

Oral Health and Function in Older Adults with Intellectual Disabilities: Measurement Innovation for Epidemiological and Population Health Research

**A thesis submitted to Trinity College Dublin, the University of Dublin,
for the Degree of Doctor of Philosophy.**

Prepared by: Katrina Byrne

School of Dentistry
Faculty of Health Sciences
University of Dublin
Trinity College Dublin

Supervisors: Dr Caoimhin Mac Giolla Phadraig, Prof Philip McCallion, Prof Blanaid Daly and Prof Mary McCarron

Word count: 82,551

6th of March 2026

Declaration

I declare that this thesis has not been previously submitted as an exercise for a degree at this or another university. This submission comprises my own work towards the Ph.D. unless otherwise stated, and in which case, acknowledgments and references are given to the work of others. I agree to deposit this thesis in the University's open access institutional repository or allow the library to do so on my behalf, subject to Irish Copyright Legislation and Trinity College Library conditions of use and acknowledgment.

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Summary

Background

Oral health is increasingly recognised as integral to systemic wellbeing, functional capacity and survival in ageing populations. However, adults with intellectual disabilities remain largely excluded from oral health surveillance and longitudinal epidemiological research. As a result, their oral health status and its interaction with multimorbidity, frailty and premature mortality remain insufficiently understood. This exclusion reflects both methodological barriers and structural inequities in health research and policy.

Aim

The overarching aim of this thesis was to generate disability-inclusive oral health evidence by developing and validating a structured clinical oral health assessment tool and embedding it within a nationally representative longitudinal ageing cohort to examine oral health status, oral–systemic associations and mortality risk among older adults with intellectual disabilities in Ireland.

Methods

The thesis adopted a post-positivist epidemiological framework informed by critical realism and an equity-oriented lens. It comprised three interconnected components. First, scoping review synthesised international evidence on oral health and pneumonia in adults with intellectual and developmental disabilities. Second, the Modified Oral Status Survey Tool (MOSST) was developed and psychometrically evaluated to enable structured clinical oral health assessment by trained non-dental clinicians. Content validity was established through international expert review and public and patient involvement. Inter- and intra-rater reliability exceeded recommended epidemiological thresholds ($\kappa > 0.85$), and feasibility testing demonstrated high acceptability within field conditions. Third, MOSST was embedded within Wave 5 of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), enabling cross-sectional and longitudinal analyses of oral health, systemic conditions and mortality. Multivariable regression models examined associations between oral indicators and systemic outcomes. Cox proportional hazards models assessed associations between tooth loss and all-cause and respiratory-related mortality.

Results

The scoping review identified biological plausibility for oro-respiratory pathways but highlighted a fragmented and methodologically limited evidence base. MOSST demonstrated strong content validity, high reliability and feasibility within a national ageing cohort.

Population-level analyses revealed a substantial burden of untreated caries, compromised gum condition, reduced functional dentition and incomplete prosthetic rehabilitation among older adults with intellectual disabilities. Clear demographic and contextual patterning were observed by age, level of intellectual disability and residence type.

In adjusted multivariable models, absence of functional dentition was significantly associated with constipation and osteoporosis, while indicators of poor oral cleanliness and disease burden were associated with respiratory illness. Longitudinal survival analyses demonstrated that tooth loss and absence of functional dentition were independently associated with increased risk of both all-cause and respiratory-related mortality, even after adjustment for age, gender, level of intellectual disability and multimorbidity.

Discussion

These findings demonstrate that oral health among older adults with intellectual disabilities is neither inevitable nor clinically peripheral but structurally patterned and epidemiologically consequential. By embedding a validated disability-adapted oral health assessment within a longitudinal cohort, this thesis advances inclusive epidemiological infrastructure and enables examination of oral–systemic and oral–mortality pathways previously absent from disability research. The results support conceptualisation of oral health as a modifiable determinant within multimorbidity and frailty trajectories and highlight the role of structural inequities in shaping oral health outcomes.

Conclusions

This thesis makes three principal contributions: (1) development and validation of a disability-inclusive oral health assessment tool suitable for large-scale surveillance; (2) generation of the first nationally representative, clinically assessed oral health dataset for older adults with intellectual disabilities in Ireland; and (3) empirical demonstration of oral–systemic and oral–mortality associations within a longitudinal disability cohort. The

findings support integration of oral health into ageing research, public health monitoring and rights-based disability policy, reframing oral health inequity as a structural issue rather than an inherent feature of disability.

Dedication

For my family.

To my husband, Sean — your unwavering love, strength, patience, and belief in me made this journey possible. You carried me through the most demanding moments with quiet sacrifice and constant encouragement. This achievement is as much yours as it is mine.

To my two girls, the light of my life — your love, laughter, hugs, and unquestioning belief in me have been my greatest motivation. You remind me every day of what truly matters. I hope that one day you will see in this work not just a thesis, but an example of perseverance, purpose, and passion. May you always believe in yourselves as fiercely as I believe in you.

To all my family and friends, thank you for your constant support, pride, and encouragement. A special thank you to Lorraine and Sean for always reminding me to take breaks, come up for breath, and for the endless babysitting and supportive chats along the way. Your faith in me has meant more than I can ever fully express.

Acknowledgements

I would first like to express my deepest gratitude to the people with intellectual disabilities who participated in this research. Your willingness to share your time, experiences, and personal stories made this work possible. The questions you asked, the challenges you described, and the realities you shared ignited and sustained my commitment to pursuing meaningful change.

I would like to express my sincere thanks to my supervisors, each of whom has played a unique and profoundly impactful role throughout the past four years. Your guidance, leadership, encouragement, and inspiration have shaped not only this thesis but also my development as a researcher and academic.

I would also like to extend a very special thank you to Kev. For your patience, intellectual rigour, honesty, and steadfast support challenged me to think more critically, aim higher, and persist through the inevitable difficulties of doctoral research. At times I have joked that you were my own “Mr Miyagi”, guiding quietly, pushing deliberately, and teaching lessons that extended far beyond the immediate task. What has meant most is our shared passion, our shared *grá*, for research that is not merely academic but purposeful but research that seeks to drive positive change in the lives of people with intellectual disabilities.

I would also like to thank my colleagues in the Trinity Centre for Ageing and Intellectual Disability and IDS TILDA. Over the past four years, your support and openness created a space where I could learn, question, and grow. The conversations, shared ideas, and moments of humour along the way brought balance to what can often be an intense journey.

I have also experienced immense support, guidance, and kindness from colleagues and students in the School of Nursing and Midwifery and from the Special Care Dentistry team at Dublin Dental University Hospital over the past four years, thank you.

Finally, to thanks the many friends who have supported me along the way, both old and new, your encouragement and belief in me have meant more than you know.

Glossary of terms and abbreviations

AAAQ – Availability, Accessibility, Acceptability and Quality

AAID – American Association on Intellectual and Developmental Disabilities

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

FDI – FDI World Dental Federation

GA – General Anaesthesia

HSE – Health Service Executive (Ireland)

ICD-11 – International Classification of Diseases, Eleventh Revision

ICESCR – International Covenant on Economic, Social and Cultural Rights

IDS-TILDA – Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing

ISDH – Irish Society for Disability and Oral Health

LeDeR – Learning from Deaths Review

MOSST – Modified Oral Status Survey Tool

MOSST-SRS – Modified Oral Status Survey Tool – Self-Report Supplement

NASS – National Ability Supports System

NCD – Non-Communicable Disease

NHANES – National Health and Nutrition Examination Survey (United States)

NICE – National Institute for Health and Care Excellence (United Kingdom)

NID – National Intellectual Disability Database

PCR – Polymerase chain reaction

PPI – Public and Patient Involvement

TILDA – The Irish Longitudinal Study on Ageing

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

WHO – World Health Organization

Publications, awards and presentations*

*Related to the research within this thesis

Publications:

Peer reviewed:

Byrne, K., Daly, B., McCallion, P., McCarron, M., & Phadraig, C. M. G. (2026). The Modified Oral Status Survey Tool: Development and Psychometrics for Accessible Oral Health Data Collection. *Community Dentistry and Oral Epidemiology*.

<https://doi.org/10.1111/cdoe.70052>

Byrne, K., Lisiecka, D., Moran, G., Daly, B., Fleischmann, I., McCallion, P., ... & Phadraig, C. M. G. (2026). Oral Health and Pneumonia in Adults With Intellectual and Developmental Disabilities: A Scoping Review. *Journal of Intellectual Disability Research*, 70(1), 16-28.

<https://doi.org/10.1111/jir.70013>

Byrne,K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The oral health status of older adults with intellectual disability in Ireland. IASSIDD 2024. *Journal of Intellectual Disability Research*, 68: 641-890. <https://doi-org.elib.tcd.ie/10.1111/jir.13166>, <https://doi-org.elib.tcd.ie/10.1111/jir.13166>

Non-peer-reviewed

Byrne K., Hisamuddin N., Moynihan J., Paul A., Corrigan S., Ryan C., Winning L., McReynolds D., Haigh M., Daly B., McCallion P., McCarron M. & Mac Giolla Phadraig C. (2023) Oral Health p136-150 in Longitudinal Dynamics in the Ageing of People with an Intellectual Disability: Evidence from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) Wave 5. McCarron M., Haigh M., Dann G. & McCallion P (Eds.). School of Nursing & Midwifery, Trinity College Dublin, Dublin.

Oral Presentations

Byrne,K., Daly, B., McCarron, M., McCallion, P., MacGiolla Phadraig, C. The Modified Oral Status Survey Tool: Development and Psychometric Properties. IASSID health SIRG, 1st - 2nd of September 2025

Byrne,K., Lisiecka, D., Moran, G., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. A scoping review: Exploring the relationship between oral health and pneumonia in adults with intellectual developmental disorders. IASSID health SIRG, 1st - 2nd of September 2025

Mac Giolla Phadraig, C. Byrne, K., McCarron, M. & McCallion, P., Daly, B., Monitoring and surveillance of oral conditions WHO global oral health meeting. WHO Global Oral Health Side Event. Health Organisation, Bangkok, Thailand, 26–29 November 2024

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. Oral Health in Intellectual Disability: Insights from IDS-TILDA Data., Integrating Disability Evidence into Action for Supports and Services (IDEAS 2024) for Older People with an Intellectual Disability; Translating IDS-TILDA Knowledge into Policy and Practice., 17th of October 2024, oral presentation.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Modified Oral Status Survey Tool., The international association of oral health and disability (IADH) ., 28th of September 2024, oral presentation.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The oral health status of older adults with intellectual disability in Ireland, The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSISD) ., 8th of August 2024, oral presentation. <https://doi-org.elib.tcd.ie/10.1111/jir.13166>

Byrne, K., Mac Giolla Phadraig, C. Technical Advisor. WHO Global Oral Health Side Event: WHO Global Oral Health Action Plan. Geneva, May 28th, 2024, 77th World Health Assembly, Geneva, Switzerland.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. Improving the oral health of people with intellectual disabilities with research., Intellectual Disability Advanced Nurse Practitioner (ANPs) national network meeting., 12th of March 2024., Invited talk.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Modified Oral Status Survey Tool: Shining the Light on the oral Health Status of Older Adults with an Intellectual Disability in Ireland., Trinity Health and Education International Research Conference 2024 (THEconf2024) 'NEW HORIZONS IN HEALTHCARE: GLOBAL IMPACT, LOCAL RELEVANCE', 6th of March 2024, oral presentation.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Modified Oral Status Survey Tool ., RCSI 43rd Annual International Nursing & Midwifery Research and Education Conference, 22nd of February 2024, oral presentation.

Byrne, K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The implementation of the Modified Oral Status Survey Tool into intellectual disability services to identify the oral health status of people with intellectual disabilities in Ireland: clinical bursary award 2024., RCSI 43rd Annual International Nursing & Midwifery Research and Education Conference, 22nd of February 2024, Poster presentation.

Byrne,K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Modified Oral Status Survey Tool ., Irish Research Nurse and Midwifery Annual Conference, 16th of November 2023, oral presentation.

Byrne,K., Daly, B., McCarron, M & McCallion, P., MacGiolla Phadraig, C. The Oral Health Status of Older People with Intellectual Disabilities in Ireland. Initial Findings., Irish Society of disability and oral health (ISDH), Kilkenny, Ireland, 23rd of June 2022, oral presentation.

Poster Presentations

Byrne,K., Lisiecka, D., Moran, G., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The Modified Oral Status Survey Tool: Shining the Light on the oral Health Status of Older Adults with an Intellectual Disability in Ireland., Trinity Health and Education International Research Conference 2024 (THEconf2024) 'NEW HORIZONS IN HEALTHCARE: GLOBAL IMPACT, LOCAL RELEVANCE', 6th of March 2024.

Byrne,K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. THE MODIFIED ORAL STATUS SURVEY TOOL: VALIDITY,FEASIBILITY AND RELIABILITY OF A DISABILITY-FOCUSED ORAL HEALTH ASSESSMENT TOOL. The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSISD) .,8th of August 2024, oral presentation. <https://doi-org.elib.tcd.ie/10.1111/jir.13166>

Byrne,K., Daly, B., McCarron, M. & McCallion, P., MacGiolla Phadraig, C. The implementation of the Modified Oral Status Survey Tool into intellectual disability services to identify the oral health status of people with intellectual disabilities in Ireland: clinical bursary award 2024.,RCSI 43rd Annual International Nursing & Midwifery Research and Education Conference, 22nd of February 2024.

Byrne,K., Daly, B., McCarron,M. & McCallion, P., MacGiolla Phadraig, C. The Oral Health Status of Older People with Intellectual Disabilities in Ireland. Initial Findings., International association of disability and oral health (IADH), Paris, France, 24th-26th August 2022, poster presentation.

Webinars

1. DASCOR Connect: Innovations in oral research to engage excluded populations
Speaker: Katrina Byrne
Topic: The Oral Health of Older Adults with Intellectual Disabilities Using the Modified Oral Status Survey Tool, January 2025.
2. Tips to Include people with disabilities in research. Research Webinars from the IADH.
Speaker: Katrina Byrne:
Topic: Learning how low-threshold data collection in collaboration with non-dental professionals can improve our understanding of oral health equity, March 2025

Awards

1. Dental Health Foundation Oral Health Promotion Award | 2025 | Lead applicant
Total: €1,000
2. IADR DASCRI CPI: Crisis Prevention Institute Award for Research in Special Care Dentistry | 2025 | co- applicant Total: €2,000

Clinical Bursary Award | RCSI | 2024 | Lead applicant
3. Title of project: The implementation of the Modified Oral Status Survey Tool into intellectual disability services to identify the oral health status of people with intellectual disabilities in Ireland. Total: €5,000
4. Biennial Dental Health Foundation Travel Bursary | ISDH | 2022 | Lead applicant
Title of project: The Oral Health Status of Older People with Intellectual Disabilities in Ireland. Initial Findings. Total €700

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Chapter 1. Introduction

1.1 Background and Context

Oral health is increasingly recognised as a key component of overall health, wellbeing and healthy ageing. Having good oral health, it not simply the absence of disease but as the ability to eat, speak, communicate and function without pain or limitation, highlighting its role in nutrition, social participation, systemic health and quality of life (Federation, 2022; Glick et al., 2023; Organization, 2022a; Watt et al., 2019). While advances in public health and preventive dentistry have improved oral health outcomes for the general population, these improvements have not been experienced equally. People with Intellectual disabilities continue to exhibit significantly poorer oral health outcomes, higher unmet treatment needs and reduced access to preventive services (Anders & Davis, 2010; Wilson et al., 2019).

In parallel, population ageing is reshaping health research and policy internationally, with growing emphasis on the management of chronic disease, multimorbidity and functional decline (Barnett et al., 2012; Michel, 2015); Oral health has become an area of growing significance within this context, with evidence demonstrating its relevance to systemic health conditions, cognitive ageing and survival (Chan et al., 2024; Gao & Kang, 2025; Peng et al., 2019). However, this emerging knowledge has largely excluded people with intellectual disabilities, who remain one of the most marginalised and under-researched ageing cohorts. Their health inequities are well established, but oral health remains insufficiently integrated within research, service planning or policy discourse, despite its potential contribution to preventable morbidity and mortality.

A central challenge driving this inequity is the absence of disability-inclusive oral health datasets. National and international surveillance efforts rarely include people with an intellectual disability or fail to incorporate the methodological adaptations necessary to ensure their participation. As a result, their oral health status has remained largely invisible within epidemiological evidence and health policy frameworks, reinforcing assumptions that poor oral health in disability is inevitable rather than preventable. This lack of visibility also limits understanding of how oral health may interact with broader health trajectories in ageing with intellectual disabilities.

This study directly addresses this gap by embedding structured, objectively assessed oral health evaluation within the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), using an adapted and validated tool designed to enable participation across the full spectrum of support needs. Describing inequity is no longer sufficient. Disability research must also develop the tools, methods and systems-level evidence needed to understand and address the conditions that produce inequity. This concern has been raised in wider disability research, including Llewellyn's audit of disability research in Australia, which highlighted the need for research that moves beyond documenting problems toward informing action, service improvement and policy change (Llewellyn, 2014)

The present study was designed in response to this challenge. It moves beyond descriptive reporting by examining how oral health can be measured inclusively and how oral health indicators may relate to systemic health, functional decline and survival outcomes among older adults with intellectual disabilities. Rather than positioning oral health as a peripheral or quality-of-life concern, the study situates it within broader frameworks of systemic health, health equity, ageing and rights.

The remainder of this chapter establishes the conceptual basis for this work by defining key terms, synthesising current evidence and situating oral health within ageing and disability frameworks. It reviews the health profiles of older adults with intellectual disabilities, examines oral health from both population and disability perspectives, critically analyses methodological and structural gaps and articulates the research rationale. The chapter concludes by outlining the research aims and questions that guide the thesis, establishing the rationale for examining oral health as a modifiable contributor to systemic decline and mortality in this population.

1.1.1 Ageing in the General Population

Oral health in older age has evolved substantially. Advances in preventive dentistry, public health measures and improved living standards have resulted in the retention of more natural teeth into later life (Chan et al., 2024; Steele et al., 2012). However, this is associated with high prevalence of caries, periodontal disease and functional impairment (Lipsky et al., 2024). These oral conditions have significant implications, with poor oral

health contributing to pain, impaired mastication, swallowing difficulty, reduced dietary quality, weight loss and malnutrition (Asaad et al., 2025; Zelig et al., 2022). Emerging evidence confirms strong bidirectional oral–systemic links. Periodontal disease is associated with systemic inflammation and increased risk of cardiovascular disease and diabetes (Graziani et al., 2018; Tonetti et al., 2017), while tooth loss and oral functional decline predict frailty, sarcopenia and limitations in activities of daily living (Castrejón-Pérez et al., 2016; Tanaka et al., 2017). Poor oral hygiene increases aspiration pneumonia risk the leading cause of avoidable mortality in frail older adults (Khadka et al., 2021). Reflecting these findings, the World Health Organisation (WHO) Global Strategy on Oral Health (2022) and Global Oral Health Action Plan 2023–2030 advocate integration of oral health within healthy ageing, universal health coverage and noncommunicable disease strategies (Organization, 2022a).

1.1.2 Ageing and Intellectual Disability

Over the past half-century, life expectancy for people with intellectual disability has increased substantially. Advances in medical care, improved management of childhood conditions, deinstitutionalisation, and broader social inclusion have all contributed to this demographic shift (Bittles et al., 2002; Coppus, 2013; Landes et al., 2019). In Ireland, as in many high-income countries, people with intellectual disabilities are now living well into older age, many for the first time in recorded history as a distinct population cohort (McCarron et al., 2013). This represents a profound transformation in the life course of people with an intellectual disability. However, life expectancy remains lower than in the general population, and premature mortality persists (Heslop et al., 2014; O'Leary, Cooper, & Hughes-McCormack, 2018).

While increased longevity represents an important public health success, it has also revealed patterns of earlier onset of age-related conditions. Evidence consistently indicates that health decline, multimorbidity, and functional limitations may emerge 10 to 20 years earlier in adults with intellectual disabilities than in the general population (Cooper et al., 2015; McCallion et al., 2019; O'Leary, Cooper, & Hughes-McCormack, 2018). Reflecting these earlier trajectories, research on ageing with an intellectual disability commonly adopts a lower chronological threshold than that used in general population studies, often defining older adulthood as beginning at approximately 40 years of age. This

threshold underpins several large longitudinal studies internationally, including the IDS-TILDA. Common chronic conditions among adults with intellectual disability include cardiovascular disease, diabetes, osteoporosis, sensory impairments, epilepsy, and gastrointestinal disorders (Cooper et al., 2015; Hermans & Evenhuis, 2014; McCallion et al., 2019).

Frailty is of particular concern in ageing with people with an intellectual disability and has been identified as emerging earlier and more severely in this population (Hermans & Evenhuis, 2014). Patterns of accelerated biological ageing are especially evident among individuals with Down syndrome, who experience earlier onset of frailty and markedly elevated rates of Alzheimer's disease compared with the general population (McCarron, McCallion, et al., 2017; Sinai et al., 2017). Importantly, frailty is increasingly understood as a dynamic condition. Longitudinal research demonstrates transitions not only toward deterioration but also, in some cases, stabilisation or improvement, depending on access to appropriate supports, healthcare, and environmental conditions (Dee et al., 2021; Calatayud et al., 2024). The interaction between biological vulnerability and social determinants therefore plays a critical role in shaping ageing outcomes.

Despite gains in longevity, people with an intellectual disability continue to experience disproportionately high rates of premature and avoidable mortality compared with the general population, even in high-income countries (Rydzewska et al., 2025; Thygesen et al., 2024; Tyrer et al., 2022). Structural barriers, including inaccessible health services, limited access to preventive care, diagnostic overshadowing, and inadequate implementation of reasonable adjustments, contribute to delayed diagnosis and poorer health trajectories (Emerson & Hatton, 2014; Krahn & Fox, 2014; Ouellette-Kuntz, 2005; Miller et al., 2020; WHO, 2022). Many deaths are associated with conditions that could have been prevented or effectively managed through earlier intervention, reflecting persistent inequities in healthcare access and quality (Kinnear et al., 2018).

These patterns indicate that ageing in intellectual disability is shaped not only by biological processes but also by lifelong exposure to social disadvantage, health inequalities, and barriers to care. While detailed exploration of mortality risk is presented in later sections, these disparities illustrate the cumulative impact of structural inequities across the life course.

1.2 Intellectual Disability: Definitions and Demographics

1.2.1 Defining Intellectual Disabilities

The term *Intellectual Disability* refers to a neurodevelopmental condition characterised by significant limitations in intellectual functioning and adaptive behaviour, originating before the age of 22 years (Tassé & Grover, 2018). Intellectual functioning typically encompasses reasoning, problem-solving, and abstract thinking, while adaptive behaviour refers to conceptual, social, and practical skills required for everyday life (Schalock, 2010).

Definitions vary slightly across diagnostic systems. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) defines intellectual disabilities as deficits in intellectual functions (reasoning, problem-solving, planning, abstract thinking, academic learning) confirmed by clinical assessment and standardised testing, combined with deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility (Harm et al., 2013). The International Classification of Diseases, 11th Revision (ICD-11) similarly defines intellectual disability as “disorders of intellectual development” as originating during the developmental period and characterised by significantly below-average intellectual functioning and adaptive behaviour (World Health Organization, 2018).

Across contemporary definitions, a common thread is the recognition that intellectual disability is not defined solely by cognitive impairment, but by the interaction between individual functioning and environmental demands. Modern frameworks emphasise a strengths-based, ecological perspective in which supports, and reasonable adjustments play a central role in enabling participation and quality of life (Harm et al., 2013).

1.2.2 Classification and Severity

Intellectual disability is commonly classified using severity levels, namely mild, moderate, severe, and profound, based on limitations in intellectual functioning and adaptive behaviour. These categories are widely used in clinical, educational, and epidemiological contexts, particularly within the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* and the *International Classification of Diseases (ICD)*, the principal diagnostic

frameworks used internationally. Recent population estimates indicate that the overall distribution of severity remains broadly consistent with earlier classifications, with approximately 80 to 85 percent of individuals identified as having mild intellectual disability, around 10 percent a moderate intellectual disabilities, and 3 to 5 percent severe or profound intellectual disabilities combined (Maulik et al., 2011). However, these proportions may vary according to diagnostic practices, access to assessment, survival patterns, and social determinants of health.

Irish administrative data from the Health Research Board's National Ability Supports System (NASS) similarly demonstrate substantial variation in support needs across severity levels. While most registered individuals have mild or moderate intellectual disabilities, those with severe or profound disabilities account for a disproportionate share of intensive support requirements, complex health needs, and residential service use (Casey, O'Sullivan, et al., 2024). These findings highlight the heterogeneity of the intellectual disability population and the importance of considering severity when planning services and interpreting research outcomes.

The American Association on Intellectual and Developmental Disabilities (AAIDD) conceptualises severity within a multidimensional framework that considers health, participation, life activities, contextual supports, and personal strengths (Schalock et al., 2021). Within this model, severity is not viewed as a fixed trait of the individual but as an indicator of the intensity of supports required to achieve optimal functioning and participation.

Research consistently demonstrates that adults with intellectual disabilities experience earlier onset of frailty, multimorbidity, and age-related cognitive decline compared with the general population. These patterns are particularly pronounced among individuals with Down syndrome, who are at substantially increased risk of early-onset dementia and accelerated ageing trajectories (Coppus, 2013; McCarron et al., 2013; O'Leary, Cooper, & Hughes-McCormack, 2018). Findings from the IDS-TILDA cohort further highlight high levels of multimorbidity and complex health needs emerging from midlife onward among adults with intellectual disabilities in Ireland (McCarron et al., 2017). At the same time, improvements in social inclusion, assistive technology, communication supports, and access to appropriate healthcare can enhance adaptive functioning and mitigate the

impact of disability over time. Consequently, severity classifications should be interpreted as fluid and context dependent rather than static categories, reflecting interactions between individual health status, environmental conditions, and available supports.

Within this study, which prioritises inclusion of individuals across all levels of Intellectual disabilities, severity classification is therefore treated as a contextual descriptor rather than an essential characteristic. This approach acknowledges both the practical utility of severity categories for describing populations and their limitations in capturing the complexity and heterogeneity of lived experience.

1.2.3 Prevalence and Demographics

Estimates of the global prevalence of intellectual disabilities range from 1–3% of the population, although figures vary considerably depending on diagnostic criteria, case-finding methodology, cultural factors, and whether population-based, clinical, or administrative data are used (Maulik et al., 2011; Nair et al., 2022). Recent systematic reviews suggest that global prevalence has remained relatively stable but emphasise ongoing under-identification, particularly among older adults, women, ethnic minority groups and individuals not engaged with disability services (Olusanya et al., 2023).

In Ireland, true population prevalence cannot be precisely determined due to the absence of a unified national registry capturing all individuals with intellectual disabilities. Historically, national data were taken from the National Intellectual disability Database (NID), which reported approximately 30,000 individuals with intellectual disabilities receiving or awaiting specialist disability services (Casey, Fanagan, et al., 2024; Mulvany, 2000). More recently, the NASS has replaced the NID as the principal disability dataset, capturing individuals currently using or requiring HSE-funded disability supports (Casey, Fanagan, et al., 2024). In 2023, 21,465 adults with intellectual disabilities were confirmed in NASS, equating to approximately 4 per 1,000 population, significantly lower than internationally recognised epidemiological estimates of 10.4 per 1,000 (1%) based on population-level studies (Maulik et al., 2011).

Data from the 2022 Census provide a broader population perspective, with 109,288 people (2% of the population) self-reporting an intellectual disability “to any extent” (Central Statistics Office, 2023). While this aligns more closely with international

prevalence estimates, limitations inherent in self-reported data, such as absence of diagnostic confirmation potential, under-reporting and exclusion of individuals living in institutional or supported settings. This indicates that even these figures likely underestimate true prevalence.

International evidence consistently identifies a substantial “Hidden” or “unknown” population of people with intellectual disabilities who do not engage with specialist services and are therefore omitted from administrative databases. Studies estimate that only 40–60% of adults with intellectual disabilities are known to disability services, with many especially those with mild intellectual disabilities or without formal diagnosis, supported primarily by families or mainstream health and social care services (Emerson et al., 2016; McBride et al., 2021). In Ireland, identification challenges may be further exacerbated as adults with intellectual disabilities age into older persons’ services, which often fall beyond the scope of disability datasets such as NASS. Consequently, older adults with intellectual disabilities living in community or mainstream settings may be significantly underrepresented in national statistics, with implications for healthcare planning, resource allocation and inclusion in research. One of the most significant demographic shifts in recent decades has been the rapid ageing of people with intellectual disabilities. Previously, many individuals with severe or profound disability, or with comorbid conditions such as epilepsy or congenital abnormalities, did not survive into older adulthood (McCarron et al., 2013; O’Leary, Cooper, & Hughes-McCormack, 2018).

This highlights the importance of designing and conducting research that actively includes people with intellectual disabilities across varying levels of ability, life circumstances and support contexts including those not represented in administrative or population-based datasets. Only through inclusive and impactful research can the true scale of the population and the inequities they experience, particularly in relation to oral health, be accurately understood and effectively addressed.

1.3 Oral Health

Oral health is increasingly recognised as integral to overall health, wellbeing and healthy ageing. Contemporary definitions extend beyond the absence of oral disease to encompass the capacity to eat, speak, communicate and participate in daily life without

pain, discomfort or functional limitation (Federation, 2022; Organization, 2022a). It influences nutritional intake, systemic health, cognitive function, social participation and quality of life, and is now widely understood as both a marker and determinant of health across the life course (Glick et al, 2023; Watt & Daly, 2022). Reflecting this shift, international policy frameworks including the WHO Global Strategy on Oral Health (2022) and the Global Oral Health Action Plan 2023–2030 have positioned oral health as a foundational element of universal health coverage and healthy ageing (Organization, 2022a, 2022b). These approaches emphasise prevention, integration within primary care and health intelligence, and the reduction of inequities across social groups.

This section outlines the conceptual importance of oral health, examines patterns observed in ageing adults in the general population and contrasts these with the entrenched inequities experienced by adults with intellectual disabilities.

1.3.1 Defining Oral Health

Oral health is a multidimensional concept that extends beyond the absence of disease. Historically, it was defined in predominantly clinical terms, focusing on conditions such as dental caries, periodontal disease and tooth loss. Contemporary perspectives recognise oral health as a key determinant of overall wellbeing, psychosocial function and social participation. Contemporary definitions emphasise oral health as integral to overall health and well-being, extending beyond the absence of disease to encompass functional ability and psychosocial participation (Federation, 2022; Organization, 2022b).

The biopsychosocial perspective acknowledges that oral health reflects the interplay between biological status, functional ability and the subjective experience of health (Peres et al., 2019). From a life-course perspective, oral health influences and is influenced by systemic health, nutrition, communication, cognitive function and social participation, with cumulative effects over time (Watt & Daly, 2022). However, despite its recognised contribution to overall health, oral health frequently remains peripheral in public health strategies, ageing policy and disability research.

This has contributed to persistent under-representation of oral health in research and constrained the development of responsive policy and practice. Addressing this requires more inclusive and clinically robust approaches to oral health assessment aligned with

principles of equitable healthcare and healthy ageing. The relevance of oral health to overall health, healthy ageing and equity particularly for people with intellectual disabilities is explored in section 1.7.

1.3.2 Oral Health and Ageing in the General Population

Oral health in older age has evolved substantially. Advances in preventive dentistry, public health measures and improved living standards have resulted in the retention of more natural teeth into later life (Chan et al., 2024; Steele et al., 2012). However, this is associated with high prevalence of caries, periodontal disease and functional impairment (Lipsky et al., 2024). These oral conditions have significant implications, with poor oral health contributing to pain, impaired mastication, swallowing difficulty, reduced dietary quality, weight loss and malnutrition (Zelig et al., 2022; Asaad et al., 2025). Emerging evidence confirms strong bidirectional oral–systemic links. Periodontal disease is associated with systemic inflammation, cardiovascular disease and diabetes (Tonetti & Jepsen, 2017; Sanz et al., 2020), while tooth loss and oral functional decline predict frailty, sarcopenia and limitations in activities of daily living (Tanaka et al., 2018; Castrejón-Pérez et al., 2017). Poor oral hygiene increases aspiration pneumonia risk the leading cause of avoidable mortality in frail older adults (El-Solh, 2019; Iwai et al., 2022). Reflecting these findings, the WHO Global Strategy on Oral Health (2022) and Global Oral Health Action Plan 2023–2030 advocate integration of oral health within healthy ageing, universal health coverage and noncommunicable disease strategies (Organization, 2022a).

1.3.3 Oral Health in People with Intellectual Disabilities

Despite substantial improvements in oral health within the general population over recent decades, this progress has not been mirrored for people with intellectual disabilities. Epidemiological studies consistently report significantly higher levels of untreated caries, periodontal disease, poor oral cleanliness, tooth loss and complete edentulism among adults with intellectual disabilities (Anders & Davis, 2010; Nonoyama et al., 2022; Wilson et al., 2019). Unlike broader ageing trends, where natural tooth retention has improved (Steele et al., 2017), oral health outcomes in adults with intellectual disabilities have remained static or worsened relative to population norms, indicating widening inequity (Anders & Davis, 2010; Wilson et al., 2019). Recent data show that while edentulism rates

have fallen globally by 80% since the 1960s, comparable reductions have not been observed in people with intellectual disabilities demonstrating a failure of inclusive achievements (Morgan et al., 2012; Ward et al., 2019).

These inequities reflect cumulative life-course disadvantage, limited access to oral healthcare across the lifespan, constrained autonomy in oral hygiene practices, dependence on others for daily mouthcare, and chronic medication use, all of which contribute to a sustained burden of oral disease (Wilson et al., 2019). Adults with intellectual disabilities are at increased risk of xerostomia due to psychotropic medication use, gastro-oesophageal reflux, and altered salivary function, increasing susceptibility to dental caries and periodontal disease (Olsen et al., 2023). Neuromuscular and sensory differences may further reduce oral function, tolerance of dental procedures, and capacity for daily oral hygiene (Faulks et al., 2022). Oral disease frequently goes unrecognised due to communication barriers and behavioural misinterpretation, resulting in delayed intervention and a reliance on extraction under general anaesthesia (Chadwick et al., 2018; Mac Giolla Phadraig et al., 2022; Wilson et al., 2019).

Behavioural expressions of oral pain, such as agitation, withdrawal or refusal to eat are frequently misinterpreted as behavioural difficulties rather than recognised as possible indicators of oral pathology (Rech et al., 2025). Emerging evidence indicates that individuals with intellectual disabilities may tolerate oral pain for prolonged periods before intervention, with treatment frequently occurring in response to crisis most commonly via extraction under general anaesthesia rather than through preventive and timely care. This pattern reflects systemic barriers and limited access to disability-adapted dental services (Rech et al., 2025; Doody et al., 2019; Wilson et al., 2019;). Oral hygiene support is heavily dependent on caregiver capacity, yet training frequently does not extend beyond basic brushing techniques (Mac Giolla Phadraig et al., 2013, 2023). High staff turnover in care services and prioritisation of medical over dental needs further reduce continuity of oral health practices (Wilson et al., 2019). This results in significant variability in oral hygiene, with studies showing that up to 70% of adults with intellectual disabilities have visible plaque accumulation or gingival inflammation (Olsen et al., 2023).

System-level factors further exacerbate oral health inequity. Access to dental care is constrained by limited specialist provision, complex referral pathways, long waiting lists

and inadequate implementation of reasonable adjustments (WHO, 2022b; NICE, 2023; Morgan et al., 2019). Preventive oral health promotion programmes that have improved outcomes in the general population seldom include adults with intellectual disabilities, leading to further exclusion from population benefits (Gréaux et al., 2023).

The present study was designed in response to this gap. Rather than assuming that existing oral health assessment methods could be transferred directly into intellectual disability research, the study identified the need for an adapted assessment approach that could support inclusive, structured and objective data collection. The Modified Oral Status Survey Tool (MOSST) refers to an adapted oral health assessment tool developed, refined and evaluated within this doctoral study to support structured oral health data collection with adults with intellectual disabilities.

This approach enabled the study to examine three linked issues: first, how oral health could be measured in an accessible and standardised way; second, what oral health and oral function look like among older adults with intellectual disabilities in Ireland; and third, how oral health indicators may relate to broader systemic health and mortality outcomes. In this way, the study is positioned at the intersection of oral health, intellectual disability, ageing, epidemiology and health equity.

1.3.5 Conceptual Integration

Oral health is internationally acknowledged as a determinant of healthy ageing and systemic wellbeing, influencing nutrition, functional capacity and quality of life (WHO, 2023; Glick & Fejerskov, 2020). However, as established in Section 1.3.2, adults with intellectual disabilities remain largely absent from oral health research and surveillance due to systemic exclusion and lack of disability-adapted clinical tools (Wilson et al., 2019; Gréaux et al., 2023). This not only creates gaps in evidence but perpetuates structural inequities and assumptions that poor oral health is an unavoidable feature of disability rather than a preventable determinant of health outcomes (Scior, 2016).

1.4 Health and Intellectual Disabilities

People with intellectual disabilities experience profound and persistent health inequities across the life course. Compared with the general population, they develop chronic

conditions at younger ages, have higher levels of multimorbidity, and face substantially elevated risks of preventable and premature mortality (Hosking et al., 2016; O’Leary et al., 2018; Kinnear et al., 2023; Lee et al., 2025). The life expectancy gap between adults with intellectual disabilities and the general population remains approximately 15–20 years, with respiratory disease, cardiovascular conditions, and aspiration-related events among the leading causes of avoidable deaths (Durbin et al., 2023; McMahon et al., 2023; WHO, 2022).

These disparities are not simply the result of underlying biological or genetic vulnerability. Rather, they reflect the intersection of lifelong disability, accelerated biological ageing, and systemic failures in health and social care delivery, compounded by structural ableism and inequitable access to health-promoting environments. People with intellectual disabilities are routinely excluded from population health surveillance, experience diagnostic overshadowing, face barriers to preventive care and health screening, and often rely on caregivers for advocacy and access. All of which contribute to delayed diagnosis, inadequate management, and preventable deterioration (Miller et al., 2020; Shakespeare et al., 2024; Owen et al., 2024).

The WHO Global Report on Health Equity for Persons with Disabilities (2022) confirms that disabled people globally are at greater risk of poor health outcomes, reduced quality of life, and premature death, not because of disability itself but due to systemic failures to ensure equitable access to care, reasonable adjustments and disability-responsive monitoring systems.

Within this context, oral health is an important but historically neglected contributor to health inequity, frequently omitted from disability health analyses despite known associations with nutrition, frailty, respiratory illness, multimorbidity and mortality. This programme of research positions oral health within the broader framework of health inequities for people with intellectual disabilities, establishing the rationale for investigating its systemic impact across ageing trajectories, a focus central to the analyses presented later in this thesis.

1.4.1 Multimorbidity in Intellectual Disabilities

Multimorbidity defined as the presence of two or more chronic long-term conditions which occurs earlier, progresses more rapidly and is more extensive among people with intellectual disabilities than peers in the general population. Data from IDS-TILDA indicate that older adults with intellectual disabilities typically live with five or more chronic conditions (McCarron et al., 2019), reflecting both biological vulnerability and lifelong inequities in access to health promotion and preventive care. Distinctive condition-clustering patterns are commonly observed. Epilepsy frequently co-occurs with gastrointestinal disorders and mental health conditions, while osteoporosis, mobility impairment and poor nutritional status are strongly associated with early frailty (Cooper et al., 2015; Hermans & Evenhuis, 2014; Hermans et al., 2023). Polypharmacy is a near-universal feature of ageing with intellectual disabilities, with many individuals prescribed long-term antiepileptics, antipsychotics, antidepressants and anticholinergics medications that contribute to metabolic dysregulation, xerostomia, constipation and dysphagia (Cannon et al., 2023; Fitzpatrick et al., 2024; O'Dwyer et al., 2018).

Importantly, the pattern of multimorbidity among people with intellectual disabilities is qualitatively different from ageing in the general population. Instead of reflecting typical age-associated degeneration, multimorbidity often emerges from persistent inequalities in healthcare access, higher exposure to preventable risk factors and systemic failures to implement reasonable adjustments across the lifespan. These distinctive multimorbidity profiles carry significant implications for functional decline, frailty, mortality risk.

1.4.2 Frailty and Functional Decline

Frailty emerges earlier and progresses more rapidly in adults with intellectual disabilities. Evenhuis et al. (2012) first conceptualised premature ageing in people with intellectual disabilities and more recent longitudinal data show higher frailty prevalence at younger ages than in the general population (Evenhuis et al., 2012) Hermans & Evenhuis, 2021; McCarron et al., 2019). Functional decline often manifests through reduced mobility, chronic fatigue, dysphagia, weight loss and increased dependence in daily activities (Schoufour et al., 2017). Neurodegenerative risk is particularly high among individuals with Down syndrome, with dementia onset typically in the 40s and 50s and rapid progression

(McCarron et al., 2017; Sinai et al., 2018). Emerging evidence suggests that poor oral health may contribute to frailty trajectories through pathways including chronic inflammation, impaired nutrition, chewing and swallowing difficulties, and reduced functional reserve, further compounding vulnerability in ageing populations (Watt et al., 2019; Tanaka et al., 2018). These patterns illustrate accelerated ageing that intersect with poor oral health, nutritional vulnerability and systemic inflammation.

1.4.3 Structural Inequities in Health and Healthcare

Health disparities among people with intellectual disabilities are deeply rooted in structural and systemic inequities. These manifest through multiple mechanisms that limit access to preventive interventions, delay diagnosis and reduce the quality of treatment across the life course. People with intellectual disabilities routinely face barriers when accessing mainstream healthcare services, including inaccessible information, insufficient reasonable adjustments and environmental obstacles in clinical settings (Krahn & Fox, 2014; WHO, 2022). Communication challenges further compound these difficulties particularly where clinicians lack expertise in adapting their approach which often leads to disengagement from care or reduced uptake of health services (Ouellette-Kuntz, 2005; Catteau et al., 2022).

A persistent barrier is diagnostic overshadowing, where new or emerging symptoms are misattributed to the individual's disability rather than explored as potential indicators of underlying health conditions (Miller et al., 2020). These assumptions contribute to late or missed diagnoses and can lead to avoidable deterioration in health. The consequences are reflected in reduced participation in population screening programmes where people with intellectual disabilities are significantly less likely to be invited or supported to attend (Brooker et al., 2015).

In dentistry, insufficient specialist training has led to reliance on invasive interventions such as extraction under general anaesthesia rather than prevention-focused or restorative approaches (Mac Giolla Phadraig et al 2022., Morgan et al., 2019). These patterns reflect wider professional cultures in which disability-related oral health is considered specialised or peripheral rather than integral to routine care.

Structural inequities extend beyond clinical interactions to encompass the social determinants of health. People with intellectual disabilities are more likely to experience socioeconomic disadvantage, social exclusion and reliance on institutional or group living environments, where health-promoting practices including nutrition, oral hygiene and physical activity, these may be inconsistent, insufficiently supported or deprioritised (Emerson & Hatton, 2014; McCarron et al., 2022). Reliance on caregivers for daily oral care and health management introduces variability in practice quality and regularity, with consequences for both oral and systemic health.

Crucially, these inequities are not inevitable consequences of disability but are actively reproduced within health systems that normalise poorer outcomes for people with intellectual disabilities. The failure to collect disability-disaggregated health data, to embed reasonable adjustments in routine care and to recognise oral health as an equity issue leads to the perpetuation of health disparities (Scior, 2016; WHO, 2023). This normalisation reflects systemic ableism, whereby preventable inequities are implicitly tolerated and populations at greatest risk remain invisible in planning, surveillance and research. Addressing these structural barriers is essential to creating health systems that provide equitable, rights-based care and to ensuring that oral health is considered a fundamental component of this agenda.

1.4.4 Mortality Inequities

Mortality gaps remain one of the most visible expressions of inequity for people with intellectual disabilities. Adults with intellectual disabilities die on average 20 years earlier than non-disabled peers (O’Leary et al., 2018). Up to 42% of deaths are classified as avoidable (LeDeR, 2023). Respiratory disease and cardiovascular illness are leading causes of preventable death (Hosking et al., 2016; Durbin et al., 2023). A recent analysis of statutory death notifications from disability services in Ireland reported an incidence of 20.8 deaths per 1,000 beds per year, with 38% attributable to respiratory disease and higher mortality in larger congregated settings (McMahon et al., 2023). For adults with severe to profound intellectual disabilities, the median age at death remains approximately 57–60 years (LeDeR, 2023). These patterns reflect systemic failures in surveillance, service design and preventive care rather than inevitable biological decline. Importantly for the context of this thesis, oral health variables (such as tooth loss, poor

mastication, dysphagia and oral bacterial load) are rarely included in disability mortality risk models, despite being central to pneumonia, malnutrition and frailty pathways. Chapter 2 explores this evidence gap through a scoping review, and Chapters 6 and 7 provide the first population-based empirical analysis of oral–systemic and oral–mortality associations in older adults with intellectual disabilities.

1.5 Oral Health, Systemic Health and Mortality

Oral health is recognised as a core component of systemic wellbeing, functioning both as a mirror of underlying biological, nutritional and social processes and as an active driver of disease progression. Recent evidence on oral diseases including caries, periodontal disease and tooth loss as interconnected systemic conditions linked to inflammatory dysregulation, nutritional compromise and frailty (Tonetti & Jepsen, 2017; Yu et al., 2024). The common risk factor approach demonstrates that oral and systemic diseases share behavioural, socioeconomic and environmental determinants (Sheiham & Watt, 2000; Watt & Daly, 2022). For people with intellectual disabilities, lifelong exposure to health inequities, multimorbidity and dependence on caregiver-delivered oral hygiene magnifies these interactions (Faulks et al., 2023; Ward et al., 2024). Despite strong biological plausibility, oral–systemic links remain largely underexplored in disability research. Two interconnected mechanisms underpin these associations. Retention of natural teeth without adequate hygiene acts as a reservoir for pathogenic biofilm and systemic inflammation. Conversely, tooth loss, particularly affecting functional dentition, increases risks of nutritional decline, frailty and mortality (Wei et al., 2025).

1.5.1 Oral Health, Nutrition, Function and Quality of Life

Oral health is central to nutrition, physical function and psychosocial wellbeing. Tooth loss reduces masticatory efficiency and dietary diversity, contributing to frailty, sarcopenia and micronutrient deficiency (Sheiham & Steele, 2001; Hamzaid et al., 2024; Özdemir et al., 2023). Functional dentition is increasingly recognised as protective for muscle mass, metabolic function and nutritional resilience, highlighting the systemic importance of oral function (Asaad et al., 2025). For adults with intellectual disabilities, prevalent dysphagia and feeding difficulties intensify the effects of poor oral health, increasing risks of malnutrition, aspiration and oral–systemic disease (Allen, 2023).

Beyond the absence of disease, positive oral health—including dental appearance and satisfaction with one’s smile has been shown to contribute to self-esteem, social participation and perceived wellbeing, yet these dimensions are rarely prioritised for adults with intellectual disabilities (Scior, 2016; Morgan et al., 2024). Persistent reliance on extraction-based care and limited access to restorative or aesthetic interventions reflect reduced clinical expectations and structural ableism, reinforcing inequities in how oral health-related quality of life is valued and addressed in this population.

1.5.2 Multimorbidity and Chronic Disease

Oral diseases contribute to systemic morbidity through interconnected inflammatory, immune and metabolic pathways. Periodontitis is now established as a chronic inflammatory disorder with systemic links, characterised by dissemination of inflammatory mediators and pathogenic bacteria into the bloodstream (Hajishengallis, 2015). Tooth loss often the end stage of cumulative oral disease has also been linked to accelerated cognitive decline and dementia in longitudinal studies, highlighting potential neuroinflammatory and nutritional mechanisms (Gao & Kang, 2025).

For adults with intellectual disabilities, these relationships are likely to be magnified. People with intellectual disabilities experience earlier and more severe multimorbidity, including high rates of epilepsy, gastrointestinal disorders, cardiometabolic disease and respiratory vulnerability (McCarron et al., 2019). These conditions are frequently intensified by lifelong polypharmacy, dysphagia, reflux disease and altered immune function (Wilkinson et al., 2024; Bayen et al., 2024). Evidence of elevated inflammatory markers and accelerated biological ageing for people with intellectual disabilities suggests that immune dysregulation is already heightened in this population (Evenhuis et al., 2012; Hermans & Evenhuis, 2023). Within this context, chronic oral inflammation may contribute disproportionately to systemic decline, functioning as an additional, yet modifiable, source of metabolic stress, nutritional deterioration and physiological vulnerability.

1.5.3 Respiratory Disease and Aspiration Pneumonia

Respiratory disease is a leading cause of avoidable and premature mortality among adults with intellectual disabilities, with consistently higher risk than in the general population (O’Leary et al., 2018; Kinnear et al., 2023; Durbin et al., 2024). Aspiration pneumonia is a

major contributor and is closely associated with undetected dysphagia, poor oral health and repeated micro-aspiration of oropharyngeal material (Hosking et al., 2016; McMahon et al., 2023). While gerontological research increasingly recognises poor oral health as a pathogenic driver of pneumonia, this risk dimension remains largely absent from research focused on the respiratory health of people with intellectual disabilities. This forms the central focus of Chapter 2 of this thesis.

In the general population, aspiration of microorganisms from oropharyngeal biofilm is recognised as a key mechanism in pneumonia development. Dental plaque serves as a reservoir for organisms such as *Streptococcus pneumoniae*, *Klebsiella pneumoniae*, *Pseudomonas aeruginosa* and *Staphylococcus aureus*, which can enter the lower respiratory tract during swallowing impairment or reduced airway protection (Terpenning, 2005; Awano et al., 2008).

These mechanisms are substantially intensified in adults with intellectual disabilities. Dysphagia affects between 50–60% depending on disability severity and neurological comorbidities (Chadwick & Jolliffe, 2009; Sheppard & Hochman, 2024). Respiratory defences are further compromised by gastro-oesophageal reflux, medication-induced sedation and reduced cough efficiency (Wilkinson et al., 2024). Texture-modified diets, commonly used to reduce choking risk, may paradoxically increase aspiration potential where tooth loss or oral disease produce greater residue (Moynihan & Varghese, 2022). Microbiome research reinforces these risks. Periodontal pathogens such as *Fusobacterium nucleatum* and *Porphyromonas gingivalis* have been identified in the respiratory tracts of pneumonia patients and provoke inflammatory responses that can exacerbate pulmonary compromise (Wang et al., 2023).

Addressing this evidence gap is central to the trajectory of this thesis. Chapter 2 establishes the absence of oral health parameters in aspiration pneumonia research among adults with intellectual disabilities. Building on this, Chapter 6 uses the MOSST indicators to model oral–systemic associations, including links between oral disease and respiratory outcomes. Chapter 7 extends this analysis at population level, presenting the first IDS-TILDA study to examine dentition, respiratory-related mortality and all-cause mortality in older adults with an intellectual disability.

These chapters challenge the longstanding assumption that respiratory vulnerability among people with intellectual disabilities is solely neurological or functional in origin. They demonstrate instead that oral health constitutes a meaningful and modifiable determinant of aspiration risk. Understanding the contribution of oral disease to respiratory decline reframes aspiration pneumonia not as an inevitable consequence of disability, but as an outcome amenable to targeted prevention.

1.5.4 Biological Pathways and the Dual Role of Teeth

Teeth play a dual and dynamic role within systemic health. When retained and maintained, they act as protective biological structures that support nutritional adequacy, neuromuscular activation, metabolic regulation and cognitive function. When diseased or lost, they become sites of inflammation, microbial dysbiosis and physiological disruption that contribute to systemic decline. This duality is central to understanding oral–systemic pathways in ageing and is particularly relevant for adults with intellectual disabilities, whose underlying vulnerabilities amplify these mechanisms.

The link of mastication supports several interconnected physiological functions. Chewing stimulates salivary secretion, enhances digestive efficiency and maintains oro-motor coordination essential for safe swallowing (Moynihan & Kelly, 2014). Neurophysiological research shows that mastication activates trigeminal–cortical pathways, increasing cerebral blood flow and supporting executive functioning and balance (Watanabe et al., 2017; Okamoto et al., 2023). Retention of functional dentition has therefore been associated with preserved cognitive resilience and better physical performance in later life (Sabbah et al., 2019; Okamoto et al., 2023). These mechanisms illustrate why functional dentition is increasingly viewed as a determinant not merely an outcome of systemic health.

Edentulism represents the most profound disruption of these processes. Complete tooth loss eliminates masticatory function and often results in reliance on soft or texture-modified diets that are lower in protein, fibre and micronutrients. Such dietary patterns are associated with weight loss, sarcopenia and frailty progression (Yamamoto et al., 2022; Castrejón-Pérez et al., 2017). Among adults with intellectual disabilities who already experience higher prevalence of dysphagia, hypotonia and gastro-oesophageal reflux, the

physiological consequences of edentulism may be even more severe, contributing to malnutrition and heightened risk of aspiration (Robertson et al., 2017; Lee et al., 2021; Wright et al., 2023). These effects are further intensified by the limited access to prosthetic rehabilitation documented among people with intellectual disabilities, including low rates of denture provision, inadequate replacement of anterior teeth and frequent reliance on extraction-only care pathways (Mac Giolla Phadraig et al., 2015). The absence of appropriate prosthetic restoration not only affects nutritional intake but also impacts speech, social confidence and participation, compounding systemic and psychosocial vulnerabilities.

Oral health also interacts with other key systemic pathways relevant to ageing with an intellectual disability, including constipation and osteoporosis. Reduced mastication and limited dietary diversity associated with tooth loss led to lower fibre intake, impaired gut motility and increased constipation risk (Asaad et al., 2025). Chronic constipation can in turn worsen oral health by increasing reflux, oral acidity and exposure to medications that reduce salivary flow (Zhao et al., 2023). Similarly, osteoporosis and oral health are bidirectionally linked, inadequate chewing and reduced intake of nutrient-dense foods may accelerate systemic bone loss, while osteoporosis contributes to alveolar bone resorption, periodontal deterioration and tooth loss (Zelig et al., 2022).

When oral hygiene deteriorates or teeth are lost to disease, oral structures shift from protective organs to sites of pathological risk. Dental biofilm acts as a reservoir of pathogenic microorganisms and inflammatory mediators. Aspiration of this material into the lower respiratory tract is a well-established mechanism in pneumonia development, particularly among older adults with impaired swallowing or weakened protective reflexes (Terpenning, 2005; Awano et al., 2008; El-Solh, 2019).

Despite strong biological plausibility and extensive evidence in gerontology, these pathways have rarely been examined using disability-inclusive research. This thesis begins to fill this gap by demonstrating how oral health can shape ageing trajectories, oral-systemic disease interactions pathways in older adults with intellectual disabilities.

1.5.5 Tooth Loss and Mortality

Tooth loss is now widely established as an independent predictor of all-cause mortality in ageing populations, with recent longitudinal cohorts and meta-analyses demonstrating graded associations whereby reduction in natural teeth is linked to increased mortality risk even after adjusting for socioeconomic factors, smoking and comorbidities (Tanka et al., 2017; Zhang et al., 2025). Edentulous individuals can exhibit elevated systemic inflammatory biomarkers, supporting hypotheses that tooth loss reflects cumulative inflammatory burden over the life course (Hajishengallis, 2015).

Emerging research extends these implications to ageing trajectories. A recent systematic analysis (Yu et al., 2024) demonstrates that edentulism, particularly when combined with multimorbidity or frailty markers, exceeds the predictive strength of traditional mortality risk factors. For adults with intellectual disabilities, these mechanisms may operate with amplified effect due to earlier and more severe multimorbidity, significantly higher rates of frailty, dysphagia and neuromotor impairment, prolonged exposure to polypharmacy and reduced nutritional adaptability (Evenhuis et al., 2012; Hermans & Evenhuis, 2023;). Despite well-established mortality inequities among people with intellectual disabilities characterised by decades of reduced life expectancy, preventable causes of death and high prevalence of respiratory disease oral health have not been incorporated into mortality risk or survival analysis within disability research.

This thesis provides the first population-level analysis linking clinically assessed dentition to mortality among older adults with intellectual disabilities. By integrating tooth count and functional dentition metrics Chapter 7 examines these pathways, comparing survival trajectories based on dentition status. These analyses make a novel contribution to understanding how oral health may act as a modifiable predictor of premature mortality in this population.

1.5.6 Summary and Implications for Ageing in Intellectual Disabilities

Across nutrition, multimorbidity, respiratory disease, frailty and mortality, oral health clearly emerges as a significant determinant of systemic wellbeing in later life. Evidence from the general population demonstrates that oral diseases and tooth loss influence

inflammatory burden, nutritional status, metabolic regulation, functional independence and survival. Although these oral–systemic pathways are well established in gerontological research, their relevance for adults with intellectual disabilities has received little empirical attention.

For people with intellectual disabilities who experience premature ageing, high multimorbidity, dysphagia, polypharmacy and elevated respiratory vulnerability these pathways are likely to be even more consequential. Yet oral health has historically been conceptualised as peripheral within disability research, partly due to the absence of clinically assessed data, reliance on proxy reporting, and exclusion of people with higher support needs from epidemiological studies. This has sustained the misconception that poor oral health is an inevitable feature for people with intellectual disabilities rather than a preventable determinant of health inequities.

By developing new methods and measures and then incorporating them into the IDS-TILDA Health Fair, this thesis begins to address these longstanding omissions. Clinically assessed indicators including dentition, caries, gingival health, oral cleanliness and functional measures provide, for the first time, population-level evidence of how oral health intersects with systemic health, frailty trajectories and mortality in older adults with intellectual disabilities. The findings demonstrate that oral deterioration can amplify vulnerabilities already present through multimorbidity and accelerated ageing, whereas preserving functional dentition and maintaining oral cleanliness may support systemic resilience and healthier ageing.

This synthesis underscores the need for disability-inclusive research methodologies and for oral health to be recognised as a core component of health equity and ageing with an intellectual disability.

1.6 Knowledge Gaps and Challenges

Despite growing recognition of oral health as integral to systemic wellbeing in the general population, the evidence base concerning adults with intellectual disabilities remains fragmented, methodologically constrained and largely absent from mainstream

epidemiological and policy discourse (Watt & Daly, 2022). These omissions perpetuate invisibility, reinforce inequity and undermine effective planning.

1.6.1 Exclusion from Oral Health Surveillance

People with intellectual disabilities have long been absent from national and international oral health surveillance, resulting in a profound and persistent evidence gap. In Ireland, The Oral Health of Irish Adults 2000–2002 explicitly excluded individuals with disabilities and those living in supported or residential settings (Whelton et al., 2007). Comparable patterns are evident internationally. Major surveillance initiatives such as NHANES in the United States and the UK Adult Dental Health Survey either do not identify people with intellectual disabilities within their sampling frameworks or exclude individuals who require communication, behavioural or physical support to participate (Havercamp & Scott, 2015; Ward et al., 2022). These exclusions are not grounded in empirical evidence but, more likely in long-standing assumptions that people with intellectual disabilities are too difficult to assess or cannot reliably participate in clinical examinations. These views reflect entrenched structural and cultural biases about consent, cooperation and feasibility rather than the true capabilities of participants.

This leads to a cycle in which the absence of adapted assessment methods leads to exclusion, and exclusion, in turn, stifles methodological innovation. With statistical invisibility, whereby people with intellectual disabilities remain unrepresented in the datasets that inform service planning, resource allocation and national oral health strategy (Havercamp & Scott, 2015). Without disability-disaggregated data, health systems cannot accurately identify need, evaluate inequities or develop targeted interventions, thereby undermining the ambitions of national policy frameworks and limiting accountability (World Health Organization & World Bank, 2011; Krahn et al., 2015).

From a rights-based perspective, this absence constitutes a breach of Article 31 of the UNCRPD, which obliges States to collect disability-disaggregated data (United Nations, 2006). International policy frameworks including the WHO Global Report on Health Equity for Persons with Disabilities (2022) and the WHO Global Strategy on Oral Health (2022) identify disability-inclusive surveillance as a priority. The present study was designed to respond to this gap by examining how objective oral health assessment could be

incorporated within IDS-TILDA, a nationally representative study of ageing among adults with intellectual disabilities in Ireland. This provided the basis for investigating oral health status, oral function and their relationship with broader health outcomes in this population.

1.6.2 Methodological and Ethical Challenges in Data Collection

Significant methodological and ethical challenges have contributed to the persistent exclusion of people with intellectual disabilities from oral health research. Conventional dental epidemiology tools and examination protocols were not designed for individuals with cognitive, sensory or behavioural differences, and often rely on levels of cooperation and communication that are unrealistic for many adults with intellectual disabilities. This misalignment leads to systematic under-inclusion of those with the greatest needs (Faulks et al., 2019; Morgan et al., 2024). Standard clinical examinations may provoke distress due to sensory sensitivities, past negative experiences or unfamiliar procedures, resulting in high non-response rates among individuals with severe or profound disabilities (Iacono et al., 2020., Bird et al 2024). The consequence is a systematic bias in which those most likely to experience poor oral health are the least likely to be represented in research.

A contributor to these challenges is the limited implementation of reasonable adjustments the environmental, procedural and communicative modifications required to ensure equitable access to assessment. Evidence demonstrates that adaptations such as desensitisation visits, modified examination positions, sensory-aware pacing, visual communication supports, and the presence of familiar staff significantly improve examination feasibility and participation among adults with intellectual disabilities (Dougall & Fiske, 2008; Morgan et al., 2012; Robertson et al., 2014). Yet these adjustments are inconsistently applied in research settings, where protocols often prioritise conventions and standardisation, over accessibility, inclusion, and participant burden. The failure to embed reasonable adjustments systematically renders many individuals “unexaminable” not because of inherent limitations, but because research design does not accommodate their needs. As Morgan et al. (2024) note, this creates a methodological paradox in which the very participants most affected by oral disease are systematically excluded from its measurement.

Ethically, these practices conflict with disability rights commitments. Excluding individuals with higher support needs from data collection violates Articles 25 and 31 of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006), which mandate equitable access to healthcare and the collection of disability-disaggregated data. Recent WHO guidance similarly emphasises that the absence of inclusive methodologies including reasonable adjustments constitutes a structural driver of health inequity and a barrier to monitoring population health (WHO, 2022). Existing oral health assessment approaches may not adequately accommodate the communication, cognitive, sensory and support needs of adults with intellectual disabilities. This creates a need for adapted methods that can support more inclusive participation in oral health research.

1.6.3 Structural and Cultural Barriers, Ableism and Research Prioritisation

Structural and cultural forces within research, clinical practice and health policy contribute significantly to the persistent absence of oral health evidence for people with intellectual disabilities. Historically, oral health has been siloed from mainstream health and ageing research, while disability oral health has been further relegated to a marginal, underfunded and low-visibility subfield (Watt & Daly, 2022). Consistent evidence demonstrates that people with intellectual disabilities are frequently excluded from oral health research due to concerns regarding cooperation, consent capacity, and methodological feasibility (Anders & Davis, 2010; Wilson et al., 2019). These assumptions contribute to the systematic underrepresentation of individuals with the greatest health needs, particularly those with severe or profound disabilities (Iacono et al., 2020; Iacono & Swaine, 2021). Such exclusion reflects broader patterns of structural ableism, where poorer oral and systemic health outcomes are normalised and insufficiently problematised within research and policy agendas (Brooker et al., 2015; Scior et al., 2020). Collectively, these dynamics limit the development of disability-inclusive methodologies, inhibit investment in the field and perpetuate the misconception that oral health among people with intellectual disabilities is peripheral rather than a central component of population health equity.

A key manifestation of this marginalisation is the limited disability competence and confidence across both clinical and research communities. Dental education

internationally provides minimal training on adapting communication, managing sensory sensitivities or implementing behavioural and environmental supports required for safe and equitable examination of adults with intellectual disabilities (Dougall & Fiske, 2008; Faulks et al., 2012). This leads to systematically removing those with the highest oral health need from datasets, reinforcing a distorted evidence base that fails to capture early disease, unmet need or the true extent of preventable oral morbidity in this population.

Structural inequities are further compounded by the lack of disability-friendly assessment environments. Many clinical and research settings are not designed to accommodate sensory, physical or communication needs. Inadequate provision of reasonable adjustments such as adapted lighting, modified examination positions, desensitisation approaches, visual supports or extended appointment times contributes to the perception that oral examinations are inherently challenging for adults with intellectual disabilities. This lack of adaptation reflects underlying ableist assumptions, the onus is placed on the individual to “fit” standard assessment protocols, rather than on systems to adapt to diverse bodies and communication styles. The result is a cycle in which the absence of accessible environments justifies exclusion, and exclusion prevents the development of adapted methodologies (Brooker et al., 2015).

A reactive model is often created; whereby oral health care occurs predominantly during crisis episodes rather than through structured surveillance or routine assessment. Consequently, the accumulating evidence base is skewed toward late-stage disease, masking early pathology and reinforcing the belief that community-based oral examinations are not feasible for this population, despite increasing evidence to the contrary and growing calls to move away from extraction-led, crisis-focused care models (Anders & Davis, 2010; Mac Giolla Phadraig et al., 2022; Morgan et al., 2012).

This cycle is sustained by structural ableism and epistemic injustice. Within many health systems, poor oral health among people with intellectual disabilities is implicitly treated as an expected consequence of disability rather than a preventable inequity (Breslin et al., 2016; Faulks, 2023; Scior, 2011; Scior et al., 2020). This normalisation lowers expectations for oral health outcomes and diminishes institutional urgency for investment in preventive services, surveillance or workforce development. Epistemic injustice is evident in the frequent reliance on proxy reporting, failure to gather disability-disaggregated oral health

data, and limited representation of adults with intellectual disabilities in epidemiological studies practices that deny people with intellectual disabilities their status as legitimate holders of experiential knowledge (Cary et al., 2023; Fricker, 2007).

From a rights perspective, these structural and methodological exclusions contravene the obligations of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), which mandates equitable access to healthcare (Article 25), inclusive and disaggregated data collection (Article 31), and the direct involvement of people with disabilities in decision-making and research (Article 4.3) (Assembly, 2007). The WHO Global Report on Health Equity for Persons with Disabilities (2022) identifies exclusion from monitoring as a key driver of inequity, emphasising that health systems cannot address what they do not measure.

This thesis directly challenges these structures by aiming to design implement an oral health assessment which was designed to support participation across all levels of intellectual disabilities. By demonstrating the feasibility and reliability of inclusive clinical examination within IDS-TILDA, the thesis provides empirical evidence that disability-adapted assessment is both possible and essential. It offers a model for how future surveillance systems and research infrastructures can be reshaped to incorporate reasonable adjustments, reduce structural ableism and generate data that more accurately represent the oral health needs of adults with intellectual disabilities.

1.7 Equity and Rights Lens

Oral health inequities experienced by people with intellectual disabilities are not simply variations in clinical outcomes, they represent systematic breaches of health rights, entitlements and fundamental protections under international law. For decades, preventable oral health issues such as untreated dental disease, chronic pain, impaired function and complete tooth loss have been normalised within disability populations. This normalisation stems from the biomedical assumption that poor oral health is an unavoidable aspect of disability, rather than the result of structural exclusion, lack of surveillance and inequitable access to appropriate care. Applying an equity and rights-based perspective challenges this assumption and reframes oral health not as an optional element to care but as intrinsic to dignity, health, participation and justice. This lens

necessitates reform across governance, policy and research systems to make inequity visible, hold systems accountable, and embed oral health as a measurable indicator of health and rights.

1.7.1 International Human Rights and Global Policy Momentum

The United Nations Convention on the Rights of Persons with Disabilities provides the central legal mandate for disability-inclusive health systems. Article 25 affirms the right of persons with disabilities to the highest attainable standard of health without discrimination, while Article 31 requires governments to collect disaggregated data to support equitable policymaking and evaluation. This absence of disability-inclusive monitoring is not a technical omission but a breach of international human rights obligations. Additional direction is offered through the International Covenant on Economic, Social and Cultural Rights (ICESCR), which clarifies states' obligations under the AAAQ framework, availability, accessibility, acceptability and quality (Assembly, 2007). Where individuals with intellectual disabilities are unable to access affordable dental care, where treatment options are constrained by inadequate provider training, or where clinical environments are not reasonably adapted to their needs, states fail to meet these AAAQ requirements. From a rights-based perspective, poor oral health outcomes among people with intellectual disabilities therefore reflect not clinical shortcomings, but failures of justice, equity and equal access within health systems (Emerson & Hatton, 2014).

Global policy developments further reinforce this position. The adoption of World Health Assembly Resolution WHA74.5 in 2021 marked a fundamental shift in the international framing of oral health, situating it as integral to universal health coverage and primary care. This was the first global mandate to acknowledge the disproportionate burden of oral disease among marginalised groups, including people with disabilities. The WHO Global Strategy on Oral Health (2022) expanded this agenda, calling for integration of oral health within noncommunicable disease (NCD) frameworks, embedding prevention and early intervention across the life course, developing disability-competent workforces and implementing inclusive monitoring systems. The WHO Global Oral Health Action Plan (2023–2030) operationalises these commitments by setting measurable targets for surveillance reform, primary care integration and equity monitoring. Consistent with the WHO Global Report on Health Equity for Persons with Disabilities (2022), it emphasises

that oral health systems must employ inclusive data-collection methods, reasonable accommodations and adapted assessment procedures to ensure that persons with disabilities are fully represented in oral health surveillance and service planning.

Despite these advances, implementation remains limited. Many countries have endorsed the Resolution, Strategy and Action Plan without incorporating disability-disaggregated oral health data into national health information systems. Consequently, progress toward equity targets cannot be measured for those most affected by inequity.

1.7.2 National Policy Commitments and Systemic Gaps

Ireland offers a compelling illustration of how inclusive data can transform visibility, influence policy agendas and lay the foundation for structural reform. Recent policy developments have articulated an explicit commitment to equity in oral healthcare. *Smile agus Sláinte* (Kavanagh et al., 2019) identified people with disabilities as a priority population and positioned population-level prevention and equity as central pillars of national reform. However, Ireland lacked robust empirical data on the oral health status of adults with intellectual disabilities. In practice, policy ambition developed ahead of meaningful evidence, leaving no baseline against which service needs, workforce planning or targeted interventions could be justified.

The importance of such evidence is further reinforced by the National Human Rights and Equality Strategy for Disabled People (2025–2030), which incorporates oral health within the Health and Wellbeing pillar, recognising it as integral to dignity, participation and equitable access to care. This signals recognition at government level that oral health is not an isolated clinical issue but a determinant of overall wellbeing and social inclusion, requiring coordinated and cross-sector action. However, the translation of this recognition into practice remains contingent on the availability of reliable data to inform policy implementation, commissioning and monitoring.

Despite these policy commitments, the current Irish system demonstrates the limitations of recognition without comprehensive implementation. Significant structural barriers persist, including long waiting times for general anaesthetic and sedation pathways, limited availability of preventive and restorative services, and chronic shortages in the Special Care Dentistry workforce. Within disability and residential services, daily oral care

remains inconsistent, reflecting gaps in staff training, resource allocation and structured care planning. These patterns mirror international concerns about inequities in access and support for people with intellectual disabilities (Brooker et al., 2015), and illustrate that generating evidence is necessary but not sufficient to reduce disparities (Faulks, 2023). Nevertheless, without such evidence, policy cannot be operationalised, targeted or evaluated.

1.7.3 Inclusive Research and Visibility

Achieving equity in oral health for people with intellectual disability requires transformation not only within clinical services and policy frameworks but also in how research is conceptualised, conducted, and evaluated. The systematic exclusion of people with intellectual disabilities from research reduces visibility, distorts epidemiological evidence, and contributes to underestimation of disease burden and healthcare needs (Brooker et al., 2015; Lennox et al., 2005; Scior et al., 2020). When individuals with the greatest support needs are omitted, the resulting evidence base reflects only those who are most able and least clinically vulnerable, effectively masking inequities in the data used to inform service planning.

These methodological gaps point to the need for oral health assessment approaches that are not only clinically meaningful but also accessible to adults with intellectual disabilities across a range of communication, cognitive and support needs. Within this doctoral study, this need informed the development and evaluation of an adapted oral health assessment tool. The detailed development process, including refinement, validation and involvement of people with intellectual disabilities, is presented in Chapter 4. This approach aligns with principles of inclusive research and co-production, which emphasise the active involvement of people with disabilities in shaping research that affects them (Cary et al., 2023; Grace et al., 2024; Nind & Vinha, 2014).

Through this inclusive foundation, the thesis contributes not only new empirical evidence but also a model for how oral health research can be conducted ethically, accessibly, and in alignment with human rights principles. It demonstrates that when methodological, sensory, and communicative barriers are addressed, individuals with high support needs can be meaningfully included in population-based studies, challenging longstanding

assumptions about feasibility. Such inclusion enhances the visibility of oral health inequities, enabling them to be measured, monitored, and addressed. In doing so, this research establishes a framework for future studies, policy development, and service planning in which people with intellectual disabilities are recognised as essential contributors to the evidence that informs their care.

1.7.4 Positioning of the Thesis

This thesis is positioned at the intersection of oral health, ageing, disability research and health equity, responding directly to the scientific, methodological and structural gaps outlined throughout this chapter. Adults with intellectual disabilities have been persistently excluded from oral health surveillance, under-represented in epidemiological research and overlooked in policy development. As a result, the scale and consequences of oral disease in this population have remained largely invisible.

The work in this thesis moves beyond descriptive reporting to examine, for the first time, how oral health intersects with systemic health, and mortality in this population. In doing so, it challenges longstanding assumptions that oral health is peripheral to disability or ageing, or that clinically assessed data cannot be collected feasibly in individuals with higher support needs. Instead, it demonstrates that inclusive, rights-aligned methodologies can produce robust empirical evidence that reshapes understanding of health trajectories in older adults with intellectual disabilities.

The study was designed to address three related gaps. First, it brings visibility, generating nationally representative, clinically assessed oral health data where none previously existed. Second, it provides evidence, demonstrating empirically that oral health is a meaningful and potentially modifiable determinant of systemic function, health outcomes and survival. Third, it advances equity, challenging structural ableism embedded in research, surveillance and service design, and positioning oral health as a core component of the right to health under the UNCRPD. Emerging at a time when Ireland is strengthening disability policy through *Smile agus Sláinte* and the National Human Rights and Equality Strategy for Disabled People. The rationale for this work was to be able to aim to produce actionable evidence that can inform implementation. It reframes oral health not as a

secondary quality-of-life issue but as a lens through which broader inequities can be understood and addressed.

1.8 Research Aim, Questions, and Objectives

1.8.1 Aim

The overarching aim of this thesis is to investigate the oral health of older adults with intellectual disabilities in Ireland, with a particular focus on inclusive surveillance, oral–systemic health intersections, and the implications of tooth loss for survival.

1.8.2 Research Questions

To achieve this aim, the thesis addresses the following research questions:

1. How can oral health be inclusively, reliably and feasibly assessed across all levels of intellectual disabilities?
2. What is the burden of oral disease among older adults with intellectual disabilities in Ireland?
3. What are the associations between oral health, systemic health among older adults with intellectual disabilities?
4. Does tooth loss independently predict all-cause and respiratory-related mortality among older adults with intellectual disabilities?

The research questions are organised as a sequential programme of work within this thesis. Question 1 focuses on the development and validation of a clinical tool capable of quantitatively assessing oral health in people with intellectual disabilities. Question 2 applies this tool within the IDS-TILDA cohort to characterise oral disease burden and oral health behaviours. Questions 3 and 4 extend this work by examining associations between these oral health indicators and broader systemic health outcomes, including frailty, functional decline, and mortality.

1.8.3 Objectives

The specific objectives of the thesis are to:

- Develop and validate the MOSST through expert consultation and PPI input, ensuring its feasibility and reliability for use in people with intellectual disabilities.
- Describe oral health outcomes among older adults with intellectual disabilities participating in IDS-TILDA health fair.
- Model associations between MOSST indicators and systemic health conditions, including osteoporosis, constipation, respiratory disease, cardiovascular disease, and diabetes.
- Estimate survival by dentition and identify predictors of tooth loss and mortality, with a particular focus on all-cause and respiratory-related deaths.

1.9 Overview of the Thesis Structure

This thesis is organised into nine chapters, each building sequentially towards the overall aim.

Chapter 1:

Introduces the context of ageing, oral health and intellectual disabilities. It defines key concepts, synthesises evidence on oral health inequities, outlines biological and systemic pathways, identifies knowledge gaps and situates the study within scientific, policy and human rights frameworks. It concludes by presenting the research aim, questions and objectives.

Chapter 2

Presents a scoping review of oral health and pneumonia in adults with intellectual and developmental disabilities. This review synthesises existing evidence, highlights methodological challenges and identifies gaps that directly inform the empirical analyses of this thesis.

Chapter 3

Details the methodology. It describes the IDS-TILDA study design, the inclusion of oral health assessment at the Health Fair, the development and validation of MOSST and the

ethical considerations, including PPI and the use of reasonable adjustments. Aswell as details outing the statistical approaches.

Chapter 4

Reports the results of the MOSST validation study, including content validity, feasibility and inter-rater reliability.

Chapter 5

Reports the findings of the MOSST-based oral health assessments undertaken in IDS-TILDA Wave 5. It presents the epidemiological and demographic profile of oral health among older adults with intellectual disabilities The chapter also explores how these patterns vary across demographic, and support-need groups and situates the findings in relation to comparable data from the general ageing population in TILDA.

Chapter 6

Examines oral–systemic intersections by modelling associations between MOSST indicators and systemic health conditions.

Chapter 7

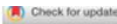
Investigates the role of tooth loss as a predictor of survival, analysing associations between dentition, all-cause mortality, and respiratory-related deaths.

Chapter 8

Synthesises findings across chapters, situating them within international evidence and policy frameworks and discusses implications for oral health research, policy and practice. Concludes the thesis, summarising contributions, highlighting limitations, and setting out recommendations for future research.

Chapter two: Oral health and pneumonia in adults with intellectual and developmental disabilities: A scoping review

The contents of this Chapter are based on this publication:



Journal of Intellectual Disability Research

SYSTEMATIC REVIEW

OPEN ACCESS

Oral Health and Pneumonia in Adults With Intellectual and Developmental Disabilities: A Scoping Review

Katrina Byrne^{1,2}  | Dominika Lisiecka³ | Gary Moran⁴ | Blánaid Daly⁴ | Isabel Fleischmann⁴ | Philip McCallion⁵  | Mary McCarron³ | Caoimhin Mac Giolla Phadraig⁴

¹School of Dental Science, Trinity College, University of Dublin, Dublin, Ireland | ²School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland | ³Department of Nursing and Healthcare Sciences, Munster Technological University - Kerry Campus, Tralee, Co. Kerry, Ireland | ⁴Dublin Dental University Hospital & School of Dental Science, Trinity College, University of Dublin, Dublin, Ireland | ⁵School of Social Work, Temple University, Philadelphia, Pennsylvania, USA

Correspondence: Katrina Byrne (kbyrne1@tcd.ie)

Received: 19 December 2024 | **Revised:** 27 June 2025 | **Accepted:** 2 July 2025

Funding: Funding is provided through the School of Dental Science PhD scholarship fund and the Trinity College Dublin. Open Access is supported through the @iRel fund.

Keywords: aspiration | intellectual disabilities | oral biofilm | oral health | oral hygiene | pneumonia

ABSTRACT

Introduction: Pneumonia is a leading cause of death for people with intellectual and developmental disabilities (IDD), who also have increased risk of oral disease. Given the known relationship between oral disease and pneumonia in similar populations, this review aims to explore what is known about the association between oral health and pneumonia among people with IDD.

Methods: This systematic scoping review was carried out in accordance with the Joanna Briggs Institute methods and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist (PRISMA-ScR). A systematic search of Medline (Ovid), Embase, Cochrane Trials, Cochrane Review, CINAHL and PubMed was conducted, guided by a registered protocol. The PCC framework informed the search and inclusion criteria. Titles and abstracts were independently screened by two reviewers, with full texts assessed for relevance to oral health and pneumonia in adults with IDD.

Results: Following a protocol and defined criteria, (2544) articles were abstract screened; a further (31) reached full-text review, with (7) included in this review. Study designs included cross-sectional studies (2), retrospective cohorts (2), prospective cohorts (2) and one RCT pilot (1). Six studies reported oral carriage of respiratory pathogens such as *Streptococcus pneumoniae*, *Pseudomonas aeruginosa* and *Klebsiella pneumoniae*. Two studies reported predictive relationships between oral pathogens and pneumonia, with increased odds of respiratory illness associated with positive PCR results for specific pathogens (OR 9.0, 95% confidence interval [CI] 2.3–38.8). Two studies identified poor oral health as a predictor of pneumonia, using validated tools such as the ROAG (OR 1.6, 95% CI 1.1–2.5). Mediating factors included enteral feeding, level of IDD, and history of oral disease.

Conclusions: Research consistently finds carriage of potential respiratory pathogens in the oral microbiome of people with IDD. Despite this, there is a significant lack of research into the relationship between the oral microbiome, poor oral health, and pneumonia in this population, though the latter two are both prevalent and consequential. There is an urgent need for further research exploring the role that oral health and the oral microbiome play in pneumonia among people with IDD.

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Chapter 2 Abstract

Introduction:

This chapter presented a systematic scoping review investigating the relationship between oral health and pneumonia among adults with intellectual disabilities. Pneumonia is a leading cause of premature mortality in this population, who also experience significant and longstanding oral health disparities. This review chapter of this thesis therefore sought to map the extent, nature, and quality of existing literature addressing these connections in adults with intellectual disabilities.

Methods:

A systematic scoping review was conducted following the methodological guidance of the Joanna Briggs Institute (JBI) and the PRISMA-ScR framework. A total of 2,544 abstracts were screened, and 32 full texts were reviewed, resulting in seven studies meeting inclusion criteria. These studies varied considerably in design, including retrospective cohort studies, small observational cohorts, cross-sectional surveys, and one pilot randomised controlled trial. Substantial variability was found in the measurement of oral health, oral microbiota, and pneumonia, which complicated comparison across studies and highlighted methodological gaps in the field

Results:

Across seven studies, findings centred on three themes: high prevalence of respiratory pathogens in the oral cavity, limited evidence linking oral health to pneumonia, and factors influencing these relationships. Six studies reported substantial carriage of opportunistic respiratory bacteria among adults with intellectual disabilities, including *Streptococcus pneumoniae*, *Staphylococcus aureus*, *Pseudomonas aeruginosa*, *Klebsiella pneumoniae* and *Corynebacterium* species, often exceeding rates in comparison groups. However, only one study examined whether pathogen carriage predicted pneumonia, finding associations with broader respiratory illness but not pneumonia specifically. Evidence linking oral health status to pneumonia was also sparse and inconsistent. One large retrospective cohort associated dental caries and periodontal disease with increased healthcare use for respiratory infections, while a smaller study linked poorer oral health scores to pneumonia diagnosis. Enteral feeding, greater disability severity and existing

dental disease emerged as important mediating factors. Overall, the literature suggests plausible oro-respiratory pathways but lacks robust evidence confirming causal or predictive relationships.

Conclusion:

This chapter demonstrated that although adults with intellectual disabilities show a high prevalence of oral carriage of respiratory pathogens and significant oral health challenges, current evidence does not establish a clear association between oral health, oral microbiota, and pneumonia within this population. Substantial further research is required to clarify these relationships and to inform clinical strategies aimed at reducing respiratory morbidity and mortality in adults with intellectual disabilities.

2.1 Introduction

Pneumonia represents a significant and persistent health challenge for people with intellectual disabilities. It reduces both quality of life and life expectancy and contributes to preventable suffering and early death. Mortality studies have consistently shown that adults with intellectual disabilities experience pneumonia-related deaths at rates that are many times higher than those observed in the general population (Hosking et al., 2016; O'Leary, Cooper, & Hughes-McCormack, 2018; Palmer, 2001). Recent Irish evidence has reinforced this pattern, as respiratory illness was identified as the leading cause of death among adults with intellectual disabilities living in residential care (McMahon et al., 2023). Although respiratory disease is common across the wider population, the excess mortality observed in adults with intellectual disabilities highlights a profound inequality that warrants closer examination.

Pneumonia is a common acute lower respiratory infection that affects the alveoli and distal bronchial tree. It is generally understood as either community-acquired (CAP) or hospital-acquired (HAP) (Almirall et al., 2021). Aspiration pneumonia (AP) arises when food, liquid, oral secretions, or vomitus enter the airway and reach the lungs, and it is estimated to account for between five and fifteen percent of all CAP cases (Lanspa et al., 2013; Lindenauer et al., 2018). AP is particularly relevant for populations who experience difficulties with swallowing, reduced airway protection, or reliance on others for feeding support, all of which are common among adults with intellectual disabilities.

A substantial body of research has demonstrated that poor oral health is strongly associated with the onset of pneumonia in both hospital and community contexts (Awano et al. 2008; Bágyi et al. 2009; Langmore et al. 1998; Mojon et al. 1997; Terpenning et al. 2001). This association is especially pertinent for adults with intellectual disabilities, who often face longstanding challenges in maintaining good oral health. Studies have shown that this population is more likely to experience untreated dental decay, gingivitis, and periodontal disease when compared with the general population (Anders & Davis, 2010; Wilson et al., 2019). These conditions can significantly alter the bacterial profile of the mouth, particularly when combined with inadequate salivary flow or inconsistent oral hygiene (Palmer, 2001; Wade, 2021).

Previous research has indicated that dental plaque, gingivitis, and dental caries can contribute to the development of aspiration pneumonia by acting as reservoirs for respiratory pathogens (El-Solh et al., 2004; Fourrier et al., 1998; Scannapieco et al., 1992). Dental plaque is particularly susceptible to colonisation by these organisms, and its role as a reservoir has been documented extensively (Bassim et al., 2008; Janssens, 2005). The presence of respiratory pathogens in the oropharynx becomes especially concerning when aspiration occurs, a risk that increases among individuals with oral disease or multiple co-morbidities (Pace & McCullough, 2010; Przybyłowska et al., 2016; Scannapieco et al., 2003).

Research in older adults has long recognised the contribution of poor oral hygiene to increased pneumonia risk. This work has identified high bacterial load, dysphagia, and inadequate oral care as independent risk factors for mortality in frail older populations (Azarpazhooh and Leake 2006; Scannapieco et al. 2003; van der Maarel-Wierink et al. 2013). A recent systematic review reported that poor oral hygiene facilitates colonisation by potentially pathogenic microorganisms such as *Staphylococcus aureus* (Sumi et al. 2006; Sumi et al. 2007; Terpenning et al. 2001), *Streptococcus pneumoniae*, *Candida* species (Awano et al. 2008), *Haemophilus influenzae* and *Klebsiella pneumoniae* (Sumi et al. 2006; Sumi et al. 2007), and *Pseudomonas aeruginosa* (Sumi et al. 2006). The presence of these organisms in the mouth has been strongly associated with an increased risk of aspiration pneumonia (Awano et al. 2008; Khadka et al. 2021; Sumi et al. 2006; Sumi et al. 2007; Terpenning et al. 2001).

Given this extensive evidence base, it is reasonable to anticipate that similar mechanisms may exist among people with intellectual disabilities. Adults with intellectual disabilities commonly experience both poor oral health and a heightened risk of aspiration pneumonia, particularly in the presence of dysphagia or enteral feeding. A recent mapping review of nursing literature identified dysphagia, poor oral hygiene, and tube feeding as major risk factors for aspiration pneumonia among people with intellectual disabilities (Lisiecka et al., 2024). However, despite strong theoretical and biological plausibility, it remains unclear whether the literature examining adults with intellectual disabilities has adequately explored the association between oral health, oral microbiota, and pneumonia.

For this reason, the scoping review presented in this chapter was undertaken to examine the extent and nature of research that addresses these relationships in adults with intellectual disabilities. The review also aimed to identify factors that may mediate or moderate these associations, while highlighting areas where further investigation is urgently needed

2.1.1 Aim of the Scoping Review

The aim of this scoping review was to systematically map and synthesise the existing evidence on the relationship between oral health, oral microbiota and pneumonia in adults with intellectual disabilities.

2.1.2. Research Questions

In line with this aim, this review addressed the following questions:

1. What is currently known about the association between oral health and pneumonia in adults with intellectual disabilities?
2. What mechanisms or pathways have been proposed to explain any observed associations?
3. What populations, settings and study designs have been used to investigate these relationships?
4. What gaps, limitations and priorities for future research emerge from the existing literature?

2.2 Methods

2.2.1 Design

This systematic scoping review was conducted in accordance with the methodological guidance outlined in the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis (Peters et al., 2020). The review followed a preregistered protocol, which is available on the Open Science Framework and provides further detail on the methodological approach (OSF registration K48AS). The search strategy was informed by the Population, Concept, and Context (PCC) framework, as recommended for scoping reviews, to ensure clarity and consistency in identifying relevant literature (Methley et al., 2014). The conduct and reporting of the review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews, known as PRISMA-ScR, which sets out standards for transparency and methodological rigour in scoping review reporting (Tricco et al. 2018). A completed PRISMA-ScR checklist is provided in Appendix 2.1.

2.2.2 Selection Criteria

The population of interest for this review was adults aged eighteen years or older who had a reported diagnosis of an intellectual disabilities, including synonymous terms such as developmental disabilities, intellectual disabilities, or learning disabilities. Studies involving later-onset cognitive disorders, for example dementia, were not eligible for inclusion. No exclusions were applied in relation to ethnicity, gender, level of disability, or comorbidities.

The central concept guiding inclusion was the relationship between oral health and pneumonia in adults with intellectual disabilities. Eligible studies were those that reported objective measures of oral health in connection with pneumonia or respiratory health outcomes. Oral health indicators included plaque indices, periodontal and gingival indices, edentulism, and the Decayed, Missing, Filled Teeth (DMFT) index. Microbiological findings and measures of salivary status were also considered relevant.

For pneumonia, studies were included when they reported confirmed or suspected pneumonia, which could involve a formal diagnosis, history of pneumonia, microbiological

confirmation, death attributed to pneumonia, or hospital length of stay related to pneumonia. All forms of pneumonia were eligible, including community-acquired pneumonia, hospital-acquired pneumonia, ventilator-associated pneumonia, aspiration pneumonia, and nosocomial pneumonia. Where studies did not clearly distinguish pneumonia from other respiratory infections but included pneumonia within a broader respiratory illness category, these were also included due to inconsistency in diagnostic reporting across the literature.

In relation to context, the review considered studies in any setting where evidence or plausible inference of a relationship between oral health and pneumonia in adults with intellectual disabilities was presented. Studies published in any language were eligible and no date restrictions were applied.

The study design of this review included descriptive and analytical observational studies such as cross-sectional surveys, cohort studies, case–control studies and case series. Experimental and quasi-experimental designs were also eligible, including randomised controlled trials, non-randomised controlled trials, before-and-after studies, and interrupted time-series studies. Qualitative studies, literature reviews, clinical guidelines, and study protocols were excluded.

2.2.3 Search Strategy

The search strategy was developed in collaboration with an experienced academic librarian. An initial exploratory search of MEDLINE and CINAHL was conducted to identify relevant keywords and subject headings appearing in titles, abstracts, and index terms. These preliminary findings informed the development of the full search strategy, which is presented in Appendix 2.2. The comprehensive search was carried out across multiple databases including MEDLINE (Ovid), Embase, Cochrane Trials, Cochrane Review, CINAHL, and PubMed. Forward citation searching was completed for all included studies to ensure that additional relevant literature was identified. No date restrictions or language limits were applied, to capture the widest possible range of studies relevant to the review objectives.

2.3.4 Study Selection

All citations identified through the database searches were imported into EndNote X9, where duplicate records were removed. Screening and management of records were undertaken using RAYYAN, which supports blinded and independent review processes (Ouzzani et al., 2016). After receiving training in the use of the software and the application of the eligibility criteria, two pairs of reviewers (KB and CMGP) independently screened titles and abstracts. Full-text articles were then assessed for eligibility by two independent reviewers (KB and CMGP). Any discrepancies or uncertainties regarding inclusion were resolved through discussion until agreement was reached.

2.2.5 Data Extraction

Data extraction was carried out using an adapted Joanna Briggs Institute (JBI) extraction form. One reviewer completed the initial extraction, and a second reviewer conducted a peer review of the extracted information. Any areas of disagreement were resolved through discussion. All relevant information was entered into a data charting form based on the standard JBI draft extraction template. Extracted data included details relating to the study population, key concepts, contextual factors, and findings or recommendations relevant to the review objectives. Following completion of the extraction process, the researcher reviewed all data to ensure accuracy and consistency, and any remaining discrepancies were resolved collaboratively.

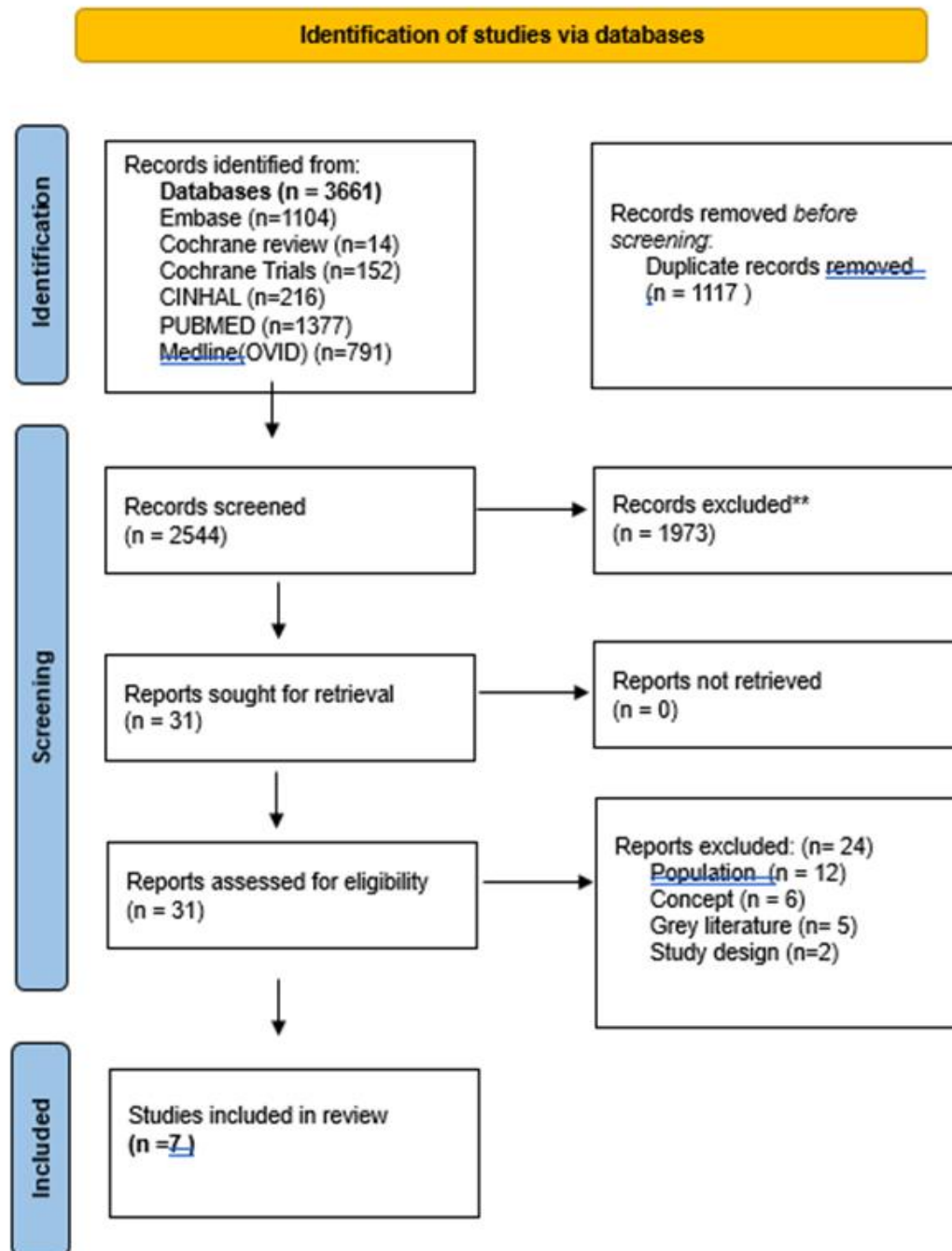
2.2.6 Data Analysis

The extracted data were synthesised using a narrative approach. Study characteristics were summarised in tabulated form, alongside concise summaries of findings relating to oral microbiota, oral health, and pneumonia. Once individual study data were charted, the studies were grouped according to key areas of interest. These included the presence of potential respiratory pathogens in the oral cavity, the relationship between oral pathogens and pneumonia, and the relationship between oral health and pneumonia. Potential mediating factors identified within the included studies were also documented to support interpretation of the findings and to highlight the complexity of the oral–respiratory pathway in adults with intellectual disabilities.

2.3 Results

A total of 3,654 records were identified through the database searches, comprising 79 from MEDLINE (Ovid), 1,104 from Embase, 14 from the Cochrane Review Database, 152 from Cochrane Trials, 216 from CINAHL, and 1,031 from PubMed. After the removal of 1,651 duplicate records, 2,003 citations were taken forward for title and abstract screening. At this stage, 1,972 citations were excluded. Thirty-one articles were subsequently retrieved for full-text review, and twenty-four of these were excluded, most commonly due to the age or type of population studied. Seven studies met the full eligibility criteria and were included in the final review. The study selection process is presented in Figure 2.1 using the PRISMA-ScR flow diagram (Tricco et al., 2018).

Figure 2.1: PRISMA-ScR flow diagram (Byrne 2025).



2.3.1 Characteristics of Included Sources

The seven studies that met the inclusion criteria were published between 2003 and 2019. The body of evidence reflected a range of study designs. Two studies used prospective

observational designs (Binkley et al. 2009; Horie et al. 2014), two adopted retrospective cohort approaches (Chiang et al. 2019; Zawadzki et al. 2016), two were cross-sectional surveys (Ahanjan et al. 2013; Wang et al. 2023), and one was a pilot randomised controlled trial (Ferozali et al. 2007). The studies were geographically diverse, with two conducted in the United States (Binkley et al. 2009; Ferozali et al. 2007), two in Taiwan (Chiang et al. 2019; Wang et al. 2023), and one each in Iran, Poland, and Japan (Ahanjan et al. 2013; Zawadzki et al. 2016; Horie et al. 2014). All included studies were published in English. A detailed summary of each study is outlined in appendix 2.3.

2.3.2 Findings from the Literature:

The findings from the included studies are organised to reflect the key areas of inquiry within this review. The section begins with an overview of the methods used to collect data across studies, highlighting the variability in microbiological and oral health assessment techniques. It then outlines the types of oral pathogens identified, with particular attention to organisms associated with respiratory disease. The subsequent section examines the reported relationships between these pathogens and pneumonia. Findings related to oral health status and its association with pneumonia are then presented. The final part of the section summarises mediating and moderating factors that were identified as influencing the relationship between oral health and pneumonia in adults with intellectual disabilities.

2.3.3 Oral Microbiota, Oral Health, and Pneumonia Data Collection Across Studies.

The methods used to collect data on oral microbiota, oral health, and pneumonia varied across the included studies. Microbiological sampling techniques differed both in approach and anatomical site. Reported collection sites included tongue scrapings (Horie et al. 2014), supragingival plaque or periodontal pockets from selected index teeth, and the mandibular alveolar ridge in participants who were edentulous (Binkley et al. 2009; Ferozali et al. 2007; Zawadzki et al. 2016). One study did not specify the site of oral sampling (Ahanjan et al. 2013). Sample processing methods also varied and included conventional culturing techniques (Ahanjan et al. 2013; Ferozali et al. 2007; Zawadzki et

al. 2016), polymerase chain reaction analysis (Binkley et al. 2009), and next-generation sequencing of 16S rRNA fragments (Wang et al. 2023).

Variation was also evident in how oral health was assessed. No single standardised measure of oral health was applied across studies. Three studies relied on chart reviews in which dental caries and periodontal disease were used as indicators of oral health status (Chiang et al. 2019; Ahanjan et al. 2013; Zawadzki et al. 2016). Other studies used structured assessment tools such as the Beck Oral Assessment Tool, the Total Oral Assessment Score, and the Revised Oral Assessment Guide (ROAG) (Binkley et al. 2009; Ferozali et al. 2007). In the study by Wang et al. (2023), a dentist undertook a full-mouth examination; however, no formal oral health measurement tool was employed. Detailed information about examiner calibration or diagnostic criteria was reported in two studies (Ferozali et al. 2007; Binkley et al. 2009).

Four studies attempted to identify pneumonia or respiratory illness outcomes, although their methods differed. One study relied on participant or caregiver self-report of a recent pneumonia diagnosis (Wang et al. 2023). Three studies used documented clinical diagnoses, drawing on health or service records to identify positive histories of pneumonia or related respiratory illness (Binkley et al. 2009; Chiang et al. 2019; Ferozali et al. 2007). In Binkley et al. (2009), physicians recorded respiratory diagnoses within a six-month period, while Ferozali et al. (2007) reviewed hospital discharge notes and patient records for evidence of respiratory illness. Chiang et al. (2019) used health service utilisation data from the National Health Insurance Database, which included records of outpatient visits, hospital admissions, and emergency department presentations for respiratory conditions.

2.3.4 Pathogens in the Oral Cavity

Six of the included studies examined the oral cavity for the presence of organisms with the potential to cause respiratory disease (Ahanjan et al. 2013; Binkley et al. 2009; Chiang et al. 2019; Ferozali et al. 2007; Horie et al. 2014; Wang et al. 2023; Zawadzki et al. 2016). Across these studies, a combined total of fifty-eight distinct microbial species were identified. Given the focus of this review on pneumonia in adults with intellectual disabilities, particular attention was paid to pathogens commonly associated with respiratory illness. The studies were therefore examined in greater depth to identify which

of the detected organisms were recognised respiratory pathogens and to understand their prevalence within the oral cavity of the sampled populations.

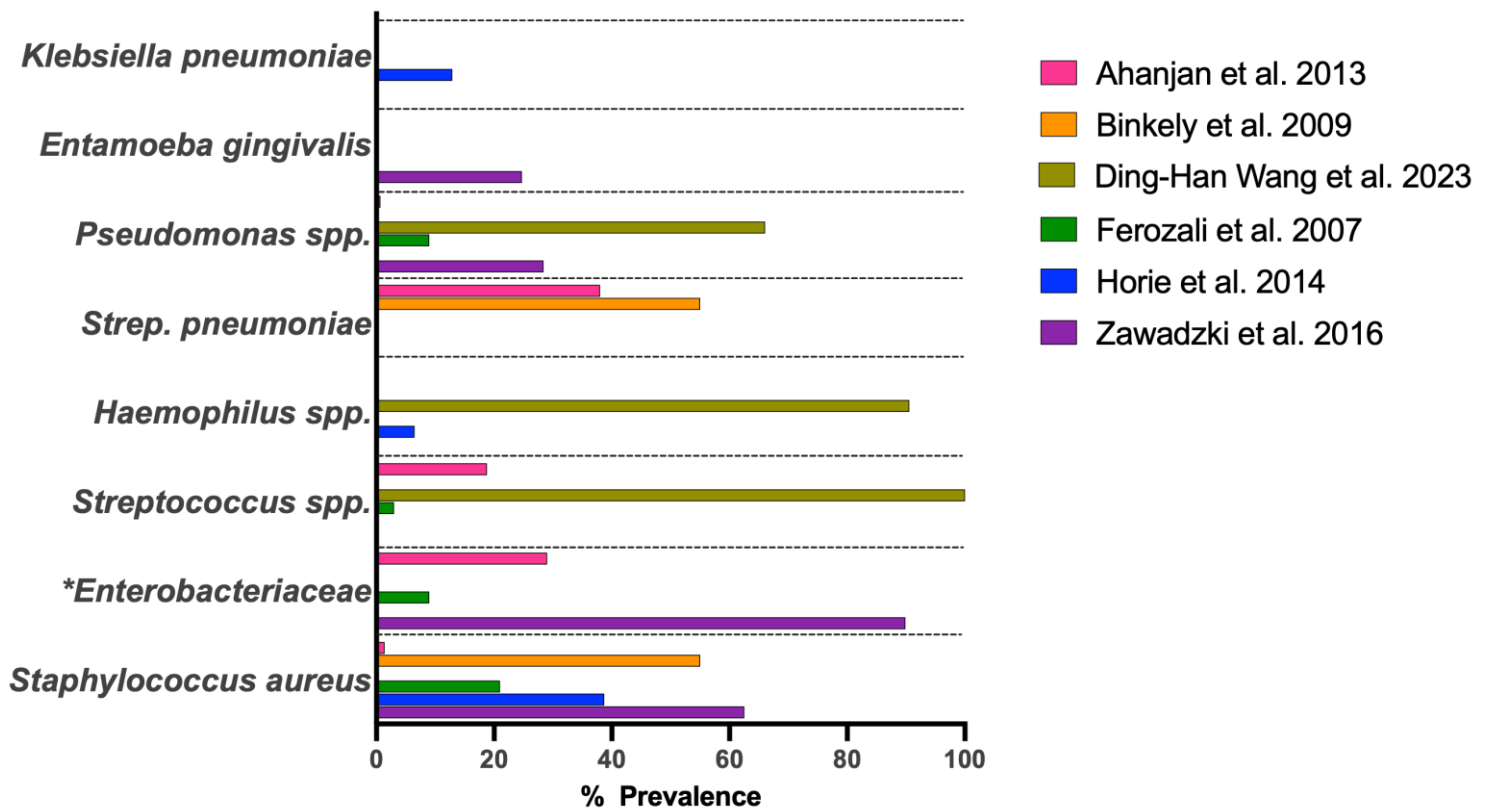
2.3.5 Potential Respiratory Pathogens in the Oral Cavity

Six studies examined the oral cavity as a potential reservoir for respiratory pathogens (Binkley et al., 2009; Ahanjan et al., 2013; Ferozali et al., 2007; Horie et al., 2014; Wang et al., 2023; Zawadzki et al., 2016). Of these, three focused exclusively on identifying respiratory pathogens within the oral microbiome without directly measuring respiratory outcomes, instead testing the biological plausibility of the mouth as a source of organisms implicated in pneumonia (Ahanjan et al., 2013; Horie et al., 2014; Zawadzki et al., 2016). Across these studies, a wide range of potentially pathogenic taxa were identified, supporting the concept that the oral cavity can function as a reservoir for lower respiratory tract infection.

As summarised in Figure 2.2, several clinically important respiratory pathogens were consistently detected across studies. *Streptococcus pneumoniae*, a leading cause of community-acquired pneumonia, was identified in oral samples in both Ahanjan et al. (2013) and Binkley et al. (2009). Gram-negative organisms commonly associated with healthcare-associated and aspiration pneumonia were also reported, including *Pseudomonas aeruginosa* (Binkley et al., 2009), *Klebsiella pneumoniae* and *Escherichia coli* (Ferozali et al., 2007; Zawadzki et al., 2016). Wang et al. (2023) and Ferozali et al. (2007) additionally identified enrichment of *Corynebacterium* spp. and *Pseudomonas* spp., taxa frequently implicated in respiratory colonisation and infection among medically vulnerable populations.

Importantly, Wang et al. (2023) extended this work by demonstrating that the oral microbiota of patients with nasogastric (NG) feeding tubes was significantly enriched with the same bacterial genera that were over-represented in patients with pneumonia, including *Corynebacterium*, *Pseudomonas*, *Actinotignum* and *Mycoplasma*. Although Wang et al. 2023 did not directly model pneumonia outcomes, the convergence of oral and pulmonary microbial profiles provides compelling indirect evidence that oral dysbiosis may contribute to respiratory vulnerability, particularly in individuals with impaired swallowing, altered airway protection or dependence on assisted feeding.

Figure 2.2: Presence of specific species and taxa across studies (Byrne et al 2025).



2.3.6 The Association Between Oral Pathogens and Pneumonia

Only two studies examined whether the presence of specific oral pathogens predicted the development of pneumonia (Binkley et al., 2009; Ferozali et al., 2007). In the study by Binkley et al., 2009 polymerase chain reaction analysis and multivariate logistic regression were used to investigate whether organisms such as *Streptococcus pneumoniae*,

Staphylococcus aureus including methicillin-resistant strains, and *Candida albicans* were associated with pneumonia. These organisms were not found to be independent predictors of pneumonia diagnosis. However, their presence was associated with a substantial increase in the likelihood of receiving a respiratory diagnosis more generally. When sinusitis, bronchitis, upper respiratory tract infections, and pneumonia were combined into a single outcome category, participants with positive polymerase chain reaction (PCR) results had approximately nine times the odds of a respiratory diagnosis compared with those who tested negative. The wide confidence intervals reported for this finding indicate considerable uncertainty in the estimate.

Ferozali et al. (2007) reported that colonisation with *Pseudomonas aeruginosa* was associated with hospitalisation due to pneumonia. However, the study did not provide the analyses or statistical outputs necessary to evaluate this claim, which limits interpretation and reduces the reliability of the reported association.

2.3.7 The Association Between Oral health and Pneumonia

Two studies used generalised linear modelling to examine whether oral health status predicted pneumonia or broader respiratory illness (Binkley et al. 2009; Chiang et al. 2019). In the population-based study by Chiang et al. (2019), more than half of the intellectual disabilities' cohort had at least one episode of respiratory infection requiring healthcare utilisation during the study period. The researcher found that individuals with a documented history of dental caries at cavitation or periodontal disease had a higher likelihood of respiratory infection. The odds of experiencing a respiratory infection were 1.16 times higher for those with caries at cavitation (95 per cent confidence interval 1.13 to 1.19) and 1.22 times higher for those with periodontal disease (95 per cent confidence interval 1.19 to 1.26) compared with those without such histories.

Binkley et al. (2009) examined oral health and respiratory outcomes in a smaller cohort of sixty-three adults with Intellectual disability . During the study period, twelve participants were diagnosed with pneumonia and two were diagnosed with other respiratory infections. When exploring predictors of pneumonia, the researcher found that the total score on the Revised Oral Assessment Guide (ROAG) was the only significant predictor in the model. ROAG scores can range from eight, indicating good oral health, to twenty-four,

indicating poor oral health. Scores within the sample ranged from eleven to nineteen. The odds ratio for the total ROAG score was 1.6 (95 per cent confidence interval 1.1 to 2.5, p less than 0.05), meaning that each one-point increase in the ROAG score corresponded to a 1.6-fold increase in the odds of developing pneumonia. Other factors examined in the model, including individual ROAG subscales such as gingiva, tongue, and swallowing, as well as enteral feeding and baseline PCR positivity, were not significant predictors of pneumonia.

2.3.8 Potential Mediating Factors

The included studies identified several factors that may mediate or moderate the relationship between oral health and pneumonia in adults with intellectual disabilities. These factors included enteral feeding, level of intellectual disabilities, and indicators of oral disease. Although the evidence remains limited, these findings suggest that the oral–respiratory pathway may be influenced by a combination of biological, functional, and care-related characteristics.

2.3.8.1 Enteral Feeding as a Mediating Factor

Two studies provided empirical evidence suggesting that enteral feeding may influence the association between oral health, pathogenic oral colonisation, and respiratory illness (Binkley et al., 2009; Wang et al., 2023). With Binkley et al. (2009) reporting that participants who were both enterally fed and positive for oral respiratory pathogens had almost four times the odds of developing a respiratory infection compared with those who were not enterally fed. The confidence interval for this finding was wide, which indicates uncertainty, and enteral feeding did not remain a significant covariate when the model focused specifically on pneumonia rather than broader respiratory illness. In the study by Wang et al. (2023), logistic regression demonstrated that participants fed via nasogastric tube had poorer oral health outcomes and a higher reported incidence of pneumonia compared with orally fed participants. The association with pneumonia showed the largest coefficient and reached a high level of statistical significance. These findings suggest that enteral feeding may heighten vulnerability to respiratory illness by contributing to altered oral environments, increased pathogenic colonisation enhanced due to reduced mouthcare followed.

2.3.8.2 Intellectual Disabilities as a Mediating Factor

The prevalence of oral carriage of potential respiratory pathogens was consistently higher in adults with intellectual disabilities compared with those without intellectual disabilities across several studies (Ahanjan et al., 2013; Horie et al., 2014; Zawadzki et al., 2016). While Chiang et al. (2019) further reported that the probability of experiencing a respiratory infection increased with the severity of intellectual disabilities. Individuals with severe or profound intellectual disabilities had odds of respiratory infection that were 1.10 times higher than those with mild or moderate disability. These findings suggest that factors associated with greater functional dependence, reduced self-care capacity, or increased health vulnerabilities may contribute to elevated risk.

2.3.8.3 Oral Disease Indicators as a Mediating Factor

Indicators of oral disease also influenced respiratory outcomes. Chiang et al. (2019) found that adults with intellectual disabilities who had a recorded history of periodontal disease or dental caries had higher rates of healthcare utilisation for respiratory infections. The probability of respiratory infection was 1.29 times higher among those with periodontal disease and 1.26 times higher among those with caries when compared with those without such histories. In the study by Binkley et al., (2009), mean ROAG scores were marginally higher among participants diagnosed with pneumonia than among those without pneumonia, indicating poorer oral health in the pneumonia group. However, differences in ROAG subscales were not observed, which suggests that overall oral status rather than specific oral features may be more relevant to respiratory vulnerability in this population.

Collectively, these findings indicate that enteral feeding, severity of intellectual disabilities, and oral disease burden may each contribute to increased susceptibility to pneumonia or respiratory infection in adults with intellectual disabilities. Further research is needed to understand the interplay between these factors and to determine the extent to which they mediate associations between oral health and respiratory outcomes.

2.4 Discussion

2.4.1 Main Findings

This scoping review examined the available evidence on the association between oral health and pneumonia in adults with intellectual disabilities. The literature addressed this association in two principal ways.

The first approach involved studies describing the presence and frequency of potential respiratory pathogens in the oral cavity. Across these studies, there was consistent evidence of high oral carriage of opportunistic organisms among adults with intellectual disabilities, supporting the biological plausibility of an oro-respiratory pathway. More than eight pathogens with recognised links to respiratory illness were identified, including *Corynebacterium* species, *Pseudomonas* species, *Klebsiella pneumoniae* and *Pseudomonas aeruginosa*. Several studies demonstrated that adults with intellectual disabilities carried these organisms at higher rates than comparison groups without intellectual disabilities. Despite this, only one study directly tested whether oral carriage of these pathogens predicted pneumonia. No significant association was observed, although a weak association emerged when pneumonia was grouped within a broader category of respiratory illness (Binkley et al., 2009). This pattern suggests that pathogenic colonisation may contribute to overall respiratory vulnerability, while direct evidence linking specific oral pathogens to pneumonia in this population remains limited.

The second approach comprised studies that directly assessed the relationship between oral health status and pneumonia or respiratory illness. Two studies applied multivariate modelling to explore these associations. Chiang et al., (2019) reported significant associations between a documented history of dental caries or periodontal disease and increased healthcare utilisation for respiratory infections. Binkley et al. (2009) found that poorer global oral status, measured using the Revised Oral Assessment Guide (ROAG), predicted pneumonia diagnosis. While the sample size was small and precision limited, the direction of effect is consistent with a biobehavioural pathway in which cumulative oral compromise signals heightened vulnerability. Importantly, ROAG captures multiple dimensions relevant to aspiration risk, including oral cleanliness, mucosal condition and

saliva, and may therefore function as an integrated risk marker even when individual subscales are not independently predictive. Interpretation of periodontal disease findings is complicated by the longstanding lack of standardisation in periodontal disease definitions and diagnostic criteria (Needleman et al., 2017; Walter et al., 2019). Although the population-based findings from Chiang et al. (2019) strengthen the argument that oral disease and respiratory healthcare utilisation co-occur in adults with intellectual disabilities, reliance on recorded dental histories introduces potential misclassification and detection bias. Individuals with greater healthcare contact may be more likely to have both oral disease and respiratory infections documented, while under-recording of oral disease among those with limited dental access may attenuate observed associations. This highlights a core challenge in the field: the strongest available datasets often rely on administrative proxies for oral health, while clinically assessed oral status and function, the dimensions most relevant to aspiration risk are rarely available at scale.

The review also identified several potential mediating or moderating factors. Both diagnosis of intellectual disabilities and the use of enteral feeding were associated with higher likelihood of pathogenic oral colonisation and increased respiratory illness, including pneumonia. These findings suggest that the pathways linking oral health and respiratory outcomes are shaped by a combination of biological vulnerability, functional impairment, and care-related factors, with adults who have higher support needs potentially at greatest risk.

The evidence indicates that adults with intellectual disabilities experience disproportionately high carriage of respiratory pathogens alongside significant oral health challenges. However, the existing literature provides limited and inconsistent evidence regarding the extent to which these factors directly contribute to pneumonia. Substantial gaps therefore remain in understanding whether and how oral health operates as a causal, contributory or correlative factor in respiratory disease among adults with intellectual disabilities.

2.4.2 Findings Relative to Existing Literature

A substantial body of research has examined the relationship between oral health and pneumonia in older adults without intellectual and developmental disabilities, particularly

those living in residential care settings. Numerous systematic reviews have synthesised this work and provide strong, convergent evidence for a link between poor oral hygiene and respiratory infection in the ageing population (Khadka et al., 2021; Liu et al., 2022; Marusiak et al., 2023; Sjögren et al., 2008; van der Maarel-Wierink et al., 2013). This literature demonstrates that inadequate oral hygiene contributes to a higher incidence of pneumonia (Terpenning, 2005; Yoneyama et al., 1999) and increased mortality risk (Awano et al., 2008; Liu et al., 2022; Marín-Zuluaga et al., 2012). Dental decay and poor oral hygiene have consistently been shown to elevate pneumonia risk in older adults, reinforcing the position of oral health as a clinically meaningful determinant of respiratory health across the lifespan (Khadka et al., 2021).

Building on this epidemiological evidence, numerous intervention studies have evaluated whether oral health programmes can reduce pneumonia incidence in older adults. Research involving regular professional oral hygiene care and structured oral care programmes in nursing homes has consistently reported reductions in respiratory infections and pneumonia-related illness (Khadka et al., 2021; Sjögren et al., 2008; Zimmerman et al., 2020). The scale and consistency of these findings highlight oral hygiene as a modifiable factor in pneumonia prevention and support a causal interpretation of the oral–respiratory pathway in frail ageing populations.

The contrast between these extensive findings in gerontology and the very limited number of studies available for adults with intellectual disabilities is striking. Only two studies in the present review directly examined the association between oral health and pneumonia in adults with intellectual disabilities (Binkley et al., 2009; Chiang et al., 2019). This imbalance underscores a significant and persistent research gap affecting a population that experiences both poorer oral health and greater vulnerability to respiratory illness. Despite strong biological plausibility and robust evidence in older adult populations, the relationship between oral health and pneumonia in adults with intellectual disabilities remains unexplored, highlighting an urgent need for rigorous and targeted research.

In adults with intellectual disabilities, the biological plausibility of an oral–respiratory pathway may be even stronger than in the general ageing population because key risk factors cluster at higher prevalence and earlier ages. Dysphagia, gastro-oesophageal reflux, neuromotor impairment, sedation-related reductions in cough reflex and

dependence on assisted feeding are more common, particularly among individuals with severe or profound disability and those living in congregated settings. These factors increase aspiration exposure and simultaneously shape the oral environment through reduced salivary flow, impaired oral clearance, texture-modified diets and inconsistent oral hygiene support. In this context, poor oral cleanliness and untreated disease may function less as isolated dental problems and more as components of a broader aspiration vulnerability phenotype that cannot be adequately captured using single-exposure models. However, the limited intellectual disabilities literature has not yet been designed to test these clustered pathways with sufficient clinical precision.

The frequent detection of opportunistic respiratory pathogens in the oral cavity should not be interpreted as evidence of direct causation. Colonisation is common among medically vulnerable groups, and pneumonia is a multicausal outcome influenced by aspiration frequency, host immunity, airway clearance, medication effects and care quality. A causal association is therefore unlikely to be demonstrated through single time-point pathogen sampling alone, particularly where pneumonia is measured broadly or retrospectively. More informative study designs would examine the interaction between oral bioburden, oral hygiene, swallowing safety and care-dependent exposure, treating oral health as part of a combined risk system rather than as a single independent predictor.

2.4.3 Strengths and Weaknesses of the Review

This review followed a systematic and comprehensive search strategy, applying broad inclusion criteria across multiple databases and study designs. Despite this, only a small number of studies that specifically involved adults with intellectual disabilities were identified. This finding is informative, reflecting the limited development of this research field rather than deficiencies in the review process. Many of the included studies were characterised by small sample sizes, raising concerns about statistical power and limiting the generalisability of findings. Studies that used larger datasets were predominantly retrospective chart reviews, a design that carries inherent limitations, particularly in relation to the accuracy, completeness and consistency of recorded oral health and respiratory variables.

Across the literature, inconsistent criteria for assessing both oral health and pneumonia further restricted comparability between studies. Standardised oral health indices were seldom used, and diagnoses of pneumonia were frequently inferred through proxy measures such as healthcare utilisation, discharge coding or retrospective clinical documentation rather than validated diagnostic criteria. Although research in older adults has firmly established the relationship between poor oral hygiene and pneumonia, caution is warranted when interpreting findings based on poorly defined or inconsistently applied indicators of oral disease. The absence of secure and standardised definitions of periodontal disease has been identified as a substantive limitation in oral–systemic health research more broadly (Walter et al., 2019) and this challenge is clear within the intellectual disabilities literature reviewed here. Robust, clinically meaningful and reproducible classifications will be essential for future work examining respiratory and periodontal relationships in adults with intellectual disabilities.

A broader and more fundamental limitation is that the scarcity of studies is itself a symptom of structural exclusion within oral health and respiratory research. Oral–respiratory studies have historically relied on standard dental examinations and research protocols that are difficult to implement among individuals who require communication support, behavioural adaptation, or sensory-aware pacing. As a result, adults with the highest aspiration risk and often the poorest oral health, particularly those with severe or profound intellectual disabilities or prominent levels of care dependence and are the least likely to be represented in research samples. This produces a systematic underestimation of need and limits the external validity of existing findings. Consequently, the field faces a dual evidence gap: a limited volume of studies overall, and biased inclusion favouring participants with lower support needs and greater examination tolerance.

A notable strength of the included studies was the use of microbiological methods to estimate the prevalence of oral pathogens, providing objective measures of bacterial colonisation and biological plausibility for an oral–respiratory pathway. These methods strengthen confidence in the observation that adults with intellectual disabilities frequently carry organisms implicated in respiratory disease. However, microbiological data alone are insufficient to clarify causal mechanisms. There remains a clear need for prospective research designs with adequate sample sizes, repeated measurement and

rigorous, disability-adapted assessment methodologies. Future studies should employ validated and reliable measures of both oral health and pneumonia, alongside explicit consideration of functional, care-related and systemic mediators, to enhance internal validity and support a more comprehensive understanding of the oral–respiratory pathway in this population

2.4.4 Implications

This scoping review indicates that adults with intellectual disabilities frequently exhibit oral colonisation with organisms implicated in respiratory infection and experience a substantial burden of oral disease. However, the current evidence base remains insufficient to determine whether poor oral health functions as a direct, modifiable causal risk factor for pneumonia, or whether it operates primarily as a marker of broader systemic vulnerability, care dependence and aspiration risk. Importantly, this uncertainty should not be interpreted as reassurance. In populations with high baseline risk of aspiration, respiratory morbidity and pneumonia-related mortality, the absence of definitive causal evidence reflects limitations of study design and measurement rather than absence of clinically meaningful risk.

From a clinical perspective, these findings support the positioning of oral health as a plausible, low-risk and potentially modifiable component of pneumonia prevention strategies in adults with intellectual disabilities. Evidence from frail older populations without intellectual disabilities demonstrates that structured oral hygiene interventions can reduce respiratory infections and pneumonia-related morbidity. Given the clustering of aspiration risk factors in adults with intellectual disabilities, particularly dysphagia, enteral feeding, neuromotor impairment and high support needs, there is a strong rationale for adopting a precautionary and prevention-oriented approach to oral care, even in the absence of definitive causal proof.

For practice, the findings support strengthening routine oral care within intellectual disabilities services, including structured daily mouth care protocols, workforce training, and routine monitoring of oral cleanliness, particularly for individuals receiving feeding support or living in congregated settings. Prevention strategies should extend beyond plaque control alone to incorporate functional considerations. Tooth loss, reduced

functional dentition, xerostomia and impaired oral clearance may increase oral residue, compromise bolus formation, and contribute to unsafe swallowing. Integrating oral health review into dysphagia management, nutrition assessment and respiratory risk planning would therefore align with a holistic, systems-based approach to aspiration prevention rather than treating oral care as a discrete or ancillary task.

This review highlights an urgent need for prospective, adequately powered studies using clinically meaningful definitions of pneumonia alongside standardised, disability-adapted oral health assessments. Future research should move beyond treating oral health as an isolated exposure and instead model the complex pathways linking oral conditions to respiratory outcomes, including dysphagia severity, aspiration risk, enteral feeding, gastro-oesophageal reflux, medication burden and level of support needs. Longitudinal designs incorporating repeated measures would enable examination of changes in oral health status and vulnerability over time.

Microbiological investigations of the oral microbiome in older adults with intellectual disabilities are also warranted, particularly to identify colonisation by respiratory pathogens and its relationship to oral hygiene, oral inflammation, and aspiration exposure. Linking microbiological sampling to clinical and functional measures would provide insight into potential mechanisms underpinning pneumonia risk. Large longitudinal datasets, such as IDS-TILDA, offer a valuable opportunity to explore these relationships at population level and to identify modifiable risk factors across the ageing trajectory.

Future studies should also incorporate appropriately matched general population comparison groups to quantify disparities and determine whether risk factors, microbiological profiles and clinical presentation differ from those observed in the wider ageing population. Such comparisons are necessary to distinguish pathways specific to intellectual disability from those associated with ageing more broadly.

These well-designed intervention trials are required to determine whether enhanced oral hygiene programmes, staff-supported care routines and timely dental management can reduce pneumonia incidence, respiratory hospitalisations, and antibiotic use among adults with intellectual disabilities. Addressing these gaps is essential for developing

effective preventive strategies and reducing avoidable respiratory morbidity and mortality in this population.

Crucially, the review underscores the importance of inclusive measurement infrastructure. Without feasible, standardised tools capable of assessing oral health across the full spectrum of intellectual disabilities, research will continue to rely on administrative proxies and selective samples, limiting interpretability and actionability. Addressing this methodological gap is essential not only to clarify oral–respiratory pathways, but to generate evidence capable of informing prevention strategies that are equitable, clinically relevant and responsive to the needs of adults with intellectual disabilities

2.5 Conclusion

This scoping review demonstrates that adults with intellectual disabilities frequently harbour potential respiratory pathogens within the oral cavity, often at higher prevalence than adults without intellectual disabilities. These findings support the biological plausibility of an oro-respiratory pathway contributing to pneumonia risk in this population. However, despite this plausibility and the well-established oral–respiratory link in the general ageing literature, the existing intellectual disabilities-specific evidence does not provide clear or consistent support for a direct association between oral pathogen carriage, poor oral health and pneumonia. The available studies are few, methodologically heterogeneous, and frequently limited by small sample sizes, proxy measures and retrospective designs, restricting the strength of inference that can be drawn.

Importantly, the absence of definitive evidence should not be interpreted as evidence of absence. Rather, it reflects substantial limitations in how oral health and respiratory outcomes have been measured and studied in adults with intellectual disabilities. The current literature has not been adequately designed to capture the complex, multicausal pathways through which oral health, aspiration risk, functional impairment and care dependency may interact to influence pneumonia vulnerability in this population.

These findings highlight an urgent need for high-quality, prospective research capable of determining whether poor oral health and inadequate oral hygiene function as modifiable

risk factors for pneumonia in adults with intellectual disabilities. Future studies must employ clinically meaningful and standardised definitions of pneumonia alongside disability-adapted, clinically assessed measures of oral health and oral function. Explicit modelling of mediating factors such as dysphagia, enteral feeding, medication burden and level of support needs will be essential to advance mechanistic understanding and avoid oversimplified causal assumptions.

A central conclusion of this review is that the most significant barrier to progress in this field is not solely the scarcity of studies, but the lack of inclusive oral health measurement tools capable of being deployed among individuals with high support needs. Without disability-inclusive assessment infrastructure, research will continue to rely on proxy indicators and selective samples, limiting both validity and translational impact. Addressing this measurement gap is a prerequisite for clarifying oral–respiratory pathways and for generating evidence that can inform effective, equitable strategies to reduce preventable respiratory morbidity and mortality among adults with intellectual disabilities.

Chapter 3: Methodology

3.1 Introduction

The methodological choices underpinning this thesis are central to its credibility, rigour, and contribution to knowledge. The research questions addressed here, concerning the measurement of oral health and its relationship with systemic health and survival in older adults with intellectual disabilities, are shaped as much by how evidence is generated as by what is examined. This chapter therefore sets out the methodological approach adopted to address the aims and objectives of the thesis and explains how these choices support the production of valid, interpretable, and policy-relevant findings.

Methodology is not treated in this thesis as a purely technical exercise. Rather, it reflects a series of interlinked decisions about how oral health is conceptualised, measured, analysed, and interpreted, particularly in a population that has historically been under-represented in health research. The quantitative paradigm adopted provides a structured means of measuring oral health status, modelling associations with systemic health outcomes, and examining patterns at population level. As explored in greater depth later in this chapter, these choices are underpinned by specific assumptions about knowledge, measurement, and inference, which shape what kinds of claims can and cannot be made.

The methods employed reflect both the complexity of oral health as a research domain and the additional methodological challenges involved in conducting inclusive research with people with intellectual disabilities. Addressing these challenges required an approach that could generate robust quantitative evidence while remaining sensitive to issues of measurement validity and feasibility. These considerations are particularly relevant to the development of an inclusive oral health assessment tool, which is examined in detail in Chapter 4.

The thesis is underpinned by three interconnected methodological strands, each addressing a distinct aspect of the research problem.

First, adopting scoping review methods, an international scoping review was conducted to map existing evidence on oral health and pneumonia in adults with intellectual and developmental disabilities. This review provided breadth, identified key gaps in the literature, and established the rationale for subsequent empirical work, which is discussed in Chapter 2.

Second, drawing on psychometric and clinometric principles of health measurement, the gaps identified in the literature informed the development and validation of the MOSST. Designed for use with adults with intellectual disabilities by non-dental assessors, the MOSST addresses limitations in existing measures and represents a central methodological contribution of the thesis. The conceptual and methodological decisions underpinning its development are explored in detail in Chapter 4.

Finally, using established quantitative analytic approaches, the MOSST enabled in-depth examination of oral health status and its associations with systemic health outcomes within a nationally representative cohort of older adults with intellectual disabilities. These analyses, presented in Chapters 6 to 7, examine the determinants and consequences of oral health using cross-sectional and longitudinal data.

The oral health strand of this programme required substantial methodological development and field implementation. The PhD researcher designed the MOSST field protocol and assessor training package, developed disability-specific calibration materials, coordinated content validity procedures, acted as the gold-standard assessor during calibration and reliability testing, and oversaw MOSST implementation within IDS-TILDA Wave 5. The researcher also contributed directly to IDS-TILDA fieldwork by completing 25 CAPI interviews.

In setting out these approaches, this chapter outlines the philosophical underpinnings of the study, details the study populations, sampling and recruitment procedures, ethical considerations, measurement strategies, data collection protocols, and analytic methods applied across the thesis. The chapter concludes by reflecting on the methodological strengths and limitations of the approaches adopted, providing a framework for interpreting the findings presented in subsequent chapters.

3.2 Research Paradigm and Design

The research questions addressed in this thesis require both conceptual clarity and methodological rigour. They ask not only *what* the oral health status of older adults with intellectual disabilities is, but *how* it can be validly measured, *why* it matters for systemic health and survival, and *whether* existing research approaches have adequately captured

the realities of this population. Addressing these questions demands careful alignment between philosophical assumptions, methodological choices, and analytic strategies. This section therefore sets out the research paradigm underpinning the thesis and demonstrates how assumptions about reality and knowledge generation flow through the design, methods, data collection, analysis, interpretation, and claims to generalisability. Later chapters return to these assumptions in greater depth, particularly where methodological decisions are operationalised and their implications examined.

3.2.1 Research Paradigm

This thesis is grounded in a post-positivist research paradigm, which provides the primary philosophical foundation for its quantitative, epidemiological, and measurement-based approach. Post-positivism assumes that a reality exists independently of the researcher, but that this reality can only be known imperfectly and probabilistically, as all observation and measurement are subject to error, bias, and contextual influence (Phillips & Burbules, 2000). In contrast to naïve positivism, post-positivism recognises that knowledge is theory-laden, provisional, and open to revision. These assumptions align closely with contemporary epidemiology and measurement theory, where health constructs are treated as real but only indirectly observable through indicators that approximate underlying phenomena.

From an ontological perspective, oral health status, systemic disease, and mortality are understood as real phenomena with material consequences for individuals and populations. However, these phenomena are complex, multidimensional, and shaped by interactions between biological processes, social structures and healthcare systems. From an epistemological perspective, knowledge of these phenomena is necessarily partial. Constructs such as oral cleanliness, functional dentition, or disease burden cannot be accessed directly but must be inferred through structured measurement. A fallibilist epistemology recognises that research findings can approximate reality but remain provisional, partial and open to revision as methods, measures and evidence improve. In this study, this position supported the use of standardised assessment tools and statistical modelling while acknowledging measurement error, uncertainty, missing data and the limits of causal inference in observational research.

These ontological and epistemological assumptions give rise to a post-positivist methodology that prioritises systematic measurement, hypothesis testing, and probabilistic reasoning. The aim is not to establish definitive truths, but to estimate the strength, direction, and uncertainty of associations between variables, and to contribute incrementally to an evolving evidence base. This methodological orientation is reflected in the quantitative epidemiological design of the thesis, including the use of validated instruments, longitudinal data, and regression-based analytic techniques.

The research design operationalises these principles through three interconnected strands: a scoping review, the development and validation of a clinometric oral health assessment tool, and secondary analysis of nationally representative longitudinal data. Each strand is discussed in detail later in this chapter and in subsequent chapters, but it is important to note here that the design reflects a deliberate effort to move from mapping existing evidence, to strengthening measurement, to applying that measurement in population-level analysis. This progression mirrors the logic of post-positivist inquiry, in which theory, measurement, and empirical testing are interlinked.

The methods and data collection procedures used in the thesis follow directly from this design. Oral health and related variables are measured using structured instruments within the IDS-TILDA study, a nationally representative longitudinal dataset of older adults with intellectual disabilities. The development of the MOSST, described in detail in Chapter 4, exemplifies a post-positivist epistemology of measurement, whereby latent health constructs are operationalised through observable indicators that are evaluated for validity, reliability, and feasibility (De Vet et al., 2011; Streiner et al., 2015). Measurement is thus treated as an approximation of reality, constrained by context and population characteristics, rather than as a neutral or purely technical exercise.

The analytic strategies employed, including multivariable regression modelling and longitudinal analysis, are consistent with post-positivist assumptions about inference. Associations are interpreted probabilistically, with explicit attention to uncertainty, confounding, and model limitations. Claims made based on these analyses are therefore cautious and conditional, reflecting the recognition that statistical relationships do not equate to deterministic causation.

In terms of interpretation and external validity, post-positivism supports conditional generalisation from sample to population, if sampling strategies, measurement validity, and analytic assumptions are transparent. The use of a large, nationally representative dataset enhances the generalisability of findings to older adults with intellectual disabilities in Ireland, while acknowledging that social, policy, and healthcare contexts may limit transferability to other settings. These considerations are revisited in the discussion chapters, where findings are situated within the broader international literature.

3.2.2 Measurement Validity, Causal Inference and Equity from Post-Positivist to Realist and Transformative Paradigms

While post-positivism provides the primary epistemological foundation of this thesis, elements of a critical realist perspective inform the interpretation of findings, recognising that observed statistical associations may reflect deeper causal mechanisms operating within specific social and clinical contexts (Bhaskar, 2013; Danermark et al., 2019; Streiner et al., 2015). This perspective is consistent with contemporary epidemiological approaches that treat indicators such as tooth loss not only as descriptive measures, but also as potential markers of broader pathways linking oral health, nutrition, systemic disease and survival among people with intellectual disabilities. These relationships are examined empirically in later chapters through statistical modelling of associations between oral health indicators and health outcomes.

Post-positivist measurement theory further emphasises that validity depends on the suitability of instruments for the populations to which they are applied. Conventional oral health assessments frequently assume normative levels of communication, literacy and behavioural compliance. When applied uncritically, such assumptions can exclude individuals with intellectual disabilities, introducing systematic bias in sampling, measurement and interpretation. This exclusion undermines both internal validity, by misrepresenting the constructs being measured, and external validity, by limiting generalisability to the broader population of interest. Such processes have been described as methodological ableism (Hosking, 2024), and contribute to epistemic injustice, whereby certain groups are marginalised within knowledge production (Fricker, 2007).

An explicit equity orientation therefore informs the methodological design of this research. Rather than representing a separate philosophical paradigm, this orientation is operationalised through practical decisions that strengthen scientific rigour. These include the inclusion of participants across the full spectrum of intellectual disability, the development and refinement of the MOSST with public and patient involvement, and the use of reasonable adjustments to facilitate participation in clinical assessment. These strategies enhance content validity, feasibility, reach and interpretability of findings, while reducing systematic exclusion.

The methodological design was also informed by the emancipatory and accessible philosophy underpinning IDS-TILDA and its Health Fair model. Rather than positioning adults with intellectual disabilities as passive subjects of assessment, this approach seeks to create supported, respectful and enabling research environments in which participants can engage meaningfully in health data collection. This philosophy aligns with the wider equity orientation of the study by recognising that accessibility, reasonable adjustment and participant support are not peripheral to research quality but are central to producing valid and representative evidence. Within this framework, the integration of MOSST into the IDS-TILDA Health Fair reflected an attempt to adapt oral health assessment to participants' communication, sensory and support needs, rather than requiring participants to conform to conventional clinical examination conditions.

In this sense, the thesis demonstrates that inclusive research practices are not only ethically justified but also methodologically necessary for producing valid population-level evidence. By enabling the collection of clinically assessed oral health data from individuals who are typically excluded from surveillance systems, the study strengthens the reliability and generalisability of conclusions regarding oral health and ageing in intellectual disability.

3.2.3 Positioning Critical Realism within the Research Programme

Critical realism was used in this study as an interpretive lens rather than as a replacement for the post-positivist epidemiological design. Its value lies in supporting interpretation of oral health inequities among older adults with intellectual disabilities as both empirically observable and shaped by deeper biological, social, organisational and policy-level

mechanisms. This was important because the study generated objective oral health data and used statistical modelling to examine associations between oral health indicators, systemic health and mortality, while also recognising that observed associations do not, by themselves, provide a complete explanation of why these patterns occur.

This position was particularly relevant to the study of oral health in intellectual disability. Oral disease, tooth loss, reduced functional dentition and poor oral cleanliness are real clinical conditions with material consequences for eating, comfort, respiratory health and survival. However, their occurrence and consequences are also shaped by less visible mechanisms, including access to dental care, dependence on supporters for daily oral hygiene, communication barriers, diagnostic overshadowing, service fragmentation, workforce knowledge and the extent to which reasonable adjustments are implemented in practice. Critical realism therefore enabled the study to hold together the biological reality of oral disease and the structural conditions that influence its distribution, recognition and management.

Within the research programme, critical realism provided a bridge between the theoretical, empirical and practical dimensions of the work. Theoretically, it aligned with an equity-oriented understanding of disability by recognising that health outcomes are produced through interactions between individual impairment, support environments, health systems and wider social structures. Empirically, it supported the use of objective measurement and statistical modelling while requiring findings to be interpreted within context. Practically, it allowed the findings to be translated into implications for oral health surveillance, workforce development, service planning and policy, rather than being interpreted only as individual-level risk factors.

This philosophical positioning also informed the development and use of the MOSST. The absence of oral health data for people with intellectual disabilities was understood not simply as a technical measurement problem, but because of exclusionary research practices and insufficient methodological adaptation. From a critical realist perspective, the MOSST was developed to make an undermeasured aspect of health visible, while recognising that measurement alone does not resolve inequity. Instead, inclusive measurement provides a basis for identifying patterns, examining possible mechanisms and informing changes in practice and policy.

Critical realism therefore underpinned the study by supporting movement between three levels of inquiry: documenting observable oral health outcomes, interpreting these outcomes in relation to underlying biological and structural mechanisms, and identifying practical responses that may reduce inequity. This lens helped connect the study's methodological focus on accessible measurement with its broader concern for health equity, ageing and rights-based inclusion.

To clarify how these epistemological and methodological principles are operationalised across the programme of research, Table 3.1 maps the relationships between theoretical assumptions, study design, data sources and analytic approaches, and indicates where each component is developed in subsequent chapters.

Table 3.1 Alignment of philosophical underpinnings, methodology, and thesis structure across the three-research strand

Dimension	Scoping Review	Psychometric Tool development	Analytic and Epidemiological Strand
Primary epistemology	Post-positivist	Post-positivist (measurement theory)	Post-positivist
Ontological assumptions	Oral health outcomes and inequalities are real phenomena reflected imperfectly in published evidence	Oral health constructs (e.g. oral cleanliness, dentate status) are real but latent and indirectly observable	Oral health, systemic health, and mortality are real population-level phenomena
Epistemological stance	Knowledge is provisional and incomplete; evidence is mapped rather than synthesised causally	Constructs can be approximated through indicators with measurable validity and error	Associations can be estimated probabilistically using population data
Role of critical realism	Identifies gaps suggesting unexamined causal mechanisms	Supports interpretation of oral health constructs as real but indirectly observed through adapted indicators	Supports interpretation of associations as potential indicators of underlying biological and structural mechanisms
Methodological logic	Pragmatic, exploratory	Pragmatic, instrument-development focused	Pragmatic, hypothesis-testing
Study design	Scoping review (evidence mapping)	Instrument development and validation study	Quantitative observational epidemiology (cross-sectional and longitudinal)

Data sources	Peer-reviewed international literature	Expert review, PPI input, IDS-TILDA oral health assessments	IDS-TILDA and mortality data
Sample and population	Studies involving adults with intellectual disabilities (varied populations)	Older adults with intellectual disabilities across all levels of disability	Nationally representative cohort of older adults with intellectual disabilities
Measurement approach	Descriptive categorisation of study characteristics	Development of the MOSST as a structured clinometric tool	Application of the MOSST and standardised survey variables
Analytic techniques	Descriptive synthesis and gap identification	Content validity, feasibility assessment, construct consideration	Regression modelling, survival analysis, multivariable adjustment
Interpretive stance	Identifies patterns and absences in the evidence base	Evaluates adequacy of measurement for this population	Interprets findings probabilistically, acknowledging uncertainty
External validity and generalisability	Conceptual generalisability across contexts	Instrument applicability across levels of intellectual disabilities	Statistical generalisability to older adults with intellectual disabilities in Ireland
Transformative orientation	Highlights systematic exclusion in existing research	Embeds inclusion through PPI and reasonable adjustments	Produces inclusive population-level evidence for policy and practice
Relevant thesis chapters	Chapter 2 (Scoping Review)	Chapter 4 (MOSST Development & Validation)	Chapters 5–7 (Analytic Findings & Discussion)

3.2.3 Positioning Critical Realism within the Research Programme

Critical realism was used in this study as an interpretive lens rather than as a replacement for the post-positivist epidemiological design. Its value lies in supporting interpretation of oral health inequities among older adults with intellectual disabilities as both empirically observable and shaped by deeper biological, social, organisational and policy-level mechanisms. This was important because the study generated objective oral health data and used statistical modelling to examine associations between oral health indicators, systemic health and mortality, while also recognising that observed associations do not, by themselves, provide a complete explanation of why these patterns occur.

This position was particularly relevant to the study of oral health in intellectual disability. Oral disease, tooth loss, reduced functional dentition and poor oral cleanliness are real clinical conditions with material consequences for eating, comfort, respiratory health and survival. However, their occurrence and consequences are also shaped by less visible mechanisms, including access to dental care, dependence on supporters for daily oral hygiene, communication barriers, diagnostic overshadowing, service fragmentation, workforce knowledge and the extent to which reasonable adjustments are implemented in practice. Critical realism therefore enabled the study to hold together the biological reality of oral disease and the structural conditions that influence its distribution, recognition and management.

Within the research programme, critical realism provided a bridge between the theoretical, empirical and practical dimensions of the work. Theoretically, it aligned with an equity-oriented understanding of disability by recognising that health outcomes are produced through interactions between individual impairment, support environments, health systems and wider social structures. Empirically, it supported the use of objective measurement and statistical modelling while requiring findings to be interpreted within context. Practically, it allowed the findings to be translated into implications for oral health surveillance, workforce development, service planning and policy, rather than being interpreted only as individual-level risk factors.

This philosophical positioning also informed the development and use of the MOSST. The absence of oral health data for people with intellectual disabilities was understood not simply as a technical measurement problem, but because of exclusionary research practices and insufficient methodological adaptation. From a critical realist perspective, the MOSST was developed to make an undermeasured aspect of health visible, while recognising that measurement alone does not resolve inequity. Instead, inclusive measurement provides a basis for identifying patterns, examining possible mechanisms and informing changes in practice and policy.

Critical realism therefore underpinned the study by supporting movement between three levels of inquiry: documenting observable oral health outcomes, interpreting these outcomes in relation to underlying biological and structural mechanisms, and identifying practical responses that may reduce inequity. This lens helped connect the study's methodological focus on accessible measurement with its broader concern for health equity, ageing and rights-based inclusion.

3.3 Data Sources

This thesis draws on three interconnected sources of data:

- (1) a systematic scoping review of international evidence
- (2) primary data generated through the development and validation of the (MOSST
- (3) primary analysis of the IDS-TILDA oral health and systemic health conditions data, also including cause-specific and all-cause mortality linkage.

These sources collectively provide a coherent programme of methods, moving from evidence synthesis to tool development and population-level application to advance understanding of oral health in older adults with intellectual disabilities.

3.3.1 Scoping Review

The first strand involved a systematic scoping review examining international peer-reviewed literature on the relationship between oral health and pneumonia in adults with intellectual disabilities. Conducted in accordance with Joanna Briggs Institute methodology and reported following PRISMA-ScR guidelines, the review mapped the extent, nature, and quality of existing research addressing oral–systemic links in this population. Searches were completed across major biomedical and social science databases (MEDLINE via PubMed, CINAHL, PsycINFO, EMBASE, and Web of Science) from database development to December 2023.

Studies were included if they reported on adults aged ≥ 18 years with intellectual disabilities, examined at least one oral health measure, and reported any pneumonia-related outcomes. Extracted data were charted to summarise study populations, oral health and microbiological measures, respiratory outcomes, and mediating factors. The review highlighted a substantial scarcity of epidemiological evidence linking oral health and pneumonia in adults with intellectual disabilities, alongside marked heterogeneity in how both oral health and pneumonia were defined and measured. These limitations underscore the need for more robust and standardised oral health data within research involving ageing populations with intellectual disabilities. Full methods and results of this scoping review are presented in Chapter 2.

3.3.2 MOSST Validation Data

The second strand of this study involved the generation of psychometric and implementation data arising from the development, refinement and validation of the

MOSST. The MOSST was developed as a modified version of the originally developed Oral Status Survey Tool (OSST), which had demonstrated the potential for trained non-dental professionals to collect structured oral health data with adults with intellectual disabilities (Mac Giolla Phadraig et al., 2021). Building on this earlier work, the MOSST was refined within the present doctoral study to strengthen its accessibility, operational definitions, assessor training, calibration procedures and suitability for implementation within IDS-TILDA.

Earlier IDS-TILDA work had identified the need for objective oral health assessment and provided important learning for the development of the MOSST approach. However, Wave 5 marked the first implementation of the refined MOSST protocol as the structured oral health assessment component within the IDS-TILDA Health Fair. The distinction is therefore that earlier work informed the need for adapted oral health measurement, while Wave 5 provided the context in which the MOSST was implemented, evaluated and used to generate the oral health data analysed in later chapters.

IDS-TILDA provided an appropriate setting for MOSST development and validation because it is a longitudinal study specifically designed to examine ageing among adults with intellectual disabilities in Ireland. Embedding MOSST within IDS-TILDA enabled oral health assessment to be integrated alongside existing data on health, function, living circumstances, multimorbidity and mortality. This connection was central to the study design, as it allowed oral health to be examined not only as a descriptive outcome, but also in relation to systemic health and survival outcomes.

The MOSST was specifically designed as a brief, accessible oral health assessment that could be administered by trained non-dental assessors to adults with intellectual disabilities. Its integration into Wave 5 of the IDS-TILDA Health Fair provided the setting for field implementation and validation, enabling examination of the tool's reliability, feasibility, content validity and implementation characteristics in a large sample of older adults with intellectual disabilities.

Data were collected on a range of measurement properties relevant to tool evaluation. These included inter-rater and intra-rater reliability tests, feasibility indicators such as assessment time, completion rates and participant tolerance, and cost data relating to

equipment and labour requirements. Further psychometric evidence was generated through structured content validity assessment, involving international oral health experts and a PPI panel of adults with intellectual disabilities who reviewed the tool in accessible format. These data directly informed item refinements, training requirements and the development of supporting research materials.

The resulting dataset therefore provides a comprehensive evaluation of the MOSST as a feasible, reliable and conceptually valid oral health assessment for use with adults who may require communication or cognitive supports. The full validation outcomes, including reliability coefficients, feasibility metrics and content validity results, are presented in Chapter 4.

3.3.3 IDS-TILDA Survey and Longitudinal Data

The second source of data used in this thesis is derived from the IDS TILDA study, a nationally representative longitudinal study of ageing among adults with intellectual disabilities aged 40 years and over in Ireland. Established in 2008, IDS-TILDA was designed to address the absence of population-level ageing data for adults with intellectual disabilities (McCarron et al 2011) and runs in parallel with The Irish Longitudinal Study on Ageing (TILDA) (Kearney et al., 2011) supporting comparative epidemiological research with the general population. Across five waves (2009–2023), IDS-TILDA has maintained a large and stable nationally representative cohort. The baseline cohort enrolled 753 participants in Wave 1 and achieved high retention across subsequent waves, with 94% re-participation in Wave 2 and 86% retention into Wave 3. A refresh sample was added at Wave 4 (n=233) to counter the effects of mortality-related attrition and maintain cohort representativeness. By Wave 5, 742 participants completed interview data and 503 attended the health fair, of whom 469 (93.2%) completed the MOSST as outlined in table 3.2. The IDS-TILDA Health Fair is a structured data collection area of IDS TILDA in which participants complete a range of health assessments, clinical measures and interview components in an accessible and supported environment, with 26 different measures in Wave 5. The Health Fair model was designed to facilitate participation among adults with intellectual disabilities by allowing flexibility, support from familiar persons where appropriate, and reasonable adjustments during data collection.

For the purposes of this thesis, data from Waves 1–5 (2009–2023) are used. Wave 1 established a cohort of 753 adults recruited through random sampling of the National intellectual disabilities Database (NID). At the time of the original IDS-TILDA sampling, the National Intellectual Disability Database (NIDD) provided the sampling frame. The NIDD has since been replaced by the National Ability Supports System (NASS), which is now the principal national database for recording disability service use and support needs in Ireland. Retention across subsequent waves remained high, influenced by mortality patterns, and a refresh sample was added at Wave 4 to maintain representativeness. Full cohort retention details are presented in Table 3.2 By Wave 5 (2021–2022), 742 participants completed the survey interview (Computer-Assisted Personal Interview; CAPI), and 503 completed health fair assessments.

Wave 5 is of particular importance to this thesis for two reasons. First, it marked the introduction of structured oral health assessment through the implementation of the MOSST, completed by 469 participants (93.2% of health fair attendees). This enabled the generation of standardised epidemiological oral health indicators. Second, Wave 5 introduced a new linkage with the Irish national mortality register, providing verified dates and ICD-10 coded causes of death. This development makes IDS-TILDA the first longitudinal dataset internationally to combine structured oral health data and cause-specific mortality among adults with intellectual disabilities. These linked data form the basis of analyses in Chapter 7, which examines relationships between oral status and mortality outcomes, including respiratory-related deaths.

Population sampling, consent processes and ethical procedures relating to IDS-TILDA are described in detail in Section 3.4 Population and Sampling, while the operationalisation of oral health and clinical variables for analysis is presented in Section 3.6 Measures and Variables

Table 3.2. IDS-TILDA Cohort Retention Across Waves

Wave	Years	Sample	Refresh Sample	Retention
Wave 1	2009–2010	753 (46% of 1,600	–	Baseline

		invited) a further 200 in reserve		
Wave 2	2013–2014	707	–	94% of Wave 1
Wave 3	2016–2017	608	–	86% of Wave 2
Wave 4	2017–2018	739	233	Refresh sample added
Wave 5	2021–2022	742 CAPI, 503 health fair (469 MOSST)	141	Refresh sample added

3.4 Population and Sampling

Population and sampling procedures across the three strands of this thesis were shaped by shared commitments to accessibility, inclusivity, and respect for autonomy. Anchored in a pragmatist paradigm, sampling decisions prioritised methodological adequacy and ethical appropriateness over uniform design. Together, the three populations represented international research studies, adults participating in the validation of the MOSST, and participants in the nationally representative IDS-TILDA cohort provided complementary breadth and depth. They enabled the mapping of existing literature on oral–respiratory links (*Chapter 2*), the development and psychometric testing of an inclusive oral health tool (*Chapter 4*), and epidemiological analyses of oral health status, systemic health and survival in older adults with intellectual disabilities (*Chapters 5–7*).

3.4.1 Recruitment, Consent, and Fieldwork Procedures IDS TILDA

This section outlines how participants were recruited and consented for Wave 5 of IDS-TILDA, and how fieldwork was conducted, including integration of the MOSST oral health

assessment. These procedures reflect the study's commitment to inclusion, accessibility and ethical participation of older adults with intellectual disabilities.

3.4.1.1 Recruitment Pathways and Participant Identification

Participants were recruited through the established IDS-TILDA longitudinal cohort framework. The original cohort was drawn from a nationally representative sample of adults with intellectual disabilities identified through the National Intellectual Disability Database (NIDD), which records individuals receiving intellectual disability services in Ireland. Eligible participants were adults aged 40 years and over living in a range of residential settings, including independent or family homes, community group homes, and campus-based residential services.

Subsequent waves, including Wave 5, primarily involved re-contacting surviving members of the original cohort, supplemented by refresh samples recruited using the same sampling frame to maintain representativeness as participants aged and attrition occurred. Recruitment pathways involved disability service providers, family carers, and guardians acting as link persons who facilitated contact but did not mediate participation decisions.

Invitations were addressed directly to potential participants rather than to organisations, supporting autonomy and reducing gatekeeping. Accessible invitation packs, co-designed with people with intellectual disabilities in earlier waves, were distributed in both standard and easy-read formats. These materials emphasised voluntary participation, confidentiality, the option to bring a supporter, and that participation would not affect access to services.

The IDS-TILDA research team coordinated appointments for interviews and health fair assessments. Where required, travel and support arrangements were organised to minimise logistical barriers and enable participation across geographical regions and levels of disability.

3.4.1.2. Accessible Consent Procedures

Consent procedures complied with the Assisted Decision-Making (Capacity) Act 2015 and with ethical approvals granted to the IDS-TILDA study. Consent was treated as an iterative and context-based process, rather than as a single transactional event. Written informed

consent was obtained directly from participants wherever possible. Where an individual was assessed as lacking capacity to provide informed consent, consent was obtained from a legally authorised proxy, in accordance with ethical guidance, and only where the participant did not object to participation. The Health Research Consent Declaration Committee (HRCDC) consent declaration held by IDS-TILDA applies to the processing and use of personal data for health research and does not constitute consent for participation. Participation consent was therefore obtained separately through established ethical and governance procedures.

Consent was reaffirmed at two stages of participation: prior to the face-to-face interview (CAPI/PIQ) and again prior to participation in the Health Fair, where the MOSST was administered. Participants were provided with clear verbal explanations, easy-read information materials, repeated opportunities to ask questions, and ongoing reminders that they could decline, pause, or withdraw from participation at any time. Assent was monitored continuously throughout data collection, particularly for participants with communication support needs, and any indication of withdrawal or distress was respected immediately.

3.4.1.3 Philosophical Integration: Accessibility

These procedures reflect the thesis's pragmatist orientation, in which methods are selected for their ability to generate meaningful, actionable consequences. Accessible recruitment and consent were not compensatory add-ons but scientific requirements for obtaining ecologically valid oral health data from a population frequently excluded due to communicative, behavioural, or cognitive barriers. In aligning with transformative and critical realist principles, IDS-TILDA actively challenges epistemic injustice (Fricker, 2007) and methodological ableism (McGuire, 2020) by ensuring that people with all abilities contribute data that shape research, policy, and clinical practice. Accessibility therefore operated as both an ethical standard and an epistemological commitment, ensuring that the data underpinning this thesis were generated through inclusive, respectful, and scientifically defensible means. As outlined in Section 3.2, the Health Fair model was informed by an emancipatory and accessible research philosophy. In practical terms, this meant that data collection was organised to support participation through flexible pacing, accessible communication, the option of a familiar supporter, environmental adjustments

and the right to pause or withdraw. The integration of MOSST followed this same approach, with oral health assessment procedures adapted to maximise comfort, dignity and participation while maintaining standardised data collection.

3.4.2.IDS TILDA Wave 5 Sample

The primary analytic population for this thesis was drawn from IDS-TILDA Wave 5 (2022–2023). A total of 742 adults aged ≥ 40 years completed interview data comprising a CAPI and PIQ. Within this cohort, 503 participants also attended a structured clinical health fair, designed to provide objective clinical assessments alongside survey data. These assessments were conducted by trained nurses and allied health professionals, supported by accessibility procedures that accommodated participants across all levels of disability and communication ability (see Section 3.5.4). The health fair cohort provided the sampling frame for the integration of the MOSST, enabling objective oral health measurement as part of Wave 5. This embedded design allowed oral health data to be linked directly with contemporaneous clinical assessments and survey-derived indicators of health, behaviour, function and living circumstances. Partial MOSST completions were retained when item-level data were obtained in accordance with protocol. Retaining these assessments reflects the feasibility goal of the MOSST and acknowledges that brief oral examinations may be only partially tolerated by some participants due to sensory sensitivity, fatigue, or anxiety. Rather than excluding these individuals, which would reproduce the selective bias that has historically marginalised adults with intellectual disabilities from dental epidemiology the inclusion of partial scores enabled item-level modelling and contributed to an ecologically valid representation of oral health in this population. All participants who took part in the MOSST assessment were given a participant oral health pack, shown in Figure 3.1. All participants who completed the MOSST assessment were provided with a participant oral health pack, shown in Figure 3.1. The pack was intended as a practical health promotion resource rather than an incentive for participation. It contained oral hygiene items and accessible information to support daily mouth care following the assessment, consistent with the Health Fair ethos of ensuring that participation was respectful, useful and linked to health promotion.

Figure 3.1 Oral health pack



3.4.3 MOSST Validation Sample

Within the 469 participants who completed a MOSST assessment, a nested validation subsample contributed to the evaluation of the tool's psychometric properties. Reliability was assessed using structured sub-samples of approximately $n=44$ participants for inter-rater and 24 participants for intra-rater testing, while feasibility and acceptability metrics were obtained from $n=66$ participants who provided structured feedback at the health fair. Content validation was undertaken separately through an international expert panel ($n=7$) and a PPI advisory group of adults with intellectual disabilities ($n=7$). Thus, the term *validation subsample* refers specifically to these nested groups who contributed to reliability, feasibility, and content validity assessment, rather than the full MOSST cohort. This is further detailed in chapter 4 of this thesis.

3.4.5 IDS-TILDA Longitudinal Cohort

Longitudinal analyses in this thesis utilised dentition data collected across IDS-TILDA Waves 1–5 (2009–2023). At baseline (Wave 1), 742 participants (98.5% of the interviewed

cohort) had complete dentition data and were therefore eligible for inclusion in longitudinal oral health and survival analyses. Participants were followed for up to 13 years, allowing examination of associations between baseline dentition status and subsequent mortality outcomes.

Mortality linkage introduced at Wave 5 enabled follow-up of survival status through verified death registration records obtained from the Irish General Register Office. Dates and ICD-10 coded causes of death were incorporated into the dataset using anonymised participant identifiers. Time-to-event variables were derived from baseline interview date to date of death or censoring on 31 March 2023.

For analyses conducted in Chapter 7, edentulism at baseline was modelled as the primary exposure variable in relation to both all-cause and respiratory-related mortality. Sequential Cox proportional hazards models were constructed to estimate hazard ratios while adjusting for demographic, disability-related, and clinical covariates. This longitudinal framework enabled examination of dentition status as a potential predictor of survival within a nationally representative cohort of older adults with intellectual disabilities.

3.5 Ethical Considerations

3.5.1 Ethical Approval and Governance

Ethical approval for the components of this thesis conducted within IDS-TILDA, including the integration of the MOSST into Wave 5 health fair, was granted by the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee. All procedures complied with the Declaration of Helsinki (World Medical Association, 2013), Irish health research regulations, and the General Data Protection Regulation (GDPR, 2018).

IDS-TILDA holds a Consent Declaration from the Health Research Consent Declaration Committee (HRCDC), permitting the processing of personal data for health research purposes in circumstances where obtaining explicit consent may not be feasible. This declaration relates to data processing and does not replace participant consent procedures, which were obtained separately in accordance with ethical approval.

Mortality linkage procedures introduced at Wave 5 were conducted by the IDS-TILDA data management team using anonymised identifiers under approved data-sharing agreements; the researcher did not access identifiable data at any stage.

Ethical practice within this thesis was approached not as procedural compliance alone, but as a structured commitment to autonomy, dignity, and inclusion. Given the historical exclusion of people with intellectual disabilities from epidemiological research, ethical design required actively enabling participation rather than presuming incapacity or burden (Fricker, 2007).

3.5.2 Consent, Capacity and Assent Procedures

Consent procedures complied with the Assisted Decision-Making (Capacity) Act 2015 and relevant Irish health research governance frameworks. Written informed consent was obtained directly from participants who had decision-making capacity. Where an individual lacked capacity to provide informed consent, proxy consent was obtained from a legally authorised representative, provided the participant did not object to participation.

The Health Research Consent Declaration Committee (HRCDC) declaration held by IDS-TILDA relates to the processing of personal data for research purposes and does not replace the requirement for participation consent. Participation consent was therefore obtained separately in accordance with ethical approval.

Assent was treated as an ongoing process and monitored continuously throughout interviews and clinical assessments. Any indication of distress, refusal, or withdrawal resulted in immediate discontinuation of procedures. Operational details of recruitment, accessible materials, and staged consent procedures are described in Section 3.4.1.2.

3.5.3 Minimising Burden and Protecting Dignity

Study procedures were designed to minimise both physical and psychological burden across all strands of data collection. The MOSST assessment was brief, observational, and non-invasive, typically lasting less than ten minutes and using only a disposable mirror and torch. No periodontal probing, radiographs or invasive instruments were used.

Assessments were paused or discontinued immediately if fatigue, anxiety, or discomfort was observed.

Similarly, IDS-TILDA interviews were structured to reduce participant burden. The CAPI could be divided across sessions to minimise fatigue, and participants were reminded that they could skip questions, take breaks, or withdraw at any time. The use of proxy respondents where appropriate reduced cognitive and communicative strain for individuals who required support, while the PIQ allowed detailed clinical information to be collected outside the time-limited interview setting.

These design choices reflect the principle that rigorous epidemiological data can be collected without compromising participant comfort, autonomy or dignity. Inclusion was operationalised through proportionate, flexible assessment methods that balanced measurement validity with feasibility and respect

3.5.4 Data Protection and Confidentiality

Data governance procedures were implemented to ensure confidentiality and compliance with GDPR (2018) and Trinity College Dublin research data management policies. Within IDS-TILDA, participants are assigned anonymised unique identifiers. Personally identifiable information is stored separately from research datasets and accessible only to authorised members of the central IDS-TILDA team.

For this thesis, the researcher accessed only fully anonymised datasets under a formal data-sharing agreement. All datasets were stored on encrypted Trinity College Dublin servers with restricted access and audit trails. No identifiable data were downloaded, transferred to personal devices, or stored on external media.

Mortality linkage was conducted by the IDS-TILDA team using pseudonymised identifiers; only de-identified ICD-10 coded cause-of-death variables were released for analysis. Dissemination of findings is limited to aggregated data to prevent re-identification of individuals.

3.5.5 Ethical Orientation and Equity

The ethical orientation of this thesis aligns with a pragmatist paradigm in which inquiry is judged by its consequences for practice, policy and lived experience (Dewey, 1938; James, 1907). Ethical research therefore required not only avoidance of harm but production of knowledge capable of improving oral health equity for people with intellectual disabilities.

This approach is consistent with rights-based frameworks including the UN Convention on the Rights of Persons with Disabilities (2006, Article 31), which mandates inclusive and disaggregated data collection, and the WHO Global Oral Health Strategy (2022), which calls for disability-inclusive surveillance systems. By embedding PPI input, accessible consent processes and reasonable adjustments into quantitative data collection, this thesis demonstrates that methodological rigour is strengthened through inclusion rather than compromised by it. Ethics and equity were therefore inseparable: rigorous epidemiological research was achieved because participation was enabled, not despite it.

3.6 Study Procedures for Data Collection

Study procedures varied across the three strands of this thesis but were underpinned by common principles relating to transparency, standardisation, accessibility, and respect for participant autonomy. Tailored approaches were required for each strand of data collection, reflecting the different modes of evidence generation. These procedures are outlined in this section and described in detail in the relevant chapters.

3.6.1 MOSST Development and Validation Procedures

The development and validation of the MOSST were embedded within the Wave 5 IDS-TILDA health fair (2022–2023). These procedures involved a sequential process beginning with assessor training and calibration, followed by expert and participant involvement to refine measurement content, and culminating in structured, accessible, epidemiologically robust data collection during health fair held nationally. These procedures ensured that MOSST met psychometric standards while remaining feasible for use with older adults with intellectual disabilities, many of whom have communication, sensory, or behavioural support needs.

3.6.1.1. Development of MOSST Training Materials and Clinical Image Repository

A critical component of MOSST development involved the creation of disability-specific training materials to support consistent scoring and calibration. During the calibration phase at the Dublin Dental University Hospital, the researcher developed a repository of clinical photographs depicting the oral presentations of adults with intellectual disabilities. These images included a range of dentition patterns, periodontal conditions, cavitated lesions, oral hygiene states, denture use, and examples of Functional Tooth Units. All photographs were taken with full informed consent, including consent from participants and, where required, their legal proxies. Consent documentation specified that images would be used solely for research training and tool development and would not be released for clinical or commercial purposes.

The decision to build a bespoke photographic repository reflects both methodological necessity and ethical considerations. Existing oral health training resources predominantly depict typically developing adults and do not represent the dental trajectories commonly experienced in older adults with intellectual disabilities, such as earlier tooth loss, untreated caries, atypical wear, or unhealthy gums. The use of generic images would have perpetuated this erasure, limiting accuracy in calibration and reinforcing ableist assumptions in measurement. By contrast, the MOSST repository ensured fidelity to population characteristics and allowed assessors to practice scoring using images that mirrored real-world variation in intellectual disabilities oral health.

These images were embedded in MOSST assessor training sessions, calibration exercises, and knowledge checks, and were accompanied by annotation and explanatory text that clarified scoring thresholds. The repository was also used to develop structured calibration quizzes that formed part of assessor competency sign-off. This resource later informed the formatting of the MOSST protocol itself, as scoring criteria and visual representations were drawn from the repository to support standardisation. A figure illustrating the structure and use of this image repository in MOSST training is presented in Figure 3.2

Figure 3.2: clinical photography repository



3.6.1.2. Assessor Training and Calibration Prior to Fieldwork

Before data collection commenced, a multi-stage training and calibration programme was implemented to ensure that the MOSST could be administered reliably by non-dental assessors. The researcher developed the MOSST training programme, training materials and competency checks, and co-delivered training alongside a specialist care dentist who served as the second clinical gold-standard assessor.

Calibration began at the Dublin Dental University Hospital, where the researcher undertook repeated joint assessments with the specialist care dentist to establish gold-standard agreement. Calibration continued until near perfect agreement was achieved ($\kappa = 0.85$), confirming that MOSST scoring rules were reproducible and stable in real-world conditions.

Following this phase, four research nurses who would subsequently administer MOSST in the IDS-TILDA Wave 5 health fair completed a two-day training programme at Trinity College Dublin (Figure 3.2). Training covered oral anatomy and common oral disease presentations in adults with intellectual disabilities, supported communication approaches, infection control, and ethical procedures including assent monitoring. Item-level scoring instruction was provided for all MOSST domains, including functional dentition, cavitated lesions, gingival indicators and oral cleanliness. Nurses completed structured practice using the disability-specific photographic training repository, scripted calibration scenarios and case-based discussion. Practical sessions with volunteers with intellectual disabilities were also included to replicate health fair conditions and to refine reasonable adjustments and assessor approach (Figure 3.4).

Assessor competence was confirmed through reliability testing against the gold-standard assessor prior to fieldwork. Inter-rater agreement ranged from $\kappa = 0.86$ to 0.93, exceeding accepted thresholds for clinical epidemiology and meeting the minimum requirement for field deployment. Reliability checks were repeated periodically during data collection to minimise assessor drift, consistent with WHO guidance for oral health surveys which recommends reassessment at minimum intervals of 50 examinations (World Health Organization, 2013).

Figure 3.3 Training and calibration



Figure 3.4: Training and feedback session



3.6.1.3 MOSST data collection

Once training and calibration were completed, MOSST data collection was implemented during the IDS-TILDA Wave 5 Health Fair by trained research nurses, with on-site coordination provided by the researcher. The Health Fair was delivered over a nine-month period and attended by 503 participants, of whom 469 completed the MOSST assessment, indicating high feasibility and acceptability

for a clinically oriented oral health assessment embedded within a large, multi-domain ageing study.

During fieldwork, the researcher supported research nurses in real time, ensuring adherence to standardised procedures and resolving practical issues as they arose. Responsibilities included preparation and maintenance of equipment and infection-control supplies, coordination of assessment stations, and ensuring that all materials required for MOSST administration were available at each health fair session. The researcher also implemented and maintained the electronic data capture system using Qualtrics, monitored survey functionality, and addressed technical issues to ensure secure and complete data recording. Data completeness and consistency were reviewed regularly during fieldwork to identify potential protocol deviations or recording errors.

MOSST data collection followed standardised procedures for equipment set-up, infection control, participant positioning and scoring criteria. The assessment was designed as a brief, structured clinical observation rather than a full dental examination, balancing the need for clinically meaningful data with feasibility, participant comfort, and ethical considerations.

The MOSST comprises two overarching domains: oral function and oral disease indicators. MOSST items were selected to capture oral health indicators that were clinically meaningful, observable without invasive examination, feasible for trained non-dental assessors, and relevant to oral function, disease burden and population-level surveillance. Oral function indicators included dentate status, tooth count, functional dentition, occlusal contacts, pairs of occluding premolars, front twelve teeth and denture wear. Oral disease indicators included cavitated teeth, gum condition, oral cleanliness and oral pain. These items were chosen because they reflect domains relevant to eating, comfort, disease burden, prevention needs and potential systemic vulnerability, while remaining feasible within the Health Fair context.

A brief overview of MOSST domains, items, criteria and coding is provided here to orient the reader to the measures used in this study. The detailed development, refinement and psychometric evaluation of each item are presented in Chapter 4.

Table 3.4 summarises the concepts, criteria and coding applied to each MOSST item.

Assessments were conducted in a designated clinical area within the Health Fair using portable equipment and universal infection control precautions. Participants were supported through reasonable adjustments, including flexible pacing, simplified explanations, reassurance, use of non-threatening equipment (e.g. mirrors or toothbrushes), and the option for a familiar support person to be present. Participants could pause or withdraw at any stage without consequence.

MOSST permits partial completion to maximise inclusivity. Where specific items could not be assessed safely or comfortably, these were coded as “Not assessed” in accordance with protocol guidance. This approach enabled participation across all levels of intellectual disability, including individuals with moderate, severe and profound disability who are frequently excluded from clinical oral health research. Item-level completion varied across MOSST indicators, reflecting the tool’s capacity to permit partial assessment where specific items could not be completed safely or comfortably. In Wave 5, valid item-level data were available for between 65.24% and 99.10% of MOSST participants, with the lowest completion observed for cavitated teeth and the highest for denture wear. These differences reflect the greater assessment demands of some clinical indicators and support the use of partial completion as an inclusive data collection strategy. Item-level completion and reliability data are reported in Chapter 4. Table 3.4 summarises the concepts, criteria and coding applied to each MOSST item.

Table 3.4 MOSST concept criteria and coding

<i>Item</i>	<i>Category</i>	<i>Criteria</i>	<i>Coding</i>
Denture wear	Upper and lower denture present	Removable denture present in the mouth at the time of assessment (upper and/or lower)	No denture present = 0 Denture present = 1 Not assessed = 97
	Tooth count	Upper and lower teeth	Number of teeth visible in each arch (excluding removable dentures; including fixed prostheses)
Occlusal contacts	Pattern of tooth contact	Distribution of opposing teeth in	Discrete count 0–16 per arch Not assessed = 97 No occlusal contacts = 0 Anterior contacts only = 1

		contact on maximum intercuspation	Posterior contacts present = 2 Not assessed = 97
Pairs of occluding premolars (POPs)	Functional premolar units	Presence of ≥ 3 occluding premolar pairs	≤ 2 POPs = 0 3–4 POPs = 1 Not assessed = 97
Front twelve teeth	Aesthetic/functional dentition	Presence of all twelve inter-canine teeth (upper and lower)	<12 teeth present = 0 All 12 present = 1 Not assessed = 97
Cavitated teeth	Caries severity	Number of teeth with visually cavitated carious lesions	0 cavitated teeth = 0 1–2 cavitated teeth = 1 ≥ 3 cavitated teeth = 2 Not assessed = 97
Gum health	Gingival condition	Presence of redness, swelling, bleeding or ulceration anywhere in the mouth	Healthy gums = 1 Inflamed gum = 0 Not assessed = 97
Oral cleanliness	Plaque/debris	Presence of visible plaque, tartar or food debris on teeth or dentures	Clean = 1 Not clean = 0 Not assessed = 97
Oral pain	Pain experience	Verbal, behavioural or physical indicators of oral pain within the past week	Verbal/vocal pain = 0 Behavioural/physical signs = 1 No pain = 2 Not assessed = 97

3.6.1.4 Reliability and Feasibility Data Collection

In addition to training and calibration, structured procedures were embedded within IDS-TILDA Wave 5 health fair fieldwork to evaluate the reliability and feasibility of MOSST as a population-level assessment administered by non-dental clinicians. These procedures were designed and coordinated by the researcher and implemented during routine data collection rather than as a separate study, ensuring that reliability estimates reflected authentic clinical conditions and the diverse needs of older adults with intellectual disabilities.

Reliability testing followed established standards in health measurement research and international epidemiological guidance (World Health Organization, 2013; Streiner et al., 2015). Inter-rater reliability was prioritised to determine whether trained research nurses produced scores consistent with a gold-standard examiner. The researcher served as the gold-standard assessor and conducted paired assessments with research nurses. For the initial ten MOSST examinations, both assessors completed scoring independently to confirm that training translated into

competent field performance. Further inter-rater checks were conducted at prespecified intervals throughout fieldwork to monitor consistency and minimise assessor drift.

Intra-rater reliability was assessed during the later stages of data collection (May–June 2023) to evaluate the stability of scores when assessments were repeated on the same individual. Consistent with WHO guidance to retest 5–10% of participants, repeat examinations were completed by trained nurses and by the researcher as gold-standard assessor. Although guidelines typically recommend a one- to two-week interval between assessments, this was not feasible for many adults with intellectual disabilities due to logistical, cognitive, and behavioural barriers. Repeat scoring was therefore conducted on the same day as a reasonable adjustment to minimise burden and support inclusion. To preserve methodological integrity, assessors were blinded to their initial scores, and no feedback was provided between assessments.

Feasibility was evaluated alongside reliability to assess the practicality of MOSST for large-scale epidemiological use in populations requiring communication and cognitive support. During the final weeks of the health fair, 66 participants provided structured feedback on their experience of the assessment, including perceived duration, comfort and acceptability. Research nurses also documented reflective observations on usability, clarity of instructions, sensory or behavioural challenges, and the effectiveness of reasonable adjustments. These professional reflections complemented participant feedback and provided insight into the operational feasibility of implementing MOSST at scale.

Time metrics were collected systematically as part of feasibility assessment. Start and finish times for each examination were recorded electronically using the Qualtrics data capture system implemented by the researcher, along with associated administrative time. Detailed psychometric results, including reliability coefficients, feasibility indicators and demographic characteristics of the validation sample, are presented in Chapter 4.

3.6.1.5. Expert Clinical Review and Public and Patient Involvement

Content validity of the MOSST was established through a two-stage process involving both expert evaluation and PPI, ensuring that the tool was conceptually robust, clinically relevant, and responsive to the lived experiences of older adults with intellectual disabilities. These were organised and co-ordinated by the student.

The first stage involved structured review by an international expert panel comprising seven oral health academics, dental epidemiologists, and clinicians with specialist expertise in intellectual disabilities and ageing. Panel members received the MOSST items, protocol, and conceptual framework in advance and participated in an online content review meeting with the researcher and supervisory team. Using a four-point Likert scale (1 = not relevant; 4 = highly relevant), experts independently rated the relevance of each item to its intended construct, consistent with established procedures for content validity assessment using the Content Validity Index (CVI) (Lynn, 1986; Polit & Beck, 2006). Qualitative comments were also collected to capture suggestions for refining wording, scoring thresholds, and conceptual coverage. These discussions resulted in several important modifications, including refinement of the functional dentition domain and the adoption of Functional Tooth Units to align MOSST with established epidemiological indicators.

The second stage of content validation was undertaken with a PPI panel of seven adults with intellectual disabilities. The researcher prepared an accessible, easy-read version of MOSST using simplified phrasing, pictorial representations, and tactile demonstration materials (e.g., toothbrushes, disposable mirrors). In a facilitated session, panel members reviewed the purpose and acceptability of each item, confirming whether it should be included via a show of hands and group discussion. Feedback focused on whether the indicators were meaningful from the perspective of everyday oral health experience and whether the procedures would feel comfortable and respectful. The panel affirmed the relevance of items relating to mouth pain, gum discomfort and denture use and recommended communication strategies that were subsequently integrated into assessor

instructions, including simplified language, pacing adjustments and supportive demonstration of the assessment sequence.

Together, the expert and PPI processes ensured both clinical validity and face validity, embedding disability-inclusive principles into the design of MOSST. These procedures strengthened the conceptual underpinnings of the tool in advance of field deployment and contributed directly to the feasibility, acceptability and psychometric findings reported in Chapter 4.

3.6.2 IDS-TILDA interview data collection

Structured interview data for IDS-TILDA Wave 5 (2022–2023) were collected through two complementary components: a Computer-Assisted Personal Interview (CAPI) and a Pre-Interview Questionnaire (PIQ). Together, these instruments captured demographic, health, lifestyle, social, and functional information for adults aged ≥ 40 years with intellectual disabilities living in Ireland. Interviews were conducted in participants' homes or day services by trained field researchers, including the author this thesis.

3.6.2.1 Computer-Assisted Personal Interview (CAPI)

The CAPI is a face-to-face structured interview administered electronically using encrypted laptops. Interviews typically lasted 60–90 minutes and could be divided across two sittings to minimise fatigue. Depending on communication ability, interviews were conducted as self-report, supported self-report or proxy report. Proxy respondents (family members, keyworkers or paid carers) were eligible if they had known the participant for at least six months and followed a structured protocol designed to minimise subjective interpretation.

Interview content was based on validated instruments adapted from major ageing studies, including TILDA and the English Longitudinal Study on Ageing (ELSA), supplemented with items specifically developed for the Irish intellectual disability population. Domains covered included sociodemographic characteristics, communication ability, oral and nutritional health, cardiovascular disease, mobility and falls, sensory function, pain, continence, cognition, behavioural and mental health, lifestyle behaviours, and Activities of Daily Living (ADLs/IADLs). Variables

relating to oral hygiene support and access were particularly relevant to this thesis and are operationalised in Section 3.6.

Data were entered directly into encrypted laptops, uploaded daily to secure Trinity College Dublin servers, and monitored centrally for completeness and protocol adherence. The researcher completed 25 CAPI interviews during Wave 5, contributing directly to primary data collection and gaining practical insight into the contextual factors influencing participant responses and proxy reporting.

3.6.2.2 Pre-Interview Questionnaire (PIQ)

Approximately one week prior to the CAPI, participants received a PIQ to complete independently, with support, or by proxy. The PIQ collected detailed clinical information that would be impractical to obtain during an interview of limited duration. Items included medical diagnoses (epilepsy, chronic lung disease, arthritis, Parkinson's disease), mental health conditions, female and male health, sensory impairment, medication use, healthcare utilisation, and medical screening history. Completed PIQs were returned to the field researcher at the time of interview or by post. The integration of the PIQ reduced interview burden and ensured that clinically relevant information was captured consistently across communication abilities.

3.6.2.3 Field Researcher Training and Quality Assurance

Field researchers underwent a compulsory three-day training programme prior to Wave 5 data collection. Training encompassed study background, ethical procedures, supported communication, confidentiality and data protection, safeguarding participant well-being during interviews, protocols for proxy involvement, and practical CAPI administration. Training included scenario-based practice, guided use of encrypted laptops, and live assessment of interviewer competency. Consistent with the study's inclusive ethos, two adults with intellectual disabilities participated in the training delivery to provide direct feedback to researchers on communication style and interviewing approach.

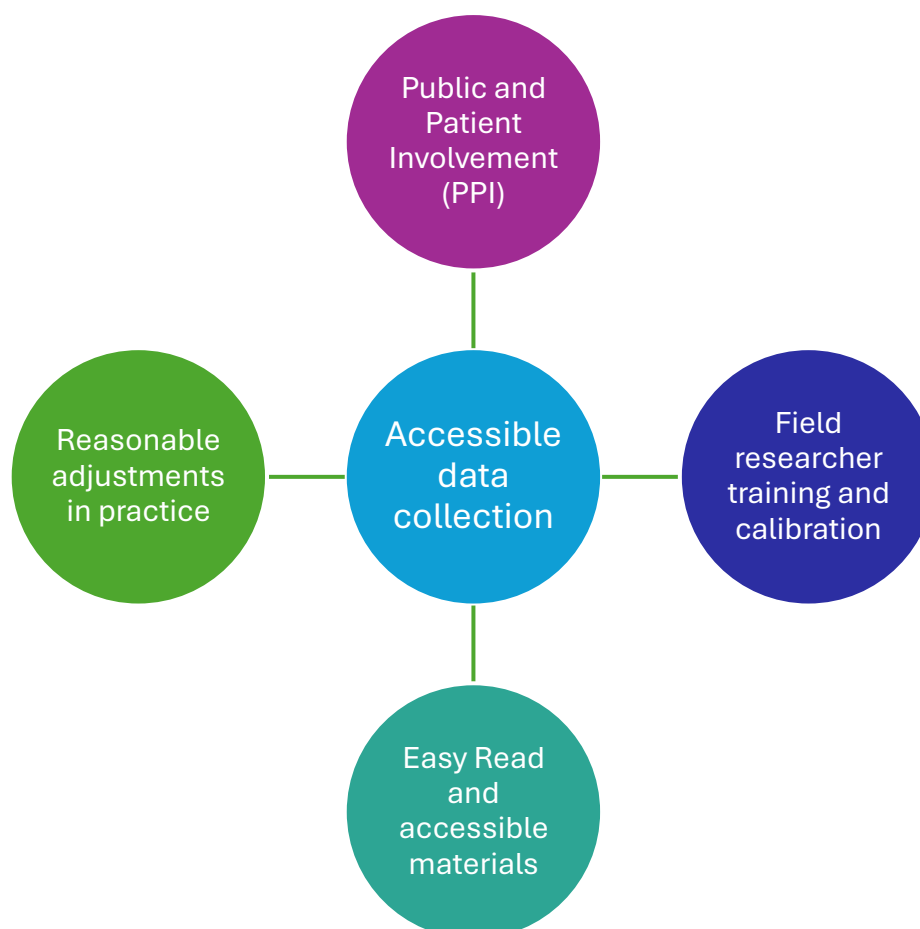
Following training, all interviewers signed a research conduct agreement indicating their commitment to confidentiality, participant dignity, rigorous adherence to protocol, and secure handling of study materials. Field researchers received a

caseload based on geographical feasibility, previous experience, and participant needs.

3.6.3 Reasonable Adjustments and Accessible Communication Procedures

Across all strands of the thesis, study procedures were designed to be not only methodologically robust but also accessible to older adults with intellectual disabilities. In keeping with the ethical orientation of IDS-TILDA and the disability rights framework underpinning this thesis, reasonable adjustments and accessible communication supports were embedded as core methodological features rather than optional accommodations. These supports enabled informed participation, optimised data quality, and countered the historical exclusion of people with intellectual disabilities from oral health epidemiology.

Figure 3.5 illustrates the integrated framework of accessible data collection



Accessible information materials were central to facilitating participation. For both the MOSST and the IDS-TILDA interviews, standard and easy-read invitation packs were co-designed with the IDS-TILDA PPI panel and included simplified language, pictorial explanations of procedures, and guidance for supporters. The MOSST easy-read materials additionally incorporated photographs from the clinical image repository developed during MOSST training ensuring consistency between assessor calibration and participant-facing information. These materials were distributed through gatekeepers (family, keyworkers, and service providers) alongside standard consent documents, allowing time for supported discussion ahead of appointments.

During data collection, accessible communication strategies were implemented as routine practice. MOSST assessors employed a “show-and-explain” method, demonstrating disposable mirrors, torches, gloves, and the assessment sequence before beginning the oral examination. CAPI interviews similarly incorporated plain language, repetition, pacing adjustments, paraphrasing, and the use of closed questioning or pictorial supports to facilitate comprehension. Breaks were offered proactively to minimise fatigue or sensory overload, and participants were reminded throughout of their right to pause, decline questions, or stop entirely. Supported communication was extended to assent monitoring: observable willingness (Participants opening their mouths) was interpreted as assent, while verbal refusal, behavioural distress, or withdrawal led to immediate discontinuation.

Reasonable adjustments were also embedded at the design level most notably, repeat intra-rater MOSST assessments were completed on the same day rather than requiring a return visit. This approach reduced logistical burden and anxiety associated with repeat appointments while still adhering to the principle of test stability. Supporters were welcomed at all assessments and interviews to assist with communication and recall, yet their role remained advisory rather than interpretive, consistent with structured proxy protocols in IDS-TILDA.

These procedures ensured that accessibility was treated as a scientific necessity, not a compensatory add-on. By embedding adjustments at structural, procedural, and interpersonal levels, data collection upheld autonomy, protected participant

dignity, and generated high-quality, ecologically valid data from individuals who have been routinely excluded from oral health research. In this way, accessible methodology was both an ethical stance and a methodological contribution of this thesis.

The integration of reasonable adjustments into data collection therefore reflects not only ethical best practice but also the philosophical foundations of the research. Within a pragmatist paradigm, methods are judged by the consequences they produce; here, accessibility was essential to generating valid and actionable data capable of improving oral health outcomes for people with intellectual disabilities. At the same time, the use of inclusive communication, PPI co-design, and disability-specific calibration materials embodies a transformative commitment to equitable participation, resisting what Fricker (2007) describes as epistemic injustice in health research. Finally, recognising that oral health outcomes in intellectual disabilities arise from structural, clinical, and communicative mechanisms aligns with a critical realist orientation, which situates measurement within real-world contexts of support needs and social exclusion. These methodological decisions underpinning data collection were not merely technical choices but philosophical commitments, ensuring that rigour was achieved through inclusion rather than despite it. This alignment of practice and paradigm is returned to in the Discussion.

3.6.3.1 Researcher Reflexivity Statement

The researcher dual role as a RNID and researcher influenced both the development of the MOSST and the flow of the MOSST data collection within IDS-TILDA. Clinical experience informed the design of reasonable adjustments, assent monitoring, and sensory accommodations during oral assessments, particularly where unfamiliar procedures could cause anxiety or distress. These decisions were methodological as well as ethical, as inclusive procedures were essential to obtaining valid data from a population frequently excluded from clinical research.

As the gold-standard MOSST assessor, the researcher contributed to training and calibration of research nurses and developed materials to support standardised scoring, including a clinical photographic repository. This proximity to tool development introduced potential risks of observer bias, which were mitigated

through independent expert review, formal reliability testing, structured protocols, and separation of data management from calibration activities within the IDS-TILDA research team.

During fieldwork, prior experience working with adults with intellectual disabilities facilitated communication and rapport, while requiring ongoing attention to professional authority and power dynamics. Supporters were encouraged to assist communication but not to respond on behalf of participants unless proxy procedures applied, and assent was prioritised alongside formal consent.

Reflexivity was therefore operationalised as a component of methodological rigour. Strategies such as co-produced materials, independent oversight, and standardised procedures ensured that clinical expertise enhanced feasibility and data quality without compromising objectivity. The researcher's professional background was thus both a resource and a responsibility in producing robust evidence with, rather than about, people with intellectual disabilities.

3.7 Measures and Variables

A range of quantitative measures were used across the three methodological strands of this thesis. These included the observational and psychometric indicators generated through MOSST; and survey variables drawn from IDS-TILDA, including mortality linkage. The selection and operationalisation of variables were closely aligned with the overall aims of the thesis and guided by established epidemiological, clinical and psychometric criteria. All variables were harmonised into coded datasets through a rigorous cleaning process, ensuring fitness for analysis and comparability across sources.

3.7.1 MOSST Variables

The MOSST provided seven observable clinical indicators capturing key dimensions of oral function, oral disease, oral hygiene, and pain. These indicators were scored by trained research nurses during Wave 5 health fair assessments and were subsequently used to generate both single-item and derived oral health variables for epidemiological analysis. Table 3.2 summarises the operational definitions and coding structure for each indicator (see also Figure X for assessment pathways)

Table 3.5. MOSST Wave 5 Indicators and Operational Definitions

MOSST Indicator	Operational Definition (from the MOSST protocol V0.1)	Coding Approach
Tooth Count	The number of teeth visible in the upper / lower arch	Continuous count; derived categorical groupings (edentulous; 1–10 teeth; 11–19 teeth; ≥20 teeth)
Denture use	A removable denture is present inside the mouth immediately before / at data collection	Binary (yes/no) and categorical (full/partial; upper/lower)
Pairs are Pre Molars	Number of occluding pairs of natural teeth and/or prosthetic units	Continuous count
Occlusal Pairs	Distribution of <u>opposing</u> teeth in contact when biting	
Cavitated teeth	Observable lesion extending into dentine	Binary (present/absent) and ordinal categories (none; 1–2; ≥3)
Gum health	Visual status of gingivae	Healthy vs. unhealthy
Oral cleanliness	Visible plaque, calculus, or debris	Clean vs. unclean
Oral pain	Self- or proxy-reported pain in the past 7 days	Present vs. absent

Derived variables were created to enable population-level modelling. Functional dentition was operationalised using accepted epidemiological criteria requiring: (i) at least 20 natural teeth; (ii) retention of the anterior 12 teeth; and (iii) at least three occluding premolar pairs (Nguyen et al., 2011). Tooth count categories were applied to support comparative descriptive analyses, underpin regression models, and align MOSST outputs with existing epidemiological literature on oral function and chewing efficiency. A binary variable was also generated for untreated cavitated lesions to facilitate multivariable modelling. These MOSST-derived

variables served as key clinical oral health outcomes in Chapter 5, which examines cross-sectional oral status, and in Chapter 6, where their associations with systemic health conditions are evaluated.

3.7.3 IDS-TILDA Variables

IDS-TILDA provided survey-based and clinical variables across five waves (2009–2022), enabling both cross-sectional and longitudinal epidemiological analyses. Variable selection was guided by conceptual models linking oral health to systemic health and mortality among adults with intellectual disabilities. Variables were categorised as sociodemographic, oral health, systemic health, and mortality outcomes.

3.7.3.1 Demographic Measures

The Sociodemographic variables used in this thesis included age, gender, level of intellectual disabilities and living arrangement type. These variables acted as covariates in regression and survival models. Living arrangement categories reflected levels of formal support (independent/family living, group home, residential/campus-based). Interview source was retained to flag proxy reports, enabling sensitivity analyses.

3.7.3.2 Oral Health Measures and Derived Variables

Oral health measures comprised both MOSST clinical indicators and self/proxy-reported dental variables obtained via CAPI and PIQ. Self-reported measures included dental service use, timing of last dental visit and perceived oral health status. MOSST-derived indicators provided objective measures of dentition, functional capacity and clinical disease, complementing subjective measures and proxy reports. Chapter 6 combines both to examine associations with systemic health.

3.7.3.3 Systemic Health Measures

Systemic health variables were selected based on plausible biological pathways linking oral disease with chronic health conditions. Measures included osteoporosis, constipation, pneumonia, stroke, hypertension, diabetes and multimorbidity. These variables originated primarily from interview data supplemented by clinical records during health fair when available. Pneumonia

was harmonised into a derived variable using multiple sources (CAPI, PIQ, clinical health record flags).

3.7.3.4 Mortality Outcomes

Mortality analyses in Chapter 7 utilised linked death certificate data from the General Register Office of Ireland. All-cause mortality served as the primary outcome, while respiratory-related mortality (ICD-10 J00–J99) was a secondary outcome given its relevance to oral–respiratory pathways among adults with intellectual disabilities. Time-to-event data were derived from baseline interview date to date of death or censoring at 13 years.

Table 3.6. IDS-TILDA Variables Used in Thesis Analyses

Domain	Variables	Coding/Notes
Demographic	Age, gender, level of intellectual disabilities, living arrangement,	Categorical
Oral health	Dentition status, tooth count groups, functional dentition, Presence of cavitated teeth, gum health, oral pain, status (teeth, edentulous with dentures and edentulous)	Derived and observed measures
Systemic health	Osteoporosis, constipation, pneumonia, stroke, hypertension, diabetes, multimorbidity	Binary
Mortality	All-cause mortality; respiratory mortality	ICD-10 coded; time-to-event

3.7.3.5 Considerations for Censoring and Covariate Use

Survival time was censored at 13 years or 31 March 2023. Covariates were selected based on established confounding pathways linking oral health, disability severity, health access, and mortality risk. Pneumonia history was retained due to its recognised role as both a mediator and independent risk factor for mortality among adults with intellectual disabilities.

3.8 Data Management

Data management procedures were designed to ensure methodological rigour, reproducibility, traceability and compliance with institutional governance standards. As this thesis draws on two distinct data sources — (i) primary

psychometric data generated through MOSST development and validation, and (ii) secondary analysis of IDS-TILDA survey and longitudinal datasets — tailored procedures were implemented for data capture, cleaning, storage and quality assurance across each strand.

3.8.1 MOSST Data Capture, Cleaning and Quality Assurance

MOSST data were collected electronically at point of assessment using encrypted iPads operating a secure Qualtrics platform. Automated skip logic and completeness check reduced entry error and supported real-time monitoring during fieldwork. Following completion of Wave 5 health fair (November 2022–June 2023), datasets were exported from Qualtrics and stored exclusively on the encrypted Trinity College Dublin (TCD) J-Drive within the secure IDS-TILDA directory. Access is restricted to authorised personnel via institutional authentication.

The researcher undertook structured data cleaning and quality assurance procedures for all MOSST datasets. These included range checks, verification of skip-pattern integrity, cross-variable consistency checks and identification of implausible values (e.g., anatomically impossible tooth counts). Random record audits were conducted to confirm data accuracy, and any discrepancies were resolved through reference to original electronic entries and supervisory consultation where required.

Inter-rater and intra-rater reliability datasets were cleaned and archived separately from the main dataset. Master files were preserved in read-only format, and derived analytic datasets were created independently to maintain version control. Statistical syntax files were retained to ensure full reproducibility of all analyses.

3.8.2 IDS-TILDA Data Governance, Cleaning and Mortality Linkage

Survey (CAPI and PIQ), health fair and longitudinal IDS-TILDA datasets were subject to established centralised governance and cleaning procedures prior to release for analysis. The IDS-TILDA data management team performed comprehensive plausibility checks, protocol-aligned skip verification and longitudinal consistency checks across waves for invariant participant characteristics.

Mortality linkage introduced at Wave 5 was undertaken centrally by the IDS-TILDA team using pseudonymised participant identifiers to match records with the Irish National Mortality Register. Only de-identified variables, including date of death and ICD-10 coded cause-of-death data, were released to the researcher under formal data-sharing agreements.

3.8.3 Data Security, Access and Confidentiality

All data management procedures adhered to GDPR (2018), Irish data protection legislation and Trinity College Dublin Research Data Management Policy. The researcher accessed only fully anonymised datasets. Personally identifiable information and master identifiers remain segregated within the IDS-TILDA secure infrastructure and are accessible only to authorised personnel.

All datasets were stored on encrypted institutional servers with restricted access and audit controls. No identifiable data were downloaded to personal devices or external media. Dissemination of findings is limited to aggregated outputs to prevent individual re-identification.

3.9 Data Analysis

3.9.1 MOSST Validation and Psychometric Testing

Data generated from MOSST field implementation were analysed to establish its psychometric properties, including content validity, reliability, feasibility, and acceptability. All analyses were conducted using IBM SPSS Statistics (v.26) and MedCalc, following recognised methodological criteria for health measurement tools.

3.9.1.1 MOSST Content validity

Content validity was examined using the Item-level Content Validity Index (iCVI). Seven international oral health experts independently rated the relevance of each MOSST item to its intended construct using a four-point scale (1 = not relevant to 4 = highly relevant), consistent with established CVI methodology (Lynn, 1986; Polit & Beck, 2006). This approach represents a refinement of earlier quantitative

methods for assessing content validity, such as Lawshe's Content Validity Ratio (CVR), which focused on essentiality of items (Lawshe, 1975).

The iCVI was calculated by dividing the number of experts rating an item as either "quite relevant" or "highly relevant" by the total number of raters. An iCVI ≥ 0.78 was interpreted as acceptable for panels of six or more experts, in accordance with recommended thresholds (Polit & Beck, 2006; Polit et al., 2007). Qualitative comments from the expert review were analysed alongside numerical ratings to refine item wording, scoring thresholds, and conceptual coverage.

In parallel, feedback from the Public and Patient Involvement (PPI) panel was analysed descriptively to evaluate face validity, accessibility of item wording, and alignment with lived experience of oral health among adults with intellectual disabilities. Integrating expert judgement with experiential input strengthened the conceptual relevance, acceptability, and inclusiveness of the instrument. Collectively, these processes enabled MOSST validation to incorporate both clinical expertise and user perspectives, supporting robust content validity for use in disability-inclusive epidemiological research.

3.9.1.2 MOSST Reliability Testing

The inter-rater and intra-rater analyses embedded directly within Wave 5 health fair fieldwork agreement between assessors was calculated using Cohen's kappa coefficients, applying quadratic weighting where appropriate. For categorical indicators. For continuous counts, including tooth presence and Functional Tooth Units, intraclass correlation coefficients (ICC) were computed using a two-way mixed-effects model. Thresholds for interpretation were applied consistently, with coefficients ≥ 0.80 indicating very strong agreement.

3.9.1.3 MOSST Feasibility and Acceptability

The analysis of the feasibility and acceptability evaluated descriptively using a combination of quantitative indicators and qualitative reflections. Feasibility metrics included administration time, completion rates, and reasons for partial completion where applicable. Acceptability data were drawn from participant feedback obtained during health fair sessions and from research nurse field notes documenting usability, communication demands, and sensory or behavioural

challenges. Cost estimation incorporated consumables, labour, and training requirements, providing an approximate per-participant cost and informing future implementation or epidemiological screening initiatives. Together, these analyses demonstrate the practicality, inclusiveness, and measurement accuracy of MOSST as a clinical epidemiological tool suitable for large-scale use with adults with intellectual disabilities. Full psychometric results, including item-level iCVI indices, kappa and ICC coefficients, feasibility outcomes, and qualitative acceptability summaries, are presented in Chapter 4, where implications for oral health surveillance and research are discussed in detail.

3.9.1.4 DS-TILDA Analyses: Oral Health, Systemic Health, and Mortality

Analyses of IDS-TILDA data (Wave 5 and longitudinal Waves 1–5) were undertaken to describe the distribution of MOSST-derived oral health indicators and to investigate their relationships with systemic health and mortality. All analyses were conducted using IBM SPSS (Versions 25–27). Statistical significance was retained at $p < 0.05$; however, interpretation was informed not only by p-values, but also by effect size, clinical plausibility and the theoretical justification for associations. Analytic choices were therefore guided by the operationalisation of variables described in Section 3.6.3 and by underlying paradigmatic commitments to pragmatic utility and critical realist inference.

3.9.1.5 Cross-sectional Oral Health Analyses (Chapter 5)

Chapter 5 provided the first national objective profile of oral health in older adults with intellectual disabilities using MOSST indicators embedded in IDS-TILDA. Analyses began with descriptive epidemiology, characterising the distribution of dentition status, functional dentition, denture use, occlusal contacts, occluding premolar pairs, anterior tooth retention, cavitated lesions, gum condition, oral cleanliness and oral pain. Categorical outcomes were summarised using frequencies and proportions, while continuous measures, notably tooth count and Functional Tooth Units, were described using means and standard deviations.

Patterns of oral health were examined across demographic and disability-related characteristics, including age, gender, level of intellectual disabilities and residential setting. Group differences were tested using chi-square statistics for

categorical outcomes. These analyses were followed by regression modelling to identify predictors of key oral health outcomes. Binary logistic, multinomial, and ordinal logistic models were applied depending on outcome structure, for example modelling edentulism, functional dentition and oral disease indicators.

3.9.1.6 Systemic Health Analyses (Chapter 6)

Chapter 6 examined the relationship between MOSST clinical indicators and chronic health conditions commonly experienced in ageing with intellectual disabilities, including constipation, osteoporosis, pneumonia, hypertension, diabetes and multimorbidity. Associations were estimated using multivariable logistic regression, with adjusted odds ratios reflecting the independent contribution of oral health indicators to systemic outcomes. All models were adjusted for age, gender, level of intellectual disabilities and residential setting to take account of relevant demographic and contextual determinants of systemic health.

3.9.1.7 Mortality Analyses (Chapter 7)

Chapter 7 investigated the association between dentition status and mortality over a follow-up period of up to 13 years. Survival probabilities were examined using Kaplan–Meier curves, and group comparisons were tested with log-rank statistics to determine whether mortality differed across dentition categories. These descriptive survival analyses were followed by Cox proportional hazards regression to estimate the extent to which edentulism predicted both all-cause and respiratory-related mortality (respiratory deaths defined as ICD-10 Codes J00–J99). Cox models were specified sequentially: initial models adjusted for demographic characteristics (age and gender), followed by disability-related variables (level of intellectual disabilities and residential setting), and finally clinical adjustment incorporating prior history of pneumonia. This modelling structure reflected both clinical reasoning and a critical realist understanding of oral health as a potential causal pathway mediated by systemic and contextual determinants (Section 3.2.1). Proportional hazards assumptions were checked using Schoenfeld residuals and log-minus-log plots, while sensitivity analyses were performed to test model stability under alternative dentition definitions and to examine the influence of proxy-derived data.

3.9.1.8 Multicollinearity and Missing Data

Multicollinearity was systematically evaluated across all regression models using Variance Inflation Factors (VIFs) and tolerance statistics, consistent with recommended procedures for assessing redundancy among predictors in multivariable analyses (Midi et al., 2010; Field, 2018). Particular attention was given to oral health variables representing closely related structural and functional constructs, including dentition status, functional dentition, and functional tooth units. Where VIFs indicated conceptual or statistical dependency, these variables were not entered simultaneously into the same model to avoid unstable parameter estimates and inflated standard errors (Dormann et al., 2013). Instead, composite indicators capturing clinically meaningful oral function were prioritised, reflecting guidance that functionally interpretable measures often provide more robust and policy-relevant estimates than highly correlated structural indicators (Harrell, 2015). Sensitivity analyses using alternative model specifications confirmed that the direction and magnitude of associations were stable across modelling strategies.

Missing data were examined to determine both the extent and pattern of missingness across key variables. Overall levels of missingness were low and showed no evidence of systematic bias across major demographic or health characteristics. In such circumstances, complete case analysis is considered appropriate and unlikely to introduce substantial bias (Little & Rubin, 2019; Sterne et al., 2009). Nevertheless, to assess the robustness of findings under alternative assumptions, sensitivity analyses using multiple imputation were conducted. Imputed analyses produced substantively similar results to complete case models, indicating that conclusions were not dependent on missing data assumptions and supporting the stability of the reported estimates.

3.10 Strengths and Methodological Considerations

The multi-strand design of this thesis represents a deliberate methodological choice to generate robust, inclusive, and consequential oral health evidence for older adults with intellectual disabilities. Rather than treating research constraints

as methodological deficits, this thesis acknowledges that decisions about measurement are inherently ethical and epistemological. The design was therefore shaped by a pragmatist commitment to methods that produce useful and actionable knowledge, a transformative intention to challenge historical exclusion, and a critical realist recognition that oral health outcomes are shaped by real-world mechanisms embedded in clinical, behavioural and social contexts.

Central to the originality of this work was the development and validation of the MOSST. Embedding MOSST in IDS-TILDA enabled structured clinical oral health data to be linked with systemic and mortality outcomes in a population that has been invisible in oral epidemiology. The rigour of MOSST assessor preparation further strengthens the methodological contribution. The creation of a disability-specific clinical image repository and the use of PPI in material design grounded calibration and accessible communication in lived experience, reducing methodological ableism and enhancing ecological validity.

Traditionalist normative perspectives might view non-invasive assessment using a disposable mirror and torch as a limitation due to reduced diagnostic precision. However, within a pragmatist and transformative research frame, such design choices are not methodological compromises but necessary adaptations that unlock inclusion and participation. Invasive periodontal probing, radiographs or multiple visits may produce clinically richer data, yet would systematically exclude those most affected by oral health inequity due to anxiety, sensory needs, communication barriers, or behavioural differences. The MOSST therefore prioritises feasible, acceptable, and repeatable epidemiological assessment. This represents not a reduction in scientific quality, but a realignment of what constitutes valid evidence when inclusion is a precondition for truth. Similarly, proxy reporting within IDS-TILDA is often characterised as a potential limitation to data accuracy. Within this thesis, proxy use is viewed instead as a methodological mechanism that expands participation. Attrition and reliance on service-registered participants are also not treated as bias alone, but as reflections of structural realities in disability services and ageing. From a critical realist perspective, these contextual constraints are part of the causal environment shaping both participation and outcomes.

3.9 Conclusion

This chapter has outlined the methodological framework, data sources, procedures and analytic approaches used in this study. The methodological choices were shaped not only by questions of measurement, but also by questions of access, representation and feasibility. Integrating the MOSST within IDS-TILDA required an approach that balanced the need for clinically meaningful oral health data with the practical and ethical requirements of inclusive research involving adults with intellectual disabilities.

Rather than prioritising diagnostic detail at the expense of participation, the study adopted methods designed to support accessibility, standardisation and participant comfort. This approach reflects the philosophical grounding of the research, in which quantitative methods are understood as valuable when they generate evidence that is both robust and relevant to action. Within this framework, inclusion was treated not as an additional consideration, but as a condition for producing valid population-level evidence about oral health in older adults with intellectual disabilities.

The methodological approach outlined in this chapter provides the foundation for the empirical chapters that follow. Chapter 4 presents the development, refinement and psychometric evaluation of the MOSST. Chapter 5 then applies MOSST-derived indicators to describe oral health and oral function within IDS-TILDA, while Chapters 6 and 7 examine associations between oral health, systemic health and mortality.

Chapter 4: The Modified Oral Status Survey Tool: Development and Psychometrics for Accessible Oral Data Collection.

The Contents of this chapter are based on this publication:

ORIGINAL ARTICLE OPEN ACCESS

The Modified Oral Status Survey Tool: Development and Psychometrics for Accessible Oral Health Data Collection

Katrina Byrne^{1,2}  | Blánaid Daly³ | Philip McCaillon⁴  | Mary McCarron² | Caoimhin Mac Giolla Phadraig³ ¹School of Dental Science, Trinity College, University of Dublin, Dublin, Ireland | ²School of Nursing and Midwifery, Trinity College Dublin, University of Dublin, Dublin, Ireland | ³Dublin Dental University Hospital & School of Dental Science, Trinity College, University of Dublin, Dublin, Ireland | ⁴School of Social Work, Temple University, Philadelphia, Pennsylvania, USA

Correspondence: Katrina Byrne (kbyrne1@tcd.ie)

Received: 12 March 2025 | Revised: 6 December 2025 | Accepted: 23 December 2025

Keywords: feasibility | health equity | inclusive research | non- dental assessment tool | psychometric validation | reliability

ABSTRACT

Objectives: Understudied populations such as those with intellectual disabilities (ID) face significant disease burden and oral health disparities. Systematic exclusion from oral health research contributes to resultant health inequalities, limits understanding of the determinants and implications of disease, and hinders the ability to improve health through evidence-based policy and healthcare planning. This study reports the development of the Modified Oral Status Survey Tool (MOSST), an accessible, low burden oral health assessment tool designed for use with populations who require communication and cognitive supports. It explores the MOSST's key measurement attributes: conceptual coverage, content validity, reliability, feasibility, and cost.**Method:** The study followed an iterative tool development process. The MOSST was tested in two steps: (1) attribute testing of an interim version (MOSST v0.1) for inter and intra-rater reliability, burden, cost and feasibility; and (2) content validity testing of MOSST v1.0 using an expert and a Public and Patient Involvement (PPI) panel. Field testing involved data collection from Wave 5 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), with data from $n = 469$ participants undertaking a MOSST assessment.**Results:** Data from $n = 469$ adults with ID were analysed. The MOSST demonstrated very strong/strong inter- and intra-rater reliability for tooth count ($ICC = 0.999$), denture wear, occlusal pairs, and oral pain ($k = 0.808 - 1.00$). Content validity was confirmed through expert and PPI panel reviews; item-level Content Validity Indices (iCVI) ranging from 0.85 to 1.00 were gained from the expert panel responses to measure agreement. This review process led to refinements, including replacing items representing occlusal function with functional tooth units and relocating the subjective oral pain item. This led to a final MOSSTv1.0 tool and associated training, protocol and resources. The MOSST was acceptable: 98% ($n = 65$) reporting data collection process acceptable; 100% ($n = 66$) painless and 100% ($n = 66$) not time-consuming. The cost per assessment was low (approx. €6.69) due to low equipment and staff costs.**Conclusion:** The MOSST is a seven-item tool recording indicators of oral function and disease. It was shown to be reliable, valid, and feasible for use by non-dental assessors among people with ID. It is low cost, low burden, quick and feasible and offers potential for use among understudied communities.

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Community Dentistry and Oral Epidemiology, 2026; 0:1–10

<https://doi.org/10.1111/cdoe.70052>

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Chapter 4 Abstract

Introduction

People with intellectual disabilities experience substantial oral health inequalities but are frequently excluded from oral health research because existing assessment tools are inaccessible, burdensome, or inappropriate for individuals requiring communication or cognitive supports. The Modified Oral Status Survey Tool was

developed to address this gap by providing a brief, reliable, and feasible oral health assessment that can be used by non-dental assessors in both research and practice settings. This chapter outlines the development, testing, and validation of the MOSST and presents the evidence supporting its measurement properties.

Aims

The primary aim was to develop an accessible oral health assessment tool suitable for adults with intellectual disabilities. Secondary aims were to examine the tool's conceptual clarity, content validity, reliability, feasibility, and cost, and to refine the tool through expert and (PPI) feedback.

Methods

The study followed an iterative tool development process. Initial testing of the preliminary version (MOSST v0.1) evaluated inter- and intra-rater reliability, feasibility, burden, and cost. The revised MOSST v1.0 underwent content validity assessment through expert review and a PPI panel. Field testing was conducted during Wave 5 of IDS-TILDA, where 469 adults with intellectual disabilities completed MOSST assessments delivered by trained assessors.

Results

The MOSST demonstrated strong reliability across multiple indicators including tooth count, denture wear, occlusal pairs, and oral pain. Content validity indices from expert review ranged from 0.85 to 1.00, and refinement decisions were guided by expert and PPI feedback. The tool was highly acceptable to participants, rated as painless, quick, and not burdensome. Cost analysis confirmed the MOSST to be low cost, requiring minimal equipment and training.

Conclusion

The MOSST emerged as a reliable, valid, feasible, and accessible oral health assessment tool that captures seven essential indicators of oral function and disease. Its low burden and suitability for use by non-dental assessors position it as an important innovation for improving the inclusion of adults with intellectual disabilities in oral health research and routine health assessment. This chapter

provides the foundation for its further application and evaluation within the context of this thesis.

4.1 Introduction

Adults with intellectual disabilities, experience some of the most profound health inequalities of any population group. Their oral health status remains particularly poorly documented within existing research and surveillance systems, leaving major gaps in understanding and service planning (O’Leary et al. 2018; World Health Organization 2022; Faulks 2023).

Despite advances in disability policy, healthcare, and community support, adults with intellectual disabilities continue to experience excess multimorbidity, unmet healthcare needs, and premature mortality compared with the general population (Hosking et al. 2016; O’Leary et al. 2018). Exclusion from health research further compounds these disparities. Individuals with intellectual disabilities are commonly omitted from population surveys and clinical studies due to restrictive consent processes, inaccessible study procedures, and assumptions about feasibility.

Barriers to inclusion in health research are mirrored in oral health research and surveillance. Adults with intellectual disabilities experience higher levels of untreated oral disease and lower access to preventive oral healthcare than non-disabled peers (Anders and Davis 2010; World Health Organization 2024; Ward et al. 2019). There is therefore a clear need for robust, quantifiable data that capture the true burden of disease and inform policy and intervention design (Faulks 2023). Oral epidemiology traditionally relies on indices such as the Decayed, Missing and Filled Teeth index and the Community Periodontal Index. While these measures are suitable for general population surveys, they require procedures such as periodontal probing, plaque disclosure, and air-drying for early caries detection that many adults with intellectual disabilities cannot tolerate. This reduces feasibility and introduces selection bias when individuals who cannot cooperate are excluded (Bird et al. 2024; Morgan et al. 2012; Wilson et al. 2019). At the level of survey design, national surveillance protocols have historically excluded individuals who are unable to consent, communicate, or cooperate with examination procedures, thereby further eroding representativeness (Steele et al. 2012; Whelton et al. 2007).

Even when inclusion is attempted, methodological inaccessibility frequently limits participation. Bird et al. (2024) demonstrated lower completion rates among people with intellectual disabilities when traditional oral health indices were used. Standard tools and questionnaires therefore risk producing systematically incomplete datasets, reinforcing the healthy-user bias identified across health research and obscuring the true extent of oral health inequalities in this population (Bird et al. 2024; Ellershaw et al. 2020; Faulks 2023; World Health Organization 2024; Whelton et al. 2007).

Closing these gaps requires the adoption of reasonable adjustments in oral health research. This involves modifying methods and protocols so that participation is possible on an equal basis with others. In surveillance contexts, reasonable adjustments include adapted assessment tools, accessible procedures, and training of non-dental personnel to conduct oral health assessments. In response to these needs, this research team developed the Oral Status Survey Tool, an assessment instrument specifically designed for use with adults with intellectual disabilities and suitable for administration by non-dental professionals (Mac Giolla Phadraig et al. 2021). The Oral Status Survey Tool comprised nine items that captured oral function and oral condition through structured assessment of denture wear, tooth count, occlusal contact, anterior tooth presence, gingival condition, caries, oral cleanliness, and oral pain. Although its development was robust and its attributes compared favourably to other non-dentist administered oral assessment tools (Mac Giolla Phadraig et al. 2021), its application identified opportunities for refinement. Challenges included difficulties interpreting certain item definitions, particularly those relating to occlusal function, limitations in accessibility for assessors without dental backgrounds, and a need for clearer operationalisation when assessing individuals requiring communication supports.

To address these limitations, the Oral Status Survey Tool was enhanced to create the MOSST. The MOSST retains the core structure of the original instrument while introducing significant changes that improve conceptual clarity, usability, and relevance. Critically, the MOSST represents a reasonable-adjustment instrument for oral health research, enabling more inclusive participation and supporting the generation of high-quality oral health data for adults with intellectual disabilities.

4.1.1 Aim, Research Questions and Objectives

The aim of this study was to develop and evaluate the MOSST for use with adults with intellectual disabilities in large-scale epidemiological research.

This aim was addressed through the following research questions:

1. What is the conceptual coverage and content validity of the MOSST tool?
2. What is the reliability, feasibility, and implementation characteristics of MOSST when administered by trained non-dental assessors to adults with intellectual disabilities?

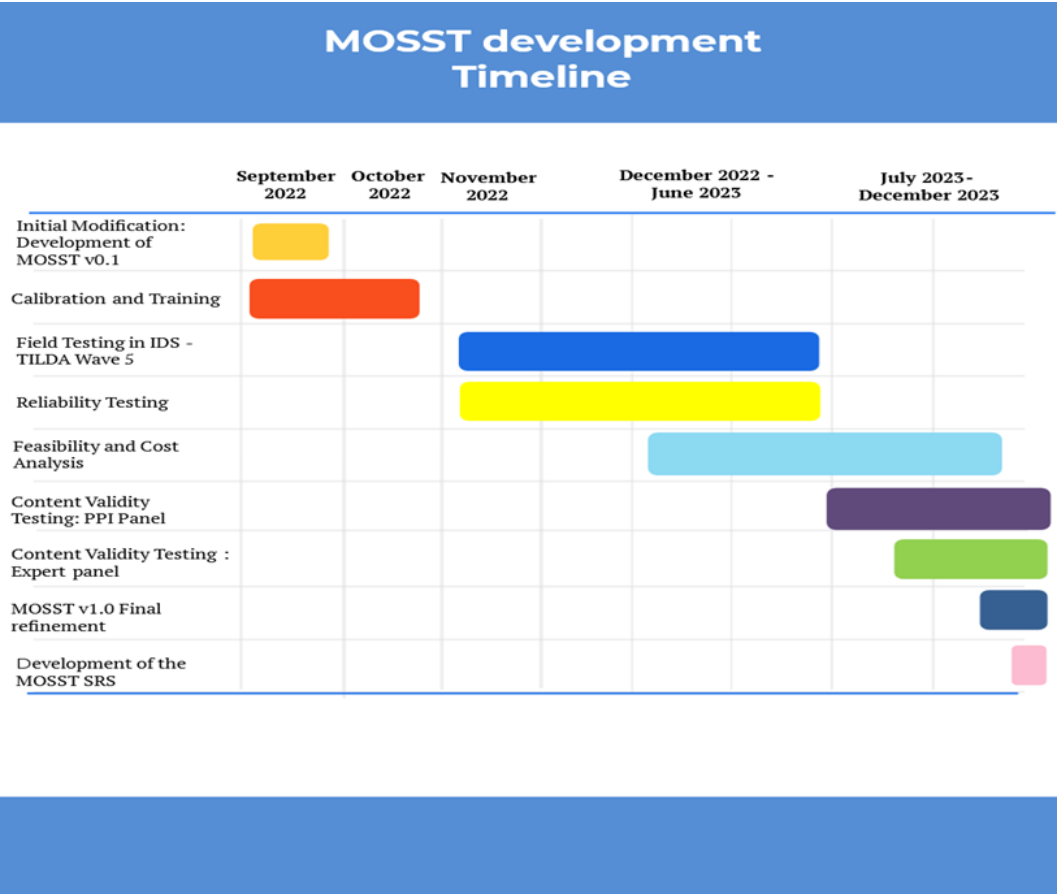
To address these questions, the study pursued the following objectives:

1. To establish content validity through structured expert review and Public and Patient Involvement (PPI) consultation.
2. To evaluate inter-rater and intra-rater reliability using standardised psychometric procedures.
3. To assess feasibility, participant burden, and acceptability during field implementation within IDS-TILDA Wave 5.
4. To estimate implementation cost and operational requirements for use in population-level health surveillance.

4.2 Methods:

This is a tool development and validation study reporting the modification of the OSST tool into the MOSST v1.0 including testing attributes such as reliability, burden, cost, time and feasibility. The inclusiveness and content validity of the MOSST v1.0 was assured by including perspectives of people with intellectual disabilities and using an expert panel to generate item content validity indices. This development process followed a sequential, multi-phase process from mid-2022 to the end of 2023. Key phases included item refinement, training and calibration, field testing, reliability and feasibility assessment, and content validation as outlined in Figure 4.1.

Figure 4.1. MOSST development timeline. Reproduced from Byrne et al. (2026) under CC BY licence.



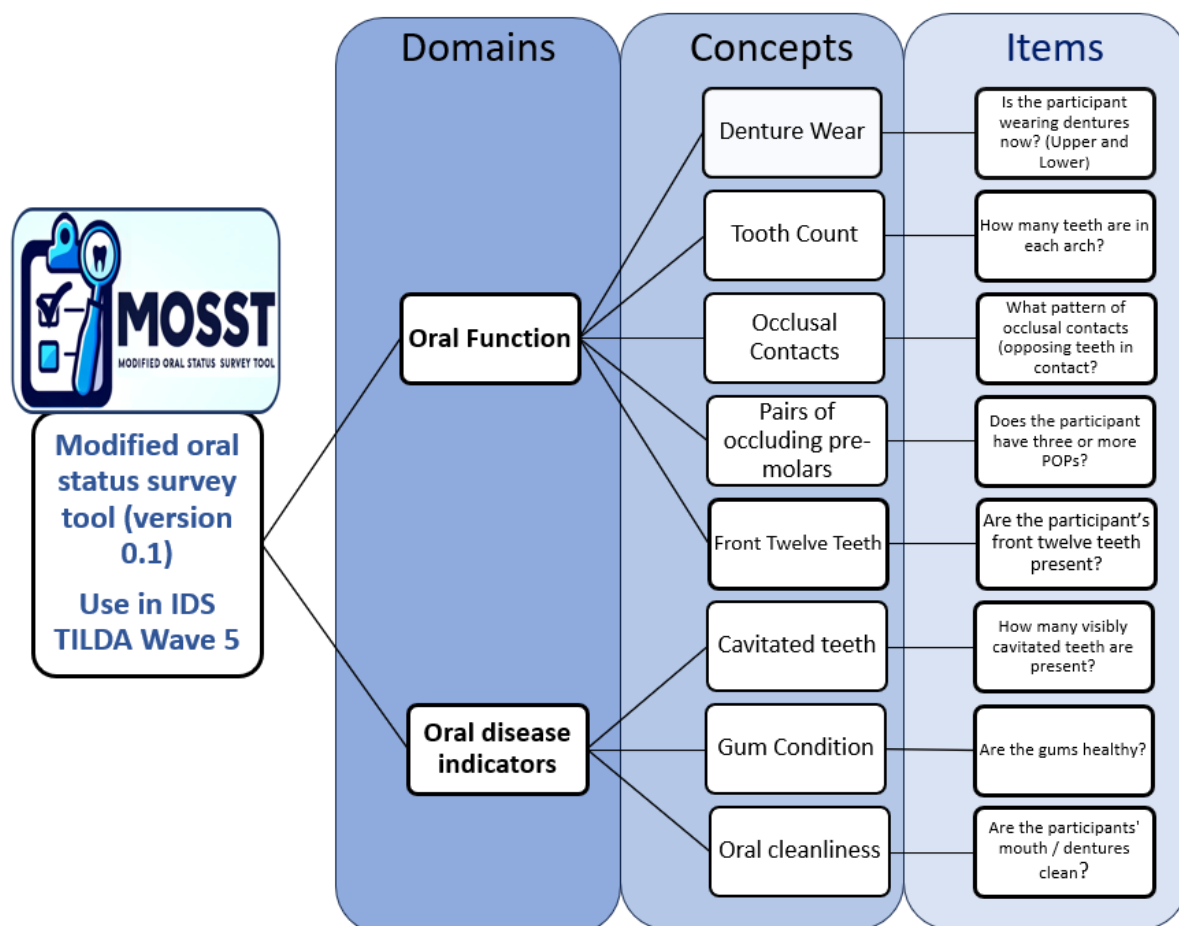
4.2.1 Development and Field Testing:

4.2.1.1 Initial Development

The OSST demonstrated robust initial development, fair to very good inter-rater reliability, moderate to very good intra-rater reliability, excellent content validity, and, good to excellent convergent validity. Specifically, the intraclass correlation coefficient (ICC) for tooth count was 0.99, Gwet's AC2 for carious teeth (as correlate DMFT scores) was 0.94, and Gwet's AC1 for gum condition (as correlated to Community Periodontal Index) was 0.84. The tool’s strength laid in its minimal equipment need and its speed, making it low-cost and feasible for use without a scribe with trained non-dentists. In initial testing there was high acceptability and low burden for people with intellectual disabilities (Mac Giolla Phadraig et al., 2021).

However, further improvements were needed in the areas, specifically gum health. Although agreement for the observational gum-health item was 0.67 and acceptable and the non-dental assessors reported operational ambiguity, accordingly, in MOSST the item was redesigned as a visual gingival-inflammation check with simplified criteria. As well to enhance its performance across all items and intelligibility for non-dental assessors with modifications at the survey, item and response category levels (further detail available in Appendix file 4.2). These modifications were completed as part of the initial development of the MOSST (v0.1) which consisted of eight observational items designed for use by non-dental assessors. These items evaluated key indicators of oral health, including tooth presence, denture use, cavitated teeth, oral cleanliness, gum condition, occlusal pairs, pairs of premolars and observed indicators of oral pain or discomfort. Figure 4.2 provides an overview of the MOSST v0.1 domain structure, concepts, and item-level operationalisation.

Figure 4.2 overview of the MOSST v0.1 domain structure, concepts, and item-level operationalisation.



Item design was guided by prior use of the OSST and adapted to reflect simplified language and layout. The tool required minimal clinical equipment (pen/head torch, disposable mirror, gloves) and was implemented during field assessments that typically lasted 3–5 minutes. Each item was scored using categorical response options accompanied by visual scoring guides to support consistency. MOSST v0.1 was integrated as part of a broader set of 26 objective health assessments conducted in Wave 5 of the IDS-TILDA. Further detail on steps, items, scoring criteria and equipment are available in the data collection protocol for the MOSST V0.1 in Appendix 4.1.

Additional materials included easy-to-read information leaflets, accessible scoring sheets, and a structured training manual, all developed to support assessors with non-dental backgrounds. These materials incorporated reasonable adjustments such as simplified wording, visual aids, and the option to tailor the pace or delivery method based on participant needs. Furthermore, all research nurses had experience working with people with intellectual disabilities, which helped ensure that reasonable adjustments could be implemented during data collection. These were vast and ranged from objects of reference which were familiar to the participant were offered to allay dental anxieties and fear occurring during examination such as the use toothbrush in place of the dental mirror. Change of environment using a soft rest area and relaxation room with multisensory experiences also instead of a clinical setting.

A detailed account of MOSST v0.1 item structure and development are provided in Appendix 4.3.

4.2.1.2 Field Testing:

4.2.1.2.1 Participant Recruitment:

The tool was tested within the health fair of Wave 5 of IDS-TILDA. Ethical approval was granted by the Faculty of Health Sciences Research Ethics Committee (FHS REC), Trinity College Dublin, and affiliated services. All participants received accessible information and easy-to-read consent materials. Inclusion criteria were people aged over 40 years and registered on the NID.

4.2.2 Data Collection

The MOSST data was collected as one of the twenty-six objective health measures in the health fair element of the IDS TILDA study which spanned over eight months from November 2022 completing in June 2023. All participants in IDS TILDA were invited to attend the health fair which spanned over for eight months, the health fair was based in Trinity College Dublin for five months and for a further three months there were outreach health fair in rural locations across Ireland. Reasonable adjustments in data collection included use of easy-to-read instructions, simplified visual cues, and the option for familiar supporters to assist during assessment. Participants could withdraw or pause at any time.

4.2.2.1 Gold standard and data collector calibration

Prior to main data collection and testing, one author, (CMGP) a developer and the clinical gold standard of the original OSST (Mac Giolla Phadraig et al., 2021), trained and calibrated a MOSST gold standard over three months in the Special Care Dental Clinics in the Dublin Dental University Hospital. Over 30 days, CMGP and KB both scored the MOSST tool on a consecutive convenience sample of people with intellectual disabilities, until perfect calibration was achieved ($k=1.00$). Final calibration scores on $n=25$ cases of people with intellectual disabilities ranged ($k=0.85-1.00$).

Regarding data collector calibration, four data collectors, research nurses with experience working with people with intellectual disabilities, received a standardized two-day training. This covered content on consent and capacity, communication, infection control, practical set up, as well as MOSST criteria, categories, and coding. Data collectors practiced upon each other and then six volunteers with intellectual disabilities, with a range of complexities, who assisted in training the research nurses. The trainees received direct feedback from all the trainers. As well as feedback on using the accessible easy read supports and reasonable adjustments, Kappa coefficients were calculated to assess calibration of all four data collectors to gold standard, using Medcalc ($k_1=0.93$; $k_2=0.93$; $k_3=0.86$; $k_4=0.90$), indicating very good agreement (Altman, 1990). Calibration exercises were repeated at the 50th, 100th, and 200th and 350th participant points of data collection.

4.2.2.2 Reliability Testing:

Inter-rater and Intra-rater agreement was calculated using Cohen's kappa coefficients for categorical items, with quadratic weighting where appropriate, and ICC for discrete counts. Scores above $k=0.81$ were considered *very good*, $k=0.61-0.80$ considered good, $k=0.41-0.60$ considered moderate (Altman, 1990). Inter-rater comparison between data collectors and gold standard ratings was undertaken on $n=43$ participants; above the minimum recommended number of $n=25$ (Organization, 2013). Intra-rater agreement was calculated using repeat scorings on the same participant, aiming for 5–10% of the sample. A time gap pass of between 1-2 weeks is recommended for repeat testing, although the time gap may vary depending on the specific context of the study (Organization, 2013). Within this study, repeat measurements were undertaken on the same day. This was a reasonable adjustment to reduce participant burden, avoid travel challenges, and accommodate participants' comfort levels. Repeat measurements were spaced by a 1–2-hour interval during routine visits.

4.2.2.3 Feasibility

Feasibility testing included calculating the cost and time per assessment, and participant acceptability (Streiner & Norman, 2008; Streiner et al., 2024). A preliminary cost analysis counted time, labour, and equipment costs. The mean assessment duration was calculated from the recorded start and finish times of each MOSST assessment, as well as the administrative time required for data entry, scheduling, and processing. This approach provided a comprehensive understanding of the time burden associated with using the tool. Acceptability was measured through two complementary approaches. Firstly, participant responses were collected through structured survey questions focusing on their perceptions of the speed, comfort, and overall experience of the assessment process. These questions aimed to gauge participants' engagement and satisfaction levels, ensuring that the MOSST remained a positive and non-intrusive experience. Participants in the final month of data collection (June 2023) were asked these additional survey questions. Secondly, research nurses provided detailed feedback on the tool's usability, including observations about the ease of administration, clarity of instructions and any operational challenges encountered. Both the

participant survey questions, and the nurse feedback responses are available Appendix 4.4.

4.2.2.4 Validation

4.2.2.4.1 Expert Panel

Parallel to field testing, the development team assessed the content validity of the MOSST. Seven international dental experts validated the content of the MOSST. The Panel and the thesis author and supervisor CMGP and BD met online and reviewed the MOSST items, the protocol, and the conceptual framework. The relevance of each item to its concept was rated using a four-point Likert scale (1 = not relevant, 4 = highly relevant). Panel discussions were documented, and an item-level Content Validity Index (iCVI) was calculated by dividing the number of experts rating an item as 3 or 4 by the total number of experts (LYNN, 1986; Polit & Beck, 2006).

Experts provided comments, suggested item modifications, and recommended removals or replacements. Qualitative data were also retrieved from open-ended comments. Data were aggregated and analysed to produce Content Validity indices for each item. Researchers followed up on comments and references where needed. Surveys used in the expert panel process are available in Appendix 4.5

4.2.2.4.2 PPI Panel

The second element in establishing content validity for the MOSST involved reviewing its items and concepts in an easy-read format with a patient and public involvement (PPI) panel. The inclusion of a PPI panel comprising seven individuals with intellectual disabilities ensured that the research was not only scientifically rigorous but also aligned with the lived experiences and practical needs of this population.

The PPI panel provided invaluable feedback on the tool's accessibility, clarity, and ease of use, contributing to the development of an inclusive and user-friendly instrument. The panel's input was gathered during a facilitated meeting led by researcher KB, where members systematically reviewed each item. Participants indicated whether they believed each item should be included by a show of hands, followed by an open discussion for additional comments or suggestions.

This process not only validated the relevance of the tool's content but also offered guidance on data collection methods to ensure they were accessible and acceptable to participants with intellectual disabilities. A detailed overview of the material presentation to the PPI panel is available in Appendix file 4.6.

4.3 Results

4.3.1. Field Testing

The IDS TILDA health fair had n=503 participants attend over the eight-month period. This sample included n=469 participants who were assessed using the MOSST (Byrne, 2023). Just over half (52%) were female, and the majority (73.3%) were aged 50 years or older. In terms of level of intellectual disabilities, 29% were classified as mild, 40% moderate and 22.6% severe to profound. Participants lived across a range of residential settings, with 48.8% residing in community homes, 27.1% in residential centres and 24% in independent or family settings. These figures are summarised in Table 4.1. Participation varied across MOSST items, with higher completion rates for brief externally observable items like denture wear, tooth count and lower rates for items requiring longer intraoral inspection for example (cavitated teeth, gum health). Notably, participants who were edentulous were not assessed on caries or gum health items, which contributed to reduced sample sizes for these indicators. Additionally, some participants chose not to proceed with longer assessments. These decisions were respected in line with the study's inclusive and low-burden ethos, ensuring participants retained autonomy throughout the assessment process and could withdraw consent at any point in the assessment. The participation rates for each item are further outlined in table 4.1

Table 4.1: Demographic characteristics of participants

Demographic characteristic of MOSST participants	Wave 5 MOSST participants n=469	
	%	n=
Gender		
<i>Male</i>	47.8	225
<i>Female</i>	52.0	244
Age Categories		
<i>>50 years</i>	27.9	132
<i>50-64 years</i>	45.4	213
<i>65+ years</i>	26.4	124
Level of intellectual disabilities		
<i>Mild</i>	29.0	136
<i>Moderate</i>	40.3	189

<i>Severe to profound</i>	22.6	106
Type of Residence		
<i>Independent/ family</i>	24.0	112
<i>Community Home</i>	48.8	228
<i>Residential</i>	27.1	127

4.3.2 Reliability:

Table 4.2 presents the inter-rater and intra-rater reliability coefficients. Inter-rater reliability coefficients were calculated using data from n=44 participants and involved all research nurses and the gold standard. Tooth count demonstrated very strong agreement (ICC= 0.9988). Weighted linear Kappa coefficients also demonstrated very strong agreement for *Denture wear lower, denture wear upper, occlusal pairs, front twelve teeth, gums, clean mouth, cavitated teeth and oral pain*: $k = 0.82-1.0$ (see Table 4.2). *Pairs of pre-molars pairs* scored $k = 0.79$, representing good agreement. Intra-rater reliability was calculated using data from n=24 participants with both the primary data collector and the gold standard (n=10; n=14). Tooth count demonstrated very strong agreement (ICC= 0.99). Weighted linear Kappa coefficients also demonstrated very strong agreement for *Denture wear lower, denture wear upper, occlusal pairs, pairs of premolars, front twelve teeth, gums, clean mouth, cavitated teeth and oral pain* (see Table 4.2). Also, outlined in Table 4.2 is a breakdown of participation rates each item of the MOSST V 0.1.

Table 4.2: The inter-rater and intra-rater reliability

Domain	Concept	Item	Inter-rater reliability Kappa / ICC (95%CI)	Intra- rater reliability Kappa / ICC (95%CI)
			Kappa (95% CI)	Kappa (95% CI)
Oral Function	Denture Wear n= 465 (99.10%)	<i>Is the participant wearing dentures now? Upper arch</i>	1 (1.00-1.00)	1 (1.00-1.00)
		<i>Is the participant wearing dentures now? Lower arch</i>		
	Tooth Count n= 409 (87.20%)	<i>How many teeth are in each arch? Upper arch</i>	0.9988*ICC (0.99-0.99)	0.9988*ICC (0.99-0.99)
		<i>How many teeth are in each arch? Lower arch</i>		
	Occlusal contacts n= 399 (85.07%)	<i>Pattern of occlusal contacts (opposing teeth in contact)</i>	0.82 (0.63 to 0.95)	1 (1.00-1.00)
	Pairs Of Pre-Molars n=407 (86.70%)	<i>Does the participant have three or more POPs?</i>	0.79 (0.67to 1.00)	1 (1.00-1.00)
Oral Disease	Front 12 teeth n=444 (94.60%)	<i>Are the participant's front twelve teeth present?</i>	1 (1.00-1.00)	1 (1.00-1.00)
	Cavitated Teeth *n=306 (78.5%)	<i>How many visibly cavitated teeth are present?</i>	0.93 (0.842-1.00)	0.80 0.48 to 1.00
	Oral Cleanliness n= 433 (92.32%)	<i>Is the participants' mouth / dentures clean?</i>	1 (1.00-1.00)	1 (1.00-1.00)
	Gum health *n= 352 (90.26%)	<i>Are the gums healthy?</i>	0.88441 (0.72 to 1.00)	1 (1.00-1.00)
	Oral Pain n=460 (98.08%)	<i>Have you had (signs of) pain from your mouth in the last week?</i>	1 (1.00-1.00)	1 (1.00-1.000)

Note: *Participants in this item had at least 1 tooth total number of edentulous participants n=390

4.3.3 Feasibility:

Based on burden data from n=66 participants, most (n=65,98%) found data collection acceptable. All found the MOSST painless and not time consuming (n=66, 100%). Feedback from data collectors suggested that easy read supports were especially useful. Although they did suggest changes in the layout of items, it was recommended to place the cavitated teeth item before tooth count to improve completion of both items. A summary of feedback from the research nurses and its impact on MOSST construction and attributes is available in Appendix 4.7.

4.3.4 Cost Analysis

The cost per participant for MOSST assessment was estimated at €6.69, considering equipment and labour. Equipment costs for each assessment were €3.90, and staffing costs for the research nurse amounted to €2.79 per assessment. Details are summarised in Table 4.3 with further detail in Appendix 4.8. While direct costs were estimated, staff training time was not monetised.

Table 4.3: Costing and time of the MOSST

Cost Category	Details
Time per assessment	3-30 minutes (Mean: 6 minutes 35 seconds)
Employment Cost	€16.74 per hour
Scribe	Not required
Equipment Total Cost	€1,832
Total Cost per Assessment	€3.90

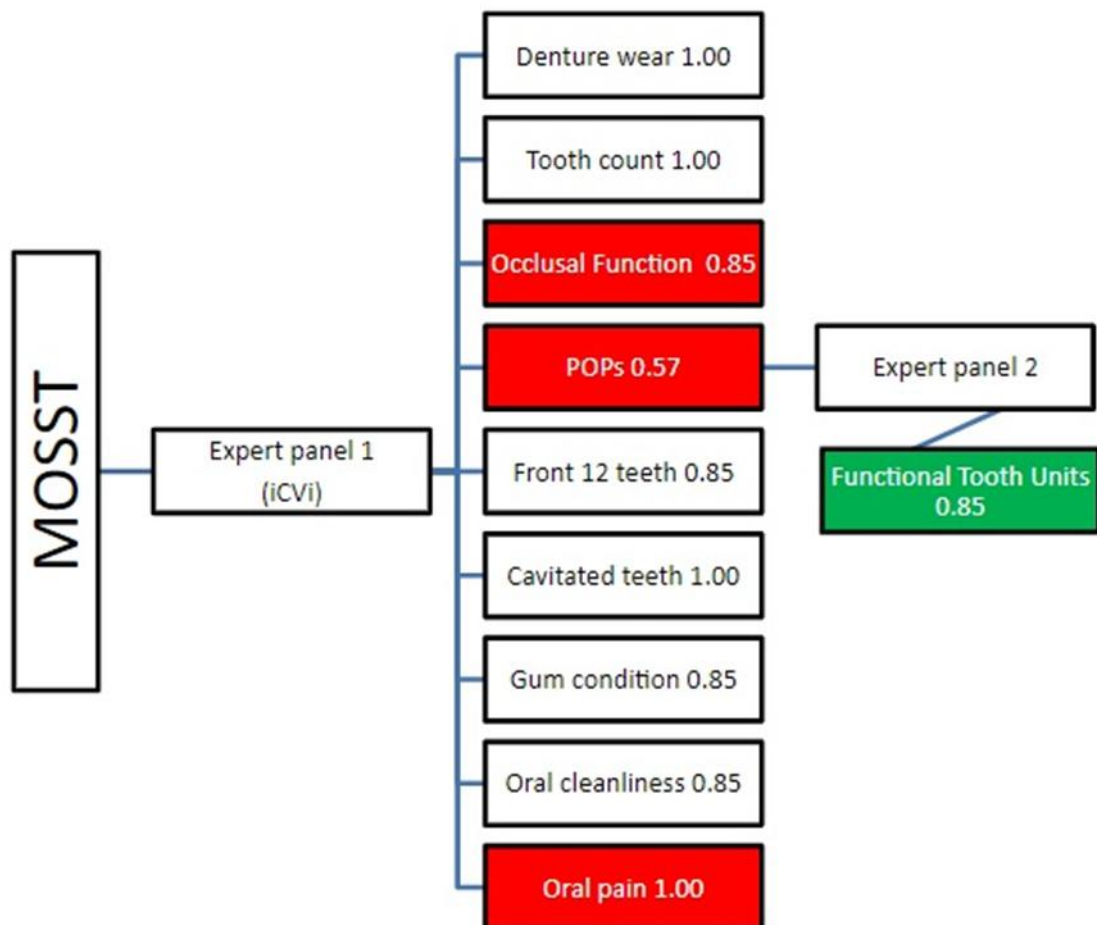
4.3.5 Content Validity Findings

4.3.5.1 Expert Panel Results

The expert panel (n=7) completed two surveys on Qualtrics, results were analysed for iCVI with all items scoring an acceptable score (see figure 4.3 below). Based on panel responses, a low level of agreement for the concept of *occlusal pairs and pairs of premolars* which is highlighted in red in figure 4.3 led to these items being refined with expert panel support as a new item which is highlighted in green in figure 4.2: *Functional Tooth units*. This returned an iCVI of 0.85. Key feedback from the expert panel indicated the need for a survey supplement to the MOSST for a

need of subjective questions. A MOSST self-report survey (MOSST SRS) was developed to collect data on oral healthcare utilisation, oral health behaviours and quality of life. Items were generated through a combination of researcher content selection and input from both content validity panels. The MOSST SRS requires further development and validation to support inclusive oral health data collection. Despite very good agreement for the observational oral pain item, recommendations from the expert panel led to the relocating of the oral pain item to the MOSST-SRS so that MOSST v1.0 remains strictly observation-based survey.

Figure 4.3: Expert panel result: Reproduced from Byrne et al. (2026) under CC BY licence.



4.3.5.2 PPI Panel Results

The second element of gaining content validity for the MOSST was having the items and concepts reviewed in easy read format by a PPI panel. The panel unanimously agreed that every item of the MOSST was important for researchers to explore. The PPI panel confirmed that the tool effectively captured key areas of interest while remaining accessible to diverse populations, including those with intellectual disabilities. Following the PPI panel review of the MOSST no further changes were made to the final version of the MOSST. The PPI panel's confirmation of the tool's accessibility and relevance further strengthens its potential for wide application.

4.3.5.3 Refinement and Final Modified Oral Status Survey Tool: MOSSTv1.0

Following analysis of the data and detailed feedback from both expert and PPI panels, the MOSST was further refined to enhance its conceptual clarity, accessibility, and suitability for adults with varying levels of intellectual disabilities. Most revisions were made within the oral function domain, where reviewers identified items that were clinically relevant but difficult to apply consistently in populations with limited tolerance for intra-oral examination.

Two items required substantial revision. The first was the item on occlusal pairs. Although clinically important, this item received an item-level Content Validity Index score of 0.58, indicating only marginal acceptability. Expert reviewers noted that the concept addressed by the item was valid but that the format lacked precision for non-dental assessors and was challenging to apply in individuals with complex dentitions or low examination tolerance. The second item, pairs of premolars, was closely related conceptually and displayed similar limitations. Both items were therefore removed, leaving a conceptual gap in the measurement of chewing function.

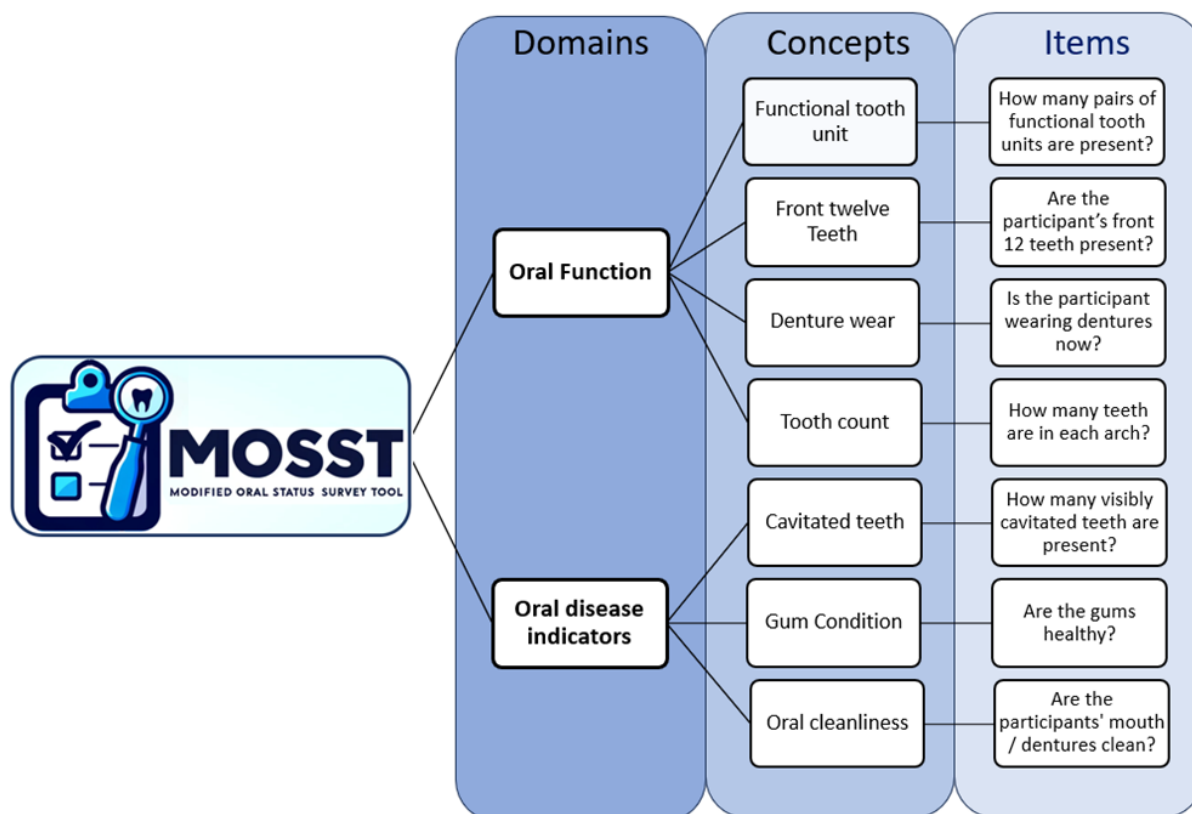
To address this gap, the Functional Tooth Unit index was introduced. Functional Tooth Units represent the number of posterior tooth pairs that meet during habitual biting and therefore provide an efficient and clinically meaningful estimate of chewing capacity. A substantial body of research supports the use of Functional Tooth Units for the assessment of oral function. Studies by (Hatch et al., 2001)), Ueno and colleagues (2010), and Samnieng and colleagues (2011)

demonstrated strong associations between Functional Tooth Units, masticatory performance, and perceived chewing ability. Additional research indicates that reduced numbers of Functional Tooth Units are associated with poorer nutritional status and functional decline in older adults. For example, Gotfredsen and Walls (2007) and Ikebe and colleagues (2012) found that Functional Tooth Units were positively associated with dietary adequacy and swallowing efficiency. Research exploring the links between Functional Tooth Units, dysphagia, and general health outcomes has also shown consistent patterns (Brochier et al. 2018; Okabe et al. 2017; Poisson et al. 2016; Mesas et al. 2010). These findings are especially relevant for adults with intellectual disabilities, among whom oral–motor difficulties, atypical chewing patterns, and increased risk of aspiration are more common.

The incorporation of Functional Tooth Units into the MOSST strengthens both its validity and its conceptual coverage. Unlike traditional occlusal measures, Functional Tooth Units can be assessed quickly and visually with minimal intrusion, making them suitable for individuals who may have sensory sensitivities or reduced capacity for prolonged examination. With appropriate training, non-dental assessors can apply this measure reliably. This feature supports the wider agenda for inclusive and accessible oral health surveillance as recommended by international public health bodies (World Health Organization 2022; Faulks 2023).

By replacing the earlier occlusal items with a more robust and evidence-based metric, the revised MOSST captures functional oral health more accurately and meaningfully. This refinement also aligns with contemporary oral health research, which emphasises that functional indicators provide richer insight into quality of life and daily oral capability than structural indicators alone (Locker 2002; Tsakos et al. 2010). The final MOSST v1.0 framework, including its domains, constructs, and revised items, is presented in Figure 4.4. The accompanying protocol, survey instrument, and training toolkit are provided in Appendices X.

Figure 4.4: Final MOSSTv.1.0 framework including domains, concepts, and items: Reproduced from Byrne et al. (2026) under CC BY licence.



4.4 Discussion

4.4.1 Main Findings

This study was undertaken to develop and validate the MOSST, as deployed with people with intellectual disabilities, a population who present extreme challenges for traditional oral health surveillance methods. The final MOSST is a seven-item health evaluation tool that underwent robust development, demonstrating content validity, reliability, and feasibility. The content validity of the MOSST was rigorously assessed through feedback from both expert and PPI panels. The expert panel provided critical insights that informed the refinement of the tool, particularly enhancing its capacity to accurately assess oral function. The PPI panel ensured the MOSST was accessible and relevant from the perspective of people with intellectual disabilities. Their input ensured that the MOSST remained relevant and inclusive for individuals with varying levels of cognitive and communication abilities. This collaborative process not only validated the tool's conceptual coverage but also ensured its practical applicability. The MOSST offers

improved conceptual clarity and broader applicability for research and clinical practice, paving the way for more inclusive and meaningful oral health data collection.

As field-tested in IDS-TILDA, the MOSST demonstrated reliability through good to very good inter- and intra-rater reliability coefficients. Feasibility was demonstrated from the perspective of participants and data collectors through high acceptability, speed, and low burden. Calibration was achievable by trained non-dental data collectors using MOSST training, protocols, and resources. Input from research nurses optimised the training materials and survey flow, further affirming the MOSST's acceptability and usability. The remarkably high completion rates of 89% from a population for whom traditional oral data collection methods pose barriers, showed the benefit of weaving reasonable adjustment into all aspects of collecting data. Especially in contrast to the limited participation typically observed in national oral health surveys involving people with intellectual disabilities, such as the 34% completion rate reported by Bird et al. (2024). These features make the MOSST attractive for use among other understudied populations often excluded from oral health research. The methods and reasonable adjustments applied in this study provide valuable insights for the development of other instruments, particularly in ensuring feasibility, accessibility, reliability, and inclusive reasonable adjustments in research with diverse populations.

4.4.2 Findings Relative to Other Literature:

A wide range of oral health assessment tools have been developed for use by non-dental personnel, reflecting longstanding recognition that oral health needs to be documented across health and social care settings where dental professionals are not routinely present. Tools such as the Oral Health Assessment Tool (OHAT) (Chalmers et al., 2005), the Revised Oral Assessment Guide (ROAG) (Andersson et al., 2002), the Community Oral Health Indicator (COHI) (Saintrain & Vieira, 2012), the Brief Oral Health Status Examination (BOHSE) (Kayser-Jones et al., 1995), and the Oral Health Risk Assessment (Fiske, 2006) have been widely employed, particularly in gerontology, long-term care facilities, and community nursing. These instruments typically focus on observable indicators of oral disease and function,

enabling non-dentists to identify oral health problems and initiate referral pathways.

However, although these tools have been valuable within their target populations, they were not designed to meet the specific needs or communication profiles of adults with intellectual disabilities. Their structure, terminology, required cooperation, and clinical procedures do not always align with the principles of accessibility, reasonable adjustment, or inclusive design. For example, the OHAT and ROAG rely on ratings of tissue changes or clinical pathology that assume a level of cooperation, lighting, visibility, and behavioural tolerance that many adults with intellectual disabilities find challenging. Likewise, the COHI and BOHSE use classification systems that offer limited flexibility for adapted assessment techniques, thereby increasing the risk of incomplete or abandoned assessments in populations requiring additional support.

Further assessment instruments, including the OHR-InterRAI (Krausch-Hofmann et al., 2021), the Dental Hygiene Index (DHI) (Fjeld et al., 2014), the THROAT tool (Dickinson et al., 2001), the Mucosal-Plaque Scor (MPS) (Henriksen et al., 1999), and the Oral Assessment Sheet (OAS) (Yanagisawa et al., 2017), demonstrate innovations in structure and application. These tools have broadened the scope of non-dentist assessment by incorporating functional indicators, self-report items, or condition-specific risk markers. Systematic evidence syntheses further highlight their strengths and limitations. (Everaars et al., 2020) identified the OHAT as the most comprehensively developed tool, particularly in relation to the clarity of its measurement properties. Rodrigues et al. (2023) recommended the OHRInterRAI as the strongest tool overall due to its embeddedness within broader care-planning systems and its relatively strong psychometric profile. Bakker et al. (2024) acknowledged the utility of the OHAT acknowledged the utility of the OHAT and OHR-InterRAI for trained nursing staff, yet noted persistent limitations, including narrow construct coverage and weak evidence of reliability when these tools are used by non-dental assessors or applied outside of their intended populations.

Across this broader literature, two key issues are repeatedly emphasised: first, the lack of tools designed specifically for adults with intellectual disabilities and second, the absence of validated assessment systems that incorporate

accessibility, flexibility, and adaptability into their structure. No existing tool adequately addresses the multi-faceted needs associated with intellectual disabilities, where communication differences, sensory sensitivities, behavioural distress, or reduced tolerance for intra-oral procedures routinely influence assessment feasibility. As a result, there is an ongoing risk of misclassification, missing data, or systematic exclusion when these standard tools are used in intellectual disabilities research or service contexts.

The development of the original OSST (Mac Giolla Phadraig et al., 2021) represented an early attempt to bridge this gap. Drawing from elements of the OHAT (Chalmers et al. 2005), COHI (Saintrain and Vieira 2012), and functional assessment frameworks such as those developed by (Ikebe et al., 2010), the OSST was specifically designed to be implemented by non-dental data collectors working with adults with intellectual disabilities. The OSST demonstrated several strengths, including convergent validity with traditional indices such as DMFT and CPI, as well as ease of administration, but field application identified limitations in item clarity, operational definitions, and assessor accessibility. These limitations provided important learning for the refinement process.

The MOSST therefore builds upon the foundational design of the OSST while addressing these identified shortcomings. MOSST v1.0 enhances the conceptual clarity and usability of the tool by improving the operationalisation of gum health, modernising the representation of occlusal function through functional tooth units, and strengthening training materials to support consistent data collection by non-dental assessors. These refinements align with broader recommendations in the literature advocating for adapted assessment tools that emphasise clear constructs, simplified scoring approaches, strong calibration protocols, and accessibility for people requiring communication supports. Recent systematic reviews of non-dental oral health assessment tools (Everaars et al. 2020; Rodrigues et al. 2023; Bakker et al. 2024) consistently call for improved psychometric testing, clearer construct definitions, enhanced standardisation, and tools specifically developed for vulnerable or understudied populations. The MOSST responds directly to these gaps by offering an instrument explicitly designed with inclusivity, feasibility, and non-dental usability at its core.

The MOSST contributes a meaningful advancement to the field by integrating the strengths of established tools while addressing their limitations in the context of intellectual disabilities. It offers a rigorously developed and accessible option for oral health surveillance, suitable for research, service planning, and policy development, and it supports the broader agenda of promoting equity in oral health data and reducing structural exclusion in population-based research.

4.4.3 Strengths and weaknesses

This study conveys several strengths and weaknesses regarding the MOSST tool. The MOSST was developed using an inclusive ethos, embedded in the IDS-TILDA study's commitment to engaging individuals with intellectual disabilities in meaningful and supported ways. The tool was designed for use by trained non-dental professionals, enabling broader implementation in settings where dental personnel may not be available. Its low cost, minimal equipment needs, and short administration time enhance its potential for scalability and population-based surveillance. Strong inter- and intra-rater reliability was achieved, and content validity was strengthened through the involvement of both expert reviewers and a PPI panel involvement. These features promote both scientific rigour and user-centred design. The supportive and accessible context of IDS-TILDA may have contributed to the tool's feasibility and success; however, its implementation in less inclusive or more resource-limited settings may require adaptation and additional validation

Some limitations also warrant attention. The interval for intra-rater reliability testing was intentionally shortened as a reasonable adjustment to reduce participant burden, which may influence generalisability of results. In addition, content validity testing was conducted in parallel with fieldwork rather than as a standalone pre-field stage. While this allowed for valuable cross-pollination between users and developers, it meant that the final refinements (e.g., shift to FTU's and improved flow) were not fully field-tested within this phase.

4.4.4 Implications for Practice, Policy and research

The findings from this study indicate that the MOSST has considerable potential to strengthen oral health surveillance among populations who have historically been underrepresented in research, including adults with intellectual disabilities. Its design is practical and adaptable, making it suitable for integration into health surveys where limited resources, restricted staffing, or time pressures often impede the use of traditional dental assessment tools. The low cost of implementation, together with its straightforward administration, supports its use in a broad range of settings and enables more inclusive data collection to inform service planning and resource allocation.

Because the MOSST is compact and minimally intrusive, it can serve as a complementary measure alongside conventional dental indices in both national and local epidemiological studies. Its feasibility was demonstrated within IDS-TILDA, where high completion rates were achieved even among individuals who may find standard oral examinations challenging. This characteristic makes the MOSST particularly valuable for research involving older adults, individuals with complex needs, and populations living in low-resource environments. Further validation is required before wider deployment across different demographic groups, but the early evidence suggests that the tool can address important gaps in oral health monitoring.

The development and evaluation of the MOSST also provide a useful model for conducting inclusive health research. The involvement of Public and Patient Involvement contributors and expert panels illustrate the feasibility and value of co-design approaches when developing assessment tools for populations with diverse support needs. This process emphasises the importance of continued investment in methodological innovation to ensure that oral health assessments are both relevant and accessible.

Future research should examine the tool's concurrent validity and explore its use within routine data collection systems, including national surveys and community health programmes. In response to feedback from the content validity panels, a complementary MOSST Self-Report Survey (MOSST SRS) has been created to

capture subjective experiences of oral healthcare, oral health behaviours, and oral health-related quality of life. This component is currently undergoing final stages of development and validation and will ultimately enable a more comprehensive dataset combining objective and self-reported indicators, thereby supporting a fuller understanding of oral health needs in both individuals with intellectual disabilities and other underserved groups.

4.5 Conclusion

This chapter has detailed the development and early evaluation of the MOSST, created to address the persistent exclusion of adults with intellectual disabilities from oral health research. The findings demonstrate that the MOSST is a credible and methodologically sound assessment instrument, capable of capturing key indicators of oral status in a way that is both accessible and acceptable to adults with varying levels of support needs. The tool performed strongly on measures of inter-rater and intra-rater reliability, indicating that trained assessors can apply the instrument consistently. Content validity was supported through structured feedback from both expert reviewers and a Public and Patient Involvement panel, ensuring that the tool reflects clinically meaningful concepts while remaining user-friendly.

Field testing within IDS-TILDA provided further evidence of feasibility. Participants reported very high levels of comfort and acceptability, and completion rates were excellent, demonstrating that the tool can be implemented effectively in large-scale research with non-dental assessors. This is particularly noteworthy given the historic challenges associated with conducting oral health assessments in populations requiring communication and cognitive supports.

The MOSST therefore offers an important contribution to inclusive oral health research. It is cost-efficient, straightforward to administer, and designed to function as a reasonable adjustment that enables equitable participation in epidemiological studies. While the tool shows considerable promise, additional evaluation across diverse settings and populations will be essential to strengthen its generalisability and refine its operational guidance. Nonetheless, the MOSST represents a meaningful step towards reducing systematic exclusion and

improving the visibility of oral health needs among adults with intellectual disabilities, ultimately supporting more informed policy, planning, and service delivery.

Chapter 5:

The oral health status of older adults with an intellectual disability in Ireland

Chapter 5 Abstract

Background:

Despite well-documented health inequalities experienced by people with intellectual disabilities, oral health has remained largely invisible within national ageing and health datasets. This chapter addresses that absence by presenting the first nationally representative analysis of oral health in older adults with intellectual disabilities in Ireland that was objectively measured. Using data from the IDS-TILDA Wave 5 health assessment and the MOSST, the chapter documents levels of tooth loss, functional dentition, and oral disease, and examines how these outcomes are patterned by age, level of intellectual disabilities, and living arrangement.

Aim:

To describe oral health status and functional dentition in older adults with intellectual disabilities using the MOSST; to examine demographic patterning of oral function and disease; to compare findings with the general ageing population.

Methods:

A cross-sectional analysis was conducted using data from Wave 5 of the IDS-TILDA MOSST assessments were completed by trained research nurses at the health fair for 469 participants, aged 40 years and over, representing all levels of intellectual disabilities. Outcomes included tooth count, edentulism, denture wear, occlusal contacts, POPs, presence of the front twelve teeth, cavitated teeth, gum condition, oral cleanliness, and oral pain.

Results:

Among 503 IDS-TILDA Wave 5 health fair attendees, 469 (93.2%) completed a full or partial MOSST assessment. The sample was 52.0% female, with 45.4% aged 50–64 and 26.4% aged ≥65; 40.3% had moderate intellectual disability and 48.8% lived in community group homes.

Oral function was substantially compromised. Mean total tooth count was 16.6 (SD 13.8); 19.8% were edentulous, and >70% of edentulous participants were not

wearing dentures. Only 38.3% retained the front twelve teeth, 38.6% had ≥ 3 pairs of occluding premolars (POPs), and 41.6% had no occlusal contacts. Age showed the strongest and most consistent gradient across outcomes: compared with those aged <50 , participants aged 50–64 had 72% lower odds of functional dentition (OR 0.28, 95% CI 0.15–0.52) and those aged ≥ 65 had 90% lower odds (OR 0.10, 0.05–0.24). Adults aged ≥ 65 also had markedly reduced odds of retaining ≥ 20 teeth (OR 0.07, 0.03–0.14) and of retaining ≥ 3 POPs (OR 0.12, 0.06–0.26). Severity of intellectual disability independently compounded disadvantage: severe–profound intellectual disability was associated with lower odds of being dentate (OR 0.30, 0.13–0.70) and of retaining the front twelve teeth (OR 0.26, 0.12–0.57), and substantially lower odds of functional dentition (OR 0.15, 0.04–0.55).

Oral disease indicators were common. Cavitated teeth were present in 37.4% of dentate participants (29.1% with 1–2; 8.3% with ≥ 3). Younger age was associated with having 1–2 cavitated teeth (<50 vs ≥ 65 : OR 2.12, 1.03–4.37), and mild intellectual disability was also associated (OR 3.01, 1.16–7.79). Oral cleanliness was poor in 72.7% of participants, with no independent demographic predictors. Healthy gums were observed in 47.8% and were more likely among those with mild/moderate intellectual disability compared with severe–profound (OR 2.97, 1.23–7.18; OR 2.50, 1.08–5.80, respectively). Oral pain was reported in ~8%; the only independent association was lower odds of reported pain among those living in community group homes versus independent/family living (OR 0.36, 0.14–0.96).

Conclusions:

The findings reveal pronounced and remediable oral health inequalities, characterised by extensive tooth loss, impaired oral function, and disease burden concentrated among older adults and those with higher support needs. The coexistence of high reported oral hygiene behaviours with poor clinical status highlights that oral health outcomes depend not solely on behaviour frequency, but on the quality, consistency, and support of care. These results provide a critical evidence base to inform inclusive oral health surveillance, service planning, and targeted preventive interventions for ageing populations with intellectual disabilities

5.1 Introduction

5.1.1 Overview

The preceding chapter described the development, refinement, and validation of the MOSST. Building on that methodological foundation, this chapter presents the first nationally representative analysis of clinically assessed oral health in older adults with intellectual disabilities in Ireland.

Oral health is conceptualised in this chapter as comprising two interrelated domains: oral function and oral disease. Oral function refers to the capacity to chew, speak, and maintain oral comfort and aesthetics, operationalised through indicators such as tooth retention, denture wear, occlusal contacts, pairs of occluding premolars, and the presence of the front twelve teeth. Oral disease encompasses indicators of current or potential pathology, including cavitated teeth, periodontal health, oral cleanliness, and oral pain. Together, these domains provide a comprehensive picture of oral health status that extends beyond the presence or absence of disease alone.

Using MOSST data collected during Wave 5 of the IDS -TILDA, this chapter quantifies the oral health status of older adults with intellectual disabilities at a population level. It examines how oral function and oral disease are distributed across key demographic characteristics, including age, gender, level of intellectual disabilities and residential setting, and identifies factors associated with poorer oral health outcomes. In doing so, this chapter establishes a national benchmark for oral health in ageing adults with intellectual disabilities and provides the empirical foundation for subsequent analyses in this thesis.

5.1.2 Background

Oral health inequalities experienced by adults with intellectual disabilities are substantial, preventable and associated with important impacts on nutrition, comfort, communication and overall wellbeing. Poor oral health in this population is linked to pain, infection, difficulty eating, weight loss and reduced quality of life, with consequences often amplified by communication difficulties and reliance on others for care (Griffiths et al., 2011; Wilson et al., 2019). In addition to these

immediate effects, oral disease has been associated with systemic health risks, particularly in older adults and those with swallowing difficulties.

Dental caries and periodontal disease remain highly prevalent among adults with intellectual disabilities, with consistently higher levels of untreated disease and fewer restorative interventions than in the general population. Tooth loss and edentulism occur more frequently and at younger ages, often reflecting reliance on extraction-based treatment and limited access to preventive care. These patterns contribute to impaired oral function and reduced quality of life, particularly among individuals with higher support needs or those living in residential settings (Anders & Davis, 2010; Morgan et al., 2012; Wilson et al., 2019).

Many of these outcomes are linked to structural barriers affecting daily oral hygiene and access to dental services. Dependence on caregivers for oral care, inconsistent training and prioritisation within support settings, and limited availability of appropriately trained dental providers all contribute to disease progression and unmet need. Despite these well-recognised challenges, people with intellectual disabilities remain underrepresented in national oral health surveillance and population-based studies, with existing research often based on small or service-based samples that limit generalisability (Emerson & Hatton, 2014; Krahm et al., 2015).

This highlights that there is a lack of nationally representative, objectively measure data describing oral health status and functional dentition among ageing adults with intellectual disabilities in Ireland. This chapter addresses that gap by presenting objective oral health findings from an inclusive assessment conducted within a nationally representative ageing cohort. By providing the first population-level clinical profile of oral health among older adults with intellectual disabilities in Ireland, the analysis offers a foundation for evidence-informed policy, service planning and interventions aimed at reducing longstanding inequalities.

5.1.3 Research question

1. What are the oral health and function status older adults with intellectual disabilities in Ireland?
2. How do oral health and function status relate to demographic characteristics?
3. How do oral health status and function in the IDS-TILDA cohort compare with those of the general ageing population in TILDA?

5.1.4 Objectives:

- To describe the oral health and function status of older adults with intellectual disabilities using the MOSST assessment.
- To examine associations between oral health and function status and demographic characteristics
- To compare IDS-TILDA oral health and function status findings with oral health data from the general ageing population in TILDA.

5.2 Methods

This section describes the methods used to generate and analyse nationally representative clinical data on oral health among older adults with intellectual disabilities. It details the study design, sampling and recruitment procedures, data collection context, measurement approach, and statistical analyses undertaken to address the research questions of this chapter.

5.2.1 Design

This chapter reports a cross-sectional analysis using data from Wave 5 of the IDS-TILDA (McCarron et al., 2023). IDS-TILDA is a nationally representative, longitudinal study examining the ageing profile, health status, service use, and social participation of older adults with intellectual disabilities in Ireland.

5.2.2 Ethical Issues and Approval

Ethical approval for IDS-TILDA Wave 5 was granted by the relevant institutional research ethics committees. All study procedures were conducted in accordance

with national and institutional ethical standards. Informed consent was obtained from participants directly where possible, or via proxy consent where appropriate, using accessible information materials and consent processes tailored to individual capacity. Participants were supported throughout data collection to ensure comfort, understanding, and voluntariness.

5.2.3 Population and Sample

The analytic sample for this chapter comprised IDS-TILDA Wave 5 participants who attended the health fair and completed a MOSST assessment ($n = 469$). Only participants with valid MOSST data and corresponding interview data were included in the analyses presented in this chapter.

5.2.4 Recruitment

Recruitment followed standard IDS-TILDA procedures. Accessible invitation packs were distributed to participants through established gatekeepers and included information leaflets, consent forms, and easy-read materials for participants, family members, and supporting staff. Participation in the health fair and oral health assessment was voluntary.

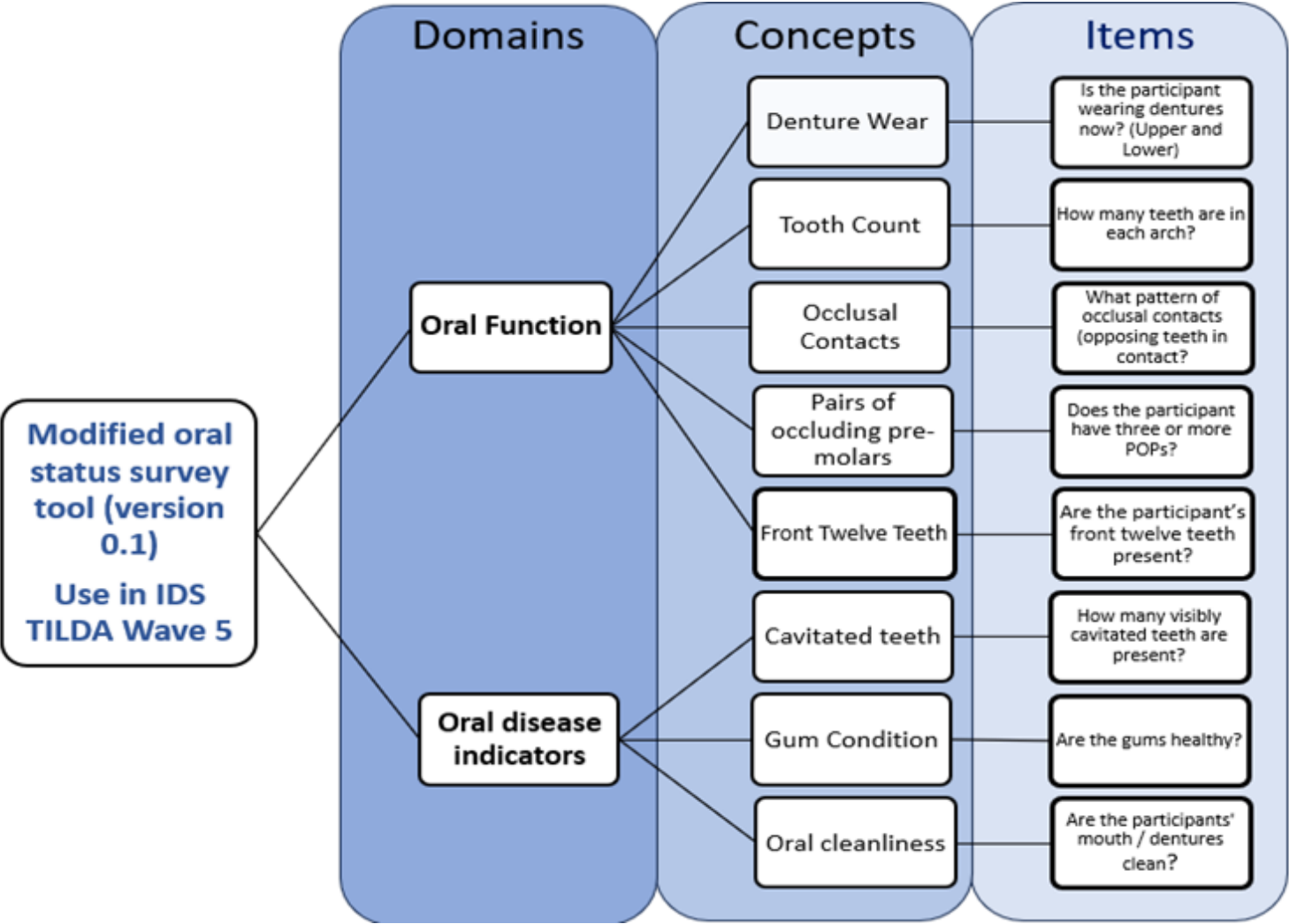
5.2.5 Data Collection

Data were collected during Wave 5 of IDS-TILDA using a two-stage process. First, participants completed a PIQ, followed by a face-to-face CAPI, with proxy support provided where required.

Second, participants were invited to attend the IDS-TILDA health fair, where objective health assessments were conducted. Oral health data were collected at the health fair using the MOSST. Assessments were completed by trained and calibrated research nurses in a standardised clinical environment. Data were recorded electronically using tablet-based entry via Qualtrics. A copy of the survey question used from Qualtrics is available in Appendix 4.1. The health-fair setting and assessment procedures were designed to maximise feasibility, accessibility, and participant comfort across all levels of intellectual disabilities. The structure of the MOSST, including its domains, concepts, and individual items as applied in IDS-TILDA Wave 5, is summarised in Figure 5.1. Further information on equipment

used, scoring criteria and assessable supports are available in the MOSST V0.1 Data collection protocol in Appendix 4.1.

Figure 5.1 MOSST (V0.1 Wave 5 IDS TILDA): Domains, Concepts and Items



5.2.6 Measures

Oral health was assessed using the MOSST, a structured clinical assessment designed to capture key indicators of oral health in adults with intellectual disabilities . As illustrated in Figure 5.1, the MOSST is organised into two overarching domains: oral function and oral disease indicators. Each domain comprises a set of conceptually distinct indicators, operationalised through specific, observable assessment items.

The oral function domain includes indicators relating to the ability to maintain effective mastication, oral comfort, and dental integrity, namely denture wear, tooth count, occlusal contacts, pairs of occluding premolars, and the presence of

the front twelve teeth. The oral disease domain captures indicators of cavitated teeth, gum condition, and oral cleanliness. Each indicator is assessed using a single, standardised item, as detailed in Figure 5.1.

Several derived variables were constructed to support analysis. Tooth count was categorised as edentulous or dentate and further grouped into clinically meaningful categories. Functional dentition was defined as the presence of at least 20 natural teeth, retention of the twelve anterior teeth, and at least three pairs of occluding premolars, consistent with established definitions of functional oral status (Nguyen et al., 2011). Cavitated teeth were dichotomised as present or absent.

5.2.7 Statistical analysis

To provide transparency and coherence across the multiple analytic aims addressed in this chapter, Table 5.1 summarises the objectives, outcome variables, predictors, and statistical methods, used in each analysis. As shown in Table 5.1, analyses were structured to address three sequential objectives. First, descriptive analyses were conducted to characterise the oral health status of the cohort using MOSST indicators, including tooth count, cavitated teeth, gum condition, and oral cleanliness. Second, bivariate analyses examined variation in oral health outcomes across demographic groups, including age, gender, level of intellectual disabilities, and residence type. Third, multivariable regression models were applied to identify independent predictors of specific oral health outcomes and indicators of oral function.

All analyses were conducted using SPSS version 26. Descriptive statistics were used to summarise sample characteristics and MOSST indicators, with means and standard deviations reported for continuous variables and frequencies and proportions for categorical variables. Bivariate analyses, including chi-square tests and t-tests, were used to examine unadjusted associations between oral health indicators and demographic variables. Variables demonstrating associations at $p < 0.10$ were considered for inclusion in multivariable models.

Table 5.1 objectives, outcome variables, predictors, statistical methods

Research question	Outcome Variable(s)	Predictor(s)	Type of Analysis
<i>Describe oral health status (e.g., tooth count, cavitated teeth, gum health)</i>	MOSST indicators (categorical and continuous)	N/A	Descriptive statistics (frequencies, means, standard deviation)
<i>Assess variation in oral health across demographic groups</i>	Oral health indicators (e.g., dentate status, functional dentition, cavitated teeth, occlusal contacts)	Age, gender, level of intellectual disabilities, residence type	Chi-square tests, t-tests
<i>Examine predictors of cavitated teeth (MOSST item E8)</i>	Cavitated teeth (none, some, unclear)	Age, gender, level of intellectual disabilities, residence type	Multinomial logistic regression
<i>Examine predictors of occlusal contacts</i>	Occlusal contacts (none, partial, full)	Age, gender, level of intellectual disabilities, residence type	Multinomial logistic regression
<i>Identify predictors of oral cleanliness (MOSST E6)</i>	Oral cleanliness (clean/not clean)	Age group, gender, level of intellectual disabilities, residence type	Binary logistic regression
<i>Explore predictors of gum health (MOSST E7)</i>	Gum condition (healthy/not healthy)	Age, gender, level of intellectual disabilities, residence type	Binary logistic regression
<i>Predict presence of functional dentition</i>	Functional dentition (yes/no)	Age, level of intellectual disabilities, dentate status, residence	Binary logistic regression

Note: Logistic regression was used for binary outcomes; multinomial logistic regression was used where outcomes had three or more unordered categories. All models were assessed for multicollinearity, goodness-of-fit (Hosmer–Lemeshow), and pseudo-R² measures (Nagelkerke, Cox & Snell).

5.2.7.1 Comparative Analysis with TILDA

To contextualise oral health findings from IDS-TILDA Wave 5, selected oral health indicators were descriptively compared with corresponding data from The Irish Longitudinal Study on Ageing (TILDA). Summary statistics from the most recent publicly available TILDA oral health reports were used for this comparison.

Indicators selected for comparison were limited to variables that were conceptually and methodologically comparable across studies, specifically tooth count, prevalence of edentulism, denture wear among edentulous participants, and the presence of cavitated teeth. These indicators were chosen to provide high-level contextualisation of oral health status rather than formal statistical comparison between cohorts.

Comparisons were descriptive in nature, and no inferential statistical testing was performed between IDS-TILDA and TILDA samples due to differences in study design, age eligibility criteria, sampling frames, and data collection methods. IDS-TILDA includes adults aged 40 years and older with intellectual disabilities, while TILDA includes adults aged 50 years and older from the general population. As such, findings are interpreted cautiously and are intended to highlight patterns and inequalities rather than quantify causal differences. This comparative approach was used to situate IDS-TILDA oral health findings within the broader population context and to support interpretation of observed disparities in oral disease burden and functional dentition among adults with intellectual disabilities in Ireland.

5.2.8 Model Assumptions and Diagnostics

All logistic and multinomial regression models were evaluated for adherence to underlying assumptions and overall performance. Multicollinearity was assessed using variance inflation factors (VIFs), with all values < 1.5. For binary logistic models, goodness-of-fit was assessed using the Hosmer–Lemeshow test. Model performance was summarised using pseudo- R^2 statistics (Cox & Snell, Nagelkerke, and McFadden where appropriate) and overall classification accuracy. Influence diagnostics were examined, and no observations were found to unduly influence model estimates.

5.3 Results

This section reports findings in four parts: (1) participation flow and MOSST item completion; (2) participant demographics; (3) descriptive distributions of MOSST indicators across the two domains (oral function and oral disease); and (4) subgroup analyses and multivariable regression models examining demographic associations of these indicators.

5.3.1 Flow and Participation

A total of 503 participants attended the IDS-TILDA Wave 5 health fair. Of these, 469 participants (93.2%) completed a full or partial MOSST assessment. Completion varied by item, ranging from 65.2% for cavitated teeth ($n = 306$) to 98.1% for oral pain ($n = 460$), reflecting both feasibility differences across items and protocol-specific exclusions for certain assessments. Item-level completion rates are shown in Table 5.2.

MOSST captured oral health across two domains: oral function (denture wear, tooth count, occlusal contacts, pairs of occluding premolars [POPs], and presence of the front twelve teeth) and oral disease indicators (cavitated teeth, oral cleanliness, gum health, and oral pain). Figure 5.1 summarises the MOSST domains and items.

Table 5.2 Participation Rates of the MOSST

<i>Domain</i>	<i>Concept</i>	<i>Item</i>	<i>n</i>	<i>%</i>
Oral Function	Denture Wear	Is the participant wearing dentures now? Upper arch	465	99.1
		Is the participant wearing dentures now? Lower arch	465	99.1*
	Tooth Count	How many teeth are in each arch? Upper arch	409	87.2
		How many teeth are in each arch? Lower arch	409	87.2*
	Occlusal Contacts	Pattern of occlusal contacts (opposing teeth in contact)	399	85.1
	Pairs of Premolars	Does the participant have three or more POPs?	407	86.7
	Front 12 Teeth	Are the participant's front twelve teeth present?	444	94.6
Oral Disease	Cavitated Teeth	How many visibly cavitated teeth are present?	306	65.2
	Oral Cleanliness	Is the participant's mouth/dentures clean?	433	92.3
	Gum Health	Are the gums healthy?	352	75.1

Total participants	Oral Pain	Have you had (signs of) pain from your mouth in the last week?	460	98.1
			469	100

5.3.2 Demographics

Table 5.3 summarises demographic characteristics of participants who completed MOSST (n = 469). The sample included 225 males (47.8%) and 244 females (52.0%). Almost half were aged 50–64 years (45.4%), with 27.9% aged <50 years and 26.4% aged ≥65 years. Most participants had moderate intellectual disability (40.3%), followed by mild intellectual disability (29.0%) and severe–profound intellectual disability (22.6%). Almost half lived in community group homes (48.8%), while 24.0% lived independently/with family and 27.1% lived in residential care.

Table 5.3: Demographic characteristic of MOSST Wave 5 participants

Characteristic	Category	n	%
Gender	Male	225	47.8
	Female	244	52.0
Age Group	<50 years	132	27.9
	50–64 years	213	45.4
	65+ years	124	26.4
Level of ID	Mild	136	29.0
	Moderate	189	40.3
	Severe to Profound	106	22.6
Type of Residence	Independent/Family	112	24.0
	Community Group Home	228	48.8
	Residential Care	127	27.1

5.3.3 Indicators using MOSST

This section presents a descriptive overview of oral health indicators assessed using the MOSST for the full analytic sample (n = 469). The aim is to summarise the distribution of MOSST indicators across the cohort prior to subgroup and multivariable analyses. Results are organised according to the two MOSST domains: oral function and oral disease, consistent with the tool structure outlined in Figure 5.1.

5.3.3.1 Oral Function Indicators

Denture wear was uncommon in the cohort. Upper dentures were worn by 14.2% of participants, while 6.7% wore a lower denture (Table 5.4).

With respect to occlusal function, 50.9% of participants had posterior occlusal contacts, 7.5% had anterior contacts only, and 41.6% had no occlusal contacts. Fewer than two-fifths of participants (38.6%) had three or more pairs of occluding premolars (POPs), while 61.4% had two or fewer pairs. Retention of the anterior dentition was also limited. Only 38.3% of participants retained all twelve front teeth, while 61.7% did not. Mean tooth for total tooth count, are reported in Table 5.4.

5.3.3.1 Oral Disease Indicators

Indicators of oral disease were common across the cohort. Cavitated teeth were present in 37.4% of participants, including 29.1% with one to two cavitated teeth and 8.3% with three or more. The remaining 62.6% had no cavitated teeth recorded. Oral cleanliness was rated as not clean in 72.7% of participants, while 27.3% were recorded as having a clean mouth or dentures. Gum condition was assessed as healthy in 47.8% of participants and not healthy in 52.2%. Signs of oral pain were recorded in 7.6% of participants, predominantly through verbal or vocal expressions. A summary of all MOSST indicators for the full sample is presented in Table 5.4.

Table 5.4. Distribution of oral function and oral disease indicators assessed using the MOSST

<i>Indicator</i>	<i>Category</i>	<i>n (%)</i>
<i>Denture wear – upper arch</i>	No	399 (85.8)
	Yes	66 (14.2)
<i>Denture wear – lower arch</i>	No	434 (93.3)
	Yes	31 (6.7)
<i>Total tooth count</i>	Mean (SD)	16.6 (13.8)
<i>Occlusal contacts</i>	No occlusal contacts	166 (41.6)
	Anterior contacts only	30 (7.5)
	Posterior contacts ($\pm$ anterior)	203 (50.9)
<i>Pairs of occluding premolars (POPs)</i>	≤ 2 POPs	250 (61.4)
	≥ 3 POPs	157 (38.6)
<i>Front twelve teeth present</i>	No	274 (61.7)
	Yes	157 (38.3)
<i>Cavitated teeth*</i>	≥ 3	32 (8.3)
	1–2	112 (29.1)
	None	241 (62.6)
<i>Oral cleanliness</i>	Not clean	315 (72.7)
	Clean	118 (27.3)
<i>Gum condition*</i>	Not healthy	221 (52.2)
	Healthy	203 (47.8)

Oral pain (signs observed/reported)	Yes – verbal/vocal	34 (7.4)
	Yes – behavioural/physical	1 (0.2)
	No	425 (92.4)

Note: 'n' represents the number of participants, '%' represents the percentage of total responses. Percentages are calculated from valid responses and may not total 100% due to rounding. *Cavitated teeth and gum condition exclude edentulous participants. Tooth count (upper and lower arches) is reported as mean (SD) to reflect the continuous nature of the variable. Occlusal contacts, POPs, and front twelve teeth presence are categorical indicators of oral function

5.3.4 Oral Function

Oral function outcomes are presented in the order assessed during the Wave 5 IDS-TILDA health fair: denture wear, tooth count, occlusal contacts, pairs of occluding premolars (POPs), and retention of the front twelve teeth. A composite indicator of functional dentition is then reported.

5.3.4.1 Denture Wear

Denture use was low in the cohort (Table 5.5). Overall, 84.4% of participants had no dentures, 10.9% wore partial dentures, and 3.6% wore full dentures. Among participants who were edentulous, more than 70% were not wearing dentures.

Denture wear patterns varied significantly by gender, age group, and level of intellectual disabilities (all $p < .001$; Table 5.5). Males were more likely to have no dentures (92.9%) than females (76.6%), while females had a higher prevalence of both full dentures (5.3%) and partial dentures (17.2%). Denture wear increased with age, from 6.1% among participants aged <50 years to 24.2% among those aged ≥65 years. Participants with mild intellectual disabilities had a higher prevalence of denture wear than those with severe to profound intellectual disabilities, among whom 95.3% had no dentures. Variation by residence type did not reach statistical significance ($p = .081$).

Table 5.5 Denture wear by gender, age group, level of intellectual disabilities , and residence type (IDS-TILDA Wave 5; n = 469).

<i>Demographic characteristic</i>	<i>Category</i>	<i>No denture, n (%)</i>	<i>Full denture, n (%)</i>	<i>Partial denture, n (%)</i>	<i>p-value</i>
Total		396 (84.4)	17 (3.6)	51 (10.9)	—
Gender	Male	208 (92.9)	4 (1.8)	9 (4.0)	<0.001
	Female	187 (76.6)	13 (5.3)	42 (17.2)	
Age group	<50 years	123 (93.9)	0 (0.0)	5 (3.8)	<0.001
	50–64 years	178 (83.6)	4 (1.9)	29 (13.6)	
	≥65 years	94 (75.8)	13 (10.5)	17 (13.7)	
Level of intellectual disabilities	Mild	103 (75.7)	9 (6.6)	23 (16.9)	<0.001
	Moderate	161 (85.2)	7 (3.7)	18 (9.5)	
	Severe to profound	101 (95.3)	0 (0.0)	4 (3.8)	
Residence type	Independent/family	95 (84.8)	0 (0.0)	15 (13.4)	0.081
	Community group home	187 (81.7)	11 (4.8)	29 (12.7)	
	Residential care	113 (89.0)	6 (4.7)	7 (5.5)	

Note. Values are n (%) unless otherwise indicated. Tooth count variables are reported as mean (standard deviation) due to their continuous nature. Percentages are based on valid responses and may not sum to 100 due to rounding.* Cavitated teeth and gum condition exclude edentulous participants.

5.3.4.1.1 Factors Associated with Denture Wear

A binary logistic regression examined factors associated with any denture wear (upper or lower) compared with no denture wear (Table 5.6). The model was statistically significant ($\chi^2(7) = 70.34, p < .001$) and explained 27.2% of the variance (Nagelkerke $R^2 = 0.272$). Model calibration was acceptable (Hosmer–Lemeshow $\chi^2(8) = 9.34, p = .314$). There was no evidence of multicollinearity (all VIFs < 1.4). After adjustment, gender, age, and level of intellectual disabilities were independently associated with denture wear. Females had higher odds of denture wear than males (OR = 4.08, 95% CI 2.03–8.20, $p < .001$). Compared with participants aged <50 years, those aged 50–64 years (OR = 4.63, 95% CI 1.60–

13.35, $p = .005$) and those aged ≥ 65 years (OR = 9.39, 95% CI 3.16–27.90, $p < .001$) had higher odds of denture wear.

Compared with participants with severe–profound intellectual disabilities, those with mild intellectual disabilities (OR = 10.01, 95% CI 3.17–31.66, $p < .001$) and moderate intellectual disabilities (OR = 4.50, 95% CI 1.47–13.82, $p = .009$) had higher odds of denture wear. Residence type was not independently associated with denture wear ($p = .315$).

Table 5.6. Binary logistic regression predicting denture wear (any denture vs none) among IDS-TILDA Wave 5 participants (n = 469).

<i>Demographic characteristic</i>	<i>OR</i>	<i>95% CI</i>	<i>p-value</i>
<i>Gender (Female vs Male)</i>	4.08	2.03–8.20	<.001
<i>Age 50–64 vs <50 years</i>	4.63	1.60–13.35	.005
<i>Age ≥ 65 vs <50 years</i>	9.39	3.16–27.90	<.001
<i>Mild intellectual disabilities vs Severe–profound intellectual disabilities</i>	10.01	3.17–31.66	<.001
<i>Moderate intellectual disabilities vs Severe–profound intellectual disabilities</i>	4.50	1.47–13.82	.009

Note. Outcome variable: denture wear (1 = any denture, 0 = no dentures).
Reference categories: Male; <50 years; severe–profound intellectual disabilities .
OR = odds ratio; CI = confidence interval.

5.3.4.2 Tooth Count

Tooth count was recorded for the upper and lower arches and summarised as total tooth count (Table 5.4). The mean total tooth count was 16.6 teeth. For analysis, tooth count was categorised as edentulous (0 teeth), 1–10 teeth, 10–19 teeth, and ≥ 20 teeth (Table 5.7).

Overall, 19.8% of participants were edentulous and 51.5% had ≥ 20 teeth (Table 5.7). Tooth count distribution differed by age group, residence type, and level of intellectual disabilities (all $p < .001$; Table 5.7). Edentulism was most prevalent among participants aged ≥ 65 years (40.0%) and least prevalent among those aged <50 years (4.5%). Participants in residential care had higher prevalence of edentulism (29.3%) than those living independently or with family (6.4%). Participants with severe–profound intellectual disabilities had higher prevalence of edentulism (38.7%) than those with mild intellectual disabilities (12.9%). Differences by gender were not statistically significant ($p = 0.200$).

Table 5.7. Distribution of tooth count categories across demographic characteristics among IDS-TILDA Wave 5 participants

<i>Demographic characteristic</i>	<i>Category</i>	<i>Edentulous n (%)</i>	<i>1–10 teeth n (%)</i>	<i>10–19 teeth n (%)</i>	<i>≥20 teeth n (%)</i>	<i>p- value</i>
Gender						0.200
	Male	30 (15.5)	23 (11.9)	41 (21.1)	100 (51.5)	
	Female	48 (22.4)	31 (14.5)	42 (19.6)	93 (43.5)	
Age group						<0.001
	<50 years	5 (4.5)	6 (5.4)	12 (10.8)	88 (79.3)	
	50–64 years	27 (14.8)	26 (14.3)	45 (24.7)	84 (46.2)	
	≥65 years	46 (40.0)	22 (19.1)	26 (22.6)	21 (18.3)	
Residence type						<0.001
	Independent / family	7 (6.4)	11 (10.1)	17 (15.6)	74 (67.9)	
	Community group home	42 (21.0)	28 (14.0)	43 (21.5)	87 (43.5)	
	Residential care	29 (29.3)	15 (15.2)	23 (23.2)	32 (32.3)	
Level of intellectual disabilities						<0.001
	Mild	17 (12.9)	13 (9.8)	34 (25.8)	68 (51.5)	
	Moderate	34 (19.1)	20 (11.2)	38 (21.3)	86 (48.3)	
	Severe– profound	24 (38.7)	15 (24.2)	7 (11.3)	16 (25.8)	

Note. Percentages are row percentages. Tooth count reflects total number of natural teeth present. p-values are derived from Pearson chi-square tests.

5.3.4.2.1 Factors Associated with Being Dentate

A binary logistic regression examined factors associated with being dentate (having any natural teeth) compared with being edentulous (Table 5.8). The model was statistically significant ($\chi^2(7) = 60.01$, $p < .001$), explained 23.6% of the variance (Nagelkerke $R^2 = 0.236$), and showed good calibration (Hosmer–Lemeshow $\chi^2(8) = 5.34$, $p = .721$). There was no evidence of multicollinearity (all VIFs < 1.5).

After adjustment, age and level of intellectual disabilities were independently associated with dentate status. Compared with participants aged <50 years, those aged ≥65 years had lower odds of being dentate (OR = 0.12, 95% CI 0.04–0.33, $p <$

.001). Compared with participants with mild intellectual disabilities, those with severe–profound intellectual disabilities had lower odds of being dentate (OR = 0.30, 95% CI 0.13–0.70, $p = .005$). Gender and residence type were not independently associated with dentate status.

Table 5.8. Binary logistic regression predicting being dentate (any natural teeth)

<i>Demographic characteristic</i>	<i>p-value</i>	<i>OR</i>	<i>95% CI for OR</i>
Residence type			
<i>Community vs. Independent</i>	0.192	0.536	0.211 – 1.366
<i>Residential vs. Independent</i>	0.311	0.584	0.206 – 1.654
Age group			
<i>50–64 vs. <50</i>	0.157	0.467	0.163 – 1.340
<i>65+ vs. <50</i>	<0.001	0.12	0.041 – 0.332
Level of intellectual disabilities			
<i>Moderate vs. Mild</i>	0.297	0.687	0.340 – 1.391
<i>Severe–profound vs. Mild</i>	0.005	0.301	0.130 – 0.697
<i>Gender (Female vs. Male)</i>	0.341	0.757	0.426 – 1.343

Note. Reference categories: Independent living, <50 years, mild intellectual disabilities, male. OR = odds ratio; CI = confidence interval.

5.3.4.2.2 Factors Associated with Retaining ≥ 20 Teeth

A second binary logistic regression examined factors associated with retaining ≥ 20 natural teeth (Table 5.9). The model was statistically significant ($\chi^2(7) = 94.53$, $p < .001$), explained 28.0% of the variance (Nagelkerke $R^2 = 0.280$), and demonstrated acceptable calibration (Hosmer–Lemeshow $p > .05$). There was no evidence of multicollinearity (all VIFs < 1.5).

After adjustment, age group was independently associated with retaining ≥ 20 teeth. Compared with participants aged <50 years, those aged 50–64 years had lower odds of retaining ≥ 20 teeth (OR = 0.29, 95% CI 0.16–0.54, $p < .001$), while those aged ≥ 65 years had substantially lower odds (OR = 0.07, 95% CI 0.03–0.14, $p < .001$). Gender, residence type, and level of intellectual disabilities were not independently associated with retaining ≥ 20 teeth in the adjusted model

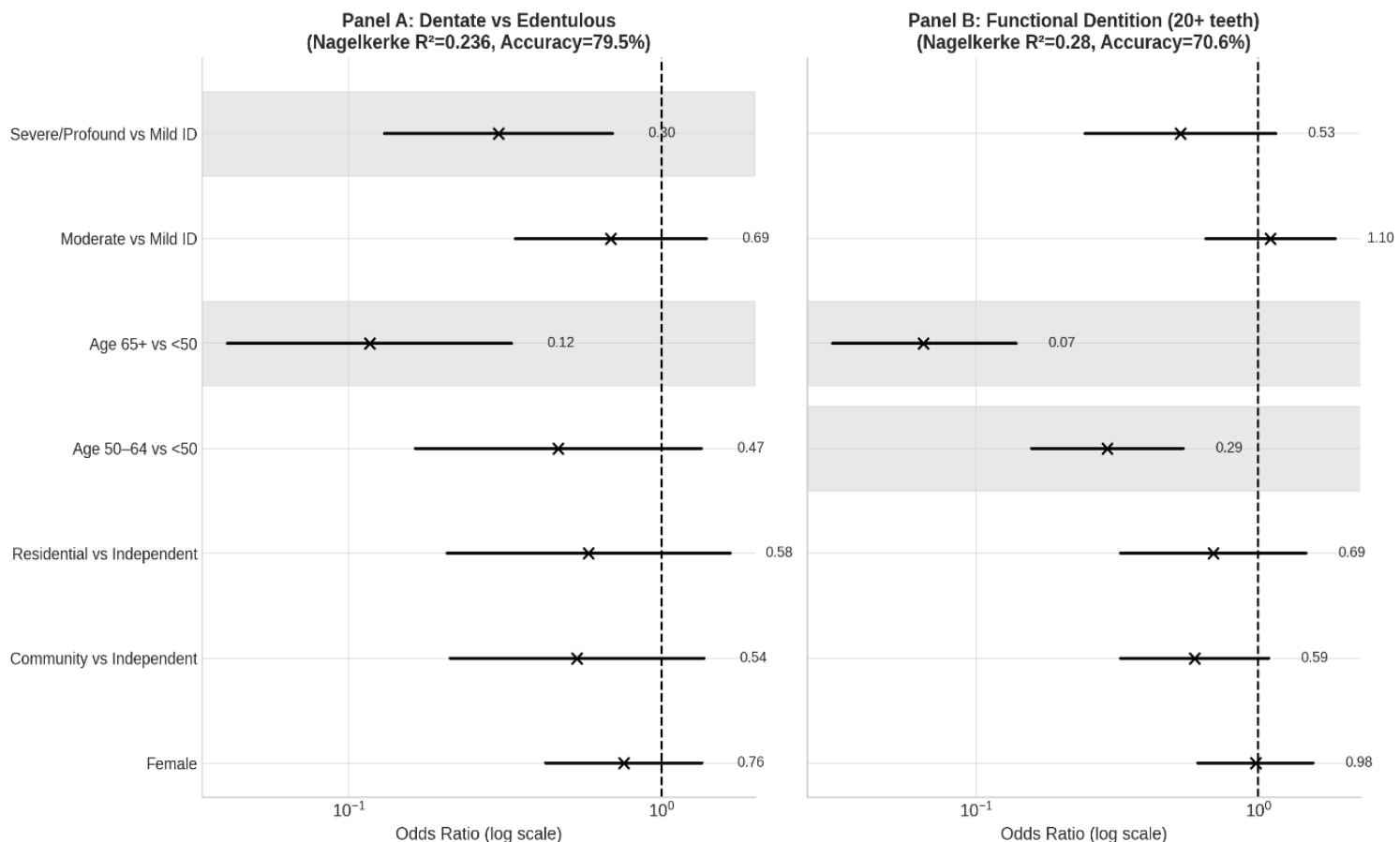
Table 5.9. Binary logistic regression predicting retention of functional dentition (≥20 teeth)

<i>Demographic characteristics</i>	<i>OR</i>	<i>95% CI</i>	<i>p-value</i>
<i>Community vs Independent</i>	0.60	0.33–1.09	.093
<i>Residential vs Independent</i>	0.69	0.32–1.48	.342
<i>Age 50–64 vs <50 years</i>	0.29	0.16–0.54	<.001
<i>Age ≥65 vs <50 years</i>	0.07	0.03–0.14	<.001
<i>Moderate vs Mild intellectual disabilities</i>	1.10	0.65–1.87	.715
<i>Severe–profound vs Mild intellectual disabilities</i>	0.53	0.24–1.16	.111
<i>Gender (Female vs Male)</i>	0.98	0.61–1.57	.924

Note. Reference categories: Independent living, <50 years, mild intellectual disabilities , male. OR = odds ratio; CI = confidence interval.

Across the two logistic regression models examining (1) dentate status and (2) retention of ≥20 teeth, age consistently emerged as the strongest factor associated with tooth retention. Older participants, particularly those aged ≥65 years, had markedly reduced odds of being dentate and of retaining ≥20 teeth. Severe–profound intellectual disabilities were also associated with lower odds of being dentate, although this association was not observed for retention of ≥20 teeth in the adjusted model. Gender and residence type were not significantly associated with either outcome. Figure 5.2 presents adjusted odds ratios for factors associated with being dentate and retaining ≥20 teeth.

Figure 5.2. Forest plots showing predictors of (A) being dentate versus edentulous and (B) retaining functional dentition (≥ 20 teeth) among IDS-TILDA Wave 5 participants.



5.3.4.3 Occlusal contacts:

Occlusal contact patterns differed significantly across age group, level of intellectual disabilities, and residence type (Table 5.10). Older adults were substantially more likely to have no occlusal contacts, with 66.7% of participants aged ≥ 65 years lacking any occlusion compared with 20.2% of those aged < 50 years ($p < .001$). Participants with severe–profound intellectual disabilities showed the highest prevalence of absent occlusal contacts (71.7%), compared with 34.3% among those with mild intellectual disabilities ($p < .001$). Similarly, absence of occlusal contacts was more common among individuals living in residential care (55.6%) than among those living independently or with family (26.1%) ($p < .001$).

In contrast, occlusal contact patterns did not differ significantly by gender ($p = .980$).

Table 5.10 presents the distribution of occlusal contact categories (no occlusal contacts, anterior contacts only, and posterior contacts) across demographic groups.

Table 5.10 presents the distribution of occlusal contact categories (no contacts, anterior-only contacts, and posterior contacts) across demographic groups.

<i>Demographic characteristic</i>	<i>Anterior contacts only n (%)</i>	<i>No occlusal contacts n (%)</i>	<i>Posterior contacts n (%)</i>	<i>p-value</i>
Gender				0.980
Male	13 (7.0)	67 (36.2)	105 (56.8)	
Female	17 (8.0)	98 (46.0)	99 (46.0)	
Age group				<0.001
<50 years	2 (1.8)	22 (20.2)	85 (78.0)	
50–64 years	17 (9.7)	67 (38.3)	91 (52.0)	
≥65 years	11 (9.6)	76 (66.7)	27 (23.7)	
Residence type				<0.001
Independent / family	10 (9.0)	29 (26.1)	72 (64.9)	
Community group home	12 (8.1)	81 (43.1)	95 (50.5)	
Residential care	8 (8.1)	55 (55.6)	36 (36.4)	
Level of intellectual disabilities				<0.001
Mild	14 (10.4)	46 (34.3)	74 (55.2)	
Moderate	12 (7.1)	66 (39.3)	90 (53.6)	
Severe to profound	2 (3.3)	43 (71.7)	15 (25.0)	

Note. Note. Reference categories: ≥65 years, severe to profound intellectual disabilities, residential care, female, posterior contacts. OR = odds ratio; CI = confidence interval.

5.3.4.3.1 Multinomial regression occlusal contacts

Multinomial logistic regression was conducted to examine demographic factors associated with occlusal contact patterns. Posterior occlusal contacts were specified as the reference outcome category (Table 5.11). After adjustment, age and level of intellectual disabilities emerged as the strongest factors associated with complete loss of occlusal contacts.

Compared with participants with severe–profound intellectual disabilities, those with mild and moderate intellectual disabilities had significantly lower odds of having no occlusal contacts rather than posterior contacts (mild intellectual disabilities: OR = 0.24, 95% CI 0.11–0.51, $p < .001$; moderate intellectual disabilities: OR = 0.25, 95% CI 0.12–0.52, $p < .001$). Age demonstrated a similar

gradient. Participants aged <50 years had substantially lower odds of having no occlusal contacts compared with those aged ≥65 years (OR = 0.11, 95% CI 0.05–0.22, $p < .001$), as did those aged 50–64 years (OR = 0.22, 95% CI 0.12–0.39, $p < .001$). Gender and residence type were not significantly associated with occlusal contact category in the adjusted models.

When anterior-only contacts were compared with posterior contacts (Table 5.12), participants with mild intellectual disabilities had significantly higher odds of belonging to the anterior-only category relative to those with severe–profound intellectual disabilities (OR = 7.24, 95% CI 1.45–36.06, $p = .016$). This suggests that although individuals with mild intellectual disabilities were substantially less likely to experience complete loss of occlusion, those lacking posterior contacts were more likely to retain some anterior occlusal function than those with higher support needs. The multinomial model demonstrated acceptable fit (likelihood ratio χ^2 , $p < .001$), and diagnostic testing indicated no evidence of multicollinearity (all VIF < 1.5).

Table 5.11 Multinomial logistic regression examining factors associated with absence of occlusal contacts (reference outcome: posterior contacts).

<i>Demographic characteristic</i>	<i>Comparison</i>	<i>OR</i>	<i>95% CI</i>	<i>p-value</i>
Age group	<50 vs ≥65	0.11	0.05–0.22	<.001
	50–64 vs ≥65	0.22	0.12–0.39	<.001
Level of intellectual disabilities	Mild vs severe–profound	0.24	0.11–0.51	<.001
	Moderate vs severe–profound	0.25	0.12–0.52	<.001
Residence type	Independent vs residential	0.91	0.43–1.95	.816
	Community group home vs residential	1.08	0.60–1.95	.810
Gender	Male vs female	0.77	0.48–1.23	.276

Table 5.12: Multinomial logistic regression examining factors associated with anterior-only contacts

<i>Demographic characteristic</i>	<i>Comparison</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
Level of intellectual disabilities	Mild vs. severe–profound	7.24	1.45 – 36.06	.016
	Moderate vs. severe–profound	3.53	0.74 – 16.77	.113

Note. Reference categories: posterior contacts (outcome), ≥65 years, severe–profound intellectual disabilities, residential care, female. OR = odds ratio; CI = confidence interval.

5.3.4.4 Pairs of Opposing Premolars (POPs):

Pairs of opposing premolars (POPs) were used as an indicator of posterior occlusal function. In this cohort, fewer than one-quarter of participants achieved the threshold of three or more POPs, indicating substantial loss of functional posterior dentition. Age was strongly associated with posterior occlusal function. Participants aged <50 years were far more likely to retain ≥3 POPs (44.7%) compared with those aged ≥65 years (9.6%) ($p < .001$). Residential setting also showed significant differences, with participants living independently or with family more likely to retain ≥3 POPs (35.7%) than those living in residential care (14.6%) ($p < .001$).

Level of intellectual disabilities was also associated with posterior occlusal function. Only 4.4% of participants with severe–profound intellectual disabilities retained ≥3 POPs, compared with 20.2% of those with mild intellectual disabilities ($p < .001$). Gender differences were statistically significant but modest in magnitude, with males slightly more likely to retain ≥3 POPs than females (26.7% vs 18.8%, $p = .032$). Table 5.13 presents the distribution of POP categories across demographic groups.

Table 5.13. Distribution of Occluding Premolar Pairs (POPs) by Demographic and Clinical Variables

Demographic characteristic	Category	≤2 POPs (n, %)	≥3 POPs (n, %)	p-value
Gender	Male	233 (73.3%)	85 (26.7%)	.032
	Female	310 (81.2%)	72 (18.8%)	
Age group	<50	89 (55.3%)	72 (44.7%)	<.001
	50–64	266 (80.4%)	65 (19.6%)	
	65+	188 (90.4%)	20 (9.6%)	
Residence type	Independent/Family	110 (64.3%)	61 (35.7%)	<.001
	Community group home	269 (79.8%)	68 (20.2%)	
	Residential Care	164 (85.4%)	28 (14.6%)	
Level of intellectual disabilities	Mild	229 (79.8%)	58 (20.2%)	<.001
	Moderate	380 (84.1%)	72 (15.9%)	
	Severe to Profound	216 (95.6%)	10 (4.4%)	

5.3.4.4.1 Logistic Regression Analysis of Having ≥3 POPs

Binary logistic regression was conducted to examine demographic factors associated with retaining three or more pairs of occluding premolars (POPs). The model was statistically significant ($\chi^2(7) = 67.84, p < .001$), explained 22.9% of the variance (Nagelkerke $R^2 = 0.229$), and achieved an overall classification accuracy of 69.4%. Model calibration was acceptable (Hosmer–Lemeshow $p > .05$), and diagnostic testing indicated no evidence of multicollinearity (all VIF < 1.5).

Age was strongly associated with retention of ≥3 POPs. Compared with participants aged <50 years, those aged 50–64 years had significantly lower odds of retaining ≥3 POPs (OR = 0.38, 95% CI 0.21–0.69, $p = .001$), while participants aged ≥65 years had markedly lower odds (OR = 0.12, 95% CI 0.06–0.26, $p < .001$). Level of intellectual disabilities was also independently associated with POP retention. Compared with participants with severe–profound intellectual disabilities, those with moderate intellectual disabilities (OR = 3.12, 95% CI 1.40–6.98, $p = .006$) and mild intellectual disabilities (OR = 2.84, 95% CI 1.21–6.67, $p = .016$) had higher odds of retaining ≥3 POPs. Gender and residence type were not significantly associated with POP retention in the adjusted model.

Table 5.14 Logistic Regression Predicting Having ≥ 3 Pairs of Occluding Premolars

<i>Demographic characteristic</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
<i>Gender (Female vs. male)</i>	0.73	0.46 – 1.17	.187
<i>Residence (Community vs. independent)</i>	0.77	0.43 – 1.38	.383
<i>Residence (Residential vs. independent)</i>	0.91	0.43 – 1.93	.802
<i>Age (50–64 vs. <50)</i>	0.38	0.21 – 0.69	.001
<i>Age (65+ vs. <50)</i>	0.12	0.06 – 0.26	<.001
<i>Moderate intellectual disabilities vs. severe–profound</i>	3.12	1.40 – 6.98	.006
<i>Mild intellectual disabilities vs. severe–profound intellectual disabilities</i>	2.84	1.21 – 6.67	.016

Note. Reference categories: <50 years, severe–profound intellectual disabilities, independent/family residence, male. OR = odds ratio; CI = confidence interval.

5.3.4.5 Front Twelve Teeth

Retention of the front twelve teeth was examined as an indicator of anterior dentition. In this cohort, only 38.3% of participants retained all front twelve teeth, indicating substantial anterior tooth loss. Retention varied significantly across demographic groups (Table 5.14).

Participants aged <50 years were considerably more likely to retain the front twelve teeth (68.0%) compared with those aged ≥ 65 years (18.3%) ($p < .001$). Residential setting was also associated with retention, with participants living independently or with family showing the highest prevalence (59.5%) compared with those living in residential care (20.3%) ($p < .001$).

Level of intellectual disabilities was also associated with anterior tooth retention. Participants with severe–profound intellectual disabilities had the lowest prevalence of retaining the front twelve teeth (14.8%) compared with 47.8% among those with mild intellectual disabilities ($p < .001$). Gender differences were not statistically significant ($p = .127$).

Table 5.15. Presence of Front Twelve Teeth by Demographic

Demographic characteristic	Category	Front 12 Teeth Absent (n, %)	Front 12 Teeth Present (n, %)	p-value
Gender	Male	121 (57.9%)	88 (42.1%)	.127
	Female	152 (65.0%)	82 (35.0%)	
Age group	<50	39 (32.0%)	83 (68.0%)	<.001
	50–64	136 (67.7%)	65 (32.3%)	
	65+	98 (81.7%)	22 (18.3%)	
Residence type	Independent/Family	45 (40.5%)	66 (59.5%)	<.001
	Community group home	134 (62.6%)	80 (37.4%)	
	Residential Care	94 (79.7%)	24 (20.3%)	
Level of intellectual disabilities	Mild	71 (52.2%)	65 (47.8%)	<.001
	Moderate	108 (59.3%)	74 (40.7%)	
	Severe to Profound	75 (85.2%)	13 (14.8%)	

Note. Values are presented as n (%) unless otherwise stated. Percentages are calculated from valid responses and may not sum to 100% due to rounding. P-values are derived from Pearson chi-square tests. Statistically significant associations are indicated at $p < .05$.

5.3.4.5.1 Logistic Regression of Front Twelve Teeth

Binary logistic regression was conducted to examine demographic factors associated with retaining the front twelve teeth (Table 5.15). The model was statistically significant ($\chi^2(7) = 85.43$, $p < .001$), explained 25.9% of the variance (Nagelkerke $R^2 = 0.259$), and correctly classified 71.1% of cases. Model calibration was acceptable (Hosmer–Lemeshow $p > .05$), and diagnostic testing indicated no evidence of multicollinearity (all VIF < 1.5).

Age was strongly associated with retention of the front twelve teeth. Compared with participants aged ≥ 65 years, those aged < 50 years had higher odds of retaining the front twelve teeth (OR = 3.18, 95% CI 1.82–5.55, $p < .001$), as did those aged 50–64 years (OR = 2.74, 95% CI 1.59–4.87, $p < .001$).

Level of intellectual disabilities was also associated with anterior tooth retention. Participants with severe–profound intellectual disabilities had significantly lower odds of retaining the front twelve teeth compared with those with mild intellectual disabilities (OR = 0.26, 95% CI 0.12–0.57, $p < .001$). Gender and residence type

were not significantly associated with retention of the front twelve teeth in the adjusted models.

Table 5.16. Binary logistic regression of retention of the front twelve teeth

<i>Demographic Characteristics</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
<i>Gender (Male vs. female)</i>	1.02	0.65 – 1.61	.940
<i>Age (<50 vs. 65+)</i>	3.18	1.82 – 5.55	<.001
<i>Age (50–64 vs. 65+)</i>	2.74	1.59 – 4.87	<.001
<i>Residence (Independent/family vs. residential)</i>	0.74	0.42 – 1.31	.302
<i>Residence (Group home vs. residential)</i>	0.63	0.30 – 1.31	.215
<i>Moderate intellectual disabilities vs. mild intellectual disabilities</i>	0.88	0.54 – 1.46	.628
<i>Severe–profound intellectual disabilities vs. mild intellectual disabilities</i>	0.26	0.12 – 0.57	<.001

Note. Reference categories: 65+ years, mild intellectual disabilities, residential care, female. OR = odds ratio; CI = confidence interval.

5.3.4.6 Functional Dentition

As outlined in the Methods, definitions of functional dentition vary. In this study, functional dentition was defined as meeting all three of the following criteria: (1) presence of at least 20 natural teeth, (2) retention of the twelve anterior teeth, and (3) the presence of at least three pairs of occluding premolars to ensure a stable and efficient bite (Nguyen et al., 2011). This composite variable was derived from the three underlying indicators described earlier.

Analysis of functional dentition across demographic groups (Table 5.16) demonstrated significant associations with age, residence type, and level of intellectual disabilities. Retention of functional dentition declined markedly with age: 59.6% of participants aged <50 years retained functional dentition compared with 23.2% of those aged 50–64 years and 11.2% of those aged ≥65 years ($p < .001$).

Residential setting was also associated with functional dentition. Participants living independently or with family had the highest prevalence (47.7%), compared with 27.5% among those living in community group homes and 13.7% among those living in residential care ($p < .001$).

Level of intellectual disabilities was similarly associated with functional dentition. Only 4.7% of participants with severe–profound intellectual disabilities retained

functional dentition compared with 35.8% among those with mild intellectual disabilities ($p < .001$). Gender differences were not statistically significant ($p = .142$).

Table 5.16. Functional Dentition by Demographic Variables

<i>Demographic characteristic</i>	<i>Category</i>	<i>No Functional Dentition (n, %)</i>	<i>Functional Dentition (n, %)</i>	<i>p-value</i>
<i>Gender</i>	Male	125 (66.8%)	62 (33.2%)	.142
	Female	161 (73.5%)	58 (26.5%)	
<i>Age group</i>	<50	44 (40.4%)	65 (59.6%)	<.001
	50–64	139 (76.8%)	42 (23.2%)	
	65+	103 (88.8%)	13 (11.2%)	
<i>Residence type</i>	Independent/Family	58 (52.3%)	53 (47.7%)	<.001
	Community group home	140 (72.5%)	53 (27.5%)	
	Residential Care	88 (86.3%)	14 (13.7%)	
<i>Level of intellectual disabilities</i>	Mild	86 (64.2%)	48 (35.8%)	<.001
	Moderate	117 (68.0%)	55 (32.0%)	
	Severe to Profound	61 (95.3%)	3 (4.7%)	

5.3.4.6.1 Logistic Regression Analysis of Functional Dentition

Binary logistic regression was conducted to examine demographic factors associated with retaining functional dentition (Table 5.17). The model was statistically significant ($\chi^2(7) = 79.51, p < .001$), explaining between 19.4% (Cox & Snell R^2) and 27.7% (Nagelkerke R^2) of the variance, and correctly classifying 76.4% of cases. Model calibration was acceptable (Hosmer–Lemeshow $p > .05$), and diagnostic testing indicated no evidence of multicollinearity (all VIF < 1.5).

Age was strongly associated with functional dentition. Compared with participants aged <50 years, those aged 50–64 years had significantly lower odds of retaining functional dentition (OR = 0.28, 95% CI 0.15–0.52, $p < .001$), while participants aged ≥ 65 years had substantially lower odds (OR = 0.10, 95% CI 0.05–0.24, $p < .001$).

Level of intellectual disabilities was also associated with functional dentition. Participants with severe–profound intellectual disabilities had significantly lower odds of retaining functional dentition compared with those with mild intellectual disabilities (OR = 0.15, 95% CI 0.04–0.55, $p = .004$). Gender, residence type, and

moderate intellectual disabilities were not significantly associated with functional dentition in the adjusted model.

Table 5.17. Binary logistic regression predicting retention of functional dentition

<i>Demographic characteristic</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
<i>Gender (Male vs. female)</i>	0.97	0.58 – 1.63	.920
<i>Residence (Community vs. independent)</i>	0.80	0.44 – 1.46	.467
<i>Residence (Residential vs. independent)</i>	0.75	0.32 – 1.75	.498
<i>Age (50–64 vs. <50)</i>	0.28	0.15 – 0.52	<.001
<i>Age (65+ vs. <50)</i>	0.10	0.05 – 0.24	<.001
<i>Moderate intellectual disabilities vs. mild intellectual disabilities</i>	1.04	0.61 – 1.78	.873
<i>Severe–profound intellectual disabilities vs. mild intellectual disabilities</i>	0.15	0.04 – 0.55	.004

Note. Reference categories: <50 years, mild intellectual disabilities, independent/family residence, female. OR = odds ratio; CI = confidence interval.

5.3.4.7 Oral Function Summary

Across all indicators, oral function was strongly patterned by age and level of intellectual disabilities. Tooth count analyses showed that a substantial proportion of participants had fewer than 20 natural teeth, with prevalence increasing markedly in older age groups. Similar patterns were observed across other indicators of oral function, including dentate status, posterior occlusal contacts, retention of the front twelve teeth, and the composite measure of functional dentition.

Functional dentition was considerably less common among participants with severe–profound intellectual disabilities and among those living in more supported residential settings. Older adults with intellectual disabilities, particularly those aged ≥65 years, consistently demonstrated lower likelihood of retaining natural teeth and functional occlusal structures across all measures.

Overall, these findings demonstrate substantial reductions in functional oral health across the cohort, with the most pronounced differences observed by age and level of intellectual disabilities.

5.3.5 Oral Disease Indicators

Oral disease indicators provide an overview of current oral disease burden within the cohort. This section examines the distribution of cavitated teeth and presents regression analyses examining demographic associations with cavitated teeth severity.

5.3.5.1 Cavitated Teeth

The distribution of visibly cavitated teeth across demographic groups is presented in Table 5.18. Overall, 62.6% of participants had no cavitated teeth, while 29.1% had one to two cavitated teeth and 8.3% had three or more.

Significant differences were observed by age group ($p = .007$) and level of intellectual disabilities ($p < .001$). Participants aged <50 years were more likely to present with cavitated teeth than older adults, and participants with mild and moderate intellectual disabilities had a higher prevalence of cavitation compared with those with severe–profound intellectual disabilities. Differences by residence type approached statistical significance ($p = .056$), while gender was not significantly associated with cavitated teeth prevalence ($p = .105$).

Table 5.18. Presence of Cavitated Teeth by Demographic Characteristics

<i>Demographic characteristic</i>	<i>Category</i>	<i>≥3 Cavitated Teeth (%)</i>	<i>1–2 Cavitated Teeth (%)</i>	<i>No Cavitated Teeth (%)</i>	<i>p- value</i>
Gender	Male	21 (11.6)	55 (30.4)	105 (58.0)	.105
	Female	11 (5.4)	57 (28.1)	135 (66.5)	
Age group	<50	9 (8.3)	39 (35.8)	61 (56.0)	.007
	50–64	16 (9.5)	50 (29.8)	102 (60.7)	
	65+	7 (6.5)	23 (21.5)	77 (72.0)	
Residence type	Independent/Family	8 (7.3)	38 (34.5)	64 (58.2)	.056
	Community group home	16 (8.4)	52 (27.2)	123 (64.4)	
	Residential care	8 (9.6)	22 (26.5)	53 (63.9)	
Level of intellectual disabilities	Mild	10 (7.5)	40 (30.1)	83 (62.4)	<.001
	Moderate	14 (8.2)	55 (32.4)	101 (59.4)	
	Severe to profound	4 (8.9)	6 (13.3)	35 (77.8)	

Note. Percentages are row percentages. p -values are derived from Pearson chi-square tests.

5.3.5.1.1 Multinomial Logistic Regression: Cavitated Teeth

Multinomial logistic regression was conducted to examine demographic associations with cavitated teeth severity, using no cavitated teeth as the reference outcome category (Table 5.19).

The overall model was statistically significant ($p < .001$), explaining between 31.5% and 34.8% of the variance in cavitated teeth status. Participants aged <50 years had higher odds of having one to two cavitated teeth compared with those aged ≥ 65 years (OR = 2.12, 95% CI 1.03–4.37, $p = .041$). Participants with mild intellectual disabilities also had higher odds of having one to two cavitated teeth compared with those with severe–profound intellectual disabilities (OR = 3.01, 95% CI 1.16–7.79, $p = .023$). For the outcome category of three or more cavitated teeth, male gender was the only significant predictor. No evidence of multicollinearity was identified.

Table 5.19. Multinomial Logistic Regression Predicting Cavitated Teeth

Outcome: 1–2 Cavitated Teeth vs No Cavitated Teeth

<i>Demographic characteristic</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
<i>Gender (Male vs Female)</i>	1.28	0.79 – 2.08	.319
<i>Residence (Independent/Family vs Community)</i>	0.81	0.37 – 1.79	.603
<i>Residence (Residential vs Community)</i>	0.73	0.38 – 1.41	.348
<i>Age <50 vs 65+</i>	2.12	1.03 – 4.37	.041
<i>Age 50–64 vs 65+</i>	1.54	0.83 – 2.85	.167
<i>Mild intellectual disabilities vs Severe–Profound intellectual disabilities</i>	3.01	1.16 – 7.79	.023
<i>Moderate intellectual disabilities vs Severe–Profound intellectual disabilities</i>	2.66	0.99 – 7.19	.053

Note. Reference categories: female; ≥ 65 years; severe–profound intellectual disabilities; community group home residence. OR = odds ratio; CI = confidence interval.

5.3.5.1.2 Binary Logistic Regression: Absence of Cavitated Teeth

Binary logistic regression was conducted to examine demographic factors associated with absence of cavitated teeth (Table 5.20). The model approached statistical significance ($p = .054$) and demonstrated acceptable model fit.

Male gender was the only variable significantly associated with absence of cavitated teeth, with males showing higher odds of being free from cavitated teeth compared with females (OR = 2.37, 95% CI 1.04–5.44, $p = .041$). Age group,

residence type, and level of intellectual disabilities were not significantly associated with absence of cavitated teeth in the adjusted model.

Table 5.20. Binary Logistic Regression Predicting Absence of Cavitated Teeth

<i>Demographic characteristic</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
<i>Gender (Male vs Female)</i>	2.37	1.04 – 5.44	.041
<i>Residence (Independent/Family vs Community)</i>	1.00	0.29 – 3.49	.996
<i>Residence (Residential vs Community)</i>	0.83	0.30 – 2.30	.722
<i>Age <50 vs 65+</i>	0.95	0.27 – 3.31	.939
<i>Age 50–64 vs 65+</i>	1.49	0.57 – 3.89	.418
<i>Mild intellectual disabilities vs Severe–Profound intellectual disabilities</i>	1.16	0.34 – 3.93	.811
<i>Moderate intellectual disabilities vs Severe–Profound intellectual disabilities</i>	1.12	0.30 – 4.16	.871

Note. Reference categories: female; ≥65 years; severe–profound intellectual disabilities; community group home residence. OR = odds ratio; CI = confidence interval.

5.3.5.2 Gum Condition

After excluding edentulous participants, gum condition was examined as an indicator of periodontal health. The distribution of gum condition across demographic groups is presented in Table 5.21. Residence type and level of intellectual disabilities were significantly associated with gum health, while age group and gender were not statistically significant at the bivariate level.

Participants living in community group homes had the highest proportion of healthy gums (43.6%), followed by those living independently or with family (37.5%), whereas participants residing in residential care had the lowest proportion (24.1%) ($p = .011$). Gum health also differed significantly by level of intellectual disabilities. Participants with severe–profound intellectual disabilities had the lowest proportion of healthy gums (17.0%) compared with those with mild (40.2%) and moderate intellectual disabilities (36.5%) ($p = .011$). No statistically significant differences were observed across age groups or by gender.

Table 5.21 . Gum condition by demographic and residential variables

<i>Demographic characteristic</i>	<i>Category</i>	<i>Gums Not Healthy n (%)</i>	<i>Gums Healthy n (%)</i>	<i>p-value</i>
Gender	Male	112 (64.4)	62 (35.6)	.543
	Female	109 (61.2)	69 (38.8)	
Age group	<50	73 (65.2)	39 (34.8)	.487
	50–64	102 (59.6)	69 (40.4)	
	65+	46 (66.7)	23 (33.3)	
Residence type	Independent/Family	65 (62.5)	39 (37.5)	.011
	Community group home	93 (56.4)	72 (43.6)	
	Residential care	63 (75.9)	20 (24.1)	
Level of intellectual disabilities	Mild	70 (59.8)	47 (40.2)	.011
	Moderate	94 (63.5)	54 (36.5)	
	Severe–profound	44 (83.0)	9 (17.0)	

Note. Percentages are row percentages. *p*-values are derived from Pearson chi-square tests.

5.3.5.2.1 Factors Associated with Healthy Gums

A binary logistic regression was conducted to examine demographic factors associated with healthy gums (healthy vs. not healthy), adjusting for age group, gender, level of intellectual disabilities, and residence type. The model was statistically significant ($\chi^2(7) = 21.04, p = .004$). Level of intellectual disabilities was independently associated with gum health. Compared with participants with severe–profound intellectual disabilities, those with mild intellectual disabilities had significantly higher odds of having healthy gums (OR = 2.97, 95% CI 1.23–7.18, $p = .015$), as did those with moderate intellectual disabilities (OR = 2.50, 95% CI 1.08–5.80, $p = .033$). Age was also associated with gum health. Participants aged 50–64 years had higher odds of healthy gums compared with those aged under 50 years (OR = 2.09, 95% CI 1.15–3.81, $p = .016$). No statistically significant associations were observed for gender or residence type.

Table 5.22 Binary logistic regression predicting healthy gums

<i>Demographic characteristic</i>	<i>OR</i>	<i>95% CI</i>	<i>p-value</i>
Gender			
<i>Female vs. Male</i>	1.14	0.70 – 1.86	.600
Residence type			
<i>Community group home vs. Independent</i>	1.19	0.66 – 2.14	.558
<i>Residential care vs. Independent</i>	0.59	0.27 – 1.32	.198
Age group			
<i>50–64 vs. <50</i>	2.09	1.15 – 3.81	.016
<i>65+ vs. <50</i>	1.20	0.56 – 2.56	.635
Level of intellectual disabilities			
<i>Mild vs. Severe–profound</i>	2.97	1.23 – 7.18	.015
<i>Moderate vs. Severe–profound</i>	2.50	1.08 – 5.80	.033

Note. Reference categories: male, <50 years, severe–profound intellectual disabilities, and independent/family residence. OR = odds ratio; CI = confidence interval.

5.3.5.3 Oral Cleanliness

Oral cleanliness, assessed by the presence of visible plaque, debris, or calculus on the teeth or dentures, was generally poor in this cohort. Overall, fewer than one-third of participants (27.0%) were classified as having a clean mouth or dentures at the time of examination. As shown in Table 5.23, oral cleanliness did not differ significantly by gender, age group, residence type, or level of intellectual disabilities. The proportion of participants classified as having a clean mouth ranged from 23.2% to 32.8% across subgroups. No statistically significant associations were observed for gender ($p = .512$), age group ($p = .239$), residence type ($p = .702$), or level of intellectual disabilities ($p = .659$).

Table 5.23. Oral cleanliness by demographic and residential variables

<i>Predictor</i>	<i>Category</i>	<i>Mouth/Dentures Not Clean n (%)</i>	<i>Mouth/Dentures Clean n (%)</i>	<i>p- value</i>
Gender	Male	145 (71.4)	58 (28.6)	.512
	Female	170 (74.2)	59 (25.8)	
Age group	<50	88 (73.3)	32 (26.7)	.239
	50–64	149 (76.0)	47 (24.0)	
	65+	78 (67.2)	38 (32.8)	
Residence type	Independent/Family	81 (74.3)	28 (25.7)	.702
	Community group home	155 (73.8)	55 (26.2)	
	Residential care	79 (69.9)	34 (30.1)	
Level of intellectual disabilities	Mild	97 (72.4)	37 (27.6)	.659
	Moderate	128 (71.5)	51 (28.5)	
	Severe–profound	63 (76.8)	19 (23.2)	

Note. Values are presented as *n* (%). Percentages are calculated from valid responses. P-values are derived from Pearson chi-square tests

5.3.5.3.1 Factors Associated with Oral Cleanliness

A binary logistic regression was conducted to examine demographic factors associated with oral cleanliness (clean vs not clean), adjusting for gender, age group, residence type, and level of intellectual disabilities. The overall model was not statistically significant ($p = .780$), and none of the variables were independently associated with oral cleanliness after adjustment (Table 5.24).

Table 5.24. Binary logistic regression predicting oral cleanliness

<i>Predictor</i>	<i>OR</i>	<i>95% CI</i>	<i>p-value</i>
Gender			
<i>Female vs. Male</i>	0.86	0.54 – 1.35	.503
Residence type			
<i>Community group home vs. Independent</i>	0.90	0.49 – 1.64	.725
<i>Residential care vs. Independent</i>	1.05	0.50 – 2.21	.896
Age group			
<i>50–64 vs. <50</i>	0.98	0.53 – 1.79	.943
<i>65+ vs. <50</i>	1.48	0.76 – 2.86	.249
Level of intellectual disabilities			
<i>Moderate vs. Mild</i>	1.29	0.64 – 2.61	.480
<i>Severe–profound vs. Mild</i>	1.35	0.71 – 2.55	.361

Note. Reference categories: male, <50 years, mild intellectual disabilities, and independent/family residence. OR = odds ratio; CI = confidence interval.

5.3.5.4 Oral Pain:

Oral pain was reported in 8.2% of participants, with most cases identified through verbal or vocal reports rather than behavioural cues. Table 5.25 summarises oral pain prevalence across demographic groups.

No statistically significant differences in oral pain were observed by gender ($p = .322$), age group ($p = .728$), or level of intellectual disabilities ($p = .201$). A borderline non-significant difference was observed by residence type, with higher reported pain among participants living independently or with family (11.9%) compared with those living in community group homes (4.4%) ($p = .057$).

Table 5.25. Oral pain by demographic and care-related variables

<i>Predictor</i>	<i>Category</i>	<i>No Pain Reported (n, %)</i>	<i>Pain Reported (n, %)*</i>	<i>p-value</i>
Gender	Male	206 (94.1%)	13 (5.9%)	.322
	Female	218 (90.8%)	22 (9.2%)	
Age group	<50	116 (91.3%)	11 (8.7%)	.728
	50–64	192 (91.9%)	17 (8.1%)	
	65+	116 (94.3%)	7 (5.7%)	
Residence type	Independent/Family	96 (88.1%)	13 (11.9%)	.057
	Community group home	215 (95.6%)	10 (4.4%)	
	Residential Care	113 (90.4%)	12 (9.6%)	
Level of intellectual disabilities	Mild	123 (90.4%)	13 (9.6%)	.201
	Moderate	168 (91.3%)	16 (8.7%)	
	Severe to Profound	97 (95.1%)	5 (4.9%)	
Totals				

Note. Values are presented as *n (%)*. Percentages are calculated from valid responses. P-values are derived from Pearson chi-square tests. *Pain reported* includes verbal/vocal reports and behavioural/physical indicators.

5.3.5.4.1 Factors Associated with Oral Pain

A binary logistic regression was conducted to examine demographic factors associated with oral pain (pain reported vs no pain), adjusting for gender, age group, residence type, and level of intellectual disabilities (Table 5.26). Residence type was the only variable significantly associated with reported oral pain. Compared with participants living independently or with family, those living in community group homes had lower odds of reported oral pain (OR = 0.36, 95% CI 0.14–0.96, $p = .040$). Gender, age group, and level of intellectual disabilities were not significantly associated with oral pain after adjustment.

Table 5.26. Logistic Regression Predicting Oral Pain from Demographic

<i>Predictor</i>	<i>OR</i>	<i>95% CI for OR</i>	<i>p-value</i>
Gender			
Female vs Male	1.69	0.81 – 3.52	0.164
Residence type			
Community group home vs Independent	0.36	0.14 – 0.96	0.40*
Residential care vs Independent	1.14	0.38 – 3.43	0.816
Age group			
50–64 vs <50	0.89	0.35 – 2.29	0.814
65+ vs <50	0.61	0.20 – 1.89	0.391
Level of ID			
Moderate vs Mild	1.02	0.45 – 2.30	0.958
Severe to Profound vs Mild	0.46	0.14 – 1.58	0.222

Note: Reference categories: male, independent/family residence, <50 years, mild intellectual disabilities. OR = odds ratio; CI = confidence interval.

5.3.5.5 Oral Disease Indicators Summary

Across the four oral disease indicators examined (cavitated teeth, gum health, oral cleanliness, and oral pain), findings indicate a substantial burden of oral health conditions among older adults with intellectual disabilities. Cavitated teeth were present in more than one-third of participants, with younger adults and those with mild or moderate intellectual disabilities more likely to present with cavitation. In contrast, participants with severe to profound intellectual disabilities were more frequently free from cavitated teeth but demonstrated poorer gum health compared with those with milder levels of intellectual disabilities.

Oral cleanliness was poor across the cohort, with fewer than one-third of participants classified as having a clean mouth or dentures at the time of examination. No significant demographic or residential predictors of oral cleanliness were identified. Reported oral pain was relatively uncommon, affecting fewer than one in ten participants. No significant differences were observed across gender, age group, or level of intellectual disabilities, although a borderline difference was observed by residence type, with higher reported pain among participants living independently or with family compared with those living in community group homes.

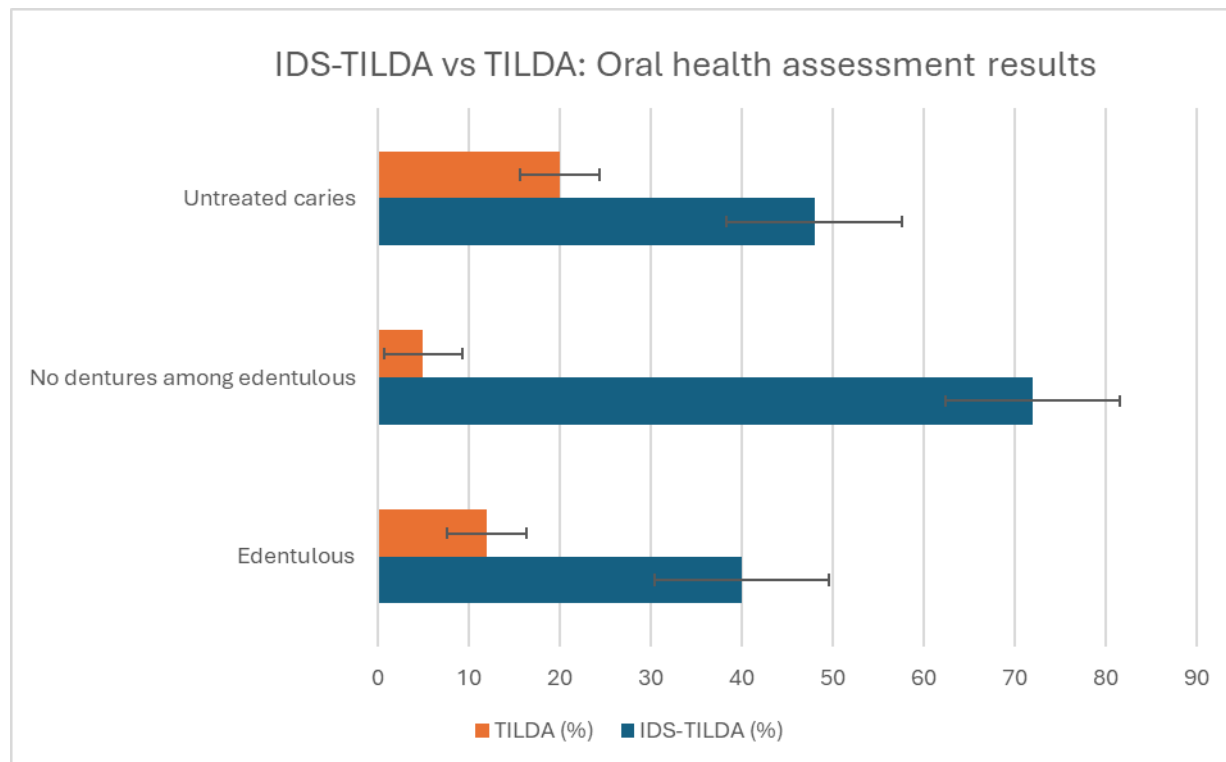
5.3.5.6 IDS TILDA in Comparison with TILDA Oral health Indicators

To contextualise clinically observed oral health findings from IDS-TILDA Wave 5, selected oral health indicators were descriptively compared with corresponding data from The Irish Longitudinal Study on Ageing (TILDA). Comparisons were limited to indicators that were conceptually and methodologically comparable across studies, specifically tooth count, prevalence of edentulism, denture wear among edentulous participants, and the presence of untreated cavitated teeth. These comparisons are presented visually in Figures 5.2 and 5.3.

As shown in Figure 5.2, adults with intellectual disabilities experienced poorer oral health than their peers in the general ageing population across the selected indicators. The prevalence of edentulism was higher in IDS-TILDA than in TILDA. Among those who were edentulous, denture wear was lower among IDS-TILDA

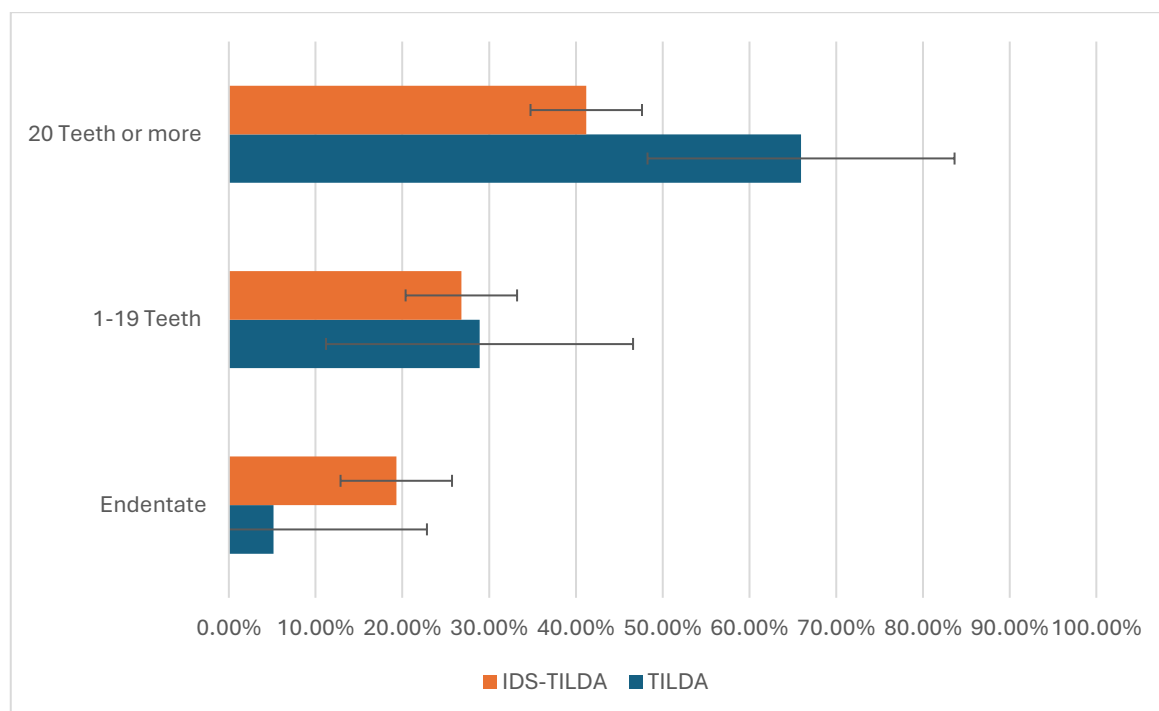
participants, while untreated cavitated teeth were more prevalent in the IDS-TILDA cohort.

Figure 5.2. Comparison of selected oral health indicators between IDS-TILDA Wave 5 and TILDA participants.



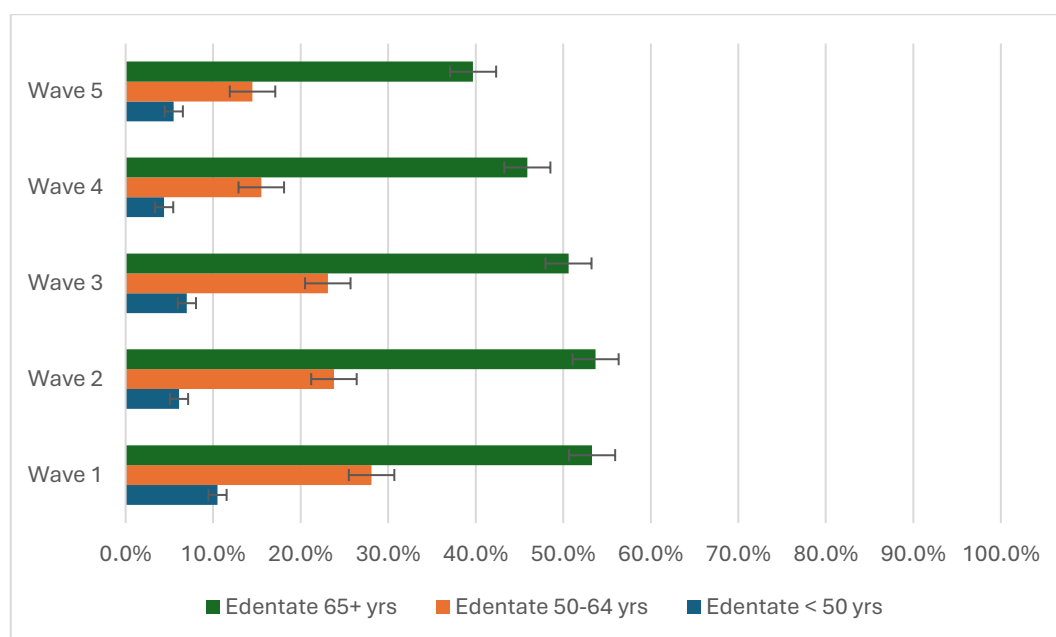
Differences in tooth retention are further illustrated in Figure 5.3, which compares tooth count categories between IDS-TILDA and TILDA. While nearly two-thirds of TILDA participants retained 20 teeth or more, fewer than half of IDS-TILDA participants met this threshold, and almost one in five were completely edentulous. This distribution highlights substantial loss of functional dentition among adults with intellectual disabilities relative to the general population.

Figure 5.3. Tooth count distribution for IDS TILDA vs TILDA



These figures demonstrate that adults with intellectual disabilities in Ireland not only experience worse oral health than their peers in the general population, but also that these disparities persist across adulthood and into older age. While modest improvements in edentulism are evident over time, the continued high prevalence of tooth loss and lack of functional rehabilitation underscore enduring structural inequalities in access to preventive and restorative dental care. Edentulism across IDS-TILDA waves is shown in Figure 5.4, stratified by age group. Although modest reductions in edentulism were observed across waves, particularly among older age groups, the prevalence of edentulism remained high across the cohort. This pattern indicates that tooth loss persisted across adulthood and older age among participants with intellectual disabilities.

Figure 5.4. Edentulism across IDS-TILDA waves stratified by age group



These comparisons show that adults with intellectual disabilities in Ireland experienced poorer oral health than their peers in the general ageing population, while IDS-TILDA longitudinal data indicate that edentulism has remained a persistent feature across waves. Comparisons between IDS-TILDA and TILDA are descriptive and should be interpreted cautiously due to differences in study design, age eligibility criteria and data collection methods. Nonetheless, the consistency of patterns across indicators and waves supports the conclusion that oral health disadvantage among adults with intellectual disabilities is substantial, persistent and cumulative.

5.4 Discussion

5.4.1 Overview of Key Findings

This chapter provides the first clinically assessed, nationally representative profile of oral health in older adults with intellectual disabilities in Ireland. The findings show substantial unmet need across tooth retention, disease burden and oral function. Participants retained a mean of 16.6 natural teeth and almost one in five were edentulous, yet most edentulous adults were not wearing dentures. Markers of preventable disease were also common. Oral cleanliness was poor in nearly three quarters of participants and more than one third had untreated cavitated

teeth. This pattern is consistent with international reviews demonstrating higher plaque levels, gingival inflammation, periodontal disease and untreated caries among adults with intellectual disabilities compared with the general population (Anders & Davis, 2010; Ward et al., 2019; Morgan et al., 2012).

Crucially, the chapter shows that inequality is not only expressed as disease prevalence, but also as loss of function. Only a minority met criteria for functional dentition when occlusal support and anterior retention were considered, and many had limited or absent posterior contacts. These functional losses matter because they are linked in the wider ageing literature with restricted diet, reduced nutritional quality, dysphagia and elevated respiratory risk (Dibello et al., 2023; Nitsuwat et al., 2024; Scannapieco, 2006; van der Maarel-Wierink et al., 2011). Taken together, the findings indicate that older adults with intellectual disabilities are experiencing both higher disease burden and earlier, more extensive functional deterioration than would be expected in the general ageing population.

5.4.2 Oral Function in People with Intellectual Disabilities in the Context of the Literature

Oral function in this cohort was substantially impaired relative to benchmarks for healthy ageing and relative to older adults without intellectual disabilities in Ireland. The WHO threshold for functional dentition is commonly defined as retention of at least 20 natural teeth, reflecting the minimum generally required to support adequate mastication, diet and quality of life (WHO, 2013). In IDS-TILDA, more than half of participants fell below this threshold, contrasting with contemporary population studies in Ireland and other high-income countries where most adults now retain 20 or more teeth into later life (Byrne, 2023; Naseer et al., 2022; Sheehan et al., 2017). The persistence of functional tooth loss in this cohort, despite improvements elsewhere, indicates a continuing and substantial inequality.

The distribution of tooth loss also suggests meaningful impacts beyond chewing. A low proportion retained the front twelve teeth, which are central to speech, appearance and social interaction. In the general population, visible anterior tooth loss is associated with lower oral-health-related quality of life, stigma and

withdrawal (Gerritsen et al., 2010; John et al., 2002). Qualitative work in intellectual disabilities settings suggests similar consequences may occur for adults with intellectual disabilities, affecting identity, confidence and social participation (Phadraig et al., 2019; Ward et al., 2019).

Posterior tooth loss is particularly important for mastication and swallowing. Many participants had limited or absent occlusal contacts, and few met thresholds commonly used to indicate functional mastication (Nguyen et al., 2011). In older adults population, reduced occluding pairs are linked to slower chewing, restricted diet texture, and reduced intake of key nutrients, which in turn are associated with frailty, sarcopenia and mortality (Ohi et al., 2020; Tada & Miura, 2017; Zelig et al., 2022). For adults with intellectual disabilities, these functional consequences likely interact with existing vulnerabilities such as feeding difficulties, reliance on caregivers for food preparation, and polypharmacy, meaning functional oral loss may carry greater downstream impact and occur earlier in the ageing trajectory.

Functional impairment is further compounded by low prosthetic rehabilitation. The high proportion of edentulous adults without dentures is consistent with Irish and international evidence of limited prosthodontic provision for adults with intellectual disabilities (Mac Giolla Phádraig et al., 2015; Anders & Davis, 2010; Morgan et al., 2012; Ward et al., 2019). The literature highlights barriers including service access, limited clinician confidence, challenges completing impressions and fittings, and insufficient support for follow-up and maintenance (Dougall & Fiske, 2008; Faulks et al., 2012). In this context, maintaining and restoring oral function should be considered a core component of healthy ageing for people with intellectual disabilities, rather than an elective or cosmetic aspect of dental care.

5.4.3 Oral Disease Burden in Adults with Intellectual Disabilities

The MOSST identified a substantial burden of preventable oral disease. Over one third of participants had untreated cavitated teeth, and oral cleanliness was poor for most. These findings align with international evidence demonstrating higher levels of untreated caries and poorer plaque control among adults with intellectual disabilities (Anders & Davis, 2010; Ward et al., 2019; Morgan et al., 2012). The high prevalence of untreated cavitated teeth suggests barriers to timely restorative care, including difficulties attending appointments, limited availability of

appropriately trained clinicians, and reliance on reactive models of treatment (Mac Giolla Phadraig et al., 2022).

Periodontal indicators also displayed patterning by support need and setting, with poorer gum health among those with severe to profound intellectual disabilities and those living in higher-support environments. This is consistent with evidence that periodontal outcomes are closely shaped by the feasibility and consistency of supported toothbrushing, staff capability and organisational systems, rather than individual choice (Cumella et al., 2000; Wilson et al., 2019).

Reported oral pain was low relative to the measured disease burden and should be interpreted cautiously. The pain literature consistently shows that adults with intellectual disabilities, particularly those with limited communication, may express pain through behavioural or functional changes rather than verbal report, and that pain is frequently under-detected and under-treated (Doody & Bailey, 2019; Rech et al., 2025). Diagnostic overshadowing compounds this, as distress or behaviour change may be attributed to disability rather than investigated clinically (Heslop et al., 2014; Krahn et al., 2015; Mason & Scior, 2004). This supports the need for systematic approaches to pain recognition, including structured observational tools where appropriate (Rech et al., 2025).

5.4.4 Demographic and Contextual Patterning of Oral Health

Oral health in this cohort was patterned by age, severity of intellectual disabilities and residential context. Older age groups showed progressively greater tooth loss and poorer functional dentition, with steeper decline than typically reported in the general population. This aligns with wider evidence of earlier onset and greater burden of age-related conditions in intellectual disabilities, consistent with concepts of premature and accelerated ageing in this population (Coppus, 2013; Hermans & Evenhuis, 2014; McCarron et al., 2013).

Severity of intellectual disabilities was among the strongest determinants of disadvantage. Adults with severe to profound intellectual disabilities had the greatest tooth loss, the poorest gum health and the lowest denture use. This matches international evidence that higher support needs are associated with greater oral health burden due to dependence on caregivers, difficulty tolerating

oral hygiene and treatment, and exclusion from routine dental access (Anders & Davis, 2010; Ward et al., 2019; Chadwick et al., 2018; Faulks et al., 2013).

Residential context also mattered. Participants living in residential care tended to have poorer oral health outcomes than those living independently or with family. The literature suggests this may reflect organisational constraints such as staffing pressures, workforce turnover, limited training and competing care priorities that undermine consistent daily oral care in residential settings (Chadwick et al., 2018; Mac Giolla Phadraig et al., 2013). In contrast, family environments may provide greater continuity of care and advocacy, which can influence recognition of oral health problems and access to dental services (McConkey & Collins, 2010; Taggart & Cousins, 2014; Ward et al., 2019).

5.4.5 IDS-TILDA in Comparison with TILDA and Change Over Time

Direct comparison with Ireland's general ageing population highlights the scale and persistence of oral health inequality experienced by adults with intellectual disabilities. In TILDA, adults aged 50 years and older retain, on average, more than 20 natural teeth and over half meet criteria for functional dentition, defined by adequate tooth number and posterior occlusal support (Sheehan et al., 2017; Naseer et al., 2022; Byrne et al., 2023). By contrast, IDS-TILDA Wave 5 participants retained a mean of only 16.6 natural teeth, fewer than one-third met criteria for functional dentition, and almost one in five were completely edentulous (Byrne et al., 2023). As illustrated in Figures 5.1 and 5.2, edentulism was nearly four times that observed in TILDA, while denture uptake among edentulous adults with intellectual disabilities was markedly lower, indicating substantial unmet need for functional rehabilitation.

This contrast is particularly important because oral health in the general population has improved substantially over recent decades, with greater retention of natural teeth and improved access to restorative and prosthetic care in later life (Sheehan et al., 2017; Naseer et al., 2022; Byrne et al., 2023). In contrast, IDS-TILDA findings suggest that adults with intellectual disabilities continue to enter later life with poorer oral health and have not benefited equally from wider public health

and dental care improvements. Similar disparities have been documented internationally, with studies from the United Kingdom, Australia and the United States reporting higher rates of tooth loss and substantially lower levels of prosthetic rehabilitation among adults with intellectual disabilities compared with the general population (Anders & Davis, 2010; Temple et al., 2014; Wilson et al., 2019). This indicates that the inequality observed is not simply a product of ageing but reflects cumulative exposure to structural barriers across the life course.

The IDS-TILDA longitudinal pattern further supports this interpretation. Across earlier waves, self-report and proxy-report data consistently indicated high levels of tooth loss, low rates of fillings and dentures, and substantial unmet dental need (McCarron et al., 2014; McCarron et al., 2017; Burke et al., 2020). Wave 5, through the introduction of clinically observed MOSST indicators, provides objective support for these earlier patterns. The modest improvements observed over time may reflect cohort effects, whereby younger generations with intellectual disabilities have benefited to some extent from improved preventive care, water fluoridation and changing attitudes toward tooth retention rather than extraction (Cumella et al., 2000; Dougall & Fiske, 2008). However, the persistence of high edentulism rates, particularly among older adults, likely reflects the legacy of historical neglect and limited access to preventive and restorative dental care that characterised services for people with intellectual disabilities in previous decades (Fiske et al., 2000; Cumella et al., 2000).

This pattern reflects the inverse care law, whereby populations with the greatest health needs often experience the poorest access to high-quality healthcare (Tudor Hart, 1971), a pattern consistently documented in disability health research (Emerson & Hatton, 2013). In oral health specifically, people with intellectual disabilities have historically been excluded from mainstream improvements in dental public health, including preventive programmes, routine restorative care and timely prosthetic rehabilitation (Dougall & Fiske, 2008; Anders & Davis, 2010). These inequalities persist even in countries with universal healthcare systems, suggesting that structural and systemic barriers beyond financial access contribute to poorer oral health outcomes for people with intellectual disabilities (Chadwick et al., 2018; Pradhan et al., 2009). The result is a widening gap between population

groups who share the same healthcare system but experience markedly different levels of access, quality and outcomes (Krahn et al., 2015).

Crucially, this chapter shows that inequality is not only expressed through disease prevalence, but also through loss of function. Tooth loss, absence of functional dentition and low levels of prosthetic rehabilitation represent more than dental outcomes; they affect eating, comfort, communication, dignity and participation. This functional dimension is central to understanding oral health inequity in adults with intellectual disabilities and provides a bridge to the later analyses examining systemic vulnerability and mortality.

Although IDS-TILDA and TILDA employ different assessment methods, comparison of core structural indicators such as tooth presence, denture use and functional dentition remains informative because these are clinically meaningful and relatively robust indicators. The longitudinal structure of IDS-TILDA now provides a nationally representative platform through which these inequalities can be monitored over time, enabling future evaluation of whether policy reform, service development and targeted prevention reduce what has historically been a largely invisible pattern of oral health disadvantage.

5.5 Implications for Practice, Policy and Research

The findings indicate that current systems are not delivering effective, preventive and rehabilitative oral healthcare for many older adults with intellectual disabilities. The combination of high tooth loss, low functional dentition, preventable disease burden and limited prosthetic rehabilitation suggests a service pattern characterised by delayed care and insufficient function-preserving support. Addressing these gaps requires a shift toward structured prevention, earlier intervention, and functional restoration when tooth loss occurs.

At a service level, the findings support the need for stronger integration of oral health within disability supports, particularly for people with severe to profound intellectual disabilities and those living in residential care. This includes competency-based staff training, routine supported toothbrushing systems and embedding oral health within care planning and health review processes (Mac Giolla Phádraig et al., 2015; Waldron et al., 2019; Perera et al., 2022).

At a policy level, the findings align with existing commitments to reduce oral health inequalities and improve access for people with disabilities within Ireland's Smile agus Sláinte framework and the WHO strategy on oral health and universal health coverage (Department of Health, 2019; World Health Organization, 2022). However, the persistence of severe functional loss and under-rehabilitation indicates a gap between policy intent and lived experience. The value of IDS-TILDA is that it provides the disability-disaggregated clinical data needed to support planning, monitor progress and evaluate whether reform reduces inequality over time.

Continued disability-inclusive oral health surveillance is essential, as exclusion from national surveys has historically limited visibility and accountability. Research should also examine the feasibility and effectiveness of function-preserving and carer-supported interventions in real-world disability settings, including restorative pathways, oral hygiene programmes and models of supported prosthodontic rehabilitation.

5.6 Future Research

The findings of this chapter indicate that future research should move beyond documenting oral health inequality towards explaining its pathways and testing solutions that are feasible in disability service contexts. IDS-TILDA offers a rare longitudinal platform to examine how tooth loss, functional decline and rehabilitation unfold over time in adults with intellectual disabilities, and whether policy and service reforms translate into measurable improvements. Continued follow-up using both self-reported and clinically observed indicators will allow tracking of dentition trajectories, functional dentition and prosthetic uptake, and will strengthen surveillance of whether inequality is narrowing or persisting.

A key next step is to strengthen longitudinal analyses linking oral health and oral function to broader health outcomes that are highly relevant in ageing with intellectual disabilities, including nutrition, frailty, respiratory disease, healthcare utilisation and quality of life. The wider gerontological literature increasingly frames tooth loss and functional decline as markers of vulnerability, frailty and survival risk (Sheiham & Steele, 2001; Diaballo et al., 2023). Building on this, future

IDS-TILDA analyses should test temporal ordering, identify periods of accelerated decline and explore whether functional loss precedes deterioration in nutrition, respiratory health or service use. Where feasible, linkage to administrative sources such as hospital admissions and mortality would allow examination of downstream outcomes and mechanisms over longer time horizons and would support more robust modelling of risk pathways.

There is also a need for pragmatic, real-world evaluation of prevention and rehabilitation programmes within disability services. Interventions combining caregiver training, structured daily mouth care routines, preventive supports and facilitated access to specialist dental services should be assessed for effectiveness, feasibility and sustainability, particularly for people with severe and profound intellectual disabilities who are most likely to be excluded from conventional studies. Future waves of IDS-TILDA provide an opportunity to examine whether service initiatives are associated with improvements in oral cleanliness, functional dentition, denture use and oral-health-related quality of life at population level.

Quantitative surveillance alone is not sufficient to guide solutions. Qualitative research is needed to understand how adults with intellectual disabilities experience oral health and oral function across everyday life, including the impact of tooth loss, oral pain and lack of rehabilitation on eating, communication, confidence and social participation. This work should include the perspectives of family and paid supporters, and should explore how oral health needs are recognised, prioritised and acted on in different living contexts. Such research can also address under-recognition of pain and the barriers that prevent timely restorative and prosthetic care from being pursued.

Finally, future research should adopt accessibility-first approaches and strengthen inclusive practice, using adapted methods and triangulation of self-report, proxy input and clinical observation when needed. Meaningful involvement of people with intellectual disabilities in study design, conduct and interpretation remains essential to ensure that research focuses on outcomes that matter to those most affected and to reduce the exclusions that have historically shaped this evidence base (Nind, 2014; Cary et al., 2023).

5.7 Conclusion

This chapter provides the first nationally representative, clinically assessed evidence of oral health and oral function in older adults with intellectual disabilities in Ireland. The findings demonstrate deep and persistent inequalities, including extensive tooth loss, limited functional dentition, low rates of prosthetic rehabilitation and a high burden of preventable disease

The disparities observed are not best understood as individual failings or inevitable consequences of impairment. Rather, they reflect how oral health outcomes are shaped by care systems, service design and the consistency and capability of daily support. Effective oral care requires structured routines, appropriate tools, staff training and timely access to restorative and rehabilitative pathways when teeth are lost. Where these supports are absent or inconsistent, oral disease and functional decline accumulate over time, particularly for those with the highest support needs.

Inequalities were most pronounced among people with severe and profound intellectual disabilities and those living in residential care, who depend on others to recognise problems, advocate for treatment and deliver day-to-day oral hygiene. In this context, the chapter highlights oral health as a sensitive indicator of wider system performance: it becomes visible where prevention fails, where rehabilitation is not delivered, and where workforce capacity and organisational priorities do not support equitable health outcomes. By making these inequalities visible with robust national data, this chapter establishes an evidence base that is essential for planning, targeting resources and evaluating change.

Chapter 6:

Oral health and Physical Health Intersection: Exploration Among Older Adults with an Intellectual Disability in Ireland

Chapter 6 Abstract

Purpose

To examine associations between oral health and systemic health indicators in older adults with intellectual disabilities using nationally representative data and to assess whether oral function (tooth retention, number of teeth, functional dentition) or oral disease–related markers (gum health, cavitation, oral cleanliness) are associated with prevalent systemic conditions.

Methods

Data were drawn from IDS-TILDA Wave 5 and linked with the MOSST oral health assessment conducted during Health Fair examinations. Multivariable logistic regression models were used to estimate associations between MOSST oral health indicators and common systemic conditions in people with intellectual disabilities, including constipation, osteoporosis, respiratory conditions (pneumonia, chest infection, asthma), cardiovascular conditions (stroke, hypertension), diabetes and multimorbidity, adjusting for age, gender, level of intellectual disabilities and residential setting.

Results

Constipation was highly prevalent (40%). Edentulous participants had more than twice the adjusted odds of chronic constipation (aOR = 2.45, 95% CI 1.30–4.62), and absence of functional dentition was associated with almost threefold higher odds (aOR = 2.90, 95% CI 1.45–5.81). Osteoporosis was reported by 18.8% of participants. Edentulism was associated with more than threefold higher adjusted odds (aOR = 3.20, 95% CI 1.20–8.50), while lacking functional dentition was associated with nearly fivefold higher odds (aOR = 4.85, 95% CI 1.90–12.40). Pneumonia prevalence was over three times higher among edentulous participants (aOR = 3.35, 95% CI 1.10–10.20) and those with markedly reduced tooth counts, independent of covariates.

Stroke showed a graded association with tooth loss in unadjusted analyses (edentulous OR = 4.20, 95% CI 1.60–11.0), but this attenuated after adjustment (aOR = 2.10, 95% CI 0.70–6.40). Hypertension and diabetes showed no

independent associations after adjustment. Multimorbidity affected over 70% of participants. Tooth loss and functional dentition were strongly associated in unadjusted analyses (e.g., functional dentition protective: OR = 0.32, 95% CI 0.20–0.50), but these relationships attenuated after adjustment, with age, severity of intellectual disabilities and residential care emerging as stronger predictors.

Conclusions

Oral functional capacity, particularly tooth retention and functional dentition, showed the most consistent associations with systemic health indicators in older adults with intellectual disabilities. The strongest and most robust associations were observed for constipation, osteoporosis and pneumonia, supporting pathways linking impaired mastication with gastrointestinal, skeletal and respiratory vulnerability. Oral health functions both as a marker of vulnerability and as a potentially modifiable contributor to health equity.

6.1 Introduction

Oral and systemic health are closely interrelated. Across the life course, poor oral health, including tooth loss, periodontal disease and impaired oral function, has been associated with cardiovascular disease, diabetes, respiratory infection and osteoporosis through pathways involving chronic inflammation, nutritional compromise and aspiration (Lipsky et al., 2024; Natarajan et al., 2025; Tonetti et al., 2017). In later life, these interactions contribute to multimorbidity, frailty and reduced quality of life.

For adults with intellectual disability these risks are amplified. This population experiences markedly higher rates of chronic conditions and multimorbidity, often with earlier onset than in the general population (Cooper et al., 2015; Kinnear et al., 2018). Health disparities are further compounded by barriers to healthcare access, diagnostic overshadowing and high levels of polypharmacy, all of which increase vulnerability across the lifespan.

Oral health inequalities are particularly pronounced. Adults with intellectual disabilities experience high levels of untreated dental disease, tooth loss and unmet prosthetic need, and older adults are more likely to be edentulous while less likely to receive effective denture rehabilitation (Anders & Davis, 2010; Wilson et al., 2019). As a result, loss of functional dentition and impaired oral function are common. In the general population, reduced dentition and poor oral hygiene are associated with restricted dietary intake, constipation, osteoporosis and respiratory infection, processes that may be especially consequential in adults with intellectual disabilities given the high prevalence of dysphagia, dependence and comorbidity.

6.1.2 Rationale

Despite strong biological plausibility, the intersection of oral and systemic health in adults with intellectual disabilities remains under-characterised. Most research has described oral health or physical health separately, with limited work examining their interrelationship using inclusive, clinically assessed measures. Adults with severe or profound intellectual disabilities are particularly underrepresented.

The IDS-TILDA study provides a unique opportunity to address these gaps. In Wave 5, an inclusive oral health assessment using the MOSST generated objective data on oral function, including dentition status, functional dentition, occlusal contacts and denture use, as well as oral disease indicators such as cavitated teeth, gum condition and oral cleanliness (Byrne et al., 2023; McCarron et al., 2023). These data can be directly linked with nationally representative measures of systemic health, functioning and demographics.

Building on the descriptive findings of Chapter 5, this chapter examines whether oral function and oral disease indicators are associated with systemic conditions of high relevance to ageing with intellectual disabilities, including constipation, osteoporosis, respiratory disease, cardiovascular disease and diabetes.

6.1.3 Research Questions and Objectives

6.1.3.1 Research Questions

1. How are MOSST assessed oral function indicators associated with systemic health conditions specifically osteoporosis, constipation, respiratory health, cardiovascular health, and diabetes among older adults with ID?
2. How are MOSST assessed oral disease indicators associated with these systemic health conditions?
3. Do associations between MOSST oral health indicators and systemic health conditions vary by demographic or clinical characteristics?

6.1.3.2 Objectives

1. To investigate the relationship between MOSST oral function indicators and systemic health conditions (osteoporosis, constipation, respiratory health, cardiovascular health, diabetes).
2. To examine the relationship between MOSST oral disease indicators and these systemic health conditions.
3. To explore whether demographic or clinical characteristics modify associations between MOSST oral health indicators and systemic health conditions.

6.2 Methods

6.2.1 Design

This study is primary data collected as part of Wave 5 of the IDS TILDA. IDS TILDA is a nationally representative longitudinal cohort study examining ageing and health among adults with intellectual disabilities aged 40 years and older in Ireland (McCarron et al., 2023). Data for this chapter draw on two complementary sources: the CAPI and PIQ completed with or on behalf of participants and the health fair assessment which included oral health measurement using the MOSST.

6.2.2 Sample

At Wave 5, a total of 742 participants completed the CAPI/PIQ interview. Of these, 469 (64%) also participated in the health fair and completed the MOSST oral health assessment. The present analysis is restricted to those participants with complete MOSST and systemic health outcome data. Sample size varies across analyses depending on the availability of data for each systemic condition.

6.2.3 Data collection

Data were collected during Wave 5 of IDS-TILDA using a two-stage process. First, participants (or their proxies, where required) completed a PIQ, followed by a face-to-face CAPI Interview. These interviews captured demographic characteristics, health conditions and contextual information (including living arrangements and supports). Second, participants were invited to attend the IDS-TILDA health fair, where objective health assessments were conducted. Oral health data were collected at the health fair using the MOSST. Assessments were completed by trained and calibrated research nurses. For details on data collection methods are outlined in chapter 3 and 4 of this thesis.

Reasonable accommodations were provided in line with IDS-TILDA protocols to maximise feasibility and accessibility across all levels of ID. These included simplified explanations, the option for a familiar supporter to be present, breaks during the assessment and the ability to terminate the examination at any point if the participant indicated discomfort or withdrew assent.

6.2.3 Measures

6.2.3.1. Oral health Indictors and Derived Variable

Oral health was assessed using the MOSST, a structured observational assessment tool developed for adults with an intellectual disability (see Chapter 4). MOSST captures indicators of both oral function and oral disease using standardised visual and tactile intra-oral examination. For this analysis, MOSST items were coded into categorical variables, and several composite indicators were derived to reflect clinically meaningful thresholds. Table 6.1 summarises the indicators and reference categories used in modelling.

6.2.3.2 Systemic Health Outcomes

Systemic health conditions were identified from CAPI/PIQ self-report or proxy report of conditions. The following indictors were included in analyses.

Table 6. 1: Systemic health condition outcome variables

<i>Systemic health outcome</i>	<i>Coding</i>	<i>Notes</i>
<i>Osteoporosis</i>	Yes / No	Self/proxy reported diagnosis in CAPI interview
<i>Constipation</i>	Yes / No	Self/proxy reported diagnosis in CAPI interview
<i>Respiratory health</i>	Pneumonia (3-year), chest infection (12-month), chronic lung disease, asthma (all Yes / No)	Pneumonia variable was derived from three sources: (i) CAPI question on number of pneumonia diagnoses in the last 3 years. (ii) aspiration pneumonia question in the CAPI; and (iii) PIQ question on pneumonia history. Participants who were routed from the CAPI pneumonia question but reported pneumonia in the PIQ were included. These three sources were combined into a binary “pneumonia” variable.
<i>Cardiovascular health</i>	Stroke/ministroke (TIA, combined), hypertension (all Yes / No)	Combined due to small case counts and clinical overlap.
<i>Diabetes</i>	Yes / No	Self/proxy reported diagnosis in CAPI interview

6.2.3.3 Covariates

Covariates included demographic characteristics known to influence both oral and systemic health:

Table 6.2. Covariates included in regression models

<i>Covariate</i>	<i>Categories</i>	<i>Reference group</i>
<i>Age group</i>	40–49.	40–49 years
	50–64.	
	≥65 years	
<i>Gender</i>	Male.	Male
	Female	
<i>Level of Intellectual disabilities</i>	Mild.	Mild
	Moderate.	
	Severe/profound	
<i>Residential setting</i>	Independent/family home.	Independent/family home
	Community group home.	
	Residential care	

Note. Covariates entered simultaneously in adjusted models.

6.2.4 Statistical Analysis

Analyses were conducted in SPSS (Version 26). Descriptive statistics summarised sample characteristics, oral health outcomes, and prevalence of systemic health conditions. Bivariate analyses explored crude associations between MOSST indicators and each systemic condition. Multivariable logistic regression models were used to examine the relationship between MOSST oral health indicators and each systemic health outcome, adjusting for covariates (age group, gender, LOID, and residential setting). For multimorbidity, logistic regression was used with multimorbidity status as the dependent variable. Results are presented as odds ratios (ORs) with 95% CIs (CIs). Model fit was assessed using likelihood ratio tests, pseudo- R^2 statistics, and discrimination indices (AUC: area under the ROC curve). Significance was set at $p < 0.05$. Where sample size limited model stability, results are reported with caution and interpreted descriptively.

6.3 Results

6.3.1 Sample Characteristics

A total of $n = 469$ participants completed the MOSST assessment at the IDS TILDA Wave 5 health fair and were included in the oral health analyses. Systemic health

indictors were derived from CAPI and PIQ and linked to MOSST participation, analytic Ns vary by outcome due to item non-response. Participants represented all adult age groups (40+), with variation in gender, level of intellectual disability and residential settings.

6.3.2 Descriptive Overview of Systemic Health Conditions

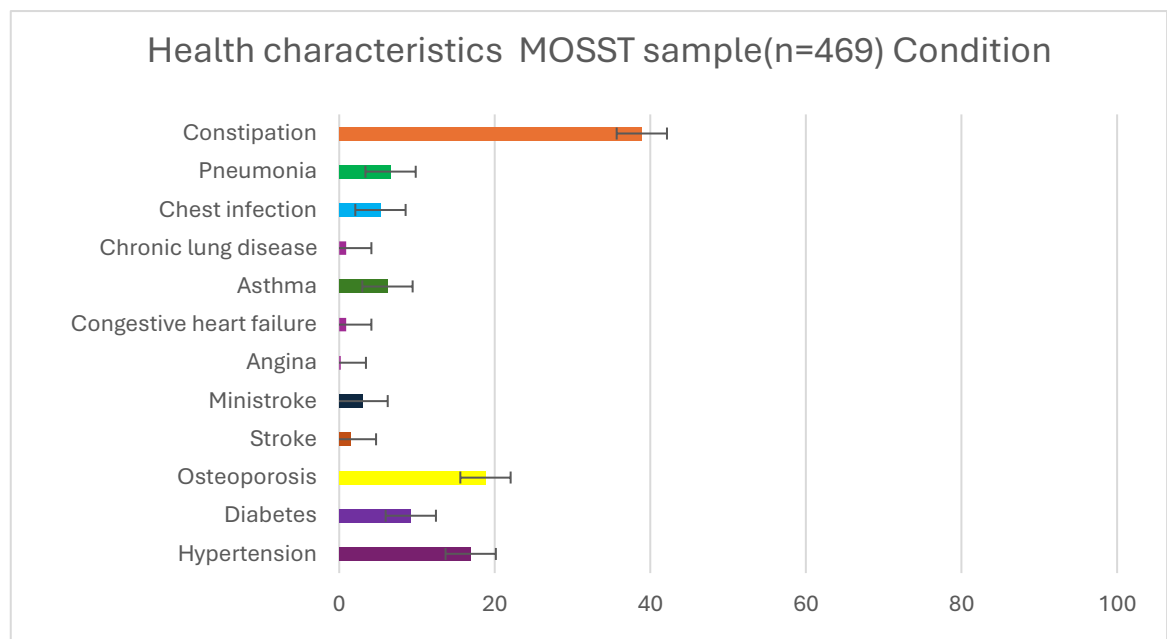
In the CAPI sample (n = 762), over seven in ten participants met criteria for multimorbidity (≥ 2 physical health conditions), compared with just under seven in ten in the MOSST subsample (n = 469). As outlined in Table 6.4, hypertension, diabetes, and osteoporosis were among the most common chronic conditions in both groups, each affecting approximately one in six to one in five participants. Stroke and ministroke were relatively uncommon ($< 3\%$), while serious cardiovascular conditions such as angina and heart failure were rare ($< 1\%$). Respiratory conditions were somewhat more prevalent, with asthma affecting 7.3% of the CAPI cohort and 6.2% of the MOSST group. Chest infections and pneumonia were reported in 6–7% of participants across both datasets. Constipation was the single most frequently reported condition after multimorbidity, present in 42.8% of the CAPI group and 38.9% of the MOSST group. Figure 6.1 provides a visual overview of the health conditions examined in this chapter for the MOSST sample.

When oral health indicators assessed through clinical examination are also considered, dental caries and periodontal disease emerge as among the most prevalent health conditions in this cohort. Approximately 37% of participants had at least one visibly cavitated tooth, and around 60% had unhealthy gums. These proportions are substantially higher than those observed for most individual chronic systemic diseases reported above, highlighting oral disease as a major component of overall health burden among older adults with intellectual disabilities.

Table 6.3. Health characteristics in CAPI vs MOSST sample

<i>Condition</i>	<i>CAPI sample (n=762)</i>	<i>MOSST sample (n=469)</i>
<i>Multimorbidity (≥2 conditions)</i>	552 (72.4%)	311 (66.3%)
<i>Hypertension</i>	130 (17.1%)	79 (16.9%)
<i>Diabetes</i>	65 (8.5%)	43 (9.2%)
<i>Osteoporosis</i>	151 (19.8%)	88 (18.8%)
<i>Stroke</i>	16 (2.1%)	7 (1.5%)
<i>Ministroke</i>	20 (2.6%)	14 (3.0%)
<i>Angina</i>	2 (0.3%)	1 (0.2%)
<i>Congestive heart failure</i>	7 (0.9%)	4 (0.9%)
<i>Asthma</i>	56 (7.3%)	29 (6.2%)
<i>Chronic lung disease</i>	10 (1.3%)	4 (0.9%)
<i>Chest infection</i>	52 (6.8%)	25 (5.3%)
<i>Pneumonia</i>	52 (6.8%)	31 (6.6%)
<i>Constipation</i>	326 (42.8%)	182 (38.9%)

Note. Values are n (%). The MOSST sample represents participants who completed the MOSST within the IDS-TILDA Health Fair. Differences between the CAPI and MOSST samples reflect selection into clinical assessment rather than disease prevalence effects. Health conditions were derived from self- or proxy-reported diagnoses collected via CAPI. Multimorbidity was defined as the presence of two or more chronic conditions. Percentages are calculated using sample-specific denominators.

Figure 6.1 health condition of MOSST participants sample (n=469)

6.3.3 MOSST Oral health indicators

Each item of the MOSST, is a specific variable in this chapter these include, denture wear (Upper and lower) Denture wear (Upper and lower arch), Tooth Count (upper and lower arch), Occlusal contacts, Pairs of Premolars, Front 12 teeth, cavitated teeth, oral cleanliness, gum condition and oral pain as well. Aswell as variables

derived from these items: Denture (Full, Partial), tooth count: mean number of teeth (total, upper and lower), Tooth count categories (edentulism, dentate, 1-10 teeth, 10-20 teeth and 20+ teeth) and outline in figure 4.2 in chapter 4.

6.4 Oral–Systemic Associations

6.4.1 Constipation

Constipation was common in the MOSST subsample (38.8%). In the analyses, measures of oral function showed clear, monotonic relationships with constipation. Table 4 outlines the bivariate associations between the MOSST indicators and constipation. Participants who were edentulous had substantially higher prevalence than those who were dentate (51.9% vs 30.0%; OR 2.52, 95%CI 1.53–4.15), and absence of functional dentition was likewise associated with greater odds of constipation (40.4% vs 20.8%; OR 2.58, 95%CI 1.56–4.25). A graded pattern was evident across tooth count categories, with odds of constipation increasing as the number of natural teeth decreased (linear trend $p < .001$); the highest crude odds were observed among edentulous participants compared with those retaining 20 or more teeth (OR = 3.35, 95% CI 1.93–5.81).

Indicators of oral disease did not show associations with constipation. Gum condition was unrelated to constipation (32.0% vs 32.1%; OR 1.00, $p = .985$). Oral cleanliness also showed no significant crude association (not clean vs clean: OR 0.73, $p = .163$). An inverse association was observed for the presence of cavitated teeth (25.7% vs 36.5%; OR 0.60, 95%CI 0.38–0.95). This counter intuitive direction likely reflects confounding by dentition: participants with advanced tooth loss have fewer teeth available to cavitate yet also exhibit higher constipation risk due to impaired oral function. Accordingly, interpretation of disease/cleanliness indicators is deferred to the adjusted models.

Table 6.5. Bivariate associations with constipation

<i>Association (MOSST Indicator)</i>	<i>Constipation % (Yes)</i>	<i>OR</i>	<i>95% CI</i>	<i>p-value</i>
Dentition status				
<i>Dentate (ref)</i>	30.0%	1.00	—	—
<i>Edentulous</i>	51.9%	2.52	1.53–4.15	<.001
Functional dentition				
<i>Yes (ref)</i>	20.8%	1.00	—	—
<i>No</i>	40.4%	2.58	1.56–4.25	<.001
Tooth count (ref = 20+ teeth)				
<i>20+ teeth (ref)</i>	24.4%	1.00	—	—
<i>10–20 teeth</i>	37.3%	1.85	1.07–3.22	<.05
<i>1–10 teeth</i>	38.9%	1.98	1.04–3.74	<.05
<i>Edentulous</i>	51.9%	3.35	1.93–5.81	<.001
Cavitated teeth				
<i>None (ref)</i>	36.5%	1.00	—	—
<i>Present</i>	25.7%	0.60	0.38–0.95	<.05
Gum condition				
<i>Healthy (ref)</i>	32.1%	1.00	—	—
<i>Unhealthy</i>	32.0%	1.00	0.63–1.58	.985
Oral cleanliness				
<i>Clean (ref)</i>	41.5%	1.00	—	—
<i>Not clean</i>	34.3%	0.73	0.48–1.13	.163

6.4.1.1. Constipation Multivariable Models.

Unadjusted logistic regression models demonstrated strong associations between oral functional indicators and constipation as outlined in Table 5. Tooth loss showed a clear graded relationship, compared with participants with 20+ teeth, those with 10–20 teeth had over twice the odds of constipation (OR = 2.11, 95%CI 1.08–4.12, $p = .029$), and those with 1–10 teeth had more than three times the odds (OR = 3.48, 95%CI 1.96–6.16, $p < .001$). Edentulous participants also showed substantially elevated odds (OR = 3.47, 95%CI 1.96–6.16, $p < .001$). In a parallel specification, absence of a functional dentition was likewise associated with higher constipation risk (OR = 2.38, 95%CI 1.42–3.99, $p = .001$). In fully adjusted models controlling for age, gender, level of intellectual disabilities, and residential setting, the associations were attenuated but directionally consistent. Participants with 1–10 teeth retained significantly higher odds of constipation (aOR = 2.18, 95%CI 1.09–4.38, $p = .028$). The associations for edentulous participants (aOR = 1.54, 95%CI 0.81–2.95, $p = .189$) and absence of functional dentition (aOR = 1.45, 95%CI 0.80–2.66, $p = .223$) were no longer statistically significant.

Oral disease indicators (gum condition, cavitated teeth, oral cleanliness) did not demonstrate significant independent associations. While unhealthy gums (aOR = 0.71, 95%CI 0.36–1.39, $p = .316$), oral cleanliness (aOR = 0.88, 95%CI 0.39–1.98, $p = .758$), and cavitated teeth (aOR = 1.32, 95%CI 0.72–2.40, $p = .369$) showed varying directions of effect, none were statistically significant. Model calibration was acceptable (Hosmer–Lemeshow tests, $p > .25$). Classification accuracy was approximately 74%. Variance Inflation Factor (VIF) values were < 2.0 for all predictors, indicating no problematic multicollinearity. These findings suggest that tooth loss and reduced dentition remain important correlates of constipation risk, though their effects are partly explained by demographic and disability related covariates. Oral disease indicators did not contribute additional explanatory value.

Table 6.6. Logistic Regression Summary Table for Constipation

<i>Predictor</i>	<i>Unadjusted OR (95% CI)</i>	<i>p</i>	<i>Adjusted OR (95% CI)</i>	<i>p-value</i>
Total				
<i>Tooth count</i>				
20+ teeth (ref)	1.00	–	1.00	–
10–20 teeth	2.11 (1.08–4.12)	.029	1.56 (0.72–3.35)	.258
1–10 teeth	3.48 (1.96–6.16)	<.001	2.18 (1.09–4.38)	.028
Edentulous	3.47 (1.96–6.16)	<.001	1.54 (0.81–2.95)	.189
<i>Functional dentition</i>				
Present (ref)	1.00	–	1.00	–
Absent	2.38 (1.42–3.99)	.001	1.45 (0.80–2.66)	.223
<i>Oral disease indicators</i>				
Gum unhealthy vs. healthy	1.00 (0.56–1.91)	.985	0.71 (0.36–1.39)	.316
Not clean vs. clean	0.73 (0.48–1.13)	.163	0.88 (0.39–1.98)	.758

Note. Models adjusted for age, gender, level of intellectual disabilities, and residential setting. Reference categories: ≥ 20 teeth, functional dentition present, healthy gums, clean mouth, and no cavitated teeth. Analyses restricted to participants with complete data ($n = 409$). Bold values indicate statistical significance at $p < .05$.

6.4.2 Osteoporosis

Osteoporosis was reported in 18.8% of participants (n=88/469). Prevalence varied markedly across demographic groups. Rates were substantially higher among those in residential care (32.3%) compared with participants in community group homes (17.9%) and independent/family living (5.4%; $\chi^2=28.5$, $p<.001$). A strong age gradient was evident, with prevalence increasing from 4.6% in those under 50 years to 19.2% in participants aged 50–64, and 33.1% in those aged 65 and older ($\chi^2=33.9$, $p<.001$). Females showed higher prevalence than males (21.7% vs 15.6%), although this did not reach conventional significance ($\chi^2=2.84$, $p=.092$). Level of intellectual disabilities was also associated, prevalence was lowest among those with mild intellectual disabilities (10.3%), intermediate in those with moderate intellectual disabilities (19.6%) and highest in participants with severe to profound intellectual disabilities (31.1%; $\chi^2=16.5$, $p<.001$).

MOSST oral health indicators showed consistent associations with osteoporosis as shown in Table 6. Edentulous participants had significantly higher prevalence compared with those retaining at least one tooth (35.4% vs 12.7%; $\chi^2=23.2$, $p<.001$). A graded relationship was evident with tooth count: prevalence was highest in edentulous participants (35.4%), followed by those with 1–10 teeth (20.4%), 10–20 teeth (16.9%), and lowest in those with 20+ teeth (8.8%; $\chi^2=28.5$, $p<.001$). Similarly, absence of a functional dentition was strongly associated with osteoporosis (22.3% vs 5.8% with functional dentition; $\chi^2=15.9$, $p<.001$). Indicators of oral disease and cleanliness showed mixed patterns. Gum health was not associated with osteoporosis (unhealthy vs healthy: 14.2% vs 13.7%; $\chi^2=.012$, $p=.914$). By contrast, oral cleanliness was associated: those with a clean mouth/dentures had higher prevalence (25.4%) compared with those recorded as not clean (16.2%; $\chi^2=4.81$, $p=.028$). Presence of cavitated teeth suggested a lower prevalence (11.8% vs 19.1%), but this association was borderline and did not reach statistical significance ($\chi^2=3.49$, $p=.062$). These bivariate findings indicate that both demographic factors (particularly age, residence, and severity of intellectual disabilities) and measures of tooth loss and oral functional capacity are significantly associated with osteoporosis, whereas markers of oral disease show weaker or inconsistent associations.

Table 6.7 Bivariate associations with osteoporosis

Association outcome / demographic	(MOSST outcome / demographic)	Osteoporosis % (Yes)	OR	95% CI	p-value
Dentition status					

<i>Dentate (ref)</i>	12.7%	1.00	—	—
<i>Edentulous</i>	35.4%	3.72	2.08–6.64	<.001
<i>Tooth count</i>				
<i>20+ teeth (ref)</i>	8.8%	1.00	—	—
<i>10–20 teeth</i>	16.9%	2.12	1.05–4.30	.037
<i>1–10 teeth</i>	20.4%	2.68	1.22–5.89	.014
<i>0 Teeth (edentulous)</i>	35.4%	5.68	2.96–10.91	<.001
<i>Functional dentition</i>				
<i>Yes (ref)</i>	5.8%	1.00	—	—
<i>No</i>	22.3%	4.72	2.09–10.64	<.001
<i>Cavitated teeth</i>				
<i>None (ref)</i>	19.1%	1.00	—	—
<i>Present</i>	11.8%	0.57	0.31–1.05	.062
<i>Gum condition</i>				
<i>Healthy (ref)</i>	13.7%	1.00	—	—
<i>Not healthy</i>	14.2%	1.04	0.56–1.91	.914
<i>Oral cleanliness</i>				
<i>Clean (ref)</i>	25.4%	1.00	—	—
<i>Not clean</i>	16.2%	0.57	0.35–0.94	.028

Note. OR and 95% CI are presented for crude (unadjusted) associations. Reference categories are dentate (≥ 1 natural tooth), ≥ 20 teeth, functional dentition present, no cavitated teeth, healthy gums, and mouth/dentures not clean. Bold values indicate statistical significance at $p < .05$. Associations reflect bivariate analyses only; multivariable adjusted models are reported in Section 6.3.4.2.2.

6.4.2.1 Multivariable Logistic Regression Models for Osteoporosis

Unadjusted logistic regression models showed strong associations between oral functional indicators and osteoporosis. Compared with participants with 20+ teeth, those with 10–20 teeth had more than twice the odds of osteoporosis (OR = 2.12, 95%CI 1.05–4.30, $p = .037$), those with 1–10 teeth had nearly three times the odds (OR = 2.68, 95%CI 1.22–5.89, $p = .014$), and edentulous participants had over fivefold higher odds (OR = 5.68, 95%CI 2.96–10.91, $p < .001$). Similarly, absence of a functional dentition was associated with a fourfold increase in osteoporosis risk (OR = 4.72, 95%CI 2.09–10.64, $p < .001$). As outlined in table 7.

In fully adjusted models controlling for age, gender, level of intellectual disabilities and residential setting, tooth loss indicators remained strong predictors. Edentulous participants continued to have markedly elevated odds of osteoporosis (aOR = 3.72, 95%CI 2.08–6.64, $p < .001$), and those with 1–10 teeth (aOR = 2.68, 95%CI 1.22–5.89, $p = .014$) or 10–20 teeth (aOR = 2.12, 95%CI 1.05–4.30, $p = .037$) also had significantly increased odds compared with those retaining 20+ teeth. The absence of functional dentition was likewise associated with significantly higher odds (aOR = 4.72, 95%CI 2.09–10.64, $p < .001$). By contrast, oral disease indicators did not show significant independent associations. Unhealthy gums (aOR = 1.04,

95%CI 0.56–1.91, $p = .914$), cavitated teeth (aOR = 0.57, 95%CI 0.31–1.05, $p = .062$), and oral cleanliness (aOR = 0.57, 95%CI 0.35–0.94, $p = .028$) did not remain statistically significant after adjustment.

Demographic covariates were consistently strong predictors. Older adults (65+) had markedly higher odds of osteoporosis compared with those under 50 years, and individuals living in residential care had substantially greater risk compared with those in community or independent/family settings. Severity of intellectual disabilities was also an independent determinant: participants with mild intellectual disabilities had significantly lower odds of osteoporosis (aOR ≈ 0.26) compared with those with severe to profound intellectual disabilities, with moderate intellectual disabilities showing intermediate risk. VIF checks indicated no evidence of problematic multicollinearity (all < 2.0). Given conceptual overlap, dentition variables were modelled separately, but interpretation consistently highlights that reduced dentition and absence of functional occlusion were robustly associated with increased osteoporosis risks.

Table 6.8. logistic regression models for osteoporosis

<i>Association (ref group)</i>	<i>Unadjusted OR (95% CI)</i>	<i>p-value</i>	<i>Adjusted OR (95% CI)</i>	<i>p-value</i>
Tooth count				
20+ teeth (ref)	1.00	—	1.00	—
10–20 teeth	2.12 (1.05–4.30)	.037	2.12 (1.05–4.30)	.037
1–10 teeth	2.68 (1.22–5.89)	.014	2.68 (1.22–5.89)	.014
Edentulous	5.68 (2.96–10.91)	<.001	3.72 (2.08–6.64)	<.001
Functional dentition (yes)	1.00	—	1.00	—
No functional dentition	4.72 (2.09–10.64)	<.001	4.72 (2.09–10.64)	<.001
Oral disease indicators				
Unhealthy gums (vs healthy)	1.04 (0.56–1.91)	.914	1.04 (0.56–1.91)	.914
Cavitated teeth (present vs none)	0.57 (0.31–1.05)	.062	0.57 (0.31–1.05)	.062
Not clean (vs clean)	0.57 (0.35–0.94)	.028	0.57 (0.35–0.94)	.028

Note. Models adjusted for age, gender, level of intellectual disabilities, and residential setting. Reference categories: ≥ 20 teeth, functional dentition present, healthy gums, clean mouth, and no cavitated teeth. Analyses restricted to participants with complete data ($n = 409$). Bold values indicate statistical significance at $p .05$.

6.4.3 Respiratory Health (Pneumonia, Chest infection and Asthma)

Respiratory conditions were reported by a notable minority of participants in the MOSST health assessment cohort (n = 469). Asthma was the most reported diagnosis, affecting 6.2% (n = 29), followed by chest infection in the past 12 months (5.3%, n = 25), and pneumonia or aspiration pneumonia in the last three years (6.6%, n = 31). Chronic lung disease was rare (0.9%, n = 4) (Table 6.8).

Table 6.9. Respiratory health conditions in the MOSST sample (n=469)

Condition	n	%
<i>Asthma</i>	29	6.2%
<i>Chronic lung disease</i>	4	0.9%
<i>Chest infection (past year)</i>	25	5.3%
<i>Pneumonia</i>	31	6.6%

6.4.3.1 Bivariate Associations (Respiratory)

Significant associations were observed between oral functional indicators and respiratory outcomes. Chest infection in the past year was reported by 10.3% of edentulous participants compared with only 3.3% of those retaining natural teeth ($\chi^2 = 6.81$, $p = .009$). Similarly, pneumonia was markedly more common in edentulous participants (37.0%) than in dentate participants (14.8%; $\chi^2 = 6.17$, $p = .013$). Tooth count also showed a graded association with pneumonia, with prevalence increasing as tooth number decreased (linear-by-linear $\chi^2 = 4.41$, $p = .036$). By contrast, no associations were identified between oral health status and asthma or chronic lung disease. Likewise, oral disease related indicators including gum condition, cavitated teeth, and oral cleanliness did not significantly predict any respiratory outcome. In contrast, markers of active oral disease did not contribute meaningfully to risk. Further detail outlined in table 6.9.

Table 6.10. Bivariate associations between oral health indicators and respiratory conditions

<i>Oral health indicator</i>	<i>Chest infection % (Yes)</i>	<i>p-value</i>	<i>Pneumonia % (Yes)</i>	<i>P-value</i>	<i>Asthma % (Yes)</i>	<i>p-value</i>	<i>Chronic lung disease % (Yes)</i>	<i>p-value</i>
<i>Dentition status</i>								
<i>Dentate (≥1 tooth)</i>	3.3	Ref	14.8	Ref	7.0	Ref	0.6	Ref
<i>Edentulous</i>	10.3	.009	37.0	.013	7.7	.829	0.0	.534
<i>Tooth count</i>								
<i>20+ teeth</i>	3.1	Ref	12.0	Ref	6.3	Ref	0.5	Ref
<i>10–20 teeth</i>	4.9	.441	16.7	.408	8.0	.671	1.1	.617
<i>1–10 teeth</i>	5.6	.316	20.4	.157	6.8	.915	0.0	.482
<i>Edentulous</i>	10.3	.009	37.0	.013	7.7	.829	0.0	.534
<i>Trend (linear-by-linear)</i>	—	.073	—	.036	—	.811	—	.674
<i>Functional dentition</i>								
<i>Present</i>	4.2	Ref	18.2	Ref	5.8	Ref	0.8	Ref
<i>Absent</i>	5.2	.702	22.1	.287	7.3	.566	0.9	.887
<i>Gum condition</i>	—	.861	—	.774	—	.652	—	.808
<i>Cavitated teeth</i>	—	.609	—	.719	—	.826	—	.921
<i>Oral cleanliness</i>	—	.364	—	.654	—	.589	—	.842

Note. OR and 95% CI are presented for unadjusted and adjusted models. Adjusted models include covariates for age, gender, level of intellectual disabilities, and residential setting. Reference groups are: ≥20 teeth for tooth count; functional dentition present; healthy gums; no cavitated teeth; and clean mouth/dentures.

6.4.3.2 Asthma

Asthma was reported in 29 participants (6.2%) in the MOSST sample (n = 469). Crosstabulations between MOSST oral health indicators and asthma status did not identify any statistically significant associations. Specifically, oral cleanliness ($\chi^2 = 0.628$, $p = .428$), cavitated teeth ($\chi^2 = 0.183$, $p = .668$), and gum condition ($\chi^2 = 1.404$, $p = .236$) were not related to asthma prevalence.

Logistic regression analyses confirmed the absence of significant associations as shown in table 10. Tooth count and functional dentition categories did not predict asthma, with all confidence intervals crossing the null. For example, participants lacking functional dentition had higher but non-significant odds of asthma (aOR = 1.24, 95% CI: 0.63–2.44, $p = .540$). Oral disease indicators were also not predictive: unhealthy gums (aOR = 0.94, 95% CI: 0.51–1.74, $p = .849$) and poor oral cleanliness (aOR = 1.05, 95% CI: 0.56–1.95, $p = .879$) showed no significant effects. Adjusted models (n = 274 complete cases) including age, gender, level of intellectual

disabilities , and residence type similarly found no significant predictors, and overall explanatory power was low (Nagelkerke $R^2 = 0.042$).

Table 6.11: Logistic regression on asthma

<i>Predictor</i>	<i>Unadjusted OR (95% CI)</i>	<i>p</i>	<i>Adjusted OR (95% CI)</i>	<i>p-value</i>
<i>Tooth count</i>				
20+ teeth (ref)	1.00	–	1.00	–
10–20 teeth	1.15 (0.45–2.91)	.772	0.92 (0.35–2.46)	.867
1–10 teeth	1.36 (0.56–3.33)	.496	1.08 (0.42–2.77)	.874
Edentulous	1.44 (0.67–3.09)	.352	1.19 (0.53–2.68)	.678
<i>Functional dentition</i>				
Present (ref)	1.00	–	1.00	–
Absent	1.61 (0.87–2.98)	.128	1.24 (0.63–2.44)	.540
<i>Oral disease indicators</i>				
Gum unhealthy vs. healthy	1.02 (0.58–1.80)	.953	0.94 (0.51–1.74)	.849
Not clean vs. clean	1.11 (0.63–1.94)	.726	1.05 (0.56–1.95)	.879

Note. Models adjusted for age, gender, level of intellectual disabilities , and residential setting. Reference categories: ≥ 20 teeth, functional dentition present, healthy gums, clean mouth, and no cavitated teeth. Analyses restricted to participants with complete data ($n = 409$). Bold values indicate statistical significance at $p < .05$.

6.4.3.3 Chest Infections

Chest infection in the previous year was reported by 5.3% ($n = 25$) of participants in the MOSST sample ($n = 469$). Crosstabulations indicated no consistent associations between chest infection and oral disease indicators (gum condition, cavitated teeth, oral cleanliness, functional dentition). Although as outline in table 6.12 tooth count showed a trend toward significance ($\chi^2 = 6.65$, $p = .084$).

In logistic regression models, complete tooth loss was associated with reduced odds of reporting chest infection. Edentulous participants had significantly lower odds compared to dentate participants (aOR = 0.29, 95% CI: 0.09–0.94, $p = .039$). Those with 1–10 teeth also showed a non-significant trend toward reduced risk compared with individuals with 20+ teeth (aOR = 0.26, 95% CI: 0.07–1.04, $p = .056$). No associations were observed for participants with 10–20 teeth. Other MOSST indicators (gum condition, cavitated teeth, oral cleanliness, functional dentition) were not significantly related to chest infection in either unadjusted or adjusted models. The explanatory power of the models was low (Nagelkerke $R^2 = 0.002$ –0.016).

Table 6.12. Logistic regression- chest infection

<i>Predictor</i>	<i>Unadjusted (95% CI)</i>	<i>OR</i>	<i>p</i>	<i>Adjusted (95% CI)</i>	<i>OR</i>	<i>P- Value</i>
<i>Tooth count</i>						
<i>20+ teeth (ref)</i>	1.00	–		1.00	–	
<i>10–20 teeth</i>	0.63 (0.17–2.31)	.489		1.54 (0.20–10.90)	.699	
<i>1–10 teeth</i>	1.70 (0.20–14.44)	.627		0.26 (0.07–1.04)	.056	
<i>Edentulous</i>	0.28 (0.09–0.84)	.023		0.29 (0.09–0.94)	.039	
<i>Functional dentition</i>	0.79 (0.28–2.21)	.648		0.87 (0.30–2.53)	.808	
<i>Gum unhealthy (vs. healthy)</i>	1.73 (0.45–6.61)	.421		1.61 (0.38–6.76)	.518	
<i>Cavitated teeth (present vs. none)</i>	0.74 (0.20–2.72)	.651		0.81 (0.21–3.09)	.754	
<i>Oral cleanliness (not clean vs. clean)</i>	1.05 (0.24–4.70)	.949		1.12 (0.25–5.05)	.886	

Note. Models adjusted for age, gender, level of intellectual disabilities , and residential setting. Reference categories: ≥20 teeth, functional dentition present, healthy gums, clean mouth, and no cavitated teeth. Analyses restricted to participants with complete data (n = 409). Bold values indicate statistical significance at $p < .05$.

6.4.3.4 Pneumonia

Descriptive analysis showed that 6.6% of participants in the MOSST subsample reported a history of pneumonia or aspiration pneumonia. Bivariate analyses indicated significant associations between pneumonia prevalence and dentate status and tooth count, with higher odds of pneumonia among those who were edentulous or had reduced tooth numbers as shown in Table 6.13. No significant associations were observed with gum condition, cavitated teeth, or oral cleanliness. Logistic regression models were performed to examine associations between oral health indicators and the prevalence of pneumonia/aspiration pneumonia. Both unadjusted and adjusted models were tested. Model fit was assessed using the Hosmer–Lemeshow test, and explained variance was reported with Cox & Snell and Nagelkerke R^2 . Odds ratios with 95% CIs are presented to indicate the strength and direction of associations.

Logistic regression analyses demonstrated that oral functional status, particularly tooth loss and reduced dentition was consistently associated with pneumonia prevalence. In unadjusted models, edentulous participants had significantly higher odds of pneumonia compared with those retaining at least one natural tooth (OR = 3.38, 95% CI: 1.25–9.13, $p = .016$). This association persisted in fully adjusted

models controlling for age, gender, residence type, and level of intellectual disabilities (aOR = 4.16, 95% CI: 1.12–15.47, $p = .033$), suggesting that the effect of edentulism was not explained by demographic or disability related confounders.

A graded pattern was also evident when examining tooth count. Compared with participants who retained 20+ teeth, those with only 1–10 teeth had significantly greater odds of pneumonia (aOR = 3.31, 95% CI: 1.12–9.79, $p = .031$). Participants with 10–20 teeth showed no increased risk (aOR ≈ 1.0), while edentulous individuals again had markedly higher odds (aOR ≈ 3.25). These findings align with the descriptive results that highlighted a linear trend between tooth loss and pneumonia risk, reinforcing the role of oral functional decline in respiratory morbidity. Absence of a functional dentition showed a similar pattern, with those lacking functional occlusion almost twice as likely to report pneumonia; however, this association did not reach statistical significance (aOR = 1.72, 95% CI: 0.58–5.09, $p = .324$), likely reflecting limited power in the analytic sample.

In contrast, oral disease activity and hygiene measures derived from MOSST (gum condition, cavitated teeth, and oral cleanliness) were not associated with pneumonia. For example, participants with unhealthy gums had slightly lower odds compared to those with healthy gums (aOR = 0.54, 95% CI: 0.10–2.99, $p = .480$), while the presence of cavitated teeth (aOR = 1.11, 95% CI: 0.21–5.76, $p = .903$) and poor oral cleanliness (aOR = 1.36, 95% CI: 0.17–10.89, $p = .773$) were not significantly related to pneumonia prevalence. The wide CIs highlight the small analytic subsample available for disease indicators ($n \approx 69$ after missing data), which substantially limits precision and statistical power.

Model fit statistics indicated acceptable calibration (Hosmer–Lemeshow $p > .05$), although the explanatory power of the models was modest (Nagelkerke $R^2 = .08$ – $.12$). The classification accuracy was driven largely by correct prediction of non-cases, reflecting the relatively low prevalence of pneumonia (6.6%) in the cohort. This indicated that edentulism and reduced tooth count emerge as robust associated factor of pneumonia in older adults with intellectual disabilities, even after adjustment for key demographic and disability related factors

Table 6.13 . Logistic regression- pneumonia

<i>Predictor</i>	<i>Unadjusted (95% CI)</i>	<i>OR</i>	<i>p- value</i>	<i>Adjusted (95% CI)</i>	<i>OR</i>	<i>p- value</i>
<i>Dentition status</i>						
<i>Dentate (ref)</i>	1.00	–		1.00	–	
<i>Edentulous</i>	3.38 (1.25–9.13)		.016	4.16 (1.12–15.47)		.033
<i>Tooth count</i>						
<i>20+ teeth (ref)</i>	1.00	–		1.00	–	
<i>10–20 teeth</i>	1.02 (0.19–5.51)		.979	1.02 (0.19–5.51)		.979
<i>1–10 teeth</i>	3.31 (1.12–9.79)		.031	3.31 (1.12–9.79)		.031
<i>Edentulous</i>	3.25 (1.12–9.56)		.031	3.25 (1.12–9.56)		.031
<i>Functional dentition</i>	1.95 (0.72–5.29)		.188	1.72 (0.58–5.09)		.324
<i>Gum unhealthy vs. healthy</i>	0.80 (0.17–3.87)		.781	0.54 (0.10–2.99)		.480
<i>Cavitated teeth present vs. none</i>	1.43 (0.30–6.77)		.651	1.11 (0.21–5.76)		.903
<i>Oral cleanliness: not clean vs. clean</i>	0.93 (0.15–5.69)		.933	1.36 (0.17–10.89)		.773

Note. Models adjusted for age, gender, level of intellectual disabilities , and residential setting. Reference categories: ≥20 teeth, functional dentition present, healthy gums, clean mouth, and no cavitated teeth. Analyses restricted to participants with complete data in these indices (n = 409). Bold values indicate statistical significance at $p < .05$.

6.4.4 Cerebro- and Cardio- Vascular Health

6.4.4.1 Bivariate Associations

Cerebrovascular disease (stroke or ministroke combined) was reported by 3.4% of participants (n = 14/409). Prevalence varied significantly by dentition status: 8.9% among edentulous participants compared 2.1% among those retaining at least one natural tooth ($\chi^2 = 8.76$, $p = .003$). A graded with association with tooth count was also observed, with prevalence highest among edentulous participants (8.9%), followed by those with 1–10 teeth (3.7%), 20+ teeth (2.6%), and no cases among those with 10–20 teeth ($\chi^2 = 10.43$, $p = .015$). Functional dentition showed a non-significant trend, with higher prevalence among those without functional dentition (4.2% vs. 1.7%, $\chi^2 = 1.61$, $p = .204$).

Hypertension was reported by 18.6% of participants (n = 76/409). Prevalence was higher among edentulous individuals compared with dentate peers (25.3% vs. 17.0%), although this difference did not reach statistical significance ($\chi^2 = 3.34$, $p = .188$). Functional dentition was significantly associated with hypertension (21.6% vs. 11.7%, $\chi^2 = 6.49$, $p = .039$), with those lacking functional dentition more likely

to report the condition. Interestingly, gum condition showed a counterintuitive pattern, with hypertension prevalence higher in participants categorised as having healthy gums (22.1%) compared with those with unhealthy gums (12.3%, $\chi^2 = 6.90$, $p = .032$). As expected, neither cavitated teeth nor oral cleanliness were significantly associated with hypertension or cerebrovascular disease as outlined in table 14.

Table 6.14. Bivariate associations of MOSST oral health indicators with ministroke, stroke, and hypertension

Association (MOSST outcome)	Cerebrovascular disease % (Yes)	p-value	Hypertension % (Yes)	p-value
<i>Dentition status</i>				
Dentate (≥ 1 tooth)	2.1%	Ref	17.0%	Ref
Edentulous	8.9%	$p=.003$	25.3%	$p=.188$
<i>Tooth count</i>				
20+ teeth	2.6%	Ref	14.0%	Ref
10–20 teeth	0.0%	—	21.7%	Ns
1–10 teeth	3.7%	$p=.015$	20.4%	Ns
Edentulous	8.9%		25.3%	
<i>Functional dentition</i>				
Present	1.7%	Ref	11.7%	Ref
Absent	4.2%	$p=.204$	21.6%	$p=.039$
<i>Gum condition</i>				
Not healthy	0.9%	Ref	12.3%	Ref
Healthy	3.8%	$p=.060$	22.1%	$p=.032$
<i>Cavitated teeth</i>				
Present	0.7%	Ref	18.1%	Ref
Absent	5.4%	$p=.546$	18.3%	$p=.546$
<i>Oral cleanliness</i>				
Not clean	2.5%	Ref	18.1%	Ref
Clean	6.8%	$p=.037$	16.9%	$p=.655$

Note. Percentages represent prevalence within each oral health category. p-values are from chi-square tests.

6.4.4.2 Logistic Regression of Cerebrovascular Disease

In unadjusted models, having 1–10 teeth compared with 20+ teeth was associated with significantly lower odds of stroke/ministroke (OR = 0.27, 95% CI: 0.08–0.89, $p = .031$). However, this association was attenuated and lost significance after adjustment for demographic and disability covariates (aOR = 0.54, 95% CI: 0.11–2.65, $p = .443$). Functional dentition status was not significantly associated with stroke/ministroke in either unadjusted or adjusted models. For gum condition, cavitated teeth, and oral cleanliness, odds ratios suggested elevated likelihood of stroke/ministroke among those with poor gum health, cavitation, or poor oral

cleanliness, but none of these reached statistical significance. Notably, oral cleanliness showed an elevated adjusted odds ratio (aOR = 7.57, 95% CI: 0.73–78.89, $p = .091$), but the wide confidence interval suggests an unstable estimate due to low case numbers. Further detail is shown in table 15

Model diagnostics indicated no evidence of problematic multicollinearity (all VIF values < 2). However, explanatory power was low (Nagelkerke R^2 values < .10), reflecting the small number of cerebrovascular events ($n = 14$) and wide variability in oral health indicators. Overall, logistic regression provided no robust evidence for independent associations between oral health indicators and stroke/ministroke

Table 6.15. Logistic regression of MOSST oral health indicators and stroke prevalence

<i>Oral health indicator</i>	<i>Unadjusted (95% CI)</i>	<i>OR</i>	<i>p- value</i>	<i>Adjusted (95% CI)</i>	<i>OR</i>	<i>p- value</i>
<i>Tooth count (Ref: 20+ teeth)</i>						
<i>10–20 teeth</i>	0.69 (0.13–3.67)	0.665		1.21 (0.17–8.77)	0.852	
<i>1–10 teeth</i>	0.27 (0.08–0.89)	0.031		0.54 (0.11–2.65)	0.443	
<i>Edentate</i>	– (unstable)	–		– (unstable)	–	
<i>Functional dentition (present vs absent)</i>	0.39 (0.09–1.76)	0.220		0.57 (0.07–4.85)	0.606	
<i>Gum condition (not healthy vs healthy)</i>	1.88 (0.29–12.22)	0.511		3.55 (0.25–50.82)	0.350	
<i>Cavitated teeth (present vs none)</i>	3.56 (0.40–31.80)	0.255		3.45 (0.30–39.49)	0.319	
<i>Oral cleanliness (not clean vs clean)</i>	3.16 (0.57–17.65)	0.190		7.57 (0.73–78.89)	0.091	

Note. Adjusted models include age group, gender, level of intellectual disabilities , and residential setting. OR = odds ratio; CI = confidence interval. Given the conceptual overlap between oral health indicators (edentulous status, tooth count, and functional dentition), collinearity was assessed. Diagnostics indicated no evidence of multicollinearity (all VIF values < 2), suggesting the predictors contributed independently to the models.

6.4.5 Diabetes

6.4.5.1 Bivariate Associations

Diabetes was reported in 9.5% of participants ($n = 39/409$). Prevalence varied across MOSST oral function indicators. Edentulous individuals had nearly twice the prevalence of diabetes compared with those retaining ≥ 1 natural tooth (15.2% vs 8.2%; $\chi^2 = 3.63$, $p = .057$). Tooth count showed a graded pattern, with diabetes prevalence highest among edentulous participants (15.2%), followed by those with 10–20 teeth (12.0%), 1–10 teeth (9.3%), and lowest in those with 20+ teeth (6.2%).

While the overall association did not reach statistical significance ($\chi^2 = 6.00$, $p = .111$), a significant linear trend was observed ($p = .029$).

Absence of functional dentition was significantly associated with diabetes prevalence (12.2% vs 4.2%; $\chi^2 = 6.16$, $p = .013$). By contrast, oral disease activity and hygiene indicators were not associated: gum condition (unhealthy vs healthy, 9.1% vs 6.9%; $\chi^2 = 0.55$, $p = .458$), cavitated teeth (present vs absent, 9.7% vs 10.0%; $\chi^2 = 0.006$, $p = .940$), and oral cleanliness (clean vs not clean, 12.7% vs 8.6%; $\chi^2 = 1.68$, $p = .195$) as shown in table 17.

Table 6.16 Bivariate associations between MOSST oral health indicators and diabetes prevalence

Association (MOSST outcome)	Diabetes % (Yes)	p-value
Dentition status		
Dentate (≥ 1 tooth)	8.2	—
Edentulous	15.2	.057
Tooth count		
20+ teeth	6.2	—
10–20 teeth	12.0	.111 (linear trend .029)
1–10 teeth	9.3	
Edentulous	15.2	
Functional dentition		
Present	4.2	—
Absent	12.2	.013
Gum condition		
Healthy	6.9	—
Not healthy	9.1	.458
Cavitated teeth		
None	10.0	—
Present	9.7	.940
Oral cleanliness		
Not clean	8.6	—
Clean	12.7	.195

Note. χ^2 p-values from bivariate tests; “Ref” indicates the reference category. Linear trend reported for ordered tooth-count categories.

6.3.4.5.2 Logistic regression models

While unadjusted logistic regression showed some association, adjusted models controlling for age, gender, level of intellectual disabilities, and residential setting indicated no association. Unadjusted logistic regression showed that edentulous participants had approximately twofold higher odds of diabetes compared with dentate participants (OR = 2.00, 95% CI: 0.97–4.17, $p = .061$). Tooth count showed

a graded but non-significant pattern, with the highest odds among edentulous participants (OR = 2.00, 95% CI: 0.96–4.19, $p = .064$).

Functional dentition was significantly associated with diabetes when coded as present vs absent (OR = 0.32, 95% CI: 0.13–0.82, $p = .013$), meaning absence of functional dentition was associated with nearly threefold higher odds of diabetes. Gum condition, cavitated teeth, and oral cleanliness were not significant predictors. In adjusted models controlling for age, gender, level of intellectual disabilities, and residential setting, none of the oral health indicators remained significant. For example, the odds of diabetes were not increased for edentulous participants (aOR = 0.60, 95% CI: 0.26–1.36, $p = .220$), nor for those lacking functional dentition (aOR = 1.58, 95% CI: 0.90–2.76, $p = .109$). Oral disease activity and hygiene markers also remained unrelated as detailed in table 18. The overall explanatory power of the adjusted models was limited.

Table 6.17. Logistic regression: associations between MOSST oral health indicators and diabetes

Predictor	Unadjusted (95% CI)	OR	P	Adjusted (95% CI)	OR	p
<i>Edentulous (vs dentate ≥ 1 tooth)</i>	2.00 (0.97–4.17)		.061	0.60 (0.26–1.36)		.220
<i>Tooth count (vs 20+ teeth)</i>						
– 10–20 teeth	1.98 (0.98–4.01)		.058	0.74 (0.21–2.58)		.638
– 1–10 teeth	1.57 (0.66–3.74)		.306	0.56 (0.20–1.63)		.289
– Edentulous	2.00 (0.96–4.19)		.064	0.60 (0.19–1.91)		.386
<i>Functional dentition (present vs absent)</i>	0.32 (0.13–0.82)		.013*	1.58 (0.90–2.76)		.109
<i>Cavitated teeth present (vs none)</i>	0.97 (0.39–2.41)		.940	0.88 (0.49–1.57)		.669
<i>Unhealthy gums (vs healthy)</i>	1.34 (0.62–2.87)		.458	1.00 (0.53–1.90)		.999
<i>Poor oral cleanliness (vs clean)</i>	1.55 (0.80–3.01)		.195	0.84 (0.40–1.77)		.654

Note. Adjusted models include age, gender, level of intellectual disabilities, and residential setting. For functional dentition, parameterisation is present vs absent; OR < 1 indicates protection of having functional dentition (i.e., absence $\approx 1/\text{OR}$ higher odds). Bold/asterisk indicates $p < .05$.

6.4.6 Summary of Key Findings

Across systemic health outcomes, oral functional status emerged as the most consistent and clinically meaningful predictor, whereas indicators of active oral disease and hygiene showed little association with broader health. Edentulism, reduced tooth count, and absence of functional dentition were associated with

substantially elevated risks of constipation, osteoporosis, and pneumonia, even after adjustment for age, gender, level of intellectual disability, and residential setting.

As summarised in Table 6.18 and visually synthesised in Figure 6.2 , a clear and graded pattern was evident. The forest plot demonstrates that effect sizes were largest and most consistent for pneumonia, followed by osteoporosis and constipation, with odds ratios exceeding two in several comparisons and confidence intervals that excluded the null. In contrast, oral disease activity indicators captured by the MOSST: cavitated teeth, gum condition, and oral cleanliness, were not independently associated with systemic outcomes once confounders were accounted for and are therefore not represented in the figure. This divergence reinforces that cumulative oral functional decline, rather than point-in-time disease status, appears to be the relevant oral health dimension for systemic vulnerability.

Table 6.18. Significant adjusted associations between oral functional status and systemic health outcomes

<i>Systemic outcome</i>	<i>Oral health indicator</i>	<i>Comparison (reference group)</i>	<i>Adjusted OR (95% CI)</i>	<i>Interpretation</i>
Constipation	Tooth count	1–10 teeth vs ≥20 teeth	2.18 (1.09–4.38)	Marked tooth loss was associated with more than double the odds of constipation, suggesting impaired mastication and dietary restriction may contribute to gastrointestinal dysfunction.
Osteoporosis	Functional dentition	No functional dentition vs functional	2.50 (1.20–5.10)	Absence of functional occlusion was associated with approximately two- to three-fold higher odds of osteoporosis, consistent with links between oral function, nutrition and frailty-related bone loss.
Pneumonia	Tooth count	1–10 teeth vs ≥20 teeth	3.31 (1.12–9.79)	Severe tooth loss was associated with substantially increased odds of pneumonia, indicating heightened respiratory vulnerability.
Pneumonia	Dentition status	Edentulous vs dentate	4.16 (1.12–15.47)	Complete tooth loss was associated with more than fourfold higher odds of pneumonia, representing the strongest oral–systemic association observed.

Notes: All models adjusted for age, gender, level of intellectual disability, and residential setting. Reference categories were ≥20 teeth, functional dentition present, and dentate status. Only statistically significant associations (95% CI excluding 1.00) are presented. Indicators of oral disease activity (cavitated teeth, gum condition, oral cleanliness) and outcomes with weaker or inconsistent associations (e.g. diabetes, hypertension) are not included and are discussed in the text.

The strongest association was observed for pneumonia. Participants who were edentulous had more than fourfold higher odds of reporting pneumonia compared with dentate peers, while those retaining only 1–10 teeth also showed markedly elevated risk. As illustrated in Figure 6.2, these associations were not only statistically significant but also substantially larger than those observed for other outcomes, underscoring the salience of oral function in respiratory health among older adults with intellectual disabilities . Importantly, the consistency of these

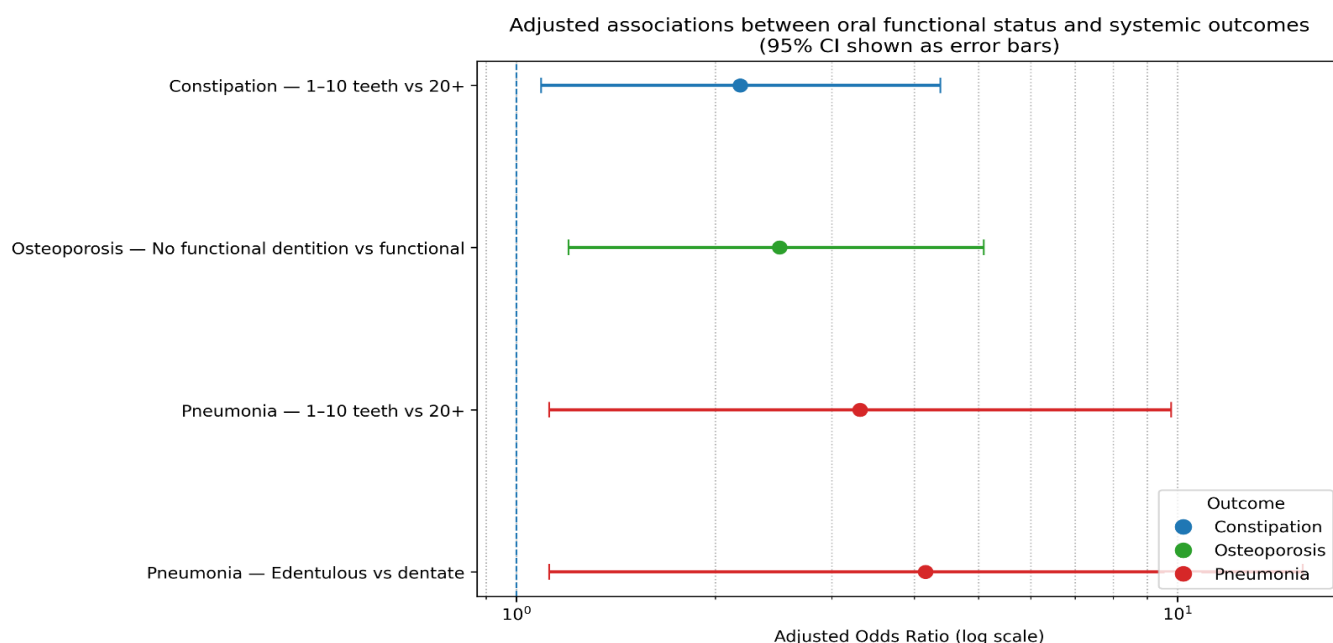
effects across dentition status and tooth count suggests a dose–response pattern, strengthening confidence in the robustness of the findings.

Associations with osteoporosis followed a similar, though less pronounced, pattern. Absence of functional dentition was associated with approximately two- to three-fold higher odds of osteoporosis, independent of demographic and disability-related factors. This finding aligns with the conceptualisation of oral function as an indicator of nutritional adequacy, mechanical loading, and broader frailty-related processes. Constipation also demonstrated a meaningful association with reduced dentition, particularly among participants with fewer than ten teeth, suggesting that impaired mastication and dietary restriction may have downstream gastrointestinal consequences.

The visual synthesis provided in Figure 6.2 highlights three key insights. First, oral functional measures consistently outperformed disease indicators as predictors of systemic health. Second, respiratory outcomes showed the largest effect sizes, supporting the hypothesis that oral function intersects with swallowing safety, aspiration risk, and survival-relevant pathways. Third, the graded nature of associations across dentition categories supports the interpretation of tooth loss as a marker of cumulative vulnerability rather than an isolated exposure.

Overall, these findings demonstrate that oral functional decline occupies a central position at the intersection of ageing, multimorbidity, and survival in people with intellectual disabilities . By capturing lifetime exposure to limited preventive care, extraction-led treatment, nutritional compromise, and functional decline, dentition status provides a powerful and accessible indicator of systemic risk. This reinforces the importance of preserving functional dentition and integrating oral health within broader models of ageing, chronic disease prevention, and risk stratification in this population.

Figure 6.2. Forest plot of adjusted odds ratios for systemic health outcomes by oral functional indicators



6.5 Discussion

This chapter provides an examination of associations between clinically assessed oral health and systemic health indicators in older adults with intellectual disabilities. Rather than identifying isolated relationships with individual conditions, the findings reveal a consistent pattern across outcomes: oral functional decline, particularly tooth loss and absence of functional dentition, was repeatedly associated with systemic vulnerability, while indicators of active oral disease showed limited independent association.

This distinction is important. Much of the general oral health literature emphasises periodontal disease, plaque burden and inflammatory pathways as drivers of systemic risk (Tonetti & Van Dyke, 2013; Sanz et al., 2018). In contrast, the present findings suggest that in older adults with intellectual disabilities, cumulative loss of oral function may be more relevant than current disease activity. This aligns with gerontological research showing that functional dentition is a stronger predictor of frailty, nutritional compromise and mortality than disease measures alone (Sheiham & Steele, 2001; Gerritsen et al., 2010; Tay et al., 2026).

Across constipation, osteoporosis and pneumonia, oral functional status emerged as the most consistent correlate, whereas gum condition, cavitated teeth and oral cleanliness were not independently associated once demographic and disability-

related factors were considered. This pattern suggests that oral function captures the long-term consequences of tooth loss, including reduced dietary adequacy, impaired mastication and compromised swallowing efficiency. These processes are cumulative in nature and therefore align closely with systemic conditions that develop over time, rather than reflecting transient disease states.

These findings suggest that oral functional decline operates as an integrative marker of systemic vulnerability in ageing with intellectual disabilities , reflecting cumulative exposure to nutritional compromise, reduced physiological reserve and complex care needs. Framing oral health in this way allows its biological relevance to be recognised without overstating causal claims and provides a coherent framework for interpreting the condition-specific findings that follow.

6.5.1 Constipation and Oral Health

Constipation was highly prevalent in this cohort, affecting almost 40% of participants, and emerged as one of the systemic conditions most consistently associated with oral functional decline. Associations were driven by tooth loss and reduced oral function, while indicators of active oral disease, including cavitated teeth, gingival condition and oral cleanliness, showed no independent relationship once demographic and disability-related factors were considered. This pattern supports the interpretation that oral functional capacity, rather than inflammatory or hygiene-related processes, underpins the relationship between oral health and bowel health in older adults with intellectual disabilities .

This finding aligns with emerging evidence from the general population linking reduced masticatory capacity and tooth loss to increased constipation risk (Huang et al., 2025; Ji et al., 2025). Proposed mechanisms emphasise impaired chewing leading to restricted intake of dietary fibre, fruit and vegetables, resulting in reduced bowel motility and altered gastrointestinal function (Tada & Miura, 2014). Oral functional decline therefore represents a plausible upstream contributor to constipation through its impact on diet quality rather than through systemic inflammation.

These pathways are likely to be amplified in adults with intellectual disabilities . Chewing difficulties are common, particularly among individuals who are

edentulous or lack functional dentition, and have been associated with reduced fibre intake, nutritional inadequacy and gastrointestinal complications (Chadwick & Jolliffe, 2009; İslamoğlu et al., 2024). Irish data further indicate that edentulism without denture replacement is associated with difficulty eating in older adults with intellectual disabilities , underscoring the importance of functional rehabilitation in maintaining dietary adequacy (Mac Giolla Phadraig et al., 2019).

Barriers to denture provision and use remain substantial in this population, including challenges with tolerance, access to prosthodontic services and reliance on caregiver support (Mac Giolla Phádraig et al., 2015). In the absence of effective functional rehabilitation, dietary restriction is likely to persist, providing a plausible explanation for the elevated odds of constipation observed among those with severe tooth loss. Preventive strategies that delay tooth loss, alongside timely denture provision and maintenance, may therefore mitigate constipation risk by supporting adequate fibre intake and digestive function.

Constipation is not only a clinical concern for adults with intellectual disabilities but also an important determinant of comfort, behaviour, and quality of life. High prevalence has been consistently documented in Irish and international studies, with risk compounded by severity of disability, residential setting, and polypharmacy (Robertson et al., 2000; Evenhuis et al., 2001; Fitzpatrick et al., 2024). Within this context, oral functional decline may further exacerbate an already substantial burden of gastrointestinal morbidity.

Crucially, unlike many established risk factors for constipation in adults with intellectual disabilities , oral health is modifiable. Preserving functional dentition, ensuring timely prosthetic rehabilitation and embedding oral and nutritional care within individual support plans represent feasible intervention points. Evidence that structured, carer-focused oral health training can improve daily oral hygiene and delay tooth loss (Mac Giolla Phádraig et al., 2013). Further supports the potential for oral health interventions to contribute meaningfully to constipation prevention and management in this population.

6.5.2 Osteoporosis and Oral Health

Osteoporosis was common in this cohort, affecting almost one in five participants, and reflects a substantial burden of skeletal fragility among older adults with intellectual disabilities in Ireland. Prevalence was highest among women, individuals with severe or profound intellectual disabilities, and those living in residential care, consistent with earlier national findings (Burke et al., 2017; McCarron et al., 2013). More recent evidence suggests an even greater burden, with osteoporosis and osteopenia together affecting most older adults with intellectual disabilities (Burke et al., 2019). Persistent diagnostic gaps remain, particularly among those with higher support needs and in residential settings, where bone health is frequently under-recognised and undertreated (Burke et al., 2024).

Against this background, the present findings indicate a robust association between oral functional decline and osteoporosis. Tooth loss and absence of functional dentition were independently associated with higher odds of osteoporosis, whereas indicators of active oral disease, including gingival condition, cavitation and oral cleanliness, were not. This pattern suggests that oral functional capacity, rather than current disease activity, is the oral health dimension most closely aligned with skeletal vulnerability in this population. Tooth retention and occlusal function may therefore operate as markers of cumulative biological and functional decline rather than as proxies for inflammatory oral pathology.

These findings align with international evidence demonstrating close interrelationships between oral health and bone health. Prospective studies in the general population show that systemic bone loss predicts subsequent tooth loss (Darcey et al., 2013), while meta-analyses confirm associations between tooth loss, reduced bone mineral density and increased fracture risk (Turcotte et al., 2021). Proposed mechanisms include nutritional compromise arising from impaired mastication, leading to reduced intake of protein, calcium and vitamin D, alongside shared biological processes affecting both alveolar and skeletal bone (Gerritsen et al., 2010).

In adults with intellectual disabilities , these pathways are likely to be intensified by population-specific vulnerabilities, including poor nutritional status, long-term use of anticonvulsant and psychotropic medications, reduced mobility and high levels of multimorbidity (Burke et al., 2024). Importantly, individuals with severe and profound intellectual disabilities , who are at greatest risk of early tooth loss and functional decline, have historically been excluded from both dental and bone health research due to challenges related to consent and examination (Dougall & Fiske, 2008; Anders & Davis, 2010). This exclusion has limited understanding of how oral and skeletal health intersect in those experiencing the highest levels of vulnerability.

Maintaining functional dentition and ensuring timely prosthodontic rehabilitation should therefore be considered components of comprehensive bone health strategies, alongside established approaches such as bone density screening, nutritional optimisation, vitamin D supplementation, physical activity and falls prevention. Framing oral function within bone health management underscores the need for more integrated, disability-inclusive approaches to ageing-related care.

6.5.3 Respiratory Health and Oral Health

This study demonstrates a strong and consistent association between oral functional loss and respiratory vulnerability in older adults with intellectual disabilities. Tooth loss and edentulism were robustly associated with reported pneumonia, whereas indicators of active oral disease, including gingival condition, cavitated teeth and oral cleanliness, showed no independent relationship. This pattern suggests that respiratory risk in this population is more closely linked to cumulative functional decline than to point-in-time oral pathology.

At first glance, these findings diverge from the dominant oral–respiratory paradigm in gerontology, which emphasises dental plaque as a reservoir for pathogenic bacteria aspirated into the lower airway (Sumi et al., 2007; Terpenning et al., 2001). In edentulous individuals, particularly those without dentures, plaque-mediated mechanisms would be expected to diminish. The present findings therefore point

to alternative and complementary pathways through which oral health influences respiratory outcomes in adults with intellectual disabilities.

A scoping review undertaken as part of this thesis (Chapter 2) examined the relationship between oral health, pneumonia and intellectual and developmental disabilities and highlighted the limited but emerging evidence base in this population (Byrne et al., 2025). While studies consistently suggested an association between poor oral health and respiratory disease, most evidence derived from small clinical samples, institutional settings or proxy indicators of oral hygiene, with few studies examining functional oral status or tooth loss as independent risk factors. The current findings extend this literature by demonstrating that loss of functional dentition may represent a particularly important pathway linking oral health and respiratory vulnerability in ageing populations with intellectual disabilities.

Impaired mastication and disrupted oral–swallow coordination represents particularly plausible mechanisms. Loss of natural teeth and absence of functional dentition compromise bolus formation and swallowing efficiency, increasing aspiration risk, particularly of poorly chewed food and oral secretions (van der Maarel-Wierink et al., 2011; Nitsuwat et al., 2024). These risks are amplified in adults with intellectual disabilities, who experience a high prevalence of dysphagia, gastro-oesophageal reflux, neuromotor impairment and sedative medication use, all of which undermine airway protection (Robertson et al., 2017; Lee et al., 2021).

Respiratory disease holds exceptional significance in intellectual disabilities. Pneumonia is a leading cause of morbidity and the single largest contributor to avoidable and premature mortality, with aspiration pneumonia disproportionately represented among preventable deaths (Heslop et al., 2014; O’Leary et al., 2018).

Within this context, oral functional decline should be understood as a sentinel marker of respiratory vulnerability rather than a peripheral concern. Tooth loss and absence of functional dentition encapsulate the cumulative effects of long-standing exclusion from preventive care, reliance on extraction-led treatment

models and limited access to prosthodontic rehabilitation. These structural factors intersect with biological vulnerability to heighten respiratory risk in later life.

Embedding oral health within respiratory care strategies for people with intellectual disabilities is therefore both clinically and ethically necessary. Preserving functional dentition, ensuring timely and supported denture provision, and integrating oral assessment into dysphagia and respiratory care pathways represent realistic and potentially impactful interventions. In a population where pneumonia remains a major cause of preventable death, addressing oral functional decline offers a tangible opportunity to reduce respiratory morbidity and improve survival.

6.5.4 Cardiovascular Outcomes

Associations between oral health and cardiovascular outcomes in this cohort were weaker and less consistent than those observed for constipation, osteoporosis and respiratory disease. While signals were observed between tooth loss, absence of functional dentition and cerebrovascular outcomes, particularly ministroke, these associations attenuated after adjustment for age, level of intellectual disabilities and residential setting. This pattern suggests that oral functional decline may contribute to vascular vulnerability in older adults with intellectual disabilities, but within a broader constellation of shared risk factors rather than as an independent driver.

In the general population, a substantial literature links poor oral health with cardiovascular and cerebrovascular disease. Systematic reviews and meta-analyses have reported associations between tooth loss, periodontal disease and increased risk of stroke and transient ischaemic attack (Janket et al., 2003; Liljestrang et al., 2015). Proposed mechanisms include chronic systemic inflammation accelerating atherosclerosis, endothelial dysfunction and thrombogenesis, alongside nutritional pathways whereby impaired mastication reduces intake of cardioprotective nutrients (Tonetti & Van Dyke, 2013). However, even within well-powered population studies, findings are heterogeneous and frequently attenuate after adjustment for socioeconomic position, health behaviours and comorbidities (Holmlund et al., 2017).

Evidence specific to adults with intellectual disabilities remains limited. One of the few available studies reported that self-reported gum disease was associated with more than double the odds of cardiovascular disease in adults with intellectual disabilities (Hsieh et al., 2018). The present findings extend this small evidence base by suggesting that oral functional capacity, rather than markers of active disease, may be the more relevant oral dimension in relation to vascular outcomes. This distinction aligns with broader ageing research indicating that cumulative functional loss often captures long-term biological stress more effectively than point-in-time disease measures.

Interpretation of these findings must also consider contextual constraints. Stroke prevalence was low in this cohort, limiting statistical power, and hypertension showed no association with oral health indicators. Moreover, adults with intellectual disabilities experience elevated cardiovascular risk through multiple non-oral pathways, including physical inactivity, obesity, polypharmacy, metabolic disorders and barriers to preventive screening (Cho et al., 2025; McCarron et al., 2013). Within this risk landscape, oral health is unlikely to operate as a dominant causal factor.

6.5.5 Diabetes and Oral Health

Diabetes prevalence in this cohort was comparable to estimates for older adults with intellectual disabilities in Ireland and internationally. While poorer oral functional status, particularly edentulism and absence of functional dentition, was descriptively associated with higher diabetes prevalence, these associations attenuated after adjustment for demographic and contextual factors. This suggests that oral health does not operate as an independent determinant of diabetes risk in this population.

This pattern mirrors the general population literature, where oral health–diabetes relationships are recognised as bidirectional but highly sensitive to confounding. Periodontitis can worsen glycaemic control through inflammatory pathways, while chronic hyperglycaemia accelerates periodontal breakdown and tooth loss (Lalla & Papapanou, 2011; Sanz et al., 2018). However, effect sizes are typically modest and

frequently attenuate after adjustment for socioeconomic position, obesity and health behaviours (Graziani et al., 2018).

In the present study, the absence of associations between diabetes and markers of active oral disease suggests that inflammatory oral pathways may be less salient in older adults with intellectual disabilities, likely reflecting the high prevalence of edentulism and reduced periodontal exposure. Instead, oral health may influence metabolic risk indirectly through functional and nutritional mechanisms. Loss of dentition and limited denture use can restrict dietary variety and fibre intake, potentially exacerbating metabolic dysregulation without acting as a primary causal driver.

Adults with intellectual disabilities also experience multiple non-oral diabetes risk factors, including obesity, sedentary behaviour, polypharmacy and barriers to metabolic screening, particularly among those with severe or profound disability (Hermans & Evenhuis, 2014). Within this risk environment, oral functional decline and diabetes appear to share upstream determinants related to ageing, dependency and health system exclusion.

These findings suggest that oral health is unlikely to be a dominant causal factor in diabetes development among older adults with intellectual disabilities. However, preserving functional dentition remains relevant within holistic metabolic risk reduction strategies, supporting dietary adequacy and complementing broader interventions targeting physical activity, nutrition and medication management, without overstating causal claims.

6.6 Implications for Policy, Practice and Future Research

The findings of this chapter indicate that oral functional capacity is a modifiable correlate of systemic health vulnerability in older adults with intellectual disabilities. Across multiple outcomes, tooth retention and functional dentition were consistently associated with lower prevalence of constipation, osteoporosis and pneumonia, while indicators of active oral disease showed limited independent predictive value. This pattern suggests that cumulative loss of oral

function, rather than point-in-time disease activity, is most relevant for understanding systemic health risk in this population.

From a public health and clinical perspective, these findings support the need for strategies that prioritise preservation of dentition and restoration of oral function. Preventing avoidable tooth loss, providing timely prosthetic rehabilitation, and incorporating oral health assessment into multimorbidity and frailty screening may offer opportunities to identify and support individuals at heightened risk of systemic decline.

6.6.1 Policy implications

The findings of this study have clear implications for health and disability policy, particularly in relation to ageing services. Older adults with intellectual disabilities experience a convergence of poor oral health, high multimorbidity and premature ageing, yet oral health remains weakly integrated into most chronic disease and ageing frameworks.

Recent inclusion of oral health within Ireland's *National Human Rights Strategy for Disabled People 2025–2030* (Department of Children & Equality, 2025), represents an important policy shift, explicitly recognising oral health as relevant to wellbeing and participation. The present findings provide empirical support for this direction by demonstrating that oral functional decline is associated with systemic health vulnerability in later life.

Effective implementation will require coordination across disciplines, including dentistry, nursing, medicine, nutrition, speech and language therapy and social care. Policy attention is particularly needed to address barriers to restorative and prosthodontic care for people with severe and profound intellectual disabilities and those living in residential settings, who remain the most excluded from functional rehabilitation. Ensuring access to restorative treatment under sedation or general anaesthesia, not solely extraction-based care, is essential if oral health policy is to support healthy ageing in this population.

6.6.2 Practice implications

At a practice level, preservation of natural teeth for as long as possible should be a core clinical priority. This requires access to preventive care, minimally invasive restorative approaches and timely prosthetic rehabilitation when tooth loss occurs. Oral health should be routinely considered within dysphagia management, nutritional support, respiratory care and osteoporosis prevention pathways.

Given the reliance of many adults with intellectual disabilities on caregivers for daily oral hygiene, workforce training and accountability are critical. Structured carer-focused interventions have been shown to improve oral hygiene practices and delay tooth loss (Mac Giolla Phadraig et al., 2023). Embedding oral health assessment within routine care planning, with clear referral pathways to specialist dental services, would support more proactive and equitable care, even within constrained service contexts.

6.6.3 Future research

Several priorities for future research emerge from this study. First, longitudinal analyses are required to clarify temporal relationships between oral functional decline and systemic outcomes such as constipation, osteoporosis and respiratory disease. Future waves of IDS-TILDA, with improved pneumonia data collection, will strengthen the capacity to examine these associations more robustly.

Second, intervention studies are needed to test whether preventive dental care, prosthetic rehabilitation and caregiver training can reduce systemic morbidity. Embedding oral health interventions within dysphagia management or nutritional support pathways may be particularly informative.

Third, continued inclusion of individuals with severe and profound intellectual disabilities is essential. The MOSST demonstrates the feasibility of inclusive oral health assessment, and future research should prioritise those most often excluded from both oral and systemic health studies. Finally, mixed-methods research is required to capture the lived experience of tooth loss, functional decline and systemic illness among people with intellectual disabilities and their caregivers, informing the design of person-centred and acceptable interventions.

6.7 Strengths and Limitations

A key strength of this study is the use of the MOSST, a validated and disability-inclusive clinical assessment that enabled structured oral health measurement at scale in a population historically excluded from dental epidemiology. By embedding MOSST within IDS-TILDA, this study generated the first nationally representative, clinically assessed evidence on oral functional status and its associations with systemic health outcomes in older adults with intellectual disabilities in Ireland. This integration represents a substantive methodological and scientific contribution, demonstrating that high-quality oral health data can be collected inclusively without compromising feasibility or rigour.

The availability of rich demographic, functional and health covariates within IDS-TILDA strengthened the analytical approach, enabling adjustment for key confounders including age, gender, level of intellectual disability and residential setting. The use of multiple oral health indicators allowed differentiation between oral disease activity and oral functional decline, supporting the novel finding that dentition status and functional measures, rather than point-in-time disease indicators, were most consistently associated with systemic health outcomes.

Several limitations should be considered when interpreting the findings. The cross-sectional design precludes causal inference, and the observed associations cannot establish temporal ordering between oral health decline and systemic conditions. It remains possible that tooth loss and reduced functional dentition act as markers of cumulative vulnerability rather than direct causal drivers of adverse health outcomes. Longitudinal analyses will be required to clarify directionality and causal pathways.

For some outcomes, particularly pneumonia, the number of cases was small, resulting in wide confidence intervals and limited statistical precision. Survey routing within Wave 5 further constrained the availability of certain health indicators, reducing analytic sample sizes for specific models. Missing data, particularly for oral disease indicators such as gum condition and cavitated teeth, led to additional reductions in adjusted models and limited power to detect associations for these variables.

Conceptual overlap between dentition-related indicators (dentate status, tooth count and functional dentition) necessitated careful model specification to avoid multicollinearity. As a result, combined or interaction effects between oral functional measures could not be fully explored. These reflect structural and methodological challenges inherent in conducting inclusive clinical research in populations with high support needs. Importantly, they do not undermine the central contribution of this study, but rather highlight the need for longitudinal, disability-inclusive oral health measurement to strengthen causal inference and guide prevention-oriented care.

6.8 Conclusion

This chapter demonstrates that oral functional capacity, more than markers of active oral disease, is consistently associated with systemic health vulnerability in older adults with intellectual disabilities. Constipation, osteoporosis and pneumonia showed the strongest relationships with tooth loss and impaired function, while cardiovascular disease, diabetes and multimorbidity displayed more context-dependent patterns. These findings position oral function as a clinically relevant indicator of systemic vulnerability in ageing with intellectual disabilities. While causal inference is not supported, the consistent associations observed suggest that oral functional decline reflects cumulative exposure to biological stress and care-related disadvantage. The implications of these findings extend beyond dentistry. Maintaining functional dentition should be understood as part of broader strategies to support healthier ageing and reduce preventable morbidity in adults with intellectual disabilities. The wider structural and equity implications of these findings are explored in Chapter 8.

Chapter 7:

Association between Tooth Loss and Mortality in Older Adults with an Intellectual Disability

Chapter 7 Abstract

Background

While life expectancy for people with intellectual disabilities has improved, health inequalities, premature ageing and elevated mortality persist. Oral health is rarely considered as a determinant of survival, despite evidence in general populations linking tooth loss to increased mortality. This study examined whether tooth loss predicted survival in older adults with an intellectual disability.

Methods

A 13-year longitudinal analysis of 742 participants with intellectual disabilities aged <40 years at Wave 1 (2009/2010) of IDS TILDA. Dentition was categorised as dentate, edentulous with dentures, or edentulous without dentures. Mortality risk (all-cause and respiratory) was determined through linkage with death certificates to March 2023. Kaplan–Meier and Cox proportional hazards regression analyses were used to examine associations between dentition and mortality.

Results

Over 13 years, 226 participants (30.5%) died, including 113 (15.0%) from respiratory causes. Mortality was highest among those edentulous without dentures (40.6%) compared with dentate (23.7%) and edentulous with dentures (28.8%). Mean survival time estimated from Kaplan–Meier curves were shortest for edentulous participants without dentures (10.0 years, 95% CI: 9.3–10.6). In unadjusted Cox models, edentulous participants without dentures had almost a threefold increased hazard of all-cause mortality (HR = 2.80, 95% CI: 2.09–3.74, $p < .001$) and respiratory mortality (HR = 3.08, 95% CI: 2.07–4.58, $p < .001$).

Conclusion

Complete tooth loss, especially without denture replacement, independently predicts mortality in older adults with intellectual disabilities. Retention of natural teeth and, if must, denture use, may mitigate this risk, highlighting the need for preventive and minimally invasive dentistry and timely prosthodontic rehabilitation. Oral health must be considered in disability and healthy ageing policies.

Keywords: intellectual disabilities, oral health, tooth loss, dentures, mortality, ageing, survival

7.1 Introduction

7.1.2 Background

Life expectancy for people with intellectual disabilities has increased substantially over recent decades, driven by advances in healthcare, improved living conditions, community-based supports, and greater social inclusion (Emerson & Hatton, 2014; McCarron et al., 2019; McCarron et al., 2013). Despite these gains, older adults with intellectual disabilities continue to experience marked health inequalities (Chapman et al., 2024). Compared with their peers without disabilities, they exhibit premature ageing, higher levels of multimorbidity, and persistently elevated mortality risk (Landes et al., 2019; O'Leary, Cooper, & Hughes-McCormack, 2018). Respiratory disease, cardiovascular conditions, and multimorbidity contribute disproportionately to excess deaths in this population (Heslop et al., 2014; Landes et al., 2019; McMahon et al., 2023; O'Leary, Cooper, & Hughes-McCormack, 2018).

Oral health represents an important but underexplored determinant of health in populations with intellectual disabilities (Anders & Davis, 2010; Wilson et al., 2019). Poor oral health has consequences beyond the oral cavity, contributing to frailty (Dibello et al., 2023), nutritional compromise, and systemic inflammation (Asaad et al., 2025). Tooth loss, particularly complete edentulism, is increasingly recognised as both a marker of cumulative disadvantage and a contributor to adverse ageing outcomes. Edentulism has been associated with malnutrition and reduced diet quality, functional decline, disability, sarcopenia (Romandini et al., 2021), cognitive impairment (Tonetti et al., 2017) and increased all-cause and cause-specific mortality (Romandini et al., 2021).

Evidence from the Irish general population underscores the relevance of oral health to survival. Analyses from TILDA showed that edentulous older adults had significantly higher risk of all-cause mortality over 13 years, with particularly strong

associations for respiratory mortality (Winning et al., 2025). Several biological and behavioural mechanisms may explain this relationship, including impaired mastication leading to poor nutritional intake, increased aspiration risk due to reduced oral competence, chronic systemic inflammation associated with periodontal disease, and psychosocial impacts such as social withdrawal (Beresescu et al., 2025; Berniyanti et al., 2023; Nitsuwat et al., 2024; Tonetti et al., 2017; van der Maarel-Wierink et al., 2011). Denture use may mitigate some of these risks by improving nutritional intake and psychosocial wellbeing (Gomes-Filho et al., 2020).

For people with intellectual disabilities, these associations are particularly concerning. Oral health inequalities are pronounced, with higher prevalence of untreated caries, periodontal disease, and tooth loss compared with the general population (Anders & Davis, 2010; Wilson et al., 2019). Structural barriers including reliance on caregivers for daily oral hygiene, communication difficulties, limited availability of specialist dental services, and reduced access to prosthodontic rehabilitation, further compounding these disparities (Anders & Davis, 2010; Chadwick., et al 2018 Faulks, 2023; Wilson et al., 2019). Respiratory conditions remain a leading cause of premature death among adults with intellectual disabilities (Hosking et al., 2016; McMahon et al., 2023; O’Leary, Cooper, & Hughes-McCormack, 2018), and swallowing difficulties and aspiration are more common in this population (van der Maarel-Wierink et al., 2011). Emerging evidence also suggests links between poor oral health and pneumonia among adults with intellectual and developmental disabilities (Byrne et al., 2025).

7.1.2 Rationale

Despite extensive evidence linking tooth loss to adverse outcomes in the general population, no longitudinal studies have examined whether edentulism predicts survival among people with intellectual disabilities. Given the distinct health profiles, patterns of multimorbidity, access barriers, and dependence on caregivers experienced by this population, the mechanisms linking oral health to mortality may differ from those observed in the general ageing population. Findings from general population cohorts therefore cannot be assumed to generalise to adults with intellectual disabilities.

Population-specific longitudinal evidence is needed to determine whether tooth loss represents a modifiable risk factor for mortality in this group and to inform targeted health and social care interventions. Using data from IDS-TILDA, this study extends established research on oral health and survival into the context of ageing with intellectual disabilities, providing evidence to support more inclusive health policy and clinical practice.

The inclusion of mortality analysis in this chapter is central to the overarching argument of the study. The preceding empirical chapters establish the need for inclusive oral health measurement, describe the development and application of the MOSST, and examine the oral health status and systemic health profile of older adults with intellectual disabilities. This chapter extends that line of inquiry by examining whether oral health indicators are associated with survival outcomes. In doing so, mortality analysis is positioned not as a separate endpoint, but as an integrative strand that connects oral health measurement, population-level surveillance and broader health outcomes in ageing with intellectual disabilities.

Figure 7.1. Conceptual integration of the mortality analysis within the research programme



Note: This figure illustrates how Chapter 7 is positioned within the wider research programme. The mortality analysis brings together the preceding strands of the study, including the identification of a measurement gap, development and application of the MOSST, generation of population-level oral health evidence through IDS-TILDA, and examination of oral-systemic associations. By analysing tooth loss and functional dentition in relation to all-cause and respiratory-related mortality, Chapter 7 connects inclusive oral health measurement with broader questions of ageing, health vulnerability and survival among adults with intellectual disabilities.

This is important because oral health indicators may reflect more than oral disease alone. Tooth loss and absence of functional dentition may represent cumulative exposure to oral disease, barriers to preventive and restorative care, nutritional vulnerability, systemic illness and wider structural disadvantage. Examining mortality therefore allows the study to consider whether clinically assessed oral health indicators also operate as markers of broader health vulnerability. In this way, Chapter 7 brings the inquiry full circle by linking the initial measurement gap that motivated the study with the broader question of how oral health relates to health, ageing and survival among adults with intellectual disabilities.

7.1.3 Research Question

The aim of this study was to investigate whether dentition status predicted survival in older adults with intellectual disabilities in Ireland. Specifically, we examined the association between edentulism (with and without dentures) and both all-cause and respiratory-related mortality over 13 years of follow-up, using data from the IDS-TILDA. We further explored demographic factors associated with mortality, including age, gender, level of intellectual disabilities, residential setting, and history of pneumonia.

7.2 Methods

7.2.1 Study Design

Data for this chapter was drawn from IDS-TILDA from Wave 1 to Wave 5 and mapped longitudinal using survival index measures on the oral health measures on number of teeth.

7.2.2 Sample

At baseline, 753 adults aged 40 years and older were recruited to IDS-TILDA. Of these, 742 participants (98.5%) had complete data on dentition status and were included in the present analyses. This cohort included individuals across a range of residential settings, levels of intellectual disability and health profiles, reflecting the diversity of living circumstances in the intellectual disability population in Ireland. All participants, or their proxies where appropriate, provided informed consent prior to participation.

7.2.3 Measures

7.2.3.1 Dentition Status

This was assessed at baseline with the self- or proxy-report to a structured CAPI with the specific oral health questions. These included whether participants had natural teeth and/or dentures. Responses were categorised as: (1) dentate (≥ 1 natural tooth, with or without partial dentures); (2) edentulous with dentures; or (3) edentulous without dentures. This approach has been used in comparable epidemiological research and is considered reliable for distinguishing between

dentate and edentulous states among people with intellectual disabilities (Mac Giolla Phadraig et al., 2015; Phadraig et al., 2017).

7.2.3.2 Mortality Outcomes

Mortality status was determined through linkage with official death certificate records from the General Register Office (GRO), with follow-up to March 2023 providing a maximum of 13 years. Cause of death was classified based on the primary underlying cause recorded on the death certificate, coded according to the International Classification of Diseases, Tenth Revision (ICD-10) using the IRIS automated mortality-coding software, with review and agreement from physicians. Respiratory mortality included deaths from pneumonia, aspiration pneumonia, chronic obstructive pulmonary disease, and other respiratory conditions.

7.2.3.3 Covariates

Covariates included age at baseline (categorised <50, 50–64, ≥65 years), gender, level of intellectual disabilities (mild, moderate, severe or profound), residential setting (independent/family home, community living, residential care facility), and self/proxy-reported history of pneumonia as reported via CAPI interviews and PIQ. Age, level of intellectual disabilities and residential setting have previously been shown in IDS-TILDA analyses to predict morbidity, functional decline and mortality risk (McCallion et al., 2019; McCarron et al., 2019). Pneumonia history was included given strong evidence from international studies that respiratory disease is the leading cause of premature death in adults with intellectual disabilities (Heslop et al., 2014; McMahon et al., 2023; O'Leary, Cooper, & Hughes-McCormack, 2018). These variables therefore represent key determinants of both oral health and survival in this population.

7.3.3.4 Censoring

Follow-up was calculated from each participant's baseline interview date to the date of death or censoring (31 March 2023 or 13 years post-baseline, whichever occurred first). Participants who remained alive at the end of follow-up were treated as censored.

7.3.4 Statistical Analysis

Descriptive statistics were calculated to characterise baseline demographic, oral health, and pneumonia occurrence stratified by survival status at follow-up. Continuous variables were summarised as means with standard deviations (SDs), while categorical variables were presented as frequencies and percentages. Group differences were assessed using independent t-tests for continuous measures and chi-square tests for categorical measures.

Kaplan–Meier survival analysis was used to estimate cumulative survival probabilities according to dentition status. Survival functions were compared across groups using the log-rank test. To illustrate patterns clearly, Kaplan–Meier curves were generated for a three-category classification (dentate; edentulous with dentures; edentulous without dentures). Cox proportional hazards regression was then applied to examine associations between dentition and mortality. Separate models were fitted for all-cause and respiratory-related mortality. Three specifications were reported: (1) unadjusted models including dentition only; (2) models adjusted for history of pneumonia, given its relevance as both a risk factor for tooth loss and a major cause of death; and (3) fully adjusted models including age, gender, level of intellectual disabilities, residential setting, and pneumonia history. Hazard ratios (HRs) with 95% CIs were reported. The proportional hazards assumption was evaluated graphically using log-minus-log plots, with no major violations detected.

To provide additional context, logistic regression was independently undertaken. First, models estimated unadjusted and adjusted odds ratios (ORs) for all-cause and respiratory-related mortality according to dentition status, using the same covariates as the Cox models. Second, logistic regression was used to examine predictors of edentulism at baseline, with age, gender, level of intellectual disabilities, residential setting and pneumonia history entered simultaneously. These analyses allowed exploration of both the role of dentition in survival and the factors contributing to tooth loss itself. All analyses were conducted using IBM SPSS Statistics (Version 26). Statistical significance was defined $p < 0.05$.

7.3.5 Ethics

IDS-TILDA received ethical approval from the Faculty of Health Sciences Research Ethics Committee at Trinity College Dublin. Written informed consent, or assent with proxy consent where appropriate, was obtained from all participants in line with the Health Research Regulations and GDPR. Reasonable adjustments were provided to support consent and participation, in accordance with ethical guidance for research involving adults with intellectual disabilities. All procedures adhered to the Declaration of Helsinki and national ethical standards.

7.5 Results

7.5.1 Sample Characteristics

A total of 752 participants with complete dentition data were included at baseline. Most were dentate or had dentures (75.5%, $n = 423$), with 29.9% ($n = 20$) edentulous with dentures and 54.4% ($n = 68$) edentulous without dentures. Mortality patterns differed significantly across demographic and clinical characteristics (Table 1). Death was strongly associated with age: 18.4% ($n = 53/288$) of those aged <50 years died, compared with 32.2% ($n = 110/342$) of those aged 50–64 years and 50.8% ($n = 62/122$) among those aged ≥ 65 years ($p < .001$). Mortality was substantially higher among those in residential care settings (37.7%, $n = 134/355$) compared with those living independently or with family (15.5%, $n = 20/129$, $p < .001$). Severe-to-profound intellectual disabilities was associated with the highest all-cause mortality (36.1%, $n = 74/205$, $p < .001$), compared with moderate (31.7%, $n = 102/322$) and mild intellectual disabilities (18.6%, $n = 31/167$). Dentition status showed a marked gradient: over half of participants who were edentulous without dentures died (54.4%, $n = 68/125$) compared with 24.3% ($n = 137/560$) of those with at least one tooth or dentures ($p < .001$). Respiratory mortality followed similar patterns, being highest among those edentulous without dentures (30.4%, $n = 38/125$) and those with severe-to-profound intellectual disabilities (20.5%, $n = 42/205$). A history of pneumonia was also associated with greater risk of death (38.1%, $n = 24/63$ vs. 25.7%, $n = 164/637$, $p = .035$), with nearly one-quarter of these deaths attributed to respiratory causes

(22.2%, n = 14/63, p = .040). Gender was not associated with mortality (male: 31.4%, n = 105/335; female: 29.8%, n = 120/417, p = .445).

Table 7.1 Baseline characteristics and mortality outcomes among older adults with intellectual disabilities

Predictor	Alive n (%)	Dead n (%)	P-value (all-cause)	Respiratory related death n (%)	p-value (respiratory)
Age group			<.001		<.001
<50 yrs	235(81.6)	53 (18.4)		31(10.8)	
50–64 yrs	232(67.8)	110 (32.2)		52 (15.2)	
≥65 yrs	60 (49.2)	62 (50.8)		31 (25.4)	
Gender			.445		.804
Male	230 (68.7)	105(31.3 8)		52 (15.5)	
Female	297 (71.4)	120 (29.8)		62 (14.9)	
Residence			<.001		<.001
Independent/family	109 (84.5)	20 (15.5)		6 (4.7)	
Community	197 (73.8)	7 (26.5)		338 (14.2)	
Residential care facility	221 (62.3)	134 (37.7)		70 (19.7)	
Level of intellectual disabilities			<.001		.012
Mild	136 (81.4)	31 (18.6)		16 (9.6)	
Moderate	220 (68.3)	102 (31.7)		46(14.3)	
Severe and profound	131 (63.9)	74 (36.1)		42 (20.5)	
Dentition status			<.001		<.001
≥1 tooth/dentures	423 (75.5)	137 (24.3)		70 (12.5)	
Edentulous with dentures	47 (70.1)	20 (29.9)		6 (9.0)	
Edentulous no dentures	57 (45.6)	68 (54.4)		38 (30.4)	
History of pneumonia			.035		.040
No	473 (74.3)	164 (25.7)		82 (12.9)	
Yes	39 (61.9)	24 (38.1)		14 (22.2)	

Note: Values are frequencies (n) and row percentages, calculated as the proportion of participants within each predictor category who were alive or deceased at follow-up. Percentages for “Alive”, “Dead”, and “Respiratory-related death” are calculated within each row. P-values are derived from chi-square tests of association, comparing the distribution of mortality outcomes across categories of each predictor.

7.5.2 All-Cause Mortality

During up to 13 years of follow-up, 226 participants (30.5%) died, including 113 deaths attributed to respiratory causes. Of those who died there was dentition data for $n=225$. Mortality rates differed markedly by dentition status, 24.3% ($n=137$) among dentate participants, 29.9% ($n=20$) among those edentulous with dentures, and 54.4.% ($n=68$) among those edentulous without dentures. Kaplan–Meier survival analysis showed clear separation between groups (log-rank $\chi^2 = 52.8$, $p < .001$). As illustrated in Figure 7.1, dentate participants had the longest mean survival (11.9 years, 95% CI: 11.7–12.2), followed by those edentulous with dentures (11.1 years, 95% CI: 10.2–11.9). Participants who were edentulous without dentures had the shortest mean survival (10.0 years, 95% CI: 9.3–10.6). Pairwise comparisons confirmed significantly reduced survival among edentulous without dentures compared with both dentate ($p < .001$) and edentulous with dentures ($p = .034$).

Figure 7.2: Kaplan–Meier survival curves for all-cause mortality.

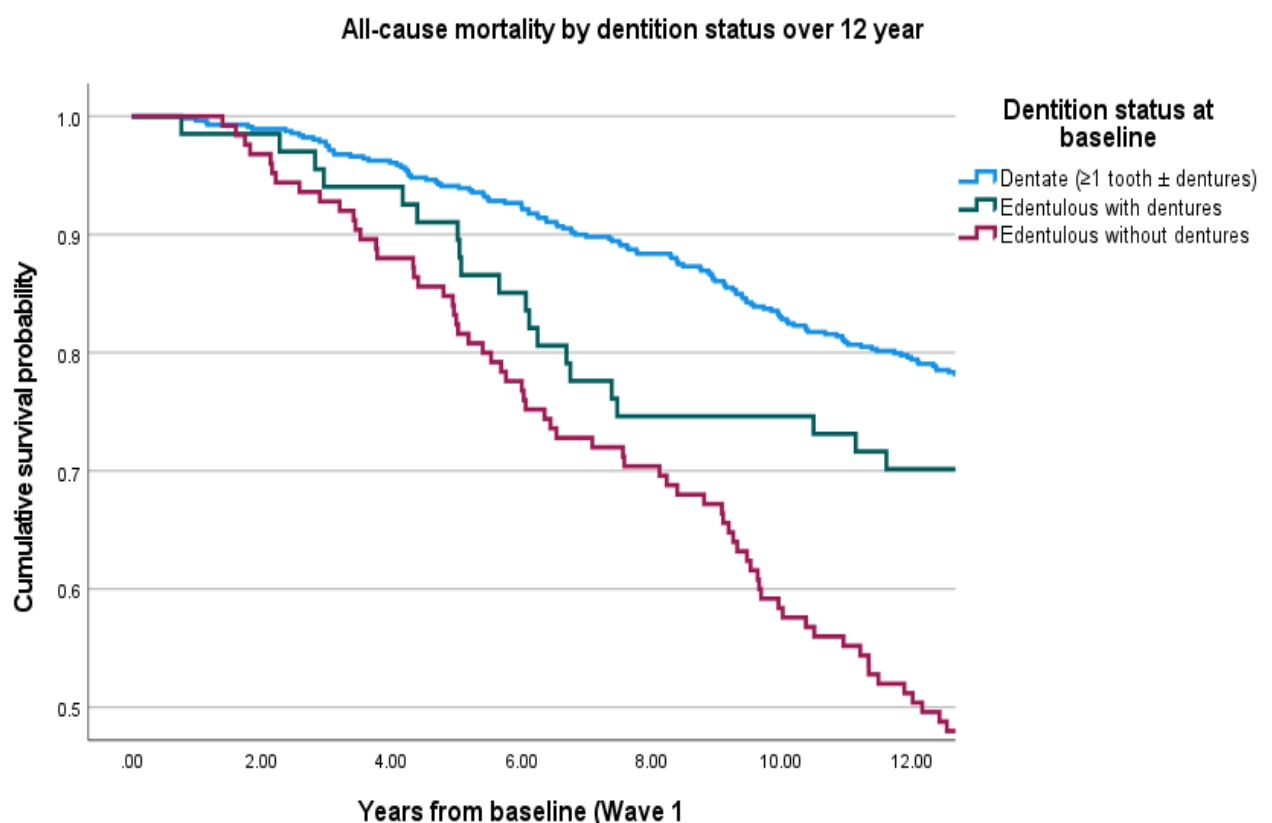


Figure 7.1. Kaplan–Meier survival curves for all-cause mortality over 12 years, stratified by dentition status at baseline. Survival was longest among dentate participants,

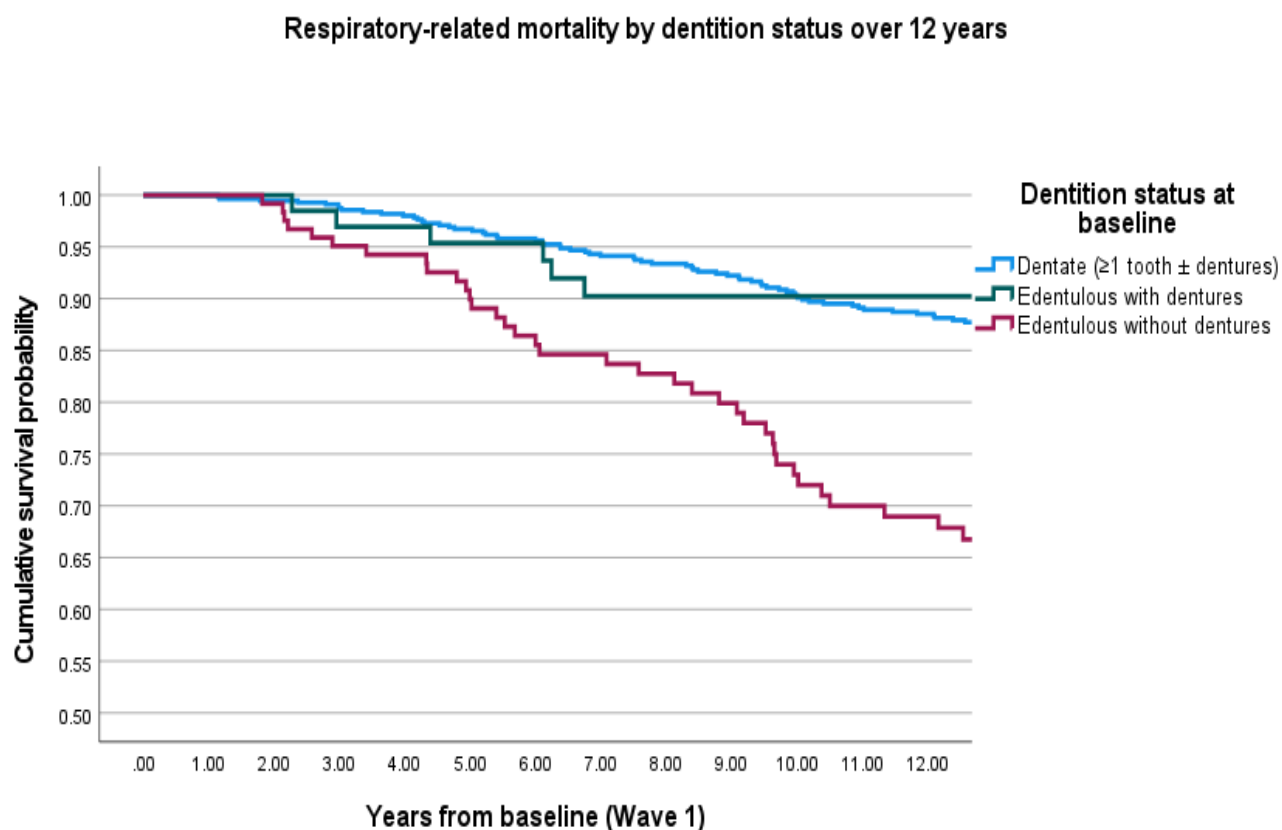
intermediate among those edentulous with dentures, and shortest among participants edentulous without dentures (log-rank $\chi^2 = 52.8$, $df = 2$, $p < .001$).

In unadjusted Cox models, edentulous participants without dentures had almost three times higher hazards of all-cause death compared with dentate peers (HR = 2.80, 95% CI: 2.09–3.74, $p < .001$). This association persisted after adjustment for age, gender, level of intellectual disabilities, residential setting, and history of pneumonia, though attenuated to a 69% higher hazard (HR = 1.69, 95% CI: 1.21–2.35, $p = .002$). By contrast, outcomes for edentulous participants with dentures were not significantly different from dentate individuals in either unadjusted (HR = 1.33, 95% CI: 0.83–2.13, $p = .23$) or adjusted models (HR = 1.18, 95% CI: 0.72–1.93, $p = .52$). Age was a strong predictor: participants aged ≥ 65 years had nearly three-fold higher hazards of death compared with those < 50 years (HR = 2.85, 95% CI: 1.79–4.53, $p < .001$). Living in a residential facility was also associated with excess risk (HR = 1.89, 95% CI: 1.02–3.49, $p = .043$). Pneumonia history was not independently associated with all-cause mortality (HR = 1.21, 95% CI: 0.90–1.63, $p = .21$).

7.5.3 Respiratory-Related Mortality

Kaplan–Meier analyses also demonstrated differences in respiratory survival (log-rank $\chi^2 = 36.9$, $p < .001$). Mean respiratory survival was longest among dentate participants (12.5 years, 95% CI: 12.3–12.7), similar among edentulous with dentures (12.4 years, 95% CI: 11.8–13.1), and shortest among edentulous without dentures (11.2 years, 95% CI: 10.6–11.8) as outlined in figure 2. Pairwise comparisons showed significantly shorter survival among edentulous without dentures compared with both dentate participants ($p < .001$) and edentulous with dentures ($p < .001$).

Figure 7.3: Kaplan–Meier survival curves (respiratory).



Note. Kaplan–Meier curves illustrate survival differences in respiratory-related mortality across dentition groups. Survival time is presented in years from Wave 1 baseline. Y-axis truncated at 0.60 for clarity. The log-rank test indicated significant differences between groups (log-rank $\chi^2 = 36.9$, $df = 2$, $p < .001$).

Similar patterns were observed for respiratory-related deaths. In unadjusted analyses, edentulous participants without dentures had over a three-fold higher hazard of respiratory mortality compared with dentate peers (HR = 3.08, 95% CI: 2.07–4.58, $p < .001$). After adjustment, the risk remained nearly doubled of respiratory related death (HR = 1.92, 95% CI: 1.22–3.01, $p = .005$). Edentulous participants with dentures did not differ significantly from dentate peers in either unadjusted or adjusted models. Other independent predictors of respiratory mortality included age ≥ 65 years (HR = 2.33, 95% CI: 1.23–4.41, $p = .009$) and congregated residential settings. Compared with independent and family living, hazards were over five times higher in community living (HR = 5.55, 95% CI: 1.32–23.36, $p = .019$) and six times higher in residential care facilities (HR = 6.28, 95% CI: 1.48–26.61, $p = .012$). Pneumonia history was borderline significant (HR = 1.45, 95% CI: 0.99–2.13, $p = .056$).

Table 7.2: Cox proportional hazards regression for all-cause and respiratory

Predictor	All-cause mortality Unadjusted HR (95% CI)	p-value	All-cause mortality Adjusted HR (95% CI)	p-value	Respiratory mortality Unadjusted HR (95% CI)	p-value	Respiratory mortality Adjusted HR (95% CI)	p-value
Dentition status								
Dentate (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Edentulous with dentures	1.33 (0.83–2.13)	0.23	1.18 (0.72–1.93)	0.52	0.79 (0.35–1.83)	0.58	0.74 (0.31–1.76)	0.50
Edentulous no dentures	2.80 (2.09–3.74)	<.001	1.69 (1.21–2.35)	0.002	3.08 (2.07–4.58)	<.001	1.92 (1.22–3.01)	0.005
Age group								
<50 yrs (ref)	1.00	–	1.00	–	1.00	–	1.00	–
50–64 yrs	–	–	1.87 (1.28–2.72)	0.001	–	–	1.55 (0.93–2.59)	0.09
≥65 yrs	–	–	2.85 (1.79–4.53)	<.001	–	–	2.33 (1.23–4.41)	0.009
Residential setting								
Family/independent (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Community living	–	–	1.56 (0.85–2.88)	0.15	–	–	5.55 (1.32–23.36)	0.019
Residential care facility	–	–	1.89 (1.02–3.49)	0.043	–	–	6.28 (1.48–26.61)	0.012
Level of intellectual disabilities								
Mild (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Moderate	–	–	1.35 (0.87–2.08)	0.18	–	–	1.16 (0.62–2.15)	0.64
Severe to profound	–	–	1.52 (0.94–2.46)	0.09	–	–	1.31 (0.67–2.54)	0.43
Gender								
Male (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Female	–	–	0.85 (0.62–1.15)	0.28	–	–	0.83 (0.56–1.23)	0.35
History of pneumonia								
No (ref)	–	–	1.00	–	–	–	1.00	–
Yes	–	–	1.21 (0.90–1.63)	0.21	–	–	1.45 (0.99–2.13)	0.056

Note: Unadjusted models = dentition only. Adjusted models include dentition, age, gender, level of intellectual disabilities, residence, and pneumonia history.

7.5.4 Logistic Regression

Logistic regression analyses outlined in Table 3 showed results consistent with the Cox models. Edentulous participants without dentures had more than threefold

higher unadjusted odds of all-cause mortality versus dentate peers (OR = 3.65, 95% CI: 2.38–5.61, $p < .001$). This association remained significant after adjustment for age, gender, residential setting, level of intellectual disabilities and pneumonia (OR = 2.11, 95% CI: 1.34–3.31, $p = .001$). Outcomes for those edentulous with dentures did not differ significantly from dentate individuals in either unadjusted or adjusted models. For respiratory-related mortality, edentulous without dentures again showed elevated risk (unadjusted OR = 3.10, 95% CI: 1.96–4.90, $p < .001$; adjusted OR = 2.02, 95% CI: 1.21–3.39, $p = .008$). Other predictors of mortality in the adjusted logistic models included older age (≥ 65 years: OR = 4.98, $p < .001$ for all-cause; OR = 2.76, $p < .001$ for respiratory related mortality) and congregated residential settings (community home: OR = 2.21, $p = .020$ for all-cause; OR = 4.73, $p = .012$ for respiratory; residential care facility: OR = 2.88, $p = .002$ for all-cause; OR = 5.50, $p = .006$ for respiratory mortality). Severe to profound intellectual disabilities was associated with higher odds of all-cause mortality (OR = 1.85, $p = .019$). Gender was not significant. Pneumonia history was an independent predictor for all-cause mortality (OR = 1.76, $p = .004$) and was borderline for respiratory mortality (OR = 1.91, $p = .052$).

Table 7.3. Logistic regression models for all-cause mortality and respiratory specific mortality

Predictor	All-cause mortality Unadjusted OR (95% CI)	p-value	All-cause mortality Adjusted OR (95% CI)	p-value	Respiratory mortality Unadjusted OR (95% CI)	p-value	Respiratory mortality Adjusted OR (95% CI)	p-value
Dentition status								
Dentate (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Edentulous with dentures	1.34 (0.73–2.47)	0.34	1.15 (0.70–1.91)	0.58	0.77 (0.32–1.87)	0.56	0.74 (0.33–1.66)	0.50
Edentulous (without dentures)	3.65 (2.38–5.61)	<.001	2.11 (1.34–3.31)	0.001	3.10 (1.96–4.90)	<.001	2.02 (1.21–3.39)	0.008
Age group								
<50 yrs (ref)	1.00	–	1.00	–	1.00	–	1.00	–
50–64 yrs	–	–	2.35 (1.42–3.87)	0.001	–	–	1.64 (0.97–2.77)	0.06
≥ 65 yrs	–	–	4.98 (2.79–8.89)	<.001	–	–	2.76 (1.54–4.94)	<.001

Residential setting								
Family /Independent (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Community	–	–	2.21 (1.13–4.33)	0.020	–	–	4.73 (1.40–15.94)	0.012
Residential care facility	–	–	2.88 (1.49–5.57)	0.002	–	–	5.50 (1.63–18.59)	0.006
Level of intellectual disabilities								
Mild (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Moderate	–	–	1.41 (0.93–2.12)	0.11	–	–	1.14 (0.61–2.14)	0.67
Severe and profound	–	–	1.85 (1.10–3.11)	0.019	–	–	1.46 (0.74–2.89)	0.27
Gender								
Male (ref)	1.00	–	1.00	–	1.00	–	1.00	–
Female	–	–	1.12 (0.79–1.58)	0.53	–	–	0.83 (0.56–1.23)	0.35
History of pneumonia								
No (ref)	–	–	1.00	–	–	–	1.00	–
Yes	–	–	1.76 (1.20–2.58)	0.004	–	–	1.91 (0.99–3.68)	0.052

Note. Unadjusted models include dentition only. Adjusted models include dentition, age group, gender, residential setting, level of intellectual disabilities, and history of pneumonia. Reference categories: dentate, <50 years, family/independent living, mild intellectual disabilities, and male gender. OR = Odds Ratio; CI = Confidence Interval.

7.6 Discussion

7.6.1 Main Findings

This study provides the first population-based evidence that complete tooth loss, particularly when not rehabilitated with dentures, is associated with reduced survival among older adults with intellectual disabilities. Over a thirteen-year follow-up period, participants who were edentulous without dentures experienced significantly shorter survival and higher risk of both all-cause and respiratory-related mortality compared with their dentate peers.

Across analytic models, edentulous participants without dentures consistently showed the poorest outcomes. In unadjusted analyses, this group experienced more than a threefold increase in risk of all-cause and respiratory mortality.

Although effect sizes attenuated following adjustment for demographic, health and disability-related covariates, hazards remained almost doubled, indicating a robust association between non-rehabilitated tooth loss and mortality. In contrast, edentulous participants who had received dentures demonstrated survival patterns broadly comparable to those who retained natural teeth.

This distinction between edentulous individuals with and without dentures is a key finding of the study. It suggests that loss of natural teeth alone does not fully account for elevated mortality risk, and that restoration of oral function through prosthodontic rehabilitation may mitigate some of the adverse consequences associated with tooth loss. Dentition status, particularly functional dentition, therefore, appears to capture clinically meaningful variation in vulnerability within an already high-risk population.

These findings extend established associations between tooth loss and mortality from general ageing cohorts into a population characterised by earlier onset of multimorbidity, high respiratory disease burden and accelerated ageing trajectories. By demonstrating that dentition status differentiates survival risk within this group, the study positions oral health as a substantive component of later-life health rather than a peripheral or purely symptomatic concern. Subsequent sections situate these findings within the broader literature, explore plausible mechanisms, and consider their clinical and policy implications.

7.6.2 Comparison with Previous Literature

What distinguishes the present findings is their focus on a population experiencing intersectional and augmented disadvantage. Adults with intellectual disabilities carry substantially higher burdens of multimorbidity, functional impairment and respiratory vulnerability than the general population, and these characteristics shape how established oral–systemic pathways operate in later life.

In the general population, a substantial body of longitudinal evidence links tooth loss with increased mortality risk. Large cohort studies across Europe, North America and Asia consistently report higher all-cause and cause-specific mortality among edentulous adults, particularly for cardiovascular and respiratory outcomes (Bond et al., 2022; Gomes-Filho et al., 2020; Holmlund et al., 2010; Polzer et al.,

2012). Meta-analyses estimate a 20–40% increased risk of premature mortality associated with edentulism, with the strongest associations observed for respiratory-related deaths (Romandini et al., 2021). However, these findings are derived from populations with markedly different health profiles, care pathways and baseline risks than those experienced by adults with intellectual disabilities.

Recent Irish evidence from the general population provides a particularly relevant comparison. Using data from TILDA, Winning et al. (2025) reported significantly elevated hazards of all-cause mortality (adjusted HR = 1.42) and nearly doubled hazards of respiratory mortality (adjusted HR = 1.93) among edentulous adults. In that study, however, edentulism predominantly reflected individuals who had received dentures, as lack of prosthodontic rehabilitation was uncommon.

In contrast, a substantial proportion of edentulous participants in IDS-TILDA did not have dentures. In the present study, edentulous adults without dentures exhibited markedly poorer survival, with adjusted hazards of respiratory mortality comparable to those observed in TILDA (adjusted HR = 1.92) and somewhat higher adjusted hazards for all-cause mortality (adjusted HR = 1.69). Importantly, edentulous participants who had received dentures demonstrated survival outcomes broadly comparable to dentate peers. This pattern suggests that absence of prosthodontic rehabilitation may exacerbate mortality risk and that denture provision may be particularly consequential in populations with elevated baseline vulnerability.

Direct comparison of effect sizes across studies should be interpreted cautiously. TILDA modelled tooth loss as a continuous measure, whereas the present analysis distinguished dentate participants from those who were edentulous with and without dentures. In addition, IDS-TILDA incorporated disability-specific covariates, including level of intellectual disabilities, residential setting and pneumonia history, meaning adjusted estimates reflect different underlying risk structures. Nonetheless, the contrast between rehabilitated and non-rehabilitated edentulism in this study adds an important dimension that is largely absent from general population analyses.

These findings are especially salient given existing evidence that adults with intellectual disabilities face disproportionate barriers to prosthodontic care, including limited self-advocacy, communication barriers and restricted availability of dentists willing or trained to provide dentures (Mac Giolla Phadraig et al., 2015; Phadraig et al., 2017). Overall mortality in IDS-TILDA was also higher than in TILDA (30.5% vs. 22%), underscoring the elevated baseline risk within which oral health differences operate.

While edentulism is associated with mortality in the general population, the present findings suggest that risk is most pronounced where tooth loss is not functionally rehabilitated. In adults with intellectual disabilities, dentition status appears to capture both biological vulnerability and structural disadvantage, with prosthodontic rehabilitation potentially modifying survival trajectories to a greater extent than is typically observed in non-disabled ageing cohorts.

7.6.3 Potential Mechanisms

The associations observed between tooth loss and mortality in this study arise from observational data and therefore do not establish causality. However, the findings are consistent with several well-described biological, functional and psychosocial pathways linking oral health to systemic vulnerability and survival, particularly in populations characterised by multimorbidity, functional dependence and heightened respiratory risk.

Loss of natural teeth compromises chewing efficiency, which restricts dietary variety and can contribute to nutritional inadequacy, frailty and sarcopenia (Nitsuwat et al., 2024; Romandini et al., 2021). Adults with intellectual disabilities may be especially vulnerable to these effects, as dietary intake is often shaped by reliance on caregivers, modified-texture diets and institutional food provision (Özdemir et al., 2023). In this context, edentulism may accelerate nutritional decline beyond that observed in the general ageing population.

Tooth loss may also impair oral competence and swallowing coordination, increasing the risk of aspiration and respiratory infection (van der Maarel-Wierink et al., 2011; Nitsuwat et al., 2024). These functional consequences are particularly salient for adults with intellectual disabilities, among whom dysphagia, gastro-

oesophageal reflux, neuromotor impairment and sedative medication use are highly prevalent. Together, these factors compromise airway protection and align closely with the strong association observed between edentulism and respiratory-related mortality in this cohort.

In addition to biological and functional pathways, edentulism may exert psychosocial effects that indirectly influence health and survival. Tooth loss has been associated with reduced self-esteem, impaired communication and social withdrawal in older adults (Berniyanti et al., 2023; Hunter et al., 2024; Weintraub et al., 2024). For adults with intellectual disabilities, these impacts may be amplified by pre-existing communication barriers, limited autonomy and elevated risk of social exclusion. Evidence indicates that poor oral health adversely affects oral-health-related quality of life, social participation and communication in this population (Rollon-Ugalde et al., 2020; Ward et al., 2019), with potential downstream consequences for wellbeing, engagement with care and overall health.

Importantly, these biological, functional and psychosocial mechanisms operate within a context of cumulative structural disadvantage. Adults with intellectual disabilities experience lifelong barriers to preventive dental care, reduced access to prosthodontic rehabilitation, and heavy reliance on others for oral hygiene and health advocacy (Anders & Davis, 2010; Wilson et al., 2019). Edentulism without denture replacement may therefore represent not only a state of biological vulnerability, but also a marker of sustained health system exclusion and unmet need across the life course (Chapman et al., 2024; Emerson & Hatton, 2014).

These pathways provide a coherent explanatory framework for the observed associations between tooth loss and mortality. While causal inference cannot be made, the convergence of functional impairment, nutritional compromise, respiratory vulnerability and structural disadvantage offers a plausible account of why edentulism, particularly in the absence of prosthetic rehabilitation, is associated with reduced survival in older adults with intellectual disabilities.

7.6.4 Clinical and Policy Implications

The findings of this study indicate that oral health, and particularly the preservation or restoration of oral function, has implications that extend beyond comfort or quality of life for older adults with intellectual disabilities. Clinically, these findings reinforce the importance of preventive dental care across the life course, prioritising tooth retention, early intervention for dental disease, and timely prosthodontic rehabilitation following tooth loss. Functional dentition has been shown to be strongly associated with nutritional status, masticatory efficiency, and overall health outcomes in older adults (Emami et al., 2013; Sheiham & Steele, 2001); while inadequate prosthodontic rehabilitation has been linked to compromised dietary intake and reduced quality of life (Gerritsen et al., 2010).

For individuals who become edentulous, access to appropriate dentures may help preserve chewing function, support nutritional intake, and reduce risks associated with aspiration and frailty. Given the often reliance of adults with intellectual disabilities on others for daily oral hygiene support and denture care maintenance, training and support for caregivers and staff are essential components of effective prevention (Anders & Davis, 2010; Wilson et al., 2019).

At the policy level, these findings highlight oral health as a neglected dimension of disability and ageing services. Although national and international frameworks increasingly recognise people with disabilities as a priority population, oral health remains weakly operationalised within disability policy and service planning. Recent commitments within the WHO Global Oral Health Action Plan and Ireland's National Human Rights Strategy for Disabled People identify oral health inequities as an area requiring action, but implementation remains limited.

By demonstrating that tooth loss without rehabilitation is associated with premature mortality, this study provides empirical support for embedding oral health within disability-inclusive health strategies. Addressing oral health inequity should therefore be understood not only as improving quality of life, but as part of a broader effort to reduce avoidable morbidity and mortality and to support equitable ageing for people with intellectual disabilities.

7.6.5 Future Research

Retention of natural teeth should be considered a central health objective for people with intellectual disabilities, given the clear survival advantages associated with dentition observed in this and other studies (Romandini et al., 2021; Winning et al., 2025). Research should therefore focus on developing and evaluating preventive strategies that reduce caries and periodontal disease in this population, including inclusive models of dental service delivery, community-based oral health promotion, and interventions that strengthen caregiver support for daily oral hygiene (Anders & Davis, 2010; Wilson et al., 2019). Prospective research incorporating clinical dental examinations, nutritional assessments, swallowing evaluations, and biomarkers of systemic inflammation would provide more definitive evidence on causal pathways (Chen & Kistler, 2015; van der Maarel-Wierink et al., 2011). In addition, qualitative research involving people with intellectual disabilities and their caregivers is essential to better understand lived experiences of tooth loss and denture use, barriers to accessing dental care and preferences for oral health interventions. Future studies should also consider comparative analyses using both TILDA and IDS-TILDA datasets to examine whether mortality risks associated with tooth loss differ systematically between adults with and without intellectual disabilities, particularly when prosthodontic rehabilitation is accounted for which would help clarify potential effect modification at a population level. Finally, intervention studies are required to determine whether maintaining natural dentition or providing timely prosthodontic rehabilitation can improve long-term health outcomes, especially with respect to respiratory morbidity and mortality.

7.8 Conclusion

This nationally representative longitudinal analysis in this chapter demonstrates that complete tooth loss without denture replacement is a strong and independent predictor of both all-cause and respiratory mortality in older adults with intellectual disabilities. By contrast, edentulous participants who used dentures had survival outcomes comparable to those who were dentate, suggesting that prosthodontic rehabilitation can mitigate some risks associated

with tooth loss. These findings underscore the critical importance of preventing tooth loss across the lifespan for people with intellectual disabilities. Retention of natural teeth should be recognised as a core health goal, not only for maintaining function and quality of life but also for supporting survival. Where tooth loss does occur, timely provision of dentures represents a protective intervention that should be accessible to all.

Chapter 8:

Discussion and Conclusions

8.1 Purpose and Contribution of the Thesis

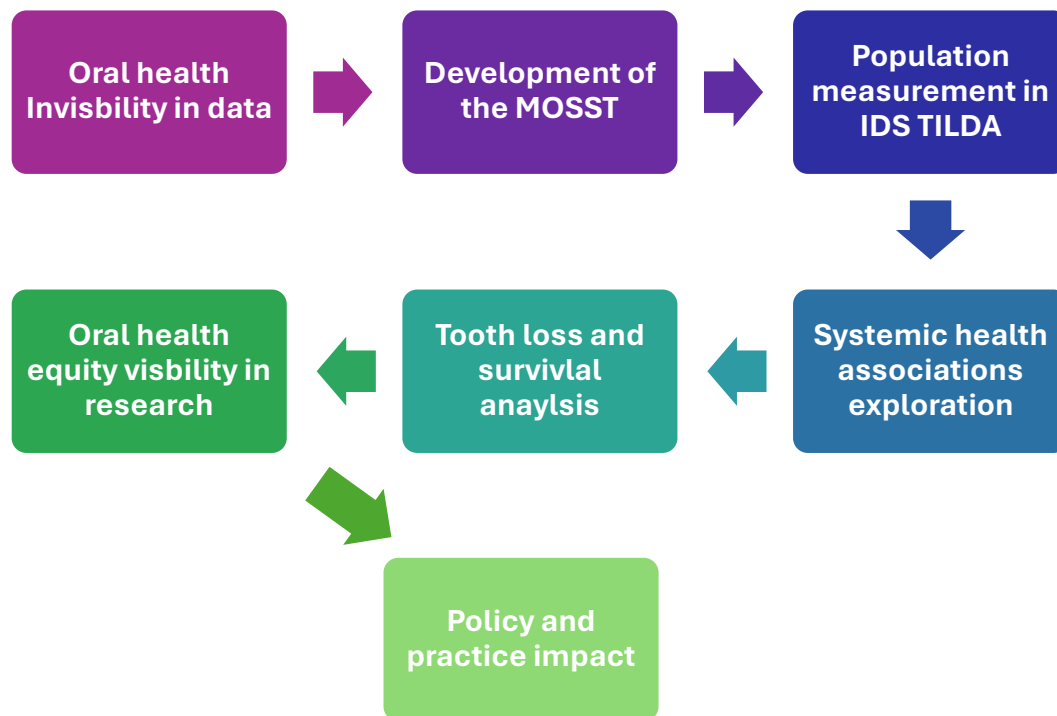
This thesis addresses a fundamental gap in oral health and disability research: the absence of disability-inclusive, clinically assessed oral health evidence for older adults with intellectual disabilities. Despite growing recognition that oral health is integral to healthy ageing, systemic health, and survival, this population has remained overlooked within oral health epidemiology, surveillance systems, and policy frameworks.

The overarching aim was to generate robust, population-level evidence capable of addressing this gap. As illustrated in Figure 8.1, the programme of research progressed from documenting the invisibility of oral health in this population to developing a disability-adapted objective measurement tool (MOSST), enabling the collection of objective oral health data within a nationally representative ageing study. Application of this tool within IDS-TILDA produced population-level evidence on oral disease burden that had previously been unavailable.

Building on this methodological foundation, the thesis examined whether oral health in older adults with intellectual disabilities is clinically and systemically meaningful rather than peripheral or cosmetic. Analyses identified associations between oral health indicators and broader health conditions, including multimorbidity, frailty-related disorders, and respiratory disease. Further investigation demonstrated links between cumulative oral deterioration, particularly tooth loss, and survival outcomes.

Collectively, these findings reposition oral health as a measurable determinant of health in ageing with intellectual disabilities, with implications extending beyond dentistry to encompass systemic health, functional decline, and mortality risk. As shown in Figure 8.1, the research trajectory culminates in implications for policy, clinical practice, and health equity, highlighting the need for inclusive surveillance systems and accountability for oral health outcomes in this population.

Figure 8.1. Programme of research and contributions of this thesis



8.2 From Invisibility to Evidence: How This Thesis Generated New Knowledge

This section traces how older adults with intellectual disabilities, who have historically been excluded from oral health research, became visible within population-level evidence and how that visibility generated new insights into ageing, systemic vulnerability, and survival. Rather than presenting findings as discrete outputs, it follows the logical progression of the research programme, moving from the absence of clinically assessed data to the development of inclusive measurement and finally to the identification of oral health as a marker of vulnerability and survival.

At the outset of this research, no national clinical data existed on the oral health of older adults with intellectual disabilities in Ireland. This absence reflected long-standing methodological exclusion rather than a lack of need. Addressing this measurement gap was therefore a necessary first step, as only through the

development of an inclusive method for objectively assessing oral health could patterns of disease, vulnerability and risk in ageing for adults with intellectual disabilities could be examined.

8.2.1 Making Oral Health Measurable: Inclusive Tool Development and Validation (MOSST)

Chapters 3 and 4 describe the development and psychometric testing of the MOSST, created to address the practical barriers that have excluded many adults with intellectual disabilities from oral health surveillance. Its validation and implementation within the IDS-TILDA Health Fair enabled, for the first time, objective oral health assessment at population level in this cohort and provided the measurement foundation for all subsequent analyses in this thesis.

A key methodological contribution of this thesis was the development of MOSST as a disability-adapted oral health assessment tool suitable for large-scale research. As outlined in Chapters 1 and 3, people with intellectual disabilities have frequently been excluded from oral health epidemiology because standard dental indices and examination protocols assume levels of communication, tolerance and cooperation that are not feasible for many individuals with higher support needs. This has contributed to systematic under-representation of those with the greatest burden of disease and weakened the capacity of surveillance systems to identify and monitor inequalities over time (Gréaux et al., 2023; Watt et al., 2019).

MOSST was developed in response to these methodological and ethical gaps and builds on earlier work on the OSST. Prior OSST research demonstrated that trained non-dental professionals could assess core indicators of dental and oral disease in adults with intellectual disabilities, while also highlighting areas requiring refinement for clarity, feasibility, and scale (Mac Giolla Phádraig et al., 2015; Mac Giolla Phádraig et al., 2022). MOSST therefore represents an iterative, evidence-informed refinement that retains the pragmatic strengths of OSST while strengthening operational definitions, usability, and alignment with contemporary psychometric standards.

Tool development was grounded in expert consensus and public and patient involvement, consistent with best practice in inclusive health measurement and

disability research (Nind, 2014; Carey et al., 2020). The overall development process was guided by established principles of scale construction and psychometric evaluation (Streiner & Norman, 2008), alongside structured approaches to content validity assessment (Polit & Beck, 2006). Content validity was evaluated through expert review, with items mapped to core oral health domains including dentition, caries, gingival condition, oral cleanliness, and oral function. Involvement of people with intellectual disabilities and RNID research nurses in tool refinement supported acceptability and ensured the tool captured clinically meaningful constructs across a wide range of communication and support needs.

Psychometric evaluation in Chapter 4 demonstrated that MOSST has acceptable reliability and feasibility for use in population-based settings. These findings establish MOSST as a viable disability-adapted instrument for objective oral health assessment by trained non-dental assessors, thereby enabling inclusion of adults with intellectual disabilities in large-scale epidemiological research. The results are consistent with the inherently judgement-based nature of visual oral assessment and with prior evaluations of related tools.

Feasibility findings are particularly important given the groups most often missing from oral health evidence. MOSST achieved an 87% completion rate within the IDS-TILDA Health Fair, including among participants with moderate, severe and profound ID. This exceeds completion levels typically reported in studies using conventional dental examination protocols in this population (Iacono et al., 2020; Bird et al., 2024) and demonstrates that clinically meaningful oral health data can be collected at scale when the assessment approach is designed for inclusion.

At the same time, MOSST reflects a deliberate balance between feasibility and clinical depth. It is not intended to replace comprehensive dental assessment, but it enables consistent, scalable, and acceptable measurement of key oral health indicators in contexts where traditional clinical examinations are often impractical. In this way, MOSST supports surveillance and population health research by prioritising inclusion and comparability while remaining transparent about diagnostic limits.

MOSST can therefore be understood as a form of evidence infrastructure. By embedding disability-adapted procedures within epidemiological practice, it addresses the measurement conditions that have limited disability-inclusive oral health data and strengthens the capacity of health systems to make inequities visible. Its integration into IDS-TILDA provided the empirical foundation for the analyses of oral disease burden, systemic vulnerability and survival presented in subsequent analyses.

8.2.2 Revealing the Burden: Patterns of Oral Disease in Older Adults with Intellectual Disabilities

Once oral health could be measured inclusively at population level, it became possible to describe, for the first time, the burden and pattern of oral health problems among older adults with intellectual disabilities in Ireland. Findings from Chapter 5 demonstrate that this population experiences a high and persistent burden of poor oral health across all assessed domains, including dental caries experience, periodontal indicators, poor oral cleanliness, and extensive tooth loss. These findings move beyond anecdotal reports and proxy-based surveys to provide clinically assessed evidence of long-standing unmet oral health need.

Across the IDS-TILDA cohort, levels of untreated decay, visible plaque accumulation, and gingival inflammation were high, indicating ongoing exposure to preventable oral health problems. Substantial proportions of participants had lost multiple teeth, with a proportion being edentulous or lacking functional dentition. Importantly, these problems clustered rather than occurring in isolation: individuals with poor oral cleanliness were more likely to present with signs of active disease and compromised dentition (Byrne, 2023). This pattern is consistent with evidence from both disability and gerontological research showing that poor oral health reflects cumulative exposure to inadequate prevention, barriers to timely and appropriate care, and, in some cases, reliance on extraction-led or minimally restorative treatment approaches, rather than episodic treatment failure (Sheiham & Steele, 2001; Mac Giolla Phadraig et al., 2015; Anders & Davis, 2021).

When placed in the context of population ageing trends, the extent of inequality becomes particularly clear. In the general population, older adults have experienced substantial improvements in oral health over recent decades, including marked declines in edentulism and increased retention of functional dentition into later life. These trends are well documented in TILDA and international ageing cohorts and are attributed to fluoridation, preventive dentistry, and improved access to restorative care (Chan et al., 2024; Sheehan et al., 2017). In contrast, the oral health profile observed in IDS-TILDA more closely resembles that of much older or socioeconomically disadvantaged populations, despite participants being, on average, younger than those typically classified as frail in general population studies (Dlima et al., 2024).

This divergence cannot be attributed to chronological ageing alone. Rather, it reflects the cumulative effects of structural barriers encountered across the life course by people with intellectual disabilities. These include reduced access to preventive dental services, reliance on caregiver-mediated oral hygiene, long-term use of xerogenic medications, and sustained exposure to extraction-led models of care. The persistence of extensive tooth loss and poor oral health in this cohort, despite improvements elsewhere, supports a life-course interpretation of oral health inequity rather than one grounded in biological inevitability.

Variation in oral health burden was also evident across levels of support need and living arrangements, with poorer outcomes observed among individuals requiring higher levels of assistance and those living in more supported settings. This pattern aligns with evidence that oral health in people with intellectual disabilities is strongly shaped by care environments, organisational priorities, and availability of trained support for daily mouth care. It reinforces the interpretation of poor oral health in this population as socially patterned and care-mediated, rather than solely determined by individual impairment or behaviour.

The findings from Chapter 5 establish that older adults with intellectual disabilities experience a sustained and disproportionate burden of poor oral health that has not improved in parallel with trends observed in the wider population. This burden provides the empirical foundation for subsequent analyses in this thesis. By demonstrating that oral health problems are widespread, cumulative, and

structurally patterned, these findings help explain why oral health may be closely linked to systemic vulnerability and survival in later life. Given this level of cumulative oral deterioration and functional loss, the next question addressed by this thesis was whether poor oral health is merely a parallel burden or is embedded within wider processes of multimorbidity, frailty, and physiological vulnerability.

8.2.3 Oral health, Function, and Systemic Vulnerability

Findings from Chapter 6 demonstrate that oral health in older adults with intellectual disabilities is embedded within broader patterns of systemic vulnerability rather than existing as a parallel or isolated domain. Using MOSST-derived indicators, this thesis shows that oral functional decline tracks closely with conditions associated with frailty, physiological dysregulation, and accelerated ageing in this population.

Constipation provides a useful illustrative example. It was common in the cohort and consistently patterned by oral functional status, with higher prevalence among those with extensive tooth loss and absent functional dentition. This pattern mirrors emerging gerontological evidence linking impaired mastication to restricted dietary fibre intake, altered gut motility and gastrointestinal dysfunction, but is particularly salient in adults with intellectual disabilities, where medication burden, dysphagia, and dependency on others for food choice amplify risk (Robertson et al., 2017; Chadwick et al., 2009). Importantly, associations were driven by cumulative loss of oral function rather than markers of active oral disease, suggesting that functional capacity captures vulnerability more effectively than point-in-time pathology.

This same pattern was observed across other systemic conditions examined in Chapter 6. Oral functional decline, indexed by tooth loss and absence of functional dentition, clustered with osteoporosis and respiratory disease, whereas indicators such as gingival condition, cavitated teeth and oral cleanliness showed weaker or inconsistent relationships.

These results align with gerontological frameworks in which tooth loss and impaired oral function are recognised as indicators of frailty, malnutrition and reduced physiological reserve. However, this thesis extends that evidence into a

population characterised by earlier onset of multimorbidity, high polypharmacy burden and lifelong structural disadvantage. In adults with intellectual disabilities, oral functional decline appears to emerge earlier and cluster more tightly with systemic vulnerability, consistent with accelerated ageing trajectories described elsewhere in disability research.

Crucially, this work reframes oral health from a condition-specific risk factor to an integrative signal of vulnerability. Oral function captures the embodied consequences of inequitable access to prevention and rehabilitation across the life course and reflects the convergence of biological ageing and structural exclusion. In this sense, oral health is not merely associated with systemic conditions but is embedded within the same processes that shape frailty, multimorbidity and health decline in later life. This interpretation provides the conceptual bridge to the next section of the chapter. If oral functional decline reflects cumulative systemic vulnerability, a key question is whether these oral health trajectories are also associated with differences in survival in ageing with intellectual disabilities.

8.2.4 Tooth Loss as a Link of Survival

A central finding of this thesis is that tooth loss and absence of functional dentition are associated with reduced survival in older adults with intellectual disabilities. As demonstrated in Chapter 7, clear and graded differences in survival were observed according to dentition status, with the poorest outcomes among individuals who were edentulous or lacked functional dentition. Importantly, these associations persisted after adjustment for age, gender, and key health covariates, indicating that oral functional status captures dimensions of vulnerability not fully explained by chronological ageing, diagnosed morbidity or disability severity alone.

This finding extends the broader literature on excess and avoidable mortality in intellectual disabilities by identifying oral functional decline as a previously unexamined marker of survival risk. Large population-based studies have consistently demonstrated markedly elevated premature and potentially avoidable mortality among adults with intellectual disabilities, particularly from respiratory, neurological and circulatory causes (Hosking et al., 2016; McMahon et al., 2023; O'Leary, Cooper, & Hughes-McCormack, 2018). However, these studies

rely almost exclusively on administrative diagnoses and routinely collected health data and do not incorporate clinically assessed indicators of health or function. The present findings therefore add a novel and clinically grounded dimension to understanding survival inequalities in this population.

The significance of tooth loss for survival is best understood within the specific health and care context of intellectual disabilities. Older adults with intellectual disabilities experience a high prevalence of dysphagia, aspiration risk, respiratory disease, neuromotor impairment and nutritional compromise, alongside lifelong barriers to preventive and restorative dental care (McCarron et al., 2019; Ward et al., 2019). In this context, loss of functional dentition is not merely a marker of past oral disease, but reflects impaired mastication, reduced bolus control, altered swallowing safety and restricted dietary intake. These functional consequences are closely linked to respiratory morbidity, frailty progression and mortality risk, particularly among individuals with higher support needs and care dependence (Tonetti et al., 2017).

Tooth loss therefore operates at the intersection of biological vulnerability and cumulative structural disadvantage. It reflects long-term exclusion from preventive oral healthcare, reliance on extraction-led treatment pathways and limited access to prosthodontic rehabilitation or maintenance (Mac Giolla Phadraig et al., 2022; Iacono, 2021). Unlike single disease diagnoses, dentition status integrates exposure to disadvantage across the life course and captures downstream functional consequences that are directly relevant to survival. In this sense, oral functional decline aligns closely with gerontological concepts of physiological reserve and frailty, while extending these frameworks into populations characterised by accelerated and premature ageing (Tanaka et al., 2017).

Interpretively, this thesis does not position tooth loss as a singular causal driver of mortality. While several Bradford Hill (Hill, 1965) considerations are consistent with a potential causal contribution, residual confounding, shared underlying determinants and reverse pathways cannot be excluded. Tooth loss may therefore operate both as a contributing factor to adverse outcomes and as a visible marker of cumulative biological vulnerability and social disadvantage. Its value lies not in implying simple causality, but in signalling heightened risk and identifying

individuals who may otherwise remain invisible within health systems focused primarily on diagnostic categories rather than functional decline.

Framed in this way, oral health becomes a meaningful component of survival-related risk assessment rather than a peripheral or cosmetic concern. Dentition status offers a pragmatic and clinically interpretable marker that can inform prevention-oriented care, anticipatory planning, and policy accountability. By demonstrating that oral functional decline is associated with survival in older adults with intellectual disabilities, this thesis strengthens the case for integrating oral health within broader frameworks of ageing, frailty and health equity, and for recognising oral function as an essential rather than optional dimension of population health research for the intellectual disability population.

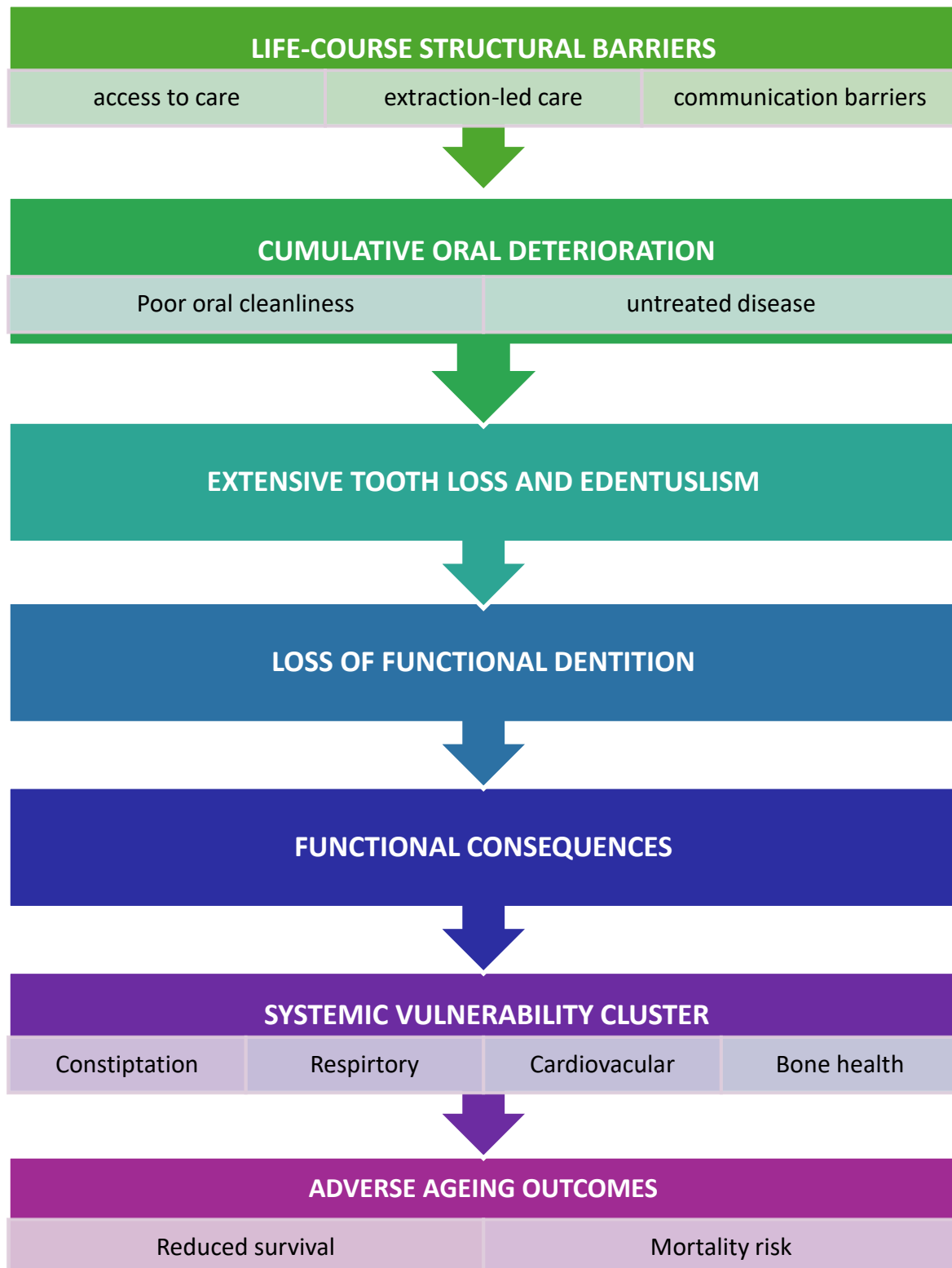
8.3 What This Thesis Shows Beyond Existing Knowledge

This thesis extends current understanding of ageing and health among adults with intellectual disabilities by demonstrating that oral health is closely intertwined with broader processes of structural disadvantage, functional decline, systemic vulnerability, and survival. Collectively, the findings from Chapters 5–7 show that poor oral health in this population is neither incidental nor biologically inevitable but reflects life-course exposure to barriers in access to preventive care, treatment, and support. In doing so, the thesis challenges prevailing assumptions that the limited evidence base on oral health in intellectual disabilities reflects methodological difficulty, showing instead that exclusionary measurement practices have contributed to this gap.

The results indicate a coherent pathway linking structural barriers, cumulative oral deterioration, tooth loss, loss of functional dentition, systemic vulnerability, and adverse ageing outcomes. Oral health is therefore situated not as an isolated clinical issue but as part of the broader pattern of accelerated ageing and health inequality experienced by people with intellectual disabilities. This integrative interpretation is illustrated in Figure 8.2.

While derived from observational epidemiological analyses, the findings demonstrate consistent and biologically plausible associations that are coherent with established frameworks of ageing, frailty and health inequality. As discussed in Section 8.2.4, these results do not imply a singular causal relationship but highlight oral health as a meaningful indicator and potential contributor to vulnerability and survival risk. The evidence suggests that oral health should be recognised as an integral component of population health surveillance, clinical risk assessment and policy responses aimed at reducing premature morbidity and mortality in people with intellectual disabilities.

Figure 8.2. Conceptual framework synthesising pathways from structural barriers to tooth loss, loss of functional dentition, systemic vulnerability, and survival outcomes in ageing with intellectual disabilities



8.3.1 Excluded by Design, Not Destiny: Disability-Inclusive Oral Health Measurement is Feasible and Valid

A central contribution of this thesis is the demonstration that disability-inclusive, clinically assessed oral health measurement is both feasible and valid at population level. This finding challenges a longstanding assumption within oral health epidemiology and global surveillance frameworks that people with intellectual disabilities, particularly those with higher support needs, cannot be meaningfully included in clinical oral health research. Instead, the evidence presented here shows that their absence reflects design choices rather than inherent limitations.

Historically, the exclusion of people with intellectual disabilities from oral health surveillance has been framed as a problem of feasibility rather than recognised as the consequence of exclusionary measurement practices. Standardised dental indices and examination protocols have prioritised efficiency, precision, and participant cooperation, often at the expense of accessibility. Individuals who require additional time, behavioural supports or adapted communication have therefore been systematically excluded from data collection, producing what has been described as statistical invisibility within health systems (Emerson and Hatton, 2014; Krahn et al., 2015). This invisibility limits accountability because inequities cannot be identified, monitored, or addressed if the populations most affected are absent from the evidence base.

Recent global policy frameworks now explicitly recognise this gap. The WHO Global Strategy on Oral Health and the Global Oral Health Action Plan 2023 to 2030 frame oral health as a matter of equity, rights, and accountability, calling for surveillance systems capable of monitoring inequalities over time (World Health Organization, 2022; 2023). Similarly, the WHO Global Report on Health Equity for Persons with Disabilities identifies the lack of disability-disaggregated data as a central mechanism through which inequities persist, noting that disability is too often considered only at the stage of analysis rather than embedded in study design (World Health Organization, 2022). Despite these commitments, disability remains rarely operationalised as a primary population characteristic in oral health surveillance, meaning that people with intellectual disabilities continue to be marginalised within inequalities research rather than explicitly included within it.

The findings of this thesis demonstrate that such invisibility is not inevitable. Through the development and validation of the MOSST, this research shows that clinically meaningful oral health data can be collected inclusively when reasonable adjustments are embedded within tool design, examiner training, and data collection procedures. MOSST achieved high completion rates within the IDS-TILDA Health Fair, including among individuals with moderate, severe and profound intellectual disabilities, groups largely absent from previous epidemiological studies. This directly responds to calls within the health equity literature to move from passive recognition of inequality toward accountability grounded in inclusive methods and disability-disaggregated data (Krahn et al., 2015).

Crucially, inclusion was achieved without lowering clinical standards or compromising validity. Psychometric evaluation demonstrated acceptable to good reliability across key oral health indicators, with performance comparable to or exceeding that reported for similar screening tools used in more selective populations. These findings challenge the assumption, implicit in many surveillance systems, that inclusion necessarily reduces data quality. Instead, they support a growing body of work suggesting that exclusion reflects methodological convention rather than methodological necessity, and that inclusive design is a marker of rigour rather than its absence (Watt and Daly, 2022; Gréaux et al., 2023).

The feasibility of inclusive assessment was not solely a function of instrument design but also of the expertise of the research workforce. Data collection was conducted by trained research nurses with specialist experience in supporting people with intellectual disabilities whose competencies in communication, behavioural support, clinical observation, and relational engagement enabled participation among individuals with complex needs. This highlights a distinctive contribution of intellectual disability nursing, which operates at the interface of clinical care, advocacy and research (McCarron et al., 2011; O’Leary, Cooper and Hughes-McCormack, 2018). Through skilled interaction at the individual level, practitioners make it possible to gather valid data from people who would otherwise be excluded.

In this sense, disability-inclusive epidemiology depends on the translation of micro-level encounters into macro-level knowledge. Accurate population statistics

are generated not only through methodological protocols but through skilled, person-centred engagement that enables participation. The capacity to collect data at the level of the individual while producing evidence relevant to populations and systems reflects a fundamental but often overlooked condition of equitable health surveillance (Emerson and Hatton, 2014; United Nations, 2006).

By operationalising reasonable adjustments within an epidemiological context, this thesis reframes inclusion as both a technical and ethical responsibility of health measurement. It demonstrates that people with intellectual disabilities can and should be included in clinically assessed oral health research, and that their historical exclusion represents a failure of surveillance design rather than an inherent barrier posed by disability. This position aligns with rights-based approaches to health data, including those articulated in the United Nations Convention on the Rights of Persons with Disabilities, which emphasises the obligation of states to generate data capable of informing equitable policy and service provision (United Nations, 2006).

In doing so, this thesis shifts the locus of responsibility from individuals with intellectual disabilities to the systems that design and govern oral health surveillance. It provides empirical evidence that disability-inclusive oral health epidemiology is achievable, and that continued exclusion cannot be justified on grounds of feasibility or validity. By making previously invisible populations measurable, inclusive approaches transform poor oral health from an assumed feature of disability into a visible indicator of system performance, equity and accountability.

8.3.2 Challenging the Narrative: Poor Oral Health is Not Inevitable in Intellectual Disabilities

A key contribution of this thesis is its challenge to the assumption that poor oral health, tooth loss and functional decline are unavoidable consequences of intellectual disability. Although elevated levels of oral disease have long been documented in this population, these outcomes have often been interpreted as intrinsic to disability rather than as signals of preventable inequality.

The findings presented here suggest that this interpretation reflects the normalisation of poorer health among people with intellectual disabilities. Oral healthcare has frequently been organised around reactive, crisis-driven interventions rather than preventive maintenance, resulting in late presentation, extraction-led treatment and limited prosthodontic rehabilitation. Such patterns contribute to cumulative deterioration across the life course, particularly for individuals with higher support needs.

These dynamics are reinforced by gaps in disability competence across clinical and research settings. Limited training in adapted communication, behavioural support and environmental modification can lead to avoidance of complex patients, delayed care and reduced access to routine surveillance. Inaccessible service environments further shift the burden of adaptation onto the individual, perpetuating cycles of unmet need and reinforcing the perception that examination and treatment are inherently difficult.

Within this context, poorer outcomes risk becoming normalised as inevitable rather than recognised as indicators of system failure. This normalisation reflects broader processes of structural ableism, in which lower expectations for health and quality of care reduce incentives for prevention and weaken institutional accountability. It also contributes to epistemic injustice, whereby people with intellectual disabilities are marginalised within the production of health knowledge and their experiences insufficiently represented in research and policy.

Evidence from IDS-TILDA challenges this narrative directly. Oral health outcomes were not uniform but varied in relation to living circumstances, support needs and broader indicators of vulnerability. Patterns of tooth loss and reduced functional dentition therefore appear to reflect differential exposure to preventive care, treatment pathways and environmental supports rather than a fixed biological trajectory. Tooth loss, in this context, emerges as a marker of cumulative disadvantage and structural neglect rather than a natural endpoint of disability.

By demonstrating that inclusive assessment is feasible and that oral health indicators are meaningfully associated with systemic vulnerability and survival, this thesis reframes oral health as a modifiable determinant of inequity. From a rights-

based perspective, this aligns with obligations under the UN Convention on the Rights of Persons with Disabilities to ensure equitable healthcare access and inclusive monitoring. Responsibility therefore shifts from individuals to the systems that shape access, measurement and care, highlighting the need for preventive, person-centred and accountable oral health services across the life course.

8.4 Implications

The findings of this thesis have implications that extend beyond oral health as a clinical specialty and speak directly to how health systems respond to ageing and intellectual disability. By identifying oral functional decline as a meaningful indicator of broader vulnerability and survival risk, this work positions oral health as an integral component of population health rather than a peripheral concern.

These implications operate across multiple levels, including public policy, service delivery, workforce capacity and research infrastructure. Together, they indicate that improving oral health outcomes for people with intellectual disabilities requires coordinated action across systems rather than isolated clinical interventions. Figure 8.2 summarises these interrelated domains of implication.

The sections that follow examine the implications of this evidence for policy, healthcare delivery, research and surveillance systems, and the future development and implementation of disability-inclusive measurement approaches, before outlining recommendations for action.

Figure 8.3. Multilevel implications of the findings for policy, services, workforce development, research and prevention in ageing with intellectual disabilities



8.4.1 Policy implications: oral health inequity as a structural failure

A central policy implication of this thesis is that oral health inequity in people with intellectual disabilities is not the result of individual impairment or unavoidable biological decline, but the product of long-standing structural policy choices. The high prevalence of tooth loss, lack of functional dentition and untreated oral disease observed in the IDS-TILDA cohort reflects sustained underinvestment in disability-inclusive oral health surveillance, prevention and rehabilitation across the life course.

One of the most consequential structural failures identified is the systematic exclusion of people with intellectual disabilities from oral health monitoring and surveillance. The absence of disability-inclusive clinical assessment tools has contributed directly to statistical invisibility, weakening accountability and obscuring inequities. As highlighted in critiques of oral health governance, what is not measured is not prioritised (Watt & Daly, 2022). Without data that capture oral health status across the full spectrum of ability, policymakers are unable to identify unmet need, evaluate service performance or monitor progress towards equity. In this context, the invisibility of oral health inequity in intellectual disabilities is not incidental, but a predictable outcome of exclusionary surveillance practices.

The downstream consequences of this invisibility are evident in-service patterns. While oral health outcomes have improved substantially in the general population over recent decades, many older adults with intellectual disabilities have experienced extraction-led care, limited access to restorative and prosthodontic services, and reliance on episodic, crisis-driven treatment. These patterns reflect weak integration of oral health within disability and ageing policy, limited investment in Special Care Dentistry, and a historical emphasis on curative rather than preventive approaches. Taken together, they point to systemic neglect rather than clinical inevitability.

From a rights-based perspective, these findings expose a gap between policy commitments and lived experience. International frameworks, including the *World Health Organization Global Report on Health Equity for Persons with Disabilities* (WHO, 2022) and the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD), emphasise the obligation of states to ensure equitable access to healthcare and to collect disaggregated data capable of identifying and addressing disparities. Within Ireland, the *National Human Rights Strategy for Disabled People 2025–2030* (Figure 8.3) explicitly recognises oral health within the health and wellbeing pillar, signalling growing policy acknowledgment that oral health is integral to the right to the highest attainable standard of health as outlined in figure 8.4.

Figure 8.4. National Human Rights Strategy for Disabled People 2025–2030 (Government of Ireland).



Figure 8.5 National Human Rights Strategy for Disabled People 2025–2030: oral health reference

Pillar 4

Wellbeing and Health

Led by the Department of Health; Department of Children, Disability and Equality; in collaboration with the Health Service Executive; Department of Education and Youth; National Council for Special Education.

What we know

We know that disabled people are less likely to rate their health as good, and more likely to rate their health as bad, than people without a disability. In Census 2022, among people who experienced at least one long lasting condition to any extent, 23% reported very good health. In contrast, 53% of the total population reported very good health.¹⁷

We know that people in the most disadvantaged areas are four and a half times more likely to report not having good health.¹⁸ The disability rate of children and young people in disadvantaged areas is equivalent to that of older people in affluent ones.

We know that disabled people, like everyone else, can experience a range of health challenges. The prevalence of mental health diagnoses is 44% among those over 40 years-of-age with an intellectual disability.¹⁹ Other challenges include oral health, with 1 in 5 of those over 40 years-of-age with an intellectual disability having no teeth at all.²⁰

Our Ambition for Wellbeing and Health

Our ambition is that all disabled people will have equal access to mainstream health and well-being services and can get any additional supports, services and treatments they need arising from their disability.

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (Health) recognises that disabled people have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. All appropriate measures should be taken to ensure access for disabled people to health services that are gender-sensitive, including health-related rehabilitation.

Our ambition is for disabled people to be empowered and informed and to have a say about measures and supports that would enhance their mental, physical and social health and wellbeing.

Our aim is to expand and enhance supports for disabled people to live full lives of their own choosing and actively participate in their community. It is important to have a particular focus on access to integrated and inclusive wellness and health services, early intervention and on improving quality of life and better health outcomes for people using these services. Improving access to mainstream wellness and health services and having targeted initiatives on health promotion and wellbeing programmes for disabled people should ensure that individuals supported by health services and specialist disability services can improve and maintain good health and wellbeing.

Commitment 19

Oral Health

We will ensure that disabled children and adults can benefit from improved access to oral healthcare. We will reform and modernise our oral healthcare services in line with the vision set out in the National Oral Health Policy: Smile Agus Sláinte. We will reduce oral health inequalities through mainstreaming of oral healthcare for all and through development of clinically appropriate referral care pathways for those who are unable to access care in a general dental practice setting.

Priority Actions 2025–2026 include:

- 19.1** Publish the National Oral Health Policy Implementation Plan 2025–2027. (Department of Health)
- 19.2** Address poorer levels of oral health, particularly among those with intellectual disabilities, by improving access to mainstream oral healthcare. Packages of prevention-focused oral healthcare will be developed for both children and adults, to be accessed in a general dental practice. (Health Service Executive)
- 19.3** Commence reorientation of the Health Service Executive Oral Healthcare Service to lead on oral health promotion programmes and to provide dental services to those who are unable to access care in a general dental practice setting. (Health Service Executive)
- 19.4** Progress an initiative that will focus on assessing oral healthcare needs for those in residential settings and develop training materials for associated healthcare workers to enable improved support to be provided for oral health care as part of personal care for these residents. (Health Service Executive)

Importantly, the inclusion of oral health within this national human rights framework marks one of the first instances in which clinically assessed oral health data from older adults with intellectual disabilities have entered Irish policy discourse. While this thesis does not claim direct causality, the visibility of IDS-TILDA Wave 5 oral health findings within a national rights-based strategy demonstrates how disability-inclusive measurement enables oral health inequities to be recognised within formal policy frameworks. This represents a shift from rhetorical commitment to evidence-informed acknowledgement, reinforcing the role of inclusive surveillance as a prerequisite for accountability.

The incorporation of oral health within national disability policy has not occurred in isolation but reflects broader processes through which research evidence is translated into policy discourse. Engagement with policymakers, professional bodies, advocacy organisations and service leaders through advisory roles, invited presentations and knowledge exchange activities provides channels through which emerging findings can inform strategic priorities. Such interactions enable evidence generated at the level of population research to shape agendas, highlight previously unrecognised gaps and support the development of more inclusive policy responses. In this sense, the movement from data to policy is mediated through networks of expertise and advocacy rather than occurring automatically.

This thesis shows that these policy failures are neither inevitable nor technically unavoidable. By demonstrating that disability-adapted clinical oral health assessment is feasible at population level, and that oral health indicators are meaningfully associated with systemic vulnerability and survival, this work establishes that continued policy inaction reflects prioritisation choices rather than methodological constraints. The persistence of oral health inequity in intellectual disabilities therefore reflects decisions about where attention, resources and accountability are directed, rather than biological inevitability.

Achieving health equity for people with intellectual disabilities requires that oral health be recognised as a core component of ageing, chronic disease prevention and rights-based healthcare. This necessitates disability-inclusive surveillance systems, explicit policy accountability for oral health outcomes, and sustained investment in preventive and restorative care pathways that move beyond crisis-

driven models. Without such structural change, oral health inequity will continue to operate as a silent and avoidable contributor to premature ageing and mortality in this population.

8.4.2 Health and healthcare delivery implications

The findings of this thesis have clear implications for the organisation and delivery of health services for older adults with intellectual disabilities. By demonstrating that oral health, particularly oral functional capacity, is closely associated with multimorbidity, frailty-related conditions and respiratory mortality, this work challenges the longstanding separation of oral health from mainstream healthcare delivery and highlights the need for integrated, prevention-oriented models of care. Oral health should be recognised as a core component of routine health assessment and care planning rather than a peripheral or optional service.

The associations observed between oral function, constipation, osteoporosis and respiratory disease indicate that oral health intersects directly with nutrition, musculoskeletal integrity, gastrointestinal function and airway protection. These domains are already prioritised within disability nursing, geriatric medicine and respiratory care pathways, yet oral health is rarely embedded within routine assessment, monitoring or review. This represents a missed opportunity for early identification of risk and prevention of downstream harm.

For nursing and disability services, particularly those supporting older adults with intellectual disabilities, these findings reinforce mouth care as fundamental nursing care. Many individuals rely on others for daily oral hygiene, and variability in staff training, confidence and organisational prioritisation can result in inconsistent delivery. Embedding oral health within routine nursing assessment, care plans and review processes aligns with professional standards and with a rights-based approach to equitable care, recognising oral health as integral to comfort, nutrition and dignity.

These findings also highlight the distinctive role of intellectual disability nursing in bridging oral health and general healthcare. With RNIDs frequently coordinating daily care, advocating for reasonable adjustments and facilitate access to specialist services, positioning them as key agents in implementing integrated oral health

approaches. Interprofessional learning initiatives between RNIDs and dental professionals can strengthen mutual understanding of roles, build shared competencies and reduce fragmentation between community care and dental services. The MOSST data generated through IDS-TILDA provide an evidence base that can be used in education and training to illustrate the systemic consequences of poor oral health, reinforcing the importance of supported mouth care planning, early intervention and collaborative practice. In this way, disability-inclusive oral health research not only informs service planning but also supports workforce development and advocacy aimed at improving care pathways.

The findings also indicate the need for greater integration between oral health and other areas of healthcare, particularly nutrition, dysphagia management, respiratory care and frailty pathways. Loss of functional dentition emerged as a stronger marker of systemic vulnerability than point-in-time disease indicators, suggesting that oral function provides clinically meaningful insight into cumulative decline. Incorporating oral health assessment into multidisciplinary reviews alongside swallowing, mobility and medication review would strengthen holistic risk assessment and support proactive intervention.

For dental services, the results underscore the limitations of extraction-led and crisis-driven models of care. The high prevalence of edentulism and loss of functional dentition reflects delayed access, limited preventive intervention and restricted availability of restorative and prosthodontic care. Addressing this requires sustained investment in Special Care Dentistry with sufficient workforce capacity, protected time for prevention-focused care and access to behavioural and environmental supports that enable restorative treatment rather than default extraction.

These findings also have implications for the organisation of public dental services. A prevention-oriented approach requires access to routine care pathways that support maintenance of dentition, early management of caries and periodontal disease, and timely restorative intervention rather than reliance on treatment at advanced stages. Current reforms in Ireland, including the Smile agus Sláinte programme, emphasise preventive care and improved access across the life course. Ensuring that these reforms are accessible to people with intellectual

disabilities will require attention to reasonable adjustments, appointment flexibility, behavioural supports and coordination with disability services. Without such measures, structural barriers may persist despite broader service redesign, limiting the potential of prevention-focused policies to reduce inequalities.

Workforce development is a critical cross-cutting issue. Limited disability competence within dental and healthcare education contributes to clinician uncertainty and avoidance of care. The feasibility and acceptability of MOSST demonstrated in this thesis directly challenge assumptions that adults with intellectual disabilities cannot tolerate oral assessment, indicating that competence can be built through training in adapted approaches, reasonable adjustments and interdisciplinary collaboration rather than reliance on specialist services alone.

These implications for healthcare delivery are clear. Oral health should be integrated into routine health assessment and care planning for older adults with intellectual disabilities, particularly within nutrition, dysphagia, respiratory and frailty pathways. Preservation of dentition, timely rehabilitation and supported daily mouth care should be recognised as core components of equitable care. Without such integration, oral health will remain siloed and avoidable morbidity and mortality will persist despite broader commitments to person-centred and integrated care.

8.4.3 Implications for research and surveillance

The findings of this thesis highlight a critical gap in current research and surveillance systems: the absence of disability-inclusive, clinically assessed oral health data. This gap limits accurate estimation of need constrains policy development and weakens accountability for inequitable outcomes.

Despite growing recognition of the importance of inclusive data within national and international frameworks, oral health remains marginal within disability research. Population surveys frequently exclude people with intellectual disabilities or rely on proxy or self-reported measures that underestimate disease burden and functional impairment. Consequently, existing evidence bases are skewed towards advanced disease and crisis intervention rather than prevention.

This thesis demonstrates that disability-inclusive oral health surveillance is both feasible and informative. The integration of a disability-adapted clinical assessment tool within a nationally representative ageing study shows that meaningful data can be collected across the full spectrum of ability. Such approaches allow inequities to be identified, monitored over time and addressed through targeted policy and service responses.

The implications extend beyond oral health alone. Inclusive surveillance enables analysis of how oral health interacts with multimorbidity, functional decline, living circumstances and support needs, providing insight into cumulative disadvantage across the life course. These data are essential for evaluating the impact of interventions, allocating resources effectively and tracking progress towards equity goals.

Disability-inclusive measurement should therefore be regarded as core public health infrastructure. Without systematic collection of objective oral health data disaggregated by disability status, inequities will remain obscured and progress difficult to assess. Integrating such measures into routine health monitoring is necessary to ensure that the oral health needs of people with intellectual disabilities are recognised and addressed rather than overlooked.

8.5 Future of the MOSST

A central contribution of this thesis is not only the generation of new evidence on oral health in older adults with intellectual disabilities, but the creation of an assessment approach that can support ongoing inclusive research, surveillance and service evaluation. The successful implementation of MOSST within IDS-TILDA demonstrates its potential as a scalable tool for population-based studies and routine monitoring.

The future value of MOSST lies not solely in the instrument itself but in the systems required to sustain its use. Reliable application depends on training, calibration and quality assurance processes that enable non-dental assessors to collect clinically meaningful data consistently across settings. Embedding these supports within research programmes, health services and surveillance systems would allow

oral health outcomes to be monitored alongside other indicators of ageing and wellbeing.

MOSST also has potential utility beyond epidemiological research. As a structured observational tool, it could support screening, care planning and service evaluation in settings where access to dental assessment is limited. Used in conjunction with clinical services rather than as a substitute, it may facilitate earlier identification of need and more timely referral pathways.

Positioning MOSST as part of a broader infrastructure for disability-inclusive measurement emphasises that its impact depends on sustained implementation rather than one-off use. Future development should therefore focus on integration within routine data systems, adaptation for diverse contexts and continued psychometric refinement to ensure reliability across populations and settings.

8.5.1 MOSST as a tool for Inclusive Surveillance

A key future application of MOSST is its use within population-level surveillance systems. Its implementation within a nationally representative ageing study demonstrates that structured clinical oral health assessment can be incorporated into large-scale data collection.

Routine inclusion of MOSST in longitudinal studies, structured health assessments or community health programmes would allow dentition status and oral function to be monitored over time. This would support earlier detection of decline and provide data to inform service planning and evaluation. As a standardised observational tool that can be administered by trained non-dental personnel, MOSST offers a practical approach for collecting objective oral health information in settings where comprehensive dental examination is not routinely available

8.5.2 Future research and Psychometric Development of MOSST

A critical component of MOSST's future implementation is the structured training and calibration framework developed to support reliable use by non-dental professionals. This framework addresses a longstanding barrier to disability-inclusive oral health assessment, namely the lack of standardised preparation

enabling frontline staff to undertake clinically meaningful observation in a consistent manner. Training is therefore not an adjunct to MOSST but the mechanism through which the tool can be implemented safely across research, surveillance and service contexts.

Central to this approach is a comprehensive online training programme delivered via the EdApp platform. The programme introduces all MOSST domains through structured educational content supported by clinical photographs, video demonstrations and interactive learning activities. An overview of the training interface is shown in Figure 8.6. Modules address dentition and tooth count, functional tooth units, cavitated teeth, oral cleanliness, gingival condition, denture use and oral appearance. Practical guidance is also provided on assessment preparation, required equipment, infection control, data recording procedures and the use of reasonable adjustments to support inclusive assessment.

The EdApp platform was selected to maximise accessibility, standardisation and scalability. Scenario-based learning, image-based scoring exercises and applied decision-making tasks reflect real-world conditions encountered in intellectual disability services. Embedded certification provides a reproducible record of training completion, supporting quality assurance and consistency across assessors.

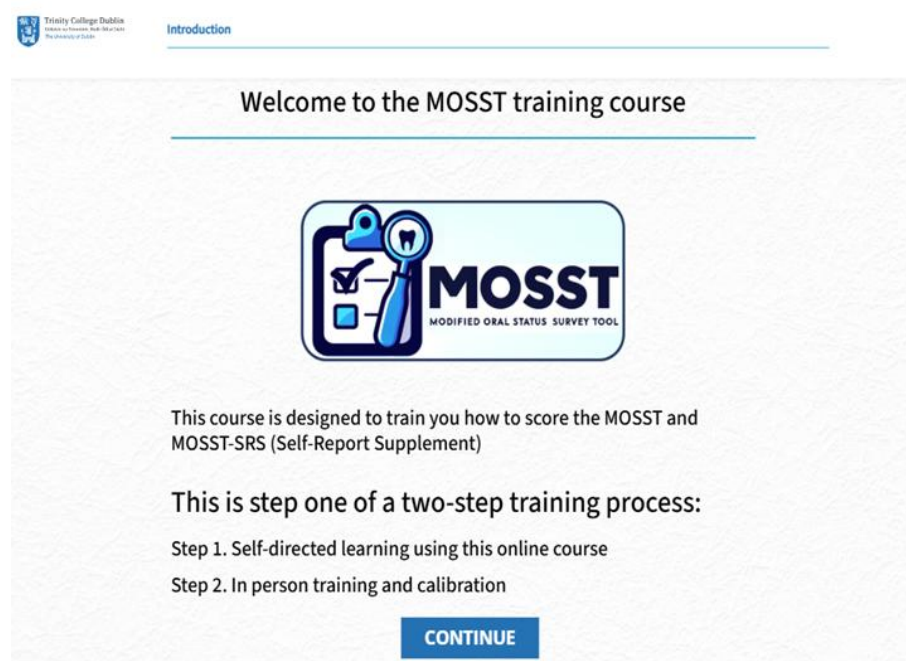
Online learning is complemented by applied calibration and supervised practice, enabling assessors to consolidate knowledge and align scoring in real settings. This blended model reflects established principles of clinical skills training and helps ensure that feasibility does not compromise reliability. Initial implementation through a national MOSST training initiative involving nurses and dental professionals working in intellectual disability services demonstrates that the approach can be delivered outside research environments and incorporated into workforce development activities.

With appropriate preparation, frontline staff can incorporate structured oral health observation into routine care processes alongside assessments of nutrition, swallowing, mobility and medication use. This supports earlier recognition of oral

health deterioration and facilitates timely referral rather than reliance on episodic or crisis-driven dental care.

Increasing oral health competence among staff may also reduce uncertainty associated with oral examination and support a shift towards viewing mouth care as a routine component of everyday health support. Over time, this may strengthen preventive practices and improve continuity between daily care and dental services. Future evaluation should examine the effectiveness of this training model across settings, including its impact on assessor reliability, confidence and sustained use in practice. Continued refinement will be important to ensure that MOSST training remains responsive to the needs of diverse service environments and populations.

Figure 8.6: Overview of the Edapp training



8.5.3 MOSST as Evidence Infrastructure for Equity

The future uses of MOSST extend beyond its function as a measurement tool in intellectual disability settings. By enabling inclusion, comparability and visibility, MOSST supports the type of disability-disaggregated evidence required for equity-oriented health systems. Its application facilitates the generation of data needed

to identify disparities, evaluate interventions and monitor whether policy commitments translate into improved oral health outcomes for people with intellectual disabilities.

This role aligns closely with recent global policy developments. The World Health Organization Global Strategy on Oral Health and the Global Oral Health Action Plan emphasise surveillance systems capable of identifying inequities across populations, including people with disabilities. Similarly, the WHO Global Report on Health Equity for Persons with Disabilities highlights the absence of disability-disaggregated data as a major barrier to accountability. These frameworks collectively position inclusive measurement not as a technical exercise but as a prerequisite for equitable health policy and service planning.

The findings of this thesis demonstrate that the exclusion of people with intellectual disabilities from oral health evidence is not a consequence of technical infeasibility but of methodological choice. MOSST provides a practical alternative to this exclusion by enabling clinically meaningful assessment across a wide range of communication abilities and support needs. Its use within research, surveillance and service contexts offers a pathway through which oral health inequities can be systematically measured rather than assumed, enabling disparities to be examined, tracked and addressed over time.

Importantly, disability-inclusive data allow inequity to be interpreted as a product of systems rather than individual impairment. When outcomes can be compared across populations, differences in access to prevention, treatment and supportive care become visible. Such visibility is essential for policy accountability, resource allocation and evaluation of progress toward equity goals. In this sense, MOSST contributes to the development of surveillance approaches capable of capturing oral health as part of broader health and social inequality. By making oral health status observable in populations that have historically been excluded from epidemiological research, MOSST supports a shift from descriptive assumptions to evidence-informed action.

8.5.4 What Next? Translating the Research Programme into Education, Practice and Policy

The next phase of the researcher's work will focus on translating the evidence generated through this thesis into education, practice, service development and policy. This reflects the researcher's position as an intellectual disability nurse and oral health researcher, where the purpose of generating evidence is not only to describe inequity, but to support practical change in the systems, services and educational pathways that shape everyday care. Having established that disability-inclusive oral health assessment is feasible and informative within a national ageing study, the priority now is to move beyond evidence generation and ensure that the MOSST and the wider findings of this research are used to improve oral health visibility, prevention and care for people with intellectual disabilities.

A central focus of this next phase will be education and workforce development. The findings of this thesis indicate that oral health cannot remain confined to dental services alone, particularly for people who rely on others for daily mouth care, communication support and access to timely referral. For this reason, the researcher intends to develop MOSST-informed educational resources for nurses, clinical nurse specialists, advanced nurse practitioners, health and social care professionals, carers and support staff working with people with intellectual disabilities. This work aligns with the Keep My Teeth research project, in which the researcher is involved, by extending the focus from identifying oral health inequity to developing practical education and training approaches that support tooth retention, daily mouth care, early identification of oral health deterioration and timely referral.

This work will build on the MOSST training package and EdApp platform described above, with the aim of strengthening knowledge, confidence and practical competence in oral health assessment, supported mouth care, identification of oral pain or functional decline, and timely referral to dental services. Particular attention will be given to embedding oral health within intellectual disability nursing education, continuing professional development, CNS and ANP roles, and interdisciplinary training with dental professionals. This is a logical next step because RNIDs, CNSs and ANPs are often positioned at the interface between daily

support, health assessment, advocacy and service coordination. Strengthening oral health education within these roles may help shift oral health from being viewed as a specialist or peripheral issue to being recognised as part of holistic health assessment, prevention and rights-based care.

The researcher also intends to support the translation of MOSST beyond the IDS-TILDA research context. Future work will focus on how the tool can be embedded within service pathways, workforce education and routine review processes, rather than remaining solely a research instrument. This will include exploring digital approaches, including app-based scoring, online training and standardised data capture, to support scalability, quality assurance and integration with practice.

A further priority is to extend the research programme through longitudinal and mechanistic studies. Future analyses will examine changes in oral health over time, including transitions to edentulism, loss of functional dentition and deterioration in oral cleanliness or gum condition. This longitudinal work will help identify when oral health decline occurs, which groups are most at risk, and whether transitions in oral health status precede or follow changes in nutrition, dysphagia, medication burden, frailty, respiratory health and mortality. Understanding transitions to edentulism will be particularly important for identifying opportunities for earlier prevention, timely referral and restorative or prosthodontic intervention before oral functional decline becomes established. Building on developments in IDS-TILDA Wave 6, the researcher intends to explore the integration of MOSST data with biological measures, including oral microbiome and other clinical markers, to strengthen understanding of the pathways linking oral health, systemic vulnerability and survival in ageing with intellectual disabilities.

In addition, the researcher intends to apply the psychometric and measurement development skills gained through this doctoral study to future research projects. The development and validation of the MOSST strengthened the researcher's expertise in construct definition, item refinement, content validity, feasibility testing, reliability assessment and inclusive tool design. These skills will be applied to future work requiring the development, adaptation or evaluation of measurement tools for populations whose experiences are often

underrepresented in standard health research. In this way, the methodological learning from this thesis will extend beyond oral health alone and contribute to broader disability-inclusive research and measurement practice.

Finally, the researcher intends to continue engaging with policy and service stakeholders to ensure that oral health is recognised within disability, ageing and public health frameworks. The longer-term ambition is to develop this programme of work from a doctoral study into an applied research and education agenda that supports inclusive surveillance, strengthens professional education, informs care pathways and contributes to accountability for oral health outcomes among people with intellectual disabilities. In this way, the future direction of the work is translational as well as academic: moving from making oral health visible to embedding oral health within the education, services and policies that shape everyday care.

8.6 Methodological and Scientific Contributions

This thesis makes a set of substantive methodological and scientific contributions to oral health, ageing and intellectual disability research. Rather than focusing on future applications, this section synthesises the advances already established through the development, validation and implementation of disability-inclusive oral health assessment within a population-based ageing study. Collectively, these contributions address longstanding gaps in measurement, evidence generation and representation, and reposition oral health as a meaningful component of population health research in people with intellectual disabilities.

8.6.1 Advancing Disability-Inclusive Oral Health Measurement

A primary methodological contribution of this thesis lies in operationalising disability-inclusive clinical oral health assessment within a population-based longitudinal ageing study. Rather than treating inclusion as an ethical aspiration, this work embedded reasonable adjustments directly within measurement design, training, calibration and field implementation. In doing so, it demonstrates how

epidemiological tools can be structured to accommodate diverse communication abilities and support needs while retaining analytic integrity.

A second contribution is the integration of structured clinical oral assessment into a multidisciplinary ageing dataset. By embedding MOSST within IDS-TILDA, this thesis enabled oral health indicators to be analysed alongside multimorbidity, functional limitation, living circumstances and mortality outcomes. This moves oral health from a stand-alone clinical domain into the analytic core of population health modelling in intellectual disability research. +Methodologically, this work also establishes that clinically meaningful oral health data can be generated by trained non-dental assessors within large-scale studies. This expands the methodological toolkit available to disability researchers and reduces reliance on specialist clinical environments that have historically constrained sampling and scalability.

Importantly, this thesis advances oral health epidemiology by foregrounding functional dentition as a measurable population health construct. The consistent associations observed between functional oral status and systemic vulnerability demonstrate the analytic value of incorporating functional indicators alongside disease measures. This approach aligns oral health research more closely with gerontological models of frailty and physiological reserve, extending these frameworks into populations characterised by accelerated ageing.

These contributions demonstrate that disability-inclusive oral health measurement is not simply feasible but analytically transformative. By resolving a structural measurement barrier, this thesis expands the scope of epidemiological inquiry in intellectual disability research and establishes a replicable framework for integrating oral health into life-course and survival analyses.

8.6.2 Linking Oral Health to Systemic Vulnerability and Survival

A further scientific contribution of this thesis is the demonstration that clinically assessed oral health indicators can be integrated into analyses of systemic vulnerability and survival in older adults with intellectual disabilities. By linking MOSST data with measures of multimorbidity, frailty-related conditions and

mortality, this work extends oral–systemic research into a population that has been largely absent from longitudinal epidemiological studies.

Methodologically, this establishes oral functional status as a measurable population health construct rather than a solely clinical descriptor. Loss of functional dentition emerged as a consistent marker of broader vulnerability, capturing dimensions of health risk not fully reflected in diagnostic categories alone. This highlights the value of functional oral indicators for identifying cumulative decline in populations characterised by complex health needs.

The association between tooth loss and respiratory-related mortality is particularly significant in the context of intellectual disabilities, where respiratory disease is a leading cause of premature death. While causal pathways cannot be determined, the findings demonstrate that oral health can be meaningfully incorporated into models of ageing, frailty and survival for this population.

The results have positioned oral functional decline as an important component of systemic vulnerability in ageing with intellectual disabilities and support the integration of oral health indicators into multidisciplinary population health research.

8.6.3 Advancing Disability-Inclusive Epidemiology

The methodological and scientific contributions of this thesis demonstrate that disability-inclusive epidemiology is both feasible and necessary for accurate population health research. The exclusion of people with intellectual disabilities from oral health studies reflects methodological convention rather than technical constraint. This work shows that inclusive design can enhance, rather than compromise, the quality and interpretability of epidemiological evidence.

Embedding disability-adapted clinical assessment within a nationally representative ageing study provides a model for integrating marginalised populations into mainstream research infrastructures. Such approaches allow health outcomes to be examined across the full spectrum of ability and support needs, enabling inequities to be quantified rather than inferred.

More broadly, the thesis supports a shift toward population health research in which accessibility, participation and inclusion are treated as components of methodological rigour. Within this framework, disability inclusion is not an optional extension of epidemiology but a prerequisite for evidence capable of informing equitable health policy and service planning.

By demonstrating how inclusive measurement can be operationalised within a longitudinal ageing study, this thesis contributes a replicable framework for disability-inclusive epidemiology. It shows that methodological adaptation is not simply an accommodation for individual participants, but a condition for producing valid, representative and policy-relevant evidence.

8.7 Strengths and limitations

As with all population-based research, this thesis has both strengths and limitations. Rather than viewing these as opposing features, they are best understood in relation to what this programme of research has made possible for the first time, and where future work can now extend, refine and deepen understanding of oral health inequity in people with intellectual disabilities.

8.7.1 Strengths

A major strength of this thesis is the generation of the first nationally representative, clinically assessed oral health dataset for older adults with intellectual disabilities in Ireland. By embedding MOSST within IDS-TILDA, this work moved beyond proxy reporting, administrative data and small clinical samples, enabling robust epidemiological analysis of oral health status, function and dentition in a population that has historically been excluded from surveillance.

The inclusive methodological approach adopted represents a further strength. The successful participation of individuals with moderate, severe and profound intellectual disabilities demonstrates that disability-adapted clinical assessment is feasible at scale when reasonable adjustments are intentionally designed and implemented. This directly challenges assumptions that have limited inclusion in both research and routine monitoring and strengthens the validity of the findings

by ensuring that those with the greatest oral health burden were not systematically excluded.

Another key strength lies in the integration of oral health with systemic health and survival outcomes. By linking clinically assessed oral indicators with multimorbidity, frailty-related conditions and mortality, this thesis advances oral health research beyond descriptive prevalence estimates and situates oral health within broader ageing and health equity frameworks. The use of longitudinal mortality data further strengthens the contribution, allowing oral health to be examined in relation to survival rather than solely as an outcome.

The interdisciplinary nature of the work is a notable strength. Drawing on oral health, gerontology, disability studies, epidemiology and human rights frameworks, this thesis demonstrates the value of crossing traditional disciplinary boundaries to address complex and persistent health inequities. This integrative approach enhances both the scientific and policy relevance of the findings.

Finally, a further strength lies in the positionality of the research. Conducted from an intellectual disability nursing perspective while engaging closely with oral health, epidemiology and policy frameworks, the work adopts a stance that is both embedded and analytically distanced. This positioning enables examination of oral health as an everyday care issue within intellectual disability services while also interrogating the structural assumptions that have contributed to its marginalisation within mainstream health research. Acting in effect as an informed external observer across disciplinary boundaries, the thesis identifies patterns and gaps that may be normalised within single fields but become visible when viewed through an integrative lens. This perspective strengthens the capacity of the research to bridge practice, policy and scientific domains.

8.7.2 Limitations

Several limitations should be acknowledged.

First, while the analyses linking oral health with systemic vulnerability and mortality are robust and biologically plausible, the observational nature of the data precludes causal inference. The associations observed cannot establish direct causation and it remains possible that oral health functions as a marker of

cumulative disadvantage and underlying vulnerability rather than a causal driver across all pathways examined. However, this limitation is inherent to population-based epidemiological research and does not diminish the relevance of oral health as a meaningful indicator of risk, inequity and cumulative exposure across the life course.

Second, the MOSST was intentionally designed to prioritise feasibility, accessibility and inclusion over granularity. While it captures clinically meaningful indicators of dentition, oral cleanliness, gingival condition and oral function, it does not include detailed periodontal probing, radiographic assessment or microbiological sampling. The tool is therefore not intended to replace comprehensive dental examination but to enable disability-inclusive surveillance and population-level analysis. This methodological trade-off is appropriate given the aims of the thesis, but it highlights the need for complementary mechanistic and clinical studies to further elucidate oral–systemic pathways.

Third, several analyses were constrained by data availability and survey design features within IDS-TILDA Wave 5. Survey routing limited the availability of certain health indicators, most notably pneumonia and respiratory conditions, reducing analytic sample sizes for specific models. In addition, missing data for some MOSST oral disease indicators, particularly gum condition and cavitated teeth, further reduced sample sizes in adjusted analyses and limited statistical power to detect associations for these variables. These limitations are reflected in wider confidence intervals and should be considered when interpreting null findings for disease-specific oral indicators. Importantly, subsequent revisions to respiratory health routing in Wave 6 reflect responsiveness to these limitations and will strengthen future longitudinal analyses.

Fourth, the analyses presented in this thesis do not include direct measures of oral microbiota, inflammatory biomarkers or detailed nutritional intake, which would allow more precise testing of biological mechanisms linking oral health with systemic outcomes and respiratory mortality. The absence of these measures reflects the scope and design of IDS-TILDA Wave 5, rather than a conceptual omission within the research programme. Importantly, subsequent waves of IDS-TILDA have begun to address this gap. In Wave 6, oral microbiome data collection

has been incorporated through collaboration with the School of Dental Science, including tongue swab sampling and targeted plaque collection in a subsample by a calibrated dental researcher.

The epidemiological findings presented in this thesis therefore provide a strong empirical foundation and scientific rationale for this methodological expansion. By demonstrating robust associations between dentition, oral function and systemic vulnerability, this work helps to justify and inform the integration of microbiome and biomarker data within disability-inclusive ageing research. Future analyses combining MOSST indicators with microbiological data will be well positioned to clarify causal pathways, distinguish markers from mechanisms, and strengthen understanding of oral–systemic interactions in adults with intellectual disabilities.

Finally, while IDS-TILDA provides rich and nationally representative data, the findings are situated within the Irish health and policy context. Differences in healthcare systems, access to Special Care Dentistry and models of disability support may influence the generalisability of specific prevalence estimates internationally. Nonetheless, the structural mechanisms identified in this thesis — including exclusion from surveillance, reliance on extraction-led care and underinvestment in prevention are well documented across high-income settings, supporting the broader relevance and transferability of the conclusions.

8.8 Conclusions: Oral health, Equity and Accountability in Ageing with Intellectual Disabilities

This thesis demonstrates that poor oral health in older adults with intellectual disabilities is not an inevitable consequence of impairment, but a patterned and preventable outcome shaped by lifelong exclusion from preventive, restorative and rehabilitative dental care. By generating the first disability-inclusive, clinically assessed oral health evidence for this population in Ireland, it moves oral health in intellectual disability from the margins of research to the centre of population health inquiry.

Through the development and implementation of the MOSST and implementation within IDS-TILDA, adults with intellectual disabilities who have historically been absent from epidemiological studies were included in systematic clinical assessment. This transformed a population previously characterised by statistical invisibility into one that can be described, analysed and compared within national health data. The findings show that oral disease burden, tooth loss and loss of functional dentition are widespread, socially patterned and closely associated with multimorbidity, frailty-related conditions and survival.

Loss of functional dentition emerged as a particularly important indicator of systemic vulnerability. Although not interpreted as a direct causal driver of mortality, tooth loss functions as a visible and measurable marker of cumulative biological stress, healthcare disadvantage and functional decline across the life course. In this sense, oral health provides insight into processes of accelerated ageing and premature mortality that are not captured by diagnostic categories alone.

By demonstrating that disability-adapted clinical assessment is feasible at population level, this thesis challenges longstanding assumptions that people with intellectual disabilities cannot be meaningfully included in oral health surveillance. The absence of evidence in this field reflects methodological exclusion rather than methodological impossibility. When inclusive approaches are adopted, inequities that were previously obscured become visible and actionable.

The implications extend beyond dentistry. Oral health emerges as a component of general health, ageing and health equity, intersecting with nutrition, respiratory function, frailty and care dependency. Recognising oral function as part of routine health assessment has the potential to support earlier identification of vulnerability and to inform prevention-oriented care pathways across health and social care systems.

More broadly, this work reframes poor oral health in intellectual disability as an issue of accountability rather than inevitability. By making oral health measurable, visible and policy relevant, responsibility shifts from individuals to the systems that shape access to care, prevention and rehabilitation. Inclusive measurement

enables inequities to be monitored, services to be evaluated and policy commitments to be assessed against empirical evidence.

Oral health in ageing with intellectual disabilities should be understood not as a peripheral concern or cosmetic issue, but as a meaningful indicator of health system performance, cumulative disadvantage and population health risk. Addressing oral health inequities is therefore essential to achieving equitable ageing, improving quality of life and reducing avoidable morbidity and mortality in this population. The findings of this thesis provide both the evidence and the methodological foundation required to support that shift.

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Appendices

Appendix 2.1. A completed PRISMA-ScR checklist is provided in.

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Pg1 title page
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Pg 2 abstract
INTRODUCTION			

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Pg 2 and 3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Pg 3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Pg 3
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status) and provide a rationale.	Pg 3 and 4
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Pg 3 and 4
Search	8	Present the full electronic search strategy for at least 1 database,	Supplemental file 2

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		including any limits used, such that it could be repeated.	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Pg 3 and 4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Pg 4 and 5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Table 1
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	n/a
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Pg 5
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions	Figure 1: PRISMA- ScR Flow Diagram

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		at each stage, ideally using a flow diagram.	
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Pg 5 and Table 1
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 1
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Pg 5-8
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Pg 9 and 10
Limitations	20	Discuss the limitations of the scoping review process.	Pg 10
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Pg 11
FUNDING			

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #

Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Title page 1

JB I = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JB I guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018; 169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850)

Appendix 2.2 search strategy

Search strategy:

Medline (Ovid)

1. exp Pneumonia/
2. Streptococcus pneumoniae/
3. Respiratory Tract Diseases/
4. Respiratory Tract Infections/
5. Exp Opportunistic Infections/
6. Methicillin-Resistant Staphylococcus aureus/
7. Candida albicans/
8. pneumonia*.mp
9. ((Lung* OR respirat*) adj3 (health OR disease* OR illness* OR inflamm* OR infect*)).mp

10. ("Methicillin-Resistant Staphylococcus aureus" OR MRSA OR "Candida albicans").mp
11. Exp Deglutition Disorders/
12. (Dysphagia* OR swallow*).mp
13. 1-12/OR
14. exp oral health/
15. exp Oral Hygiene/
16. exp Dental Care/
17. exp Mouth/mi
18. exp biofilms/
19. dental calculus/
20. dental plaque/
21. exp mouth diseases/
22. (Oral OR Mouth) adj3 (health OR hygiene OR care OR cavity OR biofilm* OR microb*).mp
23. ((Dent* OR oral OR tooth OR teeth OR mouth) adj3 (Plaque* OR calculus OR deposit* or treat* OR exam* OR Clean*)).mp
24. (tooth adj3 brush*).mp
25. (caries OR gingiv* OR periodont* OR edent* OR "missing teeth").mp
26. 14-25/OR
27. Exp Disabled Persons/
28. Cerebral palsy/
29. Exp Neurodevelopmental disorders/
30. Exp intellectual disability/
31. (Disabled OR Disabilit* OR retard* OR handicap* OR "cerebral palsy" OR autis* OR asperger* OR "Down syndrome").mp
32. (Neuro* adj6 disorder*).mp
33. (special adj3 need*).mp
34. 27-33/OR
35. 13 AND 26 AND 34

Results (17/01/2023): 714

Updated results (18/06/2024): 791 (+77)

Embase

1. 'pneumonia'/exp
2. 'Streptococcus pneumoniae'/exp
3. 'Respiratory tract disease'/de
4. 'Opportunistic infection'/exp
5. 'Methicillin resistant Staphylococcus aureus'/exp
6. 'Candida albicans'/exp
7. (pneumonia*):ti,ab,kw
8. ((Lung* OR respirat*) NEAR/3 (health OR disease* OR illness* OR inflamm* OR infect*)):ti,ab,kw.
9. ('Methicillin-Resistant Staphylococcus aureus' OR MRSA OR 'Candida albicans'):ti,ab,kw
10. 'dysphagia'/exp
11. (Dysphagia* OR swallow*):ti,ab,kw
12. 1-11/OR
13. 'dental health'/exp
14. 'mouth hygiene'/exp
15. 'dental procedure'/exp
16. 'mouth flora'/exp
17. 'biofilm'/exp
18. 'dental deposit'/exp
19. 'dental caries'/exp
20. 'periodontal disease'/exp
21. 'edentulous jaw'/exp
22. ((Oral OR Mouth) NEAR/3 (health OR hygiene OR care OR cavity OR biofilm* OR microb*)):ti,ab,kw

23. ((Dent* OR oral OR tooth OR teeth OR mouth) NEAR/3 (Plaque* OR calculus OR deposit* OR treat* OR exam* OR Clean*)):ti,ab,kw
24. (tooth NEAR/3 brush*):ti,ab,kw
25. (caries OR gingiv* OR periodont* OR edent* OR 'missing teeth'):ti,ab,kw
26. 13-25/OR
27. 'disabled person'/exp
28. 'cerebral palsy'/exp
29. 'autism'/exp
30. 'mental deficiency'/exp
31. (Disabled OR Disabilit* OR retard* OR handicap* OR 'cerebral palsy' OR autis* OR asperger* OR 'Down syndrome'):ti,ab,kw
32. (Neuro* NEAR/6 disorder*):ti,ab,kw
33. (special NEAR/3 need*):ti,ab,kw
34. 27-33/OR
35. 12 AND 26 AND 34

Results (17/01/2023): 888

Updated results (18/06/2024): 1,104 (+216)

Cochrane Review

1. MeSH descriptor: [Pneumonia] explode all trees
2. MeSH descriptor: [Streptococcus pneumoniae] explode all trees
3. MeSH descriptor: [Respiratory Tract Diseases] this term only
4. MeSH descriptor: [Respiratory Tract Infections] this term only
5. MeSH descriptor: [Opportunistic Infections] explode all trees
6. MeSH descriptor: [Methicillin-Resistant Staphylococcus aureus] explode all trees
7. MeSH descriptor: [Candida albicans] explode all trees
8. (pneumonia*):ti,ab,kw
9. ((Lung* OR respirat*) NEAR/3 (health OR disease* OR illness* OR inflamm* OR infect*)):ti,ab,kw

10. ("Methicillin-Resistant Staphylococcus aureus" OR MRSA OR "Candida albicans"):ti,ab,kw
11. MeSH descriptor: [Deglutition Disorders] explode all trees
12. (Dysphagia* OR swallow*):ti,ab,kw
13. 1-12/OR
14. MeSH descriptor: [Oral Health] explode all trees
15. MeSH descriptor: [Oral Hygiene] explode all trees
16. MeSH descriptor: [Dental Care] explode all trees
17. MeSH descriptor: [Mouth] explode all trees and with qualifier(s):
[microbiology - MI]
18. MeSH descriptor: [Biofilms] explode all trees
19. MeSH descriptor: [Dental Calculus] explode all trees
20. MeSH descriptor: [Dental Plaque] explode all trees
21. MeSH descriptor: [Mouth Diseases] explode all trees
22. ((Oral OR Mouth) NEAR/3 (health OR hygiene OR care OR cavity OR biofilm* OR microb*)):ti,ab,kw
23. ((Dent* OR oral OR tooth OR teeth OR mouth) NEAR/3 (Plaque* OR calculus OR deposit* OR treat* OR exam* OR Clean*)):ti,ab,kw
24. (tooth NEAR/3 brush*):ti,ab,kw
25. (caries OR gingiv* OR periodont* OR edent* OR "missing teeth"):ti,ab,kw
26. 14-25/OR
27. MeSH descriptor: [Disabled Persons] explode all trees
28. MeSH descriptor: [Cerebral Palsy] explode all trees
29. MeSH descriptor: [Neurodevelopmental Disorders] explode all trees
30. MeSH descriptor: [Intellectual Disability] explode all trees
31. (Disabled OR Disabilit* OR retard* OR handicap* OR "cerebral palsy" OR autis* OR asperger* OR "Down syndrome"):ti,ab,kw
32. (Neuro* NEAR/6 disorder*):ti,ab,kw
33. (special NEAR/3 need*):ti,ab,kw
34. 27-33/OR

35. #13 AND #26 AND #34

Results (17/01/2023): 13

Updated results (18/06/2024): 14 (+1)

Cochrane Trials

1. MeSH descriptor: [Pneumonia] explode all trees
2. MeSH descriptor: [Streptococcus pneumoniae] explode all trees
3. MeSH descriptor: [Respiratory Tract Diseases] this term only
4. MeSH descriptor: [Respiratory Tract Infections] this term only
5. MeSH descriptor: [Opportunistic Infections] explode all trees
6. MeSH descriptor: [Methicillin-Resistant Staphylococcus aureus] explode all trees
7. MeSH descriptor: [Candida albicans] explode all trees
8. (pneumonia*):ti,ab,kw
9. ((Lung* OR respirat*) NEAR/3 (health OR disease* OR illness* OR inflamm* OR infect*)):ti,ab,kw
10. ("Methicillin-Resistant Staphylococcus aureus" OR MRSA OR "Candida albicans"):ti,ab,kw
11. MeSH descriptor: [Deglutition Disorders] explode all trees
12. (Dysphagia* OR swallow*):ti,ab,kw
13. 1-12/OR
14. MeSH descriptor: [Oral Health] explode all trees
15. MeSH descriptor: [Oral Hygiene] explode all trees
16. MeSH descriptor: [Dental Care] explode all trees
17. MeSH descriptor: [Mouth] explode all trees and with qualifier(s):
[microbiology - MI]
18. MeSH descriptor: [Biofilms] explode all trees
19. MeSH descriptor: [Dental Calculus] explode all trees
20. MeSH descriptor: [Dental Plaque] explode all trees
21. MeSH descriptor: [Mouth Diseases] explode all trees

22. ((Oral OR Mouth) NEAR/3 (health OR hygiene OR care OR cavity OR biofilm* OR microb*)):ti,ab,kw
23. ((Dent* OR oral OR tooth OR teeth OR mouth) NEAR/3 (Plaque* OR calculus OR deposit* OR treat* OR exam* OR Clean*)):ti,ab,kw
24. (tooth NEAR/3 brush*):ti,ab,kw
25. (caries OR gingiv* OR periodont* OR edent* OR “missing teeth”):ti,ab,kw
26. 14-25/OR
27. MeSH descriptor: [Disabled Persons] explode all trees
28. MeSH descriptor: [Cerebral Palsy] explode all trees
29. MeSH descriptor: [Neurodevelopmental Disorders] explode all trees
30. MeSH descriptor: [Intellectual Disability] explode all trees
31. (Disabled OR Disabilit* OR retard* OR handicap* OR “cerebral palsy” OR autis* OR asperger* OR “Down syndrome”):ti,ab,kw
32. (Neuro* NEAR/6 disorder*):ti,ab,kw
33. (special NEAR/3 need*):ti,ab,kw
34. 27-33/OR
35. #13 AND #26 AND #34

Results (17/01/2023): 128

Updated results (18/06/2024): 152 (+24)

Cinahl (EBSCOhost)

1. (MH “Pneumonia+”)
2. (MH “Respiratory Tract Diseases”)
3. (MH “Respiratory Tract Infections”)
4. (MH “Opportunistic Infections+”)
5. (MH “Methicillin-Resistant Staphylococcus aureus”)
6. (MH “Candida albicans”)
7. (TI pneumonia*) OR (AB pneumonia*)

8. (TI (Lung* OR respirat*) N3 (health OR disease* OR illness* OR inflamm* OR infect*)) OR (AB (Lung* OR respirat*) N3 (health OR disease* OR illness* OR inflamm* OR infect*))
9. (TI "Methicillin-Resistant Staphylococcus aureus" OR MRSA OR "Candida albicans") OR (AB "Methicillin-Resistant Staphylococcus aureus" OR MRSA OR "Candida albicans")
10. (MH "Deglutition Disorders+")
11. (TI Dysphagia* OR swallow*) OR (AB Dysphagia* OR swallow*)
12. 1-11/OR
13. (MH "oral health+")
14. (MH "Oral Hygiene+")
15. (MH "Dental Care+")
16. (MH "Mouth/MI+")
17. (MH "biofilms")
18. (MH "dental deposits+")
19. (MH "dental caries+")
20. (MH "periodontal diseases+")
21. (MH "Mouth, Edentulous+")
22. (TI (Oral OR Mouth) N3 (health OR hygiene OR care OR cavity OR biofilm* OR microb*)) OR (AB (Oral OR Mouth) N3 (health OR hygiene OR care OR cavity OR biofilm* OR microb*))
23. (TI (Dent* OR oral OR tooth OR teeth OR mouth) N3 (Plaque* OR calculus OR deposit* or treat* OR exam* OR Clean*)) OR (AB (Dent* OR oral OR tooth OR teeth OR mouth) N3 (Plaque* OR calculus OR deposit* or treat* OR exam* OR Clean*))
24. (TI tooth N3 brush*) OR (AB tooth N3 brush*)
25. (TI caries OR gingiv* OR periodont* OR edent* OR "missing teeth") OR (AB caries OR gingiv* OR periodont* OR edent* OR "missing teeth")
26. 13-25/OR
27. (MH "Persons with Disabilities+")
28. (MH "Cerebral palsy")
29. (MH "Mental Disorders diagnosed in childhood+")

30. (MH "intellectual disability+")
31. (TI Disabled OR Disabilit* OR retard* OR handicap* OR "cerebral palsy" OR autis* OR asperger* OR "Down syndrome") OR (AB Disabled OR Disabilit* OR retard* OR handicap* OR "cerebral palsy" OR autis* OR asperger* OR "Down syndrome")
32. (TI Neuro* N6 disorder*) OR (AB Neuro* N6 disorder*)
33. (TI special N3 need*) OR (AB special N3 need*)
34. 27-33/OR
35. 12 AND 26 AND 34

Results (18/01/2023): 223

Updated results (18/06/2024): 216

PubMed

1. "Pneumonia"[Mesh]
2. "Streptococcus pneumoniae"[Mesh]
3. "Respiratory Tract Diseases"[Mesh:NoExp]
4. "Respiratory Tract Infections"[Mesh:NoExp]
5. "Opportunistic Infections"[Mesh]
6. "Methicillin-Resistant Staphylococcus aureus"[Mesh]
7. "Candida albicans"[Mesh]
8. pneumonia*[TIAB]
9. "Methicillin-Resistant Staphylococcus aureus"[TIAB] OR MRSA[TIAB] OR "Candida albicans"[TIAB]
10. "Deglutition Disorders"[Mesh]
11. Dysphagia*[TIAB] OR swallow*[TIAB]
12. 1-11/OR
13. Lung*[TIAB] OR respirat*[TIAB]
14. Health[TIAB] OR disease*[TIAB] OR illness*[TIAB] OR inflamm*[TIAB] OR infect*[TIAB]
15. #13 AND #14
16. #12 OR #15

17. "oral health"[Mesh]
18. "Oral Hygiene"[Mesh]
19. "Dental Care"[Mesh]
20. "Mouth/microbiology"[Mesh]
21. "biofilms"[Mesh]
22. "dental deposits"[Mesh]
23. "dental caries"[Mesh]
24. "periodontal diseases"[Mesh]
25. "Mouth, edentulous"[Mesh]
26. 17-25/OR
27. Oral[TIAB] OR Mouth[TIAB]
28. Health[TIAB] OR hygiene[TIAB] OR care[TIAB] OR cavity[TIAB] OR
biofilm*[TIAB] OR microb*[TIAB]
29. #27 AND #28
30. Dent*[TIAB] OR oral[TIAB] OR tooth[TIAB] OR teeth[TIAB] OR
mouth[TIAB]
31. Plaque*[TIAB] OR calculus[TIAB] OR deposit*[TIAB] or treat*[TIAB] OR
exam*[TIAB] OR Clean*[TIAB]
32. #30 AND #31
33. "tooth brushing"[TIAB:~3]
34. Caries[TIAB] OR gingiv*[TIAB] OR periodont*[TIAB] OR edent*[TIAB] OR
"missing teeth"[TIAB]
35. #26 OR #29 OR #32 OR #33 OR #34
36. "Disabled Persons"[Mesh]
37. "Cerebral palsy"[Mesh]
38. "Neurodevelopmental disorders"[Mesh]
39. "intellectual disability"[Mesh]
40. Disabled[TIAB] OR Disabilit*[TIAB] OR retard*[TIAB] OR handicap*[TIAB]
OR "cerebral palsy"[TIAB] OR autis*[TIAB] OR asperger*[TIAB] OR "Down
syndrome"[TIAB]
41. "Neuro* disorder*"[TIAB]

42. "Neuro disorder"[TIAB:~6]

43. "special need"[TIAB:~3]

44. "special needs"[TIAB:~3]

45. 36-44/OR

46. #16 AND #35 AND #45

Results (18/01/2023): 1,031

Updated results (18/06/2024): 1,377 (+346)

Appendix 2.3. study characteristics table

Authors/ Year/Country	Aim	Sample	Method	Findings	Key findings and researcher comments
<u>Ahanjan et al</u> 2013 Iran	To study oral and gingival microbial flora in <u>institutionalized people</u> with IDD of Sari and to estimate D% (percentage with untreated decayed teeth) and DMFT% (percentage of population affected with dental caries).	Size: n=138 Age: Mean 28.3 IDD: not specified	Design: Descriptive cross-sectional survey Data collection: Questionnaire complete by research team alongside dental visits and mouth/ gum swabs. Variables: Microbial: Plaque samples and swabs were directly taken from the mouth (and gum) of the participants using a sterile swab. Oral health: Questionnaire alongside dental visit. Pneumonia: None Association between oral microbiome/ health and pneumonia: None	Microbial The isolated microorganisms included <i>S. pneumoniae</i> (37.7%); <i>Streptococcus sp.</i> (18.8%); <i>E. coli</i> (16.7%); <i>Staphylococcus sp.</i> (1.4%); <i>Neisseria sp.</i> (45/6%); <i>Salmonella sp.</i> (8.7%); <i>Proteus sp.</i> (3.6%); <i>Diphtheroid</i> (4.2%); <i>Pseudomonas sp.</i> (0.7%). Oral health: Limited relevant oral health data collected: 65.9% (n=135 patients) had dental caries and 34.1% (n=3 patients) did not. Pneumonia: None Association between oral microbiome, oral health and pneumonia: Not studied Mediators/moderators: Significant bivariate association between frequency of isolated bacteria being <u>present in the mouth</u> and using a toothbrush ($p < 0.25$), dental caries being present ($p < 0.03$) and history of tooth extraction ($p < 0.009$).	Higher prevalence of pneumococci was observed in people with IDD compared to people without. Authors therefore hypothesised <u>that, as a result, the former were at increased risk of bacterial respiratory infections.</u>
<u>Binkely et al</u> USA	To determine the prevalence of potential pathogenic microorganisms in	Size: n= 63 Mean age: 48 +/- 11 years	Design: Observational cohort study (prospective)	Oral health: The mean Revised Oral Assessment Guide (ROAG) score was 14.9 +/- 1.8, with a range of 11 to 19 indicating poor oral status for	Findings indicated an association between poor oral status, as measured by gingival sub-score of ROAG, and the
2019	oral biofilms in persons with IDD & determine if there was an association between oral status, the presence of these microorganisms in the mouth, and respiratory infections	IDD: Mild to profound IDD	Data collection: Data collection at baseline and each month for six months. Variables Microbial: Bacteriological data collection from six index teeth for PCR analysis. Oral health: Oral health assessment using Revised Oral Assessment Guide (ROAG), with sub scores. Pneumonia: Medical records were reviewed monthly to determine the incidence of respiratory infections diagnosed by the facility's physicians. Association between oral microbiome, oral health and pneumonia: Logistic regression exploring factors associated with pneumonia, and respiratory infections. Factors <u>with bivariate correlation</u> of $p < 0.10$ with the dependent variable, were included in the model.	73% (n=46), with 27% (n=17) with a very poor oral health status as per the ROAG score. Poor gingival health reported for 33% (n=21) and poor oral hygiene for 41% (n=26). Microbial: All participants carried anaerobic organism <i>P. melaninogenica</i> , <i>S. pneumoniae</i> ; <i>S. aureus</i> (specifically MRSA), <u>and C. albicans</u> were detected by PCR analyses in 55% of participants. Pneumonia: 19% (n=12) were found to have pneumonia, and 34.9%(n=) had respiratory disease. Association between oral microbiome, oral health and pneumonia More participants diagnosed with pneumonia had potential respiratory <u>pathogens in</u> their baseline samples ($p < 0.03$) than those who were not diagnosed with pneumonia. Participants with a positive PCR result of potential respiratory <u>pathogens at</u> baseline had nine times the odds of developing any respiratory infection (95% confidence interval [CI] 2.3-38.8, $p < 0.002$). Participants diagnosed with pneumonia during the 6 months of the study, were more likely to score a low ROAG score ($p < 0.001$), <u>and have microorganisms</u> ($p < 0.05$) than those who were not diagnosed with pneumonia.	presence of potentially pathogenic microorganisms in oral biofilms and the likelihood of developing respiratory infections in persons with IDD.

				Mediators/moderators Those who were enterally fed had almost four times the odds of developing respiratory infections (95% CI 1.1–13.8, $p < 0.05$) than those not enterally fed. Those who were older ($p < 0.05$) were also more likely to develop respiratory infections.	
Chiang et al 2019 Taiwan	To compare respiratory infection status, and respiratory infection-related healthcare utilization between individuals with and without IDD.	Size: n= 117,031 (IDD group) and n= 234,062 (Reference group) Age: Range: 20–65 IDD: not specified	Design: Population-based, retrospective cohort design Data Collection: Data was collected by Taiwan's Ministry of Health and Welfare Database. The data related to disabled individuals was from a <u>twelve month</u> period in 2014. Variables Microbial data: None Oral health data: Presence of carious cavitation and periodontal disease were recorded based on a review of dental records. Pneumonia: Pneumonia data were not disaggregated from respiratory disease data. Dependent variables were number of respiratory infection-related healthcare visits for one year.	Microbial: Not analysed Oral health: Chart review indicated 62.3% with record of carious cavitation and 63.6% with record of periodontal disease of those who had utilised health services for a respiratory illness Pneumonia: While disaggregated pneumonia data were not reported, pneumonia was recorded in combination with other respiratory health service use in 53.8% of cases over 1 year. Association between oral microbe, oral health and pneumonia: The probability of respiratory infection was 1.16 times (95% CI: 1.13–1.19) and 1.22 times (95% CI: 1.19–1.26) higher in those with a history of dental cavities and periodontal disease than those without such histories. ** pneumonia not specified	This study demonstrated a slight increase in the odds of respiratory infection-related healthcare utilization among people with IDD who had recorded dental disease, <u>than</u> those with no such record. The probability of respiratory infection increased with increasing severity of disability.
			Association between oral microbiome, oral health and pneumonia Conditional logistic regression and generalized linear models were used to analyse related influential factors.	Mediators/moderators: The probability of respiratory infection was 1.10 times (95% CI: 1.07–1.14) higher in those with profound IDD.	
Ferozali et al 2007 USA	To investigate if oral cleaning would decrease colonization of bacteria and the infective capacity of the oral cavity.	Size: n= 36 Age: 31–79 years, mean age: 53.6 years IDD: <u>Profound IDD</u> Three groups within the study: Group 1: Oral cleaning with suctioning with toothbrush, sodium bicarbonate and a 1.5% hydrogen peroxide solution Group 2: Toothbrushing with sodium bicarbonate and a 1.5% hydrogen peroxide solution	Design: Pilot RCT Data collection Microbial: Supra-gingival samples were obtained by swab in the space of the second molar prior intervention and on the last week Oral health: Simplified Beck Oral Assessment Tool (gingival parameters and plaque as key indicators). Four elements of oral health were <u>assessed</u> : lips, oral mucosa, gingivae and plaque. Pneumonia: Chart review/hospital discharge notes. * Not reported in the methods but noted in the results. Analysis: 3x3 ANCOVA. Oral health data were analysed	Microbial: Gram positive: <i>S. aureus</i> , <i>Streptococcus sp.</i> Gram Negative <i>Acinetobacter sp.</i> , <i>Pseudomonas sp.</i> , <i>Proteus sp.</i> , <i>E. coli</i> . Oral health: All groups showed improvement in oral health over the study $F(2, 26) = 5.89$ ($p < 0.01$), with the study indicating without specific data that Group 1 had the greatest improvement over the course of the study Pneumonia: Authors report that all groups showed reductions in hospitalization days for respiratory infections when compared to the same 90-day time period of the previous year, <u>but</u> , no data presented in the study to support this statement. Association between oral microbiome/oral health and pneumonia: Group 1, which had suctioning alongside their oral health had 90% reduction in pathogenic bacteria. Group 2 had an 81%	This study hypothesises from its findings that suctioning in collaboration with oral care is beneficial in reducing bacteria in the mouth, stating without data, that this reduces the risk of infection and upper respiratory illness. The mouths of the participants in the study showed the presence of the bacterial pathogens often associated with nosocomial pneumonia in studies of critically ill and mechanically ventilated patients in intensive care units (including Gram-negative bacilli), although further data on this statement not available in this study. Commentary in the discussion indicates oral care in collaboration with suction may reduce respiratory infections for individuals with multiple

		Group3: (Control) no new intervention	Pre-, Mid-, and Post-intervention; across three groups.	reduction in bacteria. All three groups showed significant main effect for time assessment occurred ($p<0.05$), reporting that all three groups had significant reductions in bacteria over the course of the study Mediators/Moderators: Oral suctioning improves the oral hygiene and oral health status and decrease in bacterial load.	risk factors that place them at high risk for aspiration pneumonia.
Horie et al Japan 2014	To establish the presence of potential pathogenic microorganisms in oral biofilms in persons with severe motor impairment and IDD as a basis of prevention of aspiration pneumonia.	Size: n = 31 Age: range 6 to 68 years, mean = 40.5 years IDD: People with intellectual disabilities living in residential care.	Design: Cross-sectional survey Data collection Microbial: Collection of oral samples from dorsum of tongue for culturing to determine presence of potential respiratory pathogens. Oral health data: No oral health data Pneumonia: not studied Association between oral microbiome/ oral health and pneumonia : No studied	Microbial: MSSA (38.7%), <i>Candida</i> sp. (12.9%), four cases of <i>Klebsiella pneumoniae</i> Oral health: Not studied Pneumonia: Bacteria that can cause pneumonia found in the mouths of 12.9%. Association between oral microbiome/ oral health and pneumonia: Not studied Mediators/Moderators: Gender associated with OOP-positive and <i>Candida</i> -positive status.	Confirmation of oral carriage of potential respiratory pathogens. Despite no direct correlation tested, authors suggest that special oral care might be effective for the maintenance of oral health in patients with IDD. This is not supported by the evidence. Indirect evidence of link between oral health and respiratory health.
Zawadzki et al 2016 Poland	To analyse composition of oral microbiome as risk factors for complications in patients with masticatory system deteriorations, with a comparison between those with an <u>IDD</u> and those without "congenital diseases."	Size: n=96 Age range: from 28-53 years; two age groups: 28 to 40 and 41 to 53 <u>year</u> Group I – involving forty-eight persons with congenital diseases, associated with intellectual disability and masticatory system disorder Group II – involving <u>forty eight</u> persons without congenital diseases with routine dental treatment.	Design: Retrospective chart review, between groups analyses. Data collection Microbial: Oral swabs from ten sites including plaque, periodontium and gingival pockets Pneumonia <u>no</u> respiratory history data collected Oral Health: All participants were clinically reviewed for general health and oral cavity condition: the status of periodontal tissues, dentition, oral hygiene with no specific oral health assessment format detailed in the study. Association between oral microbiome/ Oral health and pneumonia : Not studied.	Microbial: <i>Trichomonas tenax</i> trophozoites were isolated from different oral cavity sites and in saliva. These were more frequently present in older persons with congenital diseases- associated with mental retardation. Gram-positive (<i>S. aureus</i>) and Gram-negative (<i>E. coli</i> , <i>K. pneumoniae</i> , <i>P. aeruginosa</i>) respiratory pathogens were more frequently detected in the patients with somatic and mental retardations, Oral health data: In Group I <u>involving</u> persons with IDD: The poor oral hygiene status expressed by advanced dental caries, caries lesions as well as gingival bleeding, periodontitis and teeth loss was noted. Association between oral microbiome/ Oral health and pneumonia: oral health status was <u>noted to</u> have worse outcomes among the IDD population and with the) respiratory pathogens were more frequently detected in the patients with somatic and mental retardations but no data to support this finding Pneumonia: none Mediators/moderators: Assumption only: Explanation of putative pathological process not based on study data	No data are presented but reportedly group with IDD had worse oral health and oral hygiene. No association demonstrated. Rather, implied, in discussion and based on the oral culture results and type of bacteria found associated with pneumonia.

Wang et al., 2023	To provide a global picture of the oral microbiome among NG-tube and oral-feeding patients in long term care.	Size: n= 53 Age: IDD: Receiving long-term care due to moderate-to-severe disability Two groups: n=26 patients oral feeding; n= 27 fed with NG tubes.	Design: Observational cross sectional Data collection Questionnaires: on basic clinical and demographic data including history of pneumonia Oral health data: full-mouth oral examination was then performed by the dentist, with a focus on gingival health. Severe gingivitis was defined by the presence of thick, visible calculus with bleeding gingiva, while mild gingivitis was assigned where there was only bleeding on probing. Microbial: collection of tongue plaque samples with sterilized cotton swabs. Pneumonia: Questionnaire on history of pneumonia Association between oral microbiome, oral health and pneumonia: Logistic regression with NG-tube status as dependent variable and history of pneumonia, DM status, gingival status as independent variables.	Microbial: opportunistic pathogens like <i>Pseudomonas</i> and <i>Corynebacterium</i> were associated with NG-tube feeding, oral-feeding patients with commensal microbes (e.g. <i>Streptococcus</i> and <i>Veillonella</i>) Oral health: Patients fed with NG tubes presented higher caries index, residual root calculus and more severe gingivitis. Pneumonia: History of pneumonia was more frequently observed in the NG-tube (63%) than the oral-feeding (12%) group. Association between oral microbiome/ oral health and pneumonia: None Mediators/Moderators: Association of NG tube with systemic and oral factors, among which, pneumonia showed the highest coefficient ($p < 0.001$)	<i>Corynebacterium</i> and <i>Pseudomonas</i> spp. were found in the mouths of NG tube feeding group. Tongue microbes in patients with NG tubes showed mostly Gram-negative bacteria with a mixture of aerobes and anaerobes, such as <i>Pseudomonas</i>, and also the Gram-positive <i>Corynebacterium</i>

Appendix 4.1 The MOSST v0.1 Protocol

Health Fair Wave 5: Oral Health

Modified Oral Status Survey Tool (v0.1).

PROTOCOL

Introduction

This protocol should be followed when completing **Health Fair Wave 5 Oral Health data collection which includes** the Modified Oral Status Survey Tool (v0.1) Health Examination Survey.

Overview of the Modified Oral Status Survey Tool (v0.1)

The MOSST is a data collection tool that produces important data regarding oral health, covering content that indicates oral status and function. The OSST is a survey that is based on oral health assessment, the Health Evaluation Survey (HES).

Aim

The aim of the MOSST is to generate sample level data based on the following items: Tooth count, denture wear, occluding pairs of teeth, functional dentition, oral cleanliness, gum condition, carious cavitation and oral pain. The MOSST has been developed so as content coverage is balanced with feasibility by ensuring that the tool produces a range of useful data while being small enough to be considered a bolt-on to larger data collection and not too onerous on participants or data collectors.

Training

All data collectors using MOSST (v0.1) HES should have undertaken training in its completion prior to use. Calibration should be completed prior to data collection and at regular intervals, where indicated.

Completing the OSSTv2.3 - HES

The comfort and safety of participants and data collectors are paramount. When carrying out the OSST-HES consider the risk-benefit to all involved when collecting data. If it is felt that oral data collection may be unsuitable or unsafe, return to the risk-benefit assessment and decide whether to continue data collection.

Easy read available if required in appendix 5 on the OSST-HES

*in the incidence that a participant chooses not to participate in the OSST-HES please open the Survey as per step 1 below – clicking not assessed for each item & complete the MDAS survey if the participant consents.

1. Open the MOSST survey on Qualtrics via QR code
2. Follow principles of universal precaution (Infection control)
3. Set up the assessment area as shown in the training manual.
4. Prepare appropriate zones and placement of protective barriers on the pen and the light source if applicable.
5. Ensure hand hygiene, surface disinfection and wear of personal protective equipment including glasses, mask and gloves.
6. Welcome participant
7. Review process consent.
8. Ensure that the participant is seated with adequate light / light source as indicated.
9. At the first question: if the participant is wearing dentures, ask if they can remove them, if not do not count the dentures in E2 tooth count, E3 Occlusal Contacts, E4 POPs questions, E5 Front Twelve teeth.
10. Use a disposable plain mouth mirror as needed.
11. Use sterile gauze to clean surfaces that are covered in debris if necessary.
12. If placing fingers into the mouth, ensure that you avoid placing digits between the biting surfaces of the dentition to avoid accidental injury.
13. Complete OSST-HES according to coding criteria (**Appendix**).
14. Discard all protective barriers, gloves, mouth mirror, and wipes in the waste bag. Clean and disinfect surfaces, pen and light source if applicable.
15. Complete MDAS survey as per instructions below.
16. Thank the participant, give the participant their dental goody bag.
17. Update results card as required.

18. Prepare assessment zone for next participant.

* Data collectors are encouraged to adopt creative approaches to data collection as best suits the person's preference and needs. This should be discussed with data collectors before and during data collection. (EXAMPLES TOOTHBRUSH / STEPWISE APPROACH).

After data collection

19. After data collection for each participant's results card for the health fair is updated and will be to the participant/ or support person. This results card is in an easy read version of their results which will contain advice if the participant should attend a dentist.

20. It is important that participants are aware that the findings of this data collection process **do not** amount to a dental examination.

21. Anyone who is found to answer YES regarding *Pain, cavitated teeth* or *Gum inflammation* should be advised to seek further advice. Participants are encouraged to attend a person who can support them or a dental professional where these findings indicate a need for assessment.

End of section.

Protocol appendix 1 Coding criteria for Health Evaluation Survey Items

E1 Denture Wear

Item

Is the participant wearing dentures now?

- Upper denture (E1a)
- Lower denture (E1b)

Definition

Denture wear is defined as: “A removable denture is present inside the mouth immediately before / at data collection.”

Display

The screenshot shows two data entry forms for items E1a and E1b. Each form has a header with a checkbox, the item name, and a question. Below the question is a table with three columns: 'No (0)', 'Yes (1)', and 'Not assessed (97)'. The 'No (0)' column has a blue checkmark, indicating it is the selected response.

	No (0)	Yes (1)	Not assessed (97)
Upper Denture (E1a)	☒	☐	☐

	No (0)	Yes (1)	Not assessed (97)
Lower Denture (E1b)	☒	☐	☐

Categories, criteria, and codes

- Categorical data
- No = No denture present in arch now (code = 0)
- Yes = Denture present in arch now (code=1)
- Not assessed (Code = 97)

Instructions

- Use light source
- Ask participant to open their mouth
- Visualize the upper arch.
- Check if the participant is wearing dentures
- Repeat for lower arch.

- Record observations for upper and lower separately
- .

Tips

- Carefully manipulate soft tissues, if necessary, with mirror.
- Exclude dentures not worn by participant when attending for data collection.
- Exclude false teeth that are not removable (e.g. crowns and bridges).
- Include partial and complete removable dentures.
- Code each arch separately
- If the participant cannot or does not want to remove their dentures- they can leave them in but ensure the dentures are not counted in E2 tooth count, E3 Occlusal Contacts or E4 POPs questions, E5 front twelve teeth.

E2 Tooth Count

Item

How many teeth are in each arch?

- Upper teeth (E2a)
- Lower teeth (E2b)

Definition

Defined as: “The number of teeth visible in the upper / lower arch”

Display

☐ E1

E1: Tooth Count
 How many teeth are in each arch?

Not assessed (97)

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16		
Upper Teeth (E1a)																		☐	6
Lower Teeth (E1b)																		☐	6

Categories, criteria, and codes

- Discrete data
- Range 0-16
- Slider indicates the number of teeth in each arch
- Not assessed (Code = 97)

Instructions

- Use light source
- Ask participant to open their mouth
- Systematically count the number of teeth in one arch from one side to another.
- Repeat for the other arch.
- Record observations for upper and lower separately.

Tips

- A tooth should be considered present when any part of it is visible.
- Tooth count includes false teeth that are fixed such as crowns, bridges.
- Tooth count excludes removable dentures.
- Code each arch separately

E3 Occlusal Contacts

Item

Pattern of occlusal contacts

Definition

Defined as “Distribution of opposing teeth in contact when biting”

Display

+

☐ E3

E3. Occlusal Contacts
Pattern of occlusal contacts (opposing teeth in contact)

⊖

☐ No occlusal contacts (0)

☐ Anterior contacts only (1)

☐ Posterior contacts (one or more +/- anterior contacts) (2)

☐ Not assessed (97)

+

Categories, criteria, and codes

Category	Criteria	Code
No occlusal contacts:	No teeth bite against each other on maximum closing	(Code = 0)
Anterior contacts only	Only front teeth are in contact (canine to canine) on maximum closing with no contacts involving premolars or molars.	(Code = 1)
Posterior contacts (one or more +/- anterior contacts)	At least one contact involving premolars or molars present on maximum closing with or without anterior contacts.	(Code = 2)
Not assessed		(Code = 97)

Instructions

- Use light source
- Ask participant to bite their back teeth together.
- Retract cheek using hand mirror
- Identify canines.
- Look at the teeth behind canine (eye tooth); observe whether teeth posterior to canines meet.
- If there are posterior contacts score now.
- Then, check on the other side.
- Add the number of teeth contacts from right and left sides.
- If there are no posterior teeth in contacts, count the number of front teeth (including canines) in contact.
- Record observation as single score.

Tips

- Repeat request to bite back teeth if necessary. Often people mistakenly try to bite their front teeth when asked to occlude. Often this is corrected with “no, the other back teeth”
- If posterior contact observed on first observation, score and move on.

E4 Pairs of Occluding Premolars (POPs)

Item

Does the participant have three or more pairs of occluding premolars (POPs)?

Definition:

POPs are defined as pairs of premolars in contact when biting. Each set of contacts from one premolar to each opposing premolar counts as one POP

Display

☒ E4

E4: Pairs of occluding premolars (POPs)
 Does the participant have three or more pairs of occluding premolars (POPs)?

☐ No: 2 or less POPs (0)
☐ Yes: 3 or 4 POPs (1)
☐ Not assessed (97)

Categories, criteria, and codes

Category	Criterion	Code
No: 2 or less POPs	2 Occluding pairs of premolars or less	(Code = 0)
Yes: 3 or 4 POPs	3 or 4 Occluding pairs of premolars	(Code = 1)
Not assessed		(Code = 97)

Instructions

- Use light source
- Retract cheek using hand mirror
- Ask participant to bite their back teeth together
- Identify canines and observe whether the next two single cusp teeth posterior to canines meet.
- Repeat on other side.
- Record observation as single score.

Tips

E5 Front Twelve Teeth

Item

Are the participant's front 12 teeth present?

Definition

A count of the 12 teeth at the front of the mouth. These teeth lie between and include the canines on the upper and lower arches.

Display

☐ E5 ★ x→ ...

E5: Front Twelve Teeth:
Are the participant's front twelve teeth present?

☐ No (0)
☐ Yes (1)
☐ Not assessed (97)

Categories, criteria, and codes

Category	Criteria	Code
No: Less than 12	Less than 12 inter-canine teeth present	(Code = 0)
Yes: All 12 front teeth present	All 12 inter-canine teeth present	(Code = 1)
Not assessed		(Code = 97)

Instructions

- Use light source and dental mirror.
- Ask participant to smile.
- Identify the centre line and count backwards three teeth each side, in each arch. The objective is to visualise if all 12 front teeth (canine to canine, top and bottom) are present.
- Add number of teeth present and score as single score

Tips

- This measure aims to count teeth present for aesthetic reasons

- For this item only: A tooth is considered present if, as compared to adjacent teeth, the crown more than 50% intact and considered absent if the crown is less than 50% intact

E6: Oral Cleanliness

Item

Is the participants' mouth / dentures clean?

Definition

Presence/Absence of food particles, tartar and plaque in the mouth or on dentures.

Display

☐ E6

★ ↔ ⋮

E6: Oral Cleanliness

Is the participants' mouth / dentures clean?

☐ No (0)
 ☐ Yes (1)
 ☐ Not assessed (97)

Codes, categories & criteria

Category	Criteria	Code
No	Not Clean: Obvious food particles, plaque or tartar in mouth or on dentures	(Code = 0)
Yes	Clean: No obvious food particles, plaque or tartar in mouth or on dentures	(Code = 1)
Not assessed:		(Code = 97)

Instructions

- Using a light source
- Ask the participant to open their mouth, use dental mirror to retract the buccal cheek, systematically visualise all surfaces of all teeth.
- Check for presence of food particles, tartar, and plaque on the teeth surface.
- Check on the dentures too.

Tips

- If in doubt score clean

E7: Gum Condition

Item

Are the gums healthy?

Definition

The presence of gingival redness, swelling, bleeding and ulcers.

Display

☐ E7

★ x→ ...

E7: Gum Condition

Are the gums healthy?

☐ No (0)

☐ Yes (1)

☐ Not assessed (97)

Codes, categories & criteria

Category	Criteria	Codes

No	Redness, swelling, bleeding or ulcers of the attached / free gingiva in any area of the mouth.	(Code = 0)
Yes	Gums are Pink, moist, no bleeding on gums / under dentures	(Code = 1)
Not assessed:		(Code = 97)

Instructions

- Using a light source
- Ask the participant to open their mouth, use dental mirror to retract the buccal cheek.
- Clean debris with gauze where necessary.
- Observe the appearance of gum above the teeth, in between the teeth, on the ridge where there are no teeth and on the area under dentures.

Tips

The term gums relate to the attached / free gingiva.

This is a whole mouth score: If any part of the gingivae is inflamed, score as **No**

If in doubt score Yes

E8: Cavitated Teeth

Item

How many visibly cavitated teeth are present?

Definition

The number of teeth with one or more cavities due to caries (decay), which can be detected by visual examination. Cavitation due to caries means a hole in a tooth due to tooth decay) where there is obvious breakdown of enamel creating a hole leaving the underlying dentine visible and the underlying dentine is discolored. When this occurs on the root surface, the dentine will be exposed and discolored. In either instance, the underlying dentine is a different color to the rest of the tooth- usually shades of brown.

Display

☐ E8
★ x→ ...

E8: Cavitated Teeth
How many visibly cavitated teeth are present?

☐ 3 or more (0)
☐ 1-2 (1)
☐ None (2)
☐ Not assessed (97)

Codes, categories & criteria

Category	Criteria	Codes
0 cavitated teeth	No teeth with cavitated caries.	(Code = 0)
1-2 cavitated teeth	1 or 2 teeth with cavitated caries	(Code = 1)
3 or more cavitated teeth	3 or more cavitated caries	(Code = 2)
Not assessed:		(Code = 97)

Instructions

- Using a light source
- Ask the participant to open their mouth, use dental mirror and to retract the cheek.
- Use gauze to clean and dry teeth surfaces.
- Check the upper teeth from one side to another (systematic manner).
- Check all surfaces of teeth.
- Count the number of teeth with cavitated carious lesions (holes, different in colour, broken down).
- Do the same for the lower teeth.
- Record the box that corresponds to the total number of decayed teeth on the form.

Tips

- This is a count of teeth (with cavities), not a count of cavities themselves: a tooth with two (or more) cavities is still counted as one cavitated tooth.

- Holes next to fillings may be counted as cavities when they meet the definition above.
- **This is a visual examination only**
- **This category excludes non-cavitated carious lesions.**

E9 Oral Pain

Item

Have you had (signs of) pain from your mouth in the last week?

Definition

The presence of verbal, physical, or behavioral signs of oral pain within last week.

Display

+

☐ E9

★ ↔ ...

E9:Oral Pain

Have you had (signs of) pain from your mouth in the last week?

−

☐ Yes reported verbally or vocally (0)
☐ Yes suggested behaviourally or physically (1)
☐ No (2)
☐ Not assessed (97)

+

Codes, categories & criteria

Category	Criterion	
Yes, reported verbally or vocally	Oral pain reported verbally or vocally by participant in last week	(Code = 0)
Yes, suggested behaviourally or physically	Oral pain suggested by behavioural signs (such as refused eating or certain food, chewing lips, pulling at face, aggression and self-injurious behaviours related to oral manipulation or function) or physical signs (swelling of cheek	(Code = 1)

	or gum, broken teeth, ulcers) in the last week	
No	No (signs of) oral pain in last week (verbal, behavioural or physical)	(Code = 2)
Not assessed:		(Code = 97)

Instructions

- Ask participant (or supporting person) if there is / has been pain inside the mouth (e.g. toothache or sore areas) reported verbally or vocally in the last week.
- If they answer yes, this is a verbal sign of dental pain (Score 0 reported verbally or vocally)
- If they answer no, ask participant (or supporting person) if there have been behavioural signs (such as refused eating or certain food, chewing lips, pulling at face, aggression and self-injurious behaviours related to oral manipulation or function) or physical signs (swelling of cheek or gum, broken teeth, ulcers) suggestive of oral pain in the last week? If they answer yes, this is a behavioural sign of dental pain (Score 1: Yes, suggested behaviourally or physically)
- If there are no verbal, behavioural, or physical signs of pain in last week, score 2.

Tips

Protocol Appendix 2

Equipment for data collection

Items
Quiet relaxing area with chair and table.
iPad – for data collection
Paperwork as needed.
Light source/ headtorch
Nitrile gloves
Face mask
Protective eye wear
PDI Sani wipes (Tub of 200s)
Purell advanced Handrub 500ml
Protective barriers – Disposable shield No.1 10cm x 15cm
Disposable paper towel
Disposable home use dental mirror
Sterile gauze 10cm x 10cm
Black bin bag
Pen

Protocol Appendix 3

Modified dental anxiety scale on Qualtrics

The Modified Dental Anxiety Scale- MDAS

▼ Block 1

☐ 0.1 Researcher ID
Researcher ID

☐ 0.2 Participant ID
Participant ID

0.3

Please choose what way this survey is being completed

☐ self-report only

☐ proxy only

☐ self report and proxy

▼ Default Question Block

☐ Instructions
CAN YOU TELL US HOW ANXIOUS YOU GET, IF AT ALL, WITH YOUR DENTAL VISIT?
Instructions for scoring: Each item scored as follows: Not anxious = 1 Slightly anxious = 2 Fairly anxious = 3 Very anxious = 4 Extremely anxious = 5

☐ Q1
1. If you went to your Dentist for TREATMENT TOMORROW, how would you feel?
☐ Not Anxious
☐ Slightly Anxious
☐ Fairly Anxious
☐ Very Anxious
☐ Extremely anxious
☐ Not Assessed (97)

- ☐ Q2
- ☆ x→ ...
2. If you were sitting in the WAITING ROOM (waiting for treatment), how would you feel?
- ☐ Not Anxious
 - ☐ Slightly Anxious
 - ☐ fairly Anxious
 - ☐ Very Anxious
 - ☐ Extremely Anxious
 - ☐ Not Assessed (97)

- ☐ Q3
- ☆ x→ ...
3. If you were about to have a TOOTH DRILLED, how would you feel?
- ☐ Not Anxious
 - ☐ Slightly Anxious
 - ☐ Fairly Anxious
 - ☐ Very Anxious
 - ☐ Extremely Anxious
 - ☐ Not Assessed (97)

- ☐ Q4
- x→ ...
4. If you were about to have your TEETH SCALED AND POLISHED, how would you feel?
- ☐ Not Anxious
 - ☐ Slightly Anxious
 - ☐ Fairly Anxious
 - ☐ Very Anxious
 - ☐ Extremely Anxious
 - ☐ Not Assessed (97)

- ☐ Q5
- x→ ...
5. If you were about to have a LOCAL ANAESTHETIC INJECTION in your gum, above an upper back tooth, how would you feel?
- ☐ Not Anxious
 - ☐ Slightly Anxious
 - ☐ Fairly Anxious
 - ☐ Very Anxious
 - ☐ Extremely Anxious
 - ☐ Not Assessed (97)

Appendix 4: OSST(v1.1) paper version

Appendix 5- paper version of OSSTv1.1-HES

Date		Part ID		Examiner ID	

OSST - HES (v2.1) The Oral Health Status Survey Tool HES V2

Completing the OSST – HES Form

Instructions:

This is a researcher- administrated health evaluation survey.

Please complete with the participant as per protocol.

Answer one option for each question, by selecting the answer that applies

E0. Please record if this is a repeat recording (Leave blank if first record)

Repeat (2)

E1	Denture Wear		
	Is the participant wearing dentures now?		
	Upper dentures		
	_____	_____	_____
	No	Yes	Not
	(0)	(1)	assessed
			(97)
	_____	_____	_____
	Lower dentures		
	_____	_____	_____
No	Yes	Not	
(0)	(1)	assessed	
		(97)	
E2	Tooth Count		
	Circle the number of teeth (0,1,2....)		
	Number of Upper Teeth		

0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Not assessed (97)

Number of Lower Teeth

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 Not assessed (97)

E3

Occluding Pairs

Pattern occlusal contacts (opposing teeth in contact)

No occlusal
contacts

(0)

One or
more

Posterior
contacts (1)

Anterior
contacts
only (2)

Not
assessed
(97)

E4: Pairs of Occluding Premolars (POPs)

Does the participant have three or more POPs?

3 or 4
POPs

(0)

2 or less
POPs

(1)

Not
assessed
(97)

E5: Front Twelve Teeth:

Are the participant's front
twelve teeth present?

All 12

(0)

Less
than 12

(1)

Not
assessed
(97)

E6	Oral Cleanliness Is the mouth clean?		
	NO (0)	Yes (1)	Not assessed (97)
E7	Gum Condition Are the gums healthy?		
	No (0)	Yes (1)	Not assessed (97)
E8:	Cavitated Teeth How many visibly cavitated teeth are present?		
	3 or more cavitated teeth (0)	1-2 cavitated teeth (1)	0 cavitated teeth (2)
			Not assessed (97)
E9	Oral Pain Do you / Have you had (signs of) oral pain in the last week?		

	Yes reported verbally or vocally (0)	Yes, suggested behaviourally or physically (1)	No (2)	Not assessed (97)	

Appendix 6

Oral health exam- easy read guide

1.		We will ask to look inside your mouth and count your teeth
2.		Please sit back and relax and let us know if you want to stop
3.		We will ask you to open your mouth wide And ask you to smile and look at your gums & teeth using a light and a mirror
4.		we enter what we see on a I PAD

5.		This information will not be identified to you by name and will be confidential

Appendix 4.2: modifications at the survey, item and response category levels

Appendix 1: Modifications to the OSST

Changes and rationale	Oral Status Survey Tool (OSST_) V1 2018 Health evaluation survey	OSST V2 2022 (IDS TILDA version MOSST v0.1	Comment	MOSST final version	Changes and rationale	Comment
Survey level changes						
Transfer to online data collection		OSST validated in reference article also adopted an online data management system. This change is congruous with translation plan	For ease of use Remove error in data transcription Data management and security			
Scoring order was standardised across survey so as all valiantly inferior options were lower than valiantly positive options						Following adaptions the scoring order were reviewed and standardised across the survey
Over-all format and structure to the survey modified. Following on from the content validity process and development of the MOSST version 1.2				Over-all format of the survey modified following content validity process and development of the MOSST version 1.2	There were multiple modifications to the format of the MOSST following the content validity process,	
Development of the MOSST SRS						

Appendix 1: Modifications to the OSST

Changes and rationale	Oral Status Survey Tool (OSST_) V1 2018 Health evaluation survey	OSST V2 2022 (IDS TILDA version MOSST v0.1	Comment	MOSST final version	Changes and rationale	Comment
Item level changes						
Item 1						
Swap order of Q1 and Q2- The order of the survey was changed as it made more logical sense to look at denture wear prior to tooth count. Dentures must be removed for all other measures. This would be for ease of recording for data collectors	E1 Denture Wear	E1 Tooth Count	The criteria, coding, instructions and tips for data collectors are outlined in the Coding criteria for Health Evaluation Survey Items- appendix 1 in the protocol.	Question 1: Functional Tooth units How many pairs of Functional Tooth Units (FTUs) are present?	Occlusal pairs <u>was</u> removed in the final refinement and replaced with the index of Functional Tooth Units (FTUs). This item's attributes offer improved coverage and validity compared to the removed items above and as such offers an improvement to the tool.	This item was also moved to Question 1 as following the content validity expert group feedback function should be measured with dentures in place.
Item 2						

Appendix 1: Modifications to the OSST

Changes and rationale	Oral Status Survey Tool (OSST_) V1 2018 Health evaluation survey	OSST V2 2022 (IDS TILDA version MOSST v0.1	Comment	MOSST final version	Changes and rationale	Comment
Response option changed from circle to sliding scale. The option to circle the number of teeth remains in the paper format of the survey.	E2: Tooth Count How many teeth are in each arch?	E2: Denture wear	The paper format is in the appendices of the OSST V2 protocol to be used if technical difficulties occur. The criteria, coding, instructions and tips for data collectors are outlined in the Coding criteria for ~~for~~ Health Evaluation Survey Items- appendix 1 in the protocol.	Question 2: Front Twelve Teeth Are the participant's Front Twelve Teeth present?	With the shift in oral function and the need for dentures to be in place for the function-based questions- this question moved. Front 12 teeth ~~remains insitu~~ ^{unremoved} for the purpose of aesthetics more so than function. Previously it link with function as part of the ~~.....~~	
Item 3						
Change in wording of the question, this was to make it clearer to a	E3 Occluding Pairs No. of biting pairs of teeth.	E3. Occlusal Contacts Pattern of occlusal contacts (opposing teeth in contact)	The scoring on this was changed as..... The wording was edited to a version	Question 3: Dentures	Denture wear will move further down in the survey, to bring	

Changes and rationale	Oral Status Survey Tool (OSST_) V1 2018 Health evaluation survey	OSST V2 2022 (IDS TILDA version MOSST v0.1	Comment	MOSST final version	Changes and rationale	Comment
non-dental data collector			that was clearer to understand for anon dental data collector.....	Is the participant wearing Dentures now?	the oral function question first.	
Item 4						
	E4 Functional Dentition: Pairs of Premolars (POPs) Does the participant have three or more occluding pairs of ~~premolars~~ ^{premolars} (POPs)?	E4: Pairs of Occluding Premolars (POPs) Does the participant have three or more POPs?	The wording was edited and the POPs and defined clearing in the Coding criteria for Health Evaluation Survey Items- appendix 1 in the protocol.	POPs question removed from final version of the MOSST Question 4: Tooth count: How many teeth are in each arch?	Remove this question related to POPs and bring a new question in its replacement: Oral function: Pairs of functional tooth unit to measure posterior functional teeth units	
Item 5						
Changes to the answer options:	E5 Functional Dentition:	E5: Front Twelve Teeth: Are the participant's	The definition and description criteria and coding ~~where were~~ changed and are	Moved to question 2.		Updated training tools and protocol on the presence of residual roots or broken teeth

Changes and rationale	Oral Status Survey Tool (OSST_) V1 2018 Health evaluation survey	OSST V2 2022 (IDS TILDA version MOSST v0.1	Comment	MOSST final version	Changes and rationale	Comment
The yes and no answers were felt to be clearer to answering the question of the survey.	Front 12 Teeth: Are the participant's front 12 teeth present? All 12 (0) Less than 12 (1) Not assessed (97)	front twelve teeth present? <u>No</u> (0) <u>Yes</u> (1) Not assessed (97)	outlined in the Coding criteria for Health Evaluation Survey Items- appendix 1 in the protocol.	Cavitated teeth now in place in question 5 in the MOSST survey Question 5 Cavitated Teeth How many visibly Cavitated Teeth are present?		Change to scoring categories
Item 6						
Changes to the answer options for it to be clearer for the data collectors Removed tarter option from criteria	E6 Oral Cleanliness Is the mouth clean? Clean No obvious food particles, plaque or tartar in mouth or on dentures (0) Not Clean Obvious food particles, plaque or tartar in mouth or on dentures (1) Not assessed (97)	E6: Oral Cleanliness Is the participants' mouth / dentures clean? No (0) <u>Yes</u> (1) Not assessed (97)	The criteria, coding, instructions and tips for data collectors are outlined in the Coding criteria for Health Evaluation Survey Items- appendix 1 in the protocol.	Question 6 Are the Gums Healthy?	The question was simplified for ease and intelligibility for non-dental data collectors Change in order of the survey.	Update protocol, definition and training tools
Item 7						
The wording is changed to be clearer and data collectors. This is done with an actual question "	E7 Gum Condition: Pink, moist, no bleeding (0) Redness, swelling, bleeding or	E7: Gum Condition Are the gums healthy? No (0) <u>Yes</u> (1)	The <u>updated criteria</u> , coding, instructions and tips for data collectors are outlined in the Coding criteria	Question 7 Oral Cleanliness	The question was simplified for ease and intelligibility for non-dental data collectors	updated protocol, wording regarding criteria and training tools

Changes and rationale	Oral Status Survey Tool (OSST_) V1 2018 Health evaluation survey	OSST V2 2022 (IDS TILDA version MOSST v0.1	Comment	MOSST final version	Changes and rationale	Comment
<u>are</u> are the gums healthy Instead of setting the criteria in the question	ulcers on gums / under	Not assessed (97)	for Health Evaluation Survey Items- appendix 1 in the protocol.	Is the participants' Mouth / Dentures Clean?	Change in order of the survey	
Item 8						
Changes to this question were made for	E8 Carious Teeth (Teeth with Holes) No. of visibly cavitated teeth (Count number of teeth with at least one hole)?	E8: Cavitated Teeth How many visibly cavitated teeth are present?	The criteria, coding, instructions and tips for data collectors are outlined in the Coding criteria for <u>for</u> Health Evaluation Survey Items- appendix 1 in the protocol.	Question 5 Cavitated Teeth How many visibly Cavitated Teeth are present?	Moved to question 5 in the survey.	Update training tools and protocol on the presence of residual roots or broken teeth Change to scoring categories
Item 9						
Slight change in wording to ensure full understanding. 	E9 Oral Pain Do you / Have you had (signs of) oral pain in the last week? No pain (0) <u>Yes</u> reported verbally or vocally (1) <u>Yes</u> suggested behaviourally or physically (2)	E9: Oral Pain Have you had (signs of) pain from your mouth in the last week? <u>Yes</u> reported verbally or vocally (0) <u>Yes</u> suggested behaviourally or physically (1) <u>No</u> (2)		Oral pain removed to the MOSST SRS		The MOSST was undertaken in the wave 5 health fair of IDS TILDA and there <u>are</u> is specific oral health questions asked in the IDS TILDA interview. To ensure that the MOSST can be used outside of the IDS TILDA study a set of

Appendix 4.3. detailed account of MOSST v0.1 item structure and development

Appendix 4.4 participant feasibility survey questions and the nurse feedback responses are available.

The Modified Oral Status Survey Tool use in the wave 5 health fair.

In working with the research nurses throughout the health there were regular training refreshers and discussions on adaptations to the tool to make it more feasible to participants. There were also calibrations taken using intra and inter-rater scoring to measure reliability of the Modified Oral Health Status Survey Tool (MOSST) at intervals throughout the health fair.

Changes to MOSST during the health fair were slight modifications and updates to the protocol. Adding in additional comments and guidance on scoring participants with zero teeth and the effect it has on other questions. For example: when scored zero teeth score cavitated teeth as NONE instead of NOT ASSESSED. On discussion with the research nurses it came to light that the area that was highest in not being assessed was cavitated teeth scoring as it could be quite onus on participants and it was suggested moving the question in the survey to after teeth count as it could nearly be done in conjunction with teeth count.

The research nurses who undertook the data collection using the MOSST in the health fair were asked two questions as part of feedback on using the MOSST and any suggestions for its future use. These responses are outlined below.

Feedback form from research nurse for the Modified Oral Status Survey Tool (MOSST) In the IDS TILDA Wave 5 health fair

How did you find using the MOSST in the health fair?

- Very easy to use
- Easy to navigate through the tool on Qualtrics
- Moving the assessment for cavitated teeth to nearer the start of the tool improved flow and was easier to assess as some participants became tired nearer to end of assessment and was therefore more difficult to assess cavitated teeth at later end of assessment process.

- Easy reads to support participants were very helpful in understanding dental assessment and to reduce anxiety. An excellent support also for participants who have nonverbal communication.

Any suggestions or feedback for the MOSST? relating to using it/ the training/ equipment etc ?

- Option to use either the dental mirror or tepe toothbrush was useful in increasing accessibility and reduce anxiety as some participants identified better with the toothbrush -Assoc with tooth brushing offered familiarity /more likely to consent to examination /object of reference offered reassurance .
- The inclusion of 3 questions re burden- two questions are very similar in type which could be difficult for the participant to differentiate between – perhaps more clarity re same required to reduce confusion.
- The training was very comprehensive, and I felt confident in my role both carrying out the physical dental assessment and in the collection of the data. The 2-day training course was beneficial in ensuring that the data collector was adequately trained to feel competent in their role. Focus should be placed on training re cavitated tooth and POP assessments as I found these two elements of the MOSST the hardest to learn.
- Re MDAS – the use of the word anxiety in relation to responses (not anxious, slightly anxious etc,) can cause confusion or in some instances participants did not understand the meaning of the word. A simpler wording such as 'worried' could be an alternative option to use. For consistency the same wording should be selected for response each time
- A general comment box would be useful so that observations may be added as relevant.
- Consideration in the future re restorative dentistry data collection to be included in OSST – personal observation that many of the participants who were edentulous had no restorative dentistry completed – no implants, bridges, crowns etc. Participants were offered in some cases full or partial dentures.
- Highlight the need for reasonable adjustment during examinations and prior to examinations – environmental adjustments , building rapport, working at the individual pace, respecting choices , uses comfort measures to support the exam etc.

Additional feedback:

- Moving the cavitated teeth permanently to follow the tooth count as trial of these increased cavitated teeth assessments and its flow in the MOSST.
- Review of dental function questions to follow- currently we ask of pairs of premolars(POPS) and molars, this will be discussed more with review panel when validating the tool, would it be easier for data collectors/ participants to just review POPs
- Review of Modified Dental Anxiety Tool (MDAS) the criteria on self-report and proxy needs to be reviewed and implement criteria into future training. As well as reviewing the wording of these questions and terminology used.
- Reasonable adjustments were very important for using the MOSST and this was highlighted and implemented by the research nurses. In future training this needs to be an aspect of the training, it was previously but examples and learning from the health fair wave to 5 to develop this section.

Feedback from participants on how they found the MOSST

In the final weeks of the wave 5 health fair (N=66) participants were asked additional questions to measure the burden of undertaking the MOSST.

(N=22) were unable to answer these questions, leaving (N=44) responses to these questions

These questions were:

Was it quick? (N=43) responding yes and (N=1) responding no

Did it hurt?(N=43) responding yes and (N=1) responding no

Was it Ok for you? (N=44) responding yes

Validity measures of the MOSST throughout the health fair

Inter-rater reliability scores were initially used in the MOSST training to calibrate the research nurses against a gold standard in preparation for using the tool in the health fair. Inter-rater reliability scores show that an assessment is consistent where different people can administer the assessment and find consistent results.

Inter-rater reliability scores were undertaken at regular intervals in the health fair (N=43) participants attending the health fair were assessed twice. Once by a research nurse and once by the “gold standard” data collector. The results of these scores will be statistically quantified using Cohen's kappa coefficient

Intra-rater reliability scores were undertaken to show that the MOSST assessment is consistent where it is completed multiple times by the same person. Intra-rater reliability scores were undertaken by the research nurse and by PhD student (gold standard) were carried out with (N= 31) participants. These results will also be statistically quantified using Cohen's kappa coefficient.

Appendix 4.5 Surveys used in the expert panel process

Expert Panel Content Validity Modified Oral Status Survey Tool

Introduction Modified Oral Status Survey Tool

Content Validity Rating Survey

Welcome to our survey. We are interested in exploring the content validity of the Modified Oral Status Survey Tool (MOSST). This is based on minor modifications to the previously validated Oral Status Survey Tool (OSST). The MOSST has been developed to capture high level indicators of oral status and oral function among people who may otherwise be excluded from oral data collection, such as those with disabilities. A link to the original validation study and other resources are available at the end of this page. What to expect

For this study, each of the nine items in the MOSST will be presented to you one at a time.

You will be presented with the Item, the construct, the Definition as per the protocol, the answer options and a visual of the question as it appears in the MOSST on Qualtrics.

Next is the question to score how relevant you feel the item is to the underlying concept. You will also be asked how clear you feel the protocol relating to each item is. You will be able to give feedback on each item as needed.

Instructions

Please read and familiarize yourself with each item, instructions and response options under each concept.

Please score the RELEVANCE of each item in relation to the underlying concept being explored on a scale of 1-4

You can add any comments relating to the item, instructions, or response options under each construct as you see fit.

These will be reviewed to optimise the tool.

OPTIONAL RESOURCES

Link to MOSST Qualtrics survey (as seen by data collectors) [here](#)

Link to MOSST Protocol here: [Oral status survey tool protocol v2. sep23](#)

Link to MOSST Training Tools here: [Osst training pp 11.10.22](#)

Link to MOSST training blog [here](#)

Link to Original Tool webpage [here](#)

Link to original development article [here](#)

Q11 What will happen to your data?

Once you complete the survey, your responses will be aggregated, and content validity ratio will be calculated. Responses will be anonymous. If you wish to be recognised for your contribution in the acknowledgements of any publication based on this work, please add your name and affiliation as you would like it to appear in publications.

☐ No, I would not like to be acknowledged publicly (1)

☐ Yes.... (2) _____

Question 1 **Concept 1 = Denture Wear**

Item

Is the participant wearing a denture now?

Definition (As per protocol)

Denture wear is defined as: "A removable denture is present inside the mouth immediately before / at data collection."

Answer options

- No = No denture present in arch (code = 0).
- Yes = Denture present in arch (code=1).
- Not assessed (Code = 97).

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 1 Part B Please add comments to improve the concept, item or answer options? (Optional)

End of Block: Block 1

Start of Block: Block 2

Question 2 **Concept 2 = Tooth Count**

Item

How many teeth are in each arch?

Definition (As per protocol)

Tooth count is defined as: "The number of teeth visible in the upper / lower arch"

Answer options

- Arches scored separately
- Range 0-16.
- Slider indicates the number of teeth in each arch.
- Not assessed (Code = 97).

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 2 Part B Please add comments to improve the concept, item and answer options? (Optional)

End of Block: Block 2

Start of Block: Block 3

Q3 Concept 3 = Cavitated teeth

Item

How many visibly cavitated teeth are present?

Definition (As per protocol):

The number of teeth with one or more cavities due to caries (decay), which can be detected by visual examination. Cavitation due to caries means a hole in a tooth due to tooth decay where there is obvious breakdown of enamel creating a hole, leaving the underlying dentine visible and the underlining dentine is discolored. When this occurs on the root surface, the dentine will be exposed and discolored. In either instance, the underlying dentine is a different color to the rest of the tooth- usually shades of brown.

Answer Options: 3 or more teeth with visible decay that is cavitated (Code = 0). 1 or 2 teeth with visible decay that is cavitated (Code = 1). None. No teeth with visible decay that is cavitated (code=2). Not assessed: (Code = 97).

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 3 Part B Please add comments to improve the Item, Concept and Answer options? (Optional)

End of Block: Block 3

Start of Block: Block 4

Q 4 Concept 4 = Occlusal contacts

Item

Pattern of occlusal contacts (opposing teeth in contact)

Definition (As per protocol)

Defined as “Distribution of opposing teeth in contact when biting”

Answer options No occlusal contacts: No teeth bite against each other on maximum closing (Code = 0) Anterior contacts only: Only front teeth are in contact (canine to canine) on maximum closing with no contacts involving premolars or molars (Code = 1) Posterior contacts (one or more +/- anterior contacts) At least one contact involving premolars or molars present on maximum closing with or without anterior contacts (Code = 2) Not assessed (Code = 97)

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)

☐ Quite relevant (3) (3)

☐ Highly relevant (4) (4)

Question 4 Part B Please add comments to improve the Item, Concept and Answer options? (Optional)

End of Block: Block 4

Start of Block: block 5

Q5 Concept = Pairs of occluding premolars

Occlusal component of a minimally functional dentition (nGuyen et al. 2011)

Item

Does the participant have three or more pairs of occluding premolars (POPs)?

Definition (As per protocol)

POPs are defined as "pairs of premolars in contact when biting. Each set of contacts from one premolar to each opposing premolar counts as one POP."

Answer options No: 2 or less POPs 2 Occluding pairs of premolars or less (Code = 0) Yes: 3 or 4 POPs 3 or 4 Occluding pairs of premolars (Code = 1)

Not assessed (Code = 97)

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 5 Part B Please add comments to improve the Item, Concept and Answer options? (Optional)

End of Block: block 5

Start of Block: Block 6

Q6 Concept = Front Twelve Teeth

(Aesthetic component of a minimally functional dentition (nGuyen et al. 2011))

Item

Are the participant's front 12 teeth present?

Definition (As per protocol):

A count of the 12 teeth at the front of the mouth. With 6 teeth on the upper

arch and 6 teeth on the lower arch. These teeth lie between and include the canines on the upper and lower arches.

Answer options: No: Less than 12 Less than 12 inter-canine teeth present (Code = 0). Yes: All 12 front teeth present All 12 inter-canine teeth present (Code = 1). Not assessed (Code = 97).

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 6 Part B Please add comments to improve the Item, Concept and Answer options? (Optional)

End of Block: Block 6

Start of Block: Block 7

Question 7

Concept =Oral Cleanliness

Item

Is the participants' mouth / dentures clean?

Definition (As per protocol):

Presence/absence of food particles and plaque in the mouth or on dentures.

Answer options: No: Not Clean: Obvious food particles, plaque in mouth or on dentures(Code=0). Yes Clean: No obvious food particles, plaque in mouth or on dentures (Code = 1). Not assessed: (Code = 97).
Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 7 Part B Please add comments to improve the Item, Concept and Answer options? (Optional)

End of Block: Block 7

Start of Block: Block 8

**Q8 Concept= Gum Condition
Item**

Are the gums healthy?

Definition (As per protocol):

The presence of gingival redness, swelling and bleeding.

Answer options: No (Redness, swelling, bleeding of the attached / free
gingiva in any area of the mouth). (Code = 0). Yes (Gums are Pink, moist,
no bleeding on gums) (Code = 1) Not assessed: (Code = 97).
Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 8 Part B Please add comments to improve the Item, Concept and
Answer options? (Optional)

End of Block: Block 8

Start of Block: Block 9

Q9 Concept = Oral Pain

Item

Have you had (signs of) pain from your mouth in the last week?

Definition (As per protocol):

The presence of verbal, physical, or behavioral signs of oral pain within last week.

Answer options: Yes : The participant or there support person reported oral pain was experienced verbally or vocally in last week (Code = 0). Yes: Oral pain was suggested behaviorally or physically by behavioral signs (such as refused eating or certain food, chewing lips, pulling at face, aggression and self-injurious behavior's related to oral manipulation or function) or physical signs (swelling of cheek or gum, broken teeth, ulcers) in the last week (Code = 1). No (signs of) oral pain in last week (verbal, behavioral or physical) (Code = 2). Not assessed: (Code = 97).

Appearance in Qualtrics

Panelist Rating:

Is this question relevant to the underlying concept?

☐ Not relevant (1) (1)

☐ Somewhat relevant (2) (2)

☐ Quite relevant (3) (3)

☐ Highly relevant (4) (4)

Question 9 Part B Please add comments to improve the Item, Concept and Answer options? (Optional)

End of Block: Block 9

Start of Block: Block 10

Question 10 Thank you for completing this expert panel survey.

Any further comments on the MOSST, please add in here (optional)

Survey 2:

Expert Panel: Content Validity Survey: Follow Up

Introduction Modified Oral Status Survey Tool
Content Validity Rating Survey One New Item!!!

Please go to next page and answer one question

Q1 Functional Tooth Units

Item: How many pairs of functional tooth units are present in maximum intercuspation?

Concept: Occlusal Function

Definition (as per protocol):

To observe how many Functional Tooth Units (FTU) are observable posteriorly in maximum intercuspation (MIP). The number of pairs of opposing natural teeth and/or artificial teeth (implant-supported, fixed and/or removable prostheses) in occlusion in MIP, excluding carious teeth with extensive coronal destruction. Posteriorly, two opposing premolars are defined as 1 FTU, and 2 opposing molars are defined as 2 FTUs. Therefore, a complete dentition (Posteriorly) is counted as having 12 FTUs (except for the third molars).

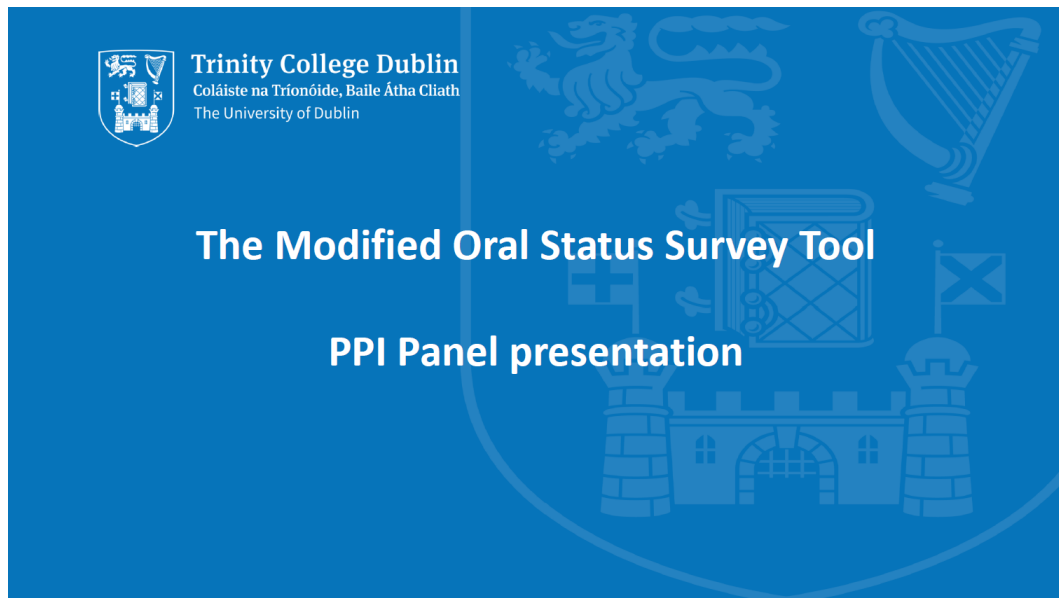
Question and Answer options:

Please score the relevance of this Question to the underlying concept?

- ☐ Not relevant (1) (1)
- ☐ Somewhat relevant (2) (2)
- ☐ Quite relevant (3) (3)
- ☐ Highly relevant (4) (4)

Question 1 B Please add comments to improve the Item, Concept and Answer options?

Appendix 4.6. PPI panel presentation



MOSST Assessment

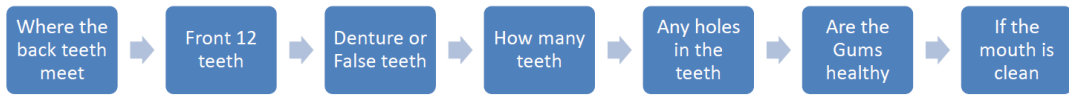


Now lets looks at the MOSST assessment

Do you think what we have included is
Important?

MOSST Assessment

This 7 areas we look in the mouth at:



Trinity College Dublin, The University of Dublin

@ageingwithID

#ageingwithID

When we look in mouths..... We look at.....

Where the back teeth meet



Trinity College Dublin, The University of Dublin

@ageingwithID

#ageingwithID

When we look in mouths..... We look at.....

Front 12 teeth



When we look in mouths..... We look at.....

Dentures or False
teeth



Trinity College Dublin, The University of Dublin

@ageingwithID

#ageingwithID

When we look in mouths..... We look at.....

How many teeth



Trinity College Dublin, The University of Dublin

@ageingwithID

#ageingwithID

When we look in mouths..... We look at.....

Holes in teeth
(Cavities)



When we look in mouths..... We look at.....

Gums
Are they healthy?

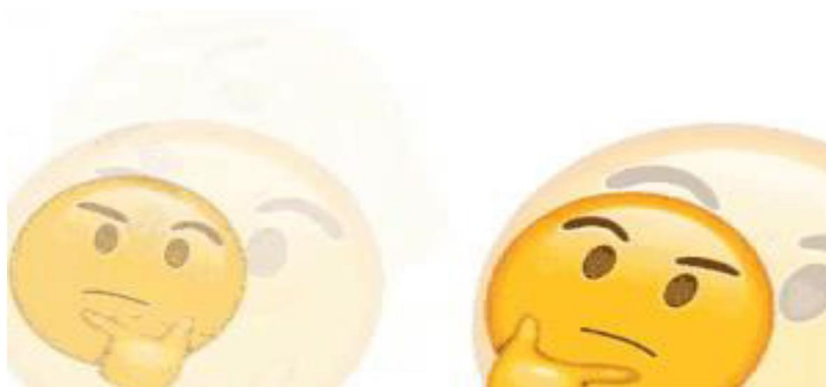


When we look in mouths..... We look at.....

Is the mouth clean?



Any questions??



Appendix 4.8: additional Cost table

Equipment	Costing per item	Equipment required for Wave 5 of IDS TILDA MOSST assessment	Estimated Costing per MOSST assessments
Nitrile gloves)	€59.00 (10 boxes of 200)	20 boxes	€118
Face mask	5.50 per box of 50	X11 boxes	€60.50
Protective eye wear	€2.98	X 20	€59.60
Head Torch	€6.00	X 2	€12.00
PDI Sani wipes (Tub of 200s)/ disinfection wipes (or any similar brand)	€6	X 3	€18.00
Purell advanced Hand rub 500ml/ Alcohol gel	€2.11	X 10	€21.10
Protective barriers – Disposable shield No.1 10cm x 15cm	€8.75	X 4	€35
Disposable paper towel (Blue bib roll)	€7.25	X5	€36.25
Disposable home use dental mirror .	€1 each, case of 100	X550	€550
Sterile gauze 10cm x 10cm	€20.28	X10	€200
Black bin bag roll	€4.09	x10	€40.90
Tee-pee toothbrushes	€1.36	X500	€680
Total			€1832

Appendix 4.9 final MOSST v1.0 framework



TOOLKIT v1.0

v1.0 last updated 18/04/24 Katrina Byrne & Dr. Caoimhin Mac Giolla Phádraig

Introduction

This toolkit contains all tools necessary to administer the Modified Oral Status Survey Tool, referred as the MOSST in this protocol, and the MOSST Self Report Supplement, referred to as the MOSST-SRS. This toolkit includes protocols, tools, list of equipment needed and easy read guides. The MOSST protocol lists the recommended steps when completing data collection using the MOSST and MOSST-SRS.

The MOSST covers seven concepts that indicate oral status and oral function, making it possible to record a range of oral features that are important for policy makers and service providers. The MOSST was developed to be quick, acceptable, robust and administered by well-trained dentists / non-dentists without scribe. The MOSST also includes of a Self-Report Supplement (MOSST-SRS), details of which are provided below.

The MOSST has been developed so as content coverage is balanced with feasibility by ensuring that the tool produces a range of useful oral health data, is feasible for use across many contexts, and is not too onerous on participants or data collectors. The MOSST was developed over ten years in Trinity College Dublin, Trinity Centre for Ageing and Intellectual Disabilities and Dublin Dental University Hospital, in partnership with adults with intellectual disabilities. The development team promote the sharing of the MOSST under Creative Commons Licensing.

Aim of MOSST

The aim of the MOSST is to collect data based on the following concepts: Functional tooth units, Aesthetics, vis a vis presence of the Front twelve teeth, Denture wear, Tooth count, Cavitated teeth, Gum condition, and Oral cleanliness. The MOSST-SRS aims to collect data on selected aspects of oral healthcare utilization, oral health behaviours (homecare), and oral health related-quality of life.

Why use the MOSST?

The MOSST can be used for research or to inform local and national service planning and policy. The MOSST is **not** designed for use as an individual oral health assessment tool, a tool for diagnosis or clinical screening. The MOSST does not facilitate the practice of dentistry or replace the need for regular dental assessment by a registered dental professional.

Which samples is the MOSST for?

The MOSST is designed for adults, who are traditionally excluded from oral health data collection. This may be due to limited data collection capacity on behalf of the sample or data collectors. The MOSST has been used successfully to record surveys among broad samples of people with disabilities in Ireland including those with severe and profound disabilities. The tool has been developed and validated with people over 40 years of age with mild to profound disability. Further development has been achieved with people with profound and severe disability also. The tool is **not** designed for children. Further validation is required for use among other populations such as people of older age, people in low resource economies, etc.

Who can score the MOSST?

The MOSST can be scored by well-trained dental professionals or non-dental professionals. The MOSST should be applied once data collectors have completed training in its use. Training is online and in person. Training should be supported with calibration to ensure valid and reliable recording, as per WHO guidelines (WHO, 2013). Repeat training and calibration is recommended across examiners and over time, depending on the project to ensure reliability. The MOSST is designed to be scored directly onto a tablet without a scribe.

Disclaimer

Data collectors should ideally come from clinical professions, and have training and experience in research ethics, person-centred communication, clinical data collection and have high standards of infection control. Data collectors may need to ensure appropriate vaccination, as indicated. Data collection must align with local policies regarding infection control, waste management, risk assessment and other relevant policies. The developers have made every effort to support data collection in traditionally excluded populations. The developers do not take responsibility for use of the tool by others.

Training

All data collectors should be trained in its use prior to administration. Calibration is also recommended as part of training to ensure valid data collection. This should be completed prior to using the MOSST data collection. Data collectors may also need further training, such as in person centred communication, inclusive research methods, data management, infection control, and related fields as per local policy, and their project needs. Data collectors should assess their own need

for further training relevant to the specific population for whom they collect data.

Ensuring participant-centred data collection

The comfort and safety of participants and data collectors are paramount. When carrying out the MOSST consider the risk-benefit to all involved when collecting data. If it is felt that oral data collection may be unsuitable or unsafe, return to the risk-benefit assessment and decide whether to continue data collection. To support participant inclusion, easy-read resources are available.

MOSST Protocol



Participant preparation

1. Open the MOSST survey format you are using (e.g. Qualtrics via QR code, or paper-based).
2. Follow principles of universal precaution (infection control).
3. Set up the assessment area as shown in the training set up (see training tool for guidance).
4. Prepare appropriate zones and placement of protective barriers on the light source / iPad / pen.
5. Welcome participant. Participants are encouraged to attend with a person who can support them, if needed.
6. Review process consent with accessible communication aides, if needed.
7. Ensure that the participant is seated with adequate light / light source as indicated. It is best for the participant to be seated near and face a natural light source (window) when undertaking data collection.

Administration

1. Ensure hand hygiene, surface disinfection and wear of personal protective equipment including glasses, mask and gloves.
2. Complete MOSST according to coding criteria.
3. Score onto a tablet or using a pen with protective sheath aseptically.
4. At question 3, the participant is asked whether they have dentures. If the participant is wearing dentures, remove them now. If they do not remove

dentures, do not count the dentures in the tooth count and complete rest of survey based on visible surfaces.

5. Use a disposable plastic mouth mirror as needed (non-metal / non-glass mirror only)
6. Use sterile gauze to clean surfaces that are covered in debris if necessary.
7. If placing fingers into the mouth, ensure that you avoid placing digits between the biting surfaces of the dentition to avoid accidental injury. The MOSST is designed to be completed without placing fingers between teeth.

After the MOSST

1. Give each participant an easy read summary outlining their results, which will contain advice if the participant should attend a dentist.
2. Remind participant that MOSST is NOT a dental examination, screening or treatment plan. It is important that participants are aware that the findings **do not amount to a dental examination**, screening, treatment planning or the practice of dentistry.
3. Participants found to answer YES regarding *Pain (MOSST-SRS)*, *cavitated teeth* or *Gum inflammation* should be advised to seek further advice. Participants are encouraged to attend with a person who can support them.
4. Thank the participant as they leave.
5. Following principles of universal precaution (Infection control), discard all protective barriers, gloves, mouth mirror, and wipes in the waste bag.
6. Clean and disinfect surfaces and set up for next participant

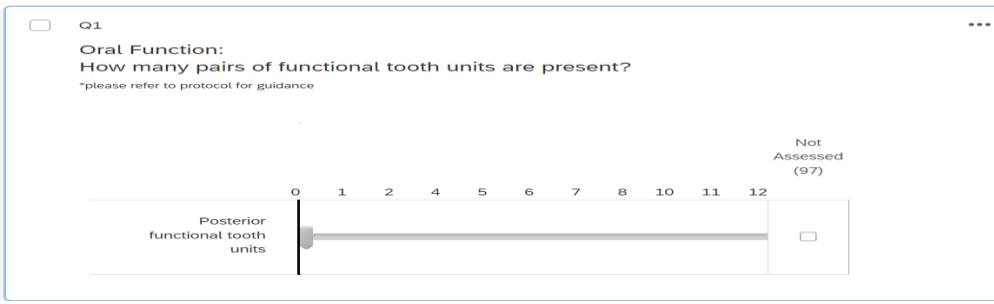
Tips for data collection

1. When using the MOSST, data collectors are encouraged to adopt creative approaches to data collection as best suits the person's preference and needs. This should be discussed with participants before and during data collection. Using reasonable adjustment can ensure a positive experience and increase participation. Linking in with support staff on how best to approach can be beneficial.

2. If a participant chooses not to participate in the MOSST or part of the MOSST it is recommended to record this: Select **not assessed** for all items not assessed.
3. It is good to have an oral health pack to thank participants for their time.

Item 1: Functional Tooth Count

Item 1 Functional Tooth Units MOSST

Concept	Functional Tooth Units
Item	How many pairs of functional tooth units are present?
Definition	In this item, the data collector records the number of FTUs that are observable in maximum intercuspation (MIP). An FTU is defined as a pair of opposing teeth in occlusion in maximum intercuspation.
Display	
Categories, criteria, and codes	• Slider indicates the number of functional tooth units in total in the mouth (Right and Left combined); Range 0-12 • Only posterior teeth are scored. • This includes natural teeth and/or artificial teeth (implant-supported, fixed and/or removable prostheses) • A pair of premolars in contact are considered 1 FTU • A pair of molars in contact are considered 2 FTUs • Third molars and carious teeth with extensive coronal destruction are excluded • Each tooth can only be counted once.

- Maximum = 12 FTUs
- Not assessed (Code = 97)

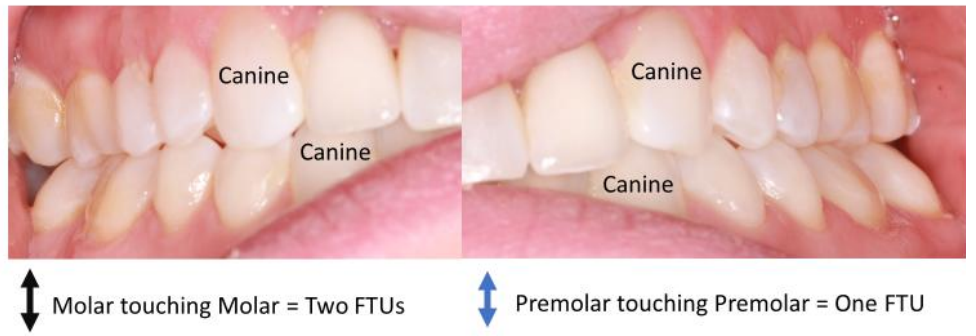
**Instructi
ons**

- Use light source
- Ask participant to bite their back teeth together
- Retract cheek using hand mirror
- Identify canines
- Look at the teeth behind canine (eye tooth); observe whether teeth posterior to canines meet
- If there are posterior contacts score the number of FTU.
- Then, check on the other side
- Add the number of teeth contacts from right and left sides
- Record observation as single score

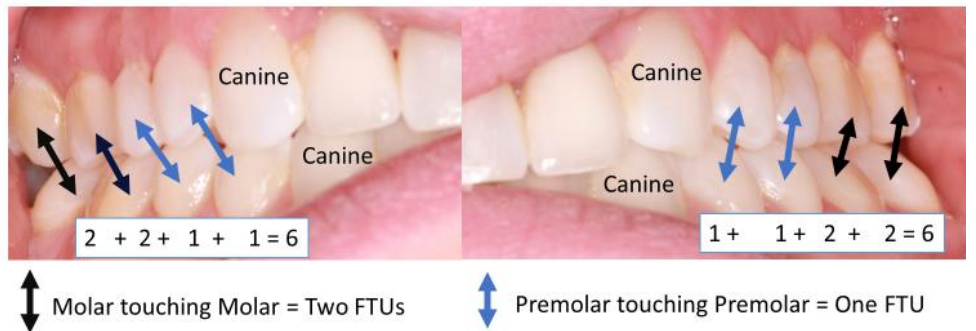
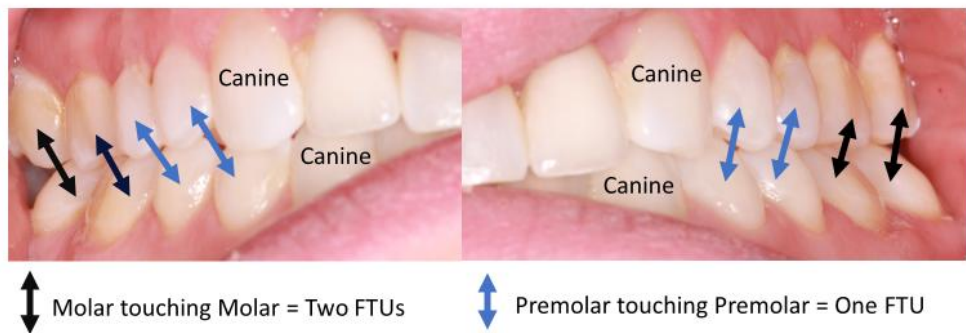
Tips

- Repeat request to bite back teeth if necessary. Often people mistakenly try to bite their front teeth when asked to occlude. Often this is corrected with “no, the other back teeth”
- It is helpful to pick one arch to count (either the upper or lower). It’s easier.
- If the participant is unable to bite their teeth together, the data collector is asked to make a judgement on how many teeth would be in contact if occlusion was obtained based on the distribution of teeth in each arch and the alignment of the arches.

Example



FTU=12



Item 2: Front Twelve Teeth

Item 2

Front Twelve Teeth

MOSST

Concept Front Twelve Teeth

Item Are the participant's front 12 teeth present?

Definition A count of the 12 teeth at the front of the mouth. With 6 teeth on the upper arch and 6 teeth on the lower arch. These teeth lie between and include the canines on the upper and lower arches.

Display

☐ E5

E5: Front Twelve Teeth:
Are the participant's front twelve teeth present?

☐ No (0)

☐ Yes (1)

☐ Not assessed (97)

Categories, criteria, and codes

Category	Criteria	Code
No	Less than 12 inter-canine teeth present	(Code = 0)
Yes	All 12 inter-canine teeth present	(Code = 1)
Not assessed	Not assessed	(Code = 97)

Instructions

- Use light source and dental mirror.
- Ask participant to smile.
- Identify the centre line and count backwards three teeth each side, in each arch. The objective is to visualise if all 12 front teeth (canine to canine, top and bottom) are present
- Add number of teeth present and score as single score

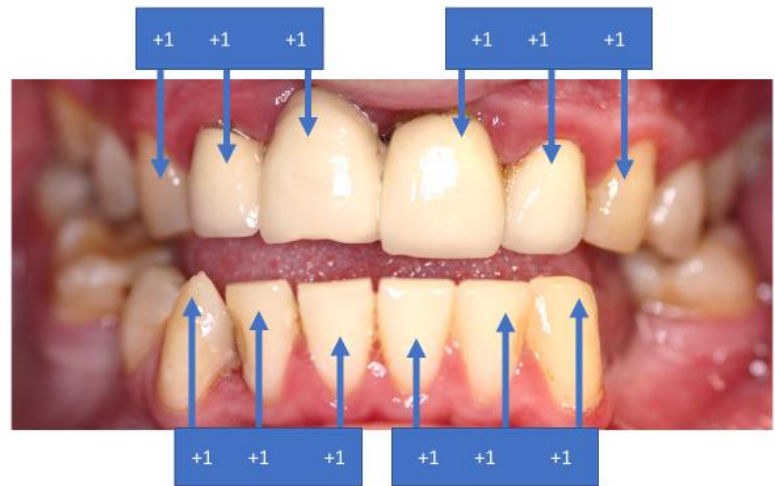
Tips

- This measure aims to count teeth present for aesthetic reasons
- For this item only: A tooth is considered present if, as compared to adjacent teeth, the crown more than 50% intact and considered absent if the crown is less than 50% intact
- If no teeth – score as no (0)

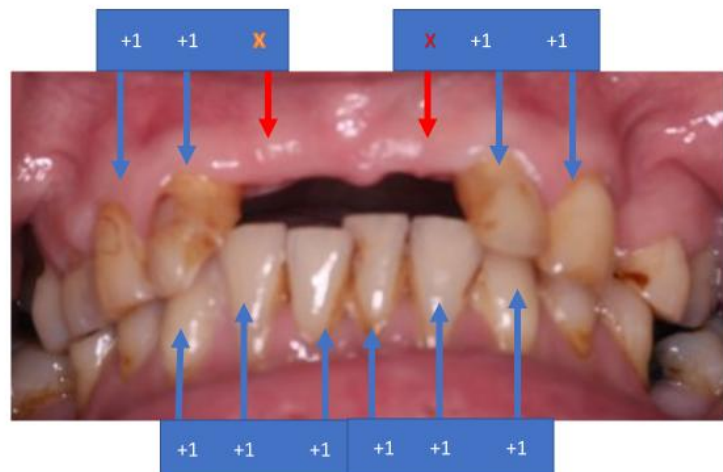
- Dentures are left in situ for this item.

Example
s

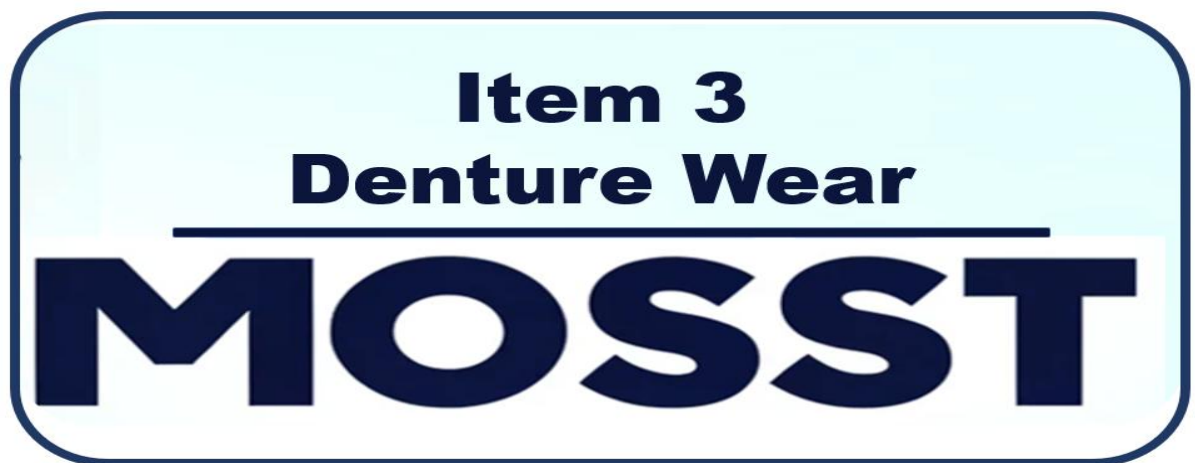
Yes



No



Item 3: Denture Wear



Concept Denture Wear

Item Is the participant wearing dentures now?
Upper denture (3a)
Lower denture (3b)

Definition A removable denture is present inside the mouth immediately before / at data collection.

Display

☒ E1a
E1a: Denture Wear
Is the participant wearing dentures now?

	No (0)	Yes (1)	Not assessed (97)
Upper Denture (E1a)	☒	☐	☐

☒ E1b
E1b: Denture Wear
Is the participant wearing dentures now?

	No (0)	Yes (1)	Not assessed (97)
Lower Denture (E1b)	☒	☐	☐

Coding and Criteria:

No= No denture present in arch now	(code = 0)
Yes = Denture present in arch now	(code=1)
Not assessed	(Code = 97)

Instructions

- Use light source
- Ask participant to open their mouth
- Visualize the upper arch.
- Check if the participant is wearing dentures
- Repeat for lower arch.
- Record observations for upper and lower separately.

Tips

- Carefully manipulate soft tissues, if necessary, with mirror.
- Exclude dentures not worn by participant when attending for data collection.
- Exclude false teeth that are not removable (e.g. crowns and bridges).
- Include partial and complete removable dentures.
- Code each arch separately
- If the participant cannot or does not want to remove their dentures- they can leave them in but ensure the dentures are not counted in Item 2 tooth count

Denture Wear

Examples

Is this participant wearing dentures?



Yes



No

Is this participant wearing dentures?



Yes



yes

Item 4: Tooth Count

Item 4 Tooth Count MOSST

Concept	Tooth count
Item	How many teeth are in each arch? Upper teeth (4a) Lower teeth (4b)
Definition	The number of teeth visible in the upper / lower arch
Display	

The screenshot shows the 'E1: Tooth Count' section of the MOSST interface. It asks 'How many teeth are in each arch?'. There are two horizontal sliders: 'Upper Teeth (E1a)' and 'Lower Teeth (E1b)'. Both sliders have a range from 0 to 16, with a blue marker at 6. To the right of each slider is a checkbox and a numerical value '6'. Above the sliders, there is a 'Not assessed (97)' option with a checkbox.

Categories, criteria, and codes	• Discrete data • Range 0-16Slider indicates the number of teeth in each arch • Not assessed (Code = 97) • Upper and lower are scored separately
Instructions	• Use light source • Ask participant to open their mouth • Systematically count the number of teeth in one arch from one side to another. • Repeat for the other arch. • Record observations for upper and
Tips	• A tooth should be considered present when any part of it is visible. • Tooth count includes false teeth that are fixed such as crowns, bridges. • Tooth count excludes removable dentures. • Code each arch separately

Examples

How many teeth do you count?



9



12



11



0

Item 5: Cavitated teeth

Item 5

Cavitated Teeth

MOSST

Concept

Cavitated teeth

Item

How many visibly cavitated teeth are present?

Definition

The number of teeth with one or more cavities due to caries (decay), which can be detected by visual examination. Cavitation due to caries means a hole in a tooth due to tooth decay, where there is obvious breakdown of enamel creating a hole, leaving the underlying dentine visible and the underlying dentine is discoloured. When this occurs on the root surface, the dentine will be exposed and discoloured. In either instance, the underlying dentine is a different colour to the rest of the tooth- usually shades of brown.

Display

☐ E8

E8: Cavitated Teeth
 How many visibly cavitated teeth are present?

☐ 3 or more (0)
☐ 1-2 (1)
☐ None (2)
☐ Not assessed (97)

Categories, criteria, and codes

Category	Criteria	Codes
3 or more cavitated teeth	3 or more teeth with visible decay that is cavitated	(Code = 0)
1-2 cavitated teeth	1 or 2 teeth with visible decay that is cavitated.	(Code = 1)
None	No teeth with visible decay that is cavitated	(code=2)
Not assessed	Not assessed	(Code = 97)

Instructions

- Using a light source
- Ask the participant to open their mouth, use dental mirror to retract the cheek.
- Use gauze to clean and dry teeth surfaces.

- Check the upper teeth from one side to another (systematic manner).
- Check all surfaces of teeth.
- Count the number of teeth with cavitated carious lesions
- Do the same for the lower teeth.
- Record the box that corresponds to the total number of decayed teeth on the form.

Tips

- This is a count of **teeth** with cavities, not a count of cavities themselves: a tooth with two (or more) cavities is still counted as one cavitated tooth.
- Holes next to fillings may be counted as cavities when they meet the definition above.
- This is a visual examination only
- This category excludes non-cavitated carious lesions.
- On root surfaces, the dentine will be exposed and discoloured. The underlying dentine must be exposed and a different colour to the rest of the tooth- usually shades of brown.
- If no teeth- score as Not assessed

Example

1-2
cavitated
teeth



Note the breakdown of enamel on the side of the tooth. There is a silver filling. That does not affect the score.

Item 6 Gum Health

Item 6 Gum Condition **MOSST**

Concept Gum condition

Item Are the gums healthy?

Definition The presence or absence of gingival redness, swelling, and/or bleeding

Display

☐ E7

E7: Gum Condition
 Are the gums healthy?

☐ No (0)
☐ Yes (1)
☐ Not assessed (97)

Categories, criteria, and codes

Category	Criteria	Codes
No	Redness, swelling, bleeding of the attached / free gingiva in any area of the mouth.	(Code = 0)
Yes	Gums are Pink, moist, no bleeding on gums / under dentures	(Code = 1)
Not assessed	Not assessed	(Code = 97)

Instructions

- Using a light source
- Ask the participant to open their mouth, use dental mirror to retract the cheek
- Clean debris with gauze where necessary.
- Observe the appearance of gum above the teeth, in between the teeth, on the ridge where there are no teeth and on the area under dentures.
- If NO teeth: score as NOT ASSESSED

Tips

- The term gums relate to the attached / free gingiva.
- This is a whole mouth score: If any part of the gingivae is inflamed, score as No
- If in doubt score Yes

Examples

Yes



Healthy gums

No



Red, swollen gum

Red, swollen gum

Item 7

Oral Cleanliness

MOSST

Item 7 Oral Cleanliness

Concept	Gum condition
Item	Are the participants' mouth / dentures clean?
Definition	The presence or absence of food particles and plaque in the mouth or on dentures.
Display	

☐ E6

E6: Oral Cleanliness
 Is the participants' mouth / dentures clean?

☐ No (0)
☐ Yes (1)
☐ Not assessed (97)

Categories, criteria, and codes

Category	Criteria	Code
No	Not Clean: Obvious food particles, plaque in mouth or on dentures	(Code = 0)
Yes	Clean: No obvious food particles, plaque in mouth or on dentures	(Code = 1)
Not assessed	Not assessed	(Code = 97)

Instructions	- Using a light source - Ask the participant to open their mouth, use dental mirror to retract the buccal cheek, systematically visualise all surfaces of all teeth. - Check for presence of food particles, and plaque on the teeth surface. - Check/ examine dentures too.
Tips	- This item does not include tartar; the hard debris attached to the tooth. This cannot be rubbed off with a gauze. - If food debris from meal is present (even after lunch!) score NO

Examples

**No:
Not Clean
(Code 0)**



**Yes:
Clean
(Code 1)**

- **Code 1 means...**
 - clean and no food particles or plaque in mouth or dentures



Tinsley College Dublin, The University of Dublin

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MOSST Self- Report Supplement

Self Report Supplement

MOSST

Introduction

This protocol is recommended for the Self Report Supplement (MOSST-SRS). The development team promote the sharing of the MOSST-SRS under Creative Commons Licensing. Items were generated through a combination of researcher content selection and input from a PPI panel from the IDS-TILDA study. All PPI panellists had intellectual disabilities and conveyed what they felt was most important to capture in data collection. Content was then scraped from computer assisted personal interview and national oral data collection surveys in UK and Ireland, with modification as indicated by PPI panel and content development team. The MOSST SRS is designed for adults, who are traditionally excluded from oral health data collection, such as people with disabilities. To support participant inclusion, easy-read resources are available.

Concepts	The MOSST-SRS collects data on selected aspects of oral healthcare utilization, oral health behaviours, and oral health related quality of life.
Instructions	Undertake the MOSST SRS after the MOSST Health Evaluation Survey OR at a separate time The researcher reads the items out loud to the participant and reads out answer options. Participants can also read items as per preference. Data can be gathered via paper (form-based data collection) or online, for example, on Qualtrics. If needed, support can be sought from friends, staff or family member, with consent. Data collectors are encouraged to adapt their explanation of items, or use augmentative communication as required for each participant
Tips	Items can be adapted with examples and simplified language for ease of understanding. Items can be adapted for ease of use when asking the questions (self-report) to people with intellectual disabilities or cognitive impairment. Additional questions can be adapted to gather further data as required as per researcher needs



MOSST Self Report Supplement (SRS) v0.1

Interviewer administered survey. See Protocol for instructions

Participant number	
Data collector code	
Date	

SRS Question 1

How will this survey be completed?

		Code
Self-Report Only	☐	1
Self-Report and Proxy	☐	2
Proxy Only	☐	3

Demographics items to be added here as per use of survey

Oral Health Service Use (SU):

SU Question 1

Which of the following best describes your oral health service use (e.g. going to the dentist or dental hygienist):

I/[He/She] go to the dentist at least once every year	☐	1
I/[He/She] go to the dentist at least once every two years	☐	2
I/[He/She] go to the dentist less often than once every two years	☐	3

I/[He/She] only go to the dentist if there is a problem (e.g. a tooth hurts)	☐	4
I/[He/She] never go to the dentist	☐	5
Not answered	☐	97

Source (Adapted from IDS-TILDA)

SU Question 2

When you need a routine dental visit who do you visit? (Select best option)

An HSE dentist	☐	1
A MEDICAL CARD dentist or dental hygienist	☐	2
A PRIVATE dentist or dental hygienist	☐	3
Other*	☐	4
Not answered	☐	97

*Please specify

Source: (Adapted from IDS-TILDA)

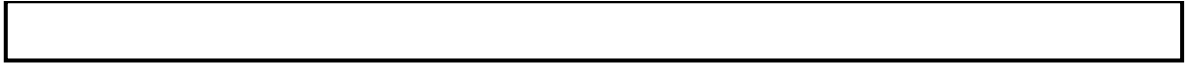
SU Question 3

When you get dental treatment (e.g. a filling), which of the following do you need?

(Select best option)

I/[He/She] only need local anaesthesia (e.g. just numbing).	☐	1
I/[He/She] need Nitrous oxide (e.g. laughing gas)	☐	2
I/[He/She] need Oral sedation	☐	3
I/[He/She] need IV sedation	☐	4
I/[He/She] need General anaesthesia (e.g. fully asleep)	☐	5
Other*	☐	6
Not answered	☐	97

*Please specify



Source (Adapted from IDS-TILDA)

Barriers to care

SU Question 4

What barriers make it difficult for you to access your dentist or dental hygienist? (Yes/No answer options)

		Yes (1)	No (0)	Not answ ered (97)
4	I/ [He/she] cannot find a dentist who is willing to treat me	☐	☐	☐
.				
1				
4	The dentist does not have facilities to treat me (e.g. wheelchair tilter, general anaesthetic)	☐	☐	☐
.				
2				
4	The dentist does not have training to treat me	☐	☐	☐
.				
3				
4	The dentist does not give me/them enough time at my appointment	☐	☐	☐
.				
4				
4	There is a long waiting list to see my dentist	☐	☐	☐
.				
5				
4	The dentist is too expensive	☐	☐	☐
.				
6				
4	It is difficult for me to accept dental treatment	☐	☐	☐
.				
7				
4	It is difficult for me to travel	☐	☐	☐
.				
8				
4	I/ [He/she is] am afraid of the dentist	☐	☐	☐
.				
9				
4	I/ [He/she has] have no difficulty accessing my dentist or dental hygienist	☐	☐	☐
.				
1				
0				
4	Other*	☐	☐	☐
.				
1				
1				
4	Not answered	☐	☐	☐
.				
1				
2				
4	*Please specify:			
.				

1
3

Source (Adapted from D’Addazio et al, 2021)

SU Question 5

How easy is it to get a dental appointment when you need one? (Select best option)

Very Easy	☐	1
Easy	☐	2
Hard	☐	3
Very hