Family Members/Guardians

This study, the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS to TILDA), aims to collect information on the health, social and living circumstances of people with intellectual disability aged 40 years and over in Ireland. Your family member/person with intellectual disability has been selected to take part in the pilot study.

By signing this form, you are agreeing to support your family member/person with intellectual disability to participate in this pilot study. They will be asked questions about their health, lifestyle, living circumstances and quality of life. Your family member/person with intellectual disability will also be asked to try and carry out some tasks such as brushing their hair and writing their name.

The study also involves taking some measurements, such as height and weight.

All the information collected during the study will be kept strictly confidential. It will be used exclusively for research purposes. The identity of your family member/person with intellectual disability will not appear in any publication or be disclosed to anyone outside of the research team.

Family Member/Guardian Declaration:

Please tick the following statements if you agree with them:

	Please tick ✓
• I have read, or had read to me, the information leaflet for this study and I understand the contents.	☐
• I knew who to contact if I had any questions.	☐
• Any questions that I might have had were answered.	☐
• I freely agree to support my family member/person with intellectual disability to be part of this research study.	☐
• I understand that taking part or not taking part will in no way affect the current or future services or supports offered to my family member/person with intellectual disability.	☐
• I understand that my family member/person with intellectual disability can withdraw from the study at any time.	☐

I voluntarily give my agreement for my family member/person with intellectual disability to participate in this study and I understand that this will not affect their rights.

Name: _____

Address:

_____

_____

_____

_____

_____

Phone number: _____ Best time of day to contact you: _____

Name of family member/person with intellectual disability:

_____

Relationship to family member/person with intellectual disability:

_____

Signature: _____ Date: _____

Appendix 15 – External Reviews of Materials

1) External Reviews of Materials Developed

While the external reviews were not for the sole purpose of reviewing the references to the measurements proposed in the IDS-TILDA materials or the accessible measurement materials developed, these items were included in the external review of all of the materials to be issued to the invited sample and their families/guardians. As the Project Manager, the researcher organised and set the criteria for the external reviews undertaken.

2) Review Undertaken by Plan English Campaign

The first review included all the materials except for the measurement showcards and was undertaken by a professional UK editing company, the Plain English Campaign (PEC). PEC assessed the materials to ensure the information was clear and easy to understand for the intended audiences. Minimal changes were suggested in the measurement materials and related references to the measurements in the pilot materials. The suggested revisions included: the placement of the phrase "arm circumference" in brackets and the insertion of "round your arm" before, or *vice versa*, where appropriate, and renaming the title of the measurement booklet from "Information about taking your measurements" to "Information booklet". No other measurement-related revisions were recommended by PEC, or made. Although PEC reviewed the materials with the intended audiences in mind, the researcher felt it was imperative that people with ID also reviewed the materials. The researcher broadly used the National Disability Authority Guidelines for Including People with Disabilities in Research (NDA 2002) to guide their involvement. Following the review and implementation of amendments suggested by PEC, the next stage of the review process was organised by the researcher.

3) Review by a National Self-Advocacy Group

The second review only involved the materials that would be issued to the invited sample (not those for families/guardians), which included all the measurement materials except for the measurement showcards. This review was completed by a national self-advocacy group, Foley Street, who undertake commissioned work in a number of subject areas. The researcher contacted the facilitator supporting this national group and outlined the overall aim of the proofing required, the items for review, the number of pages per document and the key questions for consideration (i.e. positive language, logical order, layout easy to follow and illustrations supporting the text). All the requirements were agreed by the group and seven adults with ID undertook the review with the facilitator as the note-taker. The duration of the review was three hours. Overall, the feedback on the measurement materials and related references made in the pilot materials was positive. The main comments made by the group were a need to reduce the amount of text on each page by making the sentences shorter, and increasing the use of bullet-points. No revisions to the illustrations were made. All the feedback was analysed, and the relevant materials were amended accordingly and text was re-presented in bullet-points where appropriate. This review was important as it enabled the researcher to ensure the documents were truly accessible to the intended audience. Copies of the final materials used in practice were issued to the group.

4) Review of the Measurement Showcards

The third review involved the showcards for the IDS-TILDA study, which again was not organised for the sole purpose of reviewing the measurement showcards, but they were included as part of the review undertaken. As Project Manager, the researcher approached a day-service manager in an intellectual disability (ID) service to explore the potential interest of a group of adults with ID in the service to review the accessibility of the showcards for the study. A group was sourced by the day-service manager. Twelve adults with ID agreed and undertook the review, with two facilitators from the service. An outline of the aim of the review was provided. For the measurement showcards, the researcher sought the group's views on the size and clarity of the illustrations, whether the word or number of the step – for example, "Step One" or "Step 1" – should appear under each illustration and whether laminated or non-laminated cards should be used. The feedback from the review included: approval of the size and clarity of the illustrations; preferred use of numbers as opposed to words; and non-laminated cards preferred. All the measurement showcards were revised accordingly and an example of the final showcards used in practice was issued to the group.

Appendix 16 – Interviewer Instructions

1) Measurement Introduction Provided to Interviewers

Interviewers were informed that the measurement visit is an integral part of the IDS-TILDA studies and that without it the interview data, although very useful, would be incomplete. An overview of the anthropometric measurements selected was provided. Interviewers were informed that the researcher has been specifically trained and is an international accredited anthropometrist. An overview of the training undertaken in both Ireland and the United Kingdom before the pilot study commenced was provided. The researcher then covered the following topics, which was supported by the provision of the written operational protocol:

- Introducing the measurement visit
- Agreement check and record of the response
  (a) Yes to home visit
  (b) No to home visit (withdrew consent/agreement)
  (c) Undecided, researcher to phone to discuss the measurement in more detail
- Response to anxieties or concerns about the measures
- Liaising with the researcher and communication form

Each of the above topics is summarised below. Copies of the standard guidelines were included in the interviewer's operational protocol and could be referred to at any time during their fieldwork. The researcher was also available in person and via telephone at all times, if further support was needed by interviewers. As the researcher was also the Project Manager of the IDS-TILDA study, regular contact was made with interviewers throughout Stage One and Two of the data-collection process but at no time during this contact, or at any other time, did interviewers need further support outside of the systems developed. Following the completion of an interview, interviewers were instructed to complete and return the Measurement Communications Forms developed by the researcher (see Section 5 [Appendix 16] for further details).

2) Interviewers' Introduction to the Measurement Visit at Stage Two

In the interview, there were 18 sections to be completed. At Section 17, interviewers were advised that they would be required to inform the participant/proxy that they were almost at the end of the interview, and remind them that there were three parts to the study. Interviewers would then acknowledge that the participant/proxy had just helped with the first two parts and that it was hoped they would continue to help with the third and final part, the measurement visit. Interviewers were then instructed to give the participant/proxy the accessible Measurement Information Booklet and explain that a researcher specifically trained to carry out the measurements (and who was an experienced nurse) would visit their home (or place of their choice) at a time that best suited them. If the participant was not present at the interview or at Section 17 of the interview, interviewers were advised to encourage the proxy to go through this information booklet with the participant before the visit, if they had reaffirmed their agreement to take part in Stage Three. The interviewers were also instructed to inform the participant/proxy that the measurements would take about 15 minutes.

While the researcher emphasised the importance of the interviewer conveying the above points, as part of the briefing in Section 17, the need to adapt the wording to the level of the participant's understanding was duly noted; for example, introducing one concept at a time and using short sentences. Others might also have required further information in order to

understand the importance of the Stage Three. For example, participants might want to know more about what is involved. In such cases, interviewers were advised to provide a brief overview of each measurement, using the booklet supplied. For all others, the specific detail in the booklet was for the participant to read (or the proxy to read to the participant) before the researcher visited.

3) Interviewers' Agreement Check and Record of the Response

After the interviewer had completed the introduction to Stage Three, they were advised to ask the participant/proxy if they would be happy for the researcher to visit their home/place of choice to carry out some measurements. They were also instructed to remind participants that they did not have to have any measurements taken if they did not wish to but that we very much hoped that they would agree to participate in the final stage. In Section 17, after the introduction to Stage Three, there were five pre-coded response options provided:

- Yes to home visit
- No to home visit
- Undecided, researcher to phone to discuss measurements in more detail
- Unclear response
- Refused to answer

If the participant/proxy agreed to the home visit, interviewers were instructed to explain that the researcher would telephone them shortly (within 14 days) to arrange an appointment to visit in their own home (or place of their choice) during the next few weeks. In the interim, interviewers were asked to check the participant's availability (preferred days, time and place for visit), which would be passed on to the researcher. However, if the participant/proxy was undecided about Stage Three and would like to speak to the researcher, interviewers were advised to inform them that they would be telephoned the following day, or shortly thereafter (within 3 days to cover weekends as well). Lastly, if the participant or proxy refused the visit despite their initial consent/agreement, interviewers were advised and requested to record any reasons given, as provided in Section 17, so the researcher could gain an understanding of any refusals received and decide if anything could be done to reduce the occurrence in future studies, where reasonably practicable. To assist interviewers, the researcher provided four pre-coded reasons for refusal that might be expressed, which were reported in other studies (e.g. pre-coded responses to the nurse's visit in the English Longitudinal Study on Ageing):

- Own doctor already has this information
- Given enough time already to this study/expecting too much
- Too busy, cannot spare the time
- Not interested/Can't be bothered/No particular reason

If none of the above responses matched the reason(s) given, interviewers were informed that they had the option to select the pre-coded response marked 'other', and would then be directed to specify the reasons given in the space provided. Interviewers could also tick one of the three standard response options: unclear response, don't know, or refused to answer, if it more accurately reflected the situation. Lastly, the researcher informed interviewers that a designated space was provided at the end of Section 17 for interviewers to record any other information that might be relevant to this Section or the visit.

4) Interviewers' Response to Anxieties or Concerns about the Measures

Interviewers were informed by the researcher that some participants might feel nervous about getting measurements taken, so it was important that interviewers allay any fears or concerns as best possible. Interviewers were advised to inform participants/proxies that the person with ID should not feel any discomfort when the measurements were being taken, and that only the measurements that the person was eligible for and felt comfortable doing would be taken. If participants/proxies were undecided, the researcher advised interviewers to use the points detailed in Figure 1 as a guide to address concerns expressed. Interviewers were also reminded to advise the participant/proxy that they would have time to discuss the visit and the measurements in more detail with the researcher at the beginning of the visit.

Figure 1

Key Reference Points For Interviewers – Responding to Anxieties or Concerns

- The measurements are an important part of the study - the information the researcher collects will make the study even more valuable.
- People with intellectual disability/proxy are not committing themselves in advance to agreeing to everything the researcher wants to do. The researcher will seek verbal/expressed consent to do each measurement - so the person can decide at the time if s/he does not want to help with a particular one. People can choose only to do the measurements they feel comfortable doing.
- Explain that the researcher trained to take these measurements is the best person to describe what s(he) wants to do (e.g. the type of measurements involved) and that the person can always change his/her mind after hearing more about it.
- Explain that it will only take a very short time to do, approximately 15 minutes.
- Measurements will be taken at a time and location that best suits the person.
- The researcher has been specially trained to take all the measurements for this study. The researcher is also an experienced intellectual disability nurse.
- If the person wants, s/he will be given the results of the measurements carried out by the researcher but if they would prefer not to have them written down this is okay too.
- The Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin has given approval to the study, which checks that proper safeguards are in place.
- Ethical approval for this component of the study was approved as part of the ethical approval granted by each of the respective services involved in the pilot study.

5) Interviewers' Role in Liaising with the Researcher

Interviewers were informed that the success of managing the outcome of Section 17 depended on a good working relationship between the interviewer and the researcher. Interviewers were instructed to securely and electronically contact the researcher after each completed interview, preferably the day after or shortly thereafter, with the outcome of Section 17 using the Measurement Communication Form developed (see Appendix 17). The form not only contains key information from Section 17, it also requests details of key variables from the Pre-Interview Questionnaire and the face-to-face interview to assist the researcher's preparation for, and delivery of, the measurement visit where agreement was reaffirmed. Irrespective of the outcome of Section 17 (i.e. participant agrees, withdraws or is undecided), interviewers were advised that they needed to complete and return this form to the researcher.

* Reduced quality – not scaled to actual size of original (A4 Landscape) *

Interview: Key Summary Information for the Measurement Visit

Key Questions	Answers
1. (a) Participant ID Number, (b) Age and (c) Level of ID	**1. (a)** **(b)** **(c)**
2. Who did you make the interview appointment with? Participant, proxy or both	**2.**
3. What date was the interview conducted?	**3.**
4. Who did you conduct the interview with? If a proxy was present, please specify their first name and relationship to the person with ID	**4.**
5. Who answered most of the questions? Participant, proxy or both	**5.**
6. Status of the Measurement Visit? **If refused**, please state the reasons given, if any, and go to questions 16 and 17. **If agreed or undecided**, please indicate same and go to question 7.	**6.**
7. What method of communication did the person with ID use?	**7.**
8. Did the person report any of the following conditions? Diabetes, Osteoporosis, Various Ulcers, Chronic Constipation, Multiple Sclerosis, Cerebral Palsy, Scoliosis, Muscular Dystrophy, Spina Bifida and/or Oedema	**8.**
9. Is the person a wheelchair user?	**9.**
10. (a) How did they rate their steadiness walking? and (b) standing?	**10. (a)** **(b)**
11. How did they rate their eyesight?	**11.**
12. Did they consider themselves to be…..? Overweight, underweight or about the right weight	**12.**
13. Are they on any special diet? If yes, what type?	**13.**
14. Availability and preferred place/time to have the measurements taken?	**14.**
15. Does the person currently attend a day service?	**15.**
16. Where any specific comments made by the person with ID and/or proxy?	**16.**
17. Where any specific questions asked by the person with ID and/or proxy?	**17.**
18. Final comments: (a) Is there car parking close to house? (b) Is the entrance to the house accessible (e.g. flat or steps)? (i.e. for getting the equipment into the house)	**18.**

Appendix 18 – ISAK Anthropometry Training Scheme

1) Formation and Broad Operation of ISAK

Since 1986, ISAK has developed international standards, techniques and training for anthropometric assessment through its international anthropometry accreditation scheme (IAAS). This scheme is based on a four-level hierarchy (see Section 2 below). ISAK accreditation involves a strict training programme, practical examination, and the submission of post-training proformas within six months of attending the training course. Only on the successful completion and attainment of the required standards at each of the three stages were candidates eligible for ISAK accreditation. A successful candidate (such as the researcher) is accredited for four years only from the date of qualification; those wishing to be reaccredited are required to attend a refresher course, complete the practical examination and pass the post-training proformas within six months of attending the course.

2) Overview of the International Anthropometry Accreditation Scheme

ISAK Level 1 = Level 1 is designed for the majority of ISAK-accredited anthropometrists who have little on-going requirement for more than the measurement of height, weight and eight skinfolds. At Level 1 the successful ISAK Anthropometrist is able to demonstrate adequate precision in 17 measurements (2 base, 8 skinfolds, 5 girths and 2 breaths), which make up the Restricted Profile, and will have a basic understanding of the theory of anthropometric applications, assessed during the examination.

ISAK Level 2 = Level 2 is designed for those anthropometrists who wish to offer their subjects a more comprehensive range of measurements. At Level 2 the successful candidate is able to demonstrate adequate precision in a further 22 measures, which consists of 1 more base measure, 8 girths, 8 lengths and 5 breaths, and they will have a broad understanding of the theory of anthropometry and its interpretation. At Level 2 the accredited anthropometrist is able to carry out all 39 measurements, which collectively make up the Full Profile of body measurements, and allows adiposity, muscularity and proportionality to be examined together by an anthropometrist. Prerequisites for Level 2 accreditation training application included: Level 1 accreditation, minimum 6 months practice experience and be enrolled or completed a health science degree.

ISAK Level 3 & 4 = For ISAK Anthropometrists wishing to engage in the training and accreditation of Levels 1 and 2 they are required to complete and pass Level 3 training, but to apply, they must first meet the pre-requisite requirements set by ISAK (e.g. precision, experience). The final level, Level 4, is reserved for the most senior and experienced candidates. It recognises the anthropometrist many years of practice, training and research experience, and strong publication record in the field. Level 4 consists of a relatively small group of anthropometrists; they set the standards and govern ISAK Level 1, 2 and 3 exams.

3) ISAK Status in Ireland

Currently (up to March 2014), there are no ISAK anthropometrists accredited at either Level 3 or Level 4 in Ireland. Although the number certified at Level 2 is small, the number accredited at Level 1 is growing in both the dietetic and sport science field. The researcher is the only known anthropometrist at Level 1 or 2 in the Intellectual Disability field in Ireland.

