

Factors Associated with Decision Making Capacity in Older Adults

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Declaration

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Summary

Making our own decisions goes to the heart of our autonomy. Decision Making Capacity (DMC) carries enormous significance for all people. Increasingly the DMC of older adults can be queried, this can arise for a myriad of reasons, at the time of which the individual may have a diagnosis of a medical, neurological, psychiatric disorder or be simply aging. Each of these latter conditions has potential for an adverse impact on cognitive skills that underpin DMC.

DMC is a multifaceted and dynamic concept. In recent times much consideration has been given to the adverse impact upon it by aging and the associated decline in cognitive functioning.

The aim of this study was to explore decision making capacity in older people and to examine if relationships are present between decision making abilities and a number of factors not previously explored and if there was a contribution to be made to develop further an existing model of DMC, The Person-Task Fit Model. The factors being explored included cognitive reserve and participation in decision making.

I recruited 32 participants through Day and Residential Centres, Active Retirement Groups, General Practitioners (GPs), Community Groups and word of mouth (posters etc.). 3 participants became unwell and did not complete the research (one had completed one session, another had completed two sessions and a third had completed three sessions) resulting in a remaining 29 participants.

Participants were met individually to discuss project, they were also given an information sheet which was talked through in detail with them at an appropriate pace with their understanding being monitored. Measures were taken including for example, an easy to read information sheet and consent form, inviting a third party known and familiar to the individual to the initial meeting etc. to ensure an appropriate balance between respecting

individuals' rights to make their own decisions and to a presumption of their capacity to do so and yet to be aware ethically of their potential vulnerability.

Data were collected for two groups of 29 participants (16 Females and 13 Males), aged between 56 years and 90 years, ($M=73.8$ years, $SD=9.6$). Group One ($n=15$) was older adults at low risk of impaired DMC, (i.e. without clinical diagnosis and not receiving support). Group Two ($n=12$) was older adults at increased risk of impaired decision making capacity, (i.e. with clinical diagnosis or requiring support). Data collection took place at a location convenient to the participant. No participant was paid to take part.

For each participant a semi structured interview with a questionnaire was conducted and the following assessments were also administered: ACED, LEQ, WASI and DRS. These yielded data with regard to Decision Making Abilities (health and finance domains), Cognitive Functioning, Cognitive Reserve, Physical Activity and Preference and Participation with regard to decision making.

Statistically significant positive relationships were observed between decision making abilities and cognitive reserve ($r_s=0.45$, $p < 0.05$; $r_s=0.61$, $p < 0.05$) and between decision making abilities and participation in decision making ($r_s=0.69$, $p < 0.05$; $r_s=0.65$, $p < 0.05$).

Results suggested that models of DMC may be informed further by the incorporation of the construct of cognitive reserve and life experiences, such as participation in decision making. This may contribute to explanations for DMC variances and to supports and opportunities provided by services to individuals over their life span. Further study is required. All individuals reported enjoying their participation in the research.

The study had some limitations, including the small number of participants. New avenues of research are suggested including the systematic evaluation of the impact of providing structured opportunities for decision making.

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Decision is a risk rooted in the courage of being free

Paul Tillich

Table of Contents

<i>Declaration</i>	<i>i</i>
<i>Summary</i>	<i>ii</i>
<i>Acknowledgements</i>	<i>iv</i>
<i>List of Tables and Figures</i>	<i>x</i>
<i>Glossary</i>	<i>xvii</i>
1. Abstract	2
2. Introduction	3
Literature Search Strategy	3
Context	4
2.01 Definition	4
2.02 Decision Making Process	5
2.03 Prevalence	6
2.04 Social and Legal Context	8
Theoretical Models of Decision Making Capacity	18
2.05 Conflict between Models/Theory	22
2.06 Gaps within Theories and Models	23
Assessment of Decision Making Capacity	25
2.07 Clinicians' Practice	33
2.08 Areas of DMC and Frequently Used Assessment Tools	40
2.09 Everyday Decision Making	43
2.10 Risk	49
DMC – Ethical Challenges	51
Previous DMC Research	57
2.11 Cognitive Functioning and Cognitive Aging	59
2.12 Older Adults	68
2.13 Older Adults with Intellectual Disability	81
2.14 Preference & Participation in Decision Making	86

Preference to Participate in Decision Making	87
Participation in Decision Making	89
Cognitive Reserve	93
Summary and Study Rationale	106
3. Methodology	112
Ethical Approval and Issues	112
Participants	112
3.01 Group One	113
3.02 Group Two	113
Materials and Procedures	114
3.03 Assessment of cognitive functioning and status	117
Wechsler Abbreviated Scales of Intelligence (WASI)	117
Dementia Rating Scale – 2 (DRS-2)	119
3.04 Demographics	120
3.05 Preference re Decision Making	122
3.06 Participation in Decision Making	123
3.07 Assessment of Cognitive Reserve	125
3.08 Assessments of Elements of Decision Making Capacity	127
3.09 Physical Activity/Exercise	129
3.10 Data Table	130
4. Results	132
4.1: Sociodemographic and Clinical Background – Overall and By Group	134
4.2 Assessment of Capacity of Everyday Decision Making	140

4.3:	Hypotheses One – A Relationship will be indicated between Elements of DMC and Cognitive Factors	161
4.4	Hypotheses Two – A Relationship will be indicated between Elements of DMC and Cognitive Reserve Markers	178
4.5	Hypotheses Three	200
	a. A Relationship will be indicated between Elements of DMC and An Individual's Preference to Participate in Decision Making.	
	b. A Relationship will be indicated between Elements of DMC and An Individual's Participation in Decision Making	
5.	Discussion	222
	Sociodemographic and Clinical Background	222
	Decision Making Abilities	224
	Hypotheses One – A Relationship will be indicated between Elements of DMC and Cognitive Factors	228
	Hypotheses Two – A Relationship will be indicated between Elements of DMC and Cognitive Reserve Markers	229
	Hypotheses Three	230
	a. A Relationship will be indicated between Elements of DMC and An Individual's Preference to Participate in Decision Making.	
	b. A Relationship will be indicated between Elements of DMC and An Individual's Participation in Decision Making	
	Theory Implications	234

Limitations 240

Future Research 242

Assessment Tools 245

Conclusion 246

6. Appendices

i. Appendix A Letter of Approval – Ethics 249

ii. Appendix B Information Sheets and Consent Forms
(Regular) 252

iii. Appendix C Information Sheets and Consent Forms
(Easy to Read) 256

iv. Appendix D Section II, Choice, National Consumer
Information Survey (2010)
Levinson et al. (2005) 261

v. Appendix E Questionnaire – Demographics, Participation
in & Preference for Decision Making 269

vi. Appendix F Lifetime of Experiences Questionnaire (LEQ)
279

vii. Appendix G Assessment of Capacity of Everyday
Decision-Making (ACED) –
Templates/Forms 305

viii. Appendix H Assessment of Capacity of Everyday

	Decision Making (ACED) – Measures Yielded	330
ix.	Appendix I ACED Data Coding	333
x.	Appendix J Table J.01 Summary Statistics (original) for Measures of Preference in Decision-Making Table J.02 Summary Statistics (original) for Measures of Preference in Decision-Making by Group	354
xi.	Appendix K Table K.01 Summary Statistics (original) for Measures of Participation in Decision Making Table K.02 Summary Statistics (original) for Measures of Participation in Decision-Making by Group	356
7.	References	358

List of Tables and Figures:

Tables

Table 2.1	ECF Impairments Associated with Lesion Location (Royall, 2002)	60
Table 2.2	Capacity Domains – Scope of Abilities and Skills Required (Moye & Marson, 2007)	70
Table 2.3	Medical Decision Making Capacity Associations with Cognitive Measures (Moye & Marson, 2007)	72
Table 2.4	Cognitive Abilities Associated with Elements of MDMC (Moye et al 2013)	74
Table 4.1	Demographic Characteristics of Participants (N=29)	135
Table 4.2	Statistics for Use of Prescribed Medication (N=29)	136
Table 4.3	Results for Participants’ Explanations for Medication Use (N=29)	137
Table 4.4	Demographic Characteristics of Participants by Group	139
Table 4.5	Performance of All Participants on ACED Measures of Decision Making Abilities (Medication Management) (N=29)	141
Table 4.6	Overall ACED Total Scores (Medication Management) for Participants and Use of Information Sheet for All Participants (N=29)	143
Table 4.7	Performance of Participants on Elements of Decision Making (Medication Management) by Group (2 Groups)	145
Table 4.8	Performance of All Participants on Measures of ACED (Money Management) (N=29)	148

Table 4.9	Overall ACED Total Scores (Money Management) and Use of Information Sheet for All Participants (N=29)	150
Table 4.10	Performance on Elements of Decision Making (ACED – Money Management) by Group	153
Table 4.11	Other Factors Referenced by Participants During ACED Assessment (Medication and Money Management)	156
Table 4.12	Spearman's Correlation between ACED Measures (Medication Management) and ACED Measures (Money Management) for All Participants (N=29)	160
Table 4.13	Spearman's Correlation between ACED Measures (Medication Management) and ACED Measures (Money Management) by Group (2 Groups)	161
Table 4.14	Summary Statistics Cognitive Functioning Measures (WASI) (N=29)	163
Table 4.15	Cognitive Functioning Measures (WASI) by Group	164
Table 4.16	Summary Statistics for DRS-2 Measures of Cognitive Status (N=29)	166
Table 4.17	DRS-2 Measures of Cognitive Status by Group (2 Groups)	167
Table 4.18	Spearman's Correlation between Elements of DMC (Medication Management) and Cognitive Functioning Measures (WASI) (N=29)	170
Table 4.19	Spearman's Correlation between Elements of DMC (Medication Management) and Cognitive Functioning Measures (WASI) by Group (2 Groups)	171
Table 4.20	Spearman's Correlation between Elements of DMC (Money Management) and Cognitive Functioning Measures (WASI) All Participants (N=29)	172

Table 4.21	Spearman's Correlation between Elements of DMC (Money Management) and Cognitive Functioning Measures (WASI) by Group (2 Groups)	174
Table 4.22	Spearman's Correlation between Elements of DMC (Medication Management) and Measures of Cognitive Status (DRS-2) for All Participants (N=29)	175
Table 4.23	Spearman's Correlation between Elements of DMC (Medication Management) and Measures of Cognitive Status (DRS-2) by Group (2 Groups)	176
Table 4.24	Spearman's Correlation between Elements of DMC (Money Management) and Measures of Cognitive Status (DRS-2) for All Participants (N=29)	177
Table 4.25	Spearman's Correlation between Elements of DMC (Money Management) and Measures of Cognitive Status (DRS-2) by Group (2 Groups)	178
Table 4.26	Summary Statistics for LEQ Measures of CR All Participants (N=29)	180
Table 4.27	LEQ measures of Cognitive Reserve by Group (2 Groups)	181
Table 4.28	Frequency of Physical Activity for All Participants (N=29)	184
Table 4.29	Physical Activity Category for All Participants (N=29)	185
Table 4.30	Frequency of Physical Activity by Group (2 Groups)	187
Table 4.31	Physical Activity Category by Group (2 Groups)	188
Table 4.32	Present Moderate Physical Activity by Group (2 Groups)	189
Table 4.33	Spearman's Correlation between Assessment of Capacity of Everyday Decision Making (ACED – Medication Management) and Measures of CR (LEQ) for All Participants (N=29)	190

Table 4.34	Spearman's Correlation between Assessment of Capacity of Everyday Decision Making (ACED – Medication Management) and Measures of CR (LEQ) by Group (2 Groups)	192
Table 4.35	Spearman's Correlation between Assessment of Capacity of Everyday Decision Making (ACED – Money Management) and Measures of CR (LEQ) for All Participants (N=29)	194
Table 4.36	Spearman's Correlation between Assessment of Capacity of Everyday Decision Making (ACED – Money Management) and Measures of CR (LEQ) by Group	195
Table 4.37	Relationship between ACED (Medication Management) and Physical Activity Category during each Life Stage for All Participants (N=29)	197
Table 4.38	Relationship between ACED (Money Management) and Physical Activity Category during each Life Stage for All Participants (N=29)	200
Table 4.39	Summary Statistics (converted) for Measures of Preference re Decision-Making for All Participants (N=29)	203
Table 4.40	Preference re Decision-Making Participation by Group (converted)	205
Table 4.41	Summary Statistics (converted) for Measures of Participation in Decision-Making for All Participants (N=29)	206
Table 4.42	The Choice of Staff/Home Help for Individuals (N=29)	209
Table 4.43	The Choice of Keyworker for Individuals (N=29)	209
Table 4.44	Participation in Decision-Making by Group (converted)	211
Table 4.45	Spearman's Correlation between Measures of Elements of DMC (Medication Management) and Measures of Preference re Decision Making for All Participants (N=29)	213

Table 4.46	Spearman's Correlation between Measures of Elements of DMC (Medication Management) and Measures of Preference re Decision Making by Group (2 Groups) 214
Table 4.47	Spearman's Correlation between Measures of Elements of DMC (Money Management) and Measures of Preference re Decision Making for All Participants (N=29) 215
Table 4.48	Spearman's Correlation between Measures of Elements of DMC (Money Management) and Measures of Preference re Decision Making by Group (2 Groups) 216
Table 4.49	Spearman's Correlation between Measures of Elements of DMC (Medication Management) and Measures of Participation re Decision Making for All Participants (N=29) 218
Table 4.50	Spearman's Correlation between Measures of Elements of DMC (Medication Management) and Measures of Participation re Decision Making for Group Two (N=14) 219
Table 4.51	Spearman's Correlation between Measures of Elements of DMC (Money Management) and Measures of Participation re Decision Making for All Participants (N=29) 220
Table 4.52	Spearman's Correlation between Measures of Elements of DMC (Money Management) and Measures of Participation re Decision Making for Group Two (N=14) 221

Figures

- Figure 4.1** Distribution of Scores on Measures of Decision-Making Abilities in ACED (Medication Management) for All Participants, N=29 **142**
- Figure 4.2** Distribution of Overall ACED Total Scores (Medication Management) for All Participants, N=29 **144**
- Figure 4.3** Distribution of Overall ACED Total Scores (Medication Management) by Group **146**
- Figure 4.4** Distribution of ACED Scores (Money Management), for All Participants, N=29 **149**
- Figure 4.5** Distribution of Overall ACED Total Scores (Money Management) for All Participants, N=29 **151**
- Figure 4.6** Distribution of Overall ACED Total Scores (Money Management) by Group **154**
- Figure 4.7** Distribution of WASI Subtest Scores by Group **164**
- Figure 4.8** Distribution of WASI “IQ” Scores by Group **165**
- Figure 4.9** Distribution of DRS-2 Scores by Group **168**
- Figure 4.10** Distribution of LEQ Total Scores by Group **182**
- Figure 4.11** Distribution of LEQ Scores for Each Life-Period by Group **182**
- Figure 4.12** Frequency of Current Physical Activity **185**
- Figure 4.13** Physical Activity Category for All Participants, N=29 **186**
- Figure 4.14** Present Physical Activity Category by Group **188**

- Figure 4.15** Distribution of Scores (converted) re Preference in Decision Making for all Participants, N=29 **203**
- Figure 4.16** Distribution of Scores (converted) re Preference in Decision Making for all Participants, N=29 **204**
- Figure 4.17.** Distribution of Scores (converted) re Preference to Participate (Money subscale) by Group **205**
- Figure 4.18** Distribution of Scores (converted) on Participation in Decision-Making scale and subscales for All Participants, N=29 **207**
- Figure 4.19** Distribution of Scores (converted) on Participation in Decision-Making scale and subscales for All Participants, N=29 **208**
- Figure 4.20** Distribution of Total Scores (converted) re Participation in Decision-Making –by Group **211**

Glossary

- **Decision Making Capacity (DMC)** refers to an individual's situation-specific ability to make a decision at a specific time (Moberg & Rick, 2008).
- **Mental Competence** refers to a legal construct referring to an individual's capacity to decide or perform activities of daily living (Moberg & Kniele, 2006);
- **Mental Capacity** is a clinical construct referring to an clinician's opinion of an individual's abilities to make decisions or perform certain functions (Moye, 2007);
- **Cognitive Reserve (CR)** is theorised to provide a protective buffer for cognitive functioning from the adverse affects of pathology, injury and aging (Stern, 2002; Richards and Deary, 2005).

Abbreviations Frequently Used

- **APA** – American Psychological Association
- **ABA** – American Psychological Association
- **ABI** – Acquired Brain Injury
- **AD** – Alzheimer's Disease
- **ADL** – Activities of Daily Living
- **CAS** – Cognitive Activities Scale
- **CNS** – Central Nervous System
- **CR** – Cognitive Reserve

- **DMC** – Decision Making Capacity
- **FDMC** – Financial Decision Making Capacity
- **HSE** – Health Service Executive (Ireland)
- **ID** – Intellectual Disability
- **IOM Committee** – Institute of Medicine Committee
- **MCI** – Mild Cognitive Impairment
- **MDMC** – Medical Decision Making Capacity
- **PD** – Parkinson’s Disease
- **TBI** – Traumatic Brain Injury
- **STM** – Short Term Memory
- **UNCRPD** – United Nations Convention on the Rights of Persons with Disabilities
(2006)

1. Abstract

Making our own decisions goes to the heart of our autonomy. Increasingly decision making capacity (DMC) of older adults is questioned. The aim of this study was to explore DMC in older people and examine for associations between decision making abilities and factors not previously explored, including cognitive reserve (CR) and participation in decision making. Data were collected for two groups of 29 participants (16 Females and 13 Males), aged between 56 years and 90 years, ($M=73.8$ years, $SD=9.6$). Group One ($n=15$) was older adults at low risk of impaired DMC, (i.e. without clinical diagnosis and not receiving support). Group Two ($n=12$) was older adults at increased risk of impaired decision making capacity, (i.e. with clinical diagnosis or requiring support). A semi structured interview and ACED, LEQ, WASI and DRS assessments were administered for each. These yielded data regarding decision making abilities (health and finance domains), CR, cognitive functioning and preference/participation in decision making. Statistically significant positive relationships were observed between decision making abilities and CR ($r_s=0.45$, $p < 0.05$; $r_s=0.61$, $p < 0.05$) and between decision making abilities and participation in decision making ($r_s=0.69$, $p < 0.05$; $r_s=0.65$, $p < 0.05$). Results suggested that DMC models may be informed further by consideration of CR and life experiences, such as participation in decision making. This may contribute to explanations for DMC variances and to supports and opportunities provided by services to individuals over their life span. Limitations of the study, including the small number of participants are discussed. Further study is required. New research avenues are suggested including systematic evaluation of provision of structured decision making opportunities.

2. Introduction:

Making decisions for oneself is an aspect of life perhaps taken for granted by most adults in the free world. What to wear, what to have for breakfast, when to have breakfast, making purchases, for example buying a new pair of shoes, when and if to give someone a gift, are all actions precipitated by earlier decisions that most adults make for themselves. These decisions may be influenced by environmental factors and consultations with appropriate others, but are fundamentally decisions that most adults make and act on by themselves without much consideration.

However, for some people, the ability to make decisions can be questioned and in some instances denied on the grounds of impaired decision making capacity. This study seeks to explore factors that may be associated with the decision making capacity of older adults so as to add to existing knowledge. This may then inform future developments of theory and inform supports for the maintenance and enhancement of decision making capacity.

So what is Decision Making Capacity (DMC) and whose DMC is impaired?

Literature Search Strategy

Initial search of literature was achieved using the following key terms “Decision Making Capacity”, “Mental Capacity”, “Decision Making Competence”, “Financial Decision Making Competency”, “Financial Decision Making Capacity”, “Health Decision Making Capacity”, “Medical Decision Making Capacity”, “Medical Decision Making Competency”, “Health Decision Making Competency”, “Consent Competency”, “Consent Capacity” and “Everyday Decision Making”. These terms were then combined with the following terms to identify more specific literature for later sections; “Older Adults”, “Intellectual Disability” “Mental Handicap” “Mental Retardation” “Learning Disability”,

“Preference to participate in decision making”, “Participation in decision making”, “Reserve “Brain Reserve” and “Cognitive Reserve”. These search terms reflect the focus of this study on Medical Decision Making Capacity (MDMC) and Financial Decision Making Capacity (FDMC) in the context of everyday decision making for older adults.

In addition a separate search was conducted specifically for “Reserve “Brain Reserve” and “Cognitive Reserve”.

These searches were undertaken for English language articles using the search engines PsychArticles, PsychInfo, PubMed, and MedLine.

Context

2.01 Definition.

DMC refers to a person’s ability to make their own decisions. A look at the area of DMC leads to encounters with the terms Mental Competence, Mental Capacity and Decision Making Capacity. These terms often lack clarity and are sometimes used interchangeably. There is debate as to the definitions and characteristics of each of these, illustrating the diversity of thinking within the field. This experience has been commented upon and highlighted by a number of authors (Eyler & Jeste, 2006; Hotopf, 2006; Moberg & Kniele, 2006; Moye, 2007).

As thinking evolved regarding DMC, so too did definitions, as illustrated in the following overview. Originally DMC was conceptualised as global. It was defined and determined in accordance with diagnoses or status, for example the presumption that someone with intellectual disability (ID) or mental health difficulties did not have the capacity to make decisions (Grisso, 1986). The presence of a disability or a disorder resulted in the determination that the individual lacked DMC.

DMC is now conceptualised functionally. It is succinctly reflected by Moberg and Rick (2008) who defined DMC as referring to an individual's situation-specific ability to make a decision at a specific time.

Although there is not universal acceptance of the functional approach to DMC, there is widespread usage of it as reflected in legislation (Ireland – The Assisted Decision Making (Capacity) Act 2015; England & Wales - The Mental Capacity Act, 2005), national guidance (Ireland – HSE, 2013) and professional practice guidelines (BPS, 2006; ABA/APA, 2008).

2.02 Decision Making Process.

Notwithstanding the various debates and usage of terms and definitions, consensus has emerged regarding the decision making process (Appelbaum & Grisso, 1988, 1995); Marson & Moye, 2007; Moye, 2007; Smyer, 2007), which is observed to include the following key elements:

- a) Understanding of information relevant to the choice
- b) Retaining or keeping information in mind for long enough to come to a decision
- c) Appreciation of the significance of a choice
- d) Ability to reason or rationally evaluate a choice
- e) Expression of a choice – Communicating Decision

Only when one of these key features is compromised should it be implied that someone is unable to make a particular decision and that an adverse conclusion be made regarding their DMC.

The key elements of DMC are globally agreed to be *Understanding, Appreciation, Reasoning and Expressing a Choice*.

Whilst this dissertation is concerned specifically with the individual's capacity to make decisions and the factors that may impact on this, it is of note that there is presently a growing interest within clinical and corporate governance with regard to decision making, its process and practice and maximising the likelihood of ensuring that "good" decisions are made,. A vast array of research has also been undertaken specifically exploring decision making itself separate to the question of capacity.

For the purposes of this dissertation, DMC is conceptualised as functional and reflective of the four elements Understanding, Appreciation, Reasoning and Expressing a Choice.

2.03 Prevalence.

A number of international studies have been undertaken to establish prevalence of incapacity regarding to decision making. These studies were conducted in various settings, including inpatient settings, psychiatric and acute medical care settings, individuals diagnosed with dementia and also older adults. However there are no estimates of the prevalence of impaired DMC within Irish populations.

Research by Amnesty International Ireland on DMC within mental health in the Republic of Ireland drew upon prevalence studies undertaken in the United Kingdom (Amnesty International Ireland, 2009).

In the United Kingdom (UK), a study by Raymont et al. (2004) recruited 302 consecutive acute medical care patients over a period of eighteen months. Of this number, it was estimated that approximately 40% lacked capacity to make decisions. Seventy two (24%) patients were severely cognitively impaired, unconscious or unable to express a choice and were automatically assigned to the incapacity group. Seventy one (24%) patients refused to participate or were unable to speak English. Thus a total of 159 patients

were interviewed by the researchers of which, 31% were judged to lack capacity. Raymont et al. reported that clinical teams rarely identified incapacity with just under a quarter of those identified by the researchers as lacking capacity being identified by the clinical team. The study observed that the incapacity identified was associated with impaired cognitive functioning, older age and lower educational attainment.

In a review of previous research Hotopf (2005) concluded that one third of inpatients within a general hospital setting may lack capacity and that this incapacity is driven by cognitive impairment caused by delirium or dementia. He contrasted this with incapacity experienced by psychiatric inpatients which was mainly related to psychotic illness.

A systematic review of previous research regarding capacity for patients with psychiatric disorder was conducted by Okai et al., (2007) who identified and reviewed 51 studies meeting their inclusion criteria. These indicated that the prevalence of incapacity amongst patients with psychiatric disorders was between 22% - 44%, with the lower range being demonstrated amongst patients with depression and the higher range amongst patients with schizophrenia. The reviewers noted the almost identical finding of prevalence in similar situations made by two separate studies, one in Germany and one in the USA. Higher prevalence of incapacity amongst patients with a psychotic disorder than amongst patients with a non-psychotic disorder was reflected throughout all studies.

Studies reviewed for this study evidenced the prevalence of incapacity to be higher within certain clinical groups and to be associated with higher age and more inconsistently with lower educational standards. A number of studies reported an association with lower educational standards whilst in contrast others reported no such association (Raymont et al, 2004; Hotopf, 2006; Okai et al, 2007; Porrino et al., 2015). This will be considered further in a later section.

In commenting on the findings by Raymont et al's (2004), Hotopf (2006) noted that between one quarter and one half of patients admitted to psychiatric hospitals were also estimated to lack capacity to make treatment decisions. He asserted however, that the important message to take from such research is that even in such a severe group, the majority of people with psychiatric disorders were capable of making valid treatment choices.

2.04 Social and Legal Context.

The struggle between autonomy and beneficence underpins the social and legal context of DMC within the Republic of Ireland and many other countries including United States (US), UK and Australia. A desire to protect adults perceived to be vulnerable, challenges our regard and observance for their autonomy and independent decision making. Mental capacity and DMC can be affected by a number of conditions including Acquired Brain Injury (ABI), dementia and ID. Thus older people, adults with an age related disorder, adults with an ID, adults with an ABI, adults experiencing mental health difficulties, adults with autism and adults with impaired cognitive functioning can be some of those individuals who frequently find their decision making questioned, denied or bypassed. Individuals with diagnoses and in long term residential care are not only at risk of impaired DMC but are also at risk of having their DMC underestimated and thereby denied the right to autonomous choice (Volicer & Ganzini, 2003). Moye, Marson and Edelstein (2013) observed that traditionally requests to assess DMC tended to arise for individuals with ID or mental health difficulties.

The National Intellectual Disability Database (NIDD – Republic of Ireland) was established in 1995. Its role is to provide information regarding every person with an ID in receipt of a service or who requires or expects to require a service, to the Department of Health, the health services and voluntary service providers. There were 27,887 people

registered on the NIDD at the end of December 2014 (Kelly, 2015). Based on 2011 census figures, this represents a prevalence rate of just over 6 (6.08) per 1,000 population. The prevalence for individuals with mild level of ID is just under 2 (1.99) per 1000 and the rate for moderate, severe or profound level of ID was 3.58 per 1000. Traditionally the prevalence rate for individuals with mild ID has been under reported, this is believed to still be the case.

ABI is a non-progressive injury to the brain which occurs after birth. There are no epidemiological data available with regard to ABI in the Republic of Ireland, however experts, researchers and groups working in the area estimate that approximately 13,000 people a year survive and live with a brain injury (Acquired Brain Injury Ireland, 2017).

The Irish National Health Services provider, the Health Services Executive (HSE) reported stroke to be the leading cause of adult disability. Over 10,000 people have a stroke each year in Republic of Ireland, approximately one third of people who have a stroke, will have another stroke within 5 years and there are 30,000 people who have stroke related disability (National Stroke Programme).

Mental health difficulties vary and can include for example, depression, anxiety disorders, substance abuse and psychoses. The experience is also varied, some individuals may experience once off difficulties, others may experience intermittent difficulties and for some those difficulties may be persistent and chronic. The impact on an individual's functioning, their thinking, perceptions, emotions and judgement can range from mild to severe. There are limited data regarding the prevalence of mental health difficulties within the Republic of Ireland. Some individuals may be admitted to a hospital or clinic setting for treatment, others may attend a family doctor (GP) or mental health professional. It is estimated however that one in four individuals in Republic of Ireland will experience mental health challenges over their lifetime (Mental Health Ireland, 2016).

Dementia is a multifunctional disorder where memory, reasoning, judgement and other higher mental processes are lost. Typically alterations in personality and modes of social interaction accompany these cognitive deficits. It can occur in different forms, including Alzheimer's disease (AD), senile and vascular. In the Republic of Ireland it is estimated that 42,000 people are likely to have dementia, these figures are projected to increase to between 65,000 and 140,000 over the next 30 years (Cahill et al., 2012).

Generally life expectancy has improved; individuals are living longer, resulting in increasing numbers of older adults and increasing numbers of age related disorders. Demographic changes indicating an increased older adult population in the developed world have been referenced by a number of researchers (Moye, Armesto, & Karel, 2005; Moberg & Rick, 2008; Shreve-Neiger, Houston, Christopher & Kier, 2008; Finucane & Gullion, 2010; Demakis, 2013; Dunn & Alici, 2013; Moye et al., 2013; Gross, 2017). They have reported that changing demographics have resulted in increasing requests to assess DMC of older adults.

Awareness in recent times has also increased with regard to individuals' rights, autonomy and their quality of life. There is also a greater awareness about the vulnerability of some adults and a consequent desire to protect them. Some adults struggle to make decisions or may make decisions that are unsafe or not in their best interests, resulting in for example, vulnerability to danger, loss and/or exploitation. This gives rise to autonomy versus beneficence struggle with regard to decision making for those adults considered to be vulnerable. This consequently leads to situations wherein the duty of beneficence – to protect or safeguard the welfare of an individual – supersedes the individual's autonomy (Trachsel, Hermann, & Biller-Andorno, 2015; Demakis, 2013; Smyer, 2007, Moye & Marson, 2007; Mullaly et al., 2007).

Thus the impact of sociodemographic factors such as those outlined above are seen in the demonstrable rise of requests for determination of capacity internationally (Moberg & Rick, 2008; Demakis, 2013; Dunn & Alici, 2013; Moye et al., 2013; Gross, 2017). On the impact of this, Moye et al. have commented that “capacity rights now permeate the fabric of everyday life” (p.158).

Jurisdictions within many countries, including the Republic of Ireland, UK, United States (US) and Australia have experienced an evolution in the concept of capacity. Historically the Republic of Ireland is similar to the US, with the legal origins of the concept of capacity found in English law. Moye et al. (2013) reported that the first recorded use of the term capacity in English language emerged in the late fifteenth century when in England it was used to describe “mental receiving power, ability to take in impressions, ideas, and knowledge”, “active power of mind and talent” and in legal parlance as “legal qualification” (p.161).

Until recently there was no legislative framework in the Republic of Ireland with regard to decision making for those individuals lacking capacity to make decisions themselves. Unless a legal provision such as Ward of Court/Legal Guardianship/ power of attorney was in place, Irish law did not permit another person to make a decision for any adult. This resulted in uncertainty in all areas requiring decisions and consequently the evolution of “Best Interests” practice.

For individuals identified as lacking capacity, the primary mechanisms under Irish law historically were the Lunacy Regulation (Ireland) Act (1871) and the Powers of Attorney Act (1996). The former legislation made provision for wardship and the Ward of Court system. It was paternalistic in practice and adopted a global approach to capacity, i.e. the individual either had capacity for all decisions or capacity for no decisions. This legislation included use of terms such as “lunacy”, “idiot” and “lunatic”. The Powers of

Attorney Act (1996) made provision for a person with capacity to plan for a future loss of capacity by executing an enduring power of attorney with regard to certain decisions. Both mechanisms made provision for the appointment of substitute decision-makers.

Traditionally for individuals such as those within the groups identified above (i.e. ID, mental health, dementia, ABI etc), a presumption of DMC was not the “default” practice within a range of decision making areas, such as health, finance, welfare etc. An informal “best interests” approach appeared to apply, with consent for activities such as dental treatment, medical treatment, banking being accepted from care staff or family members. Yet legally no adult could provide consent with regard to any activity on behalf of another adult unless a wardship or power of attorney situation pertained. In July 2015, there were approximately 2,600 designated Wards of Court in Ireland (Relate, 2016). For many people therefore a legal limbo existed which became more pronounced as awareness of individual rights and autonomy and of the deficits in Irish law increased.

The Law Reform Commission (LRC) is an independent statutory body within the Republic of Ireland whose main aim is to keep the law under review and to make practical proposals for its reform. It noted in a consultation paper on Vulnerable Adults, Capacity and the Law (2005) that the paternalistic concepts “at the heart of the wardship system sit somewhat uncomfortably with the more recent social and human rights models of disability and the conception of capacity in functional terms” (Section 4.02, p.78). These mechanisms were not in keeping with the European Convention on Human Rights (2003) or the United Nations Convention on the Rights of People with Disabilities (2006), to both of which the Republic of Ireland is a signatory. The LRC recommended the introduction of new comprehensive legislation with regard to DMC and recommended repeal of existing legislation such as the Marriage of Lunatics Act 1811. They recommended that new legislation reflect an emphasis on capacity rather than lack of capacity, be enabling rather

than restrictive, adopt a functional approach to DMC and be compliant with constitutional and human rights.

Increasing awareness of individuals' rights with regard to autonomy resulted in national policy and legislative developments such as the establishment of the National Advocacy Service (NAS) in 2011, the Health Services Executive's Strategy *Time to move on from Congregated Setting: a strategy for Community Inclusion* (2011), accompanied by the Department of Environment Community and Local Government's, *The National Housing Strategy for People with Disability 2011-2016* (2011). The Regulations for the inspection and monitoring of residential service provision for both older adults and adults with disabilities by the Health Information and Quality Authority (HIQA) include standards on the exercise of choice and control by residents (Health Act, 2007).

Carey & Griffiths (2016) considered the impact of Irish policy and legislation on how adults with learning disabilities make choices. They observed that both the United Nations and European Conventions were the "main drivers for the development of policies and legislation in promoting the rights of people whose mental capacity could be questioned" (p.113).

A National Consent Policy was developed by the Health Services Executive (HSE, 2013) to guide HSE & HSE funded clinicians in matters regarding the provision of Health and Social Care Services and was explicit regarding DMC. It directed that there must be a presumption of capacity regarding the individual's capacity for consent to or refusal of examination, investigation or treatment. There must not be an assumption that an individual lacks capacity,

...solely because of their age, disability, appearance, behaviour, medical condition (including ID, mental illness, dementia or scores on cognitive function), their beliefs, their apparent inability to communicate, or the fact that they make a

decision that seems unwise to the health and social care professional. (Section 5.3, p.31)

It also directed that a finding that an individual lacked DMC on a particular occasion did not mean that they lack DMC for other decisions or indeed for a similar decision at another time. This is an explicit rejection of both the *Status* and *Outcome* approach. The general principles underpinning this national policy are that

..best practice favours a ‘functional’ or decision-specific approach to defining decision-making capacity: that capacity is to be judged in relation to a particular decision to be made, at the time it is to be made – in other words it should be issue specific and time specific – and depends upon the ability of an individual to comprehend, reason with and express a choice with regard to information about the specific decision. (p. 29)

The *functional* approach to DMC recognises that there is a hierarchy of complexity in decisions and also that cognitive deficits are only relevant if they actually impact on decision making. The HSE National Consent Policy (2013) emphasised the duty that exists to maximise capacity. Best practice and human rights standards favour “supported decision-making” where possible. This requires that efforts are made to support individuals in making their own decisions where this is possible.

New legislation for the Republic of Ireland, the Assisted Decision Making (Capacity) Act 2015, has now passed and was planned to become operational on a phased basis during 2016. Whilst there has been commencement of some parts of the legislation (Parts 1, 9 and some of Part 8, October 2016), the remainder of the legislation has yet to commence.

This Assisted Decision Making (Capacity) Act 2015 seeks to establish a statutory framework to support decision-making by adults who have difficulty making decisions

without help. When fully commenced, it will repeal the Marriage of Lunatics Act (1811) and the Lunacy Regulation (Ireland) Act (1871). Significantly it changes the law from an all or nothing approach to a flexible functional approach and recognises that capacity can fluctuate in certain cases.

The Act defines capacity for decision making as the ability to understand, at the time the decision is being made, the nature and consequences of the decision in the context of the available choices. There is a presumption of capacity for all unless shown otherwise. Under the Act an individual lacks capacity to make a decision if they are unable to:

- Understand information relevant to the decision
- Retain that information long enough to make a voluntary choice
- Use or weigh that information as part of the process of making the decision
- Communicate the decision

The Assisted Decision Making (Capacity) Act 2015 enables specific persons to support an individual while enabling the individual to have their voice heard and wishes followed where possible. It incorporates three types of decision-making options to respond to the support needs that people may have with regard to decision-making capacity. These decision-making options are Assisted Decision-Making, Co-Decision-Making and Decision-Making Representative. Decisions can be made on personal welfare, property and finance using any of these three options. The Act specifically excludes capacity or consent with regard to marriage, civil partnership, judicial separation, divorce, the placing of a child for adoption, the making of an adoption order, guardianship, sexual relations, serving as a member of a jury and the making of a will. Within the legislation then is also provision for enduring power of attorney and advance healthcare directive and it establishes a Decision Support Office with a Director.

Notably within the Criminal Justice Withholding of Information (Concerning Criminal Offences Against Children and Vulnerable Persons) Act 2012 (Republic of Ireland) there is a “rebuttable presumption of no capacity” regarding any person meeting the definition of “Vulnerable Persons”. This definition is contained within the legislation and is the first such statutory definition of vulnerable person and is relatively broad. This rebuttable presumption of no capacity appears to reflect a status (global) approach and to also be at odds with the HSE National Consent Policy and the new Assisted Decision Making (Capacity) Act 2015.

Other countries have also introduced capacity legislation. Scotland introduced legislation in 2000, with the The Adults with Incapacity Act (2000). It referred to an individual who “lacks capacity” and defined “incapable” as meaning incapable of (a) acting; or (b) making decisions; or (c) communicating decisions; or (d) understanding decisions; or (e) retaining the memory of decisions. The Mental Capacity Act (2005) for England and Wales became operational in 2007 and Northern Ireland introduced the Mental Capacity Bill (2014). Similarly to the Republic of Ireland Act, this legislation references “inability” or being “unable” in relation to the four elements of decision-making for a specific decision. However, it requires that this inability to be the consequence of “an impairment of, or a disturbance in the functioning of, the mind or brain”, requiring therefore a diagnosis and impaired decision-making. In contrast the Irish legislation, the Assisted Decision Making (Capacity) Act 2015, focuses specifically on functioning with regard to the specific decision. While it specifies that the legislation applies to a “Relevant Person” (RP), it defines RP as

(a) a person whose capacity is in question or may shortly be in question in respect of one or more than one matter,

(b) a person who lacks capacity in respect of one or more than one matter, or

(c) a person who falls within *paragraphs (a) and (b)* at the same time but in respect of different matters

All the legislation referred to above, reflect a functional approach to decision-making, make provision for power of attorney and the appointment of a Public Guardian (referred to as Director of Decision Support Office in Irish legislation). The Irish legislation differs with its provision of three types of decision-making options to respond to the support needs that people may have with regard to decision-making capacity.

Legal, social and sociodemographic factors drive the awareness of DMC and drive the increasing demand for assessment. As our populations continue to grow, and the number of people living longer and with various forms of cognitive impairment increases, it is expected that the requests for DMC assessments will also rise (Clarke, Galbraith, Woodward, Holland, & Barclay, 2015; Moberg & Rick, 2008; Demakis, 2013; Dunn & Alici, 2013; Moye, Butz, Marson, & Wood, 2007; Gross, 2017). In considering the legislative requirements regarding DMC, particularly Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006), Clarke et al observed that some legal interpretations of this article argue that there is no point at which legal DMC is lost. Clarke et al's paper is considered in greater detail in a later section.

It has been observed that requests for DMC assessments appear to escalate further following the introduction of legislation with regard to DMC (BPS, 2006; Kornfeld, Muskin, & Tahlil, 2009). A contribution by Scottish Psychologists to the British Psychological Society guidance for psychologists assessing capacity reported a significant increase in requests for capacity assessments following the introduction of the Adults with Incapacity (Scotland) Act 2000 (BPS, 2006).

Theoretical Models of Decision Making Capacity and Empirical Research

The literature search undertaken identified studies that have explored DMC and its many aspects, including its conceptualisation and assessment, ethical challenges, associated factors and DMC within specific groupings of individuals.

An examination of previous research provides an overview of the journey in the conceptualisation and understanding of DMC. Pioneering research by authors such as Grisso and Appelbaum heralded the shift in perspective from conceptualising DMC as a single unitary construct to its evolution to that of a multifaceted dynamic construct.

One of the earliest models of Decision Making Capacity posited DMC as a unitary construct, determined by intellect. This resulted in a global view being taken to DMC and is illustrated in the Status (or Diagnostic) Approach (BPS, 2006). It involved an across-the-board global assessment of an individual. It viewed capacity in all-or-nothing terms; an individual either has capacity for everything or capacity for nothing. It typically involved concluding that a person had no legal capacity based on the presence of a disability or a disorder rather than on an assessment of their actual decision-making capability. Historically this approach was used to limit the decision-making of people with intellectual disabilities and/or mental health needs (Grisso, 1986). Once an individual was considered to lack capacity, this became a determination that was applied to every aspect of their lives and functioning.

The Outcome Approach reflected another model of capacity whereby the determination of a person's capacity was based on an assessment of the projected outcome of their preferred decision-making choice. An example of this is a nursing home resident who chooses to place a €1000 bet on an outside horse in a race. As the horse is not expected to win and a €1000 is viewed as a considerable amount of money, a determination is made that the person lacks DMC. The determination is based solely on the

projected outcome. The subjective basis of this Outcome approach at times resulted in the projection of the reviewer's values onto the decision of the individual. Thus the wisdom and "correctness" of the decision rather than the quality of the decision making was the focus and determined the judgement reached regarding the person's DMC. This resulted in a significant loss of autonomy whereby the right to make unwise decisions was removed (BPS, 2006).

Consideration of an individual's autonomy and how to respect and support its realisation by Grisso, Appelbaum, Buchanan and Wong amongst others, resulted in a broadening of the concept of DMC as a unitary construct to the evolution of a multidimensional perspective, heralding the Functional Approach. Moye et al. (2013) observed that a paradigm shift in capacity theory occurred with the emergence of a functional standard for incapacity in the United States. They asserted that the Uniform Guardianship and Protective Proceedings Act (UGPPA; National Conference of Commissioners on Uniform State Laws, 1982) provided recognition for the link between diagnoses and abilities in its definition of an "incapacitated person". This was then articulated by Grisso in his pioneering conceptual model of capacity, initially proposed in 1986 as including six analytical characteristics common to all legal capacity assessments, functional; contextual; casual, interactive, judgemental and dispositional. He revised this model in 2003 and combined the contextual and functional characteristics to refer to them as components. Grisso viewed the objective of an assessment to be the yielding of information about those functional abilities of an individual appropriate to the capacity in question. This identification of function in capacity was, Moye et al. asserted, the key contribution of Grisso's model and has deeply influenced those who followed (p.163). Frameworks of assessment are underpinned by this model of capacity.

The Functional Approach views DMC as decision specific and time specific with the question therefore being, has an individual the capacity to make a particular decision at this particular point in time? In *Assessment of Capacity in Adults: Interim Guidance for Psychologists (2006)* the BPS states that whilst the status (diagnostic) approach focuses exclusively on the person, the functional approach emphasises the idea that capacity reflects the interaction between a person's functional abilities and a given situation. This decision specific – person specific focus has informed the evolution of theory in this area resulting in DMC being viewed as a dynamic multidimensional construct reflected upon a continuum.

Symer (2007) continued the theoretical development of DMC as a multifaceted dynamic construct and identified three interacting elements: the Person, the Process & the Context. He asserted that using these three elements as a focus provided a framework for thinking about DMC.

The essence of the functional concept of DMC is reflected in the New South Wales Attorney General's Department (Australia) assertion that

Capacity varies from person to person and from situation to situation.

Capacity is not something solid that you can hold and measure. Neither is it something that is the same all the time. It is affected by a person's abilities and by what's happening around them. . . . Also each person's capacity can fluctuate, depending on things such as their mental and physical health, personal strengths, the quality of services they are receiving, and the type and amount of any other support. (Attorney General's Department, 2008) p.20-21.

Chalmers (2008) described capacity as a complex construct which refers to the presence of a particular set of “functional abilities” that a person needs to make use of in

order to make a specific decision. The abilities that she identified reflect those commonly accepted as elements of decision making, understanding, appreciation, reasoning and expressing a choice.

Clarke et al. (2015) also explained the concept of DMC as referring to an individual's "ability to understand, retain and balance information, and communicate a choice" (p.2). They observed it to be a psychological construct that in some countries has been enshrined in legislation. They noted DMC to be effected by factors such as the consumption of alcohol, ABI, ID or the presence of disorders such as dementia. The loss of capacity is time specific as it can be temporary, fluctuating or permanent.

There are some commonalities that emerge from most of the models of DMC and frameworks for assessment. All functional theories and models posited have identified elements related to the individual and the situation as having significance in the decision making process. The concept of decision making being an "interaction" is also a commonality. The elements within this interaction have been developed and expanded by researchers over the years. Wong et al. (2000), in agreement with Grisso asserted that capacity reflected "an interaction between the individual's relevant abilities and the demands of the particular decision making task" (p.304). Smyer (2007) identified the Person, the Process and the Context. The American Psychological Association (APA) in conjunction with the American Bar Association (ABA) (2008) expanded Grisso's model to include nine identified elements when developing a framework to guide assessment. In the *Person-Task Fit*, Finucane et al. (2005) proposed an alternative framework that views DMC as the degree of congruence between characteristics of the decision maker and the demands of the task and content. All models identified individual elements related to the individual and the situation as having significance in the decision making process. These may differ according to the specifics of the situation to be evaluated.

2.05 Conflict between Models/Theories:

There are strong conflicting views re Global Capacity versus Functional Capacity as being indicative of DMC.

Proponents of the concept of Global Capacity asserted that a measure of global functioning and diagnosis sufficed to determine capacity in all decision making situations. This negated the need for functional decision making tools such as the MacArthur Competence Assessment Tool – Treatment (MacCAT-T). This very much reflected a “blanket” approach to capacity, that is all or nothing, a person had capacity for all decision making or no capacity for any. It included no consideration of the specific decision in hand. An Irish study by Kennedy, Dornan, Rutledge, O'Neill, & Kennedy (2009) examined the impact that the provision of additional information had on the consent decisional capacity of patients diagnosed with psychosis. They concluded that a “status test based on diagnosis and symptoms, perhaps including global function may be justified over attempts to assess specific functional capacity” (p.376).

An earlier Irish study exploring capacity to consent and fitness to plead amongst individuals diagnosed with psychosis, reported findings that demonstrated that a measure of psychopathology (PANSS) and global functioning (GAF) to have performed as well as DMC measures (MacCAT-T) in distinguishing Decision Making Capacity (Rutledge, Kennedy, O'Neill, & Kennedy, 2008). A more recent Irish study utilising similar assessment tools demonstrated improvement in capacity to consent and fitness to plead over time following treatment and a strong relationship between clinicians assessment of capacity and structured rating scales (Dornan, Kennedy, Garland, Rutledge, & Kennedy, 2015). The findings of this study conversely, could be viewed as supporting the concept of DMC as being time specific.

As referenced earlier, evidence of an increased prevalence of impaired capacity within some clinical groups (including those experiencing mental health difficulties, ID and age related disorders) has been observed (Okai et al., 2007; Hotopf, 2006; Clarke et al., 2015.) A weakness however in the Global concept of capacity, is the findings in these same studies of some degree of capacity in decision making for a number of the participants within the clinical groups. In some instances, a degree of capacity that is comparable to those participants without a clinical diagnosis (Hotopf, 2006; Raymont et al., 2004). Hotopf has observed the findings of DMC amongst some individuals in such clinical groups, including those with psychiatric diagnoses, to be striking.

Whilst the conflict between a Global Approach and a Functional Approach to DMC continues, international legislation and clinical practice increasingly favours a functional model and theory of DMC. The research demonstrates that individuals with diagnoses such as psychiatric disorders, age related disorders, ABI, ID etc are at increased risk of impaired DMC but that not all will evidence such impairment.

2.06 Gaps within Theories and Models:

Gaps within existing theories and models of DMC have been identified by researchers. One such gap emerged with the identification by a number of authors of differences in the DMC of older adults that could not be accounted for by the existing models and theories (Finucane, Mertz, Slovic & Schmidt, 2005; Finucane & Gullion, 2010; Henninger, Madden & Huettel, 2010; Moye et al., 2007; Moye et al., 2013; Smyer, 2007; Mullaly et al., 2007).

One US study exploring older adults DMC in the context of task complexity, reviewed the then theoretical approaches to DMC (Finucane et al., 2005). They identified the traditional models of DMC as being

- Normative Model: this was based on subjective expected utility theory whereby an individual in assessing the options available computes the subjective expected utility by multiplying the probability (likelihood) and the utility (desirability) and selects the option that yields the highest. Research identified its drawback to include its failure to distinguish between those situations where adults deliberated about decisions and those situations where they act on impulse or out of habit. The results from research undertaken also demonstrated it to fail to accurately describe how people make decisions.
- Descriptive Model: this is focused on describing each aspect of the decision making process (as outlined earlier), thus recognising that there are multiple components of decision processes and that individuals will vary in where they fall on a multidimensional competence continuum. Finucane et al (2005) however identified its weakness in failing to include consideration of the various characteristics of the individual and the context and the way in which they may interact.

(p.71 – 72)

In agreement with Frisch & Clemen (1994), Finucane et al. (2005) posited that the theoretical framework for DMC research must incorporate underlying judgement and decision making processes. It must also explain how decision maker or task characteristics constrain or impact on the individual's decision making ability. They concluded that both of these models failed to satisfy these criteria. They therefore proposed an alternative framework which viewed DMC as the degree of congruence between characteristics of the decision maker and the demands of the task and the context. This they referred to as *The Person-Task Fit* and purports the following.

1. The quality of the judgement or decision may be influenced by characteristics of the individual such as age, education, experience etc; by characteristics of the task

such as framing, information complexity etc and characteristics of the context such as cultural values, social norms etc.

2. These characteristics may act independently or interactively to influence DMC.
3. Competent decision making occurs when an individual's cognitive abilities and other characteristics adequately match the demands of the decision task.
4. Age-related changes in DMC must be interpreted with reference to how developmental changes in decision maker characteristics influence the ability to adequately meet the demands of various decision tasks (p.72).

Finucane et al. (2005) suggested that the theoretical importance of the Person-Task Fit model was its ability to account for individual differences in older adults DMC that cannot be strictly attributed to declining cognitive abilities or inadequate knowledge about how to function in the modern world. This study is considered in greater detail when reviewing previous research regarding DMC in older adults.

Whilst increasingly comprehensive, it is unclear from the above models and theories whether all characteristics/elements relevant and appropriate to DMC have been identified and reflected. There remain deficits in our understanding, for example this is reflected in continuing efforts to account for the variance observed in older adults DMC. This is an aspect to be considered in the following sections.

Assessment of Decision Making Capacity

As people live longer lives, the number of older adults within our population has grown and will continue to grow. The number of older adults with cognitive impairment has also increased. The number of people surviving and living with complex medical conditions and needs is increasing. As noted earlier there is an increasing awareness and regard for ensuring the rights of individuals are recognised and observed. As previously

observed, this contributes to the ever increasing numbers of referrals for assessments and determinations of individuals' DMC (Moye et al., 2013; Demakis, 2013; Gross, 2017; Moberg and Rick 2008).

As capacity theories and models have evolved, so too have the areas of capacity law, research and practice. Whilst assessment frameworks are underpinned by DMC models and theories, they must by necessity incorporate legal requirements.

In commencing consideration of the assessment of DMC, an observation by Newberry and Pachet (2008) on the potentially adverse consequences for an individual of a conclusion or judgement of impaired or diminished DMC seems pertinent in setting the background to such an important area. To highlight the significance of such a judgement they quoted Pepper-Smith and Nelson that it "remains one of the most significant mechanisms in our society for the removal of a person's fundamental rights and freedoms" (p.444).

Numerous authors have noted the adverse consequences for individuals of a determination of impaired capacity (Alici & Dunn, 2013). In their article on evaluating capacity in older adults Moye et al. (2005) observed the consequences of capacity evaluation, including possibly the considerable loss of autonomy and the onus therefore to protect the dignity and autonomy of all (p.207).

So how is DMC assessed? Initially determinations may have been made regarding an individual's DMC on the basis of status, i.e. diagnosis. However as awareness and understanding evolved and formal requests were made for DMC evaluations, a process for assessment was developed. Originally these assessments consisted of interviews with clinicians. Considerable concerns, which will be discussed later in greater detail, arose regarding the consistencies and reliability of clinicians' practices (Ganzini, L., Volcier, L., Nelson, W., & Derse, A., 2003; Volicer & Ganzini, 2003; Shreve-Neiger et al., 2008;

Moberg & Rick, 2008; Alici & Dunn, 2013). A number of authors have offered practical guidance for the clinician undertaking DMC evaluations. There is commonality amongst authors regarding the steps required to be undertaken by the clinician in deciding the framework. Top of these are awareness of the law regarding capacity within the jurisdiction the assessment is being conducted and the crystallisation of the specific question that is being asked, that is the specific decision to be made (Demakis, 2013; Moberg & Rick, 2008; Moye et al., 2005).

A US study by Ganzini et al. (2003) who undertook a national survey on assessment amongst clinicians. They sent out 1600 surveys, 875 were returned and 305 of those met the inclusion criteria. Respondents were asked to rate frequency and importance to clinical care of 23 potential pitfalls and misunderstandings (myths) by clinicians who refer patients for DMC assessment. These myths included the following:

- The lack of understanding that capacity is situation specific and that it is not “all or nothing”, i.e. it is not global – an individual may have capacity to make some decisions but lack capacity for others.
- Assumption of lack of capacity as a result of the presence of dementia, ID or poor score on cognitive rating scale.

Ganzini et al. (2003) reported the difficulty experienced by some clinicians of putting into practice the principle of capacity being decision specific not global when conducting capacity assessments. They concluded that this was a frequent error. They also concluded that as those evaluating decisional capacity perceived as common, misunderstanding and knowledge deficits by referring clinicians, that educational efforts to improve understanding of DMC among medical trainees and practicing clinicians are warranted.

Sullivan proposed a neuropsychological framework of assessment, whereby cognitive abilities firstly and then the specifics of the particular decision were both assessed. She asserted that the ability to process information was the common component in capacity assessments and therefore before even considering the specific of the decision in question, this ability should be present. If there is uncertainty as to the presence of this ability it should be assessed and demonstrated. She proposed that therefore the ideal DMC assessment may be the assessment of these basic abilities and the assessment of the specifics of the particular decision. This would reflect a two stage model of DMC.

In an editorial with regard to the challenges of capacity and its assessment, Hotopf (2006) concluded that there is nothing infallible about the process of assessing mental capacity, it is “a framework for thinking about decision making, which may be influenced by a wide range of additional contextual factors” and has the advantage of ensuring that detailed reasoning must be provided where an individual’s wishes are over ridden (p.5).

The Mental Capacity legislation introduced by some countries forms the basis for the determination or assessment of capacity in that particular jurisdiction. For example in accordance with The Mental Capacity Act (2005) introduced in the UK in 2007, it firstly must be established that a person suffers from an impairment of or a disturbance in the functioning of, the mind or brain. Second, it must be shown that the impairment or disturbance results in an inability to make decisions. Inability to make decisions involves a failure to understand, retain, use or weigh relevant information or communicate the decision. The fact that the person is able to retain the relevant information for a short period only does not mean that they cannot make the decision (Dimond, 2007).

Under new Irish legislation, the Assisted Decision Making (Capacity) Act 2015 there is a presumption of capacity for all unless shown otherwise. The act sets out a functional test for the assessment of a person’s capacity. As outlined earlier the Act

specifies the deficits in abilities that must be demonstrated for it to be concluded that an individual lacks capacity to make a particular decision. These deficits are consistent with the elements commonly accepted as essential to the decision making process.

International legislation and national and international guidance with regard to best practice clearly favours the adoption of a functional approach in the assessment and determination of DMC. Such an approach is supported by a wide breadth of studies that have been subject to peer review and replication. There are however alternate studies that support the global approach with regard to DMC. This dissertation will have a regard to this debate in the study that it undertakes.

Reflecting the autonomy vs. beneficence struggle Trachsel et al. (2015) asserted that two moral requirements are required for all DMC assessments; a respect for the autonomy of all individuals who are able to make their own decisions and provision of protection for all individuals whose DMC is impaired or diminished.

Smyer (2007) asserted that the Person, the Process and the Context are the three aspects that must be incorporated into any assessment of capacity.

A clinical and neuropsychological perspective of DMC and competency in the elderly by Moberg and Rick (2008) identified an “acute and growing need for evidence based assessment to identify their decision making capacity and competence” (p.403). While highlighting the importance of every DMC assessment being decision specific and the need therefore for the evaluation to be tailored to ascertaining capacity with regard to that particular decision, Moberg and Rick observed that the strategy for DMC assessments will be similar regardless of the particular decision.

To illustrate they set out the strategy for such evaluations as follows:

1. Clarify the referral question and determine if the person receiving the consultation request is competent to address the question
2. Plan the assessment and address cultural considerations and ethical issues such as informed consent and confidentiality
3. Conduct the assessment
4. Communicate the results
5. Recommend any additional evaluations or interventions that might enhance capacity or address temporal limitations on the evaluation findings

Moberg and Rick (2008) observed that for most clinicians discerning which decision and which decisional capacity are at issue will guide the investigation (p.404). They concluded their article with the importance of a multipronged approach to the assessment and emphasise the importance of capturing both the objective (e.g. cognitive and capacity measures) and subjective (e.g. emotional or psychiatric) information necessary to inform such an assessment.

Comprehensive interim guidance for psychologists developed by the British Psychological Society (BPS, 2006) and referenced the proposal by Pepper-Smith et al (1996) that at least four different frameworks could be used in the evaluation of capacity – psychiatric, cognitive, functional and decision-making. This was followed by a conceptual framework developed by the American Bar Association Commission on Law and Aging and the American Psychological Association (2008) to provide guidance for psychologists with regard to capacity assessment expanded on this strategy to identify the following nine components.

1. Legal Standard – the legal standard for the capacity in question forms the foundation of a capacity assessment. Different capacities may have different legal requirements. The legal standard may vary from location to location.
2. Functional Elements – functioning can be categorised into the Activities of Daily Living (ADLs) and the Instrumental Activities of Daily Living (IADLs).
Assessment of “everyday functioning” encompasses interview question on the specific task in question including when possible direct assessment and observation of the individual’s functioning in this regard.
3. Diagnoses – documentation of the medical condition causing the disability or impairment in functioning, for example the onset of age related disorder such as AD, an ABI, stroke etc. Grisso’s model identified this as the “*Causal*” element. Information with regard to prognosis, intervention and treatment should also be provided here. The presence of a medical or neuropsychological disorder does not automatically result in impaired capacity.
4. Cognitive Underpinnings – the role of cognitive functioning varies across the different domains of capacity, e.g. treatment consent, driving etc.
5. Psychiatric & Emotional Factors – the presence of psychiatric or emotional disturbance does not automatically mean an impairment of capacity, however the severity of such a condition may have an adverse impact on cognitive functioning, but such an impact may be temporary and not necessarily permanent therefore it is important in such situations to include information regarding treatment and timeframes.

6. Values and Preferences – these lay the foundations for decisions. They are influenced by age and experiences and may be impacted by race, religion, culture, gender, ethnicity and sexual orientation.
7. Risk Considerations – the assessment of an individual in the context of all of the above elements must be analysed in reference to the situation.
8. Steps to Enhance Capacity – an essential component is consideration and identification of any action that can be undertaken to maximise a person's functioning.
9. Clinical Judgement – the fulcrum of a capacity assessment is the clinical judgement. This should indicate clearly yes or no as to whether an individual has capacity. On rare occasions there may be a finding of “marginal capacity”.

(p.24 – 29, ABA/APA, 2008)

Embracing a functional approach accepts that a person's capacity to make a decision may be time and situation specific, that is, an assessment would indicate the person's capacity to make a particular decision in a specific situation at that specific time. A functional approach asserts that DMC is decision-specific.

The implication therefore is that before making any declaration of impaired capacity, consideration needs to be given as to whether it would be possible to improve the person's relevant functional abilities, for example by ensuring that he or she is offered educational or additional support in relation to the decision to be made and/or simplifying or otherwise amending the information, for example simplifying information, altering the format it is presented in, pictorial aids etc. (BPS, 2006). All DMC assessments should therefore incorporate this critical consideration (BPS, 2006; ABA/APA, 2008; HSE, 2013).

2.07 Clinicians' Practice.

Frequently referenced in papers exploring DMC and its assessment, is the inconsistency in terminology, understanding and definitions utilised by clinicians. As initially assessment of DMC was conducted primarily by clinicians through clinical interview, an early focus of research was clinician practice, its reliability and its consistency.

In a study undertaken by Marson, Hawkins, McInturff and Harrell, (1997), low reliability was noted in assessment of capacity, with agreement between clinicians being rated at “near chance” levels. This finding was commented upon by Moye and Marson (2007) who undertook a review of the area of DMC for Older Adults. A more extensive review of this paper by Moye and Marson is undertaken later in this section. The APA reported that the ongoing misunderstanding about capacity increased the confusion for psychologists and believed that this may account for the low reliability noted in assessment of capacity (Marson et al., 1997), which is improved when clinicians are educated about capacity (Marson et al., 2000).

In reviewing studies regarding the assessment of DMC, Karlawish et al. (2002) observed that a number of questions required urgent addressing including what information do raters use? How do they use it? What are the consequences of these differences? Do experts, clinicians & families still disagree on capacity judgements, even with the same information and judgements? What are the ethical, legal and clinical consequences of these disagreements? How do failures to recognise affect quality adhered and outcomes of care?

Ganzini et al.'s (2003) survey amongst clinicians is frequently referenced by authors when commenting upon clinicians' practice and was also referred to earlier in this thesis. Ganzini et al. also identified differing definitions of DMC in their study as one of the pitfalls encountered in the assessment of DMC. In their paper they reported that 36% of

clinicians surveyed indicated that the most important pitfall to address in educating healthcare practitioners was the tendency towards assuming that a patient who lacks capacity for one type of medical decision also lacks capacity for all medical decisions. The authors about the concept of DMC are common and that these misunderstandings affect patient care. They concluded that education to improve understanding of DMC among trainees and practicing clinicians was warranted.

Ganzini et al. (2007) acknowledged that limitations to their study included the less than half response rate, with a smaller proportion meeting the inclusion criteria and the lack of precise definition to the frequency (rare, common, very common) and importance (not very, somewhat, or very important) measurements utilised in the survey. In reviewing this article it also appears that respondents were provided with the 23 pitfalls and misunderstandings to rate, but that there does not appear to have been an opportunity for her/him to include any additional pitfalls or misunderstandings that they may have had awareness of or felt important to include.

Volicer & Ganzini (2003) noted that outcomes in DMC assessments may vary depending on the standards applied. In a study undertaken to examine the views of health professionals on the standards of DMC re the refusal of medical treatment by individuals diagnosed with mild AD, they circulated 1,800 surveys with a vignette case report of an individual with mild dementia. 970 surveys were returned. Volicer & Ganzini concluded that even among “experts” there was no uniformity re standards considered essential. They asserted that the results of their study supported the contention that physician assessment of DMC was a “subjective, inconsistent and arguably idiosyncratic process” (p.1273).

Sullivan (2004) in setting out a neuropsychological framework of assessment of mental capacity commented on inconsistent and sometimes inaccurate DMC assessments conducted by clinicians which she suggested reflected the lack of a specific standard to

determine what test is used. She also raised the issue of whether it is appropriate for a clinician who is already involved in the care of an individual to assess DMC, as it may result in a conflicting dual role. A number of other studies specifically exploring aspects of the role of neuropsychologists and rehabilitation psychologists in assessing DMC have been undertaken (Mullaly et al., 2007; Moberg & Kniele, 2006; Saldivar, 2005).

However in a review of research regarding the assessment of mental capacity among general hospital inpatients Hotopf (2005) observed that the research indicated that notwithstanding the varying definitions, capacity can be reliably assessed provided the person performing the assessment has explicit guidelines. This was reflected in the demonstration from the research of differing reliability between those occasions when two assessors performed similar assessments on similar criteria utilising the same measure (high reliability) and those situations when researchers performed a detailed assessment and these were compared to clinicians' opinions regarding an individual's capacity to make a specific treatment decision (low reliability).

Mullaly et al. (2007) undertook a survey of Australian neuropsychologists exploring common practices in the assessment of DMC. Responses received indicated that a combination of formal assessment and informal interviews was the approach taken by most, with completion time between 6-8 hours for 39% and more than 8 hours for 35%. They concluded that respondents appeared to endorse this "two pronged approach as best practice". Respondents also expressed feeling poorly prepared by their training for such assessments.

Olumoroti, Kassim, & Hotopf (2007) undertook a survey of psychiatrists to explore if context was an influencing factor with regard to their practice in assessing DMC. A questionnaire was developed around a vignette that had four different variations. The variations resulted in different contexts being conveyed. 404 psychiatrists were then

randomly sent one of these four variations. Olumoroti et al. reported an unusually high response rate of 70%. There were no differences in the response rate to each of the vignettes. Their results indicated that clinicians' assessments of capacity were not greatly influenced by context but that psychiatric speciality had some impact. They concluded however that there were clinical implications arising from their results, including that psychiatrists' opinions varied greatly as to whether an individual was likely to have DMC and that some psychiatrists advised treatment against the patients' wishes even in those instances where they had concluded the patient to have DMC. This they felt possibly indicated a misunderstanding of the appropriate law (Mental Capacity Act 2005, England & Wales).

A cross sectional study of acute general medical inpatients undertaken by Raymont et al. (2007) demonstrated that clinicians made consistent judgements with regard to an individual's capacity. Participants underwent a clinical interview and administration of two capacity measures (MacCAT-T and Thinking Rationally About Treatment, TRAT), all recorded and transcribed. A group of clinicians, experienced in such assessments were then asked to individually rate the transcripts while blind to the patient's performance on Mini Mental State Examination (MMSE) and demographics. A high level of agreement amongst raters was observed. This was consistent with finding by Cairns et al. (2005) in another study that examined the reliability of capacity assessments for psychiatric inpatients. They reported strong agreement for capacity judgements between two clinicians utilising a clinical interview and administration of the MacCAT-T.

Moye and Marson (2007) in their review of DMC for older adults noted in their paper the report by Earnst et al. (2000) that clinicians based their capacity judgements on different cognitive skills of individuals and that Marson et al (2000) had noted that agreement between clinicians' judgements increases with training on legal standards.

Moye & Marson reported that studies exploring MDMC observed reliability between clinicians with regard to MDMC assessment for older adults with dementia to be at the level of chance, highest for Understanding and lowest for Appreciation. Agreement between clinicians and instruments assessments was reported to be poor, however agreement between capacity assessment instruments was reported to be good for understanding, fair for reasoning and expressing a choice and poor for appreciation.

Shreve-Neiger et al. (2008) in exploring the need for DMC education in hospital and long term care settings, noted that previous studies had identified a lack of awareness by physicians of current law with regard to decision making and the establishment of surrogate decision makers. They also noted previous research findings that demonstrated that physicians did not use uniform standards for assessing DMC, frequently resulting in disagreements as to the individual's DMC. Their survey assessed the level of training and knowledge that clinicians reported having re MDMC and determined the best avenue for further education. They reported inconsistencies regarding the use of terms, lack of state law knowledge, lack of uniform assessment standards and resulting disagreement on determinations. This they asserted, was further compounded by the interchangeable use of the terms "capacity" and "competency" (p.361).

In a review on DMC and competency in the elderly, Moberg and Rick (2008) observed that many clinicians have a difficult time separating their own beliefs and biases from the objective capacity assessment process and asserted that it was therefore imperative for the clinician to "walk in the shoes" of the person (p.412).

These studies supported the determination of DMC through the utilisation of both standardised formal tools and clinical judgement. They also demonstrated a need for additional education and training in the area of DMC.

Javed and Afzal (2009), asserted the need for additional training and education for medical students and trainees with regard to capacity and its assessment. They also identified the need for mental health and legal professionals to develop connections and communications.

Sessums, Zembrzuska, & Jackson, (2011) reviewed 43 previous studies in order to establish prevalence of impaired medical decision making capacity (MDMC) and the accuracy of such assessments. They reported that clinicians frequently failed to recognise impaired DMC. Their review also indicated that the utilisation of the MMSE was only useful with extreme scores and may therefore be more appropriate as a screening tool. The Aid to Capacity Evaluation (ACE) assessment tool was concluded by Sessums et al. to be the best available instrument to assist in the assessment of MDMC.

Goldman (2013) set out to convey an understanding of the role of the consulting psychiatrist in DMC assessment, an appreciation for the legal and ethical principles underlying such assessments and knowledge of the most common conditions and situations that interfere with decision-making and how to assess their role in the patient's DMC. He emphasised the importance of clinicians appreciating that DMC is decision and time specific, that capacity is not global. He provided guidance with regard to the procedure of DMC and the use of standardised instruments. He also raised some challenging ethical issues, including where an individual refuses to consent to assessments and he cautioned that a refusal to explain a decision does not automatically reflect impaired capacity. He concluded that DMC referrals is a frequent occurrence for psychiatrists, who should be aware of the ethical, legal and clinical issues involved and be prepared to provide careful documentation of the process.

Alici and Dunn (2013) observed that experts do not always agree about an individual's capacity and cautioned that such agreement between experts should not be

assumed. “Given the serious implications for an individual of being judged incapable of making a specific decision, it is therefore critical to gain a deeper understanding of how experts make their decisions” (p.312).

Gross (2017) conducted a study to investigate how psychologists and conducted MDMC assessments and to examine the methods and instruments that they used. A twenty item survey questionnaire was completed by one hundred and eight participants. Findings indicated that MDMC assessments were lengthy and complex and that the clinician’s opinion, informed by clinical interviews, a file review, standardised testing, assessment of functional abilities, medical/personal history gathered from family members/caretakers, and input from relevant team members and professionals, was considered to be the gold standard.

There are also strong views as to who should determine mental capacity. Kennedy (2008) asserted that “...in practice, because of the importance of mental state and the task itself in determining how much mental capacity is present and how much is required for the specific function or task, assessing Mental Capacity is a matter for the clinical expertise of psychiatrists.” (p.57). Whilst Kennedy utilised the term “mental capacity”, the tasks that he referenced as illustrations included consent to treatment and fitness to stand trial.

Other authors asserted that psychologists, specifically neuropsychologists, are the most appropriate to conduct such assessments (Moye et al., 2013; Mullaly et al., 2007; Moberg & Kniele, 2006; Saldivar, 2005; Sullivan, 2004). In practice whilst a number of clinicians conduct their own routine determination of DMC, in complex queries or where a specific decision is considered to be in the upper section of the decision hierarchy referrals are frequently made to psychiatrists or psychologists to determine the DMC or an individual (Saldivar, 2005).

Other studies undertaken have examined agreement in determination of capacity, some studies have looked at the rate of agreement between clinicians, and others have examined agreement between clinicians and researchers. Many studies to date have utilised vignettes and appear in the main to have focused on the judgement of psychiatrists (Olumoroti, Kassim & Hotopf, 2007). In his editorial Hotopf (2006) noted that mental capacity assessments can be made in a reliable manner, quoting Bellhouse et al. (2003), Cairns et al. (2005), Wong et al. (2000) whose studies report excellent inter-rater reliability between psychiatrists' determination of capacity re treatment decision making.

The area of clinicians practice within DMC has generated significant consideration and comment. This is not surprising given the role played by clinical interview alone in determining a person's right to assert their autonomy. Research demonstrated significant inconsistencies in the reliability of such determinations and the need for greater education and training. The research also demonstrated that the use of standardised approaches, understanding and tools to support such clinical interviews lessened such inconsistencies and increased reliability between clinicians' determinations.

2.08 Areas of DMC and Frequently Used Assessment Tools.

There are several distinct areas within a person's environment that regularly require intact decision-making capacity, including medical decision making, personal finances, driving safety and medication management. These areas include Instrumental Activities of Daily Living (IADLs). A functional approach asserts that DMC is domain specific, and that an individual may therefore demonstrate differing capacity within each domain, such as FDMC, MDMC.

Various processes and instruments have been developed to assess decisional capacity in each of these specific areas and others. Studies have been undertaken initially to ascertain their validity and reliability and then followed by later empirical research

undertaken on the use of specific tools for measuring capacity, for example MacCAT-T, Cognitive Capacity Screening Exam (CCSE). Other studies have assessed capacity through the use of vignettes. Moberg and Rick (2008) provided an overview of some of the most frequently utilised clinical rating scales of global capacity – the MacCAT-T, the Capacity to Consent to Treatment Instrument (CCTI) and the Hopemont Capacity Assessment Interview (HCAI). Overviews of some of these instruments and others are provided for information below.

In reviewing approaches to measuring DMC, Finucane & Gullion (2010) in a study undertaken by them on developing a tool for measuring the Decision Making Competence of older adults, reported the “gold standard” to be expert physicians via intuitive clinical judgement. As discussed above, considerable concerns arose regarding the consistency and reliability of clinicians’ judgements. To address these concerns, efforts were made to develop tools and instruments to measuring decision making abilities. Finucane and Gullion noted that most of the tools specifically measured abilities within medical decision making, e.g. consent to surgery. They also reported that a number of geriatric specific tools aggregated a number of abilities against guidance provided by some authors and they concluded that overall there were questions of reliability and validity for many of the tools. They specifically noted that few instruments assessing everyday decision making had been developed.

Descriptions of other various tools and measures are provided by ABA/APA’s Handbook for Psychologists (2008) for the assessing of DMC. Some of the more frequently used instruments include the following:

MacArthur Competence Assessment Tool – Treatment (MacCAT-T) (Grisso & Appelbaum, 1998) utilises a semi structured interview to guide the clinician through the assessment of the patient to make an actual treatment decision. It does not use a

hypothetical vignette but rather patients are provided with information about their condition and are then asked to “Please describe to me your understanding of what I just said”. Incorrect or omitted information is responded to with a cue or a prompt and if persistent the information is presented again, similar procedure is then undertaken for treatments including the risks and benefits of each alternative. The patient is then asked if they have any reason to doubt the information and to describe that. They are then requested to express a choice and questions are asked exploring their reasoning process, including comparative and consequential reasoning and logical consistency. This instrument was based on three precursor instruments that looked in detail at appreciation, reasoning and understanding respectively.

Financial Capacity Instrument (FCI) (Marson et al., 2000) – was designed to assess everyday financial activities and abilities. It assesses six domains of financial activity: basic monetary skills, financial conceptual knowledge, cash transactions, chequebook management, bank statement management and financial judgement. It is reported to require between 30 minutes – 50 minutes to administer, depending on the individual’s cognitive level and uses an explicit protocol for administration and scoring. At present it can only be used within the United States of America and is not standardised for use elsewhere.

Capacity to Consent to Treatment Interview (CCTI) (Marson, Ingram, Cody, & Harrell, 1995) – assessing the competency of patients with AD under different legal standards. It is based on two clinical vignettes, presented orally and in writing, a neoplasm condition and a cardiac condition. Information about each condition and related treatment alternative is presented at a primary school reading level with low syntactic complexity. Questions to assess decisional abilities in terms of understanding, appreciation, reasoning, and expression of choice are then presented to participants.

2.09 Everyday Decision Making.

An area of particular concern for families and practitioners are those situations where older people refuse assistance to address difficulties that they may experience in the day to day activities of living, such as managing their health, their finances, and their nutrition. Such activities are referred to as instrumental activities of daily living (IADLs). These areas were also considered by Moberg and Rick (2008) in addition to a number of other researchers.

The question of a person's capacity in refusing assistance in such situations poses significant challenges both ethical and clinical. As referenced earlier, the outcome of any assessment of a person's DMC in such circumstances have potentially significant consequences for a person's autonomy and independent living and carries substantial ethical, clinical and financial implications.

Everyday Decision Making (EDM) refers to an individual's capacity to make a decision with regard to solving functional problems, i.e. decisions with regard to difficulties encountered in performing instrumental activities of daily living. Individuals with impairments in this capacity are at risk for harm with regard to financial neglect, abuse or exploitation, adverse impact from medication neglect or misuse, unsafe driving and poor nutrition (Lai & Karlawish, 2007).

Lai and Karlawish (2007) reviewed approaches to assessing this DMC and highlighted the challenges of specifically assessing EDM, the need for such assessment and the dearth of "valid or clinically applicable methods". For assessment of an individual's EDM capacity, they noted that instruments were not then available to specifically assess this capacity. They argued that assessing a person's capacity to solve functional problems has the potential to improve clinical outcomes for those who must perform their own Activities of Daily Living (ADLs) to live independently; those whose

DMC determines how much assistance they receive (e.g. those in residential services/institutionalised settings); those who receive cognitive-enhancing therapies with the goal of increasing their level of independence and those with cognitive impairment who do not have dementia. They hypothesised that the failure to consider DMC in the context of discharge planning may be a factor that contributes to high rates of emergency service use and adverse outcomes after emergency department/casualty discharge amongst individuals in the above groups. They specifically identified the benefits of such assessments as being useful in assisting with support planning, improving the accuracy of financial cost estimations, the maintenance and recognition of highest possible levels of autonomy and in assisting services to distinguish their case mix (p.103).

Lai and Karlawish's (2007) review of the approach to assessing EDM identified the use of three techniques

- Existing Decision-Making Assessments
- Patient Judgement Assessments
- Proxy assessments of Patient Decision-Making

They concluded that none were well accepted nor specifically designed to determine whether an individual is capable of making decisions about how to solve their difficulties with ADLs.

Within existing Decision-Making assessments, Lai and Karlawish (2007) identified only one instrument, the Decision-making Instrument for Guardianship (DIG), as evaluating the capacity to make decisions about everyday difficulties. The DIG addresses capacity across eight hypothetical problems such as hygiene and money management from property acquisition. However Lai & Karlawish asserted that the DIG is not clinically applicable and is useful primarily as a tool for court proceedings. They specifically

identified as a deficit its use of hypothetical problems rather than actual problems. They identified two shortcomings as being the DIG's inability to assess an individual's capacity to appreciate his or her functional problems and a concern that an accurate reflection of a person's capacity may not be ascertained with the clinical value of the responses being diminished as the circumstances of the hypothetical scenario deviating from the individual's own circumstances. They particularly stated a concern with regard to the abstract nature of hypothetical situations but acknowledged the importance in assessing an individual's reasoning to consider a person's ability to generate potential consequences around an option (p.104).

In their consideration of patient judgement assessments, Lai and Karlawish (2007) noted again the use of hypothetical scenarios but specifically identified the deficit of these assessments as residing in their evaluation only of the individual's response to the problem raised. This they concluded, results in such assessments only considering one aspect of DMC and failing therefore to consider individuals abilities to understand, appreciate, reason and express a choice – all essential elements of DMC. Within this area they gave specific consideration to the Problems of Everyday Living Test, Everyday Problems Test for Cognitively Challenged Elderly and the Everyday Problems Test, and concluded that whilst these “may have value in characterizing the cognitive abilities” of the individual, they were less useful in identifying individuals with impaired decision-making (p.104 – 105). They viewed the Financial Capacity Instrument as more clinically applicable but lacking portability and being limited to assessment with regard to just one functional activity.

In consideration of Proxy Assessments of Patient Decision-Making, Lai and Karlawish (2007) acknowledged the contribution to be made by knowledgeable informants such as family members to a comprehensive assessment of an individual's capacity, but

conclude that they do not provide the type of structure and detailed assessment required by clinicians in order to make treatment decisions with regard to the limiting of an individual's independence. They also added a note of caution that contributions by such informants may be influenced by other factors such as amount of time spent by informant with individual and various conflicts of interest that may arise (P.105).

Lai and Karlawish (2007) drew upon research and experience in the area of assessing capacity to make medical decisions, to propose a semi-structured interview approach to assessing capacity to make an everyday decision that would address the four elements of decision making (understanding, appreciation, reasoning and expressing a choice) in the context of an actual functional difficulty being experienced by the individual. This approach reflected the approach of measures such as the MacCAT-T which utilises a semi-structured interview to provide clinicians with a quantitative evaluation of an individual's decision-making capacity for medical decisions. They identified both the benefits and the challenges to be overcome in the development of a capacity assessment instrument that has sufficient flexibility to be adapted to specific individuals and their specific circumstances.

Lai and Karlawish (2007) asserted that the purpose of assessing a person's capacity to make everyday decisions is to help provide individuals with the necessary decision-making assistance where they need it while preserving autonomy for other decisions where capacity is not impaired. This is in keeping with a functional approach to the assessment of capacity. They proposed a model for the assessment of Everyday Decision-Making, whereby the evaluation of an individual to make decisions with regard to addressing functional difficulties is only one component of a multistep assessment that incorporates knowledge of a person's functional, psychological, socioeconomic and medical state. They

provided an illustration for how this could be incorporated by clinicians to inform recommendations re assistance, supervision and surrogate decision-making (p.106 – 109).

The Assessment of Capacity for Everyday Decision-Making (ACED) was subsequently developed by Karlawish and Lai to specifically measure EDM capacity of individuals (Lai, Cooney, Bradley, Hawkins & Karlawish, 2008). The ACED provides individual specific assessments of decisional abilities needed for Instrumental Activities of Daily Living, including in the areas of healthcare and medication management, financial and money management and nutrition. It utilises a structured interview format in each of these areas to assess the four elements of decision making: Understanding, Appreciation, Reasoning and Expressing a choice.

There are three readymade interview templates addressing common functional problems. These templates provide prespecified text. At selected places there are spaces to fill in specifics about the patient's functional problem and options to manage that problem. A blank template is available to adapt for other difficulties. Information is presented in short blocks to individuals; questions are then put to person to establish their understanding of the problem, the options, the advantages, the disadvantages; their appreciation of the options; their comparative reasoning, consequential reasoning. They are then asked to express a choice and logical consistency of their reasoning is explored. Individuals are provided with a summary sheet of information for their use if required. This is intended to address the potential for short term memory difficulties.

Lai et al (2008) conducted a US study to demonstrate the reliability and validity of the ACED. Thirty nine persons with very mild to moderate cognitive impairment and 13 cognitively intact caregivers were administered the ACED. Eligible persons had to require assistance in at least two of three IADLs (administering medications, preparing meals and/or managing finances), in addition to being English speaking, having a Folstein Mini

Mental State Exam (MMSE) score > 12 and 6th grade reading level. Persons with untreated depression, active psychosis and delirium were excluded. ACED, MacCAT-T, MMSE and three measures of executive function were administered as such measures of cognitive function had previously been identified as predictors of decision-making ability.

The results indicated that there was good reliability for the measures of understanding, appreciation and reasoning, with the ACED having a moderate to strong correlation with the MacCAT-T. However associations with measures of executive function were mixed with moderate correlations observed only with ACED understanding and reasoning performance. Both groups were equally capable of articulating a choice but differed in their abilities to understand, appreciate and reason. 38% of patients achieved an understanding score above the lowest score observed in the caregiver group (lowest score equalled a score of seven or eight out of possible ten); 15% of patients scored in the highest category for appreciation (i.e. a score of seven or eight out of possible eight) whereas 100% of the caregiver group scored in the highest category; similarly 15% of patients achieved scores in the highest range for reasoning (i.e. nine or ten out of possible ten) whereas 100% of the caregiver group scored in the highest category. Lai et al. (2008) reported observing 77% of patients scoring above 5 points for reasoning, this, they purported, reflects the higher scores found from questions testing comparative reasoning and logical consistency. They asserted that their data demonstrates the importance of measuring all four elements of decision-making as opposed to the simpler approach of measuring only the ability to express a choice and the ability to reason it through. They noted that patients in their group were generally able to express a choice and reason through, whereas differentiation was more clearly demonstrated with regard to the other measures of understanding and appreciation. Such information they contended may be helpful in more accurately identifying persons with preserved capacity.

Lai et al. (2008) acknowledged the limitations of their study, including a sample size and the varying etiologies of their patients' cognitive impairment. It is of note that their participants did include individuals who were not actually experiencing any functional difficulties. They were however providing care to individuals who were, there are two aspects to this –hypothetical aspect and also proxy aspect – in the context of earlier comments made by researchers in their 2007 review.

Lai et al. (2008) concluded that the ACED to be a reliable and valid measure to assess decision-making capacity and that it may serve as important addition to methods used to assess everyday decision-making. They theorised that the diversity of their participants and the varied etiologies of their cognitive impairments suggested an increased usefulness in the ACED's for characterising EDM ability for persons attending a geriatrics clinic.

Lai et al. (2008) posited the ACED to be useful for assessing the capacity to solve functional problems of older persons with mild to moderate impairment. For example where an individual experiences difficulty in performing an IADL such as managing medication and refusing assistance to address this difficulty, the ACED provides person specific assessments of the decisional abilities needed to make that informed refusal. They reported the ACED to be also useful in “real-world” assessment of an individual's cognitive abilities. It also has the benefit of being useful for individuals with short term memory difficulties as it provides a summary sheet that can be referred to throughout assessment is provided.

2.10 Risk.

At the heart of beneficence is the concern that an individual is at risk and there is a subsequent urge to protect his/her welfare. Recognition of this therefore must raise the question of the role of risk assessment in any assessment of DMC. This has resulted in the

recommendation of many researchers and clinicians that consideration of risk be a part of DMC assessment (ABA/APA, 2008).

A significant contribution to the consideration of the role of risk assessment in DMC assessment has been the literature and article authored by Ruchinskas (2005). Whilst it specifically focused on the area of rehabilitation and almost all of the literature reviewed reflects this, it is regarded by researchers as a significant contribution to the consideration of risk within the area of DMC and is and frequently referenced by researchers (Moye, 2007; Demakis, 2013; Gross, 2017).

Ruchinskas (2005) undertook a literature review with regard to decision making, predictive accuracy and rehabilitation outcomes. The objective was to highlight the need for evaluating risks when examining an individual's DMC. He concluded that the level of perceived risk influenced the significance accorded to the decision within the decision hierarchy or "sliding scale", however there was less research on risk assessment than there was on the cognitive components needed for DMC (p.197). He concluded based on the research reviewed that clinical judgement of risk was often inaccurate in identifying factors that could increase risk and frequently erred when predicting future risk. He recommended therefore that all assessments of DMC should be accompanied by comprehensive assessments of risk thereby providing an adequate standard for DMC.

The article highlighted the difference between efficacy of treatments and therapies received and the accurateness of clinical judgement in predicting future risk. Ruchinskas (2005) emphasised the importance of education for all members of the MDT with regard to the results of previous research with particular regard to risk. He reported the results of a number of studies that specifically examined clinical judgement. He identified the many ways that "team approach" can affect the determination of DMC and evidenced this in the literature review (P.198 – 199).

Ruchinskas (2005) concluded that it may be more beneficial to reframe the DMC question into tasks of either improving the specific aspect of DMC that is lacking or identifying strategies to reduce the risk. Utilising the latter he argued can eliminate the need for a DMC evaluation. Where a determination of DMC is required, it should not only consider the individual's understanding, reasoning and communication but should commence with "accurate and dispassionate quantification" of potential harm or risk entailed (P.199).

The article by Ruchinskas (2005) is underpinned by the recognition that in a rehabilitation setting and/or with individuals who are cognitively compromised, there is the "inherent pull towards beneficence" within the multidisciplinary team and the resulting concern that individuals may be unnecessarily constrained in exercising their autonomy and making decisions for themselves.

The recognition of the requirement for risk consideration in DMC assessments is reflected in its inclusion as an essential element in a number of assessment frameworks, including that developed by ABA/APA (2008).

DMC – Ethical Challenges

A review of the literature within the area of DMC identified significant ethical issues and clearly demonstrated the instrumental role played by these challenges in driving research and the ongoing evolution in theory and practice. No introduction to DMC is complete without regard to these critical issues.

At the heart of these ethical challenges are the acknowledgement and protection of an individual's autonomy juxtaposed with the responsibility to safeguard the individual whose DMC is impaired from harm, danger or exploitation.

Whilst some earlier research did reference the responsibility for safeguarding of individuals with impaired DMC and occasionally illustrated this by highlighting the risk to an individual through unsafe decisions or exploitation by others, more recent research has increased this focus and in some instances specifically focused on the issue of elder abuse, exploitation by others or conflict of interest on the part of third party informants to assessments (Newberry & Pachet, 2008; Demakis, 2013; Dunn & Alici, 2013; Goldman, 2013; Terracina et al., 2015). This presents new additional complex and challenging aspects to the area of DMC, its assessment and identification of appropriate supports.

Exploitation/undue influence can arise as a cause for concern. Previous authors have highlighted the importance of consideration being given to the question of “voluntariness” in the decision making process and the avoidance of coercion, even where this is not intended. Bellhouse et al. (2001) raised the issue of an individual feeling under pressure from professional staff to consent. Similarly issues of undue influence can arise with regard to close family or friends. Eyler and Jeste’s (2006) review referenced earlier, explored coercion with regard to consent. They considered factors that may result in coercion or perceived coercion, including payment to participate and the issue of free will for those who are imprisoned. Whilst they reasoned that payment did not result in coercion as the evidence demonstrated that potential participants were still responsive to risk even where big payments were on offer, they suggested that further study was required to more clearly ascertain whether high payments may cause underestimation of risk. Even where participants come from an economically poor background, Eyler and Jeste asserted that unless the researchers were the cause of the poor economic background, payment to such participants could not be considered coercive and may indeed be of practical benefit to their present situation.

In examining correlates of susceptibility to coercion, Eyler and Jeste (2006) reported that previous studies had evidenced cognitive deficits to correlate strongly with self-report of susceptibility. A deficit in their review is that whilst they considered the issue of coercion amongst prisoners asked to participate in research, they did not reference the issue of people residing within institutional care nor include them in their consideration of coercion. Such individuals may be in receipt of care arising from needs that are a result of cognitive deficits, for example individuals with ID. There can also be present in such individuals a desire to please and therefore a reluctance to say no or a lack of awareness that they can say no or withdraw as illustrated by Goldsmith et al. (2008) amongst others. Acquiescence was identified as a subtheme in the consideration of DMC and individuals with ID, by Goldsmith et al. (2008) in their review of such literature. Research participation and consent by individuals with ID has been a considerable focus of recent research (McDonald & Kidney, 2012; Boxall & Ralph, 2011). This has resulted in the development of guidance by advocate organisations (National Federation of Voluntary Bodies (Ireland) 2005) and state bodies (HSE, 2013).

Spiritual/religious beliefs have also been reported to play a significant role in the decision making process for some individuals, where they result in the refusal to consent to life saving treatment, considerable ethical challenges can emerge for society and medical organisations, e.g. the refusal to consent to a blood transfusion either for individual or for child (Bellhouse et al, 2001).

The issue of self neglect and impaired decision making has raised and continues to raise ethical concerns and challenges (Mauk, 2011; Lauder, Ludwick, Zeller, & Winchell, 2006). Mauk defined self neglect as “the inability to provide for oneself the goods or services to meet basic needs” (p.61). In acknowledging it to be a growing source of concerns that were reported to adult protection and health services, Mauk queried as to

when did respect for an individual's autonomy to make their own decisions ethically conflict with the principle of doing no harm or promoting good. Self neglect by individuals living alone presents considerable challenges to social services.

International best practice and Irish legislation asserts that the default position for all adults is a presumption of capacity. The trigger for querying an adult's capacity cannot merely be that the decision is perceived to be unwise, or not the "right" one or is inconvenient or possibly results in disappointment for someone else. Identifying appropriate and acceptable triggers for calling an individual's DMC into question, has generated significant debate (Bellhouse, Holland, Clare & Gunn, 2001; Ganzini et al., 2003; Howe, 2009).

The preservation of and respect for an individual's autonomy is increasingly referenced by researchers as a necessary requirement to underpin all capacity evaluations whilst balancing with the responsibility to ensure appropriate protection for individuals with impaired or diminished DMC (Trachsel, Hermann, & Biller-Andorno, 2015) (Demakis, 2013) (Smyer, 2007) (Moye & Marson, 2007) (Mullaly et al., 2007). Mullaly et al commented that successfully evaluating this distinction is often complex and requires ethical and philosophical consideration in addition to clinical evaluation.

Goldman (2013) and Hurst (2004) raised the complex dilemmas that can arise when an individual is referred for DMC assessment. The assessing clinician will seek consent from the individual to proceed. The individual may refuse to consent to the assessment or there may be concerns as to whether the individual has capacity to give consent to the assessment. Hurst's paper focused on patients who refused medical treatment and refused assessment of DMC. He considered the difficulties that can arise for clinicians when an individual refuses treatment, does not provide reasons and refuses assessment of DMC. He asserted the importance of keeping in mind that just because an ability cannot be assessed

does not mean that the patient lacks it nor does the fact that assessing DMC is impossible mean that the patient is incompetent. He emphasised that the assessment of DMC is not based on *what* the patient chooses but on *how* the patient chooses. He defended the individual's right to refuse an assessment without a conclusion being made regarding his/her capacity. Hurst asserted that the obligation to have a "conversation" to convince the patient to engage, was the duty of the clinician, not the individual's.

An assessment of DMC can include probing for personal elements, such as fears, doubts and mental abilities. It is an intervention. For competent patients, interventions are subject to patient consent. There is no compelling reason for a capacity assessment to be considered differently. (p.1758).

Hurst (2004) suggested that where a refusal for assessment remained, the clinician should consider the degree of risk if the individual's wishes were to be followed. In the framework that he outlined for decision-making re capacity in defined situations, he included the identification of a person trusted by the individual with whom s/he may be willing to discuss concerns with.

Mullaly et al (2007) also identified informed consent with regard to DMC assessments as one of the most challenging issues in the area. Their survey of common practices amongst neuropsychologists indicated that less than 40% of respondents reported always seeking informed consent when commencing DMC assessments. On those occasions that they did, consent was usually obtained verbally (71%) rather than in writing. A contradiction can be perceived in seeking consent from an individual whose DMC is being queried, perhaps even in the context of treatment consent. In such instances consulting guidance issued by professional bodies and National Health Service providers, for example in Republic of Ireland, the HSE's National Consent Policy, can be helpful.

Sullivan (2004) raised the complex issue of whether it is appropriate for a clinician who is already involved in the care of an individual to assess DMC and suggested that such a dual role raised the possibility of a conflict.

Concerns regarding consent by individuals who may be at risk of impaired DMC to participate in research continue to grow (Dunn & Alici, 2013; McDonald & Kidney, 2012; Boxall & Ralph, 2011). Given the implications of the changing demographics as previously outlined, research with healthy individuals and individuals at risk of impaired cognition and/or impaired DMC in this area is an ongoing need. Participant recruitment and informed consent can result in various dilemmas that at times may result in the inclusion of family/staff with regard to proxy/surrogate decision making. Dunn & Alici therefore asserted that “investigators have the responsibility to ensure an ethically appropriate consent process” when seeking and inviting such individuals to participate in research (p.311). Highlighting the complex and challenging nature of the ethical, legal and clinical implications of consent, capacity and surrogate decision making Dunn & Alici described the journey ahead as “navigating the ethical waves of the coming silver tsunami” (p.312).

Clarke et al. (2015) conducted a service evaluation on decision-making within a UK hospital Feeding Multi-Professional Team regarding eating and drinking interventions. Their research asked three questions; how are decisions made about eating and drinking interventions (e.g. artificial nutrition) for individuals at risk of impaired decision making; what are the key decision making factors that are balanced and who is involved in the process? Whilst they specifically explored the decision making process within the hospital system, the starting point for each of these processes was the identification of an individual who was in need of nutritional support and who was at risk of impaired DMC. Some of these individuals were people with disabilities. In this context Clarke et al. raised an

interesting ethical aspect arising from Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). This Article guarantees that all individuals with disabilities “enjoy legal capacity on an equal basis with others on all aspects of life” and that countries must “provide access by persons with disabilities to the support they may require in exercising their legal capacity” (p.2). They observed that some legal interpretations of this article argued that there is no point at which legal DMC is lost. They suggested therefore that the focus of assessments should perhaps shift from being a question of whether a person has or has not DMC, towards ascertaining the support requirements of an individual for making decisions and identifying then how these support needs could be met. They concluded therefore that substituted and supported decision making may be better represented as existing on a continuum.

As illustrated earlier a number of researchers and clinicians have asserted that inherent to all capacity assessments should not only determine DMC but also include consideration as to whether there are measures or supports that could be undertaken to assist or improve the individual’s DMC (HSE, 2013; ABA/APA, 2008; BPS, 2006). The above interpretation of the UNCRPD reported by Clarke et al. (2015) would result in the shifting of this from a question of “whether and which” to just being “which”, thereby requiring identification of supports.

Within the area of DMC researchers and clinicians face and will continue to face an array of complex and challenging ethical issues being aware and willing to appraise such challenges is a necessity for all (Goldman, 2013).

Previous DMC Research

An examination of the literature identified studies that have been undertaken exploring DMC and its various aspects. Early research focused on the conceptualisation of DMC and the development of theoretical models specifically exploring DMC within

different groups, the assessment of DMC within different domains and the role and association of cognitive functioning with DMC.

Whilst studies were undertaken with individuals across differing age groups, individuals particularly focused on were those with diagnosis of mental health difficulties, AD and to a lesser extent those with a diagnoses of Mild Cognitive Impairment (MCI) or Parkinson's Disease (PD). However there has been less focus on DMC for people with other clinical diagnoses such as ID and ABI.

A significant amount of research initially focused on the area of MDMC, and then later on the area of FDMC. There is now an emerging focus on DMC with regard to participation in research.

A number of authors have conducted comprehensive reviews of previous DMC research (Eyler & Jeste, 2006; Marson & Moye, 2007; Mullaly et al., 2007; Moberg & Rick, 2008; Moye et al., 2013). Their focus has primarily been theory, assessment, consent and the domains of MDMC and FDMC. Marson and Moye and Moye et al. have identified older adults as an emerging area of distinct practice and research within DMC. Recently this has become particularly prevalent in terms of safeguarding in the context of Vulnerable Adult Protection – this too may be feeding the beneficence side of the Autonomy vs. Beneficence conflict referred to earlier (Lichtenberg, 2016; Spreng, Karlawish & Marson, 2016; Lichtenberg et al., 2016).

A small number of Irish studies have been undertaken in the area of DMC. These have included studies with regard to DMC in sexual relationships for people with ID (Dukes & McGuire, 2009; McGuire & Bayley, 2011), DMC for people with psychiatric diagnoses (Kennedy et al., 2009; Rutledge et al., 2008), FDMC (Kavanagh et al., 2008) and DMC generally (Kennedy, 2008; Hillery, Tomkin & McAuley, (1999).

An overview of key studies and their findings has been provided in the preceding sections with regard to theoretical models and assessment of DMC. This section will therefore provide an overview of previous research with regard to Cognitive Functioning, Older Adults and Adults with Intellectual Disabilities.

2.11 Cognitive Functioning and Cognitive Aging

As outlined earlier, DMC can be impaired temporarily and can fluctuate either intermittently or permanently. Cognitive functioning has been associated with such impairments and key findings of previous research examining this are presented below. This is not intended to provide a comprehensive review of all papers previously written but rather to provide an overview of key findings and selected studies. A number of articles identified have conducted reviews of previous literature; these are drawn from and referenced to identify key findings. Some individual studies exploring for specific associations are also considered in greater detail and their findings reported.

The shared belief that Moberg and Kniele (2006) identified amongst authors that “decision-making capacity is a multidimensional construct reliant on a combination of intact cognitive abilities including attention, orientation, memory, general intellectual functioning, problem solving and abstract reasoning” is useful to bear in mind when reviewing the empirical evidence available regarding the aspects of cognitive functioning associated with DMC, (p.104).

This belief reflects the findings of studies undertaken to identify factors associated with DMC. These studies have identified factors such as cognitive functioning, neuropsychological measures, older age etc. A number of studies have explored the relationship between one or more of these factors and DMC. Key findings of these studies are considered and reported on below.

Royall (2002) reported on previous research that demonstrated measures of Executive Control Function (ECF) to be the strongest determinants of each of the elements of decision making. Verbal fluency explained the most variance in Appreciation amongst AD patients, the Initiation/Preservation subscale of the Mattis Dementia Rating Scales (DRS) explained the most variance in Reasoning amongst AD patients and the DRS Conceptualisation subscale explained the most variance in participants Understanding.

Impairments of ECF are associated with lesions. As illustrated in Table 2.1, Royall (2002) identified impairments in ECF to be associated with specific lesions locations:

Table 2.1.

ECF Impairments Associated with Lesion Location (Royall, 2002)

Lesion Location	Associated Impairments
Mesiofrontal lesions	Apathy and Distractibility
Orbitofrontal lesions	Irritability, Mood Lability & Resistance to Care
Dorsofrontal Lesions	Affects Planning, Hypothesis Testing, Judgement & Insight

Royall (2002) reported frontal system impairment to be demonstrated in many medical and psychiatric disorders, using the example of AD which affects all of the above three regions. This resulted in the development of the Executive Interview (EXIT25) by Royall and his colleagues.

Raymont et al. (2004) reported that the impairment in DMC observed in their study was associated with impaired cognitive functioning, older age and lower education

attainment. Hotopf (2005) reported that a number of previous researchers had identified cognitive functioning as a factor strongly associated with DMC.

In an overview of the literature regarding DMC, Eyler and Jeste (2006) summarised issues related to the definition of DMC, discussed methods used to assess DM abilities and other aspects of informed consent and described studies who sought to understand variation in different elements of informed consent. The studies, they examined, explored variations between groups of individuals and within individuals in order to identify factors that may predict impairment in DMC.

Eyler and Jeste (2006) reported the evidence indicated that individuals within groups such as those with mental health difficulties or cognitive impairments did not perform as well on measures of DMC as individuals within groups with no such diagnoses. The review indicated that the degree of cognitive deficits was strongly related to impairments of DMC. Factors specifically related to deficits in understanding of consent-related information included lower education or vocabulary level and in some reports, old age. Among patients with mental illness, symptom severity had been found to be weakly, if at all, correlated with DMC. This caused Eyler and Jeste to conclude that some of the variation observed in DMC appeared to arise from individual differences in education and cognitive abilities, with most reported relationships indicated to be between global measures of cognition and consent-form Understanding. They also noted however that some more specific relationships have been observed for both understanding and reasoning. They observed that it remained to be seen whether cognitive deficits in particular domains (e.g. learning and memory) may be more related to particular elements of DMC (e.g. understanding) than others. Eyler and Jeste hypothesised that if this is the case; than knowledge of an individual's cognitive profile may benefit interventions to enhance informed consent. Regardless of this they suggested that brief cognitive testing

may be warranted as a screen to indicate need for more extensive assessment of DMC (p.560).

Eyler and Jeste's (2006) review also confirmed as outlined earlier that factors within an individual may result in variation, e.g. physical illness and fluctuations therein, fatigue, fluctuations in wellness, upset, trauma, periods where symptoms of mental illness are acute, situation specific factors – temperature of room, noise, crowded, lighting etc. Their review included a number of studies that examined ways of enhancing or improving DMC. From this they observed that most of the interventions have focused on ways to improve consent-related information delivery.

Other researchers more recently focused on possible neuropsychological measures as predictors of diminished and declining capacity. A US study undertaken by Moye, Karel, Gurrera, & Azar (2006) examined rates and neuropsychological predictors of treatment decision making or consent capacity among older adults with dementia over 9 months using a control group from the general population for comparison purposes. They found no main time effect with regard to follow up nine months later but concluded that Delayed Logical Memory was significant in indicating individuals with impaired capacity at initial assessment and at follow up. Boston Naming and Trails B were significant at indicating individuals with impaired capacity at 9 months follow up. Previous studies had identified difficulties with naming, memory and executive function as impacting decisional capacity. Thus Moye et al. concluded that difficulties with remembering information after a short delay, assigning language to remembered elements, and shifting back and forth between remembered elements, may best predict declining decisional capacity. They suggested that paying special attention to those patients with problems in naming, delayed memory, and flexibility may best identify which patients are likely to be decisionally impaired.

In reviewing empirical research Mullaly et al. (2007) reported that the cognitive functions frequently reported to contribute to DMC included memory, learning, attention, executive functioning, expressive and receptive language.

Moberg and Rick (2008) included an overview of the literature with regard to neuropsychological assessment of capacity. They observed that whilst there was variability in the type of cognitive measures that correlated with measures of capacity, the evidence reported demonstrated the importance of memory and executive functioning. They predicated this by referencing its particular applicability to AD and Parkinson's disease (PD).

Other studies have also been undertaken to explore the role of cognitive functioning in DMC and in some instances to develop a cognitive or neuropsychological model of DMC.

In a US study Dreer, DeVivo, Novack, Krzywanski, & Marson (2008) specifically examined the role of cognitive factors as predictors of DMC in adults with Traumatic Brain Injury (TBI). They met with 34 participants with TBI and 20 healthy participants to administer various DMC and Neuropsychological measures at initial hospitalisation (when stable and not confused) and again at six month follow up (24 participants with TBI and 20 healthy participants). They specifically explored Orientation; Language Comprehension; Attention/Concentration; Visuospatial Skills; Information Processing Speed; Memory; Executive Functioning and Fine Motor Functioning. They reported Short Term Memory (STM) to be strongly associated with impaired consent capacity in TBI at the time of initial hospitalisation. With cognitive & functional recovery post hospitalisation they reported executive functioning & working memory to be strongly associated with improved decisional capacity at 6 month follow up.

In an article examining the neuropsychology of DMC for older adults, Demakis (2013) identified comprehending, learning, recall and crystallised verbal knowledge as necessary for Understanding and executive functioning as necessary for Appreciation and Reasoning. He identified judgement, insight, working memory and the ability to abstract, plan and envision consequences as abilities included in this (p.47). He noted that the association of executive functioning was more so with FDMC than MDMC. This suggests DMC to be domain specific rather than global.

Stormoen, Almkvist, Eriksson, Sundström, & Tallberg (2014) undertook a Swedish study to identify “the most powerful cognitive component(s) that best predicted MDMC” in patients with AD and MCI (P.1305). Three groups participated, those with AD (N = 21), MCI (N=20) and Healthy (N=33). MDMC was assessed and related to demographics and 27 cognitive test measures. Stormoen et al concluded that multiple factors were involved in MDMC for individuals experiencing cognitive impairment. Verbal knowledge was indicated to be the best predictor, followed by episodic memory, cognitive speed and working memory respectively. Reading speed was indicated to be the most important single cognitive test measurement.

Terracina et al. (2015) in a US study exploring executive functioning impairment amongst adults who were referred more than once to Adult Protection Services for an assessment of DMC, noted the finding by previous researchers that executive functioning contributed more to variances with regard to money management tasks than other factors. This also suggests DMC to be domain specific rather than global.

An understanding of DMC necessitates a clear comprehension of its underpinning by cognitive functioning. The above, whilst not a comprehensive review of all studies undertaken in this area, illustrates the associations that have been demonstrated between

DMC and various cognitive functions. Consideration of the impact of normal aging on these cognitive functions aids the understanding of DMC in older adults.

A US study undertaken by Foster, Cornwell, Kisley, & Davis (2007) considered cognitive changes across the life span. They outlined current theory on normal cognitive change in the context of aging and distinguished between normal change and pathological change including cognitive decline utilising information provided from their dataset of approximately 4,000 individuals.

Foster et al. (2007) described executive function as a conglomeration of complex processes (e.g. organising, planning, initiating, inhibiting and decision making) which are loosely defined as the functions that guide higher-order complex behaviour and which are believed to be dependent on neural activity of the frontal lobes. They outlined West's proposed prefrontal cortex theory of cognitive aging, which based on earlier identification of early morphological and physiological changes in the frontal cortex, predicted that cognitive functions supported by prefrontal cortex will show early age-related decline. They reported that in the context of this theory impaired performances on tasks measuring executive functions would be expected.

From their dataset, Foster et al. (2007) examined the abilities of Verbal Recall, Spatial Memory, Working Memory, Problem Solving, and Emotion Recognition of 1,100 individuals aged between 18 years and 89 years. They reported age related decline occurring in all, albeit at a varying pace, commencing in the 40's age range.

In a US study, Wood et al., (2011) examined the impact that increasing choice options has on decision-making abilities in older versus younger adults (n=121). They observed there to be an extensive cognitive aging literature that documents declines in fluid abilities, speed of processing, working memory, and executive functioning with relatively intact crystallized abilities (p.297).

A review by Blazer and Wallace (2014) did not specifically reference DMC but rather focused on conveying learning from a substantive piece of work regarding cognitive aging and may be useful in informing understanding of aging and cognitive aging prior to consideration of DMC and Older Adults. The authors summarised content points from a US Report “Cognitive Aging: Progress in Understanding and Opportunities for Action” (Institute of Medicine (IOM) Committee) that they believed was necessary to be known by all clinicians working with older adults. They described cognitive aging as a “lifelong process of change in cognitive capacity through time. It is not a disease or a quantifiable level of function. The process is gradual and ongoing” (p. 776). Cognitive aging applies to a range of cognitive functions and varies from person to person. Blazer and Wallace asserted that cognitive aging should not be equated with normal aging. They explained that such an equation would imply that there is no effective or appropriate intervention to buffer the decline in function. They reported that cognitive aging causes are both inherent in the age process and also the influence of other factors across the lifespan such as health, social, environmental etc. An example that they used to illustrate this was the individual who worked in an environment that exposed him/her to certain pesticides that could adversely impact on cognitive performance, similarly for example the potential impact of substance misuse/abuse. They reported however that empirical evidence suggested that cognitive health can be optimised and cognitive aging slowed through engaging in practices and behaviours that are conducive to good health generally. The IOM Committee report identified three specific actions that were evidenced through previous research

1. Exercise – a considerable number of studies associate physical activity with the maintenance of physical and cognitive functioning.
2. Reduction of Cardiovascular and related Metabolic Risk Factors – for example treating diabetes, losing weight, stop smoking, maintaining good diet and nutrition.

3. Monitoring Medications – and their attendant conditions.

The IOM Committee reported that additional research is required with regard to some of the newer interventions and technologies that are also being utilised by individuals seeking to optimise cognitive functioning, e.g. Brain “Training” and Memory Games (Blazer & Wallace, 2016).

2.12 Older Adults.

As identified earlier, decision making has a considerable significance for older adults and their continued autonomy. DMC in older people is emerging as a distinct area of research and clinical practice and an evolving area of knowledge. This reflects the changing demographics internationally as outlined earlier. People are living longer and there are naturally occurring physical and cognitive impacts of aging. Such impacts, age related disorders and other health conditions increase the risk of impaired DMC for older adults. It is thus an area that generates considerable DMC queries and referrals.

Within the area of older adults the DMC research undertaken has also focused on the domains of MDMC, FDMC and in more recent times on research participation. A number of these studies have also had the added purpose of seeking to identify associated factors and predictors (Moye & Marson, 2007; Qualls & Smyer, 2007; Moye et al., 2013).

A comprehensive overview of Capacity Theory, Law, Science and Practice in Social and Demographic Contexts is provided by Moye et al., (2013) and accompanied by a table charting the evolution from the 1960's until their present day. They noted the comprehensive review of capacity research amongst older adults by Marson et al. (2012) and Palmer et al. (2012) amongst others. They observed that research has demonstrated that some functional abilities may be affected by cognitive declines associated with normal aging, for example information processing speed, various types of memory and executive functioning. Moye et al. noted the variability in the rate and nature of age related cognitive decline for each individual and thereby concluded that each person has a unique constellation of cognitive strengths and deficits that contribute collectively to their functional abilities (p.162).

In setting out the evolution of this area in the context of research and practice Moye et al. (2013) considered the construct of capacity, instrument development, patient group

comparisons, identification of clinical predictors, and the accuracy of clinicians' judgements and the evolution of the practice of DMC assessment. Of particular interest to this study were their observations of previous research with regard to the identification of clinical predictors.

Moye et al. (2013) concluded with the assertion that over the coming years, society will age with an increasing number of older adults experiencing impaired cognitive functioning thereby increasing the need for capacity assessment and they identified areas requiring future research focus, including a wider range of population within older adults specifically highlighting older adults with an ID and the need for future capacity research to make greater consideration of theories, models and research findings from judgement and decision making research.

Whilst Moye et al. (2013) demonstrated clearly the vast amount of work and development that has been undertaken within this area in the past few decades, they also clearly illustrated the growing work that requires to be undertaken, the continuing struggle for clear and consistent use of terms – even within this article and interestingly it may even have indicated a similar struggle for a “new” concept – Cognitive Aging.

As referenced earlier, a significant portion of DMC research initially focused on MDMC and later FDMC. This was similarly so within the area of DMC and the older adult. These are areas of some relevance to this dissertation and the research undertaken, key findings of such research are thus considered below.

A comprehensive review by Moye and Marson (2007) examined capacity assessment of older adults as a distinct area of clinical practice and research and provided an extensive review of existing literature with regard to MDMC and FDMC. They observed capacity as an “emerging” area and identified the socio-demographic factors outlined above, that they believed to be driving it as an issue of concern to so many. They

identified eight major capacity domains of relevance to older people, setting out the skills and abilities required for each as illustrated in Table 2.2.

Table 2.2.

Capacity Domains – Scope of Abilities and Skills Required (Moye & Marson, 2007)

Capacity	Scope: Abilities & Skills Required
Independent Living	Broad: Cognitive & Procedural
Financial Management	Broad: Cognitive & Procedural
Treatment Consent	Narrow: Cognitive
Testamentary Capacity	Narrow: Cognitive
Research Consent	Narrow: Cognitive
Sexual Consent	Narrow: Cognitive
Voting	Narrow: Cognitive
Driving	Moderate: Procedural

Moye and Marson (2007) reviewed empirical research undertaken within the domains of MDMC and FDMC. They reported treatment consent capacity in older adults to be the most extensively researched of any of the capacities. They reviewed 16 such studies with sample sizes ranging from 20 to 100 that were published between 1998 and 2006. A table summarising these studies is outlined in their paper. They reported the studies to have demonstrated that adults with dementia have lower levels of DMC when compared to healthy older adults, and that those older adults residing in nursing homes

demonstrated rates of capacity impairment between 44% and 69%. Older adults who were hospitalised also demonstrated impaired levels of DMC. Moye and Marson reported that as studies published exploring MDMC in psychiatric patients did not focus specifically on older adults, no evidence was therefore available on MDMC for older adults within this population. As outlined in greater detail in the earlier section considering clinician practice, reliability between clinicians with regard to MDMC assessment for older adults with dementia was reported to be at the level of chance. The studies reviewed by Moye and Marson reported evidence for some association between elements of MDMC and cognitive measures, as illustrated in Table 2.3.

Table 2.3.

Medical Decision Making Capacity Associations with Cognitive Measures (Moye & Marson, 2007)

MDMC Elements	Disorder	Cognitive Measure/Factors
Understanding	Alzheimer's Disease	Conceptualisation & Confrontation Naming
	Parkinson Disease	Executive Function, Memory & Comprehension
	Dementia	Neuropsychological & Verbal Retrieval Factors
Appreciation	Alzheimer's Disease	Verbal Fluency, Visual Attention & Conceptualisation
	Parkinson Disease	None identified
	Dementia	Verbal Retrieval & Problem Solving Factors
Reasoning	Alzheimer's Disease	Verbal Fluency
	Parkinson Disease	Executive Function, Mental Flexibility, Attention & Delayed Memory
	Dementia	Verbal Retrieval & Problem Solving Factors
Expressing Choice	Alzheimer's Disease	Auditory Comprehension & Confrontation
	Parkinson Disease	Executive Function, Comprehension, Attention & Memory
	Dementia	None reported

Moye & Marson (2007) reported that in an earlier factor analytic study by Dymek

et al (1999) consent capacity as a construct in AD was explained by two

neuropsychologically mediated factors associated with verbal conceptualisation and verbal memory.

Studies reviewed by Moye & Marson (2007) indicated that consent capacity declines as dementia progresses, with impaired decisional capacity at baseline, understanding, appreciation and reasoning significantly decline then over a two year period. Such decline was attributed to reasoning and was predicted by earlier difficulties with naming, verbal memory and mental flexibility (p.5-6).

Moye and Marson (2007) concluded that additional research is required in this area particularly with regard to identifying and exploring the relationship between decisional abilities and underlying cognitive abilities. They identified the need for additional research to be undertaken with patients who had psychiatric diagnosis, as the lack of such studies makes it unclear as to whether instruments presently developed for assessing capacity would be useful in other groups.

Moye and Marson (2007) categorised studies reviewed as *good, fair or poor*. Whilst this is a very useful and comprehensive review, it is uncertain from it as to what defined good, fair and poor. Whilst they specifically singled out the lack of studies with regard to older people with a psychiatric diagnosis and a lack of race and ethnic data, the populations reported on are limited to AD, PD and Dementia and therefore did not include for example older adults with MCI, with ID or with ABI. The dearth of such studies was not identified by the authors. The studies reviewed were also limited to consideration only of treatment consent; Medical DMC encompasses other aspects including medication management, assessment consent and the seeking of medical assistance.

Moye et al. (2013) also reported that the associations between elements of DMC and cognitive abilities identified by Moye and Marson (2007), continued to be demonstrated by later research. These are illustrated in Table 2.4.

Table 2.4:

Cognitive Abilities Associated with Elements of MDMC (Moye et al. 2013)

MDMC Elements	Cognitive Abilities
Understanding	Impaired Memory, Conceptualisation and Comprehension
Appreciation	Executive Functioning and Conceptualisation
Reasoning	Executive Abilities
Expressing a Choice	Confrontation Naming and Auditory Comprehension

Moye and Marson (2007) reported that FDMC differed from MDMC as it comprised a broad range of conceptual, pragmatic and judgemental abilities. They also observed that there were few working conceptual models of financial ability. In reviewing the published studies to date, they reported that FDMC of older adults to be an area that was only starting to then emerge. Seven studies were identified that explored FDMC amongst older adults with AD, MCI and Dementia and healthy older adults. All reported impaired decisional capacity with deficits being identified in both simple and complex financial abilities and tasks. One study by Tuokko et al. (2005) demonstrated linked memory functioning to future impairment in money management. Moye and Marson identified the need for additional research in this area and specifically recommended that future researchers address issues of normative longitudinal change in financial capacity over the life course, the natural history of financial capacity loss in patients with dementia and cognitive predictors of financial capacity (p.7-8).

The populations reported on within the studies identified by Moye and Marson (2007) were limited to AD, MCI and Dementia and did not include older adults with PD,

with ID or with ABI. The studies reviewed also did not explore specific associations between elements of FDMC and cognitive measures and as Moye and Marson commented represented researchers initial efforts at empirically understanding financial capacity in dementia populations.

In conclusion of their paper Moye and Marson (2007) identified a number of areas requiring future research within older adults, including a need to broaden the population being explored and the need to identify cognitive and other behavioural markers of diminished capacity.

Other studies have explored additional aspects of DMC for older adults. An overview of the themes emerging from this research is provided below.

Some studies have reported poorer DM performance amongst individuals with various types of dementia (Huthwaite et al., 2006; Marson et al., 2009; Marson & Moye, 2007; Smyer, 2007). Most older adults do not have dementia but previous studies have also reported poorer DM performance in association with older age (Brand & Markowitsch, 2010; Finucane et al., 2005; Finucane et al., 2002; Qualls & Smyer, 2007). Also older adults as a group are at higher risk for cognitive impairment than younger adults and previous research undertaken has reported cognitive impairment to be associated with impaired DM performance (Marson & Hershey, 2013; Martin et al., 2008; Martin et al., 2013; Widera, Steenpass, Marson, & Sudore, 2011). The higher risk for cognitive impairment was one of the factors identified by the American Psychological Association that would result in increasing demand for assessment of the capacities of older adults (ABA/APA 2008) and illustrated why they believe there was a need to focus on DMC in older adults.

Researchers have also reported differences in decision making between older and younger adults, with decisions by older adults resulting in poorer (Finucane et al., 2005;

Finucane et al., 2002). The identification of differences in DMC between younger and older people initially resulted in consideration of an age effect, however results of further studies did not support this, leaving uncertainty as to the reasons for identified variances within the DMC of older adults (Finucane et al., 2002; Finucane & Gullion, 2010; Henninger et al., 2010). Further developments of theoretical models of DMC were proposed to account for these variances (Finucane et al., 2005; Moye et al., 2013).

Henninger et al. (2010) examined whether differences observed between older and younger adults' DMC reflected a direct effect of aging or an indirect effect as a result of age related changes on underlying cognitive processes. The study was US based and included 54 older adult participants ($M = 70.7$ years, $SD = 3.0$), 58 younger adults ($M = 23.4$ years, $SD = 4.4$). Participants had no prior history of stroke, neurological or psychiatric disorder, brain injury or dementia. They observed that previous studies had reported that this difference in decision making particularly prevalent in decisions involving risk and thus had consequences in financial areas of decision making. Previous studies also indicated that older adults tended to avoid making risky decisions and opted instead to act on the advice of others. This was observed to occur in both financial and healthcare domains. This resulted in the interpretation that attributed the decline in the quality of decision making to be related to the increase in risk aversion across older age. However this explanation was challenged by Henninger et al. on the basis of reports by more recent studies that identified the context in which a decision was made, to have influenced whether older adults sought or avoided risk (p.262).

In their study, Henninger et al. (2010) identified processing speed and memory as domains for which evidence demonstrated age-related decline and explored their effect on decision making. As the Iowa Gambling Task (IGT), Cambridge Gambling Task (BGT) and the Balloon Analogue Risk Task (BART) involved risk, they were the decision making

measures used. Henninger et al. reported that the results of their study demonstrated that the age related differences in decision making reflected age related differences in the two underlying cognitive factors. They concluded that this demonstration of these two cognitive factors mediating age related differences in decision making was likely to generalise to other domains of decision making and may reflect different cognitive factors.

Henninger et al.'s (2010) study concluded that the differences observed in older adults DM were not necessarily a direct effect of age but rather reflected the impact of aging on an underlying ability associated with DM, i.e. the impact of aging on cognitive functioning.

In their US study, Finucane et al. (2002) compared younger (N=239) and older (N=253) adults' abilities to make judgments and decisions when given document-type information (tables and charts) about health-plan options. They focused on two aspects of DMC that they identified as comprehension and consistency. They defined comprehension as "the ability to understand information" and consistency as "the ability to integrate information in an internally consistent fashion". Results indicated that increasing age was related to greater comprehension errors and inconsistent preferences, even when covariates (education, income, gender, self-perceived skill and health, decision style, and attitude toward delegation) were taken into account. Finucane et al. highlighted the difficulties in interpreting the meaning of age differences in performance on decision tasks and concluded that there was a need for future research to explore the consequences of age differences in real-life decision tasks (p.158-160).

Finucane et al. (2005) compared older versus younger adults' decision performance on simple and complex tasks about health, finance and nutrition. They examined how decision maker characteristics and task complexity affected two dimensions of DMC, comprehension and consistency, using the person-task fit model. They hypothesised that

increasing age and task complexity were related to greater comprehension errors and inconsistency in decision making. This US study was part of an ongoing research program examining older adults' DMC. The participants were 169 older participants, recruited from community centres (M=75 years, 62% female) and 171 younger participants, recruited from the general community through newspapers advertisements, (M = 35 years, 54% female). Each participant completed a questionnaire booklet (average completion time was approximately 1 hour for older adults and 45 minutes for younger adults). It contained multiple pen and paper tasks designed to assess comprehension and consistency and to collect information about self perception and demographics (p.74). This included information on individual differences measures, including perception of health, cognitive skills (crystallised intelligence, processing speed, short term memory capacity) attitudes towards decision making and perception of skill and experience in using tables and charts.

Finucane et al.'s (2005) study demonstrated age effects for almost all comprehension and consistency tasks in all domains, with complexity effects also identified for all. However it did not identify the expected interaction between the effects of age and complexity for any task that they had hypothesised. Rather the results appeared to identify that variance in DMC within older adults was accounted for by individual differences such as social variables, health measures, basic cognitive skills and attitudinal measures. Finucane et al. therefore suggested that this meant that age-related declines in cognitive functioning "may be compensated for somehow" and that the findings of strong positive correlations provided the basis for future studies that may develop a DMC model further and account for such differences.

Finucane et al.'s study (2005) and the positing of the Person-Task Fit framework contributed to the broadening of the theoretical model by Grisso and Appelbaum from that

of a single unitary construct to that of a dynamic multifaceted construct of DMC by including the impact of the task characteristics, the individual characteristics and their interaction on DMC.

Most studies reviewed focused their explorations on one domain of decision making, e.g. health or finance. Finucane et al.'s (2005) study broadened the range of domains by examining decision making in the domains of financial, health and nutrition. These domains reflect areas most pertinent to individuals' day to day lives. An observation by some researchers has been the utilisation in DMC studies of decisions that do not arise frequently for individuals and therefore did not reflect commonly required decision making and real life. Finucane et al. observed that the use of "complex problems that are not part of everyday decision making may portray older adults as low in competence even though the same individuals may function adequately on other decisions" (p.72). Whilst the specific decisions explored in Finucane et al.'s study reflected decisions that may occasionally arise for individuals, they did not necessarily reflect everyday decision making. For example, in examining decision making in the domains of health and finance, the study included decision making with regard to private health insurance and choosing mutual fund for investment purposes. However within the nutrition domain, the study focused on decisions that would reflect consideration and application of advice commonly offered to patients by dieticians and could therefore arise on a more frequent basis in daily living.

Finucane et al.'s (2005) study identified gaps in understanding differences in DMC within older adults. A strength of the study was the inclusion of the measures of individual differences. Whilst the measures utilised were limited, their inclusion identified a new avenue of consideration with regard to DMC in older adults, thus highlighting new opportunities for future research and the possibility that age-related declines in cognitive

functioning “may be compensated for somehow” (p.80). Finucane et al. concluded that “an extended program of research – derived from a comprehensive theoretical framework – that systematically identifies which older adults have the skills to successfully cope with which decision” would best inform policies for addressing the needs of older adults (p.82). They also asserted that a multidimensional performance based assessment tool was required in order to identify need and most decision supports.

A US study then undertaken by Finucane and Gullion (2010) evaluated reliability and validity of a tool for measuring older adults DMC. They explored judgements and decisions related to health, finance and nutrition. There were three groups of participants (25yrs-45yrs, n=205; 65yrs-74yrs, n=208; 75yrs-97yrs, n=198). They utilised indices of comprehension, dimension weighting and cognitive reflection development. The results demonstrated that older adults performed poorer than younger and that variance could be accounted for by individual difference measures (social variables, cognitive skills, attitudinal, health and numeracy). Individuals with lower crystallised intelligence or poorer performance on other cognitive abilities tended to exhibit poorer performance on DMC measures. Increasing age also was reported to signify poorer performance. Finucane and Gullion suggested that DMC may be preserved with age to the extent that decision tasks are routine and predictable and that knowledge and experience of older adults with similar decisions may make up for declines in cognitive abilities. They theorised that DMC as a multidimensional construct was complex and reflected a “compiled” form of cognition, and that basic cognitive abilities were the strongest predictors of DMC. The authors therefore posited that age related changes in DMC were thus likely to have characteristics similar to age related changes in basic abilities.

Sherod et al. (2009) undertook a cross-sectional study to identify neurocognitive predictors of financial capacity across a dementia spectrum. The US study utilised the

Financial Capacity Instrument (Marson et al. (2000) and outlined earlier) and a neuropsychological battery. Participants included healthy older adults, older adults with AD and older adults with MCI. Results indicated written arithmetic skills to be a primary predictor and executive function and verbal memory to be secondary predictors of FDMC.

2.13 Older Adults with Intellectual Disability.

The advent of Normalisation signalled significant change in thinking and practices with regard to people with ID. Heightened awareness of Autonomy and Human Rights contributed to this evolution in thinking. However it has continued to be observed that people with ID still have far fewer opportunities to make decisions within and about their own lives (Kilcommons, Withers, & Moreno-Lopez, 2012; Goldsmith, Skirton, & Webb, 2008; W. M. I Suto, Clare, Holland & Watson, 2005; W. M. Irenka Suto, I. C. H. Clare, A. J. Holland, & P. C. Watson, 2005; Wehmeyer & Garner, 2003). Individuals living in large communal settings, for example institutional settings, large residential settings, hospital settings were observed to be at greater risk of decreased opportunities to make decision. Suto, Clare and Holland (2007) cautioned however, that it was not necessarily better for people living in smaller community based settings. It is difficult to identify within the literature studies that focused on DMC specifically for older adults with ID. However a number of studies were identified that examined DMC for adults with ID, the key findings of which are outlined below.

Goldsmith et al. (2008) conducted a review of the literature with regard to healthcare consent and people with ID. Throughout the literature and reflecting the area in practice, there is interchangeable use between the terms intellectual disabilities, learning disabilities, mental handicap and mental retardation. Reflecting this Goldsmith et al. incorporated these terms into their search and identified 22 studies. These 22 studies were a mixture of quantitative (10), qualitative (8), two literature reviews, one of mixed

methods, one of unclear methodology. Two were literature reviews, the remaining articles reported on US or British studies. Goldsmith et al. identified life experience, interaction between healthcare professionals and participants, ability to consent and psychometric variables as the main themes within these 22 studies.

Of particular interest are a number of the subthemes that Goldsmith et al. (2008) identified within life experience. These included *Residential Status* – whether the individual was living within an institutional or community setting and Decision Making Opportunities. The review indicated a consensus amongst authors that there was a lack of decision making experience that affected decision making abilities amongst individuals with ID. The studies reviewed had identified parents and caregivers as the main decision makers in individuals lives rather than the individuals themselves but the studies did not appear to explore a specific relationship between such experience and decision making abilities.

Goldsmith et al. (2008) included in this review a study by Heslop et al (2005) who had investigated what individuals with ID and their carers knew about the psychotropic medication that had been prescribed for their use. Their findings indicated “sketchy” knowledge on the part of the individuals as to what they had been prescribed and why they had been prescribed (p.555). The authors reported that carers of the individuals did not demonstrate much more knowledge resulting in the conclusion that there had been poor provision of information by prescribers.

Goldsmith et al. (2008) identified *Acquiescence* as another subtheme to emerge within life experience – they observed that this willingness on the part of the individual to agree may be associated with residential status and decision making opportunity and noted the warning by authors to clinicians that individuals who may appear very willing, may not

understand that they could say no or withdraw for example from participation in a research project if they wished.

Goldsmith et al.'s (2008) findings from the review indicated that there was a consensus that capacity to consent was associated with cognitive ability and verbal skills but that the attitude and behaviour of healthcare professionals were a crucial factor (p.549). Cognitive functioning (IQ) was considered by a number of researchers to have a major role in capacity. A number of the studies also observed that DMC increased for individuals as information being provided was broken down into smaller pieces and presented in a manner appropriate to the individual. They concluded that their findings supported the functional model in assessing capacity and recommended that future research with individuals with ID should utilise real life situations rather than vignettes in exploring and ascertaining capacity.

Antaki, Finlay, Walton and Pate (2008) undertook a qualitative interactional study, based on video recordings in British residential homes to explore the way in which choices are offered to individuals with ID in everyday situations in some residential homes in the UK. They identified some of the challenges that arose in offering choices and decision making opportunities to people with ID and reported six conversational practices that staff use to do this. Antaki et al. outlined the unwanted consequences of these practices and concluded that institutional processes and procedures to elicit clear and decisive choices may actually produce the opposite (p.1165).

Suto and her colleagues undertook a number of studies within the UK exploring DMC for people with ID, specifically focusing on financial decision making. These studies were part of a project on the management of finances by people with ID. (W. M. I. Suto, I. C. H. Clare, A. J. Holland, & P. C. Watson, 2005; W. M. Irenka Suto, I. C. H. Clare, A. J. Holland, & P. C. Watson, 2005; Suto, Clare, Holland, & Watson, 2006). At the outset of

their studies, they observed that contrary to the move towards a requirement to uphold an individual's autonomy with an accompanying inference that acting to the contrary would require considerable justification, there appeared to be a continued practice amongst assessors of a "status" approach with a therefore presumption of incapacity for adults with certain diagnoses. Their findings also indicated a relationship between cognitive functioning (IQ) and DMC but that such a relationship did not provide a full picture of DMC. They asserted that their findings of capacity with regard to financial decision making amongst some adults with an ID, demonstrated a rejection of the status approach to the assessment of DMC. They observed reasoning and understanding to be the most difficult of decision making abilities for all and suggested the need to consider social and emotional factors as having a role to play in DMC. They specifically raised the issue of decision making opportunities as a factor to be explored further, and in one study, W. M. Irenka Suto et al. (2005) reported results that indicated a relationship between decision making opportunities, the acquisition of basic financial skills and financial DMC for adults with intellectual disabilities. They recommended that a relationship between decision making opportunities and financial DMC for adults with intellectual disabilities be examined in future research.

Wong, Clare, Holland, Watson, & Gunn's (2000) UK study explored healthcare decision making regarding consent for a blood test amongst four groups, a group with mental health diagnoses, a group with ID, a group with dementia and a group with no diagnosis. The mean age of the group with ID was 36.8 years. Results indicated the DMC of the Dementia and ID groups to be significantly more impaired than the others. Capacity was observed to increase for individuals with ID, mental illness and no diagnosis as the decision making task was simplified but not for people with dementia. Wong et al. asserted therefore that these findings supported a functional approach "with capacity reflecting an

interaction between the individual's relevant abilities and the demands of the particular decision making task" (p.304).

Arguably though, as suggested by Jenkinson & Nelms (1994), a further ability regarding DMC needs to be considered: that of identifying that a decision needs to be made. In everyday life, individuals may not make decisions simply because they are unaware that the opportunity to do so exists.

Moye et al (2013) in their consideration of capacity in an aging society identified the need for a broadening of the research from its focus on individuals with neurodegenerative diseases or primary psychiatric disorders. They specifically identified the need to expand research studies to individuals with intellectual disabilities (p.167).

These studies indicated that it may be useful for future research to focus specifically on understanding and reasoning, considering in more depth the cognitive processes involved in these abilities, and the nature of the information that must be understood in order to make financial and other decisions.

There is also a need to identify factors affecting these particular abilities. As mentioned previously, the relationship between tested intellectual ability and decision-making abilities is not a perfect correlation.

Other factors that potentially may affect decision-making abilities include an individual's opportunities for, and past experiences of, decision making, as well as social and emotional influences. If such factors can be identified, then ways of enhancing them and thereby improving decision-making abilities may be developed. In turn, such improvements in financial decision-making may lead to greater autonomy for adults with ID.

This study:

There are three parts to this study, it examines possible relationships between DMC and

- I. Cognitive Functioning
- II. Preference and Participation in Decision Making
- III. Cognitive Reserve

An overview of cognitive functioning has been provided above. Therefore consideration is given below to previous research regarding Preference and Participation in Decision Making and Cognitive Reserve.

2.14 Preference and Participation in Decision Making

In the context of DMC there has been little research undertaken with regard to people's preference to participate in decision making.

No study has been identified that has examined any relationship between DMC and preference to participate in decision making but some studies have examined aspects of this. A small number of studies have examined preference to participate in decision making.

One study by Harvey, Kazis, & Lee (1999), was identified that explored for associations between decision-making preference, decision-making opportunity, and satisfaction with medical care. Data from the US Veterans Health Study, relating to a sample of 266 men who use Department of Veterans Affairs (VA) ambulatory health care services was examined. Results indicated that veterans with a high preference for involvement in decision-making and low provider-offered decision-making opportunities had significantly lower satisfaction with medical care compared to veterans with either low

preference for decision-making involvement with high or low opportunity, or those with a high decision-making preference and high decision-making opportunity.

Other studies identified explored either aspects of preference or aspects of participation. As can be seen below, very few of these were conducted in the context of an association with DMC but do contribute relevance.

Preference to Participate in Decision Making.

Finucane et al. (2005) included a measure of self reported attitude to decision delegation in a study undertaken by them and reviewed earlier in this section. Using a four point scale they reported that there was a higher preference for decision delegation amongst older adults when compared to younger adults but that this decision was not significant. Finucane et al. explored decision making in the areas of nutrition, finance and health, however the self report attitude measure referred to decision making generally rather than a specific area.

Levinson, Kao, Kuby & Thisted (2005) undertook a population based study to better understand public preferences for participation in decision making. The study was conducted in the US as part of the General Social Survey, a population-based survey of a fully representative sample of English-speaking adults (N = 2,765; Mean age, years (SD) 46.3, (17.4)). Three questionnaire items exploring preference about decision making were designed and included. All three questions referred to decision making with specific regard to health. The authors reported that nearly all participants (96%) preferred to be offered choices and asked their opinion; half (52%) preferred to leave final decision to Doctors; 44% preferred to rely on doctors for medical knowledge than to seek out information themselves and that preferences for an active role in decision making increased with age up to 45 years but then declined. By age 85, preferences had shifted towards doctor directed

decision making. The authors concluded that doctors needed accurate information regarding patient's preference at the outset.

In UK study undertaken regarding DMC and medical treatment and admission, Maxim et al (2009) explored decision making preference with older psychiatric patients (N=99). Participants were asked an open ended question about preference to make decisions, results for the group overall indicated that 51.5% wanted a doctor to make decisions regarding treatment and 37.4% wanted a doctor to make decisions regarding admission. Responses from participants with DMC indicated that 66% wanted a doctor to make decisions regarding treatment and 58% wanted a doctor to make decisions regarding admission. Of the responses from participants without DMC, 46% did not indicate who they wanted to make decisions re treatment and 47% did not indicate who they wanted to make decisions re admission.

In a report on a survey undertaken to assess the need for DMC education amongst clinicians, Shreve-Neiger et al. (2008) in their study regarding the need for DMC education in hospital and residential settings, considered previous research into individuals preference to participate in decision making. They noted findings by Hirschman, Xie, Feudtner, & Karlawish (2004) that older adults with AD wanted to participate in decision making for as long as possible and findings also by Su and Kjervik (2005) that many older adults indicated that they wanted to defer to doctors and families regarding medical decisions if they can no longer express their own wishes. This research was also specific to decision making regarding health.

Following a recommendation by the Council of Europe, a study was undertaken to examine public preferences for self-involvement in end-of-life care decision-making and to identify associated factors (Daveson et al., 2013). The study was a population based survey of 9,344 adults in seven EU countries (England, Belgium, Germany, the Netherlands,

Portugal, Spain and Italy). Individuals from Republic of Ireland did not participate. The survey enquired of participants with regard to both capacity and incapacity scenarios and concluded that self-involvement in decision-making is important to the European public. The results demonstrated that 74% preferred self-involvement when capable, with a smaller majority (56%) preferring no self-involvement if incapable. Interestingly for participants from England and Germany, only 39% and 17% respectively expressed a preference for no self-involvement in decision-making if incapable. The study identified four factors associated with self-involvement across both capable and incapable scenarios; they were younger-middle age, female gender, higher education attainment and a valuing of quality over quantity of life or both equally. In this context the study noted findings from research previously conducted with people in Canada that demonstrated that preference for self-involvement in decision-making may decline with older age. This European survey was limited to healthcare decision-making and was conducted via a land line telephone. With regard to the latter the authors note the potential for participant bias towards older people who are more likely to have a landline and to be at home during the day.

Participation in Decision Making.

In the context of DMC there has been little research undertaken with regard to people's participation in decision making. One study was identified that has examined specifically for a relationship between DMC (W. M. Irenka Suto et al., 2005) and participation in decision making, other studies were identified that have examined aspects of this.

A study undertaken by Hirschman et al. (2004) exploring how the role of a patient with dementia changes over time with regard to their participation in decision making observed that the majority of caregivers reported patients to still participate in decision

making. However as the severity of the dementia increased, the patient's participation decreased. As research indicated that elements of DMC (understanding, appreciation and reasoning) are impaired in "many mild stage and most moderate" stage patients, the authors recommended that future research would explore the correspondence of caregivers' reports with patients' level of DMC.

Findings from a focus group conducted with consumers of a mental health service revealed an overall dissatisfaction with information provided and the opportunity to participate in decision making (Happell, Manias, & Roper, 2004). The authors considered the failure to provide information and opportunities to participate in decision making to reflect a discriminatory attitude by Mental Health professionals and reported that in discussing the 'acknowledgement and recognition of consumers', the participants described their credibility as affected by the diagnosis of mental illness, meaning that their opinions and requests for information were frequently dismissed as symptomatic of mental illness rather than accepted as a legitimate claim for knowledge. Huby, Brook, Thompson, & Tierney (2007) in their exploration of interprofessional practice and older patients participation in decision making with regard to discharge and treatment planning cautioned against the misinterpretation of patients apparent impassivity and lack of motivation to participate in decision making. They identified processes and procedures within organisations that prevented engagement and compromise decision making and the accommodation of patients concerns and priorities. They highlighted the importance of these concerns being addressed so as to enable patients to be meaningfully involved in decision making.

A very significant study with regard to participation in decision making and referenced earlier is that undertaken by W. M. Irenka Suto et al. (2005) as part of a UK project exploring financial decision making abilities amongst individuals with ID. These

results indicated a relationship between decision making opportunities, the acquisition of basic financial skills and financial DMC for adults with intellectual disabilities. The authors recommended that a relationship between decision making opportunities and financial DMC for adults with intellectual disabilities be examined in future research. Suto et al. (2007) suggested that one of the ways to explore decision making opportunities for individuals is to look at each part of a person's day and ask did the person make the decision or did someone else choose it (P.21).

A review of healthcare/medical decision making undertaken by Goldsmith et al. (2008) and outlined in an earlier section, reported a consensus amongst authors that there was a lack of decision making experience that affected decision making abilities amongst individuals with intellectual disabilities. The studies reviewed by Goldsmith et al. did not appear to explore a specific relationship between such experience and decision making abilities.

The impact of the lack of experience in decision making has been considered by some researchers in the context of similar decisions. Moye et al. (2005) posited that experience in decision making may result in individuals learning "rules" for those decisions that later simplifies cognitive demand resulting in an "automatic" style for decision making.

In seeking to account for the variances in the DMC of older persons, Finucane & Gullion (2010) in a US study reported on earlier, considered the contribution of heuristics and suggested that DM experience in similar decisions may aid the preservation of DMC for those or similar decisions. They posited that DMC may be preserved with age to the extent that decision tasks are routine and predictable. Therefore the knowledge and experience of older adults may make up for declines in cognitive abilities and allow their problem solving to be more automatised.

A small number of studies have examined the impact of increasing choices on decision-making. Wood et al. (2011) in their study referenced earlier, examined the impact DM performance across the lifespan, of increasing choice by increasing the number of options a person has. They reported that participants performed better with less choice versus more choice.

Choice is defined as the act of selecting between two or more options (Bambara, Ager, & Koger, 1994). As outlined earlier, making and expressing a choice is an integral element of DMC.

A body of research specifically focusing on choice and people with ID has been undertaken by various researchers. These studies have reported a number of observations regarding the importance of choice in the lives of people with ID. These include:

- It leads to personal satisfaction and quality of life;
- It prepares individuals for independence;
- It increases motivation to learn and
- It may prevent “problem behaviours”.

While the literature identifies that true independence requires autonomy – being in control, making decisions etc, it is its relationship to quality of life, learning and the prevention of challenging behaviour that has garnered the most interest in the work undertaken. Bambara & Koger (1996) referenced Bannerman et al’s succinct overview of choice capturing its significance for all. “Choice is primarily a quality-of-life variable. In addition, choice may result in many positive benefits for people with and without disabilities including increased participation in activities, better performance on tasks, and the prevention of problem behaviours" (p.3).

Making decisions is an important part of an individual's autonomy. Autonomy has been linked to quality of life and the prevention of challenging behaviour. Not having the opportunity to make decisions adversely impacts autonomy and may therefore have consequences for aspects of life. A presumption or a determination of impaired DMC can result in an individual not having the opportunity to make decisions. A number of authors identified experience of decision making and opportunity to participate in decision making as having the potential to impact DMC and to therefore require additional research (Finucane and Gullion, 2010; Goldsmith et al. 2008; Suto et al., 2005; Moye et al., 2005).

Cognitive Reserve

The purpose of this section is to provide an overview of the concept of Cognitive Reserve (CR). What it is, its origins, how it occurs and how it is measured, illustrated as appropriate by the findings of research previously undertaken.

The starting point to an understanding of cognitive reserve is an initial consideration of the concept of *Reserve*. A review of the literature with regard to reserve immediately identifies two frequently utilised terms *brain reserve* (structural) and *cognitive reserve* (functional) with both being hypothesised to discharge a similar protective function. These terms in the earlier literature were sometimes used interchangeably with unclear definitions. In more recent times, there appears to be greater clarity and more consistent use and referencing of them. This lack of clarity was highlighted by Stern (2002).

The concept of reserve has its origins in the frequent observations that the degree of clinical symptoms and functional deficits demonstrated were not always reflective of the amount of damage or injury nor severity of pathology being experienced by individuals with for example AD or brain injury.

An overview by Richards and Deary (2005) of structural and functional reserve provided a concise background to the evolution of the concept of reserve and offered clear definitions and distinctions between brain reserve and cognitive reserve. They described the brain reserve as a structural passive reserve that focused on the protective anatomical features such as brain size, neural density and synaptic connectivity. Functional active cognitive reserve emphasised efficiency of neural networks and active compensation by alternative or more extensive networks after challenge. The concept of reserve maintains that there are aspects of brain structure and function that can buffer the effects of neuropathology such that the greater the reserve, the more severe the pathology must be to cause functional impairment.

Richards and Deary (2005) demonstrated how reserve may be conceived as the sum of its lifetime input. In this context, reserve therefore provides an empirical yet general model of cognitive aging and development.

They highlighted a study by Stern et al. in 1992 that compared regional cerebral blood flow in three groups of patients with AD, matching them for clinical disease severity but with different levels of education (Richards & Deary, 2005). The findings demonstrated that patients with a higher level of education had a more severe parietotemporal perfusion deficit than those with lower education, suggesting that although not preventing the acquisition of AD, the higher level of education reflected a reserve that protected against its clinical expression. This provided an explanation for other findings previously reported that identified some individuals for who neuropathological features of AD had been identified post death at autopsy but who had not previously demonstrated clinical features of AD and had remained “cognitively spared”. Satz, Cole, Hardy, & Rassovsky (2011) observed that this was explored further by Katzman who reviewed evidence for the protective effect of education with regard to the prevalence and detection

of AD and then by Satz who formulated a theory of “brain reserve capacity” for the expression of acquired neural injury.

Richards and Deary (2005) posited that “in essence, the reserve concept maintains that there are aspects of brain structure and function that can buffer the effects of neuropathology such that the greater the reserve the more severe the pathology must be to cause functional impairment”, that is the clinical expression of a pathology such as AD may be mediated or subdued in a individual with a high level of reserve whereby another individual with a similar pathology but with lesser reserve will demonstrate greater clinical expression (p.617). They considered also what it meant to say that reserve “protects against functional consequences of neuropathology”. Whilst acknowledging that “function” can be associated with activities of daily living (ADLs), they asserted that the occurrence of the impairment of ADLs may be influenced by other factors such as availability of supports, clinical services, cultural norms etc and therefore ADL impairment should not have “too much emphasis”. Rather they argued that a more empirical approach would be to equate function with measured cognitive performance.

Allegri et al. (2010) defined CR as the ability to optimize performance through differential recruitment of brain networks, which may reflect the use of alternative cognitive strategies.

Stern (2011b) explained that the CR hypothesis emerged from the observation that there is not a direct relationship between the amount of brain changes or pathology and the cognitive or functional consequences of those brain changes. Stern spoke of people’s “susceptibility to pathology”. A review of the literature suggests that it may be more useful and more accurate to consider the concept of the CR hypothesis in the context of people’s susceptibility to the *impact* of pathology. Authors have asserted that the CR hypothesis does not posit that reserve protects individuals from the acquiring of pathology but rather

that reserve protects functioning from the effects of the pathology (Allegri et al. 2010;). Stern (2002) initially considered CR as being a process of *coping* with task demands by healthy individuals, reflecting an efficiency of processing through differential recruitment of brain networks perhaps reflecting the use of alternative cognitive strategies. He proposed at this earlier stage that the concept of CR should therefore be limited to the variability seen in “non brain damaged” individuals and that the concept of *compensation* is reserved to a specific response to brain damage. He reasoned that if observed compensation reflected a change induced by damage, it should therefore be considered as separate to CR. However his reasoning evolved as he later observed that there was amongst individuals, differences in abilities to cope with or compensate for pathology arising from individual differences in how tasks were processed in the brain. This he observed is posited by the CR hypothesis.

It is clear from the above that there is emerging consensus as to the definition of reserve and the distinguishing between brain reserve and cognitive reserve. Some researchers specifically focused on brain reserve and some on CR. Whilst acknowledging that the concept of reserve is inclusive of both brain reserve and CR, this dissertation has a specific focus on CR as theorised by Stern (2002) and Richards and Deary (2005). That is that CR provides a protective buffer for cognitive functioning from the adverse affects of pathology, injury and aging.

The above outlines what CR is and the theory behind it, but what does it look like? How do individuals acquire it and how do we measure it?

As outlined, CR refers to an individual’s capacity to adaptively use neural networks to compensate for increasing damage, Satz et al (2011) identified the use of indices such as crystallised intelligence & years of education to reflect this concept. Other researchers have hypothesised CR Markers/indices to include:

- Education Level
- Occupational attainment
- Cognitive & Leisure Activity
- Premorbid IQ
- Literacy
- Socioeconomic Status
- Gender
- Crystallised Intelligence
- Cognitive & Occupational Activity at age 40yrs
- Physical Activity

Researchers in the area have asserted that one or more of the above indices/markers reflect the CR capacity of an individual. As can be seen, CR is considered by most to be a capacity that a person acquires. A number of studies have been undertaken exploring these markers, including whether there was evidence that demonstrated each to be a marker. Another question that has arisen is the time at which CR is acquired by individuals. In this regard studies have explored childhood, early adulthood, mid life and present time in an attempt to ascertain if a specific point in life can be identified as to when this occurs.

The effect of education and occupation has been a significant focus by researchers. Stern (2002) referenced findings by himself, Teri and others in previous research that demonstrated a mediating effect by education and occupation on memory. Individuals with higher education and occupational attainment showed a more rapid decline in memory following their diagnosis compared to those with lower education and occupational

attainment. This Stern asserted, was consistent with the concept that CR mediated the cognitive impact of AD, but not its acquisition or progression; hence diagnosis occurred for individuals with higher education and occupational attainment at a more advanced stage of pathology, hence the more rapid decline in memory. This suggested that the protective effect of CR was at the initial stages. Stern observed that some normal aging studies had demonstrated more rapid cognitive decline in individuals with lower educational attainment. Studies also reported greater functional decline amongst individuals with lower educational attainment. Stern (2002) concluded that these findings suggested that CR assisted people to cope with age related changes. He therefore suggested that it was important to consider noncognitive outcomes that may be mediated by CR, such as changes in day to day functioning. Such functioning is assessed by measures of basic and instrumental activities of daily living (ADLs and IADLs respectively). There are other indices of day to day functioning, including for example vocational measures.

In one review, Valenzuela and Sachdev (2006) examined 22 articles reporting cohort studies of the effects of Education, Occupation, Premorbid IQ, Cognitive & Leisure Activity. They observed the following:

- 10 of 15 studies demonstrated a significant protective effect of education
- 9 of 12 studies demonstrated a protective effect of occupational attainment
- 2 of 2 studies demonstrated a protective effect of Premorbid IQ
- 6 of 6 demonstrated a protective effect of engaging in leisure activity

Other studies showed

- Risk of dementia increased in subjects with low education

- Risk of dementia increased in individuals with low lifetime occupational attainment
- Risk was greater for subjects with both low education and low lifetime occupational attainment

Later studies that focused specifically on education within normal aging demonstrated mixed results, including a Dutch longitudinal study by Van Dijk, Van Gerven, Van Boxtel, Van der Elst, & Jolles (2008) who followed a sample of 872 healthy individuals aged between 49- 81 years at baseline over a period of 6 years and tested them on three occasions with a broad range of neuropsychological tests. Results demonstrated education to have no significant effect on cognitive change over time. Whilst the study acknowledged limitations including the relatively short period of 6 years, test-retest effects and a low number of “old-old and higher educated individuals”, the authors concluded that together with the findings of several other longitudinal studies the extent of the presumed protective effect of higher education on cognitive decline in normal aging is questionable. They did note however that studies were continuing to report findings that higher educated individuals showed faster decline of cognitive functioning once they were diagnosed with AD, which was believed to be the result of these individuals being at a more advanced stage of neuropathology at diagnosis, compared with individuals with lower education, reflecting the protective effect of education with regard to the clinical expression of AD in its initial stages.

Cognitive activity during an individual’s lifetime is also considered to be a factor contributing to CR. A study undertaken by Wilson, Scherr, Schneider, Tang, & Bennett (2007) noted that a number of previous studies undertaken had observed that people who frequently engaged in mentally stimulating activities (cognitive activity) were less apt to develop AD or experience cognitive decline. This US study utilising data from the Rush

Memory and Aging Project, followed 700 individuals who underwent clinical evaluations including medical history, neurological examination, cognitive function testing and assessment of cognitive activity participation for up to 5 years. Retrospective information regarding cognitive activity participation was also collected at baseline. Over the 5 years, 90 participants developed AD. More frequent participation in cognitive activity was associated with reduced incidence of AD and Mild Cognitive Impairment (MCI). Wilson et al. reported that a cognitively inactive person was more likely to develop AD and MCI than a cognitively active person. A neuropathologic examination was conducted on all participants who died in which the four most common causes of dementia were quantified with particular emphasis on the brain regions that support memory and cognition. In considering the possibility that lower levels of cognitive activity may be an early expression of AD or MCI, the authors observed no association between these global or regional specific measures of neuropathology and levels of cognitive activity and referenced the relationship that has been evidenced to exist between olfactory dysfunction and Parkinson gait and the pathologic lesions associated with dementia. They noted that these have been evidenced to be early predictors of dementia.

In an overview of cognitive changes across the lifespan, Foster et al (2007) concluded that findings from recent research indicated that physical exercise appeared to ameliorate cognitive decline in the elderly. They were not as definitive with regard to the findings of more recent research regarding cognitive activity. They reported that the evidence was equivocal but concluded that cognitive training did no harm and may be helpful. However as noted by Stern (2011b) and others, later studies reported findings observing cognitive activity throughout adulthood (at age 40 and in late life) to be the strongest predictor of CR.

Further studies undertaken in recent years highlighted evidence that indicated positive beneficial impact of physical activity on a wide range of areas for individuals (C3 Collaborating for Health, 2011).

The conclusions by Foster et al (2007) regarding physical exercise were supported by a review conducted by C3 Collaborating for Health (2011) which highlighted findings by various researchers as to the benefits of physical activity on physical health. These findings reported benefits for many parts of the body including the heart, skeletal muscles, bones, blood (e.g. cholesterol levels), the immune system and the nervous system with reduction in many of the risk factors for Non Communicable Diseases (NCDs) – chronic diseases. Physical activity was thus reported to play a beneficial role in many diseases such as type 2 diabetes, heart disease and many cancers. The World Health Organisation estimates that physical activity is the fourth leading risk factor for global mortality and that physical inactivity is responsible for 6% of deaths globally (C3 Collaborating for Health, 2011).

The C3 Collaborating for Health review (2011) noted that evidence of the effect of physical activity on mental health was well documented and was growing fast. They observed specific benefits to mental health to include improved mood, reducing symptoms of stress, anger and depression, alleviating anxiety and slowing cognitive decline to be growing fast.

The C3 Collaborating for Health review (2011) reported that while most studies focused on adults, some research amongst adolescents demonstrated increased leisure time physical activity to be significantly associated with fewer depressive symptoms over a two year period and that physical activity accelerated learning by increasing cognitive processes such as memory functioning.

The research reviewed reported physical activity to also be of benefit amongst older people in maintaining mental health (C3 Collaborating for Health, 2011). One study reviewed by the authors demonstrated that women aged 70-81 years of age who engaged in the highest physical activity quintile had a 20% lower risk of cognitive decline, including tests of general cognition, verbal memory and attention. Some initial evidence demonstrated physical activity to slow the progression of AD; epidemiological studies suggested that exercise reduced the risk of PD, and regular physical activity was shown to improve the quality of life in PD patients and reduced their neurological symptoms. However the review noted that the evidence was limited on the exact cognitive processes. Overall with regard to the impact of physical activity on mental health, the review concluded that further studies exploring this impact were required.

As can be seen from the above a range of variables, education, social, occupation, physical, leisure and mental activity are considered to contribute to CR. As observed by Richards and Deary (2005) these are all variables that various previous studies have associated with cognitive ability and to who's temporal affects the Central Nervous System (CNS) is sensitive. Richards and Deary concluded that such studies supported observations by Rutter and Schaie that cognitive ability is capable of being augmented across the life course.

CR Hypotheses is put forward as one explanation for a mismatch between brain pathology and epidemiology/clinical presentation and posits that CR therefore buffers the effects of brain damage on different clinical outcomes. In more recent times it is also hypothesised to have protective effect against normal cognitive deterioration associated with aging. This has resulted in the expansion of CR from being seen only to have a role in cases of pathology and injury to then being considered as also having a protective role in aging (Stern, 2002; Richards and Deary, 2005). Recognition of this is the concept of

reserve as a model of aging which was hypothesised by Richards and Deary. They described this as a *Life Course Model of Cognitive Reserve*. This model proposed at its centre, CR represented by peak pre-morbid cognitive ability, whose major proximal input comes from brain size and function (neural network density and complexity, processing capacity and efficiency). This is posited to be influenced by many factors across the life course; include genes, early social and material environment, occupational attainment, physical health, human behaviour and lifestyle. CR mediates the clinical expression of CNS lesions. These include white matter lesions, brain atrophy, plaques, tangles, vascular damage, metabolic/endocrine disease and injury, the accumulation of which is influenced by the same life factors influencing CR. Richards and Deary proposed that whilst most CNS lesions were associated with later life, their model was capable of application to earlier phases of the life course. For example, for a younger person experiencing a brain injury, it may apply to protection against the cognitive effects of such an injury. The model also accommodated and referenced other factors that may affect clinical expression such as personality, health service, cultural norms etc.

In agreeing with Stern's (2002) argument that an active approach to reserve is as equally viable for normal cognitive function as it is for explaining the clinical manifestations of the disease, Richards and Deary (2005) suggested that the reserve model be applied across the life course to cognitive development in childhood as well as to adulthood and later life, recognising that cognitive ability is modifiable at all stages of the life course.

In his commentary on the Special Series on Cognitive Reserve, Stern (2011b) identified understanding how reserve may be imparted and implemented as an "important piece of the puzzle" and concluded the commentary by articulating his hope that the CR

concept will continue to “frame research toward the important goal of preserving and improving cognition and functional abilities across the life span” (P.641).

Throughout the literature, there is increasing references to multiple factors as being indices or markers of CR and being contributors to its capacity. Phrases such as “sets of life experiences and brain variables” “cognitively active lifestyle” “influencing factors” “lifespan complex mental activity” “mentally stimulating activities” reflect the broadening views as to what imparts CR as opposed to a narrower focus on a singular factor such as education or occupational attainment ((Richards & Deary, 2005; Stern, 2011b; Valenzuela et al., 2012; Valenzuela & Sachdev, 2007; Wilson et al., 2007).

Various methods and instruments have been utilised by researchers to measure CR, these included literacy tests, NART, various occupational classifications, establishment of education levels, IQ assessments, Cognitive Activities Scale (CAS) (Stern, 2002; Wilson et al, 2002; Richards and Deary, 2005; Valenzuela & Sachdev, 2007).

A study by Valenzuela and Sachdev (2007) noted that there were limitations in the above ways that CR was being measured. These limitations included the practice of looking at these indices in isolation or at most in tandem; the scope and the range of mental activities measured were limited; there was also a tendency to assess indices in a “snapshot” fashion – taking only one aspect as the measure, for example considering only the highest level of education attained or the highest status occupation held. They also asserted that the psychometric properties of most of the data acquired in such assessments had not been tested or reported. Valenzuela and Sachdev therefore developed a comprehensive instrument for such measurement based on research to date, the Lifetime of Experience Questionnaire (LEQ) and undertook this study to validate it.

The LEQ was developed by Valenzuela and Sachdev (2007) to assess the indices of CR across the lifespan. These included all of the aforementioned indices/markers (i.e.

education, occupation, lifestyle activities etc). It is a comprehensive measure for providing a structured overview and a score for mental activity over life years. The authors reported it to therefore benefit from a high degree of “clinical face validity”.

The LEQ consists of 42 questions that are a mix of 5-point Likert Scale and free responses regarding frequency and intensity of specific activity participation. It is estimated to take approximately thirty minutes to complete. It was constructed around two major dimensions:

- i. Life- Stages (three – Young Adulthood; Mid Life and Late Life)
- ii. Specific (these are life stage specific e.g. education, occupation) versus Non Specific Mental Activity (e.g. family contact, physical activity, artistic pastimes)

It also provides a score per life period and does not merely focus on a specific time period in an individual’s life. The three identified life stages are the Young Adulthood years, (13 years to 30 years) the Mid Life years (30 to 65 or until retirement) and the Late Life years (65years onwards or retirement until present date). Each has 33⅓ % weighting towards total LEQ score. Valenzuela & Sachdev’s (2007) Australian study recruited 103 healthy volunteers who underwent comprehensive neuropsychological assessment, medical review, psychiatric and psychosocial interview and magnetic resonance imaging (MRI) with each of these (except MRI) being repeated 12 and 18 months later. 96 participants were available for follow up. The LEQ was posted out to all 103 participants for completion; 86 were returned, of these 7 were inadequately completed and were excluded leaving a sample of 79. The study found the LEQ to be consistent, coherent and to discriminate between individuals with high and low mental activity levels. Individuals with higher LEQ scores showed less cognitive decline over 18 months. Valenzuela and Sachdev

therefore concluded the LEQ to be a reliable and valid instrument for assessing complex lifespan mental activity which is protective against cognitive decline.

Whilst no study directly exploring for an association between DMC and CR was identified, some studies that explored for a relationship between DMC and factors that are considered to be one of the indices of CR. For example, Finucane et al (2010) reported that individuals with lower crystallised intelligence or poorer performance on other cognitive abilities tended to exhibit poorer performance on DMC measures. Increasing age also was reported to signify poorer performance. These measures are considered by some to be indices of CR.

Porrino et al (2015) undertook a study exploring the use of MacCAT-T to support clinical evaluations with regard to informed consent for older medical patients in an Italian hospital over a two month period. In the course of the study the authors explored if education was associated with understanding, an element of decision making ability. Education is a factor considered to be one of the indices of CR. The authors used education level as a measure of education. The authors reported that no significant relationship between education level and understanding was observed.

Summary and Study Rationale

DMC is of considerable significance for all individuals. It is at the heart of an individual's autonomy and permeates all facets of living. There is increasing demand for DMC assessments amongst older adults. Demographic changes are expected to increase further these demands (Demakis, 2013; Dunn & Alici, 2013; Moye et al., 2013; Gross, 2017).

Increasingly the DMC of older adults can be queried. This can arise for a myriad of reasons including where an individual has a diagnosis of a medical, neurological,

psychiatric disorder or be simply aging. Each of these conditions has potential for an adverse impact on the cognitive skills that underpin the elements of DMC.

DMC is a multifaceted and dynamic concept. In recent times much consideration has been given to the adverse impact on it by aging and the associated decline in cognitive functioning. Aspects of cognitive functioning underpin elements of DMC, information processing speed, memory and executive functioning have been specifically identified as having an association with the elements of DMC (References). These cognitive abilities have been demonstrated to deteriorate with age.

Key findings and observations from previous studies exploring DMC and CR, are outlined as follows:

- Poorer DMC has been observed in older adults when compared to younger adults
- Older adults who demonstrated poorer DMC displayed poorer performance in functioning in the cognitive skills associated with elements of DMC.
- Variances have been reported in older adults DMC that were initially hypothesised to be attributed to be an effect of aging, either a direct effect on DMC or indirectly as a result of the adverse impact of age related decline on cognitive abilities underpinning elements of DMC (Finucane et al., 2005; Smyer, 2007; Finucane & Gullion, 2010; Henninger et al., 2010; Moye et al., 2013).
- Seminal work conducted by Finucane et al. (2005) through the Person- Task Fit Model, posited that age related changes be interpreted with reference to the developmental changes of the individual and the impact of this then for the match between their characteristics and the demands of the decision task. They suggested that this may mean that “age-related declines in STM or processing capacity may be compensated for somehow” (p.80). They concluded that more research

demonstrating the independent contribution(s) would help to clarify what is driving the DMC variance in older adults.

- Moye et al. (2013) observed variability in the rate and nature of age related cognitive decline in affected cognitive domains for each individual and thereby concluded “thus each person has a unique constellation of cognitive strengths and deficits that contribute collectively to their functional abilities” (p.162).
- Variances in general functioning and clinical presentation of individuals with similar levels of pathology have been previously observed (Stern, 2002; Richards & Deary, 2002; Satz et al., 2011) and resulted in the theory being proposed that adverse presentation or clinical expression of the impact of pathology or injury on functioning was mediated or ameliorated by Cognitive Reserve (CR).
- Researchers hypothesised that CR not only provided a buffer for cognitive functioning from the adverse affects of pathology and injury but that it could be applied similarly to the effects of normal aging. They suggested that CR thus had a protective affect against normal deterioration associated with aging and provided a protective buffer against the adverse impact of age related cognitive decline (Richards & Deary, 2005; Richards et al., 2007; Stern, 2002, 2007, 2009, 2011; Tucker & Stern, 2011).
- A significant development in the theory of CR was the model of aging proposed by Richards & Deary (2005) *The Life Course Model*. This not a model of DMC, but it described, articulated and operationalises a number of constructs that appear to fit with DMC. It accommodated a broader range of contributors to CR and posited that influencing factors not only determined cognitive ability but were also capable of augmenting ability (or protecting it from decline) over time.

Previous studies exploring DMC, identified a number of gaps in our knowledge and understanding of capacity. These have included the following:

- Variances have been reported in DMC of older adults that have not yet been accounted for.
- There have been relatively few studies undertaken internationally examining capacity issues in older adults across varying diagnoses and functioning.
- Of those studies that have been undertaken, most have focused on older adults with age related disorders, for example AD, Mild Cognitive Impairment. The need for additional DMC research to be extended to other groupings of older adults, for example, older adults with ID, older adults with mental health issues, older adults with ABI has been highlighted (Moberg & Rick, 2008; Moye et al., 2013).
- Subjective” factors have been posited to contribute “to DMC, but these have not yet been clearly delineated (Finucane et al., 2005; Eyler & Jeste, 2006; Moberg & Rick, 2008; Finucane & Gullion, 2010; Moye et al., 2013). Moberg and Rick “subjective aspects, the ‘non cognitive’ contributions to capacity and consent” and the guidance required from future research regard the assessment of such (p.411-412).
- A number of authors have identified the experience of decision making, including an individual’s opportunity to participate in decision making, as a factor requiring additional research in the context of DMC (Goldsmith et al., 2008; Suto et al., 2005). No Specifically study exploring DMC for older adults and participation in decision making has been identified.

- Within the area of DMC, researchers have explored relationships between DMC and differing variables including education and experience, some of which have been identified as contributors to CR (Finucane et al., 2005; Porrino et al. 2013; Eyler & Jeste, 2006). However no study has been identified that has specifically explored for a relationship between DMC and CR.

Elements of DMC have been demonstrated to have an association with those cognitive abilities posited to be buffered from adverse impact by CR and to have associations with variables identified as CR contributors. The question therefore arises that if CR ameliorates the adverse impacts of aging on cognitive capabilities, does this then protect against DMC declines and is it therefore reflected in DMC variances?

This study seeks to explore those elements and their associations in the context of Richard and Deary's Life Course Model of Cognitive Reserve and Finucane et al.'s (2005) Person-Task Fit Model. Considering the role of CR, from the perspective of providing a buffer that protects cognitive functioning from the adverse impact of aging, pathology and injury, may provide an opportunity to expand Finucane et al.'s (2005) Person-Task Fit theory. This theory, in the context of the individual and his/her characteristics may also be further informed by exploration of an association between DMC and an individual's participation in decision making. An association between DMC and either CR or participation in decision making may thus contribute to a model seeking to account for DMC variance.

Thus the purpose of this study was to explore whether factors not previously so examined, would demonstrate a relationship to elements of DMC within an older adult group of varying diagnoses and functioning.

Specifically the study seeks to examine the following questions:

- a. Is there a relationship between elements of DMC and cognitive functioning?
- b. Is there a relationship between elements of DMC and an individual's preference to participate in Decision Making?
- c. Is there a relationship between elements of DMC and an individual's opportunity to participate in Decision Making?
- d. Is there a relationship between elements of DMC and CR?

Cognitive Reserve and preference and participation in decision making have been identified for two reasons; they have not previously been explored in the context of DMC and secondly, they are factors that if identified as related to DMC, may contribute to the further development of DMC theory and may have the potential to be supported and enhanced and therefore positively impact on the maintenance of and an individual's capacity to make decisions for themselves.

The overall hypotheses for this study are:

Hypothesis One – A relationship will be indicated between elements of DMC and Cognitive Factors.

Hypothesis Two – A relationship will be indicated between elements of DMC and CR Markers.

Hypothesis Three:

- i. A relationship will be indicated between elements of DMC and an individual's preference to participate in Decision Making
- ii. A relationship will be indicated between elements of DMC and an individual's participation in Decision Making

3. Methodology

Ethical Approval and Issues

This study was granted ethical approval by School of Psychology Research Ethics Committee, Trinity College Dublin, Dublin, Ireland in 2014 (Ethics Approval Letter, Appendix A,).

The inclusion as research participants of adults with impaired functioning and thereby increased possibility of impaired DMC has generated much discussion, debate and ethical concern. Therefore in accordance with best practice and guidance, an “ethically appropriate consent process” was developed (Dunn & Alici, 2013). This required maintaining a balance between a respect for the autonomy of individuals and a regard for their well being and any vulnerabilities.

Sessions were undertaken at a time, date and venue most convenient to each participant. Awareness of the number of measures being sought, the “burden” of engagement and the time commitment, resulted in individuals with later stage dementia not being sought to participate.

Participants

Thirty Two participants were recruited via contact with Day and Residential Centres, Active Retirement Groups, General Practitioners (GPs), Community Groups and word of mouth (posters etc.). This entailed corresponding, meeting and linking in with “gatekeepers”, explaining the research, speaking at gatherings such as Active Retirement Groups, Day Centres and training events for caregivers etc.

Three participants became unwell and did not complete the research (one had completed one session, another had completed two sessions and a third had completed three sessions). Their illnesses were unrelated to the research and were related to ongoing

health issues and a viral infection). Another individual was scheduled to participate, however before commencing s/he had a fall & required surgery. Following the completion of data collection and the commencement of data analysis, the researcher was also contacted by a few other prospective participants seeking to take part. Full data were collected for 29 participants. No participant was paid to take part.

There were thus 29 participants in total for whom full data were collected. They were aged between 56 years and 90 years, with mean age of 73.8 (SD = 9.6). There were 16 Females and 13 Males.

Data collection took place at a location convenient to the participant.

3.01 Group One. (Older adults at lower risk of impaired decision making capacity)

These participants were:

- 55 years or older
- Not previously diagnosed with Alzheimer Disease, Mild Cognitive Impairment or neurological disorder
- Not previously assessed with Intellectual Disability
- Have an ability to communicate verbally

There were 15 participants aged between 60 years and 87 years, with mean age of 75.7 years (SD = 8.6). There were 5 Males & 10 Females.

3.02 Group Two. (Older adults at increased risk of impaired decision making capacity)

These participants were:

- 55 years or older
- Had an ability to communicate verbally
- Were in receipt of services for individuals with Mild Intellectual Disability or to have previously been assessed as having a Mild Intellectual Disability.

or

- Had a diagnosis of dementia, neurological disorder or cognitive impairment
and/or
- Were in receipt of additional support in two areas of Instrumental Activities of Daily Living or through attending a Geriatric/Older Adult Day Centre

There were 14 participants aged between 56 years and 90 years, with mean age of 70.4 years (SD = 10.4). There were 8 Males & 6 Females.

An exclusion criterion for both Groups was:

- Undergoing treatment for any infection (following such treatment and recovery from infection, individuals may participate if they wish).

Materials and Procedures

The researcher endeavoured to keep an appropriate balance between respecting individuals' rights to make their own decisions, their rights to a presumption of their capacity to do so and yet to be aware ethically of their potential vulnerability. Consistent with recommendations of previous researchers, an ethically appropriate consent process was therefore developed (Dunn & Alici, 2013). A number of previous articles were read and considered so as to inform this process and the measures involved (Dye et al, 2004; Loue, 2004; National Federation, 2005; Eyler & Jeste, 2006; Iacona, 2006; Cameron &

Murphy, 2006; Mencap; Palmer et al, 2008; McDonald & Kidney, 2012; Dunn & Alici, 2013). Appropriate measures were taken including for example, development of an easy to read information sheet and consent form, extension of meeting invitations and information to interested family members and caregivers etc.

Participants were met individually to discuss the research project. They were also given an information sheet which was talked through in detail with them at an appropriate pace with their understanding being monitored. An easier to read information sheet and consent form was also designed to accompany the information being provided at this initial meeting and discussion with the researcher for Group Two (see Appendices B and C for Information Sheets and Consent Forms).

The researcher ensured that the invitation extended to the initial meeting was inclusive of a third party known and familiar to the individual and ensured that the individual was aware that a third party was welcome to attend any subsequent meeting that the individual may wish them to.

Information regarding the research was also provided for involved family members/advocates/key staff through the provision of Information Sheet and a telephone number to contact the researcher if they had any questions or queries. The researcher also met with relatives/staff and spoke by phone where requested to answer questions regarding the research and participation.

Whilst at the outset of this study capacity to consent to participate was presumed unless an individual was a ward of court or there was a formal guardianship in place, all consent was for protectionary purposes viewed as “assent”, treated as “process” consent and continuous attention was given by the researcher to the question of whether the participant appeared happy to continue to engage with the researcher and to proceed. All participants were informed at the outset and regularly reminded that they could take a

break, stop or withdraw from the study at any stage. They were monitored throughout for any verbal/nonverbal indicator that they wished to take a break, to stop or to withdraw. These measures were informed by studies undertaken by other researchers (Cameron & Murphy, 2007; McDonald & Kidney, 2012) and guidance issued by advocate organisations (Mencap; National Federation, 2005).

For information, no participant or prospective participant in this study was a ward of court or had a formal guardianship in place.

Each participant was requested to engage in two sessions in addition to the initial information session, the duration of each not to exceed one hour. If a session exceeded an hour, an additional session with the participant was scheduled with their agreement. Where individuals wished to shorten the duration of the session and instead attend additional sessions of shorter duration, this was also facilitated.

Including the initial information meeting therefore, participants were met on between two to five occasions each.

At the commencement of each session a mechanism for communicating a refreshment break, other break or cessation was agreed with each participant. These communication mechanisms were tailored to each individual.

The interviews took place in various locations, with the determining criteria being the convenience and comfort of the participant. All took place in a quiet room, locations varying between day centres, community centres and participants' homes. Some participants were accompanied at their request.

All participants were offered the opportunity for individual feedback in respect of their individual assessments and a copy of their cognitive assessment for their own records was offered to participants if they wished. An opportunity was provided to each participant

following data collection to discuss their experience of the study with the researcher. All participants were offered the opportunity to hear feedback of the overall study when completed.

3.03 Assessment of cognitive functioning and status.

The Wechsler Abbreviated Scales of Intelligence (WASI) was administered. This provided a measure of general cognitive functioning and meets the demand for a reliable, brief measure of intellectual ability in clinical, educational and research settings.

Specific Measures: There are four subtests with *T*-Scores being reported; *T*-Scores have a mean of 50 and a standard deviation of 10:

1. **Vocabulary** – Measure of Crystallised Intelligence
2. **Block Design** – Measure of Perceptual Organisation
3. **Similarities** – Measure of Verbal Concept Formation & Abstract Reasoning Ability
4. **Matrix Reasoning** – Measure of Nonverbal Fluid Reasoning

All are measures of general intelligence and tap various facets of intelligence such as verbal knowledge, visual information processing, spatial and nonverbal reasoning and crystallised and fluid intelligence.

Four additional measures are then yielded from the above subtests: – these reflect a scale with a mean of 100 and a standard deviation of 15

1. **FSIQ-4:** The four subtests compose the Full Scale and yield the Full Scale IQ.
2. **FSIQ-2:** is composed of the Vocabulary and the Matrix Reasoning Subtest.

3. **VIQ:** This is the Verbal IQ and composed of the Vocabulary and Similarities subtests.
4. **PIQ:** This is the Performance IQ and is composed of the Block Design and Matrix Reasoning subtests

The following reliability and validity measures are reported for the WASI with regard to adults (Psychological Corporation, 1999).

Reliability: At the subtest level, reliability was estimated from the item scores from a single administration. The subtest items were divided to form two half-tests. The variances of the two half tests were also compared to ensure that there was no significant statistical difference. The reliability coefficients of the subtest are the correlation between the total scores of the two half-tests corrected by the Spearman-Brown formula for the full subtest.

The reliability coefficients range from .90 to .98 for Vocabulary, from .84 to .96 for Similarities, from .90 to .94 for Block Design and from .88 to .96 for Matrix Reasoning, respectively. Average reliability coefficients are reported as .96 for VIQ, .96 for PIQ, .98 for FSIQ-4 and .96 for FSIQ-2. These results are consistent with those of the WAIS-III.

Test-retest stability coefficients are reported as .92 for FSIQ-4 and .88 for FSIQ-2.

In ascertaining Inter-rater reliability a special study was conducted to evaluate interscore reliability for the two verbal subtests as judgement was required in their scoring whereas the scoring criteria for Block Design and Matrix Reasoning is objective and simple resulting in interscorer agreements in the high .90s. This special study reported inter-rater reliability of .98 for Vocabulary and .99 for Similarities.

Validity: Concurrent validity was established with the following measures of intelligence: WISC–III, WAIS–III, and with Wechsler Individual Achievement Test (WIAT), a measure of achievement.

The Dementia Rating Scale – 2 (DRS-2) was also administered (Mattis, 2002).

This assesses cognitive status in adults (ages 56-105 years and older) and ascertains cognitive status to be *Intact, Mildly Impaired, Moderately Impaired or Severely Impaired*. It can be used to track changes in cognitive status over time. It yields measures for 5 Subtests.

1. Attention (**ATT**, 8 items)
2. Initiation/Perseveration (**I/P**, 11 items)
3. Construction (**Const**, 6 items)
4. Conceptualisation (**Concept**, 6 items)
5. Memory (**Mem**, 5 items)

It also yields a **DRS Total Score**. Each of these 6 scores can be age corrected (**AMSS**) and the DRS Total Score can be Age & Education corrected and yield the **DRS Total Score (AEMSS)**.

Scores of 14-18 (90 to above 99 percentile) – Above Average (Intact)

Scores of 11-13 (60-89 percentile) – Average (Intact)

Scores of 9-10 (29-59 percentile) – Below Average (Intact)

Scores of 6-8 (6-28 percentile) – Mildly Impaired

Scores of 4-5 (2-5 percentile) – Moderately Impaired

Scores of 2-3 (less than 1-1 percentile) – Severely Impaired

Reliability: Test-Retest Reliability: Coblenz et al studied the test-retest reliability for the DRS Total Score and subscales scores. The correlation coefficient for the DRS Total Score was .97 with subscale correlation coefficients ranging from .61 to .94 (Jurica et al,).

Internal Consistency: the split-half reliability of the DRS was examined by Gardner et al (1981). The split-half reliability co-efficient was .90. A t test yielded no significance difference between the two halves used in the study, thus indicating that the test was split into balanced halves. Vitaliano et al (1984) examined the internal consistency, alpha coefficients were calculated for each of the four subscales – Attention (.95), Initiation/Perseveration (.87), Conceptualization (.95) and Memory (.75).

Validity: The DRS displayed a significant correlation to the Mini-Mental State Examination (MMSE) ($r = .82$) (Salmon et al 1990). Correlations with the Wechsler Adult Intelligence Scale (WAIS) and the Paired Associate Learning (PAL) were calculated for a mixed sample of individuals aged 58 to 71 years (Coblenz et al., 1973). All healthy individuals with WAIS Full Scale IQs above 85 and normal PAL scores obtained DRS Total Scores above 140. A correlation of .75 was obtained between WAIS Full Scale IQ and DRS Total Score among the patient group. An IQ-DRS Total Score correlation of .86 was obtained for patients who had PAL scores 1 SD below the mean.

3.04 Demographics.

A semi-structured interview was undertaken to obtain demographic information and to establish participants' preference and opportunities for participation in decision making. A questionnaire was prepared by researcher to guide this semi structured interview to standardise the interviews and ensure uniformity (See Appendix E for

Questionnaire – Demographics, Preference and Participation in Decision Making).

Information gathered included the following:

- Age
- Handedness
- Marital Status (Single; Married; Separated/Divorced; Widowed)
- Residence (own home; residential service; supported living)
- Home Help/Home Staff (yes/no)
- Attending Day Centre (yes/no)
- Diagnosed Dementia/Cognitive Impairment/Parkinson's (yes/no)
- Intellectual Disability (yes/no)
- Present living arrangements (alone; with one other; with more than one other)
- Present Smoker (yes; no)
- Num of Cigarettes
- Previous Smoker (yes/no)
- If yes – Period Ceased
- If yes – Period Smoking
- If yes – Num of Cigarettes

3.05 Preference re decision making.

No study was identified that previously considered preference and participation with regard to Decision Making. Some studies were identified that included identifying individual's preference with regard to participating in decision making. Almost all of these focused exclusively on decision making regarding health. Most of these studies simply asked the participants to state their preferences. In one study Levinson et al utilised structured questions about patients' preferences (Levinson et al., 2005).

In this study, participants were asked to indicate their preference with regard to a number of statements about situations involving every day decision making, Getting up; Eating; Money; Television & Illness. These statements were derived from those utilised in a Levinson et al's study of patient preference (Appendix D).

Participants' preference with regard to participation in decision making was measured on eleven items reflecting every day decision making, Getting up; Eating; Money; Television & Illness, e.g. "I prefer staff/other to decide what I eat" (See Appendix E for Questionnaire – Demographics, Preference and Participation in Decision Making).

Each was rated on a six point scale (1 = Strongly Disagree, 2 = Moderately Disagree, 3 = Slightly Disagree, 4 = Slightly Agree, 5 = Moderately Agree, 6 = Strongly Agree). An index of preference towards participation in decision making was calculated by summing across the eleven items (range = 11 – 66) after reverse coding some items so that a high score indicated a strong preference for participation in decision making.

Measures:

- Preference re Participation in Decision Making – Total (range = 11 – 66)
- Getting up (range = 2 – 12)

- Eating (range = 2 – 12)
- Money (range = 2 – 12)
- Television (range = 2 – 12)
- Illness (range = 3 – 18)

3.06 Participation in Decision Making

A semi structured interview guided by a questionnaire provided an estimate of self reported participation in decision making

No study was identified that previously considered preference and participation with regard to Decision Making. Suto et al (2006) looked at opportunities for individuals with intellectual disability to participate in decision making through the use of the Choice Questionnaire. This questionnaire was developed by Stancliffe (1999) to explore choice for individuals with intellectual disability. Suto et al (2007) suggested that one of the ways to explore decision making opportunities for individuals is to look at part of a person's day and ask did the person make the decision or did someone else choose it. They commented that utilising a standardised questionnaire such as The Choice Questionnaire was useful if all participants were similar in population, for example all participants had an intellectual disability.

For this study parts of the day reflecting everyday decision making for participants were identified and participants were asked if they had decided, if they had help deciding or if someone else had decided. These questions were derived from similar utilised in Section 2 of National Core Indicators – National Consumer Survey (US Survey) (Appendix D).

To measure an individual's reported participation in everyday decision making, fourteen items reflecting everyday decisions were administered (e.g. "Who decides what you wear?").

- Daily Schedule (5 multiple choice questions + 1 open ended question);
- Eating (2 multiple choice questions);
- Money (1 multiple choice question);
- Personal Appearance (3 questions – 2 multiple choice question + 1 yes/no) and
- Television (2 questions – 1 multiple choice question + 1 yes/no).

There were four possible responses to each multiple choice question scored as follows:

3 = Person Decides, 2 = Person has help deciding, 1 = Someone else decides, 0 = Don't Know, no response, unclear response (range = 0 – 33),

The higher the score the higher the level of participation reported by the individual in everyday decision making.

An additional two items specifically explored an individual's participation in deciding their key worker and who helps at home. There were also Yes/No questions with regard to watching TV and Getting Hair Cut. There was an open ended question with regard to what s/he did during the day (See Appendix E for Questionnaire – Demographics, Preference and Participation in Decision Making).

3.07 Assessment of Cognitive Reserve.

The Lifetime of Experiences Questionnaire (LEQ) (Valenzuela & Sachdev 2007) was administered (see Appendix F Lifetime of Experiences Questionnaire (LEQ)). This is an instrument for assessing complex lifespan mental activity across life stages which is protective against cognitive decline and provides a measure of CR. It is a comprehensive measure that involves a structured overview and yields a score for mental activity over life years. It also provides a score for each life period and does not merely focus on a specific time period in an individual's life. There are three identified life periods, the Young Adulthood years, (13 years to 30 years) the Mid Life years (30 to 65 or until retirement) and the Late Life years (65years onwards or retirement until present date). As such it yields a range of information, categorising each into a "Stage Specific" subscore and a "Non Stage Specific" subscore for each of the three life periods. The Young Adulthood years Stage Specific subsection focuses on education, the Mid Life years Specific Stage subsection focuses on occupation and working life. Where individuals continued on or went back to education in mid life there is an "Education Bonus", similarly this is available in Late Life where individuals continued or went back to formal education. Likewise if an individual continued to work after 65 years of age, there is a "Work Bonus" available in Late Life Subsection to reflect this. There is also flexibility where someone avails of early retirement and engages in activities associated with Late Life before the age of 65, and a score to reflect this activity can be derived to yield a present or late life score.

Life Stages subscales.

- **Total LEQ**
- Young Adulthood stage specific
- Young Adulthood non-stage specific

- **Young Adult Subscore**
- Mid Life stage specific
- Mid Life non-stage specific
- Mid Life Education Bonus
- **Mid Life Subscore**
- Late Life stage specific
- Late Life non-stage specific
- Late Life Education Bonus
- **Late Life Subscore**

Reliability: Test-Retest Reliability: $r = .98$. Internal Consistency: alpha coefficients were calculated for Total LEQ and each of the LEQ Life Stages subscales.

- Total LEQ (.66),
- Young Adulthood stage specific (.43) Young Adulthood non-stage specific (.78)
- Mid Life stage specific (.78) Mid Life non-stage specific (.58)
- Late Life stage specific (.84) Late Life non-stage specific (.63)

Validity: addressed in three ways. First Item Response Theory (IRT) was used to establish that the items were generally able to discriminate between individuals with high and low complex mental activity with respect to test variance (Information function). Concurrent validity was demonstrated by positive correlation with a reconstructed version of Cognitive Activity Scales (CAS). A positive relationship between total LEQ and cognitive change was found and noted to be insensitive to exclusion of outlier data. Life-

stage subscores showed a similar relationship with cognitive decline as the total LEQ score. The LEQ total score therefore represent a useful approximation of the neuro-cognitive brain-reserve construct.

3.08 Assessment of elements of decision making capacity.

The *Assessment of Capacity of Everyday Decision-Making (ACED)* was completed with all participants. The ACED provides individual specific assessments of decisional abilities needed for Instrumental Activities of Daily Living, including in the areas of healthcare and medication management, financial and money management and nutrition. It utilises a structured interview format in each of these areas to assess the four elements of decision making: Understanding, Appreciation, Reasoning and Expressing a choice.

There are three readymade interview templates addressing common functional problems. These templates provide prespecified text. At selected places there are spaces to fill in specifics about the patient's functional problem and options to manage that problem. A Blank template is available to adapt for other difficulties. Information is presented in short blocks to individuals; questions are then put to person to establish their understanding of the problem, the options, the advantages, the disadvantages; their appreciation of the options; their comparative reasoning, consequential reasoning. They are then asked to express a choice and logical consistency of their reasoning is explored. Individuals are provided with a summary sheet of information for their use if required. This is intended to address the potential for short term memory difficulties (See Appendix G Assessment of Everyday Decision Making (ACED) – Templates/Forms).

A particularly useful aspect of the ACED for clinician is that it provides for the scoring of the interview if the clinician so wishes. Each of the individual's responses are scored on a 0 – 2 scale, where a score of "0" indicates a wholly inaccurate answer, a score of "1" indicates a partially correct or vague answer and a score of "2" indicates a complete,

accurate answer. This provides also for the opportunity to derive not only an overall score but a specific score for each of the elements of decision making, if desired. A full outline of these measures is available (see Appendix H Assessment of Capacity of Everyday Decision-Making (ACED) – Measures Yielded).

For participants within Group Two, this was administered with regard to specific concerns or difficulties arising for them within the domains of Finance (Money Management) and Health (Medication Management). The ACED provides a summary sheet of information for participant's use if required in each of these domains. This is intended to address the potential for short term memory difficulties. The options available for consideration were also provided by the researcher in text form. For most participants within Group One it was administered similarly with regard either to specific concerns or difficulties arising for them within the domains of Finance (Money Management) and Health (Medication Management) or for someone that they were providing care to. For a small number who were neither experiencing such concerns or difficulties nor providing care to someone who was, it was administered with regard to common concerns that can arise within the domains of Finance (Money Management) and Health (Medication Management) for older adults.

Reliability: Good inter-reliability for each decision-making ability, with intraclass correlation coefficients of .72, .69 and .65 respectively for understanding, appreciation and reasoning.

Internal consistency: Cronbach alpha values of .92, .88 and .84 respectively for understanding, appreciation and reasoning.

Validity: Each ACED ability measure was associated with its corresponding measure on the MacCat-T:

- Appreciation, $r_s = 0.38$ ($p = 0.02$);
- Reasoning, $r_s = 0.50$ ($p = 0.001$);
- Understanding, $r_s = 0.63$ ($p = 0.001$);
- Expressing a choice, $r_s = 0.71$ ($p < 0.001$).

3.09 Physical Activity/Exercise.

Information regarding physical activity and exercise was gathered through the administration of the LEQ (outlined above) and information gathered in the semi-structured interview. Frequency and duration measures for Mild, Moderate and Vigorous activity were ascertained for present time (Late Life) and frequency measures for Mild, Moderate and Vigorous activity were ascertained for Mid Life and Early Adulthood.

Present:

1. Mild Frequency (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
2. Mild Duration
3. Moderate (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
4. Moderate Duration
5. Moderate Activity lasting 30 minutes or more (yes/no)
 - a. If yes frequency per week (5 or more; 3-4; 1-2; Don't Know)
6. Vigorous Frequency (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
7. Vigorous Duration

Mid Life:

1. Mild Frequency (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
2. Moderate (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
3. Vigorous Frequency (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)

Early Life:

1. Mild Frequency (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
2. Moderate (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)
3. Vigorous Frequency (Daily; Weekly; Fortnightly; Monthly; Less than Monthly; Never)

3.10 Data table.

A separate data table was compiled to reflect a number of observations throughout sessions, including

- The use of Information Sheet by Participants during everyday decision making assessment.
- References by participants to “Trust”, “Risk”, “Independence” and “Dignity/Control” during everyday decision making assessment.
- References to participation in research prompting them to think about planning for future in a way they had not previously etc.

- Feedback/comments re their experience of participating – reference to “enjoyed it”, “different/felt like brain was working”, “interesting”, “did not enjoy it”
- Request for feedback on personal basis re research
- Request for feedback on overall research

4. RESULTS

- **Section 1: Sociodemographic and Clinical Background – Overall and By Group**
- **Section 2: Assessment of Capacity of Everyday Decision-Making**
 - **Medication Management**
 - **Money Management**
 - **Other Factors Referenced by Participants in Course of Decision Making Assessment (ACED)**
 - **Investigation of Relationship between ACED (Medication Management) and ACED (Money Management)**
- **Section 3: Hypothesis One – A Relationship will be indicated between Elements of DMC and Cognitive Factors**
- **Section 4: Hypothesis Two – A Relationship will be indicated between Elements of DMC and Cognitive Reserve Markers.**
- **Section 5: Hypothesis Three –**
 - a. **A Relationship will be indicated between Elements of DMC and an Individual's Preference to Participate in Decision Making.**
 - b. **A Relationship will be indicated between Elements of DMC and an Individual's Participation in Decision Making.**

Statistical analysis:

Descriptive statistics were used to describe the characteristics of the participants in the study. Categorical data were described numerically using frequency and percentage (%) and graphically using bar charts. Continuous data were described using the mean (standard deviation, SD) or median (interquartile range, IQR) as appropriate and minimum and maximum. Box plots and Dot plots were used to describe the continuous data graphically.

Inferential statistics were undertaken to investigate the three hypotheses. For comparisons of continuous variables between the two groups (Group One and Group Two), one-way analysis of variance (ANOVA) was used for normally distributed data and the Kruskal-Wallis test was used for data that were not normally distributed. Fisher's exact test was used for comparisons of categorical variables between the three groups. The strength and direction of the relationship between two continuous variables was assessed using Spearman's rank correlation coefficient (r_s). Associations were considered very weak if $|r_s| < 0.10$, weak if $0.10 \leq |r_s| < 0.30$, moderate if $0.30 \leq |r_s| < 0.50$ and strong if $|r_s| \geq 0.50$ (Cohen, 1988).

All statistical analysis was performed using IBM SPSS Statistics version 22. Graphs were drawn using Stata version 13.0. All tests were two-sided and a $p\text{-value} < 0.05$ was considered to be statistically significant.

4.1: Sociodemographic and Clinical Background – Overall and By Group

4.1.1 All Participants

There were 29 participants in the study. The demographic characteristics of the participants are described in Table 4.1. The ages of the participants ranged from 56 to 90 years with a mean (SD) of 73.8(9.6) years. Over half (n=16, 55.2%) were female and almost all (n=28, 96.6%) were right-handed. Being in a relationship (married/partnership) was the most common marital status (n=13, 44.8%), followed by being widowed (n=7, 24.1%), single (n=7, 24.1%) and separated/divorced (n=2, 6.9%). The majority (n=23, 79.3%) lived in their own home with the remainder either in supported living (n=3, 10.3%) or a residential service (n=3, 10.3%). Almost 80% (n=23, 79.3%) lived with at least one other person. The majority (n=17, 58.6%) received home help or had home staff, while over one-third (n=11, 37.9%) attended a Day Centre. Four (13.8%) participants had a clinical diagnosis while seven (24.1%) had a mild intellectual disability. The majority of participants (n=15, 51.7%) were healthy and did not have a clinical diagnosis, intellectual disability or attend a day service and were not in receipt of additional support with the remainder either having a clinical diagnosis and/or attending a Day Centre (n=7, 24.1%) or having a diagnosis of a mild intellectual disability (n=7, 24.1%). Only one participant was a current smoker, smoking on average 10 cigarettes per day. Almost all participants (n=28, 96.6%) did not currently smoke – 17 never smoked and 11 were past smokers. For the past smokers, the number of cigarettes smoked per day ranged from 5 to 65 with a median (IQR) of 10(10 to 20) cigarettes. The time since smoking had ceased ranged from 10 to 57 years with a median (IQR) of 27(17 to 44) years and the period of smoking ranged from 7 to 40 years with a median (IQR) of 30(10 to 35) years.

Table 4.1. Demographic Characteristics of Participants (N=29)

	n (%) ¹
Age (years): mean(SD)	73.8 (9.6)
minimum to maximum	56 to 90
Gender	
Female	16 (55.2)
Male	13 (44.8)
Handedness	
Right Hand	28 (96.6)
Left Hand	1 (3.4)
Marital status	
Single	7 (24.1)
Married/Partnership	13 (44.8)
Separated/Divorced	2 (6.9)
Widowed	7 (24.1)
Residential situation	
Own Home	23 (79.3)
Supported Living/Community House	3 (10.3)
Residential Service/Nursing Home	3 (10.3)
Living Arrangements	
Alone	6 (20.7)
With one other	15 (51.7)
With more than one other	8 (27.6)
Home Help/Home Staff	
Yes	17 (58.6)
No	12 (41.4)
Attending Day Centre	
Yes	11 (37.9)
No	18 (62.1)
Clinical Diagnosis	
Yes	4 (13.8)
No	25 (86.2)
Mild Intellectual Disability Diagnosis	
Yes	7 (24.1)
No	22 (75.9)
Additional support	
No	15 (51.7)
Clinical diagnosis and/or attending Day Centre	7 (24.1)
Mild Intellectual Disability Diagnosis	7 (24.1)
Smoking status	
Current smoker	1 (3.4)
Previous smoker	11 (37.9)
Never smoker	17 (58.6)

¹unless otherwise stated

4.1.2. Prescribed Medication Usage – All Participants

25 of the 29 participants were taking prescribed medication. As Table 4.2 illustrates, 23 participants could not name the medication that they were prescribed, 1 participant could name some of the medications and 1 participant could name all of the medications that they were taking.

Table 4.2. Statistics for Use of Prescribed Medication (N=29)

Name Prescribed Medication	Frequency	Percent
Not Applicable	4	13.8
No	23	79.3
Can name some	1	3.4
Can name all	1	3.4
Total	29	100.0

As Table 4.3 demonstrates, 2 participants were unable to give any reason as to why they were taking medication, 14 could explain why that they were taking some of the medications but not all of them and 9 could explain why they were taking each of the medications that they were prescribed.

Table 4.3. Results for Participants' Explanations for Medication Use (N=29)

Reason for Medication	Frequency	Percent
Not Applicable	4	13.8
No	2	6.9
Person can say why to some	14	48.3
Person can say why to all	9	31.0
Total	29	100.0

4.1.3 Demographic Characteristics According to Group (2 Groups)

The demographic characteristics of the participants split by relevant group are described in Table 4.4. Participants within Group One did not have a clinical diagnosis, intellectual disability or attend a day service and were not in receipt of additional support for activities of daily living. They were more likely to be in a relationship, live in their own home and be a previous smoker compared to those within Group Two. They were also less likely to have help at home. Participants within Group One were also more likely to have been a smoker previously (73.3%). 4 of the 15 participants within Group One had never smoked, whereas 13 of the 14 (92.9%) participants within Group Two had never smoked.

Within Group Two, 4 of the 14 (28.6%) participants had a clinical diagnosis, 7 (50%) had an intellectual disability and 11 (78.6%) attended a day service and were in receipt of additional support for activities of daily living. Only 2 of the 14 (14.3%) participants were in a relationship. Whilst only 1 of the 15 (6.7%) participants within Group One lived alone, 5 of the 14 (35.7%) participants within Group Two did so,

Table 4.4. Demographic Characteristics of Participants by Group

	Group One (n=15)	Group Two (n=14)	p-value ²
	n (%) ¹	n (%) ¹	
Age (years): mean(SD)	77.1 (7.9)	70.4 (10.4)	0.059 ³
minimum to maximum	60 to 87	56 to 90	
Gender			0.272
Female	10 (66.7)	6 (42.9)	
Male	5 (33.3)	8 (57.1)	
Marital status ⁴			0.003
Single	0 (0.0)	7 (50.0)	
Married/Partnership	11 (73.3)	2 (14.3)	
Separated/Divorced	1 (6.7)	1 (7.1)	
Widowed	3 (20.0)	4 (28.6)	
Residential situation ⁵			0.006
Own Home	15 (100.0)	8 (57.1)	
Supported Living/Community	0 (0.0)	3 (21.4)	
Residential Service/Nursing	0 (0.0)	3 (21.4)	
Living Arrangements			0.046
Alone	1 (6.7)	5 (35.7)	
With one other	11 (73.3)	4 (28.6)	
With more than one other	3 (20.0)	5 (35.7)	
Smoking status			<0.001
Current smoker	0 (0.0)	1 (7.1)	
Previous smoker	11 (73.3)	0 (0.0)	
Never smoker	4 (26.7)	13 (92.9)	
Handedness			
Right Hand	14 (93.3)	14 (100.0)	
Left Hand	1 (6.7)	0 (0.0)	
Home Help/Home Staff			
Yes	6 (40.0)	11 (78.6)	
No	9 (60.0)	3 (21.4)	
Attending Day Centre			
Yes	0 (0.0)	11 (78.6)	
No	15 (100.0)	3 (21.4)	
Clinical Diagnosis			
Yes	0 (0.0)	4 (28.6)	
No	15 (100.0)	10 (71.4)	
Mild Intellectual Disability Diagnosis			
Yes	0 (0.0)	7 (50.0)	
No	15 (100.0)	7 (50.0)	

¹unless otherwise stated²from Fisher's exact test unless otherwise stated³from independent sample t-test⁴regrouped into 2 categories (in a relationship: yes/no) prior to performing the statistical test⁵regrouped into 2 categories (own home: yes/no) prior to performing the statistical test

4.2: Assessment of Capacity of Everyday Decision-Making

The median(IQR) is given in addition to the mean(SD) as the distribution of scores on the individual measures and overall measure are skewed and hence the median is a better measure of the centre of the data and the IQR is a better measure of the spread in the data.

4.2.1 Results of ACED (Medication Management)

4.2.1.1 All participants.

The distribution of scores for each decision making ability measure obtained during administration of the ACED for Medication Management are presented in Table 4.5 and Figure 4.1, while the distribution of total ACED scores is presented in Table 4.6 and Figure 4.2. For all measures, the majority of participants scored within the highest category indicating the participants to have good decision-making abilities. Almost all participants (n=27, 93.1%) used the Medication Management information sheet including the listing of options during the assessment. This is presented in Table 4.6.

Table 4.5. Performance of All Participants on ACED Measures of Decision Making**Abilities (Medication Management)¹ (N=29)**

	n (%)
Understanding (0-10) ²	
0	1 (3.4)
1-2	2 (6.9)
3-4	0 (0.0)
5-6	0 (0.0)
7-8	2 (6.9)
9-10	24 (82.8)
mean(SD)	8.8 (2.7)
median(IQR)	10 (9 to 10)
Appreciation (0-8) ²	
0	0 (0.0)
1-2	1 (3.4)
3-4	3 (10.3)
5-6	3 (10.3)
7-8	22 (75.9)
mean(SD)	6.9 (1.9)
median(IQR)	8 (6 to 8)
Reasoning (0-10) ²	
0	1 (3.4)
1-2	0 (0.0)
3-4	2 (6.9)
5-6	4 (13.8)
7-8	1 (3.4)
9-10	21 (72.4)
mean(SD)	8.2 (2.6)
median(IQR)	9 (6.5 to 10)
Express a Choice (0-2) ²	
0	1 (3.4)
1	2 (6.9)
2	26 (89.7)
mean(SD)	1.9 (0.4)
median(IQR)	2 (2 to 2)

¹higher score represents better performance on the ability measure²possible range

Figure 4.1. Distribution of Scores on Measures of Decision-Making Abilities in ACED (Medication Management) for All Participants, N=29.

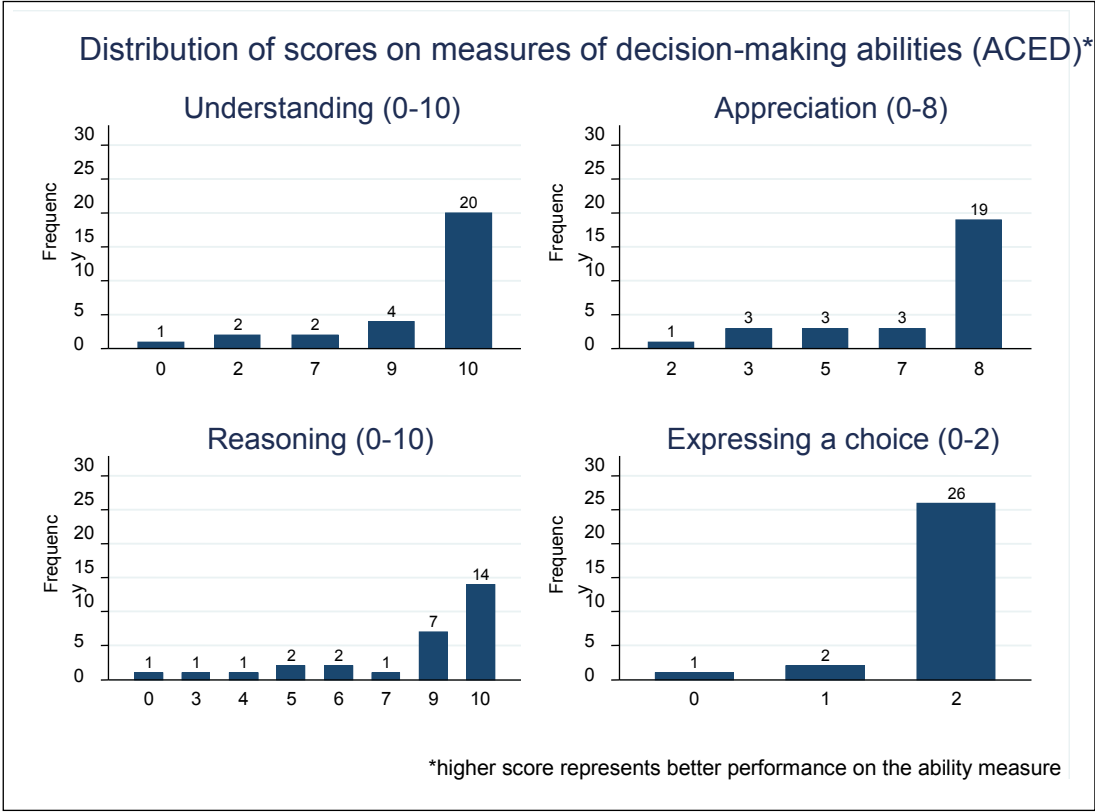


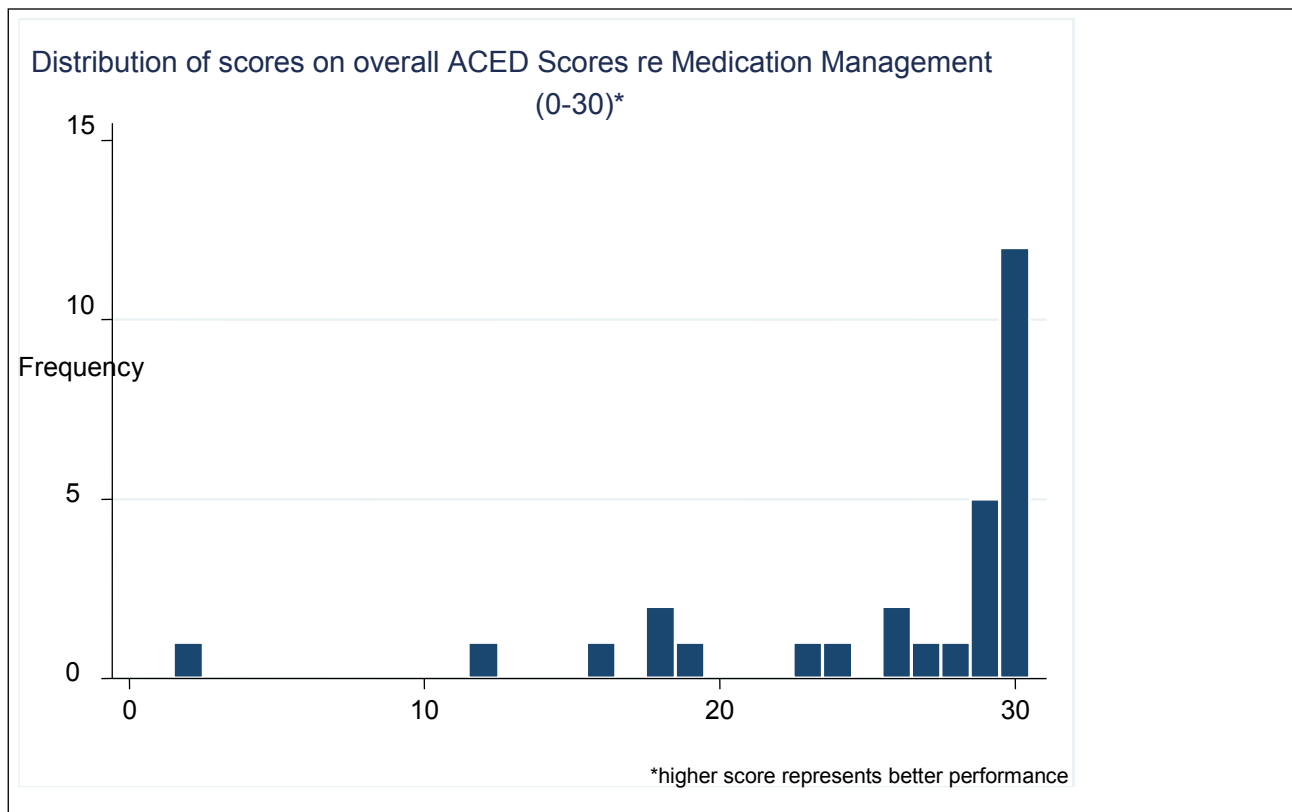
Table 4.6. Overall ACED Total Scores (Medication Management)¹ and Use of Information Sheet for All Participants (N=29)

	n (%)
Total score (0-30) ²	
0	0 (0.0)
1-5	1 (3.4)
6-10	0 (0.0)
11-15	1 (3.4)
16-20	4 (13.8)
21-25	2 (6.9)
26-30	21 (72.4)
mean(SD)	25.7 (6.8)
median(IQR)	29 (23.5 to 30)
Medication Management information sheet used by participant	
Yes	27 (93.1)
No	2 (6.9)

¹higher score represents better performance

²possible range

Figure 4.2. Distribution of Overall ACED Total Scores (Medication Management) for All Participants, N=29.



4.2.1.2 Results according to group (2 groups).

Distribution of ACED scores for the elements of everyday decision-making in Medication Management for each of the two groups is presented in Table 4.7. The distribution of scores for the overall ACED measure by group is presented in Figure 4.3.

A statistically significant difference was found between the two groups for both Appreciation ($p = 0.029$) and Reasoning ($p = < 0.001$) measures with the median scores higher in Group One (those who did not have a clinical diagnosis and who did not receive additional support).

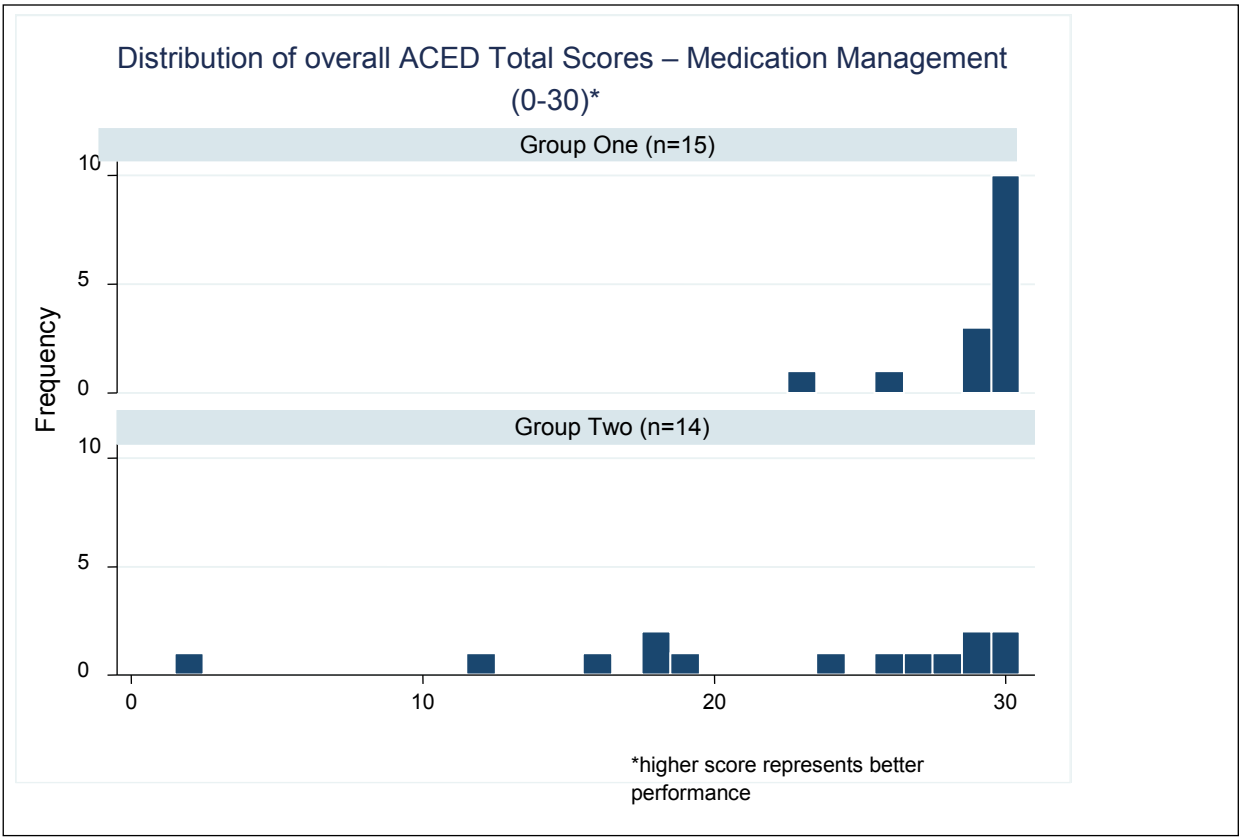
There was a statistically significant difference in the distribution of overall ACED Total Scores in the two groups ($p=0.001$) with the median score higher in Group One.

Table 4.7 Performance of Participants on Elements of Decision Making**(Medication Management)¹ by Group (2 Groups)**

	Group One (n=15)	Group Two (n=14)	p-value ³
	n (%)	n (%)	
Ability to understand (0-10) ²			
0	0 (0.0)	1 (7.1)	
1-2	0 (0.0)	2 (14.3)	
3-4	0 (0.0)	0 (0.0)	
5-6	0 (0.0)	0 (0.0)	
7-8	0 (0.0)	2 (14.3)	
9-10	15 (100)	9 (64.3)	
mean(SD)	9.9 (0.4)	7.6 (3.6)	
median(IQR)	10 (10 to 10)	9.5 (5.8 to 10)	0.057
Ability to appreciate (0-8) ²			
0	0 (0.0)	0 (0.0)	
1-2	0 (0.0)	1 (7.1)	
3-4	0 (0.0)	3 (21.4)	
5-6	1 (6.7)	2 (14.3)	
7-8	14 (93.3)	8 (57.1)	
mean(SD)	7.7 (0.8)	5.9 (2.3)	
median(IQR)	8 (8 to 8)	7 (3 to 8)	0.029
Ability to reason (0-10) ²			
0	0 (0.0)	1 (7.1)	
1-2	0 (0.0)	0 (0.0)	
3-4	0 (0.0)	2 (14.3)	
5-6	0 (0.0)	4 (28.6)	
7-8	1 (6.7)	0 (0.0)	
9-10	14 (93.3)	7 (50.0)	
mean(SD)	9.7 (0.8)	6.7 (3.0)	
median(IQR)	10 (10 to 10)	7.5 (4.8 to 9)	<0.001
Ability to express a choice (0-2) ²			
0	0 (0.0)	1 (7.1)	
1	1 (6.7)	1 (7.1)	
2	14 (93.3)	12 (85.7)	
mean(SD)	1.9 (0.3)	1.8 (0.6)	
median(IQR)	2 (2 to 2)	2 (2 to 2)	0.715
Total score (0-30) ²			
0	0 (0.0)	0 (0.0)	
1-5	0 (0.0)	1 (7.1)	
6-10	0 (0.0)	0 (0.0)	
11-15	0 (0.0)	1 (7.1)	
16-20	0 (0.0)	4 (28.6)	
21-25	1 (6.7)	1 (7.1)	
26-30	14 (93.3)	7 (50.0)	
mean(SD)	29.1 (2.0)	22.0 (8.2)	
median(IQR)	30 (29 to 30)	25 (17.5 to 29)	0.001

¹higher score represents better performance on the ability measure²possible range³from Mann-Whitney U test

Figure 4.3. Distribution of Overall ACED Total Scores re Medication Management by Group.



4.2.2 Results of ACED (Money Management)

4.2.2.1 All participants.

The distribution of scores for each decision making ability measure obtained during administration of the ACED for Money Management are presented in Table 4.8 and Figure 4.4, while the distribution of overall ACED scores for the measure is presented in Table 4.9 and Figure 4.5. For all measures, the majority of participants scored within the highest category. Almost all participants (n=27, 93.1%) used the Money Management information sheet including the listing of options during the assessments. This is presented in Table 4.9

**Table 4.8. Performance of All Participants on Measures of ACED¹ (Money Management),
(N=29)**

	n (%)
Understanding (0-10)²	
0	0 (0.0)
1-2	1 (3.4)
3-4	1 (3.4)
5-6	2 (6.9)
7-8	2 (6.9)
9-10	23 (79.3)
mean(SD)	9.0 (2.2)
median(IQR)	10 (9 to 10)
Appreciation (0-8)²	
0	0 (0.0)
1-2	1 (3.4)
3-4	2 (6.9)
5-6	3 (10.3)
7-8	23 (79.3)
mean(SD)	7.2 (1.6)
median(IQR)	8 (7 to 8)
Reasoning (0-10)²	
0	1 (3.4)
1-2	0 (0.0)
3-4	1 (3.4)
5-6	0 (0.0)
7-8	5 (17.2)
9-10	22 (75.9)
mean(SD)	8.8 (2.3)
median(IQR)	10 (8.5 to 10)
Express a choice (0-2)²	
0	1 (3.4)
1	1 (3.4)
2	27 (93.1)
mean(SD)	1.9 (0.4)
median(IQR)	2 (2 to 2)

¹higher score represents better performance on the ability measure

²possible range

**Figure 4.4. Distribution of ACED Scores (Money Management), for All Participants
N=29.**

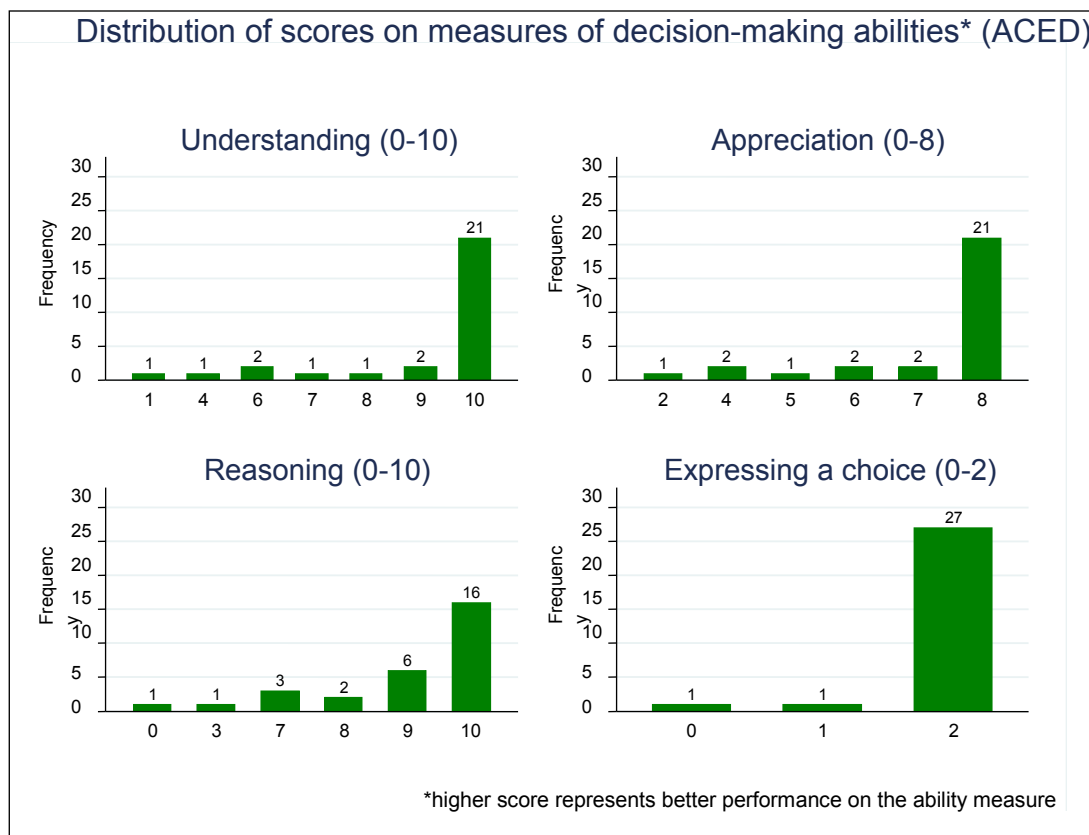


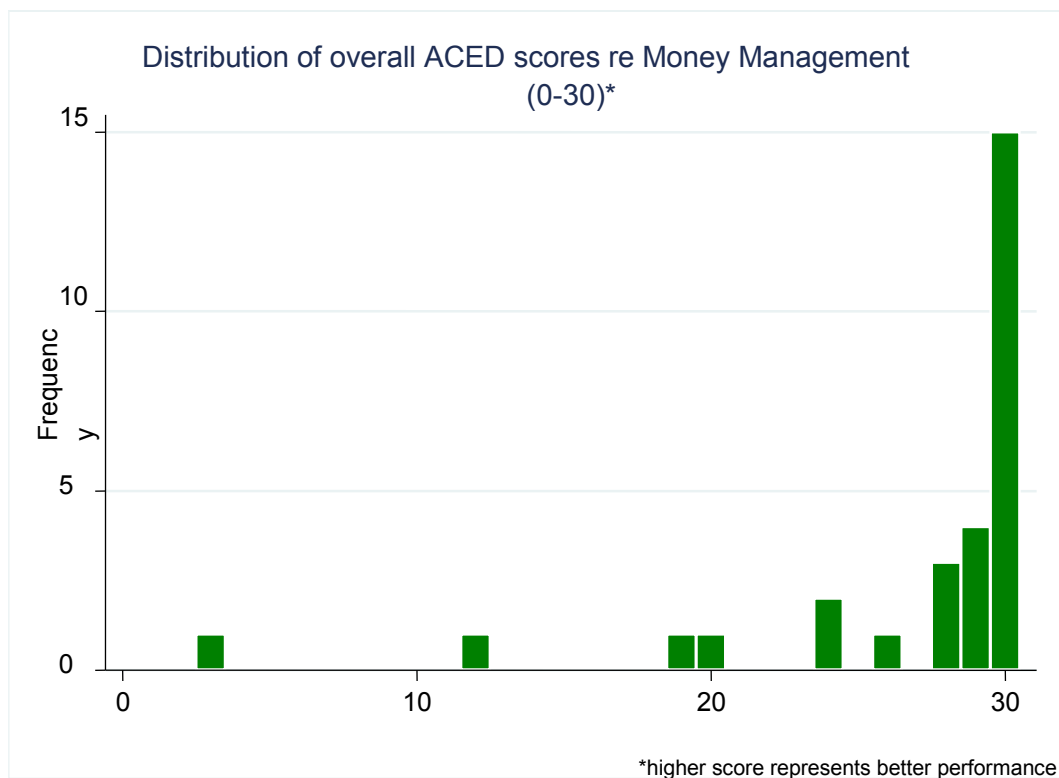
Table 4.9. Overall ACED Total Scores and Use of Information Sheet (Money Management) for All Participants (N=29)

	n (%)
Total score (0-30) ²	
0	0 (0.0)
1-5	1 (3.4)
6-10	0 (0.0)
11-15	1 (3.4)
16-20	2 (6.9)
21-25	2 (6.9)
26-30	23 (79.3)
mean(SD)	26.8 (6.2)
median(IQR)	30 (27 to 30)
Money Management information sheet used by participant	
Yes	27 (93.1)
No	2 (6.9)

¹higher score represents better performance

²possible range

Figure 4.5 Distribution of Overall ACED Total Scores (Money Management) for All Participants, N=29.



4.2.2.2 Results by group.

Distribution of ACED scores for the elements of everyday decision-making in Money Management and overall ACED Total Scores for each of the two groups is presented in Table 4.10. The distribution of overall ACED Total Scores for each group is presented in Figure 4.6.

For all measures, except expressing a choice ($p = 0.533$), a statistically significant difference was found between the two groups with the distribution of scores higher in for participants within Group One, i.e. healthy older adults, those who did not have a clinical diagnosis, intellectual disability or attend a day centre and/or be in receipt of additional support for activities of daily living ($p < 0.05$ for all). There was a statistically significant

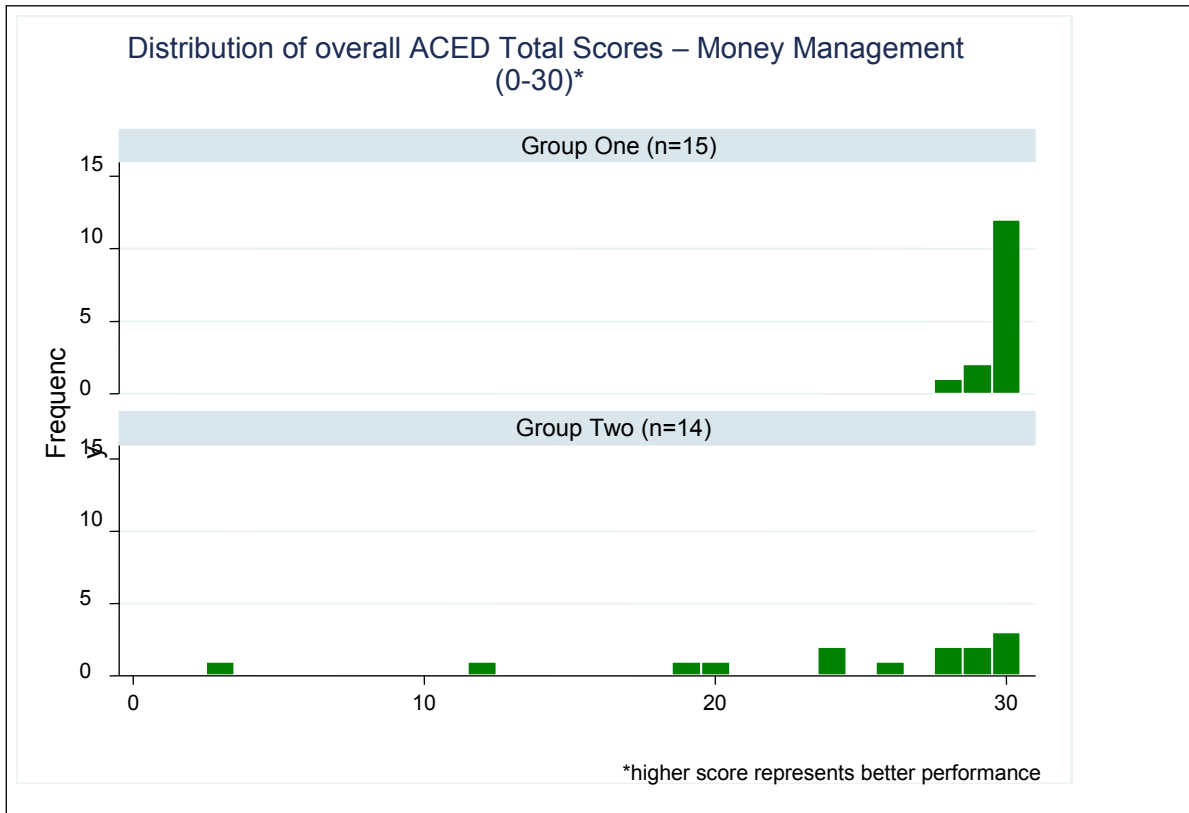
difference in the distribution of scores in the two groups ($p=0.001$) with the median score higher in Group One.

Table 4.10. Performance on Elements of Decision Making (ACED – Money Management)¹ by**Group, n=29**

	Group One (n=15)	Group Two (n=14)	p-value ³
	n (%)	n (%)	
Ability to understand (0-10) ²			
0	0 (0.0)	0 (0.0)	
1-2	0 (0.0)	1 (7.1)	
3-4	0 (0.0)	1 (7.1)	
5-6	0 (0.0)	2 (14.3)	
7-8	0 (0.0)	2 (14.3)	
9-10	15 (100.0)	8 (57.1)	
mean(SD)	9.9 (0.3)	7.9 (2.8)	
median(IQR)	10 (10 to 10)	9.5 (6 to 10)	0.033
Ability to appreciate (0-8) ²			
0	0 (0.0)	0 (0.0)	
1-2	0 (0.0)	1 (7.1)	
3-4	0 (0.0)	2 (14.3)	
5-6	0 (0.0)	3 (21.4)	
7-8	15 (100.0)	8 (57.1)	
mean(SD)	8 -	6.4 (1.9)	
median(IQR)	8 -	7 (4.8 to 8)	0.008
Ability to reason (0-10) ²			
0	0 (0.0)	1 (7.1)	
1-2	0 (0.0)	0 (0.0)	
3-4	0 (0.0)	1 (7.1)	
5-6	0 (0.0)	0 (0.0)	
7-8	0 (0.0)	5 (35.7)	
9-10	15 (100.0)	7 (50.0)	
mean(SD)	9.8 (0.4)	7.6 (2.9)	
median(IQR)	10 (10 to 10)	8.5 (7 to 10)	0.004
Ability to express a choice (0-2) ²			
0	0 (0.0)	1 (7.1)	
1	0 (0.0)	1 (7.1)	
2	15 (100.0)	12 (85.7)	
mean(SD)	2 -	1.8 (0.6)	
median(IQR)	2 -	2 (2 to 2)	0.533
Total score (0-30) ²			
0	0 (0.0)	0 (0.0)	
1-5	0 (0.0)	1 (7.1)	
6-10	0 (0.0)	0 (0.0)	
11-15	0 (0.0)	1 (7.1)	
16-20	0 (0.0)	2 (14.3)	
21-25	0 (0.0)	2 (14.3)	
26-30	15 (100.0)	8 (57.1)	
mean(SD)	29.7 (0.6)	23.7 (7.9)	
median(IQR)	30 (30 to 30)	27 (19.8 to 29.3)	0.001

¹higher score represents better performance on the ability measure²possible range³from Mann-Whitney U test

Figure 4.6. Distribution of Overall ACED Total Scores (Money Management) by Group.



4.2.3 Other Factors Referenced By Participants In Course Of Decision Making Assessment (ACED)

References to various factors were made by participants during administration of the ACED. A number of these reflected aspects not included in the information provided as part of the assessment and were therefore spontaneously raised by participants. Other references reflected information provided in the course of the assessment.

The references were contained in responses by participants to questions asked as part of the ACED administration and were recorded on participants' assessment forms. A number of these questions were open-ended and provide opportunities for the participants to elaborate. Thematic analysis was undertaken on the responses of five of these questions to identify if common themes were present (Braun & Clarke, 2006). Two questions selected were from ACED – Medication Management and three from ACED – Money Management. These questions (A-E) and their details are available in Appendix I.

Analysis involved familiarisation with all of verbal responses provided to these questions and recorded in the assessment forms. These responses were then transcribed, read and reread. A number of tentative categories were generated and the responses coded accordingly. This resulted with the identification of four categories that reflected the majority of responses. The four categories were Independence/Control/Autonomy, Trust/Risk, Emotional Wellbeing and Physical Wellbeing. The content of some responses reflected more than one category (See Appendix I for ACED Data Coding). Review of the coding was undertaken with Supervisor.

Table 4.11 provides details of frequency of reference to each category for the five sampled questions

**Table 4.11. Factors Referenced by Participants during ACED Assessment
(Medication and Money Management)**

Domain	Question	Number of Responses Provided^a	Independence/ Control/ Autonomy	Trust/ Risk	Emotional Wellbeing	Physical Wellbeing
Medication	A	20	15	1	4	8
Medication	B	27	13	2	0	4
Money	C	27	N/A ^b	3	2	0
Money	D	20	16	8	7	0
Money	E	27	16	6	3	0

^aResponse not provided if question not applicable or if participants did not respond

^bInformation provided to participant for this question included reference to control, therefore responses to this question were not considered for this category

These responses reflected participants concern regarding autonomy and independence, well being and concern trust and risk. Some verbatim quotes from participants' responses illustrating these concerns are presented below.

Independence/Control/Autonomy. Participants concerns regarding this are reflected in the following:

“I could retain my independence”

“I’d still be in control of my own medication & I’d retain independence and I’d get medication”

“You’d lose control over your money, lose some independence & privacy. You’d feel sorry for yourself that you’re reduced to that, lose control of your life and have to accept loss of independence”

“...Will lose control of your money & control of decisions about your money, bad for your independence, one more sign that you’re getting older & losing independence”

“May become over dependent on person managing money; the more you lose independence the more you lose ability – lack of confidence in ability”

“I can retain independence for as long as possible”

“Keep your independence & keep control of your life”

“I’d still be managing it, nobody else would be involved”

Trust/Risk. Participants concerns regarding their vulnerability and their fear of being exploited or of having their money taken from them is illustrated in the following:

“Lose some independence, lose control over your decisions, can be very dangerous, people can take money off older people”

“Depends on who was going to do it, if complete trust ok but opened to being ‘doodled’, feel at disadvantage...”

“They might spend it for themselves, I’d be sad & gloomy”

“I’d be very worried, I’d like to know where every penny would go; I’d like receipts & how much is left each month. It’d leave me very down to ask for price of paper & perhaps not get it; you’d have to trust person”

“Handing over big slice of the running of your life, depends on whom you’re handing it to, you’d hope person is trustworthy, worry whether they would spend in same way to your benefit”

Emotional and Physical Wellbeing. Participants concerns regarding their wellbeing reflect both physical and emotion and are illustrated in the following:

“I would lose confidence and self belief – self belief means a lot”

“I’d feel diminished, I’d hate to have someone else decide what & how much I could spend on food, travel, gifts etc.”

“Take away self esteem, independence, would feel worthless”

“....feel at disadvantage, lower self esteem & cause worry”

“I don’t know what would happen, I’d be worried & I wouldn’t be able to go out, they’d be in charge instead of me”

“..may get anxious if person administering medication wasn’t there, if requirement for after/before food, get even more anxious – can’t go to bed until person comes”

“...probably affect me, end up more sick”

The above examples also illustrate the reflection of more than one category by some responses.

4.2.4 Investigation of Relationships between ACED Measures (Medication Management) and ACED Measures (Money Management)

4.2.4.1 All participants.

The relationships between the measures of Capacity of Everyday Decision Making re Medication Management and measures of Capacity of Everyday Decision Making re Money Management for all participants were investigated using Spearman's correlation coefficient and the results are presented in Table 4.12. A strong, positive, statistically significant relationship was found between the overall Total ACED Score (Medication Management) and the overall Total ACED Score (Money Management). This indicates that participants with greater decision making abilities re Medication Management also had greater decision making abilities re Money Management. In general, this relationship was also observed for all subscales except the Expressing a Choice subscale for Medication Management.

Table 4.12. Spearman's correlation between ACED Measures (Medication Management) and ACED Measures (Money Management) for All Participants (n=29)

	Medication management: Capacity of everyday decision-making				
	Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Money management: Overall	0.67*	0.62*	0.68*	0.67*	0.34
Capacity of everyday decision-making					
Understanding	0.57*	0.72*	0.71*	0.52*	0.12
Appreciation	0.76*	0.67*	0.78*	0.73*	0.35
Reasoning	0.63*	0.65*	0.72*	0.60*	0.19
Expressing a choice	0.42*	0.49*	0.50*	0.39*	0.40*

*p<0.05

4.2.4.2 By group (2 groups).

The relationships between the Assessment of Capacity of Everyday Decision Making measures re Medication Management and Assessment of Capacity of Everyday Decision Making measures re Money Management according to group were investigated using Spearman's correlation coefficient and the results are presented in Table 4.13.

For Group Two at increased risk of impaired DMC (i.e. clinical diagnosis and/or who were in receipt of support), the relationship between overall ACED Total Scores (Medication Management) and overall ACED Total Scores (Money Management) was strong, positive and statistically significant, indicating that participants within this group who had greater decision making abilities re Medication Management also had greater decision making abilities re Money Management. In contrast, for participants within Group One, the relationship was very weak and in some aspects negative in direction.

Table 4.13. Spearman's Correlation between ACED Measures (Medication Management) and ACED Measures (Money Management) by Group (2 Groups)

Group One (n=15)		Assessment of Capacity of Everyday Decision Making re Medication Management				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Assessment of Capacity of Everyday Decision Making re Money Management	Appreciation	0.02	-0.20	-0.19	0.19	0.49
	Understanding	-0.19	-0.10	-0.10	-0.13	-0.07
	Appreciation	-	-	-	-	-
	Reasoning	0.05	-0.20	-0.20	0.22	0.53*
	Expressing a choice	-	-	-	-	-
Group Two (n=14)		Assessment of Capacity of Everyday Decision Making re Medication Management				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Assessment of Capacity of Everyday Decision Making re Money Management	Overall	0.80*	0.79*	0.91*	0.61*	0.31
	Understanding	0.76*	0.84*	0.88*	0.53*	0.20
	Appreciation	0.79*	0.65*	0.84*	0.64*	0.47
	Reasoning	0.77*	0.85*	0.94*	0.52	0.12
	Expressing a choice	0.49	0.53	0.59*	0.41	0.50

*p<0.05

4. 3: Hypotheses One – A Relationship will be indicated between Elements of DMC and Cognitive Factors

Decision making abilities for both Medication Management and Money Management were measured using the Assessment of Capacity for Everyday Decision Making (ACED). Results for these ACED measures are presented previously in Section 2. Cognitive abilities and cognitive status were measured utilising Wechsler Abbreviated Scales of Intelligence (WASI) and Dementia Rating Scales – 2nd Edition (DRS-2). Results for the WASI are presented below for all participants and also according to group in Tables 4.14, 4.15 and Figures 4.7 and 4.8. Results for the DRS-2 are presented below for all participants and also according to group in Tables 4.16, 4.17 and Figure 4.9.

To examine the above hypotheses, relationships using Spearman's correlation coefficient were investigated between:

- Elements of decision making as measured by administration of the ACED re Medication Management and cognitive functioning as measured by the WASI
- Elements of decision making as measured by administration of the ACED re Money Management and cognitive functioning as measured by the WASI
- Elements of decision making as measured by administration of the ACED re Medication Management and cognitive status as measured by the DRS – 2
- Elements of decision making as measured by administration of the ACED re Money Management and cognitive status as measured by the DRS – 2

The results for each of these investigations are presented in Tables 4.18, 4.19, 4.20 and 4.21 respectively.

4.3.1 Assessment of Cognitive Factors

4.3.1.1 Cognitive functioning measured using WASI.

4.3.1.1.1 *All participants.*

The summary statistics for cognitive functioning measures from the WASI are presented in Table 4.14. When all participants are included, the observed range for each measure is relatively wide with the mean scores indicating average cognitive functioning for the group as a whole.

Table 4.14. Summary Statistics for Cognitive Functioning¹ Measures (WASI) for All Participants (N=29)

	observed range	mean(SD)
Specific measures ²		
Vocabulary (V)	20 to 71	50.6 (18.0)
Block Design (BD)	24 to 63	41.3 (11.7)
Similarities (S)	20 to 69	47.1 (16.2)
Matrix Reasoning (MR)	20 to 74	44.4 (15.3)
Composite measures ³		
VIQ (V+S)	55 to 135	99.8 (25.8)
PIQ (BD+MR)	57 to 132	89.4 (19.9)
FSIQ-2 (V+MR)	55 to 141	98.1 (24.8)
FSIQ-4 (V+B+S+MR)	53 to 133	94.4 (23.6)

¹higher score represents better cognitive functioning

² T-scores with a mean of 50 and a standard deviation of 10

³ scale with a mean of 100 and a standard deviation of 15

4.3.1.1.2 WASI RESULTS BY GROUP (2 GROUPS)

The summary statistics for the measures of cognitive functioning arising from administration of the WASI for each group are presented in Table 4.15, Figure 4.7 and Figure 4.8. For all measures, cognitive functioning was significantly higher in Group One and as may be expected cognitive functioning was lower for individuals within Group Two.

Table 4.15. Cognitive Functioning¹ Measures (WASI) by Group

	Group One (n=15)	Group Two (n=14)	p-value ⁴
	mean (SD)	mean (SD)	
Specific measures ²			
Vocabulary (V)	64.5 (5.2)	35.7 (14.5)	<0.001
Block Design (BD)	48.9 (9.1)	33.2 (8.4)	<0.001
Similarities (S)	59.7 (5.5)	33.6 (12.4)	<0.001
Matrix Reasoning (MR)	54.2 (13.1)	34.0 (9.6)	<0.001
Composite measures ³			
VIQ (V+S)	120.5 (8.5)	77.6 (18.3)	<0.001
PIQ (BD+MR)	102.5 (16.5)	75.4 (12.1)	<0.001
FSIQ-2 (V+MR)	117.1 (13.5)	77.8 (16.3)	<0.001
FSIQ-4 (V+B+S+MR)	112.9 (11.5)	74.7 (15.8)	<0.001

¹higher score represents better cognitive functioning

²T-scores with a mean of 50 and a standard deviation of 10

³scale with a mean of 100 and a standard deviation of 15

⁴from independent samples t-test

Figure 4.7. Distribution of WASI Subtest Scores by Group.

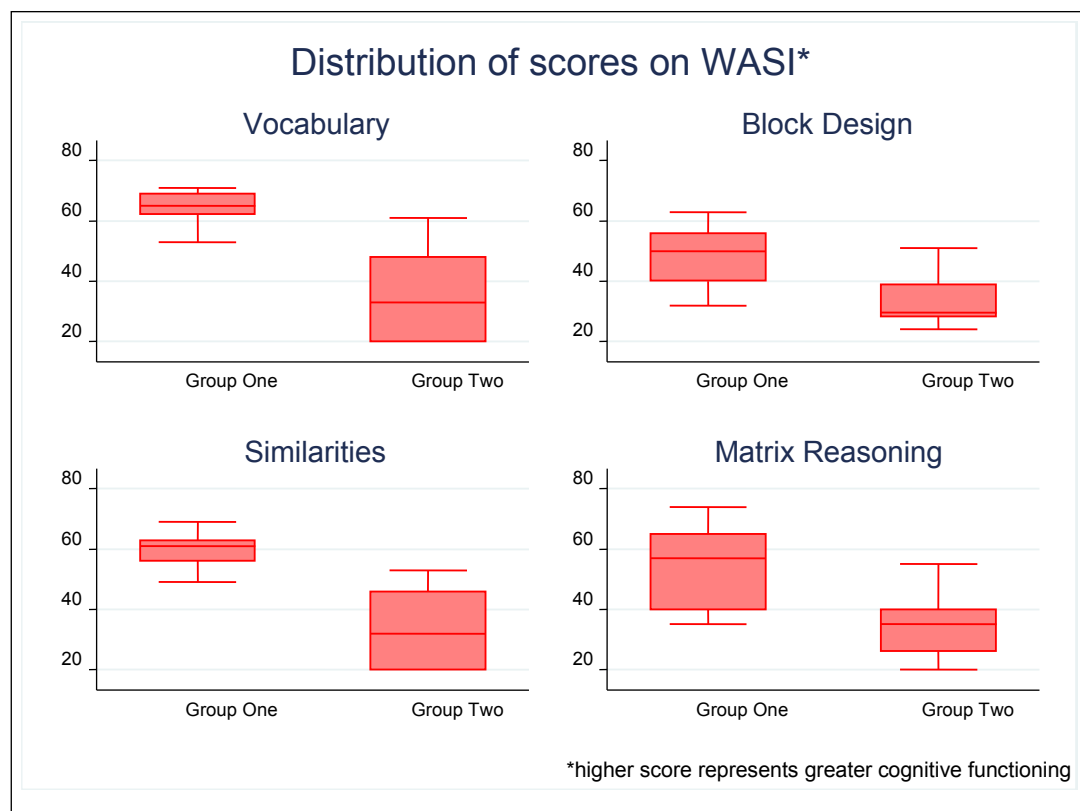
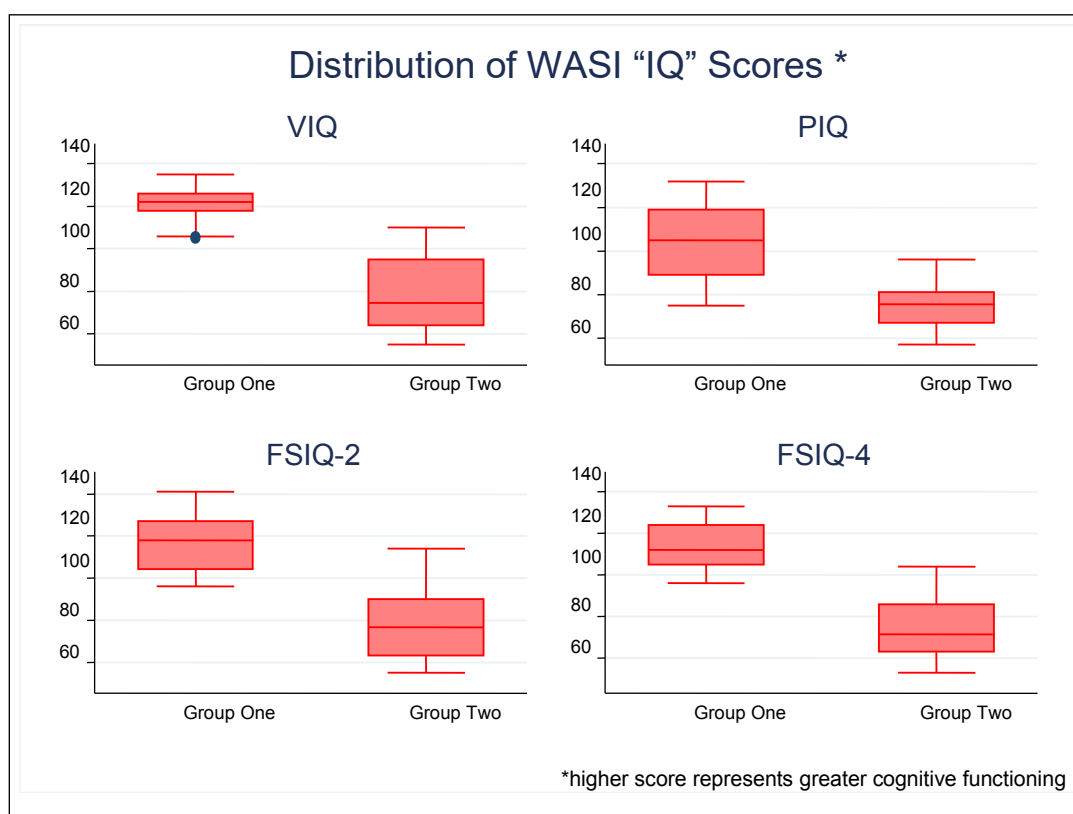


Figure 4.8. Distribution of WASI “IQ” Scores by Group.



4.3.1.2 Dementia Rating Scale (DRS-2) Results

4.3.1.2.1 All participants

The summary statistics for the measures of cognitive status as indicated by administration of the DRS-2 are presented in Table 4.16. When all participants are included, the observed range for each measure is relatively wide with the median scores indicating below average cognitive status overall (AMSS and AEMSS) and for Memory, Initiation and Conceptualisation, average cognition for Attention and moderately impaired cognition for Construction. Overall, based on the total scores as indicated by the AMSS, 34% (n=10) of the participants were classified as severely impaired, 3% (n=1) were moderately impaired, 31% (n=9) were below average and 31% (n=9) were average.

Table 4.16. Summary Statistics for DRS-2 Measures of Cognitive Status¹ (N=29)

	Summary statistics	
	observed range ²	median (IQR)
Attention (AMSS)	2 to 14	12 (8 to 13)
Initiation (AMSS)	2 to 13	10 (2.5 to 11)
Construction (AMSS)	1 to 10	5 (3.5 to 7)
Conceptualisation (AMSS)	2 to 14	10 (6 to 11.5)
Memory (AMSS)	2 to 14	9 (4.5 to 10)
DRS Total (AMSS)	2 to 13	9 (2.5 to 11)
DRS Total (AEMSS)	1 to 13	9 (2 to 11)

¹higher score represents better cognitive functioning

² possible range 1-18

4.3.1.2.2 DRS-2 Results according to group.

The summary statistics for the measures of Cognitive Status from DRS-2 split by group are presented in Table 4.17 and Figure 4.9. For all measures except Construction, functioning was significantly higher in Group One. Based on the total scores on the AMSS, participants within Group One (n=15) were classified as either below average (n=7) or average (n=8), i.e. they were cognitively intact. Within Group Two (n=14), the majority

were severely impaired (n=10), while 1 was moderately impaired, 2 were below average and 1 was average.

Table 4.17. DRS-2 Measures of Cognitive Status^{1,2} by Group

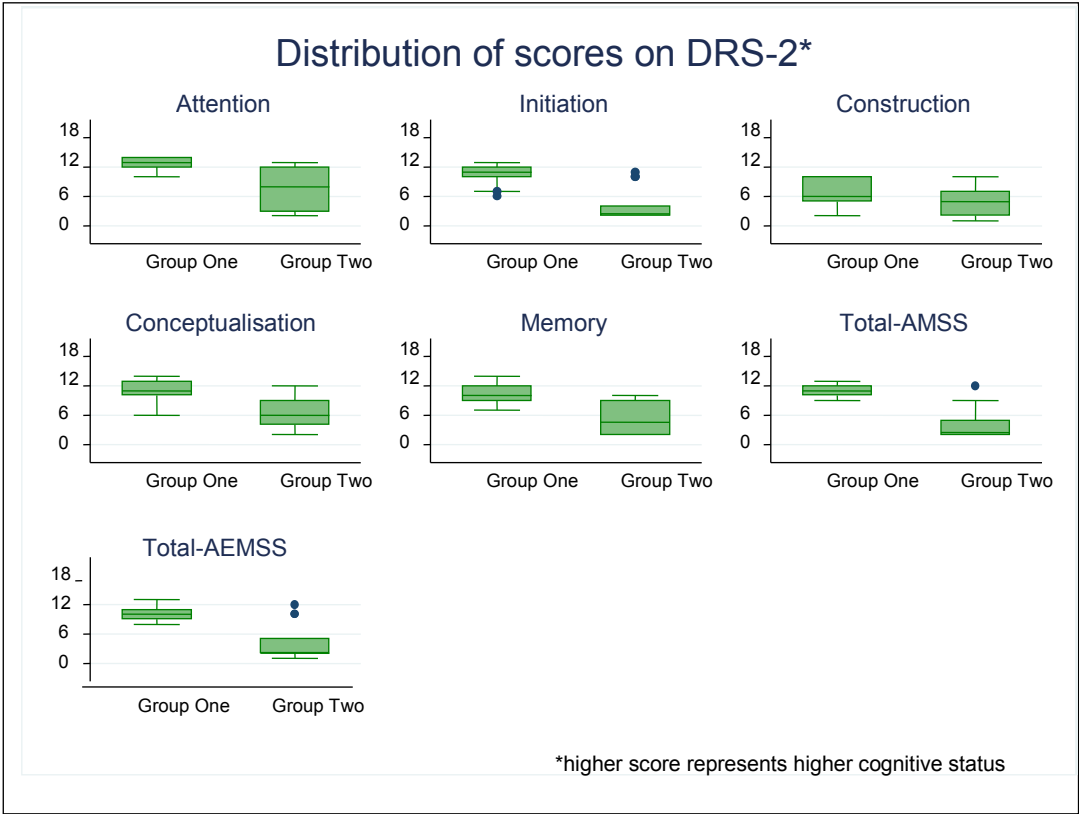
	Group One (n=15)	Group Two (n=14)	p-value ³
	median (IQR)	median (IQR)	
Attention (AMSS)	13 (12 to 14)	8 (2.8 to 12)	<0.001
Initiation (AMSS)	11 (10 to 12)	2.5 (2 to 5.5)	<0.001
Construction (AMSS)	6 (5 to 10)	5 (2 to 7)	0.033
Conceptualisation (AMSS)	11 (10 to 13)	6 (3.5 to 9.3)	<0.001
Memory (AMSS)	10 (9 to 12)	4.5 (2 to 9)	<0.001
DRS Total (AMSS)	11 (10 to 12)	2.5 (2 to 6)	<0.001
DRS Total (AEMSS)	10 (9 to 11)	2 (1.8 to 6.3)	<0.001

¹higher score represents higher cognitive status

² possible range 1-18

³ from Mann-Whitney U test

Figure 4.9. Distribution of DRS-2 Scores by Group.



4.3.2 Investigation of Relationships between Decision-Making Capacity and Cognitive Functioning

The strength and direction of the relationship between two variables was assessed using Spearman's correlation coefficient (r_s). Associations were considered very weak if $|r_s| < 0.10$, weak if $0.10 \leq |r_s| < 0.30$, moderate if $0.30 \leq |r_s| < 0.50$ and strong if $|r_s| \geq 0.50$ (Cohen, 1988).

Also, as the sample size is small (particularly when looking at the subgroups), and it is known that statistical significance is a function of sample size, there is more focus on the magnitude and direction of the correlation coefficients when commenting on them rather than their statistical significance.

4.3.2.1 Relationship between elements of decision making (medication management) and cognitive functioning

4.3.2.1.1 *All participants*

The relationships between the elements of decision making as measured by administration of the ACED (Medication Management) and cognitive functioning as measured by the WASI were investigated using Spearman's correlation coefficient and the results are presented in Table 4.18. In general, for all measures of decision making ability, except Expressing a Choice, there was a moderate to strong, positive, statistically significant relationship with measures of cognitive functioning, indicating that participants with higher scores in measures of decision making abilities in Medication Management had greater cognitive functioning ($P < 0.05$ for all).

Table 4.18. Spearman's Correlation between Elements of DMC (Medication Management) and Cognitive Functioning Measures (WASI) for All Participants (N=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (WASI)	Specific measures					
	Vocabulary (V)	0.63*	0.61*	0.54*	0.64*	0.19
	Block Design (BD)	0.39*	0.51*	0.38*	0.40*	0.11
	Similarities (S)	0.59*	0.57*	0.59*	0.59*	0.16
	Matrix Reasoning (MR)	0.44*	0.54*	0.40*	0.46*	0.16
	Composite measures					
	VIQ (V+S)	0.64*	0.63*	0.58*	0.65*	0.20
	PIQ (BD+MR)	0.43*	0.54*	0.40*	0.44*	0.16
	FSIQ-2 (V+MR)	0.54*	0.59*	0.49*	0.57*	0.19
	FSIQ-4 (V+B+S+MR)	0.56*	0.60*	0.51*	0.58*	0.17

*p<0.05

4.3.2.1.2 Relationship between elements of decision making (ACED – medication management) and cognitive functioning by group.

The relationships between the elements of decision making as measured by administration of the ACED re Medication Management and cognitive functioning as measured by the WASI within the two groups were investigated using Spearman's correlation coefficient and the results are presented in Table 4.19. For Group Two, most correlations between the elements of decision making in this domain and the measures of cognitive functioning were weak to moderate in magnitude and positive in direction. The strongest relationships were found between Understanding and the cognitive functioning measures of Vocabulary, Similarities, VIQ and FSIQ-4.

For Group One, there was very little variability in the ACED measures. The strongest relationships were found between Understanding and the cognitive functioning measures of Vocabulary and VIQ. Again, for those variables, the relationships were positive indicating that participants with higher measures of decision making abilities re

money management had greater cognitive functioning. For this group, the relationships between the other variables investigated were more varied with relationships in both directions.

Table 4.19. Spearman's Correlation between Elements of DMC (Medication Management) and Cognitive Functioning Measures (WASI) by Group (2 Groups)

		Group One (n=15)				
		<u>Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)</u>				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (WASI)	Specific measures					
	Vocabulary (V)	0.26	0.50	0.12	0.20	-0.12
	Block Design (BD)	-0.32	0.20	-0.35	-0.32	-0.28
	Similarities (S)	0.18	0.30	0.31	0.10	-0.09
	Matrix Reasoning (MR)	-0.21	0.27	-0.25	-0.27	-0.12
	Composite measures					
	VIQ (V+S)	0.26	0.50	0.15	0.24	-0.06
	PIQ (BD+MR)	-0.32	0.23	-0.35	-0.35	-0.19
	FSIQ-2 (V+MR)	-0.12	0.36	-0.20	-0.15	-0.06
	FSIQ-4 (V+B+S+MR)	-0.16	0.36	-0.18	-0.18	-0.19
		Group Two (n=14)				
		<u>Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)</u>				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (WASI)	Specific measures					
	Vocabulary (V)	0.45	0.60*	0.40	0.35	0.39
	Block Design (BD)	0.25	0.40	0.24	0.12	0.20
	Similarities (S)	0.31	0.56*	0.44	0.13	0.25
	Matrix Reasoning (MR)	0.29	0.41	0.30	0.31	0.27
	Composite measures					
	VIQ (V+S)	0.45	0.63*	0.48	0.32	0.37
	PIQ (BD+MR)	0.31	0.44	0.31	0.22	0.29
	FSIQ-2 (V+MR)	0.36	0.50	0.33	0.31	0.32
	FSIQ-4 (V+B+S+MR)	0.44	0.60*	0.45	0.34	0.36

*p<0.05

4.3.2.2 Relationship between elements of decision making (ACED – medication management) and cognitive functioning.

4.3.2.2.1 All participants.

The relationships between the elements of decision making as measured by administration of the ACED (Money Management) and cognitive functioning as measured by the WASI were investigated using Spearman's correlation coefficient and the results are

presented in Table 4.20. For almost all measures of elements of decision making, there was a moderate to strong, positive, statistically significant relationship with measures of cognitive functioning, indicating that participants with higher measures of decision making abilities in Money Management had greater cognitive functioning.

Table 4.20. Spearman's Correlation between Elements of DMC (Money Management) and Cognitive Functioning Measures (WASI) for All Participants (N=29)

		Assessment of Capacity of Everyday Decision-Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (WASI)	Specific measures					
	Vocabulary (V)	0.65*	0.53*	0.64*	0.58*	0.41*
	Block Design (BD)	0.58*	0.51*	0.53*	0.49*	0.36
	Similarities (S)	0.65*	0.53*	0.62*	0.61*	0.41*
	Matrix Reasoning (MR)	0.59*	0.50*	0.54*	0.50*	0.37*
	Composite measures					
	VIQ (V+S)	0.68*	0.56*	0.67*	0.62*	0.42*
	PIQ (BD+MR)	0.62*	0.52*	0.56*	0.53*	0.37*
	FSIQ-2 (V+MR)	0.72*	0.58*	0.64*	0.64*	0.39*
	FSIQ-4 (V+B+S+MR)	0.71*	0.59*	0.66*	0.64*	0.42*

*p<0.05

4.3.2.2.2 *By group (2 groups).*

The relationships between the elements of decision making as measured by administration of the ACED re Money Management and cognitive functioning as measured by the WASI were investigated using Spearman's correlation coefficient and the results are presented in Table 4.21. For Group Two, the most correlations between the elements of decision making in this domain and the measures of cognitive functioning ranged from weak to strong in magnitude and were positive in direction. The strongest relationships were found between the cognitive functioning measure of VIQ and overall ACED Total Score and Understanding.

For Group One, the strongest relationships were found between Understanding and the cognitive functioning measures of Similarities and VIQ. For those variables, the relationships were negative indicating that participants with higher measures of decision making abilities re Money Management had lower measures of cognitive functioning. For this group, the relationships between the other variables investigated were more varied with relationships in both directions.

For Group One, there is no variability in Appreciation or Expressing a choice for money management. Hence, correlation coefficients cannot be calculated for those variables.

Table 4.21. Spearman's Correlation between Elements of DMC (Money Management) and Cognitive Functioning Measures (WASI) by Group (2 Groups)

		Group One (n=15)				
		Assessment of Capacity of Everyday Decision Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (WASI)	Specific measures					
	Vocabulary (V)	-0.06	-0.34	-	-0.02	-
	Block Design (BD)	0.19	0.34	-	0.15	-
	Similarities (S)	-0.18	-0.43	-	-0.14	-
	Matrix Reasoning (MR)	0.23	0.28	-	0.21	-
	Composite measures					
	VIQ (V+S)	-0.13	-0.43	-	-0.08	-
	PIQ (BD+MR)	0.25	0.31	-	0.23	-
	FSIQ-2 (V+MR)	0.35	0.19	-	0.35	-
	FSIQ-4 (V+B+S+MR)	0.20	0.15	-	0.19	-
		Group Two (n=14)				
		Assessment of Capacity of Everyday Decision Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (WASI)	Specific measures					
	Vocabulary (V)	0.49	0.52	0.37	0.42	0.51
	Block Design (BD)	0.22	0.20	0.15	0.20	0.36
	Similarities (S)	0.55*	0.55*	0.31	0.52	0.51
	Matrix Reasoning (MR)	0.30	0.27	0.24	0.22	0.39
	Composite measures					
	VIQ (V+S)	0.60*	0.60*	0.42	0.54*	0.56*
	PIQ (BD+MR)	0.33	0.28	0.26	0.25	0.39
	FSIQ-2 (V+MR)	0.41	0.39	0.30	0.32	0.44
	FSIQ-4 (V+B+S+MR)	0.53	0.50	0.39	0.47	0.55*

*p<0.05

4.3.2.3 Relationship between elements of decision making (aced – money management) and cognitive functioning .

4.3.2.3.1 All participants.

The relationships between the elements of decision making as measured by administration of the ACED re Medication Management and cognitive status as measured by the DRS-2 were investigated using Spearman's correlation coefficient. The results are presented in Table 4.22. In general, for all measures of elements of DMC, except *Expressing a Choice*, there was a moderate to strong, positive, statistically significant

relationship with measures of cognitive status, indicating that participants with higher measures of decision making abilities re Medication Management had better cognitive status.

Table 4.22. Spearman's Correlation between Elements of DMC (Medication Management) and Measures of Cognitive Status (DRS-2) for All Participants (N=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive status (DRS-2)	Attention (AMSS)	0.64*	0.63*	0.55*	0.58*	0.20
	Initiation (AMSS)	0.64*	0.66*	0.63*	0.61*	0.29
	Construction (AMSS)	0.38*	0.52*	0.49*	0.31	0.04
	Conceptualisation (AMSS)	0.58*	0.67*	0.65*	0.53*	0.11
	Memory (AMSS)	0.66*	0.62*	0.66*	0.60*	0.20
	DRS Total (AMSS)	0.65*	0.70*	0.69*	0.58*	0.15
	DRS Total (AEMSS)	0.62*	0.72*	0.72*	0.52*	0.13

*p<0.05

4.3.2.3.2 *By group (2 groups).*

The relationships between the elements of decision making as measured by administration of the ACED re Medication Management and cognitive status as measured by the DRS-2 were investigated using Spearman's correlation coefficient and the results are presented in Table 4.23. In general, for Group Two, there were moderate to strong, positive relationships between all measures of elements of DMC, (except expressing a choice) and measures of cognitive Status, indicating that participants with higher measures of decision making abilities re Medication Management had better cognitive status.

For Group One, the relationships between the variables were weaker, on average and more varied with relationships in both directions. For this group, the strongest relationship was found between overall ACED Total Score and Attention, this was positive in direction.

Table 4.23. Spearman's Correlation between Elements of DMC (Medication Management) and Measures of Cognitive Status (DRS-2) by Group (2 Groups)

		Group One (n=15)				
		Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (DRS-2)	Attention (AMSS)	0.59*	0.47	0.33	0.33	-0.06
	Initiation (AMSS)	0.11	0.40	0.05	0.08	0.22
	Construction (AMSS)	-0.05	-0.05	-0.08	-0.26	-0.32
	Conceptualisation (AMSS)	0.28	0.42	0.24	0.10	0.03
	Memory (AMSS)	0.42	0.05	0.33	0.24	0.29
	DRS Total (AMSS)	0.33	0.44	0.28	0.03	-0.06
	DRS Total (AEMSS)	0.32	0.54*	0.42	-0.08	-0.19
		Group Two (n=14)				
		Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (DRS-2)	Attention (AMSS)	0.43	0.59*	0.43	0.34	0.35
	Initiation (AMSS)	0.62*	0.67*	0.71*	0.44	0.38
	Construction (AMSS)	0.51	0.62*	0.69*	0.36	0.15
	Conceptualisation (AMSS)	0.46	0.72*	0.71*	0.25	0.06
	Memory (AMSS)	0.59*	0.78*	0.76*	0.35	0.05
	DRS Total (AMSS)	0.70*	0.87*	0.83*	0.46	0.13
	DRS Total (AEMSS)	0.68*	0.74*	0.69*	0.61*	0.16

*p<0.05

4.3.2.4 Relationship between elements of decision making (aced – money management) and cognitive status.

4.3.2.4.1 All participants.

The relationships between the elements of decision making as measured by administration of the ACED re Money Management and measures of cognitive status (DRS-2) were investigated using Spearman's correlation coefficient and the results are presented in Table 4.24. In general, for all measures of elements of DMC, there was a moderate to strong, positive relationship with measures of cognitive status, indicating that participants with higher measures of decision making abilities re Money Management had better cognitive status. The weakest correlations were found between Expressing a Choice and measures of cognitive status.

Table 4.24. Spearman's Correlation between Elements of DMC (Money Management) and Measures of Cognitive Status (DRS-2) for All Participants (n=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (DRS-2)	Attention (AMSS)	0.50*	0.48*	0.56*	0.44*	0.43*
	Initiation (AMSS)	0.77*	0.67*	0.72*	0.68*	0.36
	Construction (AMSS)	0.39*	0.47*	0.56*	0.36	0.35
	Conceptualisation (AMSS)	0.80*	0.70*	0.62*	0.80*	0.43*
	Memory (AMSS)	0.63*	0.60*	0.58*	0.63*	0.38*
	DRS Total (AMSS)	0.79*	0.67*	0.71*	0.74*	0.36
	DRS Total (AEMSS)	0.74*	0.65*	0.72*	0.66*	0.30

*p<0.05

4.3.2.4.2 By group (2 groups).

The relationships between the elements of decision making as measured by administration of the ACED re Money Management and measures of cognitive status (DRS-2) within the two groups were investigated using Spearman's correlation coefficient and the results are presented in Table 4.25. In general, for Group Two, there were moderate to strong, positive relationships between measures of elements of DMC and measures of cognitive status, indicating that participants with higher measures of decision making abilities re Money Management had better cognitive status. For Group One, the relationships between the variables were weaker, on average and more varied with relationships in both directions.

Table 4.25. Spearman's Correlation between Elements of DMC (Money Management) and Measures of Cognitive Status (DRS-2) by Group (2 groups)

		Group One (n=15)				
		Assessment of Capacity of Everyday Decision-Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (DRS-2)	Attention (AMSS)	-0.32	-0.35	-	-0.30	-
	Initiation (AMSS)	0.23	0.38	-	0.20	-
	Construction (AMSS)	-0.47	-0.32	-	-0.46	-
	Conceptualisation (AMSS)	0.47	0.28	-	0.47	-
	Memory (AMSS)	-0.13	-0.45	-	-0.08	-
	DRS Total (AMSS)	0.34	0.19	-	0.34	-
	DRS Total (AEMSS)	0.10	0.06	-	0.10	-
		Group Two (n=14)				
		Assessment of Capacity of Everyday Decision-Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive functioning (DRS-2)	Attention (AMSS)	0.43	0.50	0.33	0.39	0.56*
	Initiation (AMSS)	0.74*	0.66*	0.68*	0.59*	0.38
	Construction (AMSS)	0.64*	0.68*	0.62*	0.58*	0.37
	Conceptualisation (AMSS)	0.72*	0.79*	0.46	0.74*	0.56*
	Memory (AMSS)	0.70*	0.78*	0.49	0.71*	0.42
	DRS Total (AMSS)	0.77*	0.77*	0.61*	0.75*	0.38
	DRS Total (AEMSS)	0.70*	0.65*	0.58*	0.61*	0.16

*p<0.05

Section 4.4 Hypotheses Two – A Relationship will be indicated between Elements of DMC and Cognitive Reserve Markers

Decision making abilities for both Medication Management and Money Management were measured using the Assessment of Capacity for Everyday Decision Making (ACED). Results for these ACED measures are presented previously in Section 4.2. Cognitive Reserve (CR) was measured using the Lifetimes of Experiences Questionnaire (LEQ). Results for these CR and measures are presented for all participants and also according to group in Tables 4.26, 4.27 and Figures 4.10 and 4.11. As Physical Activity has been identified as a cognitive reserve marker, some physical activity measures are presented in Tables 4.28, 4.29, 4.30, 4.31, 4.32 and Figures 4.12, 4.13 and 4.14.

To examine the above hypotheses, relationships using Spearman's correlation coefficient were investigated between:

- Elements of decision making as measured by administration of the ACED re Medication Management and Cognitive Reserve measures as yielded by the LEQ
- Elements of decision making as measured by administration of the ACED re Money Management and Cognitive Reserve measures as yielded by the LEQ

The results for each of these investigations are presented in Tables 4.33, 4.34, 4.35, 4.36, 4.37 and 4.38 respectively.

4.4.1 Assessment of Cognitive Reserve Markers

4.4.1.1 Results for LEQ – Lifetime of Experiences Questionnaire.

4.4.1.1.1 *All participants.*

The summary statistics for the measures of Cognitive Reserve from the LEQ are presented in Table 4.26. When all participants are included, the observed range for each measure, except education bonus and work bonus is relatively wide with the median scores indicating average CR overall and for each of the life periods.

Table 4.26. Summary Statistics for LEQ Measures of CR¹ for All Participants (n=29)

	Summary statistics	
	observed range	median (IQR)
Total LEQ	37.1 to 136.9	74.4 (62.4 to 102.8)
Young Adulthood		
Subscore	11.2 to 54.1	24.2 (17.7 to 32.3)
Stage specific	0 to 23.1	8.4 (4.2 to 15.8)
Non-stage specific ²	7 to 31	16 (14.5 to 20.5)
Mid Life		
Subscore	9.5 to 57.8	23.8 (17.4 to 38)
Stage specific	0 to 22	1.8 (1.8 to 16.4)
Non-stage specific ²	8 to 29	16 (15 to 21.5)
Education Bonus	0 to 11.6	0 (0 to 2.1)
Late Life		
Subscore	15.4 to 41	27.4 (24.2 to 31.6)
Stage specific	5.6 to 13.6	9.6 (8.4 to 11.8)
Non-stage specific ²	9 to 29	18.0 (14 to 19.5)
Education Bonus	0 -	0 -
Work Bonus	0 to 2.5	0 (0 to 0)

¹higher score represents higher level of cognitive reserve

² possible range 7-35

4.4.1.1.2 By group.

The summary statistics for the measures of cognitive reserve from the LEQ for each of the two groups are presented in Table 4.27 and Figures 4.10 and 4.11. For all measures, except education bonus and work bonus, cognitive reserve was significantly higher for participants within Group One.

Table 4.27. LEQ Measures of Cognitive Reserve¹ by Group (2 Groups)

	Group One (n=15)	Group Two (n=14)	p-value ³
	median (IQR)	median (IQR)	
Total LEQ	102.6 (90.4 to 114.4)	62.4 (46.2 to 68.9)	<0.001
Young Adulthood			
Subscore	31.8 (27.6 to 46.9)	17.7 (14.6 to 21.9)	<0.001
Stage specific	14.7 (8.4 to 18.9)	4.2 (1.6 to 5.3)	<0.001
Non-stage specific ²	20 (15 to 26)	15 (11.3 to 17.3)	0.006
Mid Life			
Subscore	38 (23.9 to 40.3)	17.4 (13.7 to 23.2)	<0.001
Stage specific	16 (1.8 to 17.8)	1.8 (1.5 to 3.3)	0.001
Non-stage specific ²	21 (18 to 23)	15 (13.3 to 16)	<0.001
Education Bonus	2.1 (0 to 4.2)	0 (0 to 0)	0.020
Late Life			
Subscore	31.2 (28 to 33)	24.2 (18 to 25.8)	<0.001
Stage specific	11.6 (9.6 to 12)	8.4 (6.7 to 9.6)	<0.001
Non-stage specific ²	19 (18 to 22)	14 (10.8 to 17)	<0.001
Education Bonus	0 -	0 -	-
Work Bonus	0 (0 to 0)	0 (0 to 0)	0.533

¹higher score represents higher level of cognitive reserve² possible range 7-35³from Mann-Whitney U test

Figure 4.10 Distributions of LEQ Total Scores by Group.

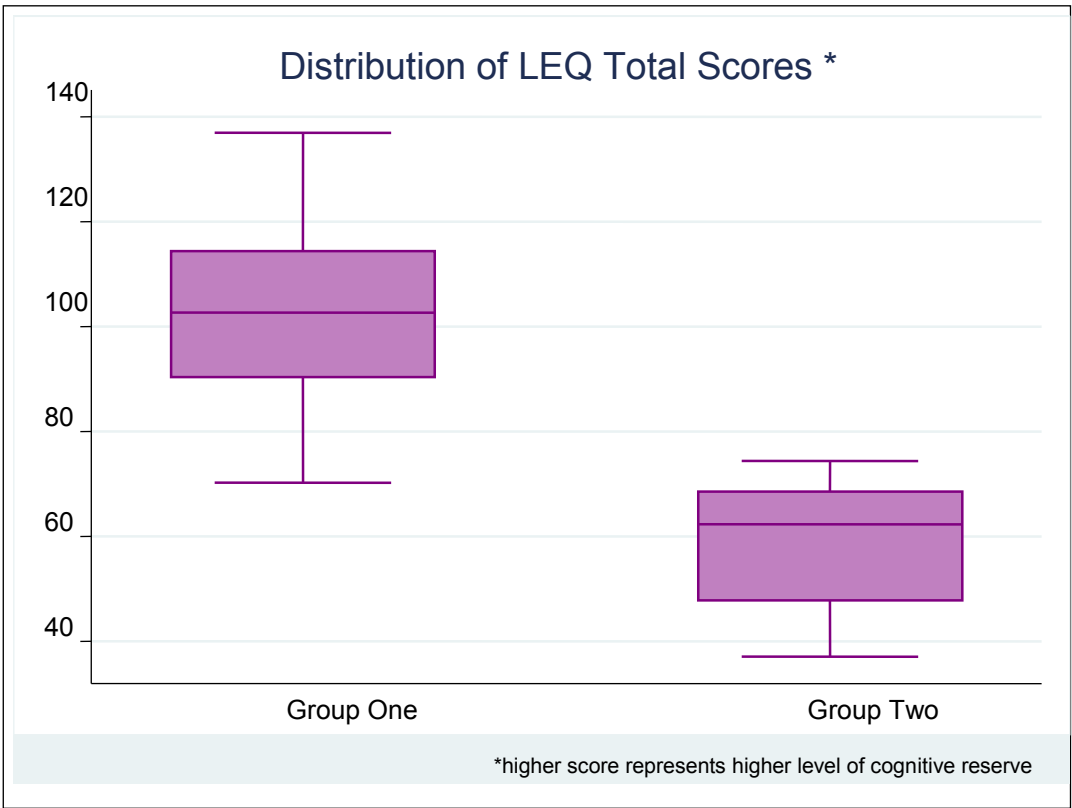
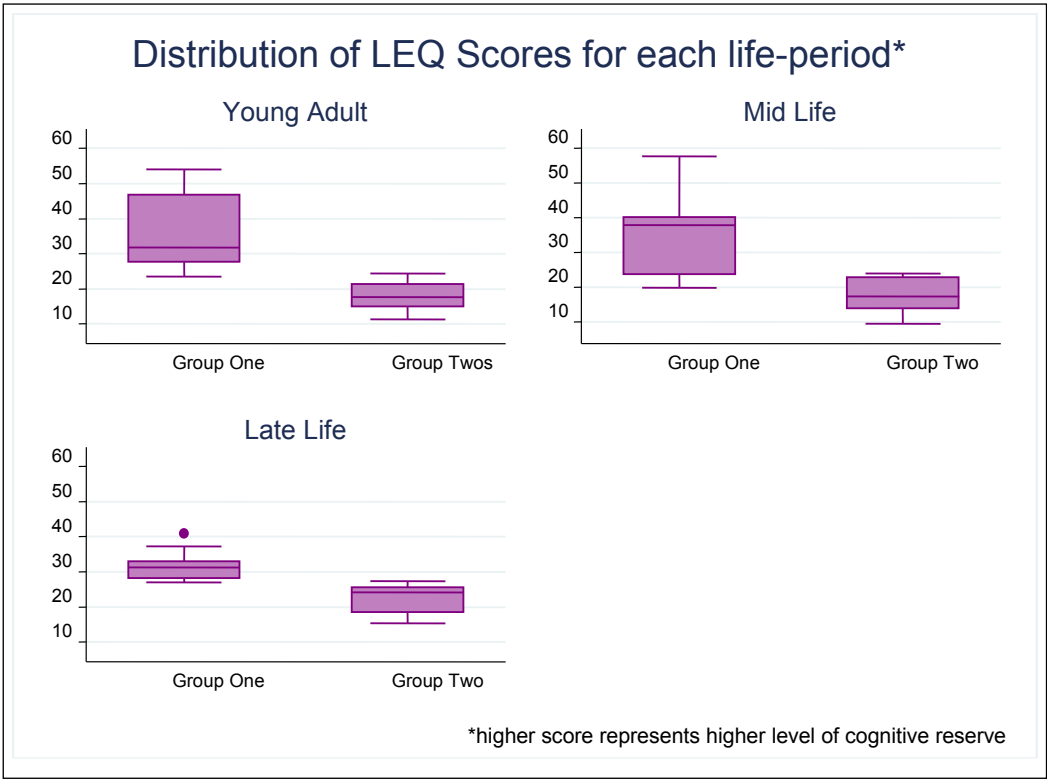


Figure 4.11 Distribution of LEQ scores for Each Life-Period by Group.



4.4.1.2 Physical activity/exercise.

For the analysis, a new variable was created for physical activity at each of the time points (present/mid life/early life). Within each time point, a participant was assigned to the vigorous group if they answered daily or weekly to the vigorous frequency question. If they were not assigned to the vigorous group, then they were then assigned to the moderate group if they answered daily or weekly to the moderate frequency question otherwise, they were assigned to the mild group.

4.4.1.2.1 *All participants.*

Participants' frequency of physical activity currently and in their mid-life and early-life are described in Table 4.28, Table 4.29, Figure 4.12 and Figure 4.13. Currently, all participants were engaging in mild physical activity either weekly or daily. Of those, 18 participants were engaging in moderate physical activity on at least a weekly basis and six were engaging in vigorous physical activity on at least a weekly basis. In comparison to present physical activity, frequency of moderate and vigorous physical activity was higher during participants' mid-life and early-life.

Table 4.28. Frequency of Physical Activity for All Participants (N=29)

	Never n (%)	Less than monthly n (%)	Monthly n (%)	Fortnightly n (%)	Weekly n (%)	Daily n (%)
Present						
Mild physical activity	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (6.9)	27 (93.1)
Moderate physical activity	4 (13.8)	0 (0.0)	1 (3.4)	0 (0.0)	13 (44.8)	11 (37.9)
Vigorous physical activity	21 (72.4)	1 (3.4)	1 (3.4)	0 (0.0)	6 (20.7)	0 (0.0)
Mid-life						
Mild physical activity	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	29 (100.0)
Moderate physical activity	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	14 (48.3)	15 (51.7)
Vigorous physical activity	10 (34.5)	2 (6.9)	7 (24.1)	2 (6.9)	5 (17.2)	3 (10.3)
Early-life						
Mild physical activity	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (6.9)	27 (93.1)
Moderate physical activity	0 (0.0)	1 (3.4)	1 (3.4)	0 (0.0)	12 (41.4)	15 (51.7)
Vigorous physical activity	9 (31.0)	1 (3.4)	4 (13.8)	0 (0.0)	9 (31.0)	6 (20.7)

Figure 4.12. Frequency of Current Physical Activity for All Participants, N=29.

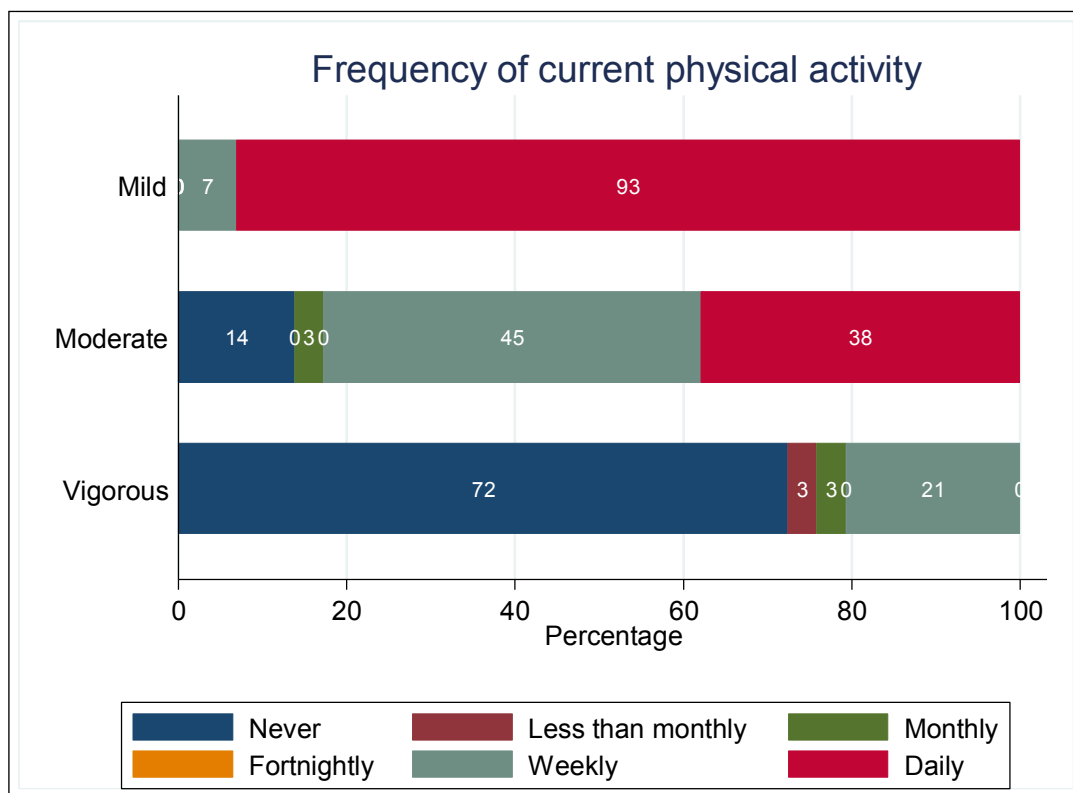
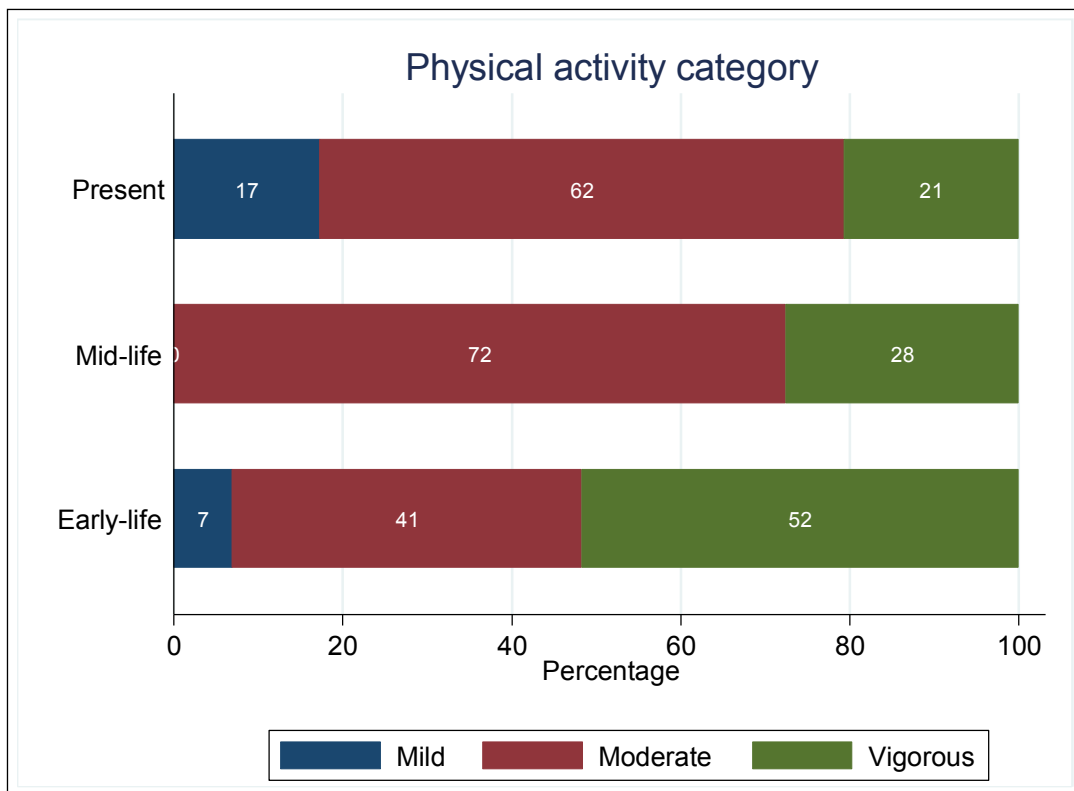


Table 4.29. Physical Activity Category for All Participants (N=29)

	n (%)
Present	
Mild	5 (17.2)
Moderate	18 (62.1)
Vigorous	6 (20.7)
Mid-life	
Mild	0 (0.0)
Moderate	21 (72.4)
Vigorous	8 (27.6)
Early	
Mild	2 (6.9)
Moderate	12 (41.4)
Vigorous	15 (51.7)

Figure 4.13. Physical Activity Category for All Participants, N=29.



4.4.1.2.2 Results according to group (2 groups).

The distribution of physical activity frequencies by group are presented in Table 4.30. No statistically significant differences were found between the two groups for either current frequency or past (mid-life; early-life) frequency. The distribution of physical activity categories by group are presented in Table 4.31 and Figure 4.10. Again, no statistically significant differences were found between the two groups.

Table 4.30 Frequency of Physical Activity by Group (2 Groups)

	Group One (n=15)	Group Two (n=14)	p-value ¹
	n (%)	n (%)	
Present frequency of			
Mild physical activity			0.224
Weekly	0 (0.0)	2 (14.3)	
Daily	15 (100.0)	12 (85.7)	
Moderate physical activity			0.497
Never	1 (6.7)	3 (21.4)	
Less than monthly	0 (0.0)	0 (0.0)	
Monthly	0 (0.0)	1 (7.1)	
Fortnightly	0 (0.0)	0 (0.0)	
Weekly	8 (53.3)	5 (35.7)	
Daily	6 (40.0)	5 (35.7)	
Vigorous physical activity			0.073
Never	8 (53.3)	13 (92.9)	
Less than monthly	1 (6.7)	0 (0.0)	
Monthly	1 (6.7)	0 (0.0)	
Fortnightly	0 (0.0)	0 (0.0)	
Weekly	5 (33.3)	1 (7.1)	
Daily	0 (0.0)	0 (0.0)	
Mid-life frequency of			
Mild physical activity			-
Daily	15 (100.0)	14 (100.0)	
Moderate physical activity			0.466
Weekly	6 (40.0)	8 (57.1)	
Daily	9 (60.0)	6 (42.9)	
Vigorous physical activity			0.140
Never	2 (13.3)	8 (57.1)	
Less than monthly	1 (6.7)	1 (7.1)	
Monthly	4 (26.7)	3 (21.4)	
Fortnightly	2 (13.3)	0 (0.0)	
Weekly	4 (26.7)	1 (7.1)	
Daily	2 (13.3)	1 (7.1)	
Early-life frequency of			
Mild physical activity			0.224
Weekly	0 (0.0)	2 (14.3)	
Daily	15 (100.0)	12 (85.7)	
Moderate physical activity			0.448
Never	0 (0.0)	0 (0.0)	
Less than monthly	0 (0.0)	1 (7.1)	
Monthly	1 (6.7)	0 (0.0)	
Fortnightly	0 (0.0)	0 (0.0)	
Weekly	5 (33.3)	7 (50.0)	
Daily	9 (60.0)	6 (42.9)	
Vigorous physical activity			0.754
Never	3 (20.0)	6 (42.9)	
Less than monthly	1 (6.7)	0 (0.0)	
Monthly	2 (13.3)	2 (14.3)	
Fortnightly	0 (0.0)	0 (0.0)	
Weekly	5 (33.3)	4 (28.6)	
Daily	4 (26.7)	2 (14.3)	

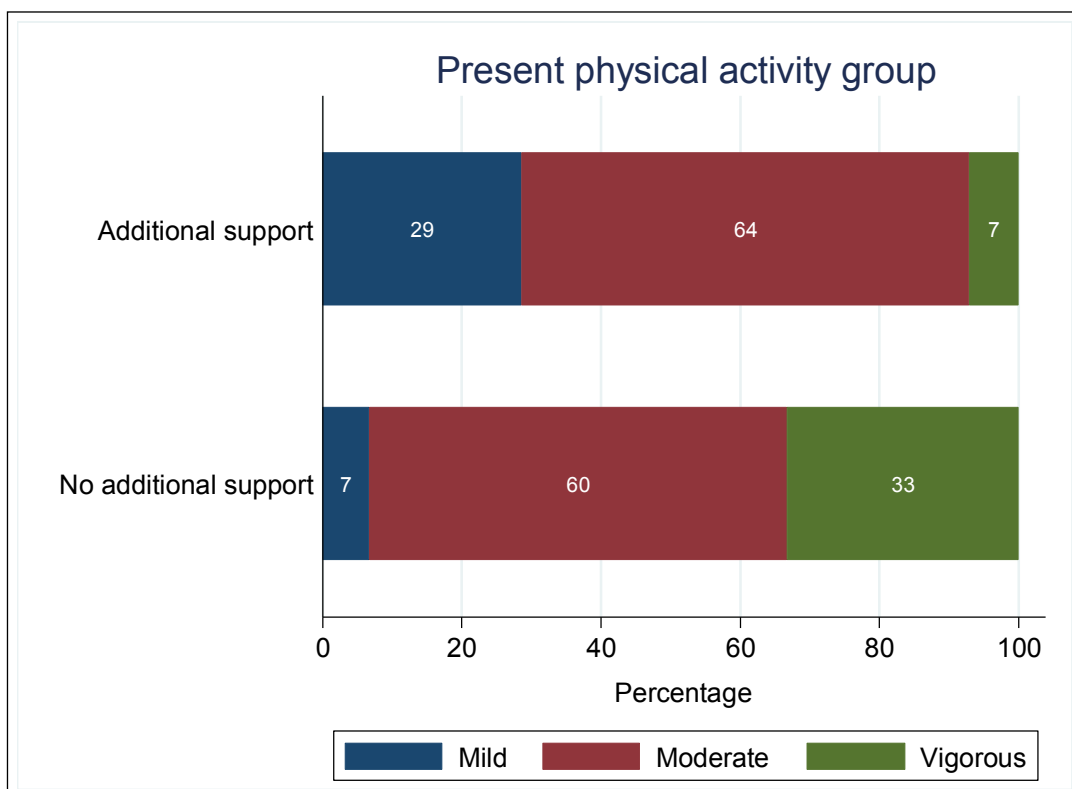
¹from Fisher's exact test

Table 4.31 Physical Activity Category by Group (2 Groups)

	Group One (n=15)	Group Two (n=14)	p-value ¹
	n (%)	n (%)	
Present			0.136
Mild	1 (6.7)	4 (28.6)	
Moderate	9 (60.0)	9 (64.3)	
Vigorous	5 (33.3)	1 (7.1)	
Mid-life			0.215
Mild	0 (0.0)	0 (0.0)	
Moderate	9 (60.0)	12 (85.7)	
Vigorous	6 (40.0)	2 (14.3)	
Early			0.715
Mild	1 (6.7)	1 (7.1)	
Moderate	5 (33.3)	7 (50.0)	
Vigorous	9 (60.0)	6 (42.9)	

¹from Fisher's exact test

Figure 4.14 Present Physical Activity Category by Group



4.4.1.2.3 Present moderate physical activity: split by group (2 groups.)

Current engagement in moderate physical activity lasting 30 minutes or more and frequency of such activity split by group are described in Table 4.32. Engagement in moderate physical activity was significantly greater for Group One ($p=0.021$). For those who engaged in moderate physical activity lasting 30 minutes or more, the frequency of moderate physical activity was not significantly different between the two groups ($p=0.781$).

Table 4.32 Present Moderate Physical Activity by Group (2 Groups)

	Group One (n=15)	Group Two (n=14)	p-value ¹
	n (%)	n (%)	
Engages in moderate physical activity lasting 30 minutes or more			0.021
No	2 (13.3)	8 (57.1)	
Yes	13 (86.7)	6 (42.9)	
Frequency per week of moderate physical activity lasting 30 minutes or more ²			0.781
1-2 times	2 (15.4)	2 (33.3)	
3-4 times	2 (15.4)	1 (16.7)	
≥ 5 times	9 (69.2)	3 (50.0)	

¹from Fisher's exact test

²of those who engage in moderate physical activity lasting 30 minutes or more

4.4.2 Relationship between Decision Making Abilities (ACED – Medication Management) and Cognitive Reserve

4.4.2.1 All participants.

The relationships between the measures of the assessment of capacity of everyday decision making in Medication Management and measures of Cognitive Reserve as yielded by administration of the LEQ were investigated using Spearman's correlation coefficient and the results are presented in Table 4.33. For all measures of decision making abilities,

except expressing a choice, there was a moderate to strong, positive, statistically significant relationship with the overall total CR measure and the CR measure yielded at each of the life-periods, indicating that participants with stronger decision making abilities with regard to Medication Management had a greater measure of Cognitive Reserve.

Table 4.33. Spearman's Correlation between Assessment of Capacity of Everyday Decision Making (ACED – Medication Management) and Measures of CR (LEQ) for All Participants (N=29)

		Assessment of Capacity of Everyday Decision Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive reserve (LEQ)	Total LEQ	0.45*	0.45*	0.43*	0.50*	0.14
	Young Adulthood					
	Subscore	0.44*	0.45*	0.42*	0.45*	0.07
	Stage specific	0.30	0.29	0.31	0.32	-0.06
	Non-stage specific	0.30	0.42*	0.24	0.29	0.14
	Mid Life					
	Subscore	0.43*	0.41*	0.49*	0.46*	0.16
	Stage specific	0.30	0.29	0.32	0.31	0.13
	Non-stage specific	0.37	0.36	0.37*	0.44*	0.14
	Education Bonus	0.30	0.26	0.20	0.32	0.00
	Late Life					
	Subscore	0.53*	0.44*	0.44*	0.59*	0.17
	Stage specific	0.42*	0.44*	0.43*	0.46*	0.13
	Non-stage specific	0.43*	0.36	0.37*	0.51*	0.16
	Education Bonus	-	-	-	-	-
	Work Bonus	0.05	0.01	0.03	-0.01	-0.19

*p<0.05

4.4.2.2 By group.

The relationships between the measures of the assessment of capacity of everyday decision making in Medication Management and measures of Cognitive as yielded by administration of the LEQ Reserve for the two groups were investigated using Spearman's correlation coefficient and the results are presented in Table 4.34. For Group Two, the relationship between decision making abilities and lifetime cognitive reserve was positive in direction indicating that participants with stronger decision making abilities re

Medication Management had a greater measure of CR. However, this relationship was weak in magnitude.

For Group One, the relationship was negative in direction indicating that within this group, participants with stronger decision making abilities with regard to Medication Management had lower cognitive reserve.

Table 4.34. Spearman's correlation between Assessment of Capacity of Everyday Decision Making (ACED – Medication Management) and Measures of CR (LEQ) by Group (2 Groups)

		Group One (n=15)				
		<u>Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)</u>				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive reserve (LEQ)	Total LEQ	-0.33	-0.02	-0.27	-0.29	-0.31
	Young Adulthood					
	Subscore	-0.28	0.09	-0.23	-0.40	-0.37
	Stage specific	-0.33	-0.16	-0.27	-0.43	-0.22
	Non-stage specific	-0.04	0.37	-0.12	-0.15	-0.37
	Mid Life					
	Subscore	-0.32	-0.27	0.08	-0.31	-0.19
	Stage specific	-0.01	0.07	0.22	-0.25	-0.06
	Non-stage specific	-0.50	-0.39	-0.34	-0.19	-0.25
	Education Bonus	0.11	0.43	-0.04	0.13	-0.29
	Late Life					
	Subscore	0.08	0.18	-0.05	0.31	0.03
	Stage specific	-0.02	0.07	0.09	0.10	-0.34
	Non-stage specific	0.03	0.07	-0.13	0.30	0.22
	Education Bonus	-	-	-	-	-
	Work Bonus	0.05	0.19	0.19	-0.14	0.13
		Group Two (n=14)				
		<u>Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)</u>				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive reserve (LEQ)	Total LEQ	0.11	0.31	0.27	-0.01	0.32
	Young Adulthood					
	Subscore	0.08	0.37	0.33	-0.13	0.13
	Stage specific	-0.26	0.01	0.04	-0.50	-0.31
	Non-stage specific ²	0.13	0.26	0.17	0.08	0.42
	Mid Life					
	Subscore	0.24	0.39	0.42	0.12	0.32
	Stage specific	0.04	0.11	-0.06	0.08	0.24
	Non-stage specific ²	0.22	0.38	0.29	0.07	0.31
	Education Bonus	-0.38	-0.37	-0.14	-0.39	0.11
	Late Life					
	Subscore	0.09	0.19	0.20	-0.03	0.19
	Stage specific	0.15	0.34	0.25	0.05	0.31
	Non-stage specific ²	0.04	0.17	0.21	-0.02	0.00
	Education Bonus	-	-	-	-	-
	Work Bonus	-0.45	-0.48	-0.47	-0.46	-0.73*

*p<0.05

4.4.3 Relationship between Decision Making Abilities (ACED – Money Management) and Cognitive Reserve

4.4.3.1 All participants.

The relationships between the measures of capacity of everyday decision making re Money Management (ACED) and measures of Cognitive Reserve (LEQ) were investigated using Spearman's correlation coefficient. The results are presented in Table 4.35. For all measures of decision making abilities, there was a moderate to strong, positive, statistically significant relationship with overall Total Lifetime CR measure and the Life Period CR measures yielded, indicating that participants with greater decision making abilities with regard to money management had greater measures of CR ($p < 0.05$ for all).

Table 4.35. Spearman's correlation between Assessment of Capacity of Everyday Decision Making (ACED – Money Management) and Measures of CR (LEQ) for All Participants (N=29)

		Assessment of Capacity of Everyday Decision Making				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive reserve (LEQ)	Total LEQ	0.61*	0.57*	0.59*	0.53*	0.41*
	Young Adulthood					
	Subscore	0.57*	0.52*	0.54*	0.52*	0.41*
	Stage specific	0.48*	0.38*	0.40*	0.48*	0.20
	Non-stage specific ²	0.37	0.44*	0.39*	0.26	0.41*
	Mid Life					
	Subscore	0.63*	0.57*	0.61*	0.55*	0.41*
	Stage specific	0.48*	0.40*	0.44*	0.38*	0.15
	Non-stage specific ²	0.53*	0.60*	0.56*	0.44*	0.42*
	Education Bonus	0.24	0.13	0.28	0.20	0.19
	Late Life					
	Subscore	0.56*	0.58*	0.61*	0.48*	0.40*
	Stage specific	0.59*	0.53*	0.52*	0.50*	0.38*
	Non-stage specific ²	0.44*	0.52*	0.52*	0.39*	0.41*
	Education Bonus	-	-	-	-	-
	Work Bonus	0.11	-0.01	-0.01	0.09	-0.27

*p<0.05

4.4.3.2 By group.

The relationships between the measures of capacity of everyday decision making re Money Management (ACED) and measures of Cognitive Reserve (LEQ) were investigated using Spearman's correlation coefficient. The results are presented in Table 4.36. For Group Two, the relationship between overall ACED Total Scores and Lifetime Cognitive Reserve was moderate in magnitude and positive in direction indicating that participants with greater decision making abilities re money management had greater cognitive reserve. For Group Two, this relationship was very weak.

Table 4.36. Spearman's correlation between Assessment of Capacity of Everyday Decision Making

(ACED – Money Management) and measures of CR (LEQ) by Group (2 Groups)

		Group One (n=15)				
		Assessment of Capacity of Everyday Decision Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive reserve (LEQ)	Total LEQ	0.09	0.19	-	0.08	-
	Young Adulthood					
	Subscore	0.03	0.25	-	0.00	-
	Stage specific	0.16	0.16	-	0.16	-
	Non-stage specific	-0.06	0.28	-	-0.10	-
	Mid Life					
	Subscore	0.07	0.00	-	0.08	-
	Stage specific	-0.03	-0.25	-	0.00	-
	Non-stage specific	0.03	0.37	-	-0.02	-
	Education Bonus	-0.20	-0.29	-	-0.18	-
	Late Life					
	Subscore	-0.18	0.03	-	-0.19	-
	Stage specific	-0.08	0.09	-	-0.10	-
	Non-stage specific	-0.18	-0.13	-	-0.18	-
	Education Bonus			-		-
	Work Bonus	0.25	0.13	-	0.25	-
		Group Two (n=14)				
		Assessment of Capacity of Everyday Decision Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Cognitive reserve (LEQ)	Total LEQ	0.31	0.47	0.25	0.19	0.51
	Young Adulthood					
	Subscore	0.25	0.40	0.18	0.26	0.51
	Stage specific	-0.09	-0.02	-0.16	0.04	-0.05
	Non-stage specific ²	0.21	0.33	0.20	0.08	0.51
	Mid Life					
	Subscore	0.50	0.60*	0.42	0.37	0.51
	Stage specific	0.19	0.23	0.05	0.03	-0.05
	Non-stage specific ²	0.32	0.51	0.27	0.23	0.54*
	Education Bonus	-0.14	-0.11	0.00	-0.25	0.11
	Late Life					
	Subscore	0.33	0.51	0.28	0.20	0.50
	Stage specific	0.46	0.47	0.24	0.35	0.43
	Non-stage specific ²	0.26	0.50	0.19	0.21	0.50
	Education Bonus	-	-	-	-	-
	Work Bonus	-0.45	-0.48	-0.47	-0.46	-0.73*

*p<0.05

4.4.4.2 Relationship between Decision Making Abilities (ACED) and Physical Activity Measures.

For the analysis presented in this section, the categorisation of physical activity at each life-stage (into mild/moderate/vigorous) as presented in Section 4.1.2 has been used.

Analysis split by group has not been performed as the numbers within each of the physical activity categories are very small and it would not be possible to find statistical significance (even if the observed differences were large).

4.4.4.2.1 *ACED (medication management) and physical activity measures.*

The relationships between the measures of capacity of everyday decision making (ACED) re Medication Management and the Physical Activity Category (Present, during Mid-life and Early-life) were investigated using the Kruskal-Wallis test and the results are presented in Table 4.37. No statistically significant relationships were found between the measures of Decision Making Abilities with regard to Medication Management and the Physical Activity Category during any life-stage.

Table 4.37. Relationship between ACED (Medication Management) and Physical Activity Category during each Life Stage for All Participants (N=29))

	median (IQR)	median (IQR)	median (IQR)	p-value ³
Present physical activity	Mild (n=5)	Moderate (n=18)	Vigorous (n=6)	
Overall (0-30) ²	19 (17 to 29.5)	29 (25.5 to 30)	29.5 (26.8 to 30)	0.339
Understanding (0-10) ²	9 (4.5 to 10)	10 (9 to 10)	10 (9.8 to 10)	0.256
Appreciation (0-8) ²	5 (3 to 8)	8 (7.8 to 8)	7.5 (6.5 to 8)	0.217
Reasoning (0-10) ²	9 (4.5 to 9.5)	9.5 (6 to 10)	10 (9 to 10)	0.233
Expressing a choice (0-2) ²	2 -	2 (2 to 2)	2 -	0.374
Mid-life physical activity	Mild (n=0)	Moderate (n=21)	Vigorous (n=8)	
Overall (0-30) ²	- -	29 (21.5 to 30)	29.5 (23.8 to 30)	0.684 ⁴
Understanding (0-10) ²	- -	10 (9 to 10)	10 (9.3 to 10)	0.756 ⁴
Appreciation (0-8) ²	- -	8 (6 to 8)	8 (5.5 to 8)	0.943 ⁴
Reasoning (0-10) ²	- -	9 (5.5 to 10)	10 (9 to 10)	0.279 ⁴
Expressing a choice (0-2) ²	- -	2 (2 to 2)	2 -	0.582 ⁴
Early-life physical activity	Mild (n=2)	Moderate (n=12)	Vigorous (n=15)	
Overall (0-30) ²	27 (24 to 30) ⁵	29 (18.3 to 30)	29 (26 to 30)	0.991
Understanding (0-10) ²	10 -	10 (7.5 to 10)	10 (9 to 10)	0.492
Appreciation (0-8) ²	8 -	8 (5 to 8)	8 (7 to 8)	0.591
Reasoning (0-10) ²	7.5 (5 to 10) ⁵	9.5 (5.3 to 10)	9 (9 to 10)	0.918
Expressing a choice (0-2) ²	1.5 (1 to 2) ⁵	2 -	2 (2 to 2)	0.106

¹higher score represents better performance on the ability measure

²possible range

³from Kruskal-Wallis test unless otherwise stated

⁴from Mann-Whitney U test

⁵minimum to maximum as n=2

4.4.4.2.1 *ACED (money management) and physical activity measures.*

The relationships between the measures of Capacity of Everyday Decision Making (ACED) in Money Management and Physical Activity Category (Present, during Mid-life and Early-life) were investigated using the Kruskal-Wallis test and the results are presented in Table 4.38. No statistically significant relationships were found between measures of decision making abilities with regard to Money Management and physical activity category during any life-stage.

Table 4.38. Relationship between ACED (Money Management) and Physical Activity Category during each Life Stage for All Participants (N=29)

	median (IQR)		median (IQR)	median (IQR)	p-value ³
Present physical activity	Mild (n=5)		Moderate (n=18)	Vigorous (n=6)	
Overall (0-30) ²	24 (19.5 to 30)		29.5 (28 to 30)	30 (28.3 to 30)	0.383
Understanding (0-10) ²	7 (6 to 10)		10 (9 to 10)	10 -	0.086
Appreciation (0-8) ²	7 (4.5 to 8)		8 (7.8 to 8)	8 (7.5 to 8)	0.228
Reasoning (0-10) ²	8 (7 to 10)		10 (9 to 10)	10 (8.8 to 10)	0.468
Expressing a choice (0-2) ²	2 -		2 (2 to 2)	2 -	0.531
Mid-life physical activity	Mild (n=0)		Moderate (n=21)	Vigorous (n=8)	
Overall (0-30) ²	- -		29 (25 to 30)	30 (30 to 30)	0.067 ⁴
Understanding (0-10) ²	- -		10 (8.5 to 10)	10 (10 to 10)	0.429 ⁴
Appreciation (0-8) ²	- -		8 (6.5 to 8)	8 (8 to 8)	0.429 ⁴
Reasoning (0-10) ²	- -		9 (8 to 10)	10 (10 to 10)	0.093 ⁴
Expressing a choice (0-2) ²	- -		2 (2 to 2)	2 -	0.720 ⁴
Early-life physical activity	Mild (n=2)		Moderate (n=12)	Vigorous (n=15)	
Overall (0-30) ²	29 (28 to 30) ⁵		28.5 (24 to 30)	30 (29 to 30)	0.525
Understanding (0-10) ²	10 -		9.5 (7.3 to 10)	10 (10 to 10)	0.138
Appreciation (0-8) ²	7 (6 to 8) ⁵		8 (7 to 8)	8 (8 to 8)	0.696
Reasoning (0-10) ²	10 -		9 (7.3 to 10)	10 (9 to 10)	0.301
Expressing a choice (0-2) ²	2 -		2 (2 to 2)	2 (2 to 2)	0.920

¹higher score represents better performance on the ability measure

²possible range

³from Kruskal-Wallis test unless otherwise stated

⁴from Mann-Whitney U test

⁵minimum to maximum as n=2

SECTION 4.5 Hypotheses Three –

- c. A Relationship will be indicated between Elements of DMC and an Individual's Preference to Participate in Decision Making.**
- d. A Relationship will be indicated between Elements of DMC and an Individual's Participation in Decision Making.**

Decision making abilities for both Medication Management and Money Management were measured using the Assessment of Capacity for Everyday Decision Making (ACED). Results for these ACED measures are presented previously in Section 4.2 of this Results chapter.

Measures of an individual's Preference to Participate in Decision Making were obtained from responses to number of items regarding everyday decision making situations. Results for these preferences are presented below for all participants and according to group in Tables 4.39, 4.40, 4.41, 4.42 and Figures 4.15, 4.16 and 4.17.

Measures of an individual's Participation in Decision Making opportunities were obtained from responses to number of items regarding everyday decision making situations. Results regarding participation are presented below for all participants and according to group in Tables 4.43, 4.44, 4.45, 4.46, 4.47 and 4.48 and Figures 4.18, 4.19 and 4.20.

To examine this hypothesis, relationships using Spearman's correlation coefficient were investigated between:

- Elements of decision making as measured by administration of the ACED re Medication Management and measures of an individual's Preference to Participate in Decision Making

- Elements of decision making as measured by administration of the ACED re Money Management and measures of an individual's Preference to Participate in Decision Making
- Elements of decision making as measured by administration of the ACED re Medication Management and measures of an individual's Participation in Decision Making opportunities
- Elements of decision making as measured by administration of the ACED re Money Management and measures of an individual's Participation in Decision Making opportunities

The results for each of these investigations are presented in Tables 4.49, 4.50, 4.51, 4.52, 4.53, 4.54, 4.55 and 4.56.

4.5.1 Assessment of Preference to Participate in Decision Making

4.5.1.1 All participants.

The summary statistics for the subscales and overall scale measuring preference to participate in decision making are presented in Table 4.39 (scores converted to 1-6 scale), Figure 4.15 (scores converted to 1-6 scale) and Figure 4.16 (scores converted to 1-6 scale). Table J.01 with original data prior to conversion is included in Appendix J. With the exception of the Illness subscale, the participants scored highly on the subscales and the overall scale, indicating that they had a strong preference for autonomous decision making. In contrast, participants did not have a preference for autonomous decision making regarding their medical care.

Table 4.39. Summary Statistics (converted) for Measures of Preference in Decision-Making* for All Participants (N=29)

	Summary statistics			
	possible range	observed range	mean(SD)	median(IQR)
Overall scale	1 to 6	3.6 to 5.6	4.8 (0.5)	4.9 (4.5 to 5.1)
Subscales				
Getting up	1 to 6	4 to 6	5.6 (0.6)	6 (5 to 6)
Eating	1 to 6	2.5 to 6	5.6 (0.7)	6 (5.5 to 6)
Money	1 to 6	4 to 6	5.5 (0.7)	6 (5 to 6)
TV	1 to 6	4 to 6	5.7 (0.6)	6 (5.8 to 6)
Illness	1 to 6	1 to 5.3	2.8 (1.0)	2.7 (2.3 to 2.7)

*higher score represents greater autonomy

Figure 4.15. Distribution of Scores (converted) re Preference in Decision Making for All Participants, N=29.

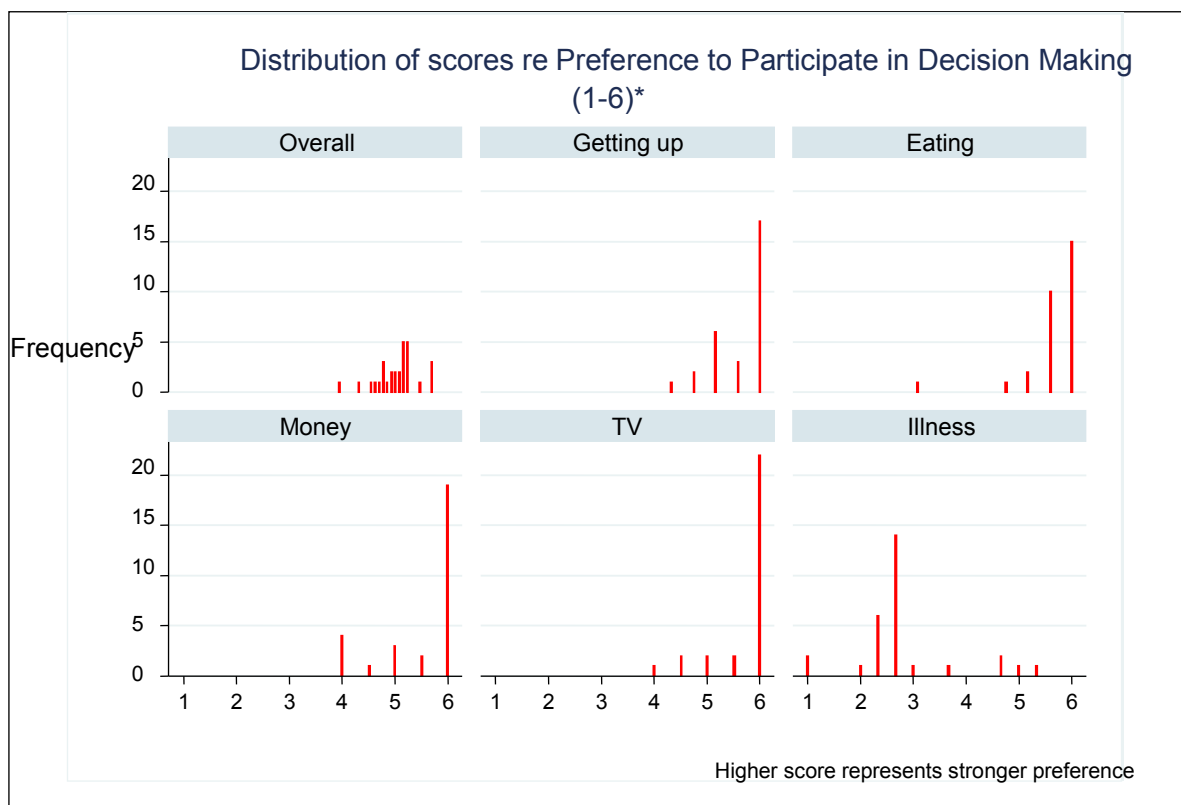
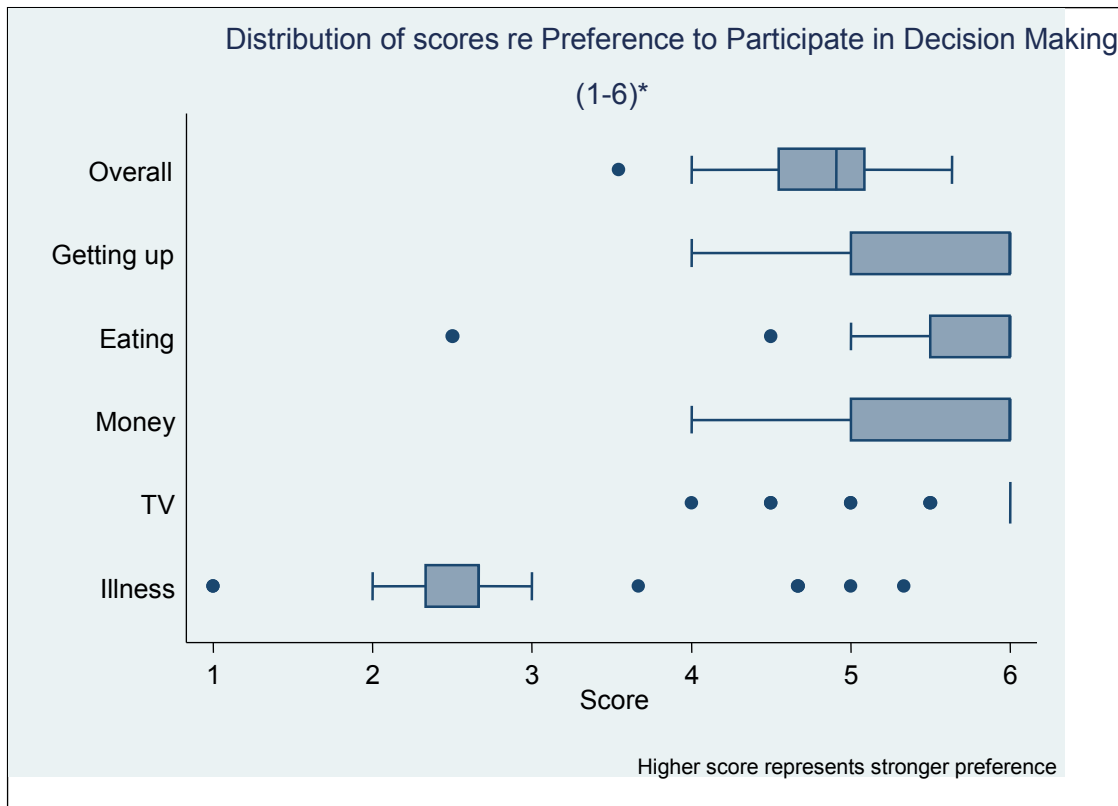


Figure 4.16. Distribution of Scores (converted) re Preference in Decision Making, N=29.



4.5.1.2 Preference to Participate in Decision Making by Group.

The summary statistics for the subscales and overall scale measuring preference to participate in decision making for each of the two groups are presented in Table 4.40 (scores converted to 1-6 scale). Table J.02 with original data prior to conversion are included in Appendix J.

The only statistically significant difference found between the two groups for preference to participate in decision making was with regard to situations concerning money ($p=0.041$). Group Two had the lower median score, indicating that, in general, this group had a lesser preference for participating in decision making with regards to money.

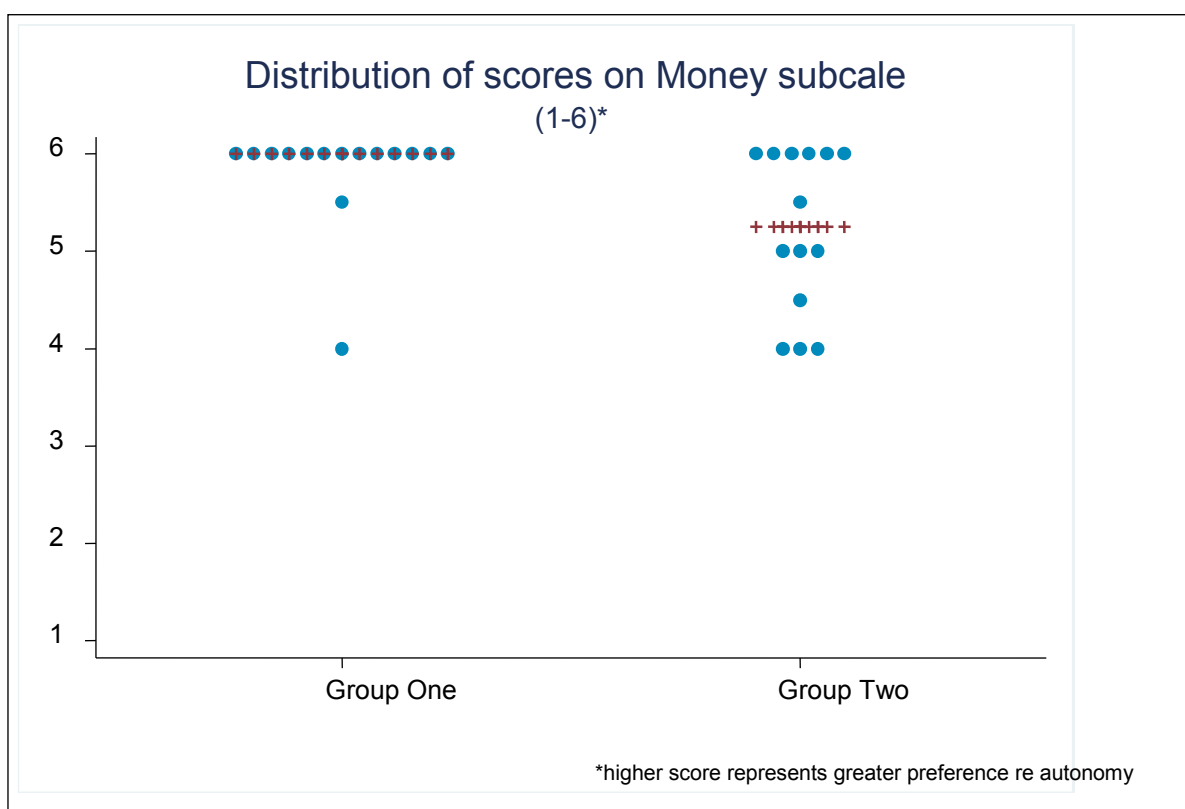
Table 4.40. Preference re Decision Making Participation¹ by Group (converted)

	Group One (n=15)	Group Two (n=14)	
	median (IQR)	median (IQR)	p-value ²
Overall scale	5 (4.7 to 5.1)	4.8 (4.4 to 5)	0.070
Subscales			
Getting up	6 (5.5 to 6)	5.8 (5 to 6)	0.477
Eating	5.5 (5.5 to 6)	6 (5.5 to 6)	0.652
Money	6 (6 to 6)	5.3 (4.4 to 6)	0.041
TV	6 (5 to 6)	6 (6 to 6)	0.331
Illness	2.7 (2.3 to 4.7)	2.7 (2.3 to 2.7)	0.146

¹possible range 1-6 with higher score representing greater autonomy

²from Mann-Whitney U test

Figure 4.17. Distribution of Scores (converted) re Preference to Participate (Money subscale) by Group.



4.5.2 Assessment of Participation in Decision Making

4.5.2.1 All participants.

The summary statistics for the subscales and overall scale measuring participation in decision making are presented in Table 4.41 (scores converted to 0-3 scale), Figure 4.18 (scores converted to 0-3 scale) and Figure 4.19 (scores converted to 0-3 scale). Table K.01 with original data prior to conversion are included/available/contained in Appendix K.

Participants scored highly on the subscales and the overall scale, indicating that they participated in decision making.

Table 4.41. Summary Statistics (converted) for Measures of Participation in Decision-Making¹ for All Participants (N=29)

	Summary statistics			
	possible range	observed range	mean(SD)	median(IQR)
Overall scale	0 to 3	1.3 to 3	2.8 (0.4)	3 (2.9 to 3)
Subscales				
Getting up	0 to 3	1.2 to 3	2.8 (0.4)	3 (3 to 3)
Eating	0 to 3	1 to 3	2.8 (0.5)	3 (3 to 3)
Money	0 to 3	1 to 3	2.8 (0.5)	3 (3 to 3)
TV	0 to 3	1 to 3	2.8 (0.5)	3 (3 to 3)
Illness	0 to 3	2 to 3	2.9 (0.3)	3 (3 to 3)

¹higher score represents greater autonomy

Figure 4.18. Distribution of Scores (converted) on Participation in Decision-Making scale and subscales for All Participants, N=29.

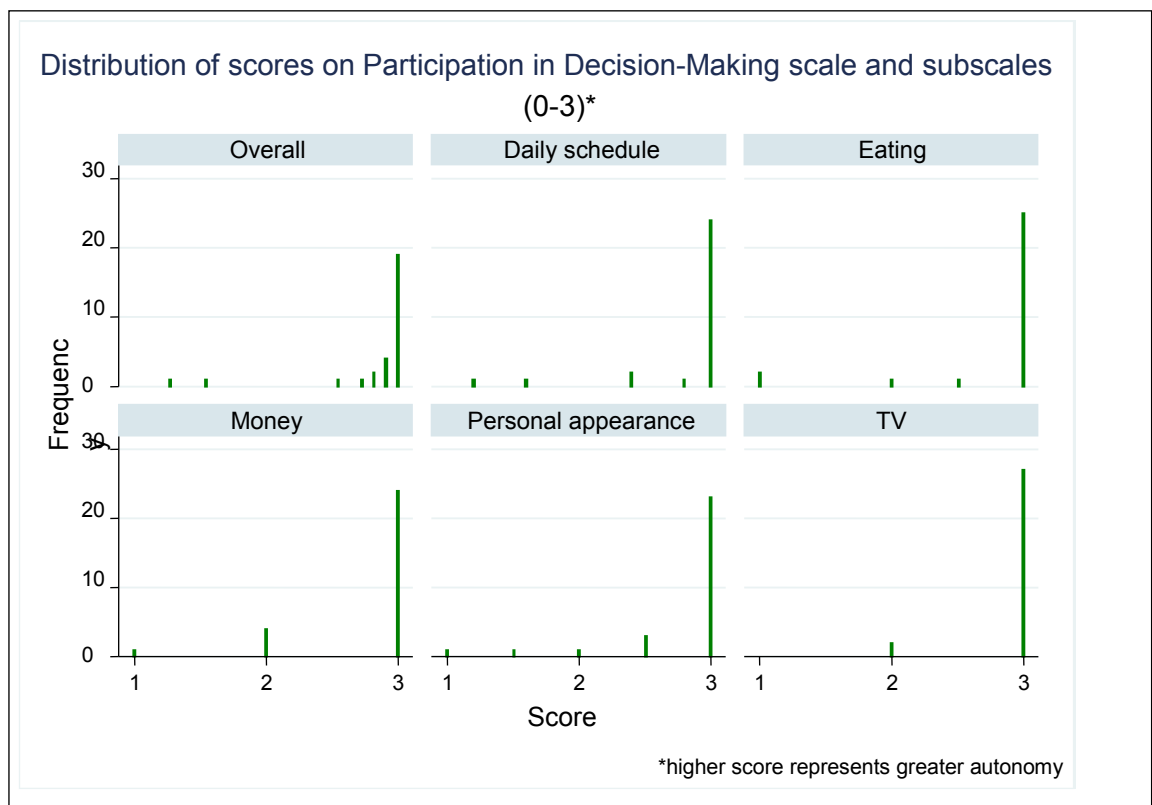
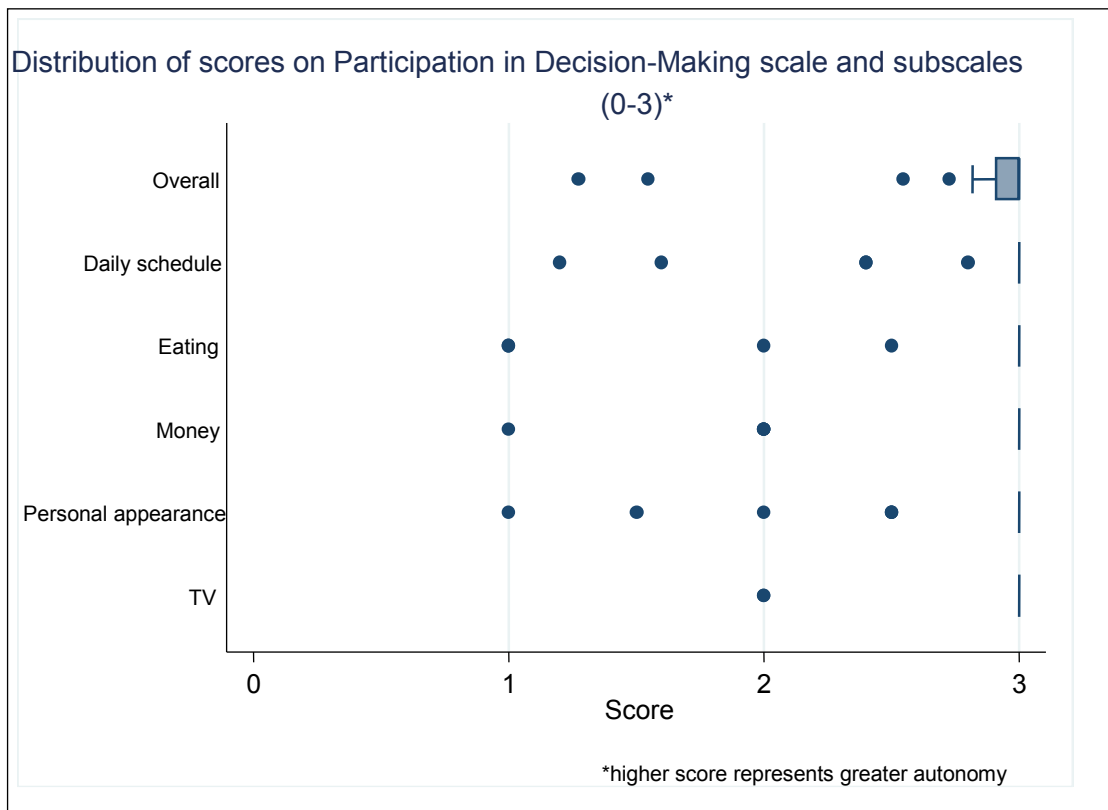


Figure 4.19. Distribution of Scores (converted) on Participation in Decision-Making scale and subscales, for All Participants (n=29).



4.5.2.2 Participation in decision making – choosing staff/home help: all participants.

Some form of assistance, ranging from help with household chores to full time organisational staff, was reported by 16 of the 29 participants (55.2%). As illustrated in Table 4.42, 11 of the 16 reported that the person providing this assistance was chosen by someone else, five reported that they choose the person.

Table 4.42. The Choice of Staff/Home Help for Individuals (n=29)

Who Chose Staff/Home Help	Frequency	Percent
Not Applicable	13	44.8
Someone Else	11	37.9
Person Chose	5	17.2
Total	29	100.0

In addition, seven of the participants had a “Keyworker” – a member of staff assigned to co-ordinate their care and support specifically. As illustrated by Table 4.43 all seven reported that this Keyworker was chosen by someone else and not themselves. No participant reported choosing their Keyworker him/her self.

Table 4.43. The Choice of Keyworker for Individuals (n=29)

Who Chose Keyworker	Frequency	Percent
Not Applicable	22	75.9
Someone Else	7	24.1
Person Chose	0	0
Total	29	100.0

4.5.2.3 Results re participation in decision making by group.

The summary statistics for the subscales and overall scale measuring participation in decision making for each group are presented in Table 4.44 (scores converted to 0-3 scale) and Figure 4.20 (scores converted to 0-3 scale). Table K.02 with original data prior to conversion are included/available/contained in Appendix K.

A statistically significant difference was found between the two groups for overall opportunity to participate in decision making ($p=0.001$). Group Two had the lower median score, indicating that, in general, this group had less opportunity for participating in decision making overall compared to the opportunities to participate in decision making by Group One.

Table 4.44. Participation in Decision Making¹ by Group (converted)

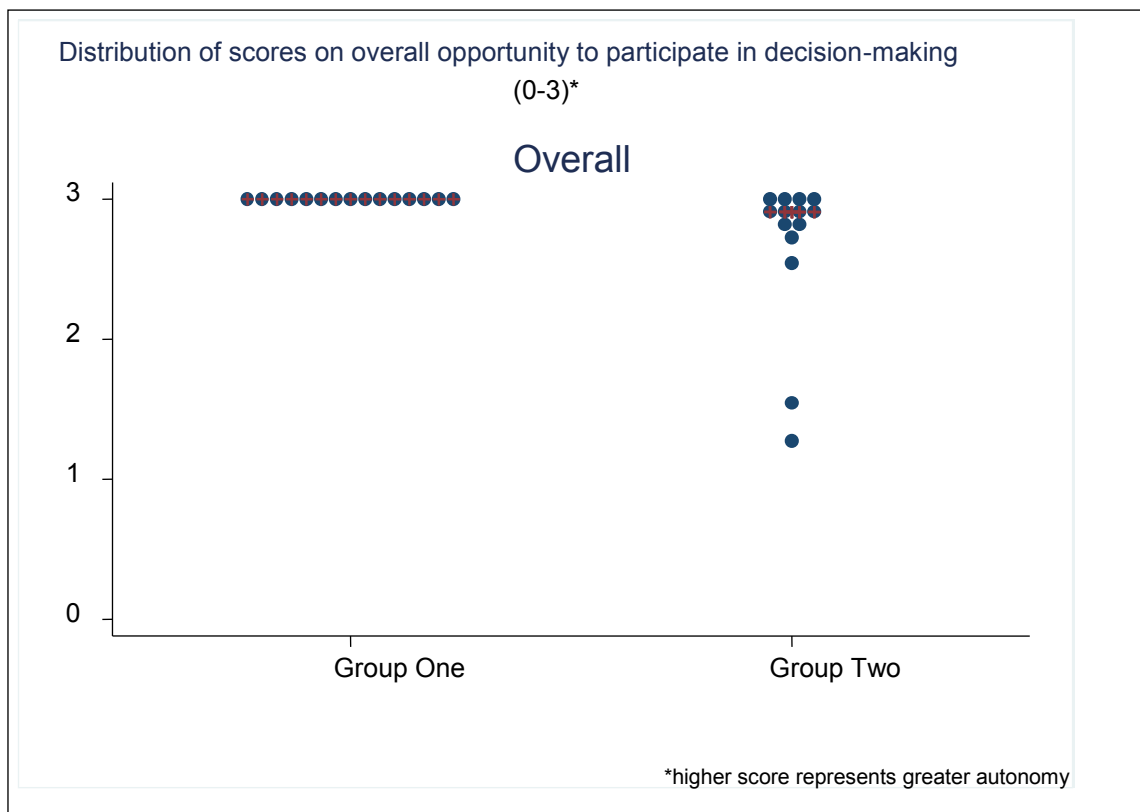
	Group One (n=15)		Group Two (n=14)		p-value ²
	median (IQR) ³		median (IQR)		
Overall scale	3	-	2.9 (2.7 to 3)		0.001
Subscales					
Daily schedule	3	-	3 (2.4 to 3)		0.102
Eating	3	-	3 (2.4 to 3)		0.201
Money	3	-	3 (2 to 3)		0.102
Personal Appearance	3	-	3 (2.4 to 3)		0.051
TV	3	-	3 (3 to 3)		0.533

¹possible range 0-3 with higher score representing greater autonomy

²from Mann-Whitney U test

³results are constant for this group

Figure 20. Distribution of Total Scores (converted) re Participation in Decision Making by Group.



4.5.3 Investigation of Relationships between Decision-Making Capacity (ACED) and Preference re Decision Making Participation

4.5.3.1 ACED – (Medication Management) and preference re decision making participation.

5.3.1.1 *All participants.*

The relationships between the elements of decision making in ACED – Medication Management and measures of Preference re participating in Decision Making were investigated using Spearman's correlation coefficient and the results are presented in Table 4.45. A weak, positive correlation ($r_s=0.24$) was found between the overall measure of capacity and the overall measure of preference with regard to decision making participation.

The strongest correlation was found between the decision making ability, Expressing a Choice and preference with regard to getting-up in the morning ($r_s=0.47$, $p=0.010$), indicating that participants with greater ability to Express a Choice had a stronger preference for decision-making specifically regarding getting-up. Medium, positive correlations were also found between the decision making ability Understanding and overall preference with regard to decision making ($r_s=0.36$), preference specifically regarding money decisions ($r_s=0.37$) and preference specifically re decisions with regard to illness ($r_s=0.34$), although these correlations were not statistically significant. Similarly, medium correlations were found between preference specifically regarding money decisions and the total overall score of Assessment of Everyday Decision Making Capacity (ACED) and all the elements' subscores except Expressing a Choice. Preferences regarding TV were negatively correlated with all measures of the elements of decision making, indicating that participants with greater measures on the decision making abilities had a weaker preference for Preference re decision making specifically regarding the TV.

Medium, negative, and statistically significant relationships were found between TV preference and the total overall score of ACED ($r_s=-0.38$, $p=0.041$), Appreciation ($r_s=-0.39$, $p=0.035$) and Reasoning ($r_s=-0.40$, $p=0.032$).

Table 4.45. Spearman's Correlation between Measures of Elements of DMC (Medication Management) and Measures of Preference re Decision Making for All Participants (N=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Preference re decision making - Autonomy	Overall	0.24	0.36	0.16	0.23	0.21
	Getting up	0.21	0.12	0.05	0.25	0.47*
	Eating	0.12	0.16	0.02	0.05	0.17
	Money	0.35	0.37	0.32	0.36	0.26
	Television	-0.38*	-0.21	-0.39*	-0.40*	-0.19
	Illness	0.23	0.34	0.22	0.28	0.14

* $p<0.05$

4.5.3.1.2 By group (2 groups).

The relationships between the measures of the elements of Decision Making in Medication Management and measures of Preference re Decision Making Participation by group were investigated using Spearman's correlation coefficient and the results are presented in Table 4.46.

For both groups there was a weak correlation between the overall measure of capacity and the overall measure of autonomy. For Group One, the strongest correlation was between capacity regarding Expressing a Choice and preference re decision making participation with regard to Getting-up ($r_s=0.52$), while for Group Two, the strongest correlation was between capacity regarding Expressing a Choice and the overall score for preference re participation in decision making ($r_s=0.50$). In general, weaker correlations were found between DMC and preference re decision making participation for Group One compared to those participants within Group Two.

Table 4.46. Spearman's Correlation between Measures of Elements of DMC (Medication Management) and Measures of Preference re Decision Making by Group (2 Groups)

Group One (n=15)						
Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)						
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Preference re decision making - Autonomy	Overall	-0.13	0.32	-0.11	-0.13	-0.19
	Getting up	-0.07	-0.27	-0.27	0.15	0.52*
	Eating	0.18	0.25	-0.05	0.23	0.41
	Money	-0.27	-0.15	-0.15	-0.19	-0.10
	Television	-0.21	0.16	-0.27	-0.34	-0.18
	Illness	-0.10	0.28	0.08	-0.05	-0.39
Group Two (n=14)						
Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)						
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Preference re decision making - Autonomy	Overall	0.27	0.29	0.14	0.21	0.50
	Getting up	0.28	0.28	0.13	0.22	0.39
	Eating	0.16	0.23	0.17	-0.05	0.02
	Money	0.35	0.41	0.32	0.22	0.39
	Television	-0.35	-0.38	-0.42	-0.28	-0.17
	Illness	0.24	0.24	0.13	0.34	0.49

*p<0.05

4.5.3.2 Investigation of relationships between ACED (MONEY MANAGEMENT) and preference re participation in decision making.

4.5.3.2.1 All participants.

The relationships between elements of decision making for Money Management as measured by administration of ACED and measures of Preferences with regard to Participation in Decision Making were investigated using Spearman's correlation coefficient. The results are presented in Table 4.47.

A weak, positive correlation ($r_s=0.25$) was found between the total overall ACED score with regard to Money Management and the overall measure of Preferences with regard to Decision Making. The strongest correlation was found between Understanding and preferences with regard to decision making specifically regarding Illness ($r_s=0.45$, $p=0.014$), indicating that participants with higher measure regarding Understanding had a stronger preference for decision-making specifically regarding Illness. Similarly, a medium

positive correlation was found between preferences with regard to decision making specifically regarding illness and the total overall ACED score and the individual decision making abilities scores, with the exception of Reasoning. A medium positive correlation was also found between preferences with regard to decision making specifically regarding Money and the elements of Understanding and Appreciation. Preferences in decision making specifically regarding TV were negatively correlated with all elements of decision making, indicating that participants with higher measures of decision making abilities re Money Management had a weaker preference for autonomous decision making regarding the TV. A medium, negative, and statistically significant relationship was found between TV preference and overall capacity ($r_s = -0.37$, $p = 0.045$).

Table 4.47. Spearman's Correlation between Elements of DMC (Money Management) and Measures of Preference re Decision Making for All Participants (N=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Preference re decision making - Autonomy	Overall	0.25	0.28	0.26	0.15	0.23
	Getting up	0.18	0.12	0.13	0.11	0.05
	Eating	0.08	-0.03	-0.13	0.18	0.20
	Money	0.28	0.31	0.40*	0.20	0.16
	Television	-0.37*	-0.20	-0.34	-0.37	-0.15
	Illness	0.36	0.45*	0.33	0.22	0.35

* $p < 0.05$

4.5.3.2.2 By group (2 groups).

The relationships between the elements of decision making in Money Management as measured by administration of the ACED and measures of Preference with regard to autonomous Decision Making for each group were investigated using Spearman's correlation coefficient. The results are presented in Table 4.48.

For both groups there was a weak correlation between the overall ACED Total Score and the overall measure of autonomy. For Group One, the strongest correlation was

between the decision making ability of Reasoning and preference for participating in decision making with regard to Eating ($r_s=0.46$) while for Group Two, the strongest correlation was between the decision making ability of Appreciation and preference for participating in decision making with regard to TV ($r_s=-0.42$).

Table 4.48. Spearman's Correlation between Elements of DMC (Money Management) and Measures of Preference re Decision Making by Group (2 Groups)

Group One (n=15)						
Assessment of Capacity of Everyday Decision Making (ACED - Money Management)						
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Preference re decision making - Autonomy	Overall	-0.07	0.03	-	-0.08	-
	Getting up	0.06	-0.18	-	0.09	-
	Eating	0.45	0.17	-	0.46	-
	Money	-0.19	-0.10	-	-0.20	-
	Television	-0.34	-0.18	-	-0.34	-
	Illness	0.04	0.36	-	0.00	-
Group Two						
Assessment of Capacity of Everyday Decision Making (ACED - Money Management)						
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Preference re decision making - Autonomy	Overall	0.17	0.25	0.15	-0.01	0.20
	Getting up	0.09	0.14	0.06	-0.03	0.03
	Eating	0.03	0.06	-0.03	0.18	0.34
	Money	0.17	0.26	0.24	0.08	0.12
	Television	-0.31	-0.15	-0.42	-0.32	-0.17
	Illness	0.34	0.41	0.27	0.12	0.41

* $p<0.05$

4.5.4 Investigation of Relationships between Decision-Making Capacity (ACED) and Participation in Decision Making

4.5.4.1 Between ACED (medication management) and participation in decision making

4.5.4.1.1 *All participants*

The relationships between the measures of elements of decision making for Medication Management as measured by Assessment of Capacity of Everyday Decision Making (ACED) and measures of Participation in decision making were investigated using Spearman's correlation coefficient. The results are presented in Table 4.49. A strong, positive, statistically significant correlation was found between the total overall ACED score and the overall measure Participation in Decision-Making ($r_s=0.69$, $p<0.001$) indicating that participants with higher measures of decision making abilities in Medication Management had greater opportunity to participate in decision-making. This was also the strongest correlation observed. In general, for all measures of participation, except TV, there was a positive relationship with measures of elements of decision making with the majority reaching statistical significance. No statistically significant relationships were found between participation in decision making regarding the TV and measures of the elements of decision making ($p>0.05$ for all).

Table 4.49. Spearman's Correlation between Elements of DMC (Medication Management) and Measures of Participation in Decision Making for All Participants (N=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Participation re decision making	Overall	0.69*	0.68*	0.62*	0.68*	0.31
	Daily schedule	0.52*	0.41*	0.50*	0.48*	0.46*
	Eating	0.34	0.49*	0.44*	0.26	0.24
	Money	0.60*	0.58*	0.55*	0.55*	0.49*
	Personal appearance	0.64*	0.65*	0.60*	0.59*	0.18
	TV	0.06	0.16	0.13	-0.08	-0.09

*p<0.05

4.5.4.2.2 By group (2 groups).

The relationships between the elements of decision making as measured by administration of the ACED re Medication Management and measures of Participation re Decision Making for each group were investigated using Spearman's correlation coefficient. The results are presented in Table 4.50.

As there was no variability in any of the measures of opportunity to participate in decision making for Group One, no correlations could be calculated for this group. For Group Two there was a strong, positive, statistically significant correlation between the overall ACED Total Score and the overall measure of participation in decision-making ($r_s=0.65$, $p=0.012$) indicating that participants with higher measures of decision making abilities in medication management had greater opportunity to participate in decision-making. In general, there was a positive relationship between elements of DMC and measures of opportunity to participate in decision-making. The weakest relationships were found between autonomy regarding the TV and the elements of decision making, with the exception of Reasoning.

Table 4.50. Spearman's Correlation between Elements of DMC (Medication Management) and Measures of Participation in Decision Making for Group Two (N=14)

Group Two (n=14)		Assessment of Capacity of Everyday Decision Making (ACED - Medication Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Participation re decision making	Overall	0.65*	0.69	0.53	0.47	0.46
	Daily schedule	0.47	0.43	0.47	0.30	0.55*
	Eating	0.32	0.51	0.42	0.05	0.29
	Money	0.63	0.60*	0.57*	0.47	0.64*
	Personal appearance	0.72*	0.70*	0.60*	0.49	0.23
	TV	-0.08	0.08	0.03	-0.44	-0.17

*p<0.05

4.5.4.2 Investigation of Relationships between ACED (Money management) and participation in decision making .

4.5.4.2.1 All participants

The relationships between the measures of elements of decision making as measured by administration of ACED in Money Management and measures of Participation re Decision Making were investigated using Spearman's correlation coefficient. The results are presented in Table 4.51. A strong, positive, statistically significant correlation was found between the total overall ACED score and the overall measure of Participation in Decision-Making ($r_s=0.74$, $p<0.001$) indicating that participants with higher measures in decision making abilities in Money Management reported greater participation in decision-making. In general, for all measures of participation, except TV, there was a positive relationship with measures of elements of decision making with the majority reaching statistical significance. For TV, the only statistically significant relationship was with Understanding ($r_s=0.39$, $p=0.035$).

Table 4.51. Spearman's Correlation between Elements of DMC (Money Management) and Measures of Participation re Decision-Making for All Participants (n=29)

		Assessment of Capacity of Everyday Decision-Making (ACED)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Participation re decision making	Overall	0.74*	0.76*	0.72*	0.64*	0.40*
	Daily schedule	0.58*	0.42*	0.72*	0.46*	0.30
	Eating	0.53*	0.66*	0.45*	0.51*	0.33
	Money	0.63*	0.63*	0.76*	0.49*	0.63*
	Personal appearance	0.49*	0.53*	0.52*	0.53*	0.27
	TV	0.30	0.39*	0.14	0.28	-0.07

*p<0.05

4.5.4.2.2 By group.

The relationships between the measures of elements of decision making as measured by ACED re Money Management and measures of Participation re Decision Making for each group were investigated using Spearman's correlation coefficient and the results are presented in Table 4.52.

As there was no variability in any of the measures of opportunity to participate in decision making for Group One, no correlations could be calculated for this group. For Group Two, there was a strong, positive, statistically significant correlation between the overall ACED Total Score and the overall measure of opportunity to participate in decision-making ($r_s=0.61$, $p<0.001$) indicating that participants with higher measures in decision making abilities in Money Management had greater opportunity to participate in decision-making. Most correlations were medium to strong in magnitude and positive in direction. The weakest relationships were found between participation in decision-making with regard to TV and the elements of decision making capacity.

Table 4.52. Spearman's Correlation between Elements of DMC (Money Management) and Measures of Participation re Decision-Making for Group Two (N=14)

		Group Two (n=14)				
		Assessment of Capacity of Everyday Decision Making (ACED - Money Management)				
		Overall	Understanding	Appreciation	Reasoning	Expressing a choice
Participation re decision making	Overall	0.61*	0.68*	0.47	0.50	0.31
	Daily schedule	0.51	0.36	0.59*	0.39	0.27
	Eating	0.47	0.60*	0.31	0.43	0.29
	Money	0.65*	0.63*	0.69*	0.48	0.64*
	Personal appearance	0.42	0.47	0.38	0.51	0.23
	TV	0.13	0.24	-0.03	0.10	-0.17

*p<0.05

5. Discussion

The findings of this study are considered below in the context of demographics, decision making abilities and each of the three hypotheses. Consideration is also then given to possible implications for theory and future research.

Sociodemographic and Clinical Background

The differences in the demographics reported between the two groups illustrate a contrast on living situations and personal relationships. Participants within Group Two were more likely to be living in accommodation that was provided by an organisation e.g. residential services, rather than living in their own home and were less likely to be in a relationship than those participants within Group One. No participant within Group One was single, all were in a relationship (73.3%) or had previously been (26.7%) whereas only 14.3% of the participants within Group Two were in a relationship, 28.6% had previously been and half were single. All participants in Group One lived in their own home, whereas 42.8% of participants within Group Two lived in a residential service or supported living setting. Only 1 participant (6.7%) within Group One lived alone, whereas 5 (35.7%) of participants within Group Two did.

Findings regarding the living circumstances for Group Two are of interest in the context of the theme of residential status as a possible factor in DMC, identified by Goldsmith et al (2008) in their review of the literature regarding adults with intellectual disability and healthcare consent and discussed in an earlier section of this dissertation.

Previous researchers have identified residential status as a factor that may impact DMC (Goldsmith et al., 2008 and Suto et al., 2006). The studies identified have focused on people with intellectual disabilities. They posited also that opportunities to participate in decision making may be limited for those living within residential services. Suto et al

cautioned that to moves to smaller community settings may adversely impact decision making opportunities as a consequence of a lack of appropriately trained staff to provide decision making support. This will be discussed further in the context of hypotheses three and participation in decision making.

An interesting observation to emerge from the demographics is the low number of people who are left handed participating in the study with only 1 left handed participant out of 29. This is perhaps reflective of participants' ages and the period that they were of school going age. Being "right handed" at that time, was considered to be the norm and considerable efforts were made to alter any preference towards left-handedness being demonstrated by young children. A number of participants recall initially using their left hand when starting to attend school, but were then required to use their right hand, in some instances by being physically restricted from using their left hand. Prevalence of left-handedness worldwide is estimated to be 10% of the population with some geographical and cultural differences resulting in a higher incidence for some areas, e.g. parts of Europe and United States and a lower incidence in others, e.g. India (McManus, 2009).

Participants awareness, knowledge and understanding of the medications that they were taking as reported in this study reflects previous findings by Heslop et al. (2005) regarding individuals with intellectual disability and reported in Goldsmith et al. (2008). The authors reported the knowledge of the medication that participants were taking to be "sketchy" with not much more knowledge being demonstrated by their carers (p.555). Whilst the numbers of participants in the present study were low, they included individuals with a range of diagnoses in addition to participants with intellectual disabilities. Seven participants had intellectual disability and although 25 of the 29 participants reported taking prescription medication, only 1 could name all their medication and only 9 could explain why they were taking prescribed medication.

Decision Making Abilities

In measuring decision making abilities for both the domains of Health (Managing Medication) and Finance (Money Management), overall total ACED scores in addition to the scores yielded for individual decision making abilities were used for comparison purposes. Whilst high scores in one or more of the decision making abilities indicate strength for that or those specific abilities, a high total ACED score does not automatically indicate unimpaired DMC. A significant deficit in one element of decision making may result in impaired DMC.

Significant differences observed in decision making abilities between both groups demonstrated poorer decision making abilities amongst those individuals at increased risk for impaired DMC, i.e. individuals within Group Two. This is consistent with findings of previous research that reported adults with diagnoses such as age related disorders, ID and ABI to be at increased risk of impaired DMC (Hotopf, 2006; Suto et al., 2006; Goldsmith et al., 2008; Moye et al., 2013).

Performances by a number of participants within Group Two on the ACED Medication Management and/or ACED Money Management demonstrated capacity for that specific area of everyday decision making and were equal to or better than participants within Group One. This also is consistent with findings by other researchers of capacity within clinical groups even where significant numbers of participants demonstrated incapacity (Hotopf, 2006; Raymont et al., 2004). Thus the findings observed in this present study, reinforce the assertion that DMC is not global nor indicated by status or diagnoses.

The ability to express a choice was evidenced to be the least impaired decision making ability for both decision making domains in this study. These results are consistent with previous studies that have reported expressing a choice to be the last decision making ability affected by the onset and progression of a pathology such as AD, with difficulties

firstly being experienced in the abilities of understanding, appreciation and reasoning (Goldsmith et al., 2008; Moye et al., 2013). Given the diversity of older adults in the overall group of participants and their experience of diagnoses other than dementia, it is of note that the results of this study re expressing a choice, are consistent with these previous findings.

The use of the information sheet by 27 of the 29 participants in both the Managing Medication and Managing Money interviews is striking. Participants either utilised the information sheet of their own initiative or were prompted to utilise the sheet when observed to have difficulty responding to questions regarding the information provided.

These sheets include brief bullet point reminders of the information provided with regard to the importance of the particular functional area, two possible options for addressing difficulties in this area and some possible advantages and disadvantages of some of the provided options. A listing of the options for each domain was also provided with this sheet by the researcher (Appendix G). The authors of the instrument specifically developed the accompanying information sheet to be of assistance to individuals with memory difficulties, particularly short term difficulties. Of interest to note therefore is that the Median/Mean of Memory subscale of the DRS for the 29 participants demonstrated a below average performance in this area of functioning.

Findings of previous research have reported short term memory difficulties to be associated with impaired DMC. A functional approach requires that all steps to support a person's DMC should be undertaken before a determination is made that an individual's DMC is impaired. In the provision of the information sheet, the ACED proactively supports an individual's memory.

A number of the questions within the ACED provided participants with the opportunity to elaborate on their understanding and reasoning. Participants responses to

five questions sampled from the Managing Medication and Managing Money interviews were explored to examine this further. Striking in a number of responses to these questions were the references to trust, well-being and autonomy. Trust and/or fear of exploitation arose on 17 occasions within the responses to the three questions sampled from the ACED –Money Management. It arose for 8 of the 20 participants (40%) who were asked to consider what would happen if they were to have someone else manage their money. Yet trust and/or fear of exploitation was not listed or identified in the information provided to the participant or in the information sheet as one of the disadvantages. Rather on the information sheet the provided possible disadvantages with regard to someone else assisting with Money Management are some loss of Independence and loss of control regarding financial decisions

All participants who raised trust and/or fear of exploitation, spoke of the need to have trust in whoever may be assisting them financially and all spoke of a concern that their money would not be used for their benefit but rather for the benefit of the person helping them and that in the worst case scenario they may find that their bills still remained unpaid. A reflection of this fear is demonstrated in the response to the question above of one participant who has a mild intellectual disability, “they may use my money for themselves and then I would be grumpy and sad”.

This unprompted reference to trust and/or fear of exploitation is particularly interesting in the context of the earlier observation in this thesis to the increased focus and mention in more recent DMC literature on the issue of elder abuse, exploitation by others or conflict of interest on the part of third party informants to assessments (Blazer & Wallace, 2016; Terracina et al., 2015; Goldman, 2015; Demakis, 2013). Such issues present additional new complex and challenging aspects to the area of DMC, its assessment and identification of appropriate supports. References within this study by

participants across all ability levels to trust and the potential for exploitation appear to indicate awareness of risk and fear on the part of individuals. A recent article by Blazer and Wallace reviewing aspects of Cognitive Aging referenced the MetLife study of elder abuse which reported that older adults within the United States of America were the victims of financial exploitation and fraud to the value of 2.9 billion dollars in the year 2010 alone. Blazer and Wallace referenced this in the context of the vulnerability of older adults to fraud and financial abuse, observing later life to be a time when “many consequential decisions must be made” (p.780). Further consideration of this aspect for people and how best to address and acknowledge same is required.

Another theme to emerge within the study was that of the potential impact on well-being of decisions being made by others on behalf of participants. This also arose spontaneously and was not referenced within the information provided to participants in the course of the administration of the ACED. One participant commented “I’d feel diminished, I’d hate to have someone else decide what & how much I could spend on food, travel, gifts etc.”, other comments included “(it would) take away self esteem, independence, would feel worthless” and “depends on who was going to do it, if complete trust ok but opened to being ‘doodled’, feel at disadvantage, lower self esteem & cause worry”.

Participants within this study also articulated a concern that they may find themselves having to request access to their own money from someone else. As one participant put it “I might even have to ask for the money to buy a newspaper and then I might be told no”. Another participant commented “you’d lose control over your money, lose some independence & privacy. You’d feel sorry for yourself that you’re reduced to that, lose control of your life and have to accept loss of independence”. Again this reflects the theme of autonomy that was present throughout most of the participants’ responses.

Independence and control are referenced in the information provided to participants in the course of administration of the ACED.

Hypothesis One – A Relationship will be indicated between Elements of DMC and Cognitive Factors

Findings observed in the study supported this hypothesis. A moderate to strong positive relationship was indicated between cognitive factors and decision making abilities in both health (Medication Management) and Finance (Money Management) domains.

The cognitive factors explored were yielded from the WASI and the DRS-2. Previous studies have sought to explore for associations between DMC and a range of cognitive factors including those yielded from the WASI and the DRS-2 (Moye & Marson, 2007; Moye et al., 2013).

As the sample size for each of the two groups within this study is small and there is little variability, more focus is placed on magnitude and direction of the correlation coefficient for the total sample (N=29) than on the statistical significance. These results demonstrated participants with higher measures of decision making abilities to have greater cognitive functioning. Whilst there were differences between the results for decision making abilities in medication management and decision making abilities in money management, a moderate to strong positive correlation with cognitive functioning overall was demonstrated for both domains supporting the hypothesis.

Findings, in this study, demonstrated a moderate to strong positive association between DMC and WASI and are therefore consistent with the results of previous studies (Moye & Marson, 2007; Moye et al., 2013).

The relationship between DRS measures and decision making abilities for participants demonstrated in this study for both the domains of Medication and Money

Management are also consistent with findings of previous studies that have observed a relationship between scores yielded by the Dementia Rating Scales (DRS) and DMC (Moye & Marson, 2007; Moye et al, 2013). However, unlike those studies which reported specific relationships between specific DRS measures and specific decision making abilities, this study reported strong relationships between all DRS measures and all decision making abilities with the exception of Expressing a Choice.

These findings are consistent with previous studies that have demonstrated relationship between decision making abilities and cognitive functioning (Moye & Marson, 2007; Moye et al., 2013).

Hypothesis Two – A Relationship will be indicated between Elements of DMC and Cognitive Reserve Markers.

The findings observed in the study supported this hypothesis with a strong positive relationship reported between Cognitive Reserve and decision making abilities in both the domains of Medication and Money Management. This suggests the possibility that the presence of CR may influence or may be a factor in decision making abilities. No other previous study was identified that specifically examined for a relationship between DMC and CR. However some previous studies have explored possible relationships between DMC and factors, which are identified as CR Markers, including for example education. As outlined in the earlier Introduction section, such studies have reported mixed findings with regard to a possible relationship between DMC and education (Porrino et al., 2015; Raymont et al., 2004).

Previous studies specifically exploring CR have reported a relationship between CR and Cognitive Functioning (IQ) (Valenzuela & Sachdev, 2006). A strong positive relationship is reported in this study between decision making abilities and Cognitive

Functioning (IQ) as measured by WASI (Tables 4.42 and 4.43), which as previously observed is also consistent with the findings of previous research.

A question arises as to whether the strong positive relationship observed in this study between DMC and CR is reflective only of the association already reported between DMC and IQ and does not therefore reflect a unique contribution to DMC by CR. This could be explored further by examining the relationship if any, between DMC and CR whilst controlling for IQ, by conducting for example a multiple regression or partial correlation. However the small sample size and the skewed nature of the data as a result of the absence of a normal distribution within the measures yielded by the ACED prevent the undertaking of such examinations for this study.

It is also important to be cognisant that correlation results do not imply causality, therefore these results are best viewed as a classification and not an explanation of these effects

Whilst recent research reports many positive benefits of physical activity across a range of areas including physical health, mental health, cognitive functioning etc, no relationship specifically between physical activity and decision making abilities was observed in this study (C3 Collaborating for Health, 2011). Measures of physical activity were included in the CR measure (LEQ) for which a positive relationship was observed as discussed earlier. Measures of physical activity vary considerably, with quantification a challenge and may impact study results and subsequent interpretation.

Hypothesis Three –

- c. **A Relationship will be indicated between Elements of DMC and an individual's Preference to Participate in Decision Making.**

d. A Relationship will be indicated between Elements of DMC and an individual's Participation in Decision Making.

The results identified in the study supported this hypothesis with a strong preference on the part of individuals to participate in decision making being observed in all the areas of daily living sampled with the exception of their medical care.

Participants self reported preference regarding decision making in a number of areas sampled in daily living indicated a strong preference by most/all to participate in decision making. in the course of administration of ACED for both domains and excluding those questions that prompted autonomy and control, number of participants referenced autonomy and control, also reflecting the significance that such independence holds for them. The area of daily living that participants reported the lowest levels of preference to participate in decision making was that of medical care. These questions were similar to those utilised by Levinson et al. (2005), who reported that nearly all participants (96%) preferred to be offered choices and asked their opinion; half (52%) preferred to leave final decision to Doctors; 44% preferred to rely on doctors for medical knowledge than to seek out information themselves and that preferences for an active role in decision making increased with age up to 45 years but then declined. The participants in Levinson et al.'s study had a mean age 46.3 years (SD 17.4) whereas all of the participants in this study were over 50 years of age, with a mean age of 73.8 years (SD 9.6). Levinson et al. highlighted the importance of doctors having accurate information with regard to patients preference from the outset.

Participants in Maxim et al.'s study were older in age and results for the group overall indicated that 51.5% wanted a doctor to make decisions regarding treatment and 37.4% wanted a doctor to make decisions regarding admission. The results from this

present study are more consistent with Maxim et al.'s findings, although inferences are limited as the questions utilised in the two studies differ.

Previous studies exploring preference amongst people to participate in decision making have mainly focused on decision making in the area of healthcare. These have reported a preference on the part of individuals not to participate if incapable. Other studies have reported a declining preference to participate in decision making on the part of individuals as they get older. Observations from this study indicate that this preference not to participate may be specific to healthcare and that it may not necessarily extend to other areas of daily living.

This therefore cautions against the application of a blanket/global approach to individuals' preferences regarding participation in decision making and highlights the necessity to explore further people's preferences with regard to participating in decision making across all areas of daily living.

The results reported in this study also supported the hypothesis that a relationship will be indicated between elements of DMC and individuals participation in decision making with a statistically significant positive relationship for participants between participation in decision making and decision making abilities being observed.

Few previous studies were identified that have explored DMC and participation in decision making. Those identified focused mainly on decision making for people with ID (Goldsmith et al., 2008; Kilcommons et al., 2012). They reported fewer opportunities for individuals with ID to participate in decision making. The lower levels of participation in decision making reported in this study for participants within Group Two are consistent with these previous findings and illustrate the greater risk for individuals living in hospital, institutional and residential settings of decreased opportunities to make decisions, identified by these researchers and others (Suto et al., 2005). Suto et al. also cautioned that

opportunities to participate in decision making are not necessarily better in smaller community settings as a result of lack of appropriately trained staff to provide support in decision making.

The observation of a statistically significant positive relationship for participants between participation in decision making and decision making abilities raises the possibility that the lack of opportunity to engage in such simple decisions, for example choosing one's clothes to wear, may adversely compromise a person's decision-making ability with regard to decision making re instrumental activities of daily living. The issue echoes the concerns identified by Goldsmith et al. (2008) in their review of literature regarding DMC re healthcare issues and the lack of decision making opportunities for people ID. It is also consistent with the finding by Suto et al. (2005), whose study identified a relationship between financial decision making, the acquisition of financial skills and participation in decision making.

Further exploration of the relationship reported in this study between participation in decision making and decision making abilities was impeded by the small sample numbers and the lack of normal distribution amongst the decision making abilities measures. Whilst it is not apparent which supports which, the findings identify the importance of providing decision making opportunities to all individuals in receipt of support. Such opportunities can be provided on a naturally occurring basis in a manner appropriate to the individual and can range from simple to complex as appropriate. For example, offering an individual a choice between two shirts/blouses or between a shower and a bath. All individual support plans should include opportunities for individuals to participate in decision making, including participation in the development of the support plan itself. This requires awareness and skill on the part of the service provider and should be incorporated into all basic training and education courses for staff. Recent service

developments internationally require services and their staff to evidence and support participation in decision making by individuals (Coulter, Parsons, & Askham, 2008).

In the course of previous research, a number of authors have posited that experience in decision making may result in heuristics, individuals learning “rules” for those decisions (Finucane et al., 2002) and may contribute later to their maintenance of decision making abilities for those or similar decisions (Moye et al., 2005; Finucane et al., 2002, Goldsmith et al., 2008). The person who does not have the opportunity to participate in decision making, has no opportunity to neither learn these “rules” nor acquire a familiarity with such decisions.

Theory Implications:

The results reported in this study support a functional approach to DMC. The strong association reported in this study between elements of decision making ability and cognitive ability as assessed by the WASI and DRS-2 could be perceived to support a “status” or “global” model of DMC or the assertion that a cognitive assessment would be a sufficient tool to assess for DMC. However the results observed in this study also suggest that cognitive functioning is just one factor associated with DMC and that there are also potentially other factors, for example participation in decision making and CR, thereby challenging the global approach. These results support a multifaceted model of DMC and a functional approach to the assessment of DMC, illustrating that a cognitive assessment by itself is not sufficient to ascertain capacity and indeed were it to be so used, it could result in the unfair denial of autonomy to individuals who may have capacity.

Demonstration of decision making abilities for some participants within Group Two also provide further support for a functional approach to the assessment of DMC, highlighting the potential for unjust restriction of autonomy against individuals for

example with intellectual disability if a global approach on the basis of diagnosis towards DMC assessment was to be taken.

Also of interest in this study is the observation of the relationship between the domains of Medication and Money Management for the overall group of participants but not so observed within Group One (“healthy” older adults). This appears to indicate that DMC is not unitary but rather is domain specific, providing additional strength in favour of the functional approach.

As outlined in the earlier introduction section, the evolution of DMC models and theories was underpinned by a recognition that DMC reflected an interaction between the decision maker and the decision making task (Wong, 2000; Smyer, 2007). DMC is multifaceted and dynamic. It remains unclear if existing DMC theories and frameworks have captured all relevant characteristics. The results of this study suggest that characteristics such as time, experience (of similar type decisions, of decision making generally and experience of decision subject), present opportunities to participate in decision making may contribute to a framework of DMC and are not presently reflected in existing DMC models and theories. The underlying principle within functional models is seen in the accepted interaction between the person, the decision and the context.

There are factors associated with it that do not appear to be adequately captured or accounted for by previously posited models to date. These include for example the issues of aging and its impact.

A number of authors have observed that there is a contribution by “subjective” factors to DMC, but that these have not yet been clearly delineated (Finucane et al., 2005; Moberg & Rick, 2008; Finucane & Gullion, 2010). The evolution of theory to conceptualise DMC as an interaction between the characteristics of the person and characteristics of the decision task provides for the consideration of subjective factors.

Cognitive Reserve may be one such subjective factor. If so it offers a possible explanation for the variances in the DMC of older people. It may also contribute to the proactive steps that can be undertaken to maintain and enhance a person's DMC thereby contributing to the maximising/prolonging of a person's autonomy for as long as possible.

Moye et al. (2005) reviewed the general model of capacity posited by Grisso (2003) "incongruence between functional abilities and the environmental demands/supports are of sufficient magnitude to warrant a finding of incapacity" – similarly to the role that CR is posited to play in mediating the adverse impact of clinical conditions on functioning, it may play a similar role in mediating the "incongruence between functional abilities and the environmental demands/supports".

Models of DMC may be informed further by the incorporation of the construct of cognitive reserve and life experiences, such as participation in decision making. This may contribute to explanations for the variance in older adults DMC.

Incorporating CR into models of DMC may have implications for the supports and opportunities provided by services to individuals.

Finucane et al. (2005) posited that their proposed Person – Task Fit Model would ensure that decision making in older adults must be considered in the context of the impact of aging as there were variances within individuals performances in decision making that could not be accounted for. As outlined in detail earlier, CR is posited by theorists to buffer cognitive functioning against the adverse impact of aging, pathology and injury. However the model posited by Finucane et al. did not appear to consider CR as a factor nor include provision for determination of any potential impact of CR. The construct of CR, although not a theory of DMC, has conceptualised experiences of the person across the lifespan, such as social and leisure experiences, physical activity in addition to education and occupation.

In considering the impact of aging and age related decline, Moye et al. (2013) suggested that “....each person has a unique constellation of cognitive strengths and deficits that contribute collectively to their functional abilities” (p.162). They asserted that cognitive aging alone was not sufficient to cause incapacity but that it could in tandem with other factors put older individuals at risk for impaired DMC. Moye et al’s assertion of a unique constellation of cognitive strengths and deficits for each person is in keeping.....

The Life Course Model as proposed by Richard and Deary (2005) is a model of aging based on cognitive reserve theory. Whilst not a model of DMC, it describes, articulates and operationalises a number of constructs that appear to fit with DMC. It could therefore contribute to the Person – Task Fit Model by “fleshing out” further the “Person” and contribute to the realisation of the model’s aim to account for individual variances in decision making performances. Ironically CR theory was initially posited as an explanation for the individual variances that were observed in cognitive functioning amongst older adults, people diagnosed with pathology such as AD and those individuals who acquired a brain injury but variances that could not be explained.

Another factor not sufficiently accounted for within the DMC models and theories, is that of life experiences. The results observed in this study for the overall group of participants suggest that there is an association between DMC and one such life experience that is participation in decision making, which may further inform a model of DMC. Frameworks for the assessment of DMC are based on the models of DMC. The deficit in the consideration of life experiences within the present models has resulted in present frameworks for DMC assessments not including consideration of the individual’s participation in decision making, either past or present.

While this study did not examine impacts of possible interventions to support, maintain and enhance DMC, the pattern of results in this study suggests that a

determination should be made when assessing DMC as to whether the individual has the opportunity to participate in decision making. If s/he does not, then providing opportunities to participate in decision making should be considered and explored with regard to its merits as an intervention to support or enhance DMC. This may be particularly pertinent where an individual who expresses a preference to make the decision him/her self, does not presently participate in decision making and is assessed as having impaired DMC. Not participating in decision making results in an individual not utilising decision making abilities and may adversely impact the maintenance or development of these abilities. For example choice making and expressing a choice has long been considered an ability that is necessary to be taught and practiced. Bannerman, Sheldon, Sherman, & Harchik (1990) asserted in agreement with Shevin and Klein that the focus was on choice as a “permissible activity” rather than a “teaching target”. They criticised the lack of attention being provided to the development of a curricula for teaching students to discriminate their preferences and make choices (p.81). The idiom “use it or lose it” comes to mind. The maintenance of skills requires practice, where individuals do not have an opportunity to practice skills that they have acquired, such skills may be lost or proficiency deteriorate.

It is not possible to indicate from the results, the directionality of the association i.e. is it DMC that supports participation in the decision making or is it the participation in decision making that supports DMC. However, the results of this study indicate a strong, positive statistically significant correlation between decision making abilities and participation in decision making for the overall group of participants in both the Medication and Money Management domains. The literature review conducted by Goldsmith et al. (2008) with regard to DMC and people with ID identified life experience and the sub-theme of opportunity to participate in decision making as a theme within DMC. A previous study by Suto et al. (2005) demonstrated a relationship between decision making abilities in the domain of financial decision making and participation in decision

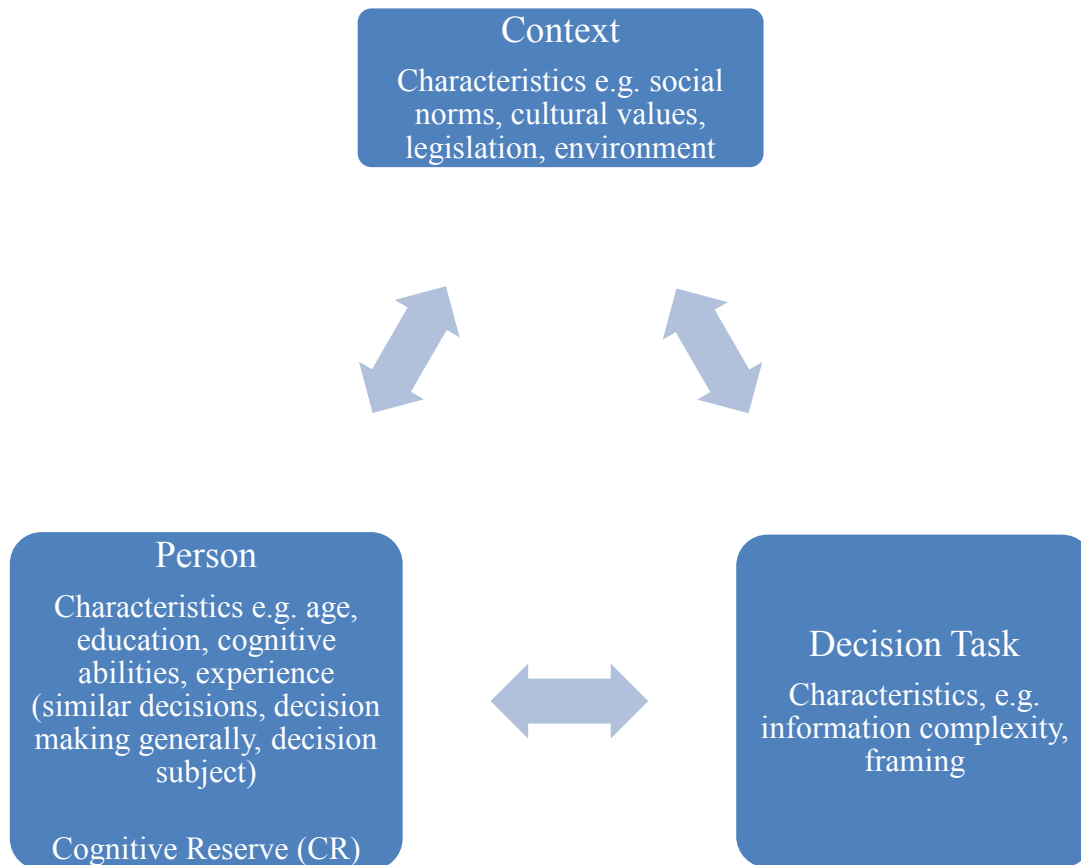
making for adults with an intellectual disability. Dye et al. (2007) suggested that limited decision making opportunities in the lives of individuals with ID will limit their capacity to consent. Previous authors have commented that greater decision making experience in comparison groups may skew results regarding DMC in their favour (Goldstein et al., 2008). Whilst previous studies identified exploring participation in decision making in the context of DMC have mainly focused on individuals with ID, there may be relevance for all individuals. It appears therefore that there may be an association between both DMC and individuals participating in decision making that has relevance for all individuals and that life experiences such as participation in decision making may have a role within a model of DMC and a framework of assessment.

Whilst the limitations of this study restrict the interpretations that can be drawn from the findings, a framework reflecting DMC as the product of an interaction between the characteristics of a person, the characteristics of the task and the characteristics of the context may be informed further by

- The enhancement/broadening of the characteristics of the person to include
 - The person's experience
 - of similar type decisions
 - of decision making generally and
 - experience of decision subject
 - The person's present participation in decision making
- Contribution of Cognitive Reserve in buffering the impact of aging on cognitive functioning (incorporating Life Course Model of Cognitive Reserve)

An expansion/further development of a framework of DMC by inclusion/merger of life course model of cognitive reserve.

Potential Development of DMC Model:



Limitations:

There are a number of limitations to this study including the small numbers contained in each of groups, the result of which precludes statistical power, therefore interpretation is limited and caution is urged in this regard. As statistical power is not possible, it is wise to view the results in the context of patterns.

Sample size for both groups was small and is a limitation of this study. Group Two was diverse with the inclusion of individuals who accessed a range of additional supports

and diagnoses of ID, dementia, PD, ABI and cognitive impairment. Its considerable diversity of diagnoses and aetiology are also limitations to this study.

Both sample size and the diversity of diagnoses limit the strength of the findings and conclusions that can be drawn from the study. Also limited are the generalisations that can be made with regard to specific diagnostic groups. However the diversity of diagnoses, similarly to the study conducted by Lai & Karlawish (2008), is a reflection of the diversity seen amongst older adults attending GPs, Day Centres or Geriatric clinics. It is therefore useful in suggesting possible trends or patterns that may be useful to pursue further.

Exploration of the relationships identified in this study were further limited as the results yielded for the measures of decision making abilities (ACED) were not normally distributed. This therefore limited the statistical analysis that it was possible to undertake.

The examination of preference with regard to decision making and participation in decision making was limited to a sampling of a small number of everyday activities. While useful to identify possible tendencies, a more comprehensive examination of these factors is required. The development of a standardised measure similar to that of The Choice Questionnaire developed by Stancliffe (1999) may be of benefit.

Goldsmith et al. (2008) posited that unless characteristics such as residential status, employment status and health experience were taken into account, it was not possible to ensure that they had not influenced the findings. The results in this study demonstrated poorer decision making abilities for participants within Group Two. The results also indicated an increased likelihood for participants within Group Two to live within residential services, these results support the further exploration of these characteristics in the context of DMC.

Future Research

As has been identified by previous researchers, greater diversity within the population of older people is required for future research being undertaken in the area of DMC.

Differences in the DMC of older adults have been reported by a number of authors (Moye et al., 2013; Henninger et al., 2010; Finucane & Gullion, 2010; Smyer, 2007; Finucane et al., 2005). Cognitive abilities underpin DMC. Adverse impact on these cognitive abilities may compromise and impair DMC. As age related declines have been observed in these cognitive abilities, Finucane et al. posited that differences between the DMC of older and younger adults could be interpreted with regard to developmental changes associated with aging. However a study undertaken to explore this demonstrated no age effect but rather indicated that variances were being accounted for by measures of individual differences that had been included in the study. Finucane et al. posited that this may mean age related declines in cognitive functioning were “being compensated for somehow” (p.80).

CR is posited by theorists to compensate for the adverse impact of pathology and aging on cognitive functioning.

The findings in this present study of strong positive associations between decision making abilities and CR provides the basis for future study that may develop a DMC model further and account therefore for the variances observed on older persons DMC.

The findings of this study suggest that there may be a relationship between CR, as measured by the LEQ, and DMC. The question arises as to whether such a relationship reflects the previously reported relationship between decision making and Cognitive Functioning (IQ) or whether it reflects something additional. Future studies to explore this

would be useful, but would require the limitations experienced by this study to be addressed. Assessing DMC for decisions of increasing complexity would increase the likelihood of variability being demonstrated in participants' decision making abilities. Use of such an assessment and utilisation of larger sample sizes in future studies may address the limitations experienced by this study.

As CR reflects life experiences, a relationship between it and DMC that reflects something additional to the previously reported relationship between cognitive functioning and DMC may have implications for the life experiences and opportunities that are sought by individuals and provided by services supporting individuals. Frequently the life experiences of individuals diagnosed with conditions such as ID, ABI, AD, age related disorders may reflect the opportunities (or lack thereof) that are available to them through the support that they receive.

The results of this study also suggest that there is an association between participation in decision making and DMC. There is a need for future research to explore this relationship further but similarly such a study would necessitate a larger sample and/or assessment of DMC with regard to decisions of increasing complexity in order to overcome the limitations experienced by this study. Longitudinal research in this regard may also be of benefit.

Future studies in these latter two areas may be helpful in considering further a Model of DMC that comprehensively accommodates Aging and Life Experience.

It may be useful also for future research in exploring further the role of participation in decision making within DMC, to evaluate the impact on DMC if any, of the provision of structured decision making participation opportunities as an intervention for individuals assessed as experiencing difficulty with decision making abilities. If effectiveness as an intervention is to be accurately assessed, it is important that the

individual be supported to participate in such decision making opportunities. The decision to be made should be presented in a meaningful way to the individual, i.e. consideration given to the most appropriate presentation of the information, short sentences, simple and familiar language. The information should be broken down and presented in small pieces at a pace appropriate to the individual. Accompanying decision aids such as a sheet with written information points, pictures/photographs, miniatures, labels, concrete props etc should be provided. For individuals with an intellectual disability especially it is necessary to give consideration to the most beneficial format for information to be presented. The number of options provided should not be overwhelming, ideally limited to between two and four. Checks should be undertaken to ensure that an individual has their correct pair of glasses, if required and that their hearing aid if needed is turned on and in working order. There should not be time pressures applied and ideally such opportunities should particularly occur at times of the day most appropriate to the individual. Antaki et al (2008) have identified some of the challenges that can arise in offering choices and decision making opportunities to people with an intellectual disability, e.g. where too many options were provided.

Given the significance of capacity in everyday decision making for individuals with ID who strive to live as independently as possible, DMC assessment should offer as thorough a breakdown as possible of decision making difficulties in a standardised way that strengthens the identification of appropriate supports with regard to decision making.

This study indicates a preference on the part of participants, older adults, to participate in decision making in areas of daily living, with the exception of the area of medical care. Studies exploring preferences in individuals have mainly focused on the area of healthcare, given the importance of a person's autonomy, further research with regard to older people's preference may be of benefit in ensuring there is not a misunderstanding

with regard to older people's preference, and that previous findings are not interpreted in a global manner with regard to preference.

Assessment Tools:

There is the need for additional development of instruments particularly for utilisation with older adults with intellectual disability in the assessment of Everyday DMC. Observations from this study indicate potential for an instrument such as the Assessment of Capacity for Everyday Decision Making (ACED) to be adapted for such use and to be an effective framework for use with individuals with intellectual disability. For example expanding the Information Sheet provided, to include not only easy to read text but also to include concrete props/cues and pictures could broaden the use of the instrument for individuals with more significant levels of intellectual disability and literacy difficulties. It may also enhance the assessment process of the individual's DMC.

The ACED provides a structured assessment that can be tailored to specific everyday situations and yields a comprehensive breakdown of information with regard to each of the decision making abilities which can inform the identification and provision of targeted interventions or supports appropriate to the individual's needs. This is particularly relevant for practitioners adopting a functional approach to DMC. Most ethical and clinical guidance require that prior to a determination of impaired DMC, all efforts must first be made to support and enhance the individual's capacity. In some countries, including Ireland, where legislation and/or national guidance are in place regarding DMC, this is also a legal requirement.

Administration of the LEQ to establish CR demonstrated a significant difference between the two groups for all measures with the exception of the Education Bonus measure in Later Life and the Work Bonus measure in Later Life, with significantly higher measures demonstrated for participants within Group One. No participant received an

Education Bonus for Late Life. This score is only assigned to formal structured educational courses. A deficit in the LEQ is the challenge of assessing the contribution to CR measures of learning by individuals who have not accessed further formal third level education such as structured lengthy courses, but who have engaged in other learning. For example some professions are required to engage in Continuous Professional Development/Education (CPD/CPE) on an ongoing basis, with minimum requirements to meet and in some instances examinations or evaluations to complete. It also does not capture shorter skill enhancement courses or shorter learning courses, even where there are a number of such courses undertaken or examinations completed. Capturing and assigning a measure to this is an ongoing challenge for the LEQ and may be addressed by the allocation of perhaps one point per 5 year period re CPD or allocation of points per 12 months accumulated within a set period etc. This challenge is recognised by the authors of the LEQ and consideration is presently being provided as to possible ways forward.

Conclusion:

This study explored DMC within older adults in the context of factors not previously so considered. Participants included individuals with diagnoses other than AD. Whilst the study and its findings are limited by a small sample size, patterns observed indicate associations between DMC and CR, and DMC and participation in decision making. Such associations have implications for models of DMC, assessment, identification of supports to enhance and maintain DMC and program content. Models of DMC may be informed further by the incorporation of the construct of cognitive reserve and life experiences, such as participation in decision making. This may also contribute to an explanation for DMC variances. Incorporating CR into models of DMC may have implications for the supports and opportunities provided by services to individuals over their life span. Further study is therefore merited.

Making decisions for oneself is an aspect of life taken for granted by most adults in the free world. Adults becoming older are at increased risk for having their capacity to make decisions questioned but also at increased risk for their decision making abilities to diminish. All participants in this study indicated some level of preference for participating in decision making. Trust/risk was raised by a number of participants regarding decision making. Increasing numbers of recent studies have reported financial exploitation of older adults. Exploring with individuals their preferences re decision making and supports for older life may be beneficial.

A person's refusal to consent or participate in an assessment of DMC will continue to present the evaluating clinician with challenges particularly as observed by Goldman and Hurst that a refusal to provide reasons for a decision does not automatically denote impaired or diminished DMC (Goldman, 2013; Hurst, 2004). The practical guidance offered by Goldman and Hurst for such situations may be useful. Goldman suggested making use of "diplomacy or focusing on the refusal process itself (e.g. "Can you at least explain why you prefer not to give us your reason?" p.74)". Similarly Hurst suggested a "conversation" and outlined a framework. Both also suggested that involving family members, loved ones or trusted friends may be of assistance.

Within the area of DMC researchers and clinicians face and will continue to face an array of complex and challenging ethical issues, being aware of and willing to appraise such challenges is a necessity for all and a useful first step to addressing these. As many of the researchers reviewed in this study have observed, assessment of DMC holds clinical and ethical obligations for the clinician. Highlighting this are the profound consequences for an individual for whom a determination of impaired decision making capacity is made.

6. APPENDICES

APPENDIX A

Ethics Committee Approval

25th March 2013

F.A.O. Maria Corrigan

School of Psychology Research Ethics Committee

Dear Maria,

The Research Ethics Committee has reviewed your application entitled “Decision-making capacity in older adults” and I am pleased to inform you that it was approved subject to the following amendment(s):

The description of Study 2 is very vague because it is contingent on the findings of study 2. If the design and methods cannot be more clearly defined then the two studies should be dealt with in separate applications.

Section 6 is not correctly filled out

Far more detail is needed on section 7, how exactly will each of the groups be assessed (i.e., how will AD and mild intellectual disability be determined) and exactly how will you go about recruiting them? What inclusion and exclusion criteria will be implemented? How will capacity for consent be determined for the two clinical groups? Seeking consent from a family member may be necessary.

Section 19 “action will be taken immediately to provide reassurance and to resolve the distress”, please explain precisely what the nature of these actions will be.

Section 23. Is the researcher trained in the administration of the WASI-II? If not then, if scores are given to participants, they should be accompanied by a statement to the effect that they do not constitute a formal test of intelligence.

All participant information is too complex for a group of adults with potential cognitive deficits; resupply appropriate sheets.

Participants need to be able to give informed consent to the study appropriate to their cognitive ability.

Please attach a cover letter to your amendments identifying specifically where in the resubmitted material each change requested by the Committee has been made by you. Also, please ensure that the letter states clearly the month in which the application was made, i.e., March 2013.

DO NOT RESUBMIT THE ENTIRE APPLICATION; ONLY THE SPECIFIED AMENDMENTS/RELEVANT SECTIONS OF THE FORM ARE REQUIRED.

Once satisfactory paper copies of these amendments have been received by Luisa Byrne, to the locked boxes under the staff photo wall in the School, you will be notified in writing that your application has been granted full ethics approval. This letter will be left in the post-box beside the Ethics submission boxes for collection by you.

*Please note that only one copy of the amended material is needed.

Yours sincerely,

Prof. Richard Carson

Chair

School of Psychology Research Ethics Committee

APPENDIX B

Information Sheets and Consent Forms (Regular)

Decision Making Capacity in Older Adults

Information & Consent Form

My name is Maria Corrigan. I am a Principal Clinical Psychologist undertaking a research study for a PhD Degree in Trinity College Dublin (School of Psychology).

The study is called **Decision Making Capacity in Older Adults**.

The research project is looking at factors that might affect decision making capacity in older adults. Such information might help older people maintain capacity to continue making decisions for themselves.

What is Involved:

Participants in the project are asked to take part in the following

- Cognitive Assessment – this assesses cognitive abilities e.g. information processing, attention and concentration, memory etc
- Activities of Daily Living Assessment – assesses how individuals make decisions in the different areas of daily living, e.g. shopping, healthcare, personal care etc. I may need to talk to someone who knows you very well and ask them if they have noticed any decision being difficult for you. I will only do this with your permission and only contact the person that you say is ok.
- Finance Capacity Assessment – assesses how individuals make decisions with regard to their financial affairs.
- Dementia Rating Scale – Tool for assessing difficulties with thinking and memory in older people.
- Complete Questionnaire – seeks information about interests, hobbies, education, employment etc

Confidentiality: Information collected in this project is confidential with the exception of information about any person being hurt. The identity of participants is confidential and will only be recognisable to the researcher (me). I will inform you about the results of your assessment and will provide you with a copy of your cognitive assessment for your records if you wish.

You can change your mind at anytime and stop taking part in this project. Participation is completely voluntary.

I would appreciate your participation in this research

Decision Making Capacity in Older Adults

Contact Details:

Maria Corrigan: School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2. Ph: 083 8358188, email corrigm2@tcd.ie

Supervisor: Dr Kevin Tierney, School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2. Ph: 01-8962609, email: tiernen@tcd.ie

Decision Making Capacity in Older Adults

Consent Form:

I _____ agree to participate in this project. I understand the details as explained above. I know that I can stop taking part at any time that I wish.

Signed: _____

Date: _____

Witness: _____

Date: _____

APPENDIX C

Information Sheets and Consent Forms (Easy to Read)

Decision-Making Research Study

Information Sheet

My name is **Maria Corrigan** and I am a Psychologist.

I am doing a research project about **Decision Making for older people**.



Making our own decisions is important.

Sometimes making decisions can be hard.

As we get older, some parts of decision-making can get harder.

What is the Research?



There are 2 meetings with me.

Each meeting is 1 hour long.

At the meeting we will talk, do puzzles and tests.

The tests measure how you think, how you learn and how you make decisions every day.

The meetings will be on different days.

I may have to talk to someone who knows you very well. You will decide who.

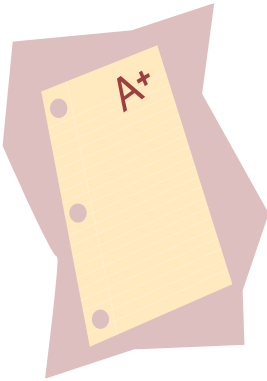




Your information is confidential.

It will be kept safe.

I will use your results for my research but I will not use your name.



I will tell you your results.

I will give you a copy of your cognitive test results if you want.



You can stop anytime you want.

You do not have to say why.

Stopping will not affect anything that you do.

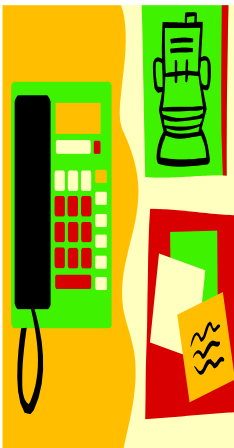


Is there anything that you want to ask me?

Would you like to take part?

Decision-Making Research Study

Contact Details



Researcher:

Maria Corrigan: School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2.

Ph: **083 8358188**, email corrigm2@tcd.ie

Supervisor: Dr Kevin Tierney, School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2. Ph: 01-8962609, email: tiernen@tcd.ie

Consent Form



Have you read or being told the information about this Project

Yes

No



Have you had the chance to ask questions?

Yes

No



Are you happy with the answers that you were given?

Yes

No



Do you understand that it is your choice to help with the project?

Yes

No



Do you understand that you can stop helping with the project at any time?

Yes

No



Are you happy to take part in the Project?

Yes

No

I _____ agree to take part in the research. I know I can stop at anytime.

Signature:

Witness:

Date:

APPENDIX D

National Consumer Information Survey

Section II – Choices (2010)

Relevant extract from Levinson et al. (2005)

Not All Patients Want to Participate in Decision Making, A National Study of Public Preferences

CHOICES

The intent of these questions is to determine the extent to which persons receiving services are involved in decision-making.

- In this section, code "2" only if you can convince yourself that this person played a major role in making the decision. The person may have consulted with others but ultimately made the decision for him/herself.
- Code "1" if you think the person had some input in making the decision.
- Choices made with spouses/partners should be coded as "person made the choice".
- Do not overuse the "NOT APPLICABLE" code here. It is not appropriate to use "8" to indicate NOT ALLOWED or NOT CAPABLE of making decisions in this area. There is a code for indicating that someone else made the decision.

Read one of the following introductions to the respondent(s):

For Individuals:

I'm going to ask some questions now about some decisions you may have made or helped make. For each question, I'd like you to tell me if you made the choice yourself, if you had some say about it, or if someone else decided for you.

For Other Respondents:

I'm going to ask some questions now about decisions this person may have made. For each question, please indicate if s/he made the decision, if s/he had some input in making the decision, or if someone else made the decision for him/her.

PS-7


64) Do you choose (or pick) who helps you at home? *(Do you get to interview them? Did you get to meet different people or was someone assigned to you? Could you request someone different?)*

Did you choose _____ to work with you?
(Other respondent – Does this person choose his/her residential staff?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __8 NOT APPLICABLE - no staff in the home
- __2 Yes, person choose staff
- __1 Staff are assigned but can be changed if requested by person
- __0 No, someone else chose
- __9 Don't know, no response, unclear response

65) Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?

(Other respondent – Who decides this person's daily schedule, like when to get up, when to eat, when to go to sleep?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __2 Person decides
- __1 Person has help deciding
- __0 Someone else decides
- __9 Don't know, no response, unclear response

66) Who decides how you spend your free time (when you are not working, in school or at the day program)?

(Other respondent – Who decides how this person spends his/her free time?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __2 Person decides
- __1 Person has help deciding
- __0 Someone else decides
- __9 Don't know, no response, unclear response

69) Do you choose (or pick) who helps you at your job? *(Do you get to interview them? Was someone assigned to you? Could you request someone different?)*

PS-7


Did you choose _____ to help you at your job?

(Other respondent – Does this person choose his/her job staff?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __8 NOT APPLICABLE – no community job or job staff
- __2 Yes, person chose staff
- __1 Staff are assigned but can be changed if requested by person
- __0 No, someone else chose staff
- __9 Don't know, no response, unclear response

Questions 70-72 refer to choices made concerning day programs or other activities during the day.

70) Who chose (or picked) where you go during the day? *(Did you help make the choice?)*

PS-8


Did you choose to go to _____ ?

(Other respondent: Who chose the place where s/he goes during the day? Did s/he have any input in making the decision?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- __8 NOT APPLICABLE – no day program or other activity
- __2 Person made the choice
- __1 Person had some input
- __0 Someone else chose
- __9 Don't know, no response, unclear response

73) Do you choose what you buy with your spending money?

Do not include things like rent or groceries.

(Other respondent – Does this person choose how to spend his/her money?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 2 Person chooses
- ☐ 1 Person has help choosing what to buy, or has set limits
(such as can buy small items, but not big items)
- ☐ 0 Someone else chooses
- ☐ 9 Don't know, no response, unclear response

74) Did you choose or pick your case manager/service coordinator?

PS-3


Did you choose _____ to work with you?

(Other respondent – Did this person choose his/her case manager/service coordinator?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 8 NOT APPLICABLE - no case manager/service coordinator
- ☐ 2 Yes, chose case manager/service coordinator
- ☐ 1 Case manager/service coordinator was assigned but can be
changed if requested by person
- ☐ 0 No, someone else chose case manager/service coordinator
- ☐ 9 Don't know, no response, unclear response

77) Are you allowed to use the phone and internet when you want to?

If person is unable to use the phone or internet, or doesn't have access, code as "NOT APPLICABLE."

(*Other respondent* – is this person allowed to use the phone or internet when s/he wants to?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 8 NOT APPLICABLE - doesn't have access or unable to use phone/internet
- ☐ 2 Yes, can use anytime, either independently or with assistance
- ☐ 0 No, there are rules/restrictions on use of phone/internet
- ☐ 9 Don't know, no response, unclear response

78) Have you ever participated in a self-advocacy group meeting, conference, or event? (*A self advocacy group is where people meet together to talk about things in their lives that are important to them.*

Some groups include People First, Speaking for Ourselves, and Self-Advocates Becoming Empowered – SABLE. Do not include human rights groups sponsored by provider agencies.)

PS-9



(Have you ever gone to a _____ meeting or event?)

(*Other respondent* – Has this person ever attended a self-advocacy group meeting or event?)

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- ☐ 8 NOT APPLICABLE – there is no self-advocacy group in the area
- ☐ 2 Yes
- ☐ 1 Had the opportunity but chose not to participate
- ☐ 0 No
- ☐ 9 Don't know, no response, unclear response

81) Interviewer: Please indicate all respondents to Section II

(check all that apply):

- ☐ 1 Person receiving services
- ☐ 2 Advocate, Parent, Guardian, Personal Representative,
Relative, Friend
- ☐ 3 Staff who provides supports where person lives
- ☐ 4 Staff who provides supports at a day or other service
location
- ☐ 5 Other

Measures of Preferences for Participation in Decision Making

Relevant extract from Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005)

Not All Patients Want to Participate in Decision Making, A National Study of Public Preferences

These items were modified based on extensive cognitive testing of a pilot questionnaire and feedback from respondents regarding clarity of wording and full understanding of the underlying concept.

The resulting 3 questionnaire items comprised the following statements: “I prefer to rely on my doctor’s knowledge and not try to find out about my condition on my own” (Knowledge); “I prefer that my doctor offers me choices and asks my opinion” (Options); and “I prefer to leave decisions about my medical care up to my doctor” (Decision).

Respondents were asked to rate each item on a 6-point scale ranging from “strongly agree” (1) to “strongly disagree” (6) with categories for moderate and slight agreement or disagreement between the anchors.

(p.532)

APPENDIX E

Questionnaire

Demographics, Participation in & Preference for Decision Making

Questionnaire

Demographics, Participation in & Preference for Decision Making

1. Participant ID: _____

2. Date of Birth: _____

2. Gender: M____ F____

4. Marital Status: _____

5. Residence: _____

6. Education Level: _____

7. Do you live:

Alone _____

With one other _____

More than one other _____

8. Do you smoke or chew tobacco: Yes _____

No _____

9. Did you ever smoke or chew tobacco: Yes _____

No _____

10. If yes, when did you stop? _____

11. Do you engage in any moderate physical activity? (Moderate physical activity is an activity that causes some increase in breathing or heart rate. Examples include, but are not limited to, brisk walking, swimming, bicycling, cleaning, and gardening)

Yes _____

No _____

Don't Know _____

12. If yes, does the moderate physical activity last 30 minutes or more?

Yes _____

No _____

Don't Know _____

13. If yes, how many times per week?

Five or more _____ Three to Four _____ One to Two _____ Don't Know _____

Participation in Decision Making

14. Do you have help during the day or night from staff/assistants/home help?

Yes _____ No _____ Don't Know _____

15. Do you choose (or pick) who helps you? (Do you get to interview them? Did you get to meet different people or was someone assigned/sent to you? Could you request someone different?)

Not Applicable – no staff in home _____

Yes, person chooses staff _____

Staff are assigned but can be changed if requested by person _____

No, someone else chose _____

Don't know, no response, unclear response _____

16. Who decides your daily schedule? (when to go to sleep, when to get up, when to eat etc)

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

17. Who decides when you go to bed/sleep?

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

18. Who decides when you get up?

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

19. Who decides when you eat?

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

20. Who decides what you eat?

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

21. Who decides what you wear?

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

22. Who decides what you do with your free time?

Person decides	_____
Person has help deciding	_____
Someone else decides	_____
Don't know, no response, unclear response	_____

23. What do you do during the day? _____

24. Who decided that?

Person decided	_____
Person had some input	_____
Someone else decided	_____
Don't know, no response, unclear response	_____

25. Do you choose what you do with your money?

Person chooses	_____
Person has help choosing/has set limits	_____
Someone else chooses	_____
Don't know, no response, unclear response	_____

26. Do you get your hair cut/styled?

Yes _____	No _____	Don't Know _____

27. Who decides when you get your hair cut/styled?

Person decides _____

Person has help deciding _____

Someone else decides _____

Don't know, no response, unclear response _____

28. Do you watch TV?

Yes _____ No _____ Don't Know _____

29. Do you choose what you watch?

Person chooses _____

Person has help choosing/has set limits _____

Someone else chooses _____

Don't know, no response, unclear response _____

30. Did you choose your key worker/service co-ordinator?

Not Applicable – no key worker/service co-ordinator _____

Yes, Person chose _____

Key worker/service co-ordinator was assigned but can be changed if requested by person

No, someone else chose _____

Don't know, no response, unclear response _____

Preference re Participation in Decision Making

Getting up:

31. I prefer to be given a choice about what time I get up

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

32. I prefer staff/other to decide what time I get up

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

Eating:

33. I prefer to be given a choice about what I eat

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

34. I prefer staff/other to decide what I eat

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

Money:

35. I prefer to be given a choice about what I spend my money on

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

36. I prefer staff/other to manage/organise my money

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

Television (TV)

37. I prefer to be given a choice about what I watch on TV

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

38. I prefer staff/other to decide what TV programmes to watch

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

If I am sick:

39. I prefer to rely on my doctor's knowledge and not try to find out about my condition on my own

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

40. I prefer that my doctor offers me choices and asks my opinion

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

41. I prefer to leave decisions about my medical care up to my doctor

Strongly Agree	_____
Moderately Agree	_____
Slightly Agree	_____
Slightly Disagree	_____
Moderately Disagree	_____
Strongly Disagree	_____

APPENDIX F

Lifetimes Experience Questionnaire (LEQ) (Valenzuela & Sachdev 2007)

The Lifetime of Experiences Questionnaire (LEQ)

What is the LEQ?

The LEQ is a questionnaire to determine both your current *mental activity levels* and how active you have been over your lifetime.

Why is mental activity important?

From a brain health perspective, a number of studies have linked participation in mental activities with reduced dementia risk. Mental activity has a number of positive effects on the brain – from the level of the individual cell, to overall brain connectivity and performance.

What's the LEQ for?

In order to determine how mental activity patterns vary in the Australian community. The LEQ was designed for this purpose and assesses the full range of complex mental pursuits that build up over a person's lifetime. The LEQ is designed for individuals over the age of 65 years, or those already retired, and divides their experiences into the young adulthood, middle age and late life stages. Your educational, occupational and mental and leisure pursuits are assessed at each of these life stages.

Has the LEQ been scientifically validated?

Yes. We have published our validation study in the following international peer-reviewed scientific journal: M. Valenzuela & P. Sachdev. Assessment of complex mental activity across the lifespan: development of the Lifetime of Experiences Questionnaire (LEQ). *Psychological Medicine* (2007) 37:1015-1025

How do I proceed?

To complete the LEQ please continue and answer each question as accurately as possible. Completing the LEQ will take about 20 minutes.

Thank you for your participation.

Dr Michael Valenzuela and Professor Perminder Sachdev

General Instructions (Applicable to Optical Reading Print Format)

- 1. Use a pencil (preferable 2B)**
- 2. Erase your mistakes**
- 3. Do not use red or felt tip pens**
- 4. Do not write outside boxes or in page margins**
- 5. Do not fold**
- 6. Try not to make stray marks**
- 7. Try to use capital letters**
- 8. Do not cross out questions or boxes**

The Lifetime of Experience Questionnaire (LEQ)

YOUR DETAILS

First Name

Surname

E-Mail Address

Date of Birth

Age

Sex

Female

Male

Please answer the following questions as accurately as possible.

Choose the option which most closely fits with your experience.

LEQ YOUNG ADULTHOOD

The following questions apply to the time in your life between 13 and 30 years of age

Specific

Tip! Please answer all questions

I. How many years of Primary School did you complete?

None

1

2

3

4

5

6

II. How many years of High School (i.e. secondary school or grades *after* Year 6) did you complete?

None

1

2

3

4

5

6

III. Did you gain an end of High School Certificate (e.g., a High School Certificate, Matriculation Exam, O-Level, SAT)?

No

Yes

IV. Did you continue with any type of training or study after leaving school (only between the ages of 13 to 30 years of age)?

No

Yes

If Yes, please fill in the table below. If No go to "General" Question I (page 7)

Please specify what type(s) of training or study you attempted up until 30 years of age and for how long you were enrolled. Some categories are given below. If your experience is not covered by this list please fill in the details under 'any other course'.

Tip! If you choose one option, please complete the entire row.

Type of Course	Number of Years Enrolled in course? <u>Options:</u> 1 2 3 4 5	F/T or P/T?	% of course you completed <u>Options:</u> 25% 50% 75% 100%

	6 years		
Clerical, administrative or basic book-keeping training			
Business Course			
Trade Apprenticeship			
Other Technical Course			
College Diploma			
University Undergraduate (4 year degree)			
University Undergraduate (5 or 6 year degree, e.g. Medicine)			
University Masters			
University PhD/ Doctorate			
Other Graduate Course			
Any other course(s)? Name of the course(s), number of years enrolled, part-time or full-time, and whether it was fully completed.			

The following questions also apply to the time in your life between 13 and 30 years of age:

Tip! Please choose only one option in each question.

General

I. How often were you seeing a member of your family or friend during this time?

Never Less than Monthly Monthly Fortnightly Weekly Daily

II. How often were you practicing or playing a musical instrument?

Never Less than Monthly Monthly Fortnightly Weekly Daily

III. How often would you practice or develop an artistic pastime (e.g. drawing, painting, writing, acting)?

Never Less than Monthly Monthly Fortnightly Weekly Daily

IV How often would you take part in sports or activities that were mildly energetic, moderately energetic or vigorous:

IVa. Mildly energetic: e.g. walking, woodwork, weeding, hoeing, bicycle repair, playing pool, general housework.

Never Less than Monthly Monthly Fortnightly Weekly Daily

IVb. Moderately energetic: e.g. scrubbing, polishing car, dancing, golf, cycling, decorating, lawn mowing, leisurely swimming.

Never Less than Monthly Monthly Fortnightly Weekly Daily

IVc. Vigorous: e.g. running, hard swimming, tennis, squash, digging, cycle racing.

Never Less than Monthly Monthly Fortnightly Weekly Daily

V. How often did you read (material of any sort) for more than 20 minutes?

Never Less than Monthly Monthly Fortnightly Weekly Daily

VI. How often would you practice speaking, reading, writing or learning a second language?

Never Less than Monthly Monthly Fortnightly Weekly Daily

VII. Did you travel to any of the following continents between the ages of 13-30 years?

Choose as many options as applicable

None

Pacific Islands

Asia/Subcontinent

Latin/Central America

North America

Western Europe

East Europe/former USSR

Africa

Middle East

VIII. Between the ages of 13 to 30 years did you have any other pastime, hobby or special interest not mentioned in this questionnaire?

YES NO

If YES, please list:

LEQ MID LIFE

We are now moving on to your experience during your middle age years.

This refers to the time from 30 years until 65 years of age

Specific

- I. Please provide a history of the jobs or occupations that you have been involved in, from prior to retirement back to your early thirties. If you had multiple jobs during any one time period, please indicate the main job or occupation which you were involved with.

Please also refer to the separate ASCO JOB CLASSIFICATION GUIDE for help on how to work out the classification for each of your listed occupations.

****ASCO guidelines and this question to appear on same double-page spread******

It could be useful to include ASCO after this question, on the following page, to facilitate answers

Tip! Please provide an answer for each age range or row

Age Range	Job Classification	Job Title (free response)
	<u>Options</u> 1. Managers 2. Professionals 3. Associate Professionals/Running Own Business 4. Tradespersons and related workers 5. Advanced clerical and service workers 6. Intermediate Clerical, sales and service workers 7. Intermediate production and transport workers 8. Elementary clerical, sales and service workers 9. Labourers and related workers	Tip! Please print neatly and complete each row

	10. Nil – retired or not employed 11. Homecare or housewife	
60-65 years		
55-59 years		
50-54 years		
45-49 years		
40-44 years		
35-39 years		
30-34 years		

(On sent LEQs , the chronological order is opposite this)

- II.** Did any of your jobs or occupations mean that you were in charge of, directing, or responsible for other people?

If yes, please indicate below the approximate number of people you were in charge of. **If NO, please continue to QI “General” (pg 11).**

Age range	Job title	Number of people in charge of?
	Tip! Please print neatly and complete each row	Tip! Please complete each row <u>Options</u> 1. a. None/Not applicable 2. b. 1-5 people 3. c. 6-10 people 4. d. > (more than) 10 people

60-65 years		
55-60 years		
50-55 years		
45-50 years		
40-45 years		
35-40 years		
30-35 years		

The following questions also apply to the time in your life from 30 years of age until 65 years of age.

Tip! Please choose only one option in each question.

General

I. How often were you seeing a member of your family or friend during this time?

Never Less than Monthly Monthly Fortnightly Weekly Daily

II. How often were you practicing or playing a musical instrument?

Never Less than Monthly Monthly Fortnightly Weekly Daily

III. How often would you practice or develop an artistic pastime (e.g. drawing, painting, sculpture, creative writing, acting, etc)?

Never Less than Monthly Monthly Fortnightly Weekly Daily

IV How often would you take part in sports or activities that were mildly energetic, moderately energetic or vigorous:

IVa. Mildly energetic: e.g. walking, woodwork, weeding, hoeing, bicycle repair, playing pool, general housework.

Never Less than Monthly Monthly Fortnightly Weekly Daily

IVb. Moderately energetic: e.g. scrubbing, polishing car, dancing, golf, cycling, decorating, lawn mowing, leisurely swimming.

Never Less than Monthly Monthly Fortnightly Weekly Daily

IVc. Vigorous: e.g. running, hard swimming, tennis, squash, digging, cycle racing.

Never Less than Monthly Monthly Fortnightly Weekly Daily

V. How often did you read (material of any sort) for more than 20 minutes?

Never Less than Monthly Monthly Fortnightly Weekly Daily

VI. How often would you practice speaking, reading, writing or learning a second language?

Never Less than Monthly Monthly Fortnightly Weekly Daily

VII. Did you travel to any of the following continents between the ages of 30-65?

Pacific Islands

Asia/Subcontinent

Latin/Central America

North America

Western Europe

East Europe/former USSR

Africa

Middle East

VIII. Between the ages of 30 to 65 years did you have any other pastime, hobby or special interest not mentioned in this questionnaire?

YES NO

If YES, please list:

XIV. Between the ages of 30-65 years did you undertake any type of formal study?

Yes No

If YES, please indicate the details on the list below. **If NO please continue to LEQ Late Life on page 10**

Tip! If you choose one option, please complete the entire row.

Type of Course	Number of Years Enrolled in course? <u>Options:</u> 1 2 3 4 5 6 years	F/T or P/T?	% of course you completed <u>Options:</u> 25% 50% 75% 100%
Clerical, administrative or basic book-keeping training			
Business Course			
Trade Apprenticeship			
Other Technical Course			
College Diploma			
University Undergraduate (4 year degree)			

University Undergraduate (5 or 6 year degree, e.g. Medicine)			
University Masters			
University PhD/ Doctorate			
Other Graduate Course			
Any other course(s)? Name of the course(s), number of years enrolled, part-time or full-time, and whether it was fully completed			

LEQ Questions LATE LIFE

You will now be asked questions about the present phase of your life, beginning from 65 years of age.

Specific

I. Have you retired? Please choose only one of the following three options:

- a. Yes (= no ongoing paid work)
 - i. At what age did you retire?
- b. Sort Of (= part-time or casual ongoing paid work)
 - i. Number of hours of paid work per week?
 - ii. What is the main occupation title (free response)?
 - iii. What is the main occupation classification (see *ASCO JOB CLASSIFICATION GUIDE for help*)? Options:

Managers

Professionals

Associate Professionals/Running Own Business

Tradespersons and related workers

Advanced clerical and service workers

Intermediate Clerical, sales and service workers

Intermediate production and transport workers

Elementary clerical, sales and service workers

Labourers and related workers

- c. No (=full time ongoing paid work)
 - i. Number of hours of paid work per week?
 - ii. What is the main occupation title (free response)?
 - iii. What is the main occupation classification (see *ASCO JOB CLASSIFICATION GUIDE for help*)? Options

Managers

Professionals

Associate Professionals/Running Own Business

Tradespersons and related workers

Advanced clerical and service workers

Intermediate Clerical, sales and service workers

Intermediate production and transport workers

Elementary clerical, sales and service workers

Labourers and related workers

II. Do you currently reside (choose one option):

Alone With a partner With a friend With family Other
arrangement: List

III. Are you currently an active member of any social clubs or groups?

No Yes

If YES: please indicate how many:

IV. Do you do any charity or volunteer work?

No Yes

If YES: please indicate how many:

V. How often might you make an outing to see a family member, friend or group of friends?

(choose one option):

Never Less than Monthly Monthly Fortnightly Weekly Daily

VI. What types of events or entertainment have you undertaken in the last 2 months?

Please fill in ovals for any event or entertainment you have attended:

Nil

Movies

Plays/Drama

Pub/RSL Club

Concert/Recital

Special Performance

Dancing

Visiting friends

Sporting event

Restaurant

Other: Describe

VII. How would you spend a typical day?

Please circle any of the following activities if you undertake them on a typical day

	Pet Care
Sleep/Nothing	Artistry
House work	(e.g. drawing, painting, sculpture,
TV	creative writing, acting, etc)
Radio	Prayer/Religious activity
Listening to Music	Playing Music
Email	Brain Training Games
Internet use	(e.g. on computer or Nintendo)
Walking	Learning something new
Gardening	Hobby/Pastime
Crosswords or Sudoku	
Pet Care	Intellectual /Professional
Socialising	Taking care grandchildren
Reading	Sewing / knitting /embroidering
Writing	
Studying	
Teaching	
Volunteer work	
Paid work	
Strategic games	
(e.g., Chess, Bridge, Cards)	
Helping friends/family	

VIII. How do you usually acquire your information about world and national events?

Choose as many as are relevant to you

No particular way

Friends

TV

Radio

Newspapers

Magazines

Internet

Other: Describe

IX. What kinds of materials are you reading on a regular basis? Choose as many as appropriate

Just what is needed to get by

Newspaper articles

Magazines articles

Novels

Fiction stories

Journals or Monographs

Non-Fiction Books

All of above

Other: Describe

- X. Please give the typical number of hours per week you spend in sports or activities. (Enter '0' in hours and minutes if not undertaken at all.)

Mildly energetic (e.g. walking, weeding): _____ hours _____ minutes

Moderately energetic (e.g. dancing, cycling): _____ hours _____ minutes

Vigorous (e.g. running, squash): _____ hours _____ minutes

The following questions also apply to the current period in your life from 65 years of age.

Tip! Please choose only one option in each question.

General

- I. How often are you seeing a member of your family or friend during this time?

Never Less than Monthly Monthly Fortnightly Weekly Daily

- II. How often are you practicing or playing a musical instrument?

Never Less than Monthly Monthly Fortnightly Weekly Daily

- III. How often do you practice or develop an artistic pastime (e.g. drawing, painting, sculpture, creative writing, acting, etc)?

Never Less than Monthly Monthly Fortnightly Weekly Daily

IV How often do you take part in sports or activities that are mildly energetic, moderately energetic or vigorous:

IVa. Mildly energetic: e.g. walking, woodwork, weeding, hoeing, bicycle repair, playing pool, general housework.

Never Less than Monthly Monthly Fortnightly Weekly Daily

IVb. Moderately energetic: e.g. scrubbing, polishing car, dancing, golf, cycling, decorating, lawn mowing, leisurely swimming.

Never Less than Monthly Monthly Fortnightly Weekly Daily

IVc. Vigorous: e.g. running, hard swimming, tennis, squash, digging, cycle racing.

Never Less than Monthly Monthly Fortnightly Weekly Daily

V. How often do you read (material of any sort) for more than 20 minutes?

Never Less than Monthly Monthly Fortnightly Weekly Daily

VI. How often do you practice speaking, reading, writing or learning a second language?

Never Less than Monthly Monthly Fortnightly Weekly Daily

VII. Have you traveled to any of the following continents since the age of 65 years?
Choose as many options as applicable

None

Pacific Islands

Asia/Subcontinent

Latin/Central America

North America

Western Europe

East Europe/former USSR

Africa

Middle East

VIII. Have you had any other pastime, hobby or special interest not mentioned in this questionnaire?

YES NO

If YES, please list:

IX. Since the age of 65 years, have you undertaken any form of formal study?

Yes No

If YES, please indicate the precise nature on the list below:

Tip! If you choose one option, please complete the entire row.

Type of Course	Number of Years Enrolled in course? <u>Options:</u>	F/T or P/T?	% of course you completed <u>Options:</u>
	1		25%
	2		50%
	3		75%
	4		100%

	5 6 years		
Clerical, administrative or basic book-keeping training			
Business Course			
Trade Apprenticeship			
Other Technical Course			
College Diploma			
University Undergraduate (4 year degree)			
University Undergraduate (5 or 6 year degree, e.g. Medicine)			
University Masters			
University PhD/ Doctorate			
Other Graduate Course			
Any other course(s)? Name of the course(s), number of years enrolled, part-time or full-time, and whether it was fully completed			

Thank you for taking the time to complete this questionnaire. Please revise your responses one last time and then put your completed LEQ into the pre-paid envelope and mail back to our centre.

APPENDIX G

Assessment of Capacity of Everyday Decision-Making (ACED)

Templates/Forms

Assessment of Capacity for Everyday Decision-Making (ACED)

Volume II

Templates for interviews designed to assess capacity to solve problems related to medication management, money management, and meal preparation.



The ACED was developed by:

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INDEX

1a. ACED managing medications summary sheet	4
1b. ACED managing medications instrument	5
2a. ACED managing finances summary sheet	15
2b. ACED managing finances instrument	16
3a. ACED preparing meals summary sheet	26
3b. ACED preparing meals instrument	27

Introduction

What materials are provided in Volume II of the ACED manual?

This volume presents three versions of the ACED (managing medications, finances, and preparing meals). These ready made interviews address three common functional problems.

For each interview, we provide a summary sheet that the patient during the interview can use. This is not required. It is designed to address a patient's potential problems with short term memory.

These interview templates provide prespecified text. At selected places, there are spaces to fill in specifics about the patient's functional problem and options to manage that problem. These interviews follow the general flow as outline in Volume I, page 4.

For questions, please contact Dr. Karlawish at jason.karlawish@uphs.upenn.edu, or write to:

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ACED Instrument: Medication Management

The following pages show the Medication Management ACED interview. The first page is a summary sheet that the patient can use as a guide throughout the interview. This sheet is not mandatory. The interview for medication management follows.

Managing Medications

- Why it is important:
 - Medications help maintain your health
- Options for people who have problems managing their medications:
 - 1) You could use something to help you to remember to take your medications
 - 2) Someone could administer your medications to you
- These options have advantages:
 - Fewer missed medications
 - Less worry about taking the wrong medication
- These options have disadvantages:
 - You may lose some independence
 - You may not know which medications you are taking

Medication Management

Instructions for the Interviewer

Prior to starting the interview, the interviewer must speak with a knowledgeable informant to obtain a specific problem experienced by the patient with respect to medication management as well as a potential consequence of that problem. The interviewer must then record this information in the appropriate boxes under Q2 in the "Understanding the Problem" section below. Afterwards, you may proceed with the interview.

Introduction

"The purpose of this interview is to talk about your ability to manage your medications. This interview will take about 10 to 15 minutes. I will provide you with some information and then ask you a series of questions. Do not hesitate to ask a question if something that I say is not clear. OK? Now, let's get started..."

Understanding the Problem

Q1. Disclosure: "What I am going to do is read you some information. Then, what I'd like you to do is tell me, in your own words, what you understand about that information. Ready?"

"Properly managing your medications is important because, medications are important for maintaining your health.

Inquire: "Please, tell me in your own words, what I just told you.

Q1- Understanding Problem Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "please tell me again, what is your understanding of the importance of managing your medications?"
- Depending on the information omitted or misstated. You may also inform the patient that he or she is free to refer to the sheet.

Q2. Disclosure: "Ok, now I am going to talk about some problems people have in managing their medications and the consequences of these problems"

ACED Instrument: Medication Management

[Now, using the information below, make a statement about the problem and the potential consequences of that problem. For example, "Persons who frequently forget to take their medications may have a worse health condition and need to make more visits to the doctor."]

Problem Experienced by Patient	Potential Consequence of Problem

Inquire: "Please, tell me in your own words, what I just told you."

Q2- Understanding Problem Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "please tell me again- what is your understanding of the problems that may occur with managing your medications?"

Appreciation of Problem

Inquire: "Do you have any problems with [state the problem experienced by the patient]?"

Appreciation of Problem Response	Score

Instructions for Probes:

- If the patient responds with a simple yes or no, and fails to explain why, then you may ask, "Why do you think this?"
- If the patient denies having the problem, because someone else performs this function, ask, "If you were to do this by yourself, would you be able to?"
- For patients who deny having a problem, you may ask them to explain their answer by asking, "Are there reasons or events that have occurred

ACED Instrument: Medication Management

that might make other people think you have a problem with [state the problem]?"

- The interviewer may pursue a similar line of questioning until he or she is able to discern the patient's level of appreciation for his or her problem and whether it is based on inconsistent or fragmented logic.

Understanding the Options

Disclosure: If the patient denies having a problem managing her medications, the interviewer may choose to start by saying, "I realize that you do not believe that you have a problem with [state problem]. Nevertheless, I would like you to consider these two other options for managing your medications: [state the two options below]."

If the person admits having a problem then continue by saying, "Now, there could be several ways to deal with this problem. Two possibilities are:

- 1) You could use something to help you to remember to take your medications
- 2) Someone could administer your medications to you

Inquire: "Please, tell me in your own words, what I just told you."

Understanding Options Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "What again is your understanding of the options I have just presented to you?" and inform the patient that he or she is free to refer to the sheet.

Understanding the Advantages

Disclosure: "Now there are advantages and disadvantages to these options. Two advantages are:

- 1) You may experience fewer missed medications
- 2) You may have less worry about taking the wrong medication"

Inquire: "Please, tell me in your own words, what I just told you."

Understanding Advantages Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "Please tell me again what is your understanding of the advantages I just presented to you," and inform the patient that he or she is free to refer to the sheet.

Understanding the Disadvantages

Disclosure: "As I said before, there are also drawbacks to these options. Two disadvantages might be:

- 1) You may lose some independence
- 2) You may not know which medications you are taking"

Inquire: "Please, tell me in your own words, what I just told you."

Understanding Disadvantages Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "Please tell me again what is your understanding of the disadvantages I just presented to you," and inform the patient that he or she is free to refer to the sheet.

Appreciation of the Options

Q1. Disclosure: "You may or may not decide that one of the two options I have presented is one you actually want to use. For now, just consider these two choices [you may restate the two options]."

Inquire: "Now, do you think using something to help you to remember to take your medications could benefit you?"

Appreciation of Options Q1 Response	Score

Instructions for Probes:

- If the patient responds yes/no then ask, "Why do you think so?"

ACED Instrument: Medication Management

- The purpose is to examine whether patients' beliefs about the options involve false, distorted, or delusional ideas.
- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons for why the patient believes that the proposed options would or would not be helpful.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Q2. Inquire: "Now, do you think that having someone administer your medications to you could benefit you?"

Appreciation of Options Q2 Response	Score

Instructions for Probes:

- If the patient responds yes/no then ask, "Why do you think so?"
- The purpose is to examine whether patients' beliefs about the options involve false, distorted, or delusional ideas.
- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons for why the patient believes that the proposed options would or would not be helpful.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Q3. Inquire: "Now, could you think of reasons why these options [you may restate the options] might not help you, or perhaps even make things worse for you?"

Appreciation of Options Q3 (Disadvantages) Response	Score

Instructions for Probes:

- If the patient responds yes/no then ask, "Why do you think so?"
- The purpose is to examine whether patients' beliefs about the options involve false, distorted, or delusional ideas.
- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons for why the patient believes that the proposed options might not be helpful to his or her specific situation.

First Choice

Disclosure: "Overall there are four choices:

- 1) You could take your medications by yourself, completely
- 2) You could use something to help you to remember to take your medications,
- 3) Someone could administer your medications to you, or
- 4) You could continue what you are doing now."

Inquire: "Of these choices, which do you think you are most likely to want?"

Instructions for Probes:

- If the patient responds with choice 4), you should ask the patient to explain what her current situation is.

Choice:

Comparative Reasoning

Given the patient's choice, ask the following two questions. In choosing an option for comparison, choose an option that differs from the patient's choice. In cases where the patient's current situation is the same as one of the options (e.g. the patient's current situation (choice 4) is to have someone directly administer her medications to her (choice 3)), you should select one of the other two options.

Q1. Inquire: "Now, what makes your choice seem better than [State one of the following]:

- 1) ☐ Managing your medications by yourself, completely,
- 2) ☐ Using something to help you to remember to take your medications,
- 3) ☐ Someone administering your medications to you, or
- 4) ☐ Continuing what you are doing now."

Comparative Reasoning Q1 Response	Score

Instructions for Probes:

- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons why the patient believes that the chosen option is better than others.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Q2. Inquire: "Alright, now what makes your choice seem better than: [State one of the following, but not the option used in Q1]:

- 1) ☐ Managing your medications by yourself, completely,
- 2) ☐ Using something to help you to remember to take your medications
- 3) ☐ Someone administering your medications to you, or
- 4) ☐ Continuing what you are doing now."

Comparative Reasoning Q2 Response	Score

Instructions for Probes:

- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons why the patient believes that the chosen option is better than others.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Consequential Reasoning

Given the patient's choice, ask the following two questions. In choosing an option for comparison, choose an option that differs from the patient's choice. In cases where the patient's current situation is the same as one of the options (e.g. the patient's current situation (choice 4) is to have someone directly administer her medications to her (choice 3)), you should select one of the other two options.

Q1. Inquire: "Now consider what would happen if you had to [State one of the following]:

- 1) ☐ Take your medications by yourself, completely,
- 2) ☐ Use something to help you to remember to take your

ACED Instrument: Medication Management

Medications,

- 3) ☐ Have someone administer your medications to you, or
4) ☐ Continue what you are doing now."

Consequential Reasoning Q1 Response	Score

How would this affect your life?"

Instructions for Probes:

- If the patient is unclear, you may say again "how would that affect your daily life?" The goal is to get the most vivid answer with respect to consequences of the choice on her everyday life.

Q2. Inquire: "Now consider what would happen if you had to [State one of the following, but not the option used in Q1]:

- 1) ☐ Take your medications by yourself, completely
2) ☐ Use something to help you to remember to take your medications
3) ☐ Have someone administer your medications to you, or
4) ☐ Continue what you are doing now."

Consequential Reasoning Q2 Response	Score

How would this affect your life?"

Instructions for Probes:

- If necessary, the interviewer should ask questions so that the patient must clearly identify what he or she feels would result given this scenario.

Expressing a Choice

Inquire: "A few moments ago, you stated that [insert patient's choice of option] was your first choice. Now, after having discussed everything, do you still want to do that? I know you've already explained some of this, but can you tell me why?"

Expressing a Choice Response	Score

Reasoning- Logical Consistency

Logical Consistency Response	Score

ACED Instrument: Money Management

The following pages show the Managing Finances ACED interview. The first page is a summary sheet that the patient can use as a guide throughout the interview. This sheet is not mandatory. The interview for managing finances follows.

Managing Money

→ Why it is important:

- Money is used to pay bills, buy food, and purchase other items needed for independent living

→ Options for persons who have problems managing their money:

- 1) Someone could double-check how you spend your money
- 2) Someone else manages your money completely

→ These options have advantages:

- Fewer mistakes
- Less worry about your money

→ These options have disadvantages:

- You may lose some independence
- You may lose control over decisions with your money

Managing Money

Instructions for the Interviewer

Prior to starting the interview, the interviewer must speak with a knowledgeable informant to obtain a specific problem experienced by the patient with respect to money management as well as a potential consequence of that problem. The interviewer must then record this information in the appropriate boxes under Q2 in the "Understanding the Problem" section below. Afterwards, you may proceed with the interview.

Introduction

"The purpose of this interview is to talk about your ability to manage your money. This interview will take about 10 to 15 minutes. I will provide you with some information and then ask you a series of questions. Do not hesitate to ask a question if something that I say is not clear. OK? Now, let's get started..."

Understanding the Problem

Q1. Disclosure: "What I am going to do is read you some information. Then, what I'd like you to do is tell me, in your own words, what you understand about that information. Ready?"

"Managing your money is important. Money is used to pay bills, buy food, and purchase other items needed for independent living."

Inquire: "Please, tell me in your own words, what I just told you."

Q1- Understanding Problem Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "Please tell me again, why is managing your money important?" depending on the information omitted or misstated. You may also inform the patient that he or she is free to refer to the sheet.

Q2. Disclosure: "Ok, now I am going to talk about some problems people have with managing their money and the consequences of these problems."

[Now, using the information below, make a statement about the problem and the potential consequences of that problem. For example, "Persons who frequently

ACED Instrument: Money Management

neglect to pay their electric bill may have their electricity turned off and lose the ability to cook or to use a nebulizer.”]

Problem Experienced by Patient	Potential Consequence of Problem

Inquire: “Please, tell me in your own words, what I just told you.”

Q2- Understanding Problem Response	Score

Instructions for Probes:

- If the patient’s description omits information or describes an element incorrectly, the interviewer may ask, “Please tell me again- what is your understanding of a problem that may occur with managing your money?”

Appreciation of Problem

Inquire: “Do you have any problems with [state the problem experienced by the patient]?”

Appreciation of Problem Response	Score

Instructions for Probes:

- If the patient responds with a simple yes or no, and fails to explain why, then you may ask, “Why do you think this?”
- If the patient denies having the problem, because someone else performs this function, ask, “If you were to do this by yourself, would you be able to?”
- For patients who deny having a problem, you may ask them to explain their answer by asking, “Are there reasons or events that have occurred that might make other people think you have a problem with [state the problem]?”
- The interviewer may pursue a similar line of questioning until he or she is able to discern the patient’s level of appreciation for his or her problem and whether it is based on inconsistent or fragmented logic.

Understanding the Options

Disclosure: If the patient denies having a problem managing his or her finances, the interviewer may start by saying, "I realize that you do not think that you have a problem with [state problem]. Nevertheless, I would like you to consider these two other options for managing your money: [state the two options below]."

If the person admits having a problem then continue by saying, "Now, there could be several ways to deal with this problem. Two possibilities are:

- 1) Someone could double-check how you spend your money
- 2) Someone else could manage your money completely"

Inquire: "Please, tell me in your own words, what I have just told you."

Understanding Options Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "What again is your understanding of the options for managing your money that I have just presented to you?" and inform the patient that he or she is free to refer to the sheet.

Understanding the Advantages

Disclosure: "Now there are advantages and disadvantages to these options.

Two advantages are:

- 1) You are less likely to make a mistake with your money
- 2) You may worry less about managing your money"

Inquire: "Please, tell me in your own words, what I have just told you."

Understanding Advantages Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "Please tell me again what is your understanding the advantages I just presented to you," and inform the patient that he or she is free to refer to the sheet.

Understanding the Disadvantages

Disclosure: "As I said before, there may also be drawbacks to these options.

Two disadvantages might be that:

- 3) You may lose some independence
- 4) You may lose control over your financial decisions"

Inquire: "Please, tell me in your own words, what I have just told you."

Understanding Disadvantages Response	Score

Instructions for Probes:

- If the patient's description omits information or describes an element incorrectly, the interviewer may ask, "Please tell me again what is your understanding the disadvantages I just presented to you," and inform the patient that he or she is free to refer to the sheet.

Appreciation of the Options

Q1. Disclosure: "You may or may not decide that one of the two options I have presented is one you actually want to use. For now, just consider these two choices [you may restate the two options]."

Inquire: "Now, do you think that having someone double-check how you spend your money could benefit you?"

Appreciation of Options Q1 Response	Score

Instructions for Probes:

- If the patient responds yes/no then ask, "Why do you think so?"
- The purpose is to examine whether patients' beliefs about the options involve false, distorted, or delusional ideas.
- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons for why the patient believes that the proposed options would or would not be helpful.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Q2. Inquire: "Now, do you think that having someone else manage your money completely could benefit you?"

Appreciation of Options Q2 Response	Score

Instructions for Probes:

- If the patient responds yes/no then ask, "Why do you think so?"
- The purpose is to examine whether patients' beliefs about the options involve false, distorted, or delusional ideas.
- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons for why the patient believes that the proposed options would or would not be helpful.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Q3. Inquire: "Now, could you think of reasons why these options [you may restate the options] might not help you, or perhaps even make things worse for you?"

Appreciation of Options (Disadvantages) Q3 Response	Score

Instructions for Probes:

- If the patient responds yes/no then ask, "Why do you think so?"
- The purpose is to examine whether patients' beliefs about the options involve false, distorted, or delusional ideas.
- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons for why the patient believes that the proposed options might not be helpful to his or her specific situation.

First Choice

Disclosure: "Overall there are four choices:

- 1) You could manage your money by yourself
- 2) Someone could double-check how you spend your money,
- 3) Someone else could manage your money for you completely, or
- 4) You could continue what you are doing now."

Inquire: "Of these choices, which do you think you are most likely to want?"

ACED Instrument: Money Management

Instructions for Probes:

- If the patient responds with choice 4), you should ask the patient to explain what her current situation is.

Choice:

Comparative Reasoning

Given the patient's choice, ask the following two questions. In choosing an option for comparison, choose an option that differs from the patient's choice. In cases where the patient's current situation is the same as one of the options (e.g. the patient's current situation (choice 4) is having someone double-check her day to day financial transactions (choice 2)), you should select one of the other two options.

Q1. Inquire: "Now, what makes your choice seem better than [State one of the following]:

- 1) ☐ Managing your money by yourself
- 2) ☐ Having someone double-check how you spend your money
- 3) ☐ Having someone else manage your money for you completely, or
- 4) ☐ Continuing what you are doing now."

Comparative Reasoning Q1 Response	Score

Instructions for Probes:

- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons why the patient believes that the chosen option is better than others.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Q2. Inquire: "Alright, now what makes your choice seem better than: [State one of the following, but not the option used in Q1]:

- 1) ☐ Managing your money by yourself
- 2) ☐ Having someone double-check how you spend your money

ACED Instrument: Money Management

- 3) ☐ Having someone else manage your money for you completely, or
 4) ☐ Continuing what you are doing now."

Comparative Reasoning Q2 Response	Score

Instructions for Probes:

- If necessary, the interviewer should ask questions so that the patient must clearly identify the reasons why the patient believes that the chosen option is better than others.
- The interviewer should pursue follow-up questions until he or she is able to discern whether the patient's reasons are based on sound reasoning or inconsistent fragmented logic.

Consequential Reasoning

Given the patient's choice, ask the following two questions. In choosing an option for comparison, choose an option that differs from the patient's choice. In cases where the patient's current situation is the same as one of the options (e.g. the patient's current situation (choice 4) is having someone double-check her day to day financial transactions (choice 2)), you should select one of the other two options.

Q1. Inquire: "Now consider what would happen if you had to [State one of the following]:

- 1) ☐ Manage your money by yourself,
 2) ☐ Have someone double-check how you spend your money,
 3) ☐ Have someone else manage your money for you completely, or
 4) ☐ Continue what you are doing now."

Consequential Reasoning Q1 Response	Score

How would this affect your life?"

Instructions for Probes:

- If the patient is unclear, you may say again "how would that affect your daily life?"; the goal is to get the most vivid answer.

Q2. Inquire: "Now consider what would happen if you had to [State one of the following, but not the option used in Q1]:

ACED Instrument: Money Management

- 1) ☐ Manage your money by yourself,
- 2) ☐ Have someone double-check how you spend your money,
- 3) ☐ Have someone else manage your money for you completely, or
- 4) ☐ Continue what you are doing now."

Consequential Reasoning Q2 Response	Score

How would this affect your life?"

Instructions for Probes:

- If necessary, the interviewer should ask questions so that the patient must clearly identify what he or she feels would result given this scenario.

Expressing a Choice

Inquire: "A few moments ago, you stated that [insert patient's choice of option] was your first choice. Now, after having discussed everything, do you still want to do that? I know you've already explained some of this, but can you tell me why?"

Expressing a Choice Response	Score

Reasoning- Logical Consistency

Logical Consistency Response	Score

APPENDIX H

Assessment of Capacity of Everyday Decision-Making (ACED)

Measures Yielded

Assessment of Capacity of Everyday Decision-Making (ACED) – yields the following measures of elements of Decision Making Capacity with regard to two aspects of everyday decision making – **Health - Medication Management** and **Finance – Money Management**

Decision Making – Medication Management:

1. Understanding the Problem - Q1 + Q2 (range: 0-4)
 - a. Q1 (0;1;2)
 - b. Q2 (0;1;2)
2. Understanding the Options (0;1;2)
3. Understanding the Advantages (0;1;2)
4. Understanding the Disadvantages (0;1;2)
- 5. Understanding – Total = (21) + (22) + (23) + (24) (Range: 0-10)**
6. Appreciation of the Problem (0;1;2)
7. Appreciation of the Options Q1 + Q2 + Q3 (range: 0-6)
 - c. Q1 (0;1;2)
 - d. Q2 (0;1;2)
 - e. Q3 (0;1;2)
- 8. Appreciation – Total = (26) + (27) (Range: 0-8)**
9. Reasoning – Comparative Reasoning - Q1 + Q2 (range: 0-4)
 - f. Q1 (0;1;2)
 - g. Q2 (0;1;2)
10. Reasoning – Consequential Reasoning - Q1 + Q2 (range: 0-4)
 - h. Q1 (0;1;2)
 - i. Q2 (0;1;2)
11. Reasoning – Logical Consistency (0;1;2)
- 12. Reasoning – Total = (9) + (10) + (11) (Range: 0-10)**
- 13. Expressing a Choice (0;1;2)**
- 14. M;Total (Range 0-30)**

Decision Making – Finance - Money Management:

15. Understanding the Problem - Q1 + Q2 (range: 0-4)
 - a. Q1 (0;1;2)
 - b. Q2 (0;1;2)
16. Understanding the Options (0;1;2)
17. Understanding the Advantages (0;1;2)
18. Understanding the Disadvantages (0;1;2)
- 19. Understanding – Total = (1) + (2) + (3) + (4) (Range: 0-10)**
20. Appreciation of the Problem (0;1;2)
21. Appreciation of the Options Q1 + Q2 + Q3 (range: 0-6)
 - c. Q1 (0;1;2)
 - d. Q2 (0;1;2)
 - e. Q3 (0;1;2)
- 22. Appreciation – Total = (6) + (7) (Range: 0-8)**
23. Reasoning – Comparative Reasoning - Q1 + Q2 (range: 0-4)
 - f. Q1 (0;1;2)
 - g. Q2 (0;1;2)
24. Reasoning – Consequential Reasoning - Q1 + Q2 (range: 0-4)
 - h. Q1 (0;1;2)
 - i. Q2 (0;1;2)
25. Reasoning – Logical Consistency (0;1;2)
- 26. Reasoning – Total = (9) + (10) + (11) (Range: 0-10)**
- 27. Expressing a Choice (0;1;2)**
- 28. F;Total (Range 0-30)**

APPENDIX I

Assessment of Capacity of Everyday Decision-Making (ACED)

ACED Data Coding

Data – ACED

Five questions were explored to provide details of the following:

- How many participants were asked the question/or provided a response
- The response content

Two questions were sampled from ACED – Managing Medications and three questions from ACED – Managing Money. The questions sampled were

ACED – Managing Medications

- A. **Consequential Reasoning – Question:** “Now consider what would happen if you had to ‘have someone administer your medication to you’
- B. **Expressing a choice – Question:** “A few moments ago, you stated that (*reference participant’s choice of option*) was your first choice. Now after having discussed everything, do you still want to do that? I know you’ve already explained some of this, but can you tell me why?”

ACED – Managing Money

- C. **Understanding the Disadvantages – Question:** “As I said before, there are also drawbacks to these options

Initially two possible options were identified to address difficulties with managing money.

These were

- **Someone else may help by double checking or**
- **Someone else may help by managing the money completely.**

Advantages and disadvantages of these options were outlined and the participant's understanding was explored by asking them to set out in their own words the advantages and disadvantages. The disadvantages provided were:

- **You may lose some independence**
- **You may lose some control over your financial decisions**

Question: "As I said before, there are also drawbacks to these options. Two disadvantages may be

- You may lose some independence
- You may lose some control over your financial decisions

Please tell me in your own words what I have just told you"

D. **Consequential Reasoning – Question:** "Now consider what would happen if you had to 'have someone else manage your money for you completely'

E. **Expressing a choice – Question:** "A few moments ago, you stated that (*reference participant's choice of option*) was your first choice. Now after having discussed everything, do you still want to do that? I know you've already explained some of this, but can you tell me why?"

A number of tentative categories were generated and each of the responses were then coded accordingly. This resulted with the identification of four categories that reflected the majority of responses. The content of some responses reflected more than one category. The four categories were

Independence/Control/Autonomy – ICA

Physical Well Being – PWB

Emotional/Psychological Well Being – EPWB

Trust/Risk – TR

Details of the responses to the questions sampled and the categories that they reflected are set out below.

Managing Medication

1. **Consequential Reasoning** – “Now consider what would happen if you had to
‘have someone administer your medication to you’

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

ID	Questioned Asked?Y(1)/N(0)	Response Content	Category
01	1	I’d have had a stroke – only reason it would happen. It would annoy me, would get my med but I wouldn’t like it	ICA
02	1	May get anxious if person admin med wasn’t there, if requirement for before/after food, even more anxious – can’t go to bed until person comes	EPWB/ICA
03	1	Become totally reliant on other person with consequences for general well being	ICA/EPWB
04	1	You’d know she’d be alright & less chance of anything happening to her	PWB
05	1	Lose ctrl over own health issues, person could fall ill or be unable to admin med & therefore may not get med	ICA/PWB
06	1	Health has better chance of holding up, very significant health consequences of some meds	PWB

07	0	(this was Participant's chosen option)	n/a
08	0	(this was Participant's chosen option)	n/a
09	1	Don't think it would make any difference to me	
10	1	They're administered, I'd try to be a good patient, it would be starting point of taking responsibility	
11	1	I would have to take them but I would not like someone coming in even though it might work perfectly	ICA
12	1	Would have to be in res home – (Q affect life?) – not too much, my independence would have gone	ICA
13	1	I would lose confidence & self belief; slf/blief means a lot	EPWB
14	0	(this was Participant's chosen option)	n/a
15	1	Don't know – probably affect me, end up more sick	PWB
16	1	Getting meds while person available but creates reliance on someone else; must have someone around all time to ensure med taken so create loss of independence	ICA
17	1	Depends on who it is, is it someone u can rely on; it would be ok if you weren't capable but u lose independ	ICA/TR

18	1	U'd become childlike, could become very depend on someone else	ICA
19	0	(this was Participant's chosen option)	n/a
20	1	Take independ away, but if u didn't even know what to do, they'd have to give med to make sure right	ICA/PWB
21	0	(this was Participant's chosen option)	n/a
22	1	Would improve it, would help & there'd be less worry	PWB/EPWB
23	0	(this was Participant's chosen option)	n/a
24	1	Better for my health, I'd get to rely on them, wouldn't want that, loss of independence	ICA/PWB
25	0	(this was Participant's chosen option)	n/a
26	1	Lose their privacy & have to rely on someone else	ICA/P
27	1	Would be better than not taking med, might feel bit of independ going	ICA/PWB
28	1	U'd feel restricted & u'd feel u'd have to be there for person rather than person there for u	ICA
29	1	There's other tablets	

Categories: ICA - Independence/Control/Autonomy; TR - Trust/Risk; PWB - Physical

Well Being; EPWB - Emotional/Psychological Well Being

Managing Medication

1. Expressing a choice

Categories: ICA - Independence/Control/Autonomy; TR - Trust/Risk; PWB - Physical

Well Being; EPWB - Emotional/Psychological Well Being

ID	Questioned Asked?Y(1)/N(0)	Response Content	Category
01	1	COO – it's good reminder & I'm capable of taking meds myself	ICA
02	1	COO – it leaves independ & you're not waiting for someone to come & something like a pillbox provides a check, if not taken	ICA
03	1	COO – good for you, helps you take med & have a say in it, keep independence	ICA/PWB
04	1	COO – because sure she's getting right dose & safe	PWB
05	1	COO – still in ctrl of own med & retain independ & get med	ICA
06	1	COO – could retain my independence	ICA
07	1	COO – if not able it's safest, reminder might not help	TR
08	1	COO – glad to have someone to help you	
09	1	COO – should you forget there's always someone to help	

10	1	DNCOO – 4 to 2 – I think visually that would help	
11	1	COO – because I will remember to take med	
12	1	COO – having med organised by someone I trust would work	TR
13	1	COO – I'd be more sure of myself with timer & I'd know I'd get my med	
14	1	COO – it's handier	
15	1	COO – try to do it yourself, independence	ICA
16	1	COO – Meds org, correct dose, correct time with reminder supports even if noone there to give med	
17	1	COO – I feel I'm in ctrl, my memory is good enough to sort out tabs at start of week, I feel secure about it	ICA
18	1	COO – for a start I would; not wanting to be reliant on someone else	ICA
19	1	COO – someone giving med the best but likes option of taking it completely by self	ICA
20	1	COO – because all sorted out for me	
21	1	COO – Staff give you meds, in case you might do harm to yourself	PWB
22	1	COO – if you're doing it yourself & have system, u know u need to do it properly u	

		will concentrate & with reminders take right med at right times	
23	1	COO – someone to give med to me, it'd help more	
24	1	COO – I'd rather be responsible for my own actions	ICA
25	1	COO – if not capable – would be afraid of something happening & ending up in hospital	PWB
26	1	COO – still got independence; as long as have reminder to take med, not relying on someone else	ICA
27	1	COO – I would be doing the reminding not someone else	ICA
28	1	COO – wouldn't have to rely on anyone (uses contr	ICA
29	1	DNCOO – don't know	

COO = Participant confirmed original option chosen

DCOO = Participant did not confirm original option chosen

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

Managing Money

1. Understanding – Disadvantages

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well

Being; **EPWB** - Emotional/Psychological Well Being

ID	Questioned Asked?Y(1)/N(0)	Response Content	Category
01	1	Someone might use your money for something else; you'd lose your independence	ICA/TR
02	1	You may lose control of your money & decisions & may lose your independence re decision making	ICA
03	1	Lose control over your money; lose some independence & privacy, feel sorry for yourself that you're reduced to that, lose control of your life & accept loss of independence	ICA/EPWB
04	1	Loss of independ & would lose ctrl over money	ICA
05	1	Will lose ctrl of money & ctrl of decisions about your money, bad for your independence, one more sign that you're getting older & losing independ	ICA

06	1	Lose independ; could lose ctrl over financial decis	ICA
07	1	Lose some independ; lose ctrl over your decisions, can be very dangerous, people can take money off older people	ICA/TR
08	1	If you had money you could lose it & forget where you put it	
09	1	(uncertain – couldn't see applicability)	
10	1	Loss of independence; loss of control	ICA
11	1	Lose some independence; lose control over decisions of your money altogether	ICA
12	1	Loss of independence; not able to decide what money used for where person managing, you lose ctrl over decisions	ICA
13	1	U would lose ctrl over your money & how to spend it; u lose part of your indep, very important	ICA
14	1	Don't know	
15	1	Lose independence; lose control	ICA
16	1	Lose some indep; lose complete ctrl over decisions about money	ICA
17	1	Lose indep as result; misappropriation cld happen	ICA/TR
18	1	May lose some of their independence;	ICA

		lose control over decisions about money & spending	
19	1	Lose indep; someone else makes decs instead of u	ICA
20	1	Someone else making decision; taking your confidence away	ICA/EPWB
21	1	Money safe – rejected the disadvantages	
22	1	U would lose indep & lose ctrl of exps & finances	ICA
23	1	Might lose indep; might lose control over money	ICA
24	1	Loss of independ; loss of control over how u spend & manage money	ICA
25	1	Losing your independence; losing control over financial decisions with your money	ICA
26	1	Lose ctrl over mgt money; may lose independ	ICA
27	1	Loss of independ & ctrl over what money spent on	ICA
28	1	Loses indep; loses financial ctrl on money	ICA
29	1	Don't know	

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

Managing Money

- 1. Consequential Reasoning** – “Now consider what would happen if you had to
‘have someone else manage your money for you completely’

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

ID	Questioned Asked?Y(1)/N(0)	Response Content	Category
01	1	I'd worry that they would forget, you would still have to check; if it was family, you wouldn't have to worry that money had gone astray, you stay in control	EPWB/TR
02	1	I'd feel diminished, I'd hate to have someone else decide what & how much I could spend on food, travel, gifts etc	ICA/EPWB
03	1	Depending on other person's honesty that they wouldn't take money, bills might not be paid, back where started. If honest must accept independence given away	ICA/TR
04	1	Take away self esteem, independ, would feel worthless	EPWB
05	1	If all your money handed over, complete loss of independ, leave you very depend on that person all the time for your needs, would not	ICA

		be good situation	
06	1	Depends on stage, may bring a lot of relief	
07	1	If you weren't able to cope it would be safer; if you weren't quite well, it would be bi rd mif	
08	0	(This was her chosen option)	
09	1	If I could help it, it wouldn't happen, I wouldn't like it	ICA
10	1	Certain disenfranchisement, no feeling for money, lose idea of personal economy, no ctrl in carry out, when money tight less spending when money not spnd & save	ICA
11	1	Would affect them badly, would lose their independence	ICA
12	1	Independ is better if you can manage it properly, depends on person, provided capable it's question of independence, would feel not able & give up the ghost	ICA/EPWB
13	1	U'd have to trust the person, I'd find it hard to trust	TR
14	1	It'd be alright	
15	1	I'd end up with no money – I don't think so (re option)	ICA
16	1	Loss of indep & ctrl, leaves u open to exploitation, you'd feel that u wouldn't have	ICA/TR

		ctrl or input into DM	
17	1	Depends on who was going to do it, if complete trust ok but opened to being ‘doodled’, feel at disadv lower self esteem & cause worry	TR
18	1	May become over dependent on person mging money; the more u lose indep the more u lose ability – lack of confidence in ability	ICA/EPWB
19	1	They might spend it for themselves, I’d be sad & gloomy	TR
20	1	I don’t know what would happen, I’d be worried & I wouldn’t be able to go out, they’d be in charge instead of me	ICA/EPWB
21	0	(this was Participant’s chosen option)	n/a
22	1	Take away your independence	ICA
23	1	Wouldn’t have my indep, wouldn’t be able to buy food or anything u needed yourself	ICA
24	1	It would be better than nothing, loss of ctrl & indep	ICA
25	1	I’d be very worried, I’d like to know where every penny would go; I’d like receipts & how much is left each month. It’d leave me very down to ask for price of paper & perhaps not get it; u’d have to trust person	ICA/TR

26	1	Nothing, would make life easier, someone else paying bills, wouldn't have to worry	
27	1	Handing over big slice of the running of ur life, depends on whom u're handing it to, hope person is trustworthy, worry they would spend in same way to ur benefit	ICA/TR
28	1	Secure in knowledge bills paid, won't cut off services	
29	1	No	

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

Managing Money

1. Expressing a choice

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

ID	Questioned Asked?Y(1)/N(0)	Response Content	Category
01	1	COO – I feel that I’m in ctrl, I don’t have to bother other people & bills get paid	ICA
02	1	COO – because it’s a windfall & it’s different from situation now & you’d need advice, unprecedented	
03	1	COO – because getting help but have degree of ctrl	ICA
04	1	COO – would how much money had to spend, wouldn’t lose ctrl completely but better managed	ICA
05	1	COO – all your bills would be paid, safe in knowledge that you’d not be cut off (D/C) & would still have your money to spend as you want	ICA
06	1	COO – I can retain independ for as long as possible	ICA
07	1	COO – it’s nice to be in control, if worse	ICA

		option 3 would be better	
08	1	COO – you know it’s safe (if you had any money!)	TR
09	1	COO – because I trust them to do it the way that they’re doing it & to do what I tell them to do	TR
10	1	COO – 3 too totalitarian, 2 not enough	ICA
11	1	COO – I think it’s best option, you’re independent & bills are getting paid	ICA
12	1	COO – question of indep & managing my own affairs without difficulty	ICA
13	1	COO – I’d trust it more than the others	TR
14	1	DNCOO – switched to 3 “staff – it’s handier”	
15	1	COO – be independent	ICA
16	1	COO – yes puts you into driving seat, ensures bills get paid in time; with debt, there’s bother services cut off – u can still make decisions yourself	ICA
17	1	COO – security feeling that bills will be paid on time, less worry about it	EPWB
18	1	COO – because of Independence	ICA
19	1	COO – easier, you & staff have to sign, easier to manage money	

20	1	COO – I understand it better, I can sort it better & it's always correct	ICA
21	1	COO – staff office so no one can get it	TR
22	1	COO – uses reminders at moment, makes more indep, know where u stand with money & what due	ICA
23	1	Might get mixed up with money if managing completely yourself	
24	1	COO – keep your indep & keep control of your life	ICA
25	1	COO – it's safest, peace of mind & worry off my mind, I know my bills are paid	EPWB/TR
26	1	COO – more content	EPWB
27	1	COO – I'd still be mging it, nobody else'd be invol	ICA
28	1	COO – unless there's someone who can be trusted, (option) u wouldn't have to go to bank yourself, bills'd be paid & easier to know what's in bank	TR
29	1	DCOO	

COO = Participant confirmed original option chose

DCOO = Participant did not confirm original option chosen

Categories: **ICA** - Independence/Control/Autonomy; **TR** - Trust/Risk; **PWB** - Physical Well Being; **EPWB** - Emotional/Psychological Well Being

APPENDIX J

Results - Table J.01

Summary Statistics (original) for Measures of Preference in
Decision-Making

Results - Table J.02

Preference in Decision Making
Participation¹ by Group (original)

Table J.01. Summary Statistics (original) for Measures of Preference re Decision-Making* (n=29)

	Summary statistics			
	possible range	observed range	mean(SD)	median(IQR)
Overall scale	11 to 66	39 to 62	53.3 (5.1)	54 (50 to 56)
Subscales				
Getting up	2 to 12	8 to 12	11.1 (1.2)	12 (10 to 12)
Eating	2 to 12	5 to 12	11.2 (1.4)	12 (11 to 12)
Money	2 to 12	8 to 12	11.1 (1.5)	12 (10 to 12)
TV	2 to 12	8 to 12	11.4 (1.1)	12 (11.5 to 12)
Illness	3 to 18	3 to 16	8.4 (3.0)	8 (7 to 8)

¹higher score represents greater autonomy

Table J.02. Preference in Decision Making Participation¹ by Group (original)

	Group One (n=15)	Group Two (n=14)	p-value ³
	median (IQR)	median (IQR)	
Overall scale (11-66) ²	55 (52 to 56)	52.5 (48.8 to 55.3)	0.070
Subscales			
Getting up (2-12) ²	12 (11 to 12)	11.5 (10 to 12)	0.477
Eating (2-12) ²	11 (11 to 12)	12 (11 to 12)	0.652
Money (2-12) ²	12 (12 to 12)	10.5 (8.8 to 12)	0.041
TV (2-12) ²	12 (10 to 12)	12 (12 to 12)	0.331
Illness (3-18) ²	8 (7 to 14)	8 (6.8 to 8)	0.146

¹higher score represents greater autonomy

²possible range

³from Mann-Whitney U test

APPENDIX K

Results - Table K.01

Summary Statistics (original) for Measures of Participation in
Decision-Making

Results - Table K.02

Participation in Decision Making by Group (original)

Table K.01. Summary Statistics (original) for Measures of Participation in Decision-Making¹ for All Participants (n=29)

	Summary statistics			
	possible range	observed range	mean(SD)	median(IQR)
Overall scale	0 to 33	14 to 33	31.2 (4.5)	33 (32 to 33)
Subscales				
Daily schedule	0 to 15	6 to 15	14.2 (2.2)	15 (15 to 15)
Eating	0 to 6	2 to 6	5.6 (1.1)	6 (6 to 6)
Money	0 to 3	1 to 3	2.8 (0.5)	3 (3 to 3)
Personal Appearance	0 to 6	2 to 6	5.6 (1.0)	6 (6 to 6)
TV	0 to 3	2 to 3	2.9 (0.3)	3 (3 to 3)

¹higher score represents greater autonomy

Table K.02. Participation in Decision Making¹ by Group (original)

	Group One (n=15)		Group Two (n=14)	p-value ³
	median (IQR) ⁴		median (IQR)	
Overall scale (0-33) ²	33	-	32 (29.5 to 33)	0.001
Subscales				
Daily schedule (0-15) ²	15	-	15 (12 to 15)	0.102
Eating (0-6) ²	6	-	6 (4.8 to 6)	0.201
Money (0-3) ²	3	-	3 (2 to 3)	0.102
Personal Appearance (0-6) ²	6	-	6 (4.8 to 6)	0.051
TV (0-3) ²	3	-	3 (3 to 3)	0.533

¹higher score represents greater autonomy

²possible range

³from Mann-Whitney U test

⁴results are constant for this group

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