Appendix 19 – ISAK Anthropometrist Certification

Level One Anthropometrist Technician – Restricted Profile

ISAK

International Society for the Advancement of Kinanthropometry

This is to certify that

Janet Swinburne

has attended a training course at the
Heriot-Watt University, Edinburgh, United Kingdom

From 18-20 January 2008

and has met all requirements for accreditation as a

LEVEL ONE ANTHROPOMETRIST
(TECHNICIAN - RESTRICTED PROFILE)

Accreditation valid until
20 July 2012

President ISAK
Professor M. Marfell-Jones

Secretary-General ISAK
Professor H de Ridder

ISAK

Level Two Anthropometrist Technician – Full Profile

ISAK

International Society for the Advancement of Kinanthropometry

This is to certify that

Janet Swinburne

has attended an ISAK training course at the
University of Portsmouth
Portsmouth, United Kingdom

From 4 to 7 February 2009

and has met all requirements for accreditation as a

LEVEL TWO ANTHROPOMETRIST

(TECHNICIAN - FULL PROFILE)

Accreditation valid until
7 August 2013

Professor H. de Ridder
President ISAK

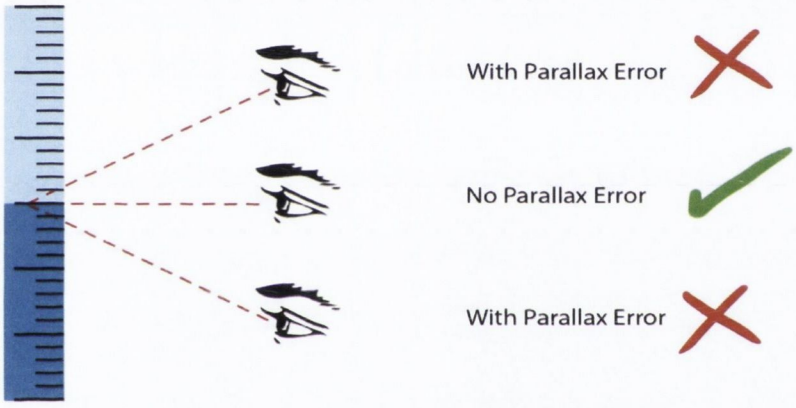
Professor M. Marfell-Jones
Secretary-General ISAK

Appendix 20 – Measurement-Related Factors

1) Avoidance of Parallax Error

The concept of parallax error is related to the displacement or difference in the apparent position of an object viewed along two different lines of sight, which is measured by the angle or semi-angle of inclination between those two lines (Oxford English Dictionary 1989). In practice this means that, depending on the angle from which the reading is viewed on the piece of equipment, such as the segmometer, skinfold caliper or measuring tape, the results will vary (see Figure 1) and the true value may not be obtained. To avoid parallax error, all measurements should be consistently read with the researcher's line of sight in front of the value, as opposed to it being slightly off to the side. Measurements should always be taken looking straight down (e.g. on the scales), or ahead (line of sight), depending on the equipment.

Figure 1



2) Landmarking Sites

Three of the selected measurements (ulna length, mid-upper arm and waist circumferences) require skeletal landmarks located by palpation of overlying soft tissue:

- Ulna length: midpoint of the styloid process (prominent bone in the wrist)
- Mid-upper arm circumference (MUAC): acromion bone (at the top of the shoulder blade)
- Waist circumference on bare skin: iliocristale (iliac crest)

Once the site is found, as per the standardised procedures (see Appendix 7), the site should be released to remove any distortion of the skin, then relocated and marked using a *hypoallergenic skin marking pencil* with a short horizontal line (approx 1cm) directly over the landmark (Marfell-Jones *et al.* 2006). The mark should then be rechecked to ensure that there was no displacement of the skin relative to the underlying bone. One of these selected measurements, MUAC, will also require one non-skeletal landmark (direct on soft tissue). The researcher will be required to mark the midpoint of the linear distance between the acromiale and the olecranon process landmarks with a short horizontal line. For ease of administration, the researcher should use the housing branch of the segmometer to mark the skin by rubbing the tip of the pencil on the branch edge before the measurement begins, instead of using the pencil to directly mark the skin with a short horizontal line, where possible. This action should speed up

the process. If it is not possible to use the segmometer to landmark this site, the site should be marked with a pencil.

All the landmarks should be removed before the second round of measurements. Details of all the steps involved in each of these measures are provided in Appendix 7. As part of the briefing and demonstration stage, participants should be informed of the landmarks needed and shown the type of line required, so that they are familiar with all the steps involved before it is undertaken.

3) Right Side Positioning

All measurements should be taken on the right side of participants, unless other specified; for example, ulna length was measured on both sides, and mid-upper arm circumference (MUAC) was measured on the left arm, as the Malnutrition Universal Screening Tool was used to interpret the findings (BAPEN 2003). However, in some cases, it may not be appropriate or feasible to measure on the right or the left in the case of MUAC, so the measurements should be taken on the opposite side, but any revised positioning should be recorded in the Results Workbook.

a) Personal Space of Participants

It is acknowledged and appreciated that everyone has an area of around their body known as 'personal space' and that if this area is invaded they are likely to feel uncomfortable. This is why most of the measurements should be taken from the side or behind the participant. However, for the ulna length measurement, it is necessary to stand almost in front of the participant. The briefing and demonstration given on the ulna length measurement that is conducted before the measurement seeks to give participants a good insight into the measure before agreeing to take part; if they do not feel comfortable with it, the measurement should not be conducted. The physical or emotional well-being of participants is of paramount importance at all times (see Chapter 3, Section 3.10.2 for further details of actions taken). For any measurement requiring direct contact with participants, in length and girth measurement, minimal contact should be applied. As part of the demonstration stage, participants should be encouraged to locate the relevant landmark sites, where applicable, so that they are more aware of where the researcher will identify the landmark required.

b) Position for Measurements

Ideally all of the measurements should be taken in a standing position but this is not always feasible. Depending on the type of measurement, some can be taken in a sitting or lying position if required; the relevant guidance is outlined in the measurement procedures (Appendix 7). The position of the participant for the relevant measurements should be recorded in the Results Workbook. Similarly, the position of the arm for the ulna length measurement and the side of the body measured for MUAC, waist and hip circumferences should also be recorded in the Results Workbook.

4) Time of Measurement

Even though the time of day the measurements are taken cannot be standardised across the sample population, every effort should be made to secure appointments with participants as early in the day as possible (e.g. to reduce the possible diurnal effects on the standing height measurement).

Survey Respondent ID Number				
P	1			
Researcher ID Number				
I	D	S		

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

An Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Anthropometric Measurement Results Workbook (Pilot Proforma)

Intellectual Disability Supplement to TILDA,
The University of Dublin, Trinity College, School of Nursing & Midwifery,
24 D'Olier Street, Dublin 2, Ireland

Telephone: +353 1 8963186 Fax: +353 1 8963001 Email: idstotilda@tcd.ie

Date ☐☐/☐☐/☐☐

Section A: Consent & Withdrawal

Written Consent

NOTE: WRITTEN CONSENT WAS SECURED AT THE BEGINNING OF THE STUDY (PRIOR TO INTERVIEW).

Background Information for Setting the Scene [SAMPLE ONLY – breakdown the key points into sections / short sentences and build the understanding from there to suit each individual and the circumstances]

IWER: Thank you for consenting to take part in this pilot study on ageing, and for reaffirming your willingness to participate in the measurement visit at the end of your interview. As you know, I am going to ask you to complete some measurements, such as your height and weight, where possible. The results of this visit will help to improve our knowledge of the measurements and the suitability of the equipment for the national study. The measurement results will also begin to build our understanding of the links between the general build, diet and health of people with intellectual disability aged 40 plus in Ireland. Each measurement is entirely voluntary. You do not have to have any measurements taken if you do not wish but, of course, we very much hope you will agree to all eligible measures, as they are a very important part of this study, and with your help we will become more informed about them.

Verbal Consent/Assent

VERBAL CONSENT/ASSENT WILL BE NEGOTIATED THROUGHOUT THE MEASUREMENT PROCESS.

IWER: Check the SR* received the measurement information booklet (If not, provide a copy) and the appointment card, and then provide an overview of the measurements and use the showcards to guide your description.

VC1 IWER: Is the SR willing to participate [happy to take part]?

Yes	☐ 1	See NOTE
No	☐ 5	Go to VC2

NOTE: Record the name of the proxy present. If there is no proxy present, check if the SR would like to have someone present and if necessary source the identified person before continuing or at the time expressed by SR.

VC1 (A) IWER: What is the proxy's name?

(IDS-TILDA)

Withdrawal from Measurement Visit

VC2 IWER: If *{SR/Proxy}* decides to withdraw from this aspect of the study, and reasons are given, please record the details below.

(IDS-TILDA)

***=Survey Respondent / Participant**

Section B: Preparation Phase

PP1 IWER: Where the following checks and briefings completed?

	Yes	No		Yes	No
Measurement information booklet check	1	5	Informed that they can stop at any time to ask questions, have a break or end the visit	1	5
Appointment card check	1	5	SR eaten or drank anything in the last 30 minutes	1	5
Overview of measurements	1	5	Use of bathroom facilities if required (sensitivity)	1	5

(IDS-TILDA)

Section C: Height Measurement

Time :

HM1 Height Measurement

IWER (If eligible): *I would now like to measure your height.* Provide a brief overview of the height measurement. Use the showcard to guide your description and demonstrate the measurement.

IWER: *Would you be willing to have your height measured?* Code one box per measure. If consent/assent is given, attempt to measure and code below. Include 'disguised' refusals such as 'It will take too long' etc. as code 4.

	1st Measure	2nd Measure	3rd Measure (Only if required – applies throughout)	
Height measured	1	1	1	Go to HM2
Height attempted, not obtained	2	2	2	Go to HM6
Height not attempted	3	3	3	Go to HM7
Height refused	4	4	4	Go to HM8

(Adapted from ELSA/IDS TILDA)

HM2 Record Measurement

IWER: Record standing height in centimetres and measure to the nearest millimeter e.g. 163.2cm.

1st measurement (cms) ___ . ___ [Go to HM2(A)]

2nd measurement (cms) ___ . ___ (See NOTE)

3rd measurement (cms) ___ . ___

NOTE: Third measurement taken only if the first two measurements differ by more than 0.5cm.

HM2 (A) IWER: Enter the time the measurement was taken using the 24 hour clock.

__ __ : __ __

(Adapted from ELSA/IDS-TILDA)

HM3 Validity of Measurement

IWER: Record the validity of the measurement. Code one box per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure	
No problems experienced, valid measurement obtained	1	1	1	Go to HM4
Problems experienced - measurement:				
Valid	2	2	2	Go to HM3 (A)
Invalid	3	3	3	Go to HM3 (A)

(Adapted from ELSA)

HM3 (A) IWER: Brief description of problem(s) and insert the number of the measure it refers to.

(IDS-TILDA)

HM4 Type of Floor Surface

IWER: Record the type of floor surface. Code one only.

- Linoleum/tile/wood 1
- Low-pile carpet 2
- High-pile carpet 3
- Concrete 4
- Not sure 5
- Other (specify) 96

(Adapted from HRS/ELSA)

HM5 Invalid Measurement

IWER: What caused the measurement to be invalid? Code reason(s) per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	1	1	1
Hairstyle or wig	1	1	1
Wore shoes	1	1	1
Back not straight (stopped)	1	1	1
Legs not straight	1	1	1
Did not stretch to fullest (inhale deeply)	1	1	1
Did not stand still	1	1	1
Difficulty standing	1	1	1
Heels lifted up	1	1	1
Not putting equal weight on both feet	1	1	1
Head was not in Frankfort plane position	1	1	1
Stadiometer faulty	1	1	1
SR was prevented from giving full effort by illness, pain, or other symptoms or discomfort	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(Adapted from ELSA/IDS-TILDA)

HM6 Height Attempted, Not Obtained

IWER: Code reason(s) for not obtaining the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	1	1	1
SR unsteady on feet	1	1	1
SR cannot stand upright/too stooped	1	1	1
Legs not straight	1	1	1
SR felt ill/tired	1	1	1
Stadiometer faulty	1	1	1
SR did not stand still	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(Adapted from ELSA)

HM7 Height Not Attempted

IWER: Code the reason(s) for not attempting the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR is confined to bed	1	1	1
SR is a wheelchair user	1	1	1
SR felt it would not be safe	1	1	1
Proxy felt it would not be safe	1	1	1
Anthropometrist felt it would not be safe	1	1	1
SR did not understand the procedure	1	1	1
No suitable space available	1	1	1
SR too ill/frail/tired	1	1	1
SR cannot stand upright/too stooped	1	1	1
SR is unsteady on feet	1	1	1
Stadiometer faulty	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(Adapted from HRS/ELSA/NDNS/IDS-TILDA)

HM8 Height Refused

IWER: Code the reason(s) for the refusal per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
Cannot see point/Height already known/ Doctor has measurement	☐ 1	☐ 1	☐ 1
Too busy/Taken too long already/No time	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1
Considered intrusive information	☐ 1	☐ 1	☐ 1
SR too anxious/nervous/shy/embarrassed	☐ 1	☐ 1	☐ 1
SR refused (no other reason given)	☐ 1	☐ 1	☐ 1
SR did not understand the procedure	☐ 1	☐ 1	☐ 1
Proxy refused on SR's behalf	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/NDNS)

HM9 Equipment (Completion of Measurements)

IWER: Did you encounter [or observe] any difficulties with the measuring equipment?

Yes ☐ 1 **Go to HM9 (A)**

No ☐ 5 **Go to HM10**

(IDS-TILDA)

HM9 (A) IWER: What difficulties did you encounter [or observe]?

(IDS-TILDA)

HM10 Any Other Comments (Completion of Measurements)

IWER: Is there anything else you think we need to know about this measurement?

Yes ☐ 1 **Go to HM10 (A)**

No ☐ 5 **Next Measurement**

(IDS-TILDA)

HM10 (A) IWER: What else do we need to know about this measurement?

(IDS-TILDA)

Section D: Ulna Length Measurement

ULM1 Ulna Length Measurement

IWER (If eligible): *I would now like to measure your ulna length (left and right).* Provide a brief overview of the ulna length measurement. Use the showcard to guide your description and demonstrate the measurement.

IWER: *Would you be willing to have your ulna [arm] lengths measured?* Code one box per measure. If consent/assent is given, attempt to measure and code below. Include 'disguised' refusals such as 'It will take too long' etc. as code 4.

	1st Measure	2nd Measure	3rd Measure (Only if required – applies throughout)	
Ulna length measured	☐ 1	☐ 1	☐ 1	Go to ULM2
Ulna length attempted, not obtained	☐ 2	☐ 2	☐ 2	Go to ULM6
Ulna length not attempted	☐ 3	☐ 3	☐ 3	Go to ULM7
Ulna length refused	☐ 4	☐ 4	☐ 4	Go to ULM8

(Adapted from ELSA/IDS-TILDA)

ULM2 Record of Measurement

IWER: Record the measurement in centimeters and measure to the nearest millimeter e.g. 27.2cm.

(A) LEFT ULNA

1st **measurement (cms)** 2nd **measurement (cms)** 3rd **measurement (cms)**

☐☐ • ☐ ☐☐ • ☐ ☐☐ • ☐

IWER: Third measurement taken only if the first two measurements differ by more than 0.5cm.

(B) RIGHT ULNA

1st **measurement (cms)** 2nd **measurement (cms)** 3rd **measurement (cms)**

☐☐ • ☐ ☐☐ • ☐ ☐☐ • ☐

IWER: Third measurement taken only if the first two measurements differ by more than 0.5cm.

(IDS-TILDA)

ULM3 Validity of Measurement

IWER: Record the validity of the measurement. Code one box per measure (left and right), **where relevant.**

	1st Measure (a) Left	1st Measure (b) Right	2nd Measure (a) Left	2nd Measure (b) Right	3rd Measure (a) Left	3rd Measure (b) Right	
No problems experienced, valid measurement obtained	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	**Go to ULM4 & ULM4 (A)**
Problems experienced - measurement:							
Valid	☐ 2	☐ 2	☐ 2	☐ 2	☐ 2	☐ 2	**Go to ULM3 (A)**
Invalid	☐ 3	☐ 3	☐ 3	☐ 3	☐ 3	☐ 3	**Go to ULM3 (A)**

(Adapted from ELSA)

ULM3 (A) IWER: Brief description of problem(s) and insert the number of the measure it refers to.

(IDS-TILDA)

ULM4 & 4(A) Position of the Survey Respondent

IWER: Record the position per measure, **where relevant.** Code one only per measure (left and right).

	1st Measure (a) L	1st Measure (b) R	2nd Measure (a) L	2nd Measure (b) R	3rd Measure (a) L	3rd Measure (b) R
Standing	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Sitting	☐ 2	☐ 2	☐ 2	☐ 2	☐ 2	☐ 2
Lying down	☐ 3	☐ 3	☐ 3	☐ 3	☐ 3	☐ 3

ULM4 (A) IWER: Record the position of arm, **where relevant.** Code one only per measure (as above).

	1st Measure (a) L	1st Measure (b) R	2nd Measure (a) L	2nd Measure (b) R	3rd Measure (a) L	3rd Measure (b) R
Arm diagonal across their chest (preferred)	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Arm across their stomach (at naval)	☐ 2	☐ 2	☐ 2	☐ 2	☐ 2	☐ 2
Arm resting on a table/arm of chair	☐ 3	☐ 3	☐ 3	☐ 3	☐ 3	☐ 3

(Adapted from Scottish Health Survey/IDS-TILDA)

ULM5 Invalid Measurement

IWER: What caused the measurement to be invalid? Code reason(s) per measure (as above), **where relevant.**

	1st Measure (a) L	1st Measure (b) R	2nd Measure (a) L	2nd Measure (b) R	3rd Measure (a) L	3rd Measure (b) R
SR did not remain still	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Segmometer faulty	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR was prevented from giving full effort by illness, pain, or other symptoms or discomfort	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Other (specify & insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/HRS/IDS-TILDA)

ULM6 Ulna Length Attempted, Not Obtained

IWER: Code the reason(s) for not obtaining the measurement per measure (left and right), **where relevant.**

	1st Measure (a) L	1st Measure (b) R	2nd Measure (a) L	2nd Measure (b) R	3rd Measure (a) L	3rd Measure (b) R
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR felt ill/tired	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR did not remain still	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Segmometer faulty	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Other (specify & insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/IDS - TILDA)

ULM7 Ulna Length Not Attempted

IWER: Code the reason(s) for not attempting the measurement per measure (as above), **where relevant.**

	1st Measure (a) L	1st Measure (b) R	2nd Measure (a) L	2nd Measure (b) R	3rd Measure (a) L	3rd Measure (b) R
SR did not understand the procedure	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR is unable to straighten arm	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Segmometer faulty	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Other (specify & insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/Scottish Health Survey/HRS)

ULM8 Ulna Length Refused

IWER: Code the reason(s) for the refusal per measure (left and right), **where relevant.**

	1st Measure (a) L	1st Measure (b) R	2nd Measure (a) L	2nd Measure (b) R	3rd Measure (a) L	3rd Measure (b) R
Cannot see point/height already known/Doctor has measurement	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Too busy/taken too long already/No time	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Considered intrusive information	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR too anxious/nervous/shy/embarrassed	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR refused (no other reason given)	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
SR did not understand the procedure	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Proxy refused on SR's behalf	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1	☐ 1

(Adapted from ELSA)

ULM9 Equipment (Completion of Measurements)

IWER: Did you encounter [or observe] any difficulties with the measuring equipment?

Yes ☐ 1 **Go to ULM9 (A)**
No ☐ 5 **Go to ULM10**

(IDS-TILDA)

ULM9 (A) IWER: What difficulties did you encounter [or observe]?

(IDS-TILDA)

ULM10 Any Other Comments (Completion of Measurements)

IWER: Is there anything else you think we need to know about this measurement? Code one only.

Yes ☐ 1 **Go to ULM10 (A)**
No ☐ 5 **Next Measurement**

(IDS-TILDA)

ULM10 (A) IWER: What else do we need to know about this measurement?

(IDS-TILDA)

Section E: Mid-Upper Arm Circumference

MM1 Mid-Upper Arm Circumference Measurement (MUAC)

IWER (If eligible): *I would now like to measure your mid-upper arm circumference (MUAC).* Provide a brief overview of the MUAC measurement. Use the showcard to guide your description and demonstrate the measurement.

IWER: *Would you be willing to have your MUAC [or arm] measured?* Code one box per measure. If consent/assent is given, attempt to measure and code below. Include 'disguised' refusals such as 'It will take too long' etc. as code 4.

	1st Measure	2nd Measure	3rd Measure (Only if required – applies throughout)	
MUAC measured	☐ 1	☐ 1	☐ 1	Go to MM2
MUAC attempted, not obtained	☐ 2	☐ 2	☐ 2	Go to MM6
MUAC not attempted	☐ 3	☐ 3	☐ 3	Go to MM7
MUAC refused	☐ 4	☐ 4	☐ 4	Go to MM8

(Adapted from ELSA/IDS-TILDA)

MM2 Record Measurement

IWER: Record MUAC in centimetres and measure to the nearest millimeter e.g. 22.2cm.

1st measurement (cms) ☐☐ • ☐ [Go to MM2(A)]

2nd measurement (cms) ☐☐ • ☐ (See NOTE)

3rd measurement (cms) ☐☐ • ☐

NOTE: Third measurement taken only if the first two measurements differ by more than 0.5cm.

MM2 (A) Arm measured

Left Arm ☐ 1 (preferred) **Right Arm** ☐ 2

(Adapted from ELSA/IDS-TILDA)

MM3 Validity of Measurement

IWER: Record the validity of the measurement. Code one box per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure	
No problems experienced, valid measurement obtained	☐ 1	☐ 1	☐ 1	Go to MM4
Problems experienced - measurement:				
Valid	☐ 2	☐ 2	☐ 2	Go to MM3 (A)
Invalid	☐ 3	☐ 3	☐ 3	Go to MM3 (A)

(Adapted from ELSA)

MM3 (A) IWER: Brief description of problem(s) and insert the number of the measure it refers to.

(IDS-TILDA)

MM4 Position of the Survey Respondent

IWER: Record the position per measure, **where relevant.** Code one only per measure.

	1st Measure	2nd Measure	3rd Measure
Standing	☐ 1	☐ 1	☐ 1
Sitting	☐ 2	☐ 2	☐ 2
Lying down	☐ 3	☐ 3	☐ 3

(Adapted from Scottish Health Survey)

MM5 Invalid Measurement

IWER: What caused the measurement to be invalid? Code reason(s) per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1
SR wore unsuitable clothing	☐ 1	☐ 1	☐ 1
SR did not remain still	☐ 1	☐ 1	☐ 1
SR was prevented from giving full effort by illness, pain, or other symptoms or discomfort	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Segmometer faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from HRS/NDNS/IDS-TILDA)

MM6 MUAC Attempted, Not Obtained

IWER: Code reason(s) for not obtaining the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1
SR felt ill/tired	☐ 1	☐ 1	☐ 1
SR did not remain still	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Segmometer faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/IDS-TILDA)

MM7 MUAC Not Attempted

IWER: Code the reason(s) for not attempting the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR did not understand the procedure	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1
Swelling and inflammation	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Segmometer faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/HRS/IDS-TILDA)

MM8 MUAC Refused

IWER: Code the reason(s) for the refusal per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
Too busy/taken too long already/No time	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1
Considered intrusive information	☐ 1	☐ 1	☐ 1
SR too anxious/nervous/ shy/embarrassed	☐ 1	☐ 1	☐ 1
SR refused (no other reason given)	☐ 1	☐ 1	☐ 1
SR did not understand the procedure	☐ 1	☐ 1	☐ 1
Proxy refused on SR's behalf	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA)

MM9 Equipment (Completion of Measurements)

IWER: Did you encounter [or observe] any difficulties with the measuring equipment?

Yes ☐ 1 **Go to MM9 (A)**
No ☐ 5 **Go to MM10**

(IDS-TILDA)

MM9 (A) IWER: What difficulties did you encounter [or observe]?

(IDS-TILDA)

MM10 Any Other Comments (Completion of Measurements)

IWER: Is there anything else you think we need to know about this measurement? Code one only.

Yes ☐ 1 **Go to MM10 (A)**
No ☐ 5 **Next Measurement**

(IDS-TILDA)

MM10 (A) IWER: What else do we need to know about this measurement?

(IDS-TILDA)

Section F: Weight Measurement

WM1 Weight Measurement

IWER (If eligible): *I would now like to measure your weight.* Provide a brief overview of the weight measurement. Use the showcard to guide your description and demonstrate the measurement.

IWER: *Would you be willing to be weighed?* Code one box only. If consent/assent is given, measure weight and code below. If SR weighs more than 200kg do not weigh. Include 'disguised' refusals such as 'It will take too long', as code 4.

	1st Measure	2nd Measure	3rd Measure (Only if required – applies throughout)	
Weight measured	☐ 1	☐ 1	☐ 1	**Go to WM2**
Weight attempted, not obtained	☐ 2	☐ 2	☐ 2	**Go to WM7**
Weight not attempted	☐ 3	☐ 3	☐ 3	**Go to WM8**
Weight refused	☐ 4	☐ 4	☐ 4	**Go to WM9**

(Adapted from ELSA/IDS -TILDA)

WM2 Record of Measurement

IWER: Record weight in kilograms as it appears on the scales. Record weight with one decimal digit, using the full stop as decimal point.

1st measurement (kg) ☐☐☐.☐ [Go to WM2 (B)] (Raw figure, if needed_____)

2nd measurement (kg) ☐☐☐.☐ (See NOTE) (Raw figure, if needed_____)

3rd measurement (kg) ☐☐☐.☐ (Raw figure, if needed_____)

WM2 (A) Chair / Wheelchair (If applicable)

1st measurement (kg) ☐☐☐.☐

2nd measurement (kg) ☐☐☐.☐

IWER: Third measurement taken only if the first two measurements differ by more than 0.5kg.

WM2 (B) IWER: Enter the time the measurement was taken using the 24 hour clock.

☐☐:☐☐

(Adapted from ELSA/IDS TILDA)

WM3 Validity of Measurement

IWER: Record the validity of the measurement. Code one box per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure	
No problems experienced, valid measurement obtained	☐ 1	☐ 1	☐ 1	**Go to WM4**
Problems experienced - measurement:				
Valid	☐ 2	☐ 2	☐ 2	**Go to WM3 (A)**
Invalid	☐ 3	☐ 3	☐ 3	**Go to WM3 (A)**

(Adapted from ELSA)

WM3 (A) IWER: Brief description of problem(s) and insert the number of the measure it refers to.

(IDS-TILDA)

WM4 Position of the Survey Respondent

IWER: Record the position per measure, **where relevant.** Code one only per measure.

	1st Measure	2nd Measure	3rd Measure
Standing	1	1	1
Sitting	2	2	2

(IDS-TILDA)

WM5 Type of Floor Surface

IWER: Record the type of floor surface. Code one only.

- Linoleum/tile/wood 1
- Low-pile carpet 2
- High-pile carpet 3
- Concrete 4
- Not sure 5
- Other (specify) 95

(Adapted from HRS/ELSA)

WM6 Invalid Measurement

IWER: What caused the measurement to be invalid? Code reason(s) per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	1	1	1
SR wore shoes	1	1	1
SR wore heavy clothing	1	1	1
SR unsteady on feet	1	1	1
SR did not stand still	1	1	1
SR pockets were holding heavy items	1	1	1
Scales faulty	1	1	1
SR was prevented from giving full effort by illness, pain, or other symptoms or discomfort	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(IDS-TILDA/NDNS)

WM7 Weight Attempted, Not Obtained

IWER: Code reason(s) for not obtaining the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	1	1	1
SR got off the scales before the reading was displayed	1	1	1
SR felt ill/tired	1	1	1
SR unsteady on feet	1	1	1
SR did not stand still	1	1	1
Scales faulty	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(Adapted from ELSA/IDS-TILDA)

WM8 Weight Not Attempted

IWER: Code the reason(s) for not attempting the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR is confined to bed	1	1	1
SR weighs over 200 kg	1	1	1
SR felt it would not be safe	1	1	1
Proxy felt it would not be safe	1	1	1
Anthropometrist felt it would not be safe	1	1	1
SR did not understand the procedure	1	1	1
No suitable space available	1	1	1
SR too ill/frail/tired	1	1	1
Scales faulty	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(Adapted from ELSA/HRS/IDS-TILDA)

WM9 Weight Refused

IWER: Code the reason(s) for the refusal per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
Cannot see point/weight already known/Doctor has measurement	1	1	1
Too busy/taken too long already/No time	1	1	1
SR too ill/frail/tired	1	1	1
Considered intrusive information	1	1	1
SR too anxious/nervous/shy/embarrassed	1	1	1
SR refused (no other reason given)	1	1	1
SR did not understand the procedure	1	1	1
Proxy refused on SR's behalf	1	1	1
Other (specify and insert no. of the measure it refers to)	1	1	1

(Adapted from ELSA/NDNS)

WM10 Equipment (Completion of Measurements)

IWER: Did you encounter [or observe] any difficulties with the measuring equipment? Code one only.

- Yes 1 **Go to WM10 (A)**
- No 5 **Go to WM11**

(IDS-TILDA)

WM10 (A) IWER: What difficulties did you encounter [or observe]?

(IDS-TILDA)

WM11 Any Other Comments (Completion of Measurements)

IWER: Is there anything else you think we need to know about this measurement? Code one only.

- Yes 1 **Go to WM11 (A)**
- No 5 **Next Measurement**

(IDS-TILDA)

WM11 (A) IWER: What else do we need to know about this measurement?

(IDS-TILDA)

Section G: Waist Circumference Measurement

WCM1 Waist Circumference Measurement (WCM)

IWER (If eligible): *I would now like to measure your waist circumference (WC).* Provide a brief overview of the waist circumstance measurement. Use the showcard to guide your description and demonstrate the measurement.

IWER: *Would you be willing to have your WC [or waist] measured?* Code one box only. If consent/assent is given, measure WC and code below. Include 'disguised' refusals such as 'It will take too long' etc. as code 4.

	1st Measure	2nd Measure	3rd Measure (Only if required – applies throughout)	
WC measured	☐ 1	☐ 1	☐ 1	Go to WCM2
WC attempted, not obtained	☐ 2	☐ 2	☐ 2	Go to WCM5
WC not attempted	☐ 3	☐ 3	☐ 3	Go to WCM6
WC refused	☐ 4	☐ 4	☐ 4	Go to WCM7

(Adapted from ELSA/IDS - TILDA)

WCM2 Record of Measurement

IWER: Record waist circumference in centimeters and measure to the nearest millimeter e.g. 93.2cm. Record waist circumference with one decimal digit.

(A) Over-Single Layer of Light Clothing

1st measurement (cms) ☐☐☐ • ☐ [Go to WCM2 (B)]

2nd measurement (cms) ☐☐☐ • ☐ (See NOTE)

3rd measurement (cms) ☐☐☐ • ☐

NOTE: Third measurement taken only if the first two measurements differ by more than 0.5cm.

(B) Clothing Thickness

1st measurement (mm) ☐☐ • ☐

2nd measurement (mm) ☐☐ • ☐

(C) Side Measured

Right ☐ 1 (preferred) **Left** ☐ 2

(D) Bare Skin (End of Measurement Visit – Anthropometrist and Proxy)

1st measurement (cms) ☐☐☐ • ☐

2nd measurement (cms) ☐☐☐ • ☐

3rd measurement (cms) ☐☐☐ • ☐

(D1) Specify if valid or invalid (1st):

(D2) Specify if valid or invalid (2nd):

(D3) If eligible (bare skin) and it was attempted - not obtained, not attempted or refused, record the reason(s):

(IDS-TILDA)

WCM3 Validity of Measurement

IWER: Record the validity of the measurement. Code one box per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure	
No problems experienced, valid measurement obtained	☐ 1	☐ 1	☐ 1	Go to WCM4
Problems experienced - measurement:				
Valid	☐ 2	☐ 2	☐ 2	Go to WCM3 (A)
Invalid	☐ 3	☐ 3	☐ 3	Go to WCM3 (A)

(Adapted from ELSA)

WCM3 (A) IWER: Brief description of problem(s) and insert the number of the measure it refers to.

(IDS-TILDA)

WCM4 Invalid Measurement

IWER: What caused the measurement to be invalid? Code reason(s) per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1
Unable to locate the specific edge of the iliac crest	☐ 1	☐ 1	☐ 1
SR wore shoes	☐ 1	☐ 1	☐ 1
SR clothing was not suitable	☐ 1	☐ 1	☐ 1
SR did not stand still	☐ 1	☐ 1	☐ 1
SR held breath	☐ 1	☐ 1	☐ 1
SR was prevented from giving full effort by illness, pain, or other symptoms or discomfort	☐ 1	☐ 1	☐ 1
Posture difficulty	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from HRS/NDNS/IDS-TILDA)

WCM5 WC Attempted, Not Obtained

IWER: Code reason(s) for not obtaining the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1
Unable to locate the specific edge of the iliac crest	☐ 1	☐ 1	☐ 1
SR unsteady on feet	☐ 1	☐ 1	☐ 1
SR embarrassed/sensitive about their size	☐ 1	☐ 1	☐ 1
SR felt ill/tired	☐ 1	☐ 1	☐ 1
SR did not stand still	☐ 1	☐ 1	☐ 1
SR held breath	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA / IDS-TILDA)

WCM6 WC Not Attempted

IWER: Code reason(s) for not attempting the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR is confined to bed	☐1	☐1	☐1
SR is a wheelchair user	☐1	☐1	☐1
SR was not able to stand comfortably or steady	☐1	☐1	☐1
SR felt it would not be safe	☐1	☐1	☐1
Proxy felt it would not be safe	☐1	☐1	☐1
Anthropometrist felt it would not be safe	☐1	☐1	☐1
SR did not understand the procedure	☐1	☐1	☐1
No suitable space available	☐1	☐1	☐1
SR too ill/frail/tired	☐1	☐1	☐1
SR is embarrassed /sensitive about their size	☐1	☐1	☐1
Tape faulty	☐1	☐1	☐1
Other (specify and insert no. of the measure it refers to)	☐1	☐1	☐1

(Adapted from ELSA/HRS/IDS TILDA)

WCM7 WC Refused

IWER: Code the reason(s) for the refusal per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
Cannot see point/weight already known/Doctor has measurement	☐1	☐1	☐1
Too busy/taken too long already/No time	☐1	☐1	☐1
SR too ill/frail/tired	☐1	☐1	☐1
SR is too stooped	☐1	☐1	☐1
Considered intrusive information	☐1	☐1	☐1
SR too anxious/nervous/ shy/embarrassed	☐1	☐1	☐1
SR is embarrassed/sensitive about their size	☐1	☐1	☐1
SR refused (no other reason given)	☐1	☐1	☐1
SR did not understand the procedure	☐1	☐1	☐1
Proxy refused on SR's behalf	☐1	☐1	☐1
Other (specify and insert no. of the measure it refers to)	☐1	☐1	☐1

(Adapted from ELSA)

WCM8 Equipment (Completion of Measurements)

IWER: Did you encounter [or observe] any difficulties with the measuring equipment? Code one only.

Yes ☐1 **Go to WCM8 (A)**
No ☐5 **Go to WCM9**

(IDS-TILDA)

WCM8 (A) IWER: What difficulties did you encounter [or observe]?

(IDS-TILDA)

WCM9 Any Other Comments (Completion of Measurements)

IWER: Is there anything else you think we need to know about this measurement? Code one only.

Yes ☐1 **Go to WCM9 (A)**
No ☐5 **Next Measurement**

(IDS-TILDA)

WCM9 (A) IWER: What else do we need to know about this measurement?

(IDS-TILDA)

Section H: Hip Circumference Measurement

HCM1 Hip Circumference Measurement (HCM)

IWER (If eligible): *I would now like to measure your hip circumference (HC).* Provide a brief overview of the hip circumstance measurement. Use the showcard to guide your description and demonstrate the measurement.

IWER: *Would you be willing to have your HC [or around your hips] measured?* Code one box only. If consent/assent is given, measure HC and code below. Include 'disguised' refusals such as 'It will take too long' etc. as code 4.

	1st Measure	2nd Measure	3rd Measure (Only if required – applies throughout)	
HC measured	☐1	☐1	☐1	Go to HCM2
HC attempted, not obtained	☐2	☐2	☐2	Go to HCM5
HC not attempted	☐3	☐3	☐3	Go to HCM6
HC refused	☐4	☐4	☐4	Go to HCM7

(Adapted from ELSA/IDS - TILDA)

HCM2 Record of Measurement

IWER: Record MUAC in centimetres and measure to the nearest millimeter e.g. 22.2cm.

1st measurement (cms) ☐☐•☐ **2nd measurement (cms)** ☐☐•☐ (See NOTE) **3rd measurement (cms)** ☐☐•☐

NOTE: Third measurement taken only if the first two measurements differ by more than 0.5cm.

(A) Side Measured

Right ☐1 (preferred) **Left** ☐2

(Adapted from ELSA / IDS - TILDA)

HCM3 Validity of Measurement

IWER: Record the validity of the measurement. Code one box per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure	
No problems experienced, valid measurement obtained	☐1	☐1	☐1	Go to HCM4
Problems experienced - measurement:				
Valid	☐2	☐2	☐2	Go to HCM3 (A)
Invalid	☐3	☐3	☐3	Go to HCM3 (A)

(Adapted from ELSA)

HCM3 (A) IWER: Brief description of problem(s) and insert the number of the measure it refers to.

(IDS-TILDA)

HCM4 Invalid Measurement

IWER: What caused the measurement to be invalid? Code reason(s) per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1
SR wore shoes	☐ 1	☐ 1	☐ 1
SR clothing was not suitable	☐ 1	☐ 1	☐ 1
SR did not stand still	☐ 1	☐ 1	☐ 1
SR pockets were holding items	☐ 1	☐ 1	☐ 1
SR was prevented from giving full effort by illness, pain, or other symptoms or discomfort	☐ 1	☐ 1	☐ 1
Posture difficulty	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from HRS/NDNS/IDS-TILDA)

HCM5 HC Attempted, Not Obtained

IWER: Code reason(s) for not obtaining the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR tried but did not understand the procedure	☐ 1	☐ 1	☐ 1
SR unsteady on feet	☐ 1	☐ 1	☐ 1
SR embarrassed/sensitive about their size	☐ 1	☐ 1	☐ 1
SR felt ill/tired	☐ 1	☐ 1	☐ 1
SR did not stand still	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA / IDS-TILDA)

HCM6 HC Not Attempted

IWER: Code reason(s) for not attempting the measurement per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
SR is confined to bed	☐ 1	☐ 1	☐ 1
SR is a wheelchair user	☐ 1	☐ 1	☐ 1
SR was not able to stand comfortably or steady	☐ 1	☐ 1	☐ 1
SR felt it would not be safe	☐ 1	☐ 1	☐ 1
Proxy felt it would not be safe	☐ 1	☐ 1	☐ 1
Anthropometrist felt it would not be safe	☐ 1	☐ 1	☐ 1
SR did not understand the procedure	☐ 1	☐ 1	☐ 1
No suitable space available	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1
SR is embarrassed /sensitive about their size	☐ 1	☐ 1	☐ 1
Tape faulty	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA/HRS/IDS TILDA)

HCM7 HC Refused

IWER: Code the reason(s) for the refusal per measure, **where relevant.**

	1st Measure	2nd Measure	3rd Measure
Cannot see point/weight already known/Doctor has measurement	☐ 1	☐ 1	☐ 1
Too busy/taken too long already/No time	☐ 1	☐ 1	☐ 1
SR too ill/frail/tired	☐ 1	☐ 1	☐ 1
SR is too stooped	☐ 1	☐ 1	☐ 1
Considered intrusive information	☐ 1	☐ 1	☐ 1
SR too anxious/nervous/shy/embarrassed	☐ 1	☐ 1	☐ 1
SR is embarrassed/sensitive about their size)	☐ 1	☐ 1	☐ 1
SR refused (no other reason given	☐ 1	☐ 1	☐ 1
SR did not understand the procedure	☐ 1	☐ 1	☐ 1
Proxy refused on SR's behalf	☐ 1	☐ 1	☐ 1
Other (specify and insert no. of the measure it refers to)	☐ 1	☐ 1	☐ 1

(Adapted from ELSA)

HCM8 Equipment (Completion of Measurements)

IWER: Did you encounter [or observe] any difficulties with the measuring equipment? Code one only.

Yes ☐ 1 **Go to HCM8 (A)**
No ☐ 5 **Go to HCM9**

(IDS-TILDA)

HCM8 (A) IWER: What difficulties did you encounter [or observe]?

(IDS-TILDA)

HCM9 Any Other Comments (Completion of Measurements)

IWER: Is there anything else you think we need to know about this measurement? Code one only.

Yes ☐ 1 **Go to HCM9 (A)**
No ☐ 5 **Next Measurement**

(IDS TILDA)

HCM9 (A) IWER: What else do we need to know about this measurement?

(IDS-TILDA)

Section I: Measurement Record Card

Time :

IWER: Following the completion of the anthropometric measures, thank SR for their co-operation and write the results of the measurements, where applicable, onto the SR's Measurement Record Card.

(IDS-TILDA)

Section J: Final Questions

IWER: *Now I have two final questions before we reach the end of my visit.*

FQ1 IWER: *Did you find the appointment card useful?*

PROMPT IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes	1	Go to FQ3
No	5	Go to FQ2
Unclear response	97	Go to FQ3
Don't know	98	Go to FQ3
Refused to answer	99	Go to FQ3
Not applicable – did not receive it	94	Go to FQ3

SR 01 | Proxy 02 | SR & P 03

(IDS-TILDA)

FQ2 IWER: *Which part(s) did you not find useful?*

SR 01 | Proxy 02 | SR & P 03

(IDS-TILDA)

FQ3 IWER: *Did {you/SR} find the measurement information booklet useful?*

PROMPT IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

Yes	1	Go to FQ5
No	5	Go to FQ4
Unclear response	97	Go to FQ5
Don't know	98	Go to FQ5
Refused to answer	99	Go to FQ5
Not applicable – did not receive it	94	Go to FQ5

SR 01 | Proxy 02 | SR & P 03

(IDS-TILDA)

FQ4 IWER: *Which part(s) did you not find useful?*

SR 01 | Proxy 02 | SR & P 03

(IDS-TILDA)

FQ5 Any Other Information/Feedback (e.g. booklet easy/hard to understand etc):

(IDS-TILDA)

Section K: Final Observations

TO BE COMPLETED BY THE ANTHROPOMETRIST

FO1 IWER: Did you use the measurement showcards?

Yes	1	Go to FO2
No	5	Go to FO2

(IDS-TILDA)

TO BE COMPLETED BY THE ANTHROPOMETRIST

FO2 IWER: Did you find the measurement showcards useful?

Yes	1	Go to FO4
No	5	Go to FO3

(IDS-TILDA)

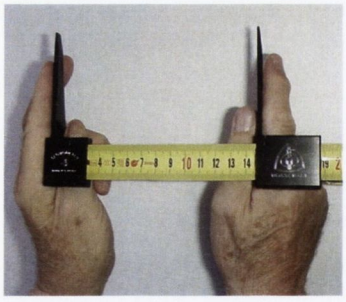
FO3 IWER: Which part(s) did you not find useful?

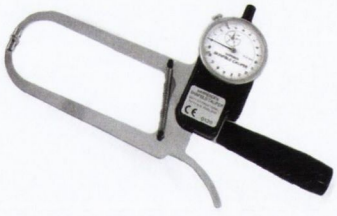
(IDS-TILDA)

FO4 Any Other Information (Feedback, Observations or Reflections):

(IDS-TILDA)

Appendix 22 – Selected Anthropometric Equipment

Name & Type	Brand	Image
Height Measure Leicester	**Seca**	 (Image via www.seca.com)
Height Measure 217	**Seca**	 (Image via www.seca.com)
Segmometer 4	**Rosscraft**	 (Image via www.quickmedical.com)
Measuring Tape *W606PM*	**Lufkin**	 (Image via www.lufkintool.com)

Name & Type	Brand	Image
Wheelchair Scale 677	**Seca**	 (Image via www.seca.com)
Flat Scale 877	**Seca**	 (Image via www.seca.com)
Skinfold Caliper	**Harpenden**	 (Image via www.harpenden-skinfold.com)

Equipment Suppliers Listing

www.seca.com

www.rosscraft.ca/instruments.html

www.lufkintool.com

www.harpenden-skinfold.com

Appendix 23 – Equipment Calibration Checks and Record Form

Daily and Weekly Calibration Checks

Note: All the equipment was new and calibrated by the manufacturers.

Daily Calibration Checks	
Weighing Scales (Wheelchair and Flat)	At the beginning and end of each examining day, each scale needs to be checked. Both scales need to be placed on a level floor. Once activated, the certified BAR test weight M1 of 5kg should be placed on the scale. If the display reads 5kg, no recalibration is necessary. If the wheelchair scale is moved to a different location during the day, the calibration of the scale should be re-checked each time. Before each measurement, check the scale to ensure it reads "0.0".
Skinfold Caliper	At the beginning of each examining day, the skinfold caliper must be checked. It should be opened to approximately 20mm and allowed to close several times. Check the pointer to ensure it is positioned at "0". If it is not positioned at "0", the dial indicator should be reset to zero, by rotating the bezel to the appropriate position. The repeatability of the zero reading within one division (0.2mm) also needs to be checked. Before each measurement, check the caliper to ensure the dial is at "0".
Segmometer	At the beginning and end of each examining day, the segmometer should be checked against a meter stick to ensure the values corresponded correctly (25cm).
Weekly Calibration Checks	
Measuring Tape	At the beginning and end of each week of visits, the tape should be checked against a meter stick to ensure the placement of the values corresponds correctly (50cm).
Stadiometer	At the beginning and end of each week of visits, a meter stick should be placed on the baseplate, and the headplate be lowered to check the value is correct (90cm).

Equipment Calibration Record Form – Single Investigator Form

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

Calibration Check By: _____ **ID Number:** _____ **No of Record:** _____

Daily and Weekly Calibration Checks

	Daily				Weekly	
	Wheelchair Scale	Flat Scale	Skinfold Caliper	Segmometer	Tape	Stadiometer
Date (DD/MM/YY)						

Calibration Problems

Equipment Details		Action Required (tick box)				Brief Details
Type	Date	Repair	Replace	None	Other	Please specify relevant details

Appendix 24 – Accessible Appointment Card

* Reduced quality – not scaled to actual size of original (A5 Folded) *

Outside

Thank you very much for your help with this important study.

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College,
School of Nursing & Midwifery, 24 D'Olier Street, Dublin 2

Telephone: 01-8963186/3187 Fax: 01-8963001
Email: idstotilda@tcd.ie

tilda

If you cannot keep this appointment,
please phone Janet on _____
to make another appointment.

Appointment card

Janet Swinburne will visit on

☐ Mon ☐ Tues ☐ Wed ☐ Thurs ☐ Fri ☐ Sat

Date: _____ **Time:** _____

Inside

On the day of the measurement visit

It would be very helpful if you:

- wear a short sleeve t-shirt or shirt and loose fitting trousers or a skirt
- avoid wearing a belt

to make the measurements easier.

If possible, please do not eat or drink anything 30 minutes before Janet visits.

Janet will answer any questions you may have before taking the measurements.

Appendix 25 – Accessible Measurement Information Booklet

* Reduced quality – not scaled to actual size of original (A4 Portrait) *

Outside

Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
School of Nursing & Midwifery
24 D'Olier Street
Dublin 2
Ireland

Telephone: (01) 896 3186 or (01) 896 3187
Fax: (01) 8963001
Email: idstotilda@tcd.ie

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing is funded by the Health Research Board

tilda

The pilot of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

Information booklet on taking your measurements



This study is being carried out by Trinity College Dublin.

Inside

1. Introduction



We would like to take some measurements such as your height and weight, and this booklet will tell you how we will do this.

2. Why are the measurements important?



The results of the measurements will provide us with a more complete picture of the health of people as they get older.

3. What measurements will we take?



We would like to measure your:

- height
- weight
- arm
- waist
- and hips

1

4. How will we measure your height?



We will ask you to:

- take off your shoes and any heavy clothes, such as a jacket
- stand as tall as you can with your heels together and your feet flat on the ground



If you cannot stand or if you find it difficult, we will estimate your height by measuring your arm from the elbow to the wrist.

5. How will we measure your arm?



We will ask you to:

- put your arm across your chest
- point your fingers toward your shoulder

Or you can rest your arm on a table.

2

Inside

6. How will we measure your weight?



We will ask you to:

- take off your shoes and any heavy clothes, such as a jacket
- stand or sit to get weighed

7. How will we measure around your arm?



We will ask you to roll up your sleeve and we will put a tape around the middle of your arm.

8. How will we measure your waist?



We will ask you to stand and we will put a measuring tape around your stomach just above your hip bone.

9. How will we measure your hips?



We will ask you to stand and we will put a measuring tape around your hips.

10. How many times will we take each measurement?



We will take each measurement twice.

11. Will any of the measurements cause discomfort?



You should not feel any discomfort when the measurements are being taken.

12. How long will it take?



The measurements will take about 15 minutes.

13. Who will take the measurements?



A researcher called Janet Swinburne will visit you and take the measurements.

Janet has been specially trained to take all the measurements.

14. Will we let you know the results?



Yes. Janet will give you a copy of your results.

15. Is there anything else you need to think about?



Yes. You need to think about:

- where and when it suits you meet Janet
- if you want to bring someone with you

16. Who do you contact if you have any questions?



If you need more information or if you have any questions, please contact one of the people below.

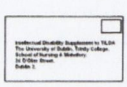


Janet Swinburne
Project Manager / PhD Student
Phone: 01–8963186 or 01–8963187
Email: swinburj@tcd.ie



Professor Mary McCarron
Principal Investigator
Phone: 01–8963186 or 01–8963187
Email: mccarrm@tcd.ie

Or write to us at:

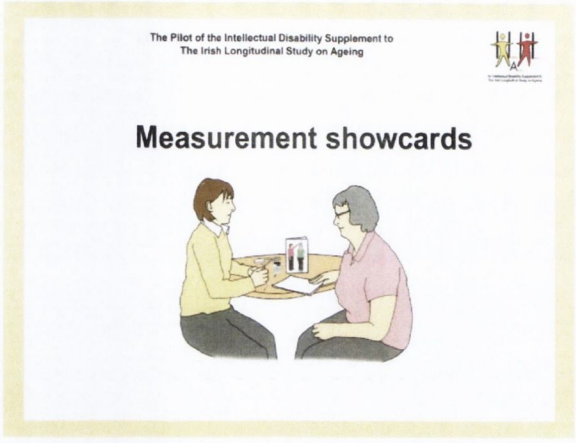


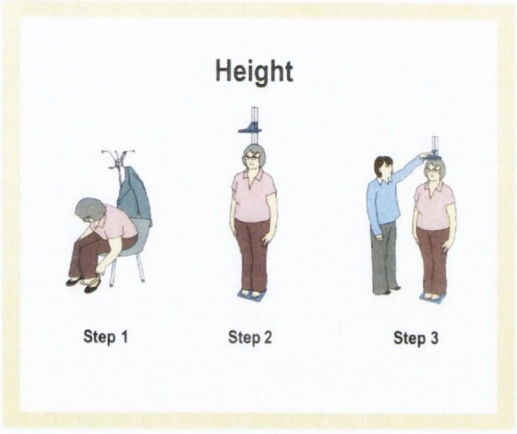
Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College,
School of Nursing & Midwifery,
24 D'Olier Street, Dublin 2.

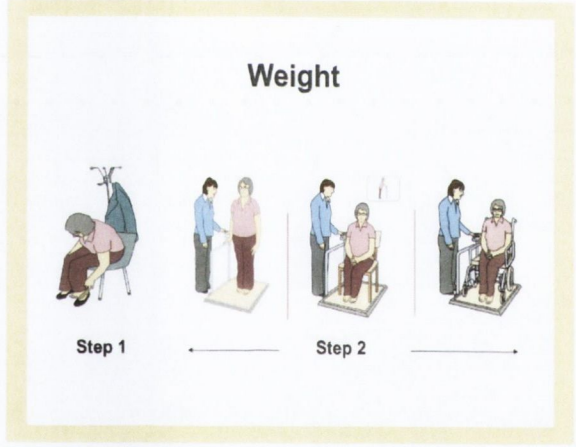
Email: idstotilda@tcd.ie

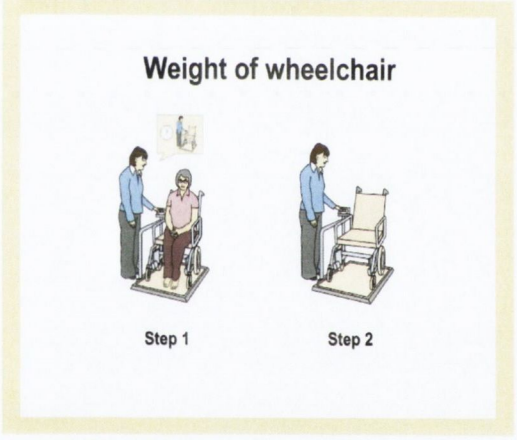
Appendix 26 – Sample of the Accessible Measurement Showcards

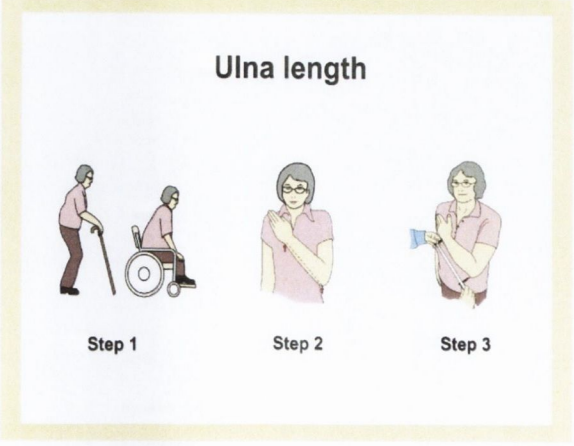
* Reduced quality – not scaled to actual size of original (A4 Landscape) *

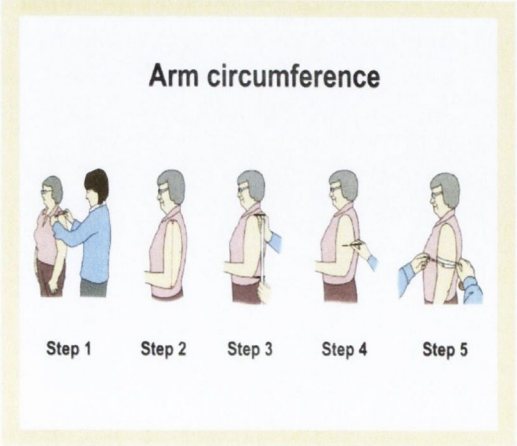












Appendix 27 – Accessible Measurement Record Card

* Reduced quality – not scaled to actual size of original (A4 Folded) *

Outside

The pilot of the Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

Thank you for your help with this important study.

Measurement Record Card



Intellectual Disability Supplement to TILDA
The University of Dublin, Trinity College
School of Nursing & Midwifery
24 D'Olier Street
Dublin 2

Telephone: (01) 8963186 or (01) 8963187
Fax: (01) 8963001 Email: idstotilda@tcd.ie

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing is funded by the Health Research Board.

Name: _____

Date of Visit: _____

Researcher: _____

Inside

This information was collected as part of the pilot study of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (TILDA).

The measurements were carried out by a specially trained researcher. The study has been approved by the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin, which checks that proper safeguards are in place.

The results of the measurements in this study will improve our understanding of the links between the general build, diet and health of people with intellectual disability aged 40 and over.

Measurement Results



Standing Height (If Applicable)

1st Measurement: _____ cms
2nd Measurement: _____ cms



Arm (Ulna) Length

1st Measurement: _____ cms
2nd Measurement: _____ cms



Weight

1st Measurement: _____ kgs
2nd Measurement: _____ kgs



Arm Circumference

1st Measurement: _____ cms
2nd Measurement: _____ cms



Waist & Hip Circumference (If Applicable)

	1st Measurement	2nd Measurement
Waist:	_____ cms	_____ cms
Hip:	_____ cms	_____ cms

Appendix 28 – List of Materials for the Measurement Visit

List of Materials for the Measurement Visit
• Sample invitation pack x 2 • Accessible measurement information booklet x 5 • Sample appointment card x 2 • Accessible measurement record card x 5 • Keeping Well – An accessible booklet x 5 • Accessible measurement showcards x 2 • Anthropometric measurement Results Workbook x 5 • Measurement standards x 1 • Assortment of health and nutritional related leaflets x 5

Appendix 29 – Supplemental Communication Guidelines

1) Getting to Know the Participant

At the beginning of the visit, the most important task was simply getting to know the participant and continuing to build the connection between the completed interview and the measurement visit. During communication exchanges, the researcher used the words the participant used (or words the participant was likely to know), where appropriate and feasible. Technical terms were kept to a minimum. Although it takes time to build trust, the study design sought to establish the trust, confidence and motivation of participants before carrying out the measurements. While it was acknowledged that some participants might bring someone to support them (taking an active or passive role) during the measurement visit, the participant always remained the primary focus of communication. The researcher spoke directly to the participant, using clear, short sentences with sufficient pauses to allow them time to process the information. Visual aids (e.g. accessible measurement showcards) were used to support verbal explanations, where needed. Only one topic was introduced or one question was asked at a time and sufficient response time was provided. Throughout the visit, participants were kept informed about what the researcher was doing, especially when taking the measurement readings, where possible, so as to avoid the participant unintentionally adjusting their position to look at what the researcher was doing (i.e. participant looking down at the measuring tape).

2) Comprehension of Spoken Language

If a situation arose where the researcher did not understand the participant, they were asked to repeat what they had said or repeat the action on their communication aid and/or the researcher paraphrased or restated what they had heard if they were not sure what the participant had communicated. If necessary, with the participant's permission (where possible), the researcher asked a third party to assist with understanding. If all attempts failed, the researcher apologised for failing to understand them. It was acknowledged that some participants might have difficulty understanding the purpose of the measurement visit, which may have been agreed to by their proxy, if they were not active reporters at the interview (Stage Two of the IDS-TILDA studies). In such situations, the researcher was particularly sensitive and aware to the non-verbal cues (e.g. facial expressions, vocalisations, body language and behaviours) the participant gave to the researcher (e.g. did not understand the instructions) and these cues were respected and acted upon. If it was clear that they did not wish to take part, wish to continue and/or if they did not understand the instructions for the measurement even with the support of the proxy, it was not attempted or continued. Equally, if the researcher believed the participant could not comprehend the instructions well enough (even with the use of the accessible measurement showcards or support from proxy) for them to safely and accurately carry out the measurement instructions, the researcher did not carry it out and/or prolong the visit any further. All related communication experiences and actions taken, where relevant, during the measurement process, were recorded in the Results Workbook.

During the implementation of the familiarisation procedures, the researcher identified what participants could do for themselves and gauged their level of understanding by asking them to describe in their own words or demonstrate understanding; for example, by pointing to their wrist bone for the ulna length measurement. If required, briefings or demonstrations were repeated as needed. The researcher believed that the more the participant understood the more likely they were to feel at ease about taking part, and that this would also maximise their level of independent involvement in the measurement process (i.e. reduce the need for support

from a third party). Importantly, irrespective of the participant's level of intellectual disability, each visit followed the same standardised protocol, but the methods of communication were adjusted accordingly. Even though in such situations a third party might be responding to the factual questions on behalf of the participant, where needed, the participant remained central to the discussion in terms of the researcher's eye contact, body language and direction of their verbal responses. The type of support given by proxies (e.g. reassurance, practical assistance) per measurement, where relevant and if required, was recorded in the Results Workbook.

Appendix 30 – Eligibility, Non-Eligibility and Practice Considerations

1) Eligibility for Measurements

From the outset, once the inclusion criteria for the measurement visit had been fulfilled, the participant had reaffirmed their willingness to take part and the preparation phase been completed (see Section B in Appendix 21), the researcher worked from the assumption that all measurements were possible until the participant was assessed against the exclusion criteria for each measurement. As discussed earlier, in some cases it might have been impossible or inappropriate to take some of the measurements or become clear that the measurement would have been far from valid or safe to take. If any of these situations arose, the measurement was coded as 'not attempted' and the reasons were recorded in the Results Workbook. However, whenever the researcher thought a valid measurement could be taken, it was attempted with the participant's agreement. Prior to each measurement, the participant's initial eligibility was checked before the individual briefing and demonstration stage was initiated.

2) Non-Eligibility for Measurements

The combined review of the Measurement Communication Form prior to the visit and the status of the participant on entering the room during the introductory and preparation phases (e.g. wheelchair-user, mobility restrictions such as unsteady on feet) might have collectively led the researcher to code the measure as 'not attempted' in response to the eligibility question in the Results Workbook. The reasons for not attempting the measurement were coded in the relevant section of the workbook (see Appendix 21) and sensitively explained to the participant. If the participant disagreed, the reasons were discussed further with them. However, if the status changed during the visit and both the participant and researcher felt it was safe to attempt the measure, the standard measurement protocol was applied. For all other participants where there were no predetermined or evident factors preventing an attempt to undertake the measurement, the standard measurement protocol was followed. However, in some situations it might have become clear that the participant was unable to meet the standards required and/or it was unsafe to complete the measurement, once the briefing and demonstration stage had been completed. If such situations arose, the response option 'not attempted' was selected and the reasons were specified in the Results Workbook. The safety and well-being of participants took priority over the research at all times, and the monitoring of both was sensitively conducted so it did not distract from the atmosphere created during the visit.

3) Rotation Order of Anthropometric Measurements Administration

The preferred rotational order of the administration was: standing height, ulna lengths (left and right), mid-upper arm circumference, weight, and waist (over a single layer of clothing) and hip circumferences. If needed, the rotational order was revised to meet the participant's needs or preferences and the revisions were recorded in the Results Workbook. Towards the end of the visit, waist circumference (WC) on bare skin was taken with eligible participants. However, before taking the first measurement, participants were informed that the researcher would like to take each measurement twice, so as to improve the accuracy of the results and ensure that no errors were made by the researcher. In some situations, a third measurement might be required. None of the measurements were taken consecutively, except for the WC on bare skin, where possible, which reduced the risk of recall bias.

Participants were advised that the second round of measurements would go much faster than the first as they would be more familiar with the measurements and steps involved. Between the first and second round of measurements, a short break (ranging from 2 to 5 minutes) was provided. This break enabled the participant to engage with the researcher on general topics of conversation if they so wished and/or provided them time to relax and/or to look through the accessible materials brought to the visit. It also enabled the researcher to make any adjustments needed to the equipment and prepare for the second round of measurements. Breaks were no longer than five minutes, with the period determined by the participant, where possible. However, if the participant did not start to prepare for the second round of measurements close to the end of the five minutes, the researcher asked if they were ready to continue, and then measurements were resumed. As per the first round of measurements, the practice of process consent/assent was repeated in the second round, and participants were reminded that each measurement was voluntary and all the same procedures applied.

4) Briefing Participants on the Second Round of Measurements

As part of the opening briefing and at the start of the second round of measurements, participants were informed that, following the completion of the second measurement, the researcher would review the results and if they (first and second) differed more than the limits set (as discussed in Chapter 3, Section 3.8.6.1), a third measurement would be taken, if they agreed. If the reason for the difference was known, it was explained (and recorded), so that the participants were kept fully informed. On the second round of measurements, all the same preparation and measurement instructions were repeated. All landmarks were removed before the second round commenced. Similarly, all the items previously recorded, where relevant, were repeated but coded under the second measurement columns in the Results Workbook.

Appendix 31 – Malnutrition Universal Screening Tool (MUST)

Table 1

Estimating Height from Ulna Length

Height (m)	men (<65 years)	1.94	1.93	1.91	1.89	1.87	1.85	1.84	1.82	1.80	1.78	1.76	1.75	1.73	1.71
	men (≥65 years)	1.87	1.86	1.84	1.82	1.81	1.79	1.78	1.76	1.75	1.73	1.71	1.70	1.68	1.67
	Ulna length (cm)	32.0	31.5	31.0	30.5	30.0	29.5	29.0	28.5	28.0	27.5	27.0	26.5	26.0	25.5
Height (m)	Women (<65 years)	1.84	1.83	1.81	1.80	1.79	1.77	1.76	1.75	1.73	1.72	1.70	1.69	1.68	1.66
	Women (≥65 years)	1.84	1.83	1.81	1.79	1.78	1.76	1.75	1.73	1.71	1.70	1.68	1.66	1.65	1.63
Height (m)	men (<65 years)	1.69	1.67	1.66	1.64	1.62	1.60	1.58	1.57	1.55	1.53	1.51	1.49	1.48	1.46
	men (≥65 years)	1.65	1.63	1.62	1.60	1.59	1.57	1.56	1.54	1.52	1.51	1.49	1.48	1.46	1.45
	Ulna length (cm)	25.0	24.5	24.0	23.5	23.0	22.5	22.0	21.5	21.0	20.5	20.0	19.5	19.0	18.5
Height (m)	Women (<65 years)	1.65	1.63	1.62	1.61	1.59	1.58	1.56	1.55	1.54	1.52	1.51	1.50	1.48	1.47
	Women (≥65 years)	1.61	1.60	1.58	1.56	1.55	1.53	1.52	1.50	1.48	1.47	1.45	1.44	1.42	1.40

Source: British Association for Parenteral and Enteral Nutrition (BAPEN) (2003) Malnutrition Universal Screening Tool (MUST). BAPEN, Redditch.

Table 2

Estimating BMI category from Mid-upper Arm Circumference

If MUAC is <23.5 cm, BMI is likely to be <20 kg/m².
If MUAC is >32.0 cm, BMI is likely to be >30 kg/m².

Source: British Association for Parenteral and Enteral Nutrition (BAPEN) (2003) Malnutrition Universal Screening Tool (MUST). BAPEN, Redditch.

Appendix 32 – Extracted Questions (PIQ and Main Interview)

Pre-Interview Questionnaire – Questions Extracted		
Questions	**Response Options (If Applicable)**	
What is your date of birth?	Open space; Don't know (DK)	
What is your level of intellectual disability?	Not verified; Mild; Moderate; Severe; Profound; and DK	
What is the cause of your intellectual disability?	Down syndrome; Cause of intellectual disability; Other, specify; and DK	
What is your height without shoes?	Feet and inches; Inches; Centimetres; DK	
What is your weight without clothes?	Stones and pounds; Pounds; Kilos; DK	
Has a doctor ever told you that you have any of the following conditions.....?	Yes; No; DK	
High cholesterol A heart murmur An abnormal health rhythm High blood pressure Angina Congestive heart failure Diabetes (and type) Asthma Stomach ulcers Varicose ulcers Cirrhosis, or serious liver damage Chronic constipation Coeliac disease	Phenylketonuria (PKU) Thyroid disease Gastroesophageal reflux disease Osteoporosis Multiple sclerosis Cerebral palsy Scoliosis Muscular dystrophy Spina bifida Chronic lung disease Arthritis Cancer Parkinson's disease	Emotional, nervous or psychiatric conditions Alzheimer's disease Dementia, Organic brain syndrome or senility Serious memory impairment Epilepsy Or had..... Heart attack Stroke Ministroke or TIA Any other heart trouble
[High blood pressure] About how old were you when you were first told by a doctor you had high blood pressure?	Open space; DK	
[Diabetes] About how old were you when you were first told by a doctor that you had diabetes?	Open space; DK	
Have you ever had a blood test for cholesterol?	Yes, within the last 2 years; Yes, over 2 years ago; No; DK	
Have you ever had your blood pressure measured?	Yes, within the last 2 years; Yes, over 2 years ago; No; DK	
Have you ever had a thyroid function test?	Yes, within the last 2 years; Yes, over 2 years ago; No; DK	
Have you ever had a blood glucose test?	Yes, within the last 2 years; Yes, over 2 years ago; No; DK	
Please write down all medications you take and how often you take them.	Name and Frequency [Daily; Weekly; When required; DK); DK what medication I am taking; Don't take any medication	
Face to Face Interview – Questions Extracted		
Questions	**Response Options (If Applicable)**	
[Prescreen] Can you tell me your age? Cross check the DOB on PIQ. Is xx/xx/xx correct?	Open space; Age provided by proxy; DK; Refused to answer (RA) Yes; No	
Is the participant male or female?	Male; Female	
Are you....?	single (never married); living with a partner as if married; with a partner but no living with his/her; married; separated; divorced; widowed; Unclear response (UR); DK; RA	
What type of residence do you live in most of the time?	At home with both parents; At home with one parent; At home with sibling; At home with other relative; Adoption; Foster care and boarding–out arrangements; Living independently; Living semi-independently; 5-day community	

	group home; 7-day (48 week) community group home (goes home for holidays); 7-day (52 week) community group home; 5-day residential centre; 7-day (48) residential centre (goes home for holidays); 7-day (52-week) residential centre; Nursing home; Mental health community residence; Psychiatric hospital; Intensive placement (challenge behavior); Intensive placement (profound or multiple disability); Other (please specify); UR; DK; RA
What is the highest level of education you have completed?	Some primary (not complete); primary or equivalent; Intermediate/junior/group or equivalent; Leaving certification or equivalent; Diploma/certificate/Primary degree/Postgraduate/higher degree/None; Other (please specify); UR; DK; RA
Are you currently attending or did you participant in any courses or any other education and training in the last year?	Yes; No; UR; DK; RA
Would you say your health is....?	excellent; very good; good; fair; poor; UR; DK; RA
How would you rate your eyesight (using glasses or contact lenses I you use them)...?	excellent; very good; good; fair; poor; UR; DK; RA
Is your hearing (with or without a hearing aid)...?	excellent; very good; good; fair; poor; UR; DK; RA
In general, would you consider yourself to be ...?	overweight; underweight; or about the right weight; UR; DK; RA
In general, how healthy is your overall diet? Would you say.....?	excellent; very good; good; fair; poor; UR; DK; RA
Do you smoke at the present time?	Yes; No; UR; DK; RA
Do you drink alcohol?	Yes; No; UR; DK; RA
During the last six months, how often have you drunk any alcoholic beverages, like beer, cider, wine, spirits or cocktails?	Almost every day; Five or six days a week; Three or four days a week; Once or twice a week; Once or twice a month; Less than once a month; Not at all in the last six months; UR; DK; RA
How often to you eat the following? Breakfast; Lunch; Dinner; Snacks	Daily; Most of the time; Some of the time; Never; UR;DK; RA
On average, in the last year, how often did you eat the following....? Fruit; Vegetables	More than 4 times a day; 2-3 times a day; Once a day; 5-6 times per week; 2-4 times per week; Once a week; 1-3 times per month; Never or less than once a month; UR; DK; RA
On average, how often do you take part in [vigorous; moderate energetic; mildly energetic] physical activities?	More than once a week; Once a week; One to three times a month; Hardly ever or never; UR; DK; RA
[Use of equipment or devices – walking or moving across a room] Which equipment is that? Wheelchair	Yes; No; UR; DK; RA
How steady do you feel....? Walking; Standing; Getting up from a chair	Very steady; Slightly steady; Slightly unsteady; Very steady; UR; DK; RA
ADLs – Please indicate the level of difficulty, if any, you have with.....?	No difficulty; Some difficulty; A lot of difficulty; Cannot do at all; UR; DK; RA
....dressing, including putting on shoes and socks; walking across a room; bathing or showering; cleaning your teeth/taking care of your dentures; eating such as cutting up food, use of utensils, drinking from a cup/glass; getting in or out of bed; and using the toilet, including getting up or down.	
IADLs – Please indicate the level of difficulty, if any, you have with.....?	No difficulty; Some difficulty; A lot of difficulty; Cannot do at all; UR; DK; RA
....preparing a hot meal; shopping for groceries; making telephone calls; managing money, such as paying bills and keeping track of expenses; doing household chores, such as laundry and cleaning;	

Pre-Interview Questionnaire: Self-Report Height and Weight Data

Automated Converison Chart for Interviewers

1 inch = 0.0254 meter

ft & in		meters	in only	meters	cm	meters
5	3	1.60	63	1.60	160	1.60
4	11	1.50	59	1.50	150	1.50
6	3	1.91	75	1.91	191	1.91
		0.00		0.00		0.00
		0.00		0.00		0.00
		0.00		0.00		0.00
		0.00		0.00		0.00

1 lb = 0.454 kg

stone & lb		kg	lb only	kg
10	4	65.38	144	65.38
12	0	76.27	168	76.27
8	2	51.76	114	51.76
		0.00		0.00
		0.00		0.00
		0.00		0.00
		0.00		0.00

Ref: JS Anthropometric Measurements

Appendix 34 – Supplementary Qualitative Data on Each Measurement

Section 1 - Height Measurement	
a) Height Problems Experienced, Valid Measurements	
Theme	**Contextual Details & Analytic Memos**
Heels Not at Back of Baseplate	After the most frequently cited problem experienced (i.e. problems with equipment), the position of the participant's heels on the baseplate was the next most frequently recorded item. Although their heels were not positioned at the back of the baseplate, they were close. The main reason for this difficulty was the weight distribution around the abdominal and hip area, resulting in the participant standing further forward on the baseplate. This could not be avoided. *"Heels not at back – due to weight, the participant's weight distribution means that [they] have to stand further out from the back of the stadiometer. A longer headplate would be useful. Participant carried a lot of [their] weight in the lower trunk area." [45]*
Leaning Slightly	The participant's body position, leaning slightly forward or to the left, was noted in a few cases but none was significant enough to affect the validity of the measurement readings. *"... leaned very slightly to the left." [57] and "... leaned slightly forward." [24]*
Height Problematic (very tall, need a stool)	In a very small number of cases, the height of the participant relative to the researcher was noted as causing some difficulty: *"... very tall compared to myself – consider a portable stool for future roll-out." [57]* *"Participant very tall, so difficult to see the reading – moved the stadiometer once [they] had stepped off to cross-check it. A portable stool or step would be ideal." [3]*
Poor Understanding	Poor understanding by the participant was recorded in a very small number of cases but did not prevent measurement from being completed, although proxy support was required: *"Participant did not fully understand the procedures and needed the support of the proxy to guide [them] onto the baseplate [new stadiometer model]." [71]*
Other Observations	In a few cases, the following observations were noted: one of the participant's head was slightly tilted and another's head was not exactly in the Frankfort plane position but was very close. In one case, the participant lifted his heels so he could be taller at the time of measurement, so with his permission the proxy assisted with the checks required. Similarly, in one case, there was a very slight slope (but remained within the limits set) to the floor but this did not affect the validity of the measurement readings.

b) Problems with Equipment – Height Measurement	
Theme	**Contextual Details & Analytic Memos**
Side-Rim Restrictions (Old Model)	The side rim was recorded as restricting (i.e. the placement of the participants feet on baseplate required more attention) to the measurement process in 33 of the 38 cases. *"Participant seemed nervous by the side rim when stepping onto the stadiometer, more so than others who were conscious of it yet steady on their feet. No reason for the side rims." [7]* *"... slightly cautious stepping onto the baseplate." [5]* However, the model was changed during the study and significant improvements were recorded for the new model: *"Removal of side rims means there is an easier transition onto the baseplate once the participant finds [their] footing [stepping from floor onto the baseplate]." [68]*
Baseplate Too Small (Old Model)	In the old model, the baseplate was observed as being too small for some participants, which was further affected by the side rims – for example, for those who needed more support stepping on, or who needed support on the baseplate, and/or those with wider body shapes.
Baseplate: Removal of Footprints and Change of Colour (New Model)	While the removal of the side rims was very helpful, the removal of the footprints to guide the placement of participants' feet was notably missed. More significantly, the colour change of the baseplate meant that participants required more time and/or support stepping onto the baseplate, as the colour was often too close to the flooring on which it sat. The combination of this new problem and the removal of the footprints were the two main problems recorded against the new model. *"The colour of the baseplate is not ideal against the kitchen floor. The footprints are missed as a reference point during the demonstration and measurement stage [guidance given to the participant]. It is now easier for participants to step onto the base without the rim but the colour nearly creates the same problem as other model (side-rims) but the reason for cautiousness is different." [61]*
Nervousness of Participants (Old and New Model)	Despite the change in model design, the incidence of recordings of the participant being nervous (although the number is relatively small) did not change greatly. Yet the factors contributing did change. In the old model, the cause was the side rims; in the new model, it was the change of colour and its similarity in colouring to most flooring – both of which related to the transition of the participant's feet from a place of security (floor) to a base placed on the floor surface. *Old Model: "... cautious stepping onto the baseplate, placing [their] feet between the raised side rims." [3]* *New Model: "Colour of baseplate is too similar to flooring, difficult to judge the difference between the floor and baseplate – cautious stepping onto stadiometer." [60]*

Headplate (Old and New Model)	For the majority of participants using the old model, the size of the headplate was sufficient for body shape and resulting stance, except for two participants, where it was noted that the headplate could have benefited from being slightly longer in length (wider body shapes). *Old Model: "Due to wider body shape [abdominal and hip area], it would have been useful if the headplate could have been longer and baseplate bigger." [56]* In the new model, the headplate was also sufficient for most participants except for one, due to the same reasons mentioned above for the old model. However, the reduced size of the headplate in length and diameter was reported frequently as an observation; it was also observed that the new model might not take account of the different body shapes and resulting stances of an older population. *New Model: "Headplate seems significantly smaller in width and length, which does not provide the same space for an adult population or stance which might be dictated by weight distribution e.g. more weight around the middle to lower back area may push people out further. I am not sure if this headplate will adequately support these people, where valid measurements could otherwise be obtained. It still may not be possible in all situations, like this visit – as other factors also made the measurement unfeasible irrespective of the headplate." [69]*
c) Description of Any Other Information – Height Measurement	
Theme	**Contextual Details & Analytic Memos**
Extra Guidance and Support from Researcher Needed	In a substantial number of cases, extra guidance and support was required and provided by the researcher (most observations related to the participant's stepping onto the stadiometer). *"Participant just needed a little more guidance and support stepping onto the baseplate but was very much able to complete the rest independently." [70]* *"Second demonstration - particular emphasis was placed on the importance of slowly stepping onto the stadiometer, and keeping their legs straight and feet flat on the base during the measurement." [38]*
Time of Measurement	In some cases, it was observed that the time of day may affect outcomes, which reaffirms the importance of the instruction to secure appointments as early in the day as possible. *"Although the 2nd and 3rd measurements were valid, we need to consider the time of day that height measurements are taken [possible diurnal effect]. If height was measured in the morning would it yield a significantly higher reading?" [73]* *"Time of measurements (late evening) needs to be considered."[13]* Also of note, the rate of invalid height measurements was greater from mid-afternoon onwards (3.00pm) compared to those taken earlier in the day (before 2.59pm) in the first (60%; *n*=9 vs. 40%; *n*=6) and second (73%; *n*=8 vs.27%; *n*=3) series of measurements.

Space as a Concern	During some visits, space was recorded as a concern for this measurement: *"Very tight space – it made the measurement process a bit more awkward. The living room was not suitable as it was carpeted and there was no other suitable space but the kitchen." [1]*
Other Observations	Other factors recorded infrequently included the floor level (e.g. importance of the instruction in the protocol to check the levels); the impact of participants wearing trousers (e.g. need to ask the participant to tuck the bottom of their trousers into their socks, so the position of their heels is in full view); the participant being distracted by other things going on in the vicinity, and the weight distribution of the participant (e.g. body shape affecting the participant's stance).

Section 2 - Ulna Length Measurement

a) Ulna Length Problems Experienced, Valid Measurements

Theme	Contextual Details & Analytic Memos
Styloid Process Difficult to Locate	The most frequently cited problem experienced with this measurement was the difficulty with immediately locating the Styloid process due to the distribution of tissue surrounding the wrist and the immediate area of the Styloid, which resulted in the bone not being as prominent. *"Styloid process was not found immediately due to (excess) tissue in this region." [39]* *"Left styloid process took longer than the right to find." [27]* *All cases: Review of the codes in this category, cross-referenced with quantitative information (n=16), showed that 100% (n=8) of the cases with known measured BMI scores (n=8) were overweight or obese, and the majority, 63% (n=5), were aged between 40 and 59 years. Similarly, when cross-referenced against known self-report BMI scores (n=10), all were overweight and obese, and 70% (n=7) of them were aged between 40 and 59 years. The majority of those with unknown measured BMI scores (n=8) and this cited problem, difficulty locating the Styloid process, were aged between 40 and 59 (63%; n=5), while for unknown self-report BMI scores (n=6), 50% also fell into this age category (n=3). **Participants with Down syndrome (DS) only: For half of the participants with DS (50%; n=5) in the study (n=10), the styloid process was difficult to locate but, similarly to other participants, valid readings were achieved. On review of the codes in this category (n=5) against known measured BMI score, four of the participants were overweight or obese, and the majority were aged between 40 and 59 years (80%; n=4). The fifth participant's self-report BMI score was within the obese range.
Arm Movement Hampered Timing of Reading	Although fewer, a significant number of observations noted the movement of the participant's arm as a difficulty in terms of taking the actual reading, but often after further interaction or support a period of rest followed, if it did not happen naturally. In some cases it was also noted that a shorter segmometer would have responded more easily and faster to the movement of the participant's arm and rechecking of the landmark sites.

	"Participant needed more support from proxy, as [they] were moving [their] arms a lot before the reading. With support from proxy and interaction ongoing during the measurement, the reading was possible." [10] *"Moving slightly but the participant had periods of no movement." [34]*
Wheelchair and Seated Position Delayed Reading	Again, although less than with the main cited difficulty, there were a significant number of cases where participants in wheelchairs (*n*=8; 42%) and/or in a seated position experienced problems if arm-rests existed and/or they needed support. In both situations there was often limited room for the participant to adjust and/or for the placement of the segmometer at the landmark sites, which increased the time needed to prepare and take the measurement readings. Both the theme of *"restricted space as a barrier"* and *"segmometer too long"* emerged on further coding this observation (see Section 2b for further details on both themes). *"Difficult to measure in seated position with segmometer length (high arm-rests), especially when the participant also needs support - very little room." [47]* *"Segmometer needs to be smaller for people in wheelchairs – little room available to adjust with arm-rests." [51]*
Did Not Fully Understand the Instructions	In a small number of cases the participant did not fully understand the instructions: *"Measurements were taken consecutively in groups of first measure left and right and then 2nd measure left and right as [they] did not fully understand that we would do one set at a time and repeat and also got the feeling we may not get all completed." [48]* *"Support needed – participant placed arm in position but did not fully understand that it needed to rest in that position for a short period." [52]*
Breathing Pattern	In a very small number of cases, the influence and effect of the participant's breathing pattern at the time of the measurement reading was highlighted. The importance of taking the reading at the end of a normal expiration needs to be highlighted in both the protocol and training. The variance ranged from 0.1cm to 0.4cm and was influenced by their breathing pattern.
b) Description of the Equipment Problems – Ulna Length Measurement	
Theme	**Contextual Details & Analytic Memos**
Segmometer too long	The most cited difficulty was the length of the segmometer: *"A smaller segmometer would be useful when in a restricted space and when the participant prefers or needs to sit to have the measurement taken, as the current length gets in the way of the seat, if the participant cannot adjust and with adjustment it may not be enough with chair type (e.g. narrow, arm-rests etc)." [31]* The positioning of the participant was central to this reported problem, where the participant was seated (e.g. wheelchair or chair) or lying down, thereby restricting space:

	"A shorter segmometer would have made it easier as the participant was lying in bed." [41] *"A shorter segmometer would be better to accommodate people sitting in chairs when there isn't a lot of room [and/or if they are unable to adjust]."[14]*
Restricted Space – Poor Performance	Allied to the previous reported observation where the participant's position created a space problem was the physical space in which some measurements were taken: *"Room very small (bedroom) with participant, proxy, myself and another support worker in the background (doorway) observing and with the participant sitting in a chair close to the wall, it didn't leave a lot of room." [53]* *"A shorter segmometer would have been useful as the participant was unable to adjust seated position – very limited room." [74]*
Wheelchair Use – Poor Performance	Space problems as reported where the segmometer was too long were universally difficult when there was a wheelchair involved: *"Segmometer needs to be shorter when measuring participants in a wheelchair." [18]* *"A shorter segmometer needed for measuring people in wheelchairs." [20]*
c) Any Other Information – Ulna Length Measurement	
Theme	**Contextual Details & Analytic Memos**
Participant Adjusted Position	The most frequently cited observations – of equal proportion to the category *"type of guidance from proxy"* – were of a positive nature, where the participant could alter position while seated: *"Chair caused no restrictions (no arm-rests). The participant just needed a little extra guidance on which arm was first but was able to complete independently." [71]* *"Chair was suitable and the participant was able to adjust for ease of measurement, so no problems were encountered with the equipment." [46]*
No Obstruction with Seating	In a slightly smaller but significant number of positive observations, the researcher reported no restriction with seating. There were restrictions; however, when the chair had arm-rests (see Section 2b and the last theme discussed in Section 2c). *"There was plenty of room for [them] to adjust seated position, no problems with this position. Styloid process was very easy to find. I asked if they would prefer to sit for this measurement to rest their ankle and [they] said yes." [33]* *"No restrictions with chair (1st measurement)." [45]*

Extra Guidance from Researcher Needed	In some cases, extra guidance was required and provided by the researcher: *"Participant only needed guidance (arm needed), able to do independently" – Participant with a moderate level of intellectual disability* [42] *"Participant needed some further guidance from me but once shown again was able to do independently" – Participant with a severe level of intellectual disability [75]* *"Participant needed a bit more support on the position of their arm but seemed to understand request (and measurement) from the demonstration and showcard" – Participant with a severe level of intellectual disability* [46]
Arm-rests Caused Restrictions	There were several recoded observations where not having arm-rests was recorded as the reason the measurement could be completed without difficulty; these notes were coded to *"arm-rests cause restrictions"*: *"Participant was able to adjust in seated position and seating had no restrictions (arm-rests)." [72]* *"Participant was able to adjust seating position so there were no difficulties with equipment and the chair had no arm-rests." [70]*

Section 3 - Mid-Upper Arm Circumference (MUAC) Measurement

a) MUAC Problems Experienced, Valid Measurements

Theme	Contextual Details & Analytic Memos
Arm Movement Hampered Reading	The most frequently cited problem experienced with this measurement was the movement of the participant's arm, often slightly, when taking the reading and then rechecking that the tape had not moved off the landmark side. However, similarly to the ulna length measurement, a period of rest followed, often after further interaction or support if it did not happen naturally. *"Participant needed support of proxy, kept moving arms. [They] moved less on second measurement. Readings were taken when [their] arm wasn't moving." [10]* *"Participant moved arm very slightly during 2nd part of measurements." [52]*
Wheelchair Position Delayed Reading	There were some observations where locating the acromion bone and/or placing the segmometer with participants in wheelchairs were reported as problems, due to restrictive space and the longer-than-needed segmometer. In one of these observations, the participant had the measurement taken on the right side as they leaned too much to the left and it was not possible to locate the landmark. *"Acromion bone is not as easy to locate when the participant is in a wheelchair." [2]* *"... segmometer difficult to position due to wheelchair." [18]*

Negotiating with the Participant	Of equal proportion to the previous observation, negotiating with the participant was recorded a number of times during this measurement: *"Participant requested for the 2nd measurement to be taken after the first one. I said that this was no problem but that we will let [their] arm relax for a minute and then take the 2nd measure (this allowed for the removal of the landmark, some conversation and break between measures, although taken consecutively) – the participant agreed." [39]* *"Participant did not want any delays when the tape was placed on [their] arm. Measurement was taken as quickly as possible." [47]*
Other Observations	In a very small number of cases, the participant did not fully understand the procedures and needed support from the proxy to make adjustments. However, in one case where this occurred, the proxy's negative support did not provide the optimal measurement conditions (see Chapter 4, Section 4.3.3.3 [k(ii)]). Limited space and unsuitable clothing (e.g. long-sleeve shirts or tight garments around the acromion bone) were also noted as not ideal for the measurement, and more time was required to make the adjustments needed. Both of these items also made it difficult to locate the acromion bone, as well as the extra tissue in this area in a small number of cases.
b) Description of the Equipment Problems – MUAC Measurement	
Theme	**Contextual Details & Analytic Memos**
Segmometer Too Long	As was the case with the previous ulna length measurement, the segmometer was found to be too long in many instances, particularly where the participant was using a wheelchair. *"A shorter segmometer is needed for measurements in a seated position when adjustments can't be made easily by the participant or are not possible." [53]* *"When we got to this measurement each time, [their] seating position changed – lying back in the chair slightly after ulna, which would have been okay if the segmometer was shorter – took a bit of adjusting to adequately get it positioned." [77]*
Problems with Wheelchairs or Seated Position	As with previous measurements (ulna length), taking the measurements with the participant in a wheelchair or seated position with restricted space or room for adjust was regularly recorded as problematic due to the length of the segmometer. *"Segmometer needs to be shorter for using with people in wheelchairs." [18]*
Problems with Lying Position	In two cases, the participant's lying in bed raised a similar consideration: *"Segmometer needs to be shorter, (lying) participant unable to adjust positioning which resulted in the measurement being attempted but not obtained." [22]* *"A shorter segmometer would have made the measurement easier. Participant is very thin so acromion bone was easy to locate (lying position). I am not sure if this measurement would be as easy if the person was in the same position but had excess tissue in this area and were unable to adjust for the segmometer." [41]*

c) Any Other Information – MUAC Measurement	
Theme	**Contextual Details & Analytic Memos**
Unsuitable Clothing	In a substantial number of cases, the participant's clothing (restrictive shirt/top covering all or some of the upper landmark area, acromion bone) was recorded as a source of difficulty – mostly as a barrier to completing a valid measurement: *"Participant did not have suitable clothing on and despite the best efforts of the participant and proxy it wasn't possible. If suitable clothing had been worn, a valid measurement could have been possible." [31]* *"Unsuitable clothing [less restrictive shirt/top from the upper to lower arm area needed] – had suitable been worn a valid measurement could have been possible." [37]* The following observation reflects the benefits of suitable clothing being worn: *"Loose clothing makes such a difference, all landmarks were so easy to locate." [45]*
Participant Adjusted for Segmometer	As with previous measurements (ulna length), there were many positive observations of the participant adjusting position for the segmometer: *"Same as ulna length, the participant was able to adjust and chair was suitable." [65]* *"Participant only needed a bit more guidance from me about 1st position and then moved onto 2nd stage on [their] own, when needed." [74]* Significantly linked to the adjustments made by those in a seated position was the frequently recorded observation that suitable chairs (e.g. no arm-rests) did not cause restrictions but that a shorter segmometer would aid the measurement process and reduce the adjustments needed. *"... was able to adjust where needed and there were no restrictions with the chair." [62]*
Participant's Position as a Factor	However, there was a similar level of recordings of the participant's position as a factor that impeded, though it did not prevent, a valid measurement: *"Participant was seated for this measurement as it was a very hot day. If the conditions were cooler, the standing position would have been possible. In the seated position, the participant adjusted (themselves) slightly to maximize the positioning of the segmometer." [58]*
Participant's Weight as a Factor	Some observations were recorded noting that, where the participant was thin or slender, the acromion bone was easy to locate: *"Participant is very thin so the acromion bone was easy to locate." [41]* *"Participant very thin – it was easy to find the acromion border." [18]* For those who were heavier and with extra tissue in this area, locating the acromion bone could be more difficult and take more time, as noted in Section 2(a).

Other Observations	In a small number of cases, the participant needed some further guidance from the researcher during the measurement on the positioning of their arms. This and an administration issue – where the appointment card did not arrive, resulting in the participant not receiving the final reminder to wear loose clothing – made up the small remainder of observations.

Section 4 - Weight Measurement

a) Weight Problems Experienced, Valid Measurements

Theme	Contextual Details & Analytic Memos
Negotiating with Participant	As noted for previous measurements (e.g. mid-upper arm circumference), negotiating with the participants was a feature of this process in several cases: *"At the end of the 2nd measurement, the participant seemed to be getting bored, but when checked if [they] were happy to continue [they] said 'yes'. I reminded the participant that [they] can change [their] mind at any stage and just let me know and replied 'okay'. Measurements continued ..." [39]* *"During the 1st visit the participant started to get tired and I suggested that we finish the remaining measures on the 16.08.10 including weight, participant agreed and expressed [their] appreciation for flexibility." [62]* *"... put their shoes back on after 2nd MUAC and wanted to keep them on for this measurement. Didn't want to get shoes weighed separately [after the measurement] but then decided to take them off and get weighed without shoes." [76]*
Refused to Remove Footwear / Clothing	In a number of cases, participants wanted to keep their shoes on for this measurement, and in one case, their jumper; the items were weighed afterwards and the relevant subtractions were made: *"Participant wanted to keep [their] shoes on but was willing to have them weighed at the end of the visit." [19]*
Looking Down or Moving Feet	Some observations reported that participants looked down or moved their feet to see the result of measurement, which increased their reading. In response to this problem, a picture of the study logo was held in front of the participant to keep their focus forward. *"Participant tended to look down at the measurement reading. As a result, I used the picture of a logo to distract attention straight ahead." [24]*
Other Observations	Two other observations concerned the measurements being taken on a very slight slope (floor not exactly level but 75% of the spirit-level bubble remained within the two lines of the gauge), and measurements being taken consecutively, as the participant spends most of the day in bed and it was not appropriate to complete any other way, highlighting the value of the flexibility accounted for in the protocol.

b) Description of the Equipment Problems – Weight Measurement	
Theme	**Contextual Details & Analytic Memos**
Logistics as a Factor with Wheelchair Scale	The single biggest recorded difficulty with equipment in the weight category was with the logistics of transferring and moving the wheelchair scale, often into confined spaces: *"Wheelchair scale took about 15 minutes to set up [transfer from car to calibration checks] – not easy lifting it out of the car on my own – this scale is not feasible for wider roll-out except for clinic-style set-ups. Since I was unable to prop the door open of the unit, it took several trips to get the equipment in. The only advantage is that once they are set up, they will be used by several participants during this visit and most importantly, very feasible to measure."[2]* *"Set-up of wheelchair scale took a little over 15 minutes [transfer from car boot to calibration check]. Room very small with furniture – had to adjust/move pieces so the scale could be feasibly placed in the room. No parking nearby which meant I had to pull up as close as I could and then drop off the scale, go and park and quickly go back to the scale and move it into the unit – not ideal, particularly by oneself." [19]*
Space as a Factor with Wheelchair Scale	*Physical space was recorded as problematic in many observations:* *"Wheelchair scale may have led to a valid measurement but I am not sure of the feasibility of setting up the scale in this room re: location of the plug to connect the portable monitor. The participant would have had to turn around to step off or step backwards and while [they] had no difficulty walking forward with support, side stepping or stepping backwards appeared more difficult." [35]* *"... room very small with furniture – had to adjust / move pieces so the scale could be feasibly placed in the room." [19]* *"... measurement process took longer, with adjustments needed in the room." [53]*
Other Observations	A small number of observations related to a technical issue with the wheelchair scale (needed to reset the scale and repeat the calibration check during the set-up phase), and the participant's ability to stand and walk being inconsistent with the interviewer's notes on the Measurement Communication Form. As a result, the correct scale (i.e. wheelchair scale) was not initially set up. However, where possible, the right scales (wheelchair and flat scales) were set up (in all but one case; the location of the plug for the wheelchair scale was not suitable for the set-up required). *"The numbers on the wheelchair scale kept jumping while the participant was on the scale yet they were not moving – re-checked calibration and restarted, all okay." [11]* *"Interviewer reported the participant to be very steady walking and standing but that was not my experience and noted this shortly after the visit began. As a result, I went and got the wheelchair scale [flat scale uncomfortable for participant] but getting and setting these up added 20 minutes to visit, as there was no parking nearby." [28]*

c) Any Other Information – Weight Measurement	
Theme	**Contextual Details & Analytic Memos**
Wheelchair Scale Already Set Up by Researcher	After the most frequently cited observation (i.e. type of guidance from proxy), observation of the use and benefits of the wheelchair scale compared to the flat scale followed, in relation to participants who were not wheelchair-users but used this scale as it was already set up. The wheelchair scale was used by all participants when it was set up for wheelchair-users at the relevant locations. *"Wheelchair scale already set up, so no time wasted" [21]* *"...easy transition between measures." [7]* *"Used the wheelchair scale as it was already set up, participant had plenty of room to adjust – this scale is ideal for all participants if they were only easier to transport." [68]* *"Wheelchair scale is ideal for clinic settings." [75]* None of these participants except for one required support when stepping on or off the wheelchair scale. Some of them might have needed support if the flat scale had been used. "Used the wheelchair scale – already set up for another participant (wheelchair-user); no support was needed getting on or off the scale. They used the bar to assist themselves onto the scale and released at the time of measurement." [52]
Weight of Wheelchair or Seat	Similarly, a substantial number of observations concerned the methods used to obtain the weight of the participant's wheelchair or seat used, where required. The methods fell into three categories: the wheelchair was weighed before or after use, where feasible [seats were weighed before use]; proxy reported the weight of the wheelchair from records; or the weight was taken from the manufacturer's stamp, if provided. *"Weighed wheelchair before the participant was transferred into it for the visit." [41]* *"Weighed the seat before the participant got up to use the scale." [53]* Of note, all the preparatory wheelchair transfers for the visit were completed by the proxies, where required. However, with the participant's permission and where support was required, the researcher assisted participants on and off the wheelchair scale (see theme below).
Researcher Supporting the Participant onto the Scales	Several observations of the researcher supporting the participant moving on or off the scales (wheelchair and flat scales) were recorded: *"Participant needed some support stepping onto the flat scale but steady on scale – but did look down at feet but distraction of study logo diverted attention." [25]* *"Participant used the wheelchair scale but was able to stand comfortable; [they] did not want to sit down on a chair. Held bar with one hand. Gave [them] a little bit of support stepping on and off scale but otherwise was able to complete independently." [65]*

Participant's Shoes as a Factor	In cases where the participant wanted to keep their shoes on it was noted that a protocol to weigh the shoes separately should be in place; this process was followed in these instances: *"Note for protocol: If the participant wants to keep their shoes on for the measurement although not ideal, ask them if they would be willing to get their shoes weighed at the end but note that the timing of this request will depend on each individual." [19]* *"Wanted to keep shoes on for this measurement but agreed to get them weighed separately afterwards." [52]*
Other Observations	In one case, oedema was observed on the lower part of the body, particularly around the ankles and feet, during the measurement; the participant and proxy were aware of this. In another case, the participant's weight was a matter of concern: *"Spoke to staff [x2] about the participant's weight and asked if a dietician was involved, and one is involved. I also mentioned the importance of hydration and it was noted that there is a fluid chart in place and that staff are monitoring weight loss. Staff was very open to the concern expressed." [41]* The importance of checking the floor level during the set-up stage was noted. *"Using the spirit level, I tested the flat scale in number of locations around the room as the floor was uneven in several places until a suitable location was found (within the limits set). This visit reinforces the importance of checking the levels." [12]*

Section 5 - Waist Circumference (WC) Measurement

a) WC Problems Experienced, Valid Measurements

Theme	Contextual Details & Analytic Memos
Clothing Hampered Process	The most frequently cited problem experienced with this measurement was difficulty with clothing, which related to either its unsuitability or there was more than a single layer worn on initial measurement; the measurement then had to be repeated over a single layer only, with the participant's permission. *"Clothing type was not great – polyester top, measuring tape kept slipping." [1]* *"Although participant/proxy indicated clothing was a single layer it didn't feel like it, which was later confirmed following a repeat demonstration, the raw figures were not reported. The final readings were taken over a single layer (vest)." [26]* The following associated recommendation was reported in one of the observations recorded: *"...consider measuring clothing thickness at the beginning of the WC measurement as opposed to the end for future roll-out, so the number of layers can be verified then." [16]*

Movement Hampered Reading	Slight movements among participants were recorded as a problem during this measurement, which required the landmarks to be re-checked and/or the reading to be taken at a period of rest that, if it did not happen naturally, was often supported by further action by the proxy. Movement mainly consisted of adjustment of feet and/or leaning slightly. *"Briefly started on the right side but changed to left side as the participant leaned slightly to the right, so left was more appropriate." [40]* *"Left leg shaking slightly (less than before the measurement) – took reading at the point when the participant moved least." [70]*
Difficulty Locating the Iliac Crest	Of equal proportion to the previous observation, it was noted that the iliac crest was not found immediately, which was often linked with extra weight among participants around the abdominal area, but such situations were handled with great sensitivity. The other reason for the iliac crest being difficult to locate was the iliac crest falling parallel to the participant's waistband. *"Iliac crest was not located immediately due to tissue in this region, but was found – took a short rest break between tries (approx 1 min) to allow the skin to relax, so the participant did not get uncomfortable. Managed sensitively like all measurements." [36]* *"Weight distribution around the abdominal area can influence whether the iliac crest can be located or not [e.g. the more tissue in the area, the greater the difficulty]." [66]*
Position as a Factor	In a few cases, due to the extent of leaning or for ease of administration based on the participant's stance, the position of the measurement was changed from the right side to the left side, which supports the planned and specified flexibility detailed in the operational protocol. In one case, the back of a chair was placed in front of the participant to assist a standing position. *"Measured on the left side, as they leaned to the right so difficult to locate iliac crest." [40]* *"Participant leaned slightly to the right and the proxy stood to the right of them for support when needed, so the measurement was taken on the left side." [35]*
Other Observations	In a small number of cases, the participants were very aware of the timing of the measurement reading, which resulted in them not exhaling fully; with additional engagement, regular breathing patterns were established and the readings were taken. The importance of monitoring the breathing patterns of the participant was noted in one case: *"Participant was initially very conscious of measurement reading being taken, as they were holding their breath/not exhaling fully at the beginning of each measurement but was interactive and after some time they got distracted from the measurement." [13]* Lastly, similar to other measurements, small spaces with limited room for manoeuvring around the participant was noted as a barrier to maximising the administration of this measure.

b) Any Other Information – WC Measurement	
Theme	**Contextual Details & Analytic Memos**
Clothing as a Factor	The most cited observation in the 'any other information' category related to the participant's clothing being unsuitable for the WC measurement. *"Polyester clothing is not suitable for the waist circumference measurements. Despite my best efforts, I was unable to keep the tape from slipping and then the tape was being held by the proxy, and this meant that we did not get a valid reading." [8]* *"Measurement was over two layers. Even though I checked with the participant and one layer of clothing was confirmed by them, they also had a vest on which I noted when I measured the thickness of their t-shirt at the end of the visit. [16]* *"Jeans are unsuitable ..." [33]* *"... also need to add the avoidance of suspenders on the appointment card beside belts in the future." [72]* Ninety-six percent (n=50) of participants that attempted the WC measurement complied with the request to avoid wearing jeans, the remaining 4% (n=2) did not comply.
Other Observations	The importance of managing this measurement in a sensitive manner and of including it not only in the operational protocol but also in training was noted: *"Iliac crest not found immediately – had explained to the participant that it isn't always possible, as the bone can be hard to locate but that we could give it a try if they were willing. It is so important that sensitivity is exercised during this measurement and it will also be important to include this item as a factor in future training as well." [37]* *"Iliac crest was not found immediately due to extra tissue in this area. The measurement was managed sensitively like all measurements." [56]* For one participant who got distracted easily, the researcher placed the back of a chair within the measurement area and invited them to hold onto it for support during the measurement. In response, the participant held onto the back of the chair and looked forward.

Section 6 - Hip Circumference (HC) Measurement

a) HC Problems Experienced, Valid Measurements	
Theme	**Contextual Details & Analytic Memos**
Negotiation with Participant	The most frequent observation noted concerned negotiating with the participants, particularly as this measurement was the last one at the end of the first and second series of measurement readings. *"Continued positive interaction throughout this measure led to valid readings, particularly as the participant's interest in the visit was fading by the 2nd series." [55]*

Weight Distribution	Two observations were recorded where the participant's weight distribution in the abdominal area extended to the hip circumference area, which increased the time required to make the adjustments needed for positioning the tape measure. *"Due to the weight distribution in the abdominal area which extended to hip circumference, positioning of the tape took longer than usual, [slid] off during the placement stage when the participant moved slightly – tape repositioned." [12]*
Leaning to Right	Similarly, two observations noted that, where the participant leaned slightly to the right, the measurement was taken on the left side. *"Stood to the left of the participant and took that measurement at this side, as [they] leaned to the right and proxy stood beside the participant for support." [35]*
Other Observations	In one case, the participant moved slightly to see what the researcher was doing but, following interaction, maintained the desired position. Also in one case, due to unsuitable clothing (i.e. polyester clothing making the landmark area slippery) the support of the proxy was required. *"Participant needed support of proxy, as their clothing needed to be adjusted. If clothing was suitable, the participant could have completed it with no support." [26]*

Appendix 35 – Supplementary Qualitative Data on the Measurement Visit

Feedback, Observations or Reflections from the Measurement Visit	
Theme	**Contextual Details & Analytic Memos**
Briefings and Demonstrations Worked Well	The single most cited observation was that briefings and demonstrations worked well and were well received irrespective of the participant's level of intellectual disability. *"Briefings and demonstrations well received and worked well. Showcards were used just as general reference to the stages only." [1]* *"Participant really liked the demonstrations and showcards. Proxy noted how well [they] understood the briefings and demonstrations and was surprised at how much [they] participated in the session e.g. pointed to their wrist bone." [6]* *"Participant was very happy to take part, very chatty! Briefings and demonstrations were well received. [They] liked the showcards and followed the steps listed." [9]* *"Briefings and demonstrations were well received. Participant did not require any support, there was no proxy present but staff support was available if needed. Participant liked the showcards, said they were clear and followed the steps listed as I went through the briefing and demonstration." [72]* For those with limited or no verbal communication: *"Adapted briefings and demonstrations were well received. I am not sure how much the participant understood but [they] got the key messages i.e. was able to complete the ulna length and MUAC measurements independently." [50]* *"Adapted briefings and demonstrations were well received. Participant was able to be weighed with no support and also understood what to do for ulna length measurement, but [they] did not understand the length of time they needed to keep their arm positioned for the measurement – proxy assisted." [52]* *"Participant was mostly non-verbal, had a few words. Adapted the briefings but I am not sure how much [they] understood. The participant did look at the showcards from time to time and watched the demonstrations – seeing what to expect. The proxy guided them through most of the measures. Participant clearly communicated that [they] did not want the second height measurement." [25]* *"Participant mainly used gestures and non-verbal signs during the visit. [They] seemed to understand nearly everything I was saying, only adapted the briefings slightly. The demonstrations were well received." [77]*

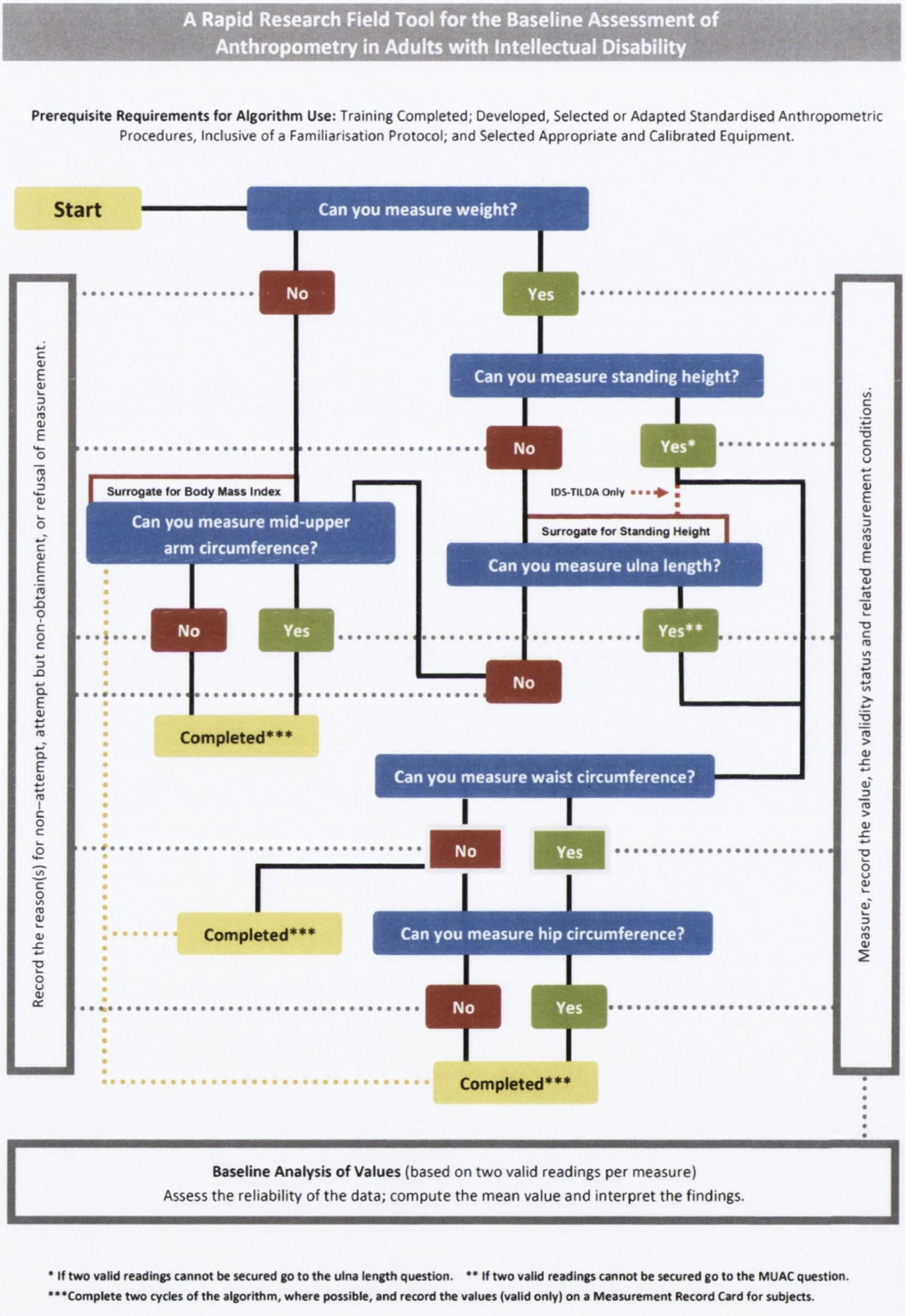
	Participants' Level of Interest in the Materials The incidence of a poor level of interest was relatively very small. In the main, the materials refer to the showcards used during the visit (briefing stage before each measurement), the accessible booklet *Keeping Well* (DSS 2007) and the accessible Measurement Information Record Card, which details the measurement results (both were given to the participant towards the end of the visit). *"Participant seemed to like the materials, was flicking through 'Keeping well' while I was recording information in the results booklet and the record card." [56]* *"Participant was looking at the showcards when I was recording the readings and at the end of the visit [they] were flicking through the 'Keeping well' booklet." [51]* *"Participant liked the booklet and the record card and asked for it all to be placed in an envelope for safe keeping until they get home". [63]*
Participant Understood and Communicated	Similarly there were high levels of observational data recorded of participants demonstrating a clear understanding and communicating that understanding during the measurement process. *"Participant was in good form, hard of hearing but could communicate and understood the process. Briefings and demonstrations were well received and liked the showcards and materials." [5]* *"Participant was happy to take part, initially thought I was the chiropodist when we met in the living room but looked at the appointment card and knew that I was here for the measurements. [They] were very interactive throughout the visit." [11]* *"Participant used gestures and sounds mainly during visit; [they] liked the showcards, by facial expressions and hand gestures towards the cards. The participant appeared to understand the adapted briefings and demos (watched me)." [42]*
Proxy and Staff Fully Engaged	Proxies and staff were noted as being generally helpful and fully engaged in the processes. *"Proxy interested in the study and glad that they are helping out." [1]* *"Proxy said the description and approach taken was very good and really empowered the participant before the actual measurements began." [6]* *"Participant appeared to really enjoy the visit and interaction. [They] stretched [their] arm out to give me a hug at the end of visit. All very welcoming, staff assisted in any way they could." [20]* *"Prior to the participant's arrival a senior member of staff said that the success of the visit will depend on the participant's mood and he may not wish to take part, I said that we will take it a step at a time and that if they do not wish to proceed or want to stop this will be fully respected – visit went really well, all measurements completed." [44]*

Participant – Level of Understanding and Modes of Communication	Of equal proportion to the previous observation, there were several instances, mainly involving participants with severe and profound ID, where their level of understanding of the adapted briefings and demonstrations was unclear, but non-verbal communication, such as gestures, were used by many of these participants. This assisted in the assessment of support needed during the measurement and, most importantly, the assessment of their assent to participate in each eligible measure. *"Participant was non-verbal, required assistance from proxy throughout the visit. I am unsure about how much of the adapted briefings and demonstrations the participant understood but they looked at showcards a few times." [10]* *"Participant was non-verbal during visit, did make gestures – seemed happy to take part, was hiding behind [their] arm and then moving it to see if I was looking and then smiling." [21]* *"Participant was non-verbal, smiling and looking at what I was doing, seemed happy to be taking part, good form. Held the showcards while I was doing the adapted briefings and demonstrations – I am not sure how much they understood e.g. did not understand ulna length and position of arm or the position of arm for the first part of the MUAC measurement..." [23]*
Participant Enjoyed the Visit	As already apparent from the observations quoted previously, it was regularly noted in the qualitative observations if the participant particularly enjoyed the visit: *"Proxy said the briefings and demonstrations really worked well for the participant. [Researcher] Heard the participant repeating 'I enjoyed that' and 'she was nice' to the proxy as they went up the corridor back to the hall." [29]* *"Participant responded well to briefings and demonstrations, and liked the showcards. Said [they] enjoyed the visit and liked taking part." [43]* *"Participant liked the materials and said if he could help out any further with the study to contact [them] – very interested in this aspect and the main study. Very welcoming and said [they] really enjoyed the visit, learning about the measures and seeing the different types of equipment." [73]*
Proxy Distant Support Enabled Focus on Participant	It was noted that, where the proxy limited support to stepping in and out where required and, when present in part or fully, stayed in the background when not needed, it greatly assisted the researcher to focus on the participant, and was noted as very beneficial to the process. *"Staff very welcoming – did not get involved unless requested e.g. waist circumference on bare skin. No assistance required but proxy remained in the room – very limited interaction which enabled the full focus to be on the participant." [13]* *"No support needed from proxy except for waist circumference on bare skin. Proxy remained in the background and only joined in conversation where relevant which really supported 110% focus on the participant and no distraction for either party." [29]*

	"Proxy present in the room but just in a supportive role/observing – allowed all the time to be focused on the participant." [15]
Importance of Sensitivity	Of equal proportion to the previous observation, the importance of sensitivity (e.g. locating specific landmarks) towards the participant was noted in several observations under the feedback section of the qualitative observations. *"... excess tissue can make it difficult to locate specific landmarks – it was more time consuming and sensitivity is so important, particularly if it cannot be found to always say at the beginning that it is not always possible to find this bone but if you are happy we will give it a try. It is critical to emphasise in training." [1]* *"Participant seemed unsteady side stepping and backwards (fine going forward and standing in one place for short periods) which would be needed for height, so I sensitively said we would skip this measurement." [35]* *"At the end of the visit, Proxy said 'you were lucky to get the measurements you did', which supports that approach employed to take the measurements in this study [e.g. staged release of information, briefings, demonstrations etc]." [52]*
Negotiating with Proxy	In a very small number of exceptional cases, it was noted that it was necessary to negotiate with the proxy in order to successfully complete the measurement process. *"Proxy very welcoming but equally anxious and eager to get the measurements completed as soon as possible – questioned why the measurements had to be repeated. Explained the importance of taking two measurements.....Also explained that if [they – the participant] don't want to continue or indicate non-verbally through cues or body language that they've had enough this will be respected – proxy was happy with this response." [26]* *"Throughout the visit the proxy's comments were not very supportive – for example, '[they] wouldn't do that', 'why do you need to do it twice?', and '[they] won't take off [their] jacket' etc – to encourage participant in the process – even when comments were deflected it continued. As a result, I think the participant had enough towards the end of the visit. The other support worker was much more supportive and encouraging, where possible. Both staff were very welcoming but I don't think the primary proxy felt the measurements were important." [55]* *"At times it was difficult to maintain direct dialogue with the participant while carrying out the measurements, as the proxy also engaged in conversation (very friendly). Although the dialogue was effectively redirected back most times, a spotter/recorder would have been useful (i.e. to write down the results)." [45]*

Appendix 36 – Key Methodological Reference Materials

Figure 1: Rapid Research Field Tool Developed for Baseline Assessment of Anthropometry



* If two valid readings cannot be secured go to the ulna length question. ** If two valid readings cannot be secured go to the MUAC question.
***Complete two cycles of the algorithm, where possible, and record the values (valid only) on a Measurement Record Card for subjects.

Figure 2: Self-Report Collection Guide for Height and Weight Data

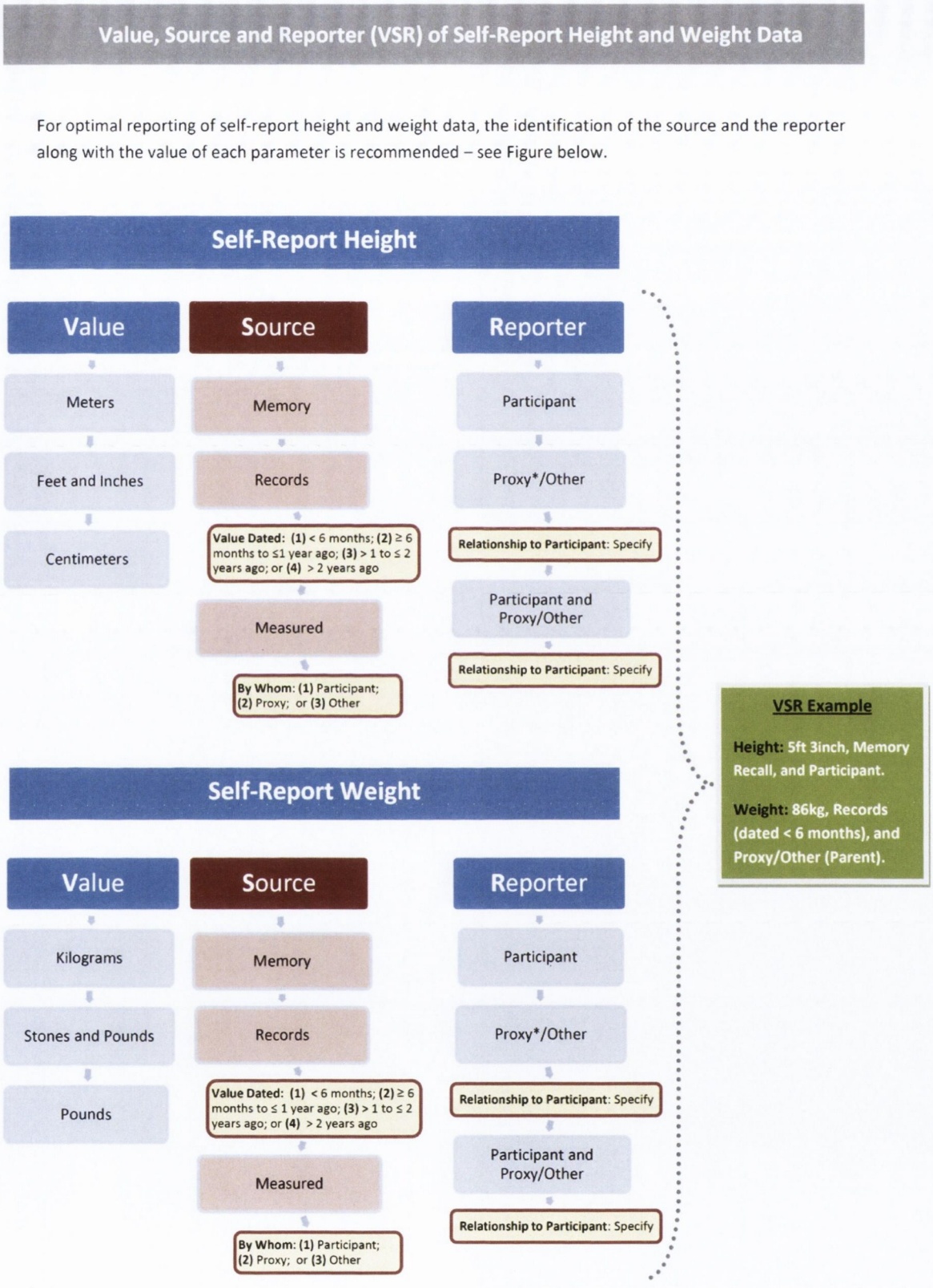


Figure 3: Blueprint of the Methods, Instructional Materials/Procedures and Guidance

Stages	Type of Methods	Instructional Materials / Procedures	Type of Guidance
Recruitment	• Text/verbal symbols • Pictures/ visual symbols • Photo	• Consent form* • Information booklet* • Guardian agreement form & leaflet	• Text • Visual
Interview	• Text/verbal symbols • Pictures/ visual symbols • Photo	• Briefing by interviewers • Measurement Information Booklet*	• Verbal • Text • Visual
Appointment	• Text/verbal symbols • Pictures/ visual symbols • Photo	• Key reminders via telephone • Appointment card with reminders*	• Verbal • Text • Visual
Measurement	• Text/verbal symbols • Pictures/ visual symbols • Photo • Demonstrations • Direct experience	• Researchers ID • Ice-breaker dialogue • Briefings by the researcher • Measurement showcards* • Demonstrations • Get to know the equipment • Practice option • Conduct measurements • Record the results on a record card* • Explain key learning (debriefing)	• Verbal • Text • Visual • Manual

Figure 4: Key Influential Factors on Anthropometric Assessment Process

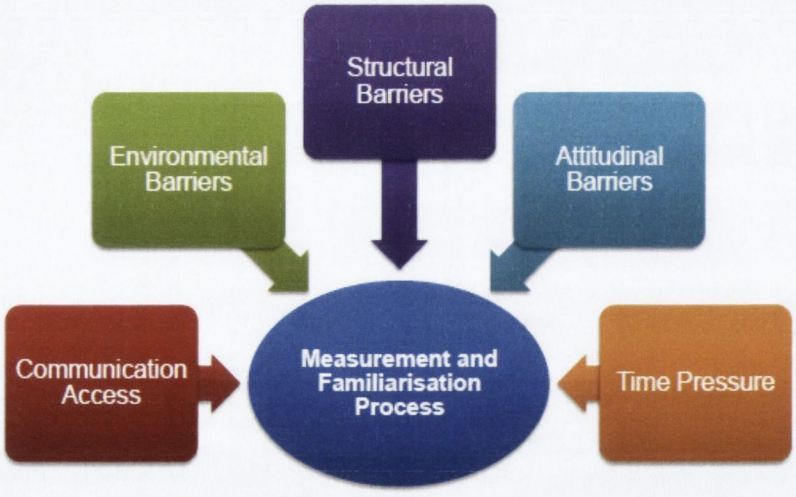
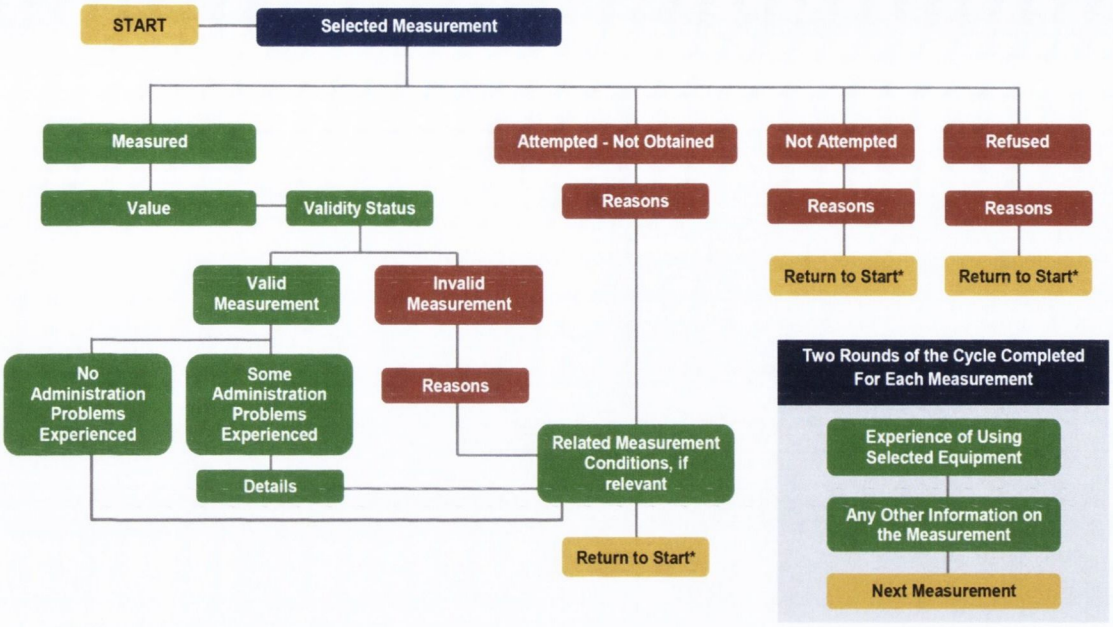


Figure 5: General Outline of the Measurement Reporting Cycle



* Complete two rounds of this reporting cycle for each measurement, where possible.
Note: Participants may be catergorised differently each round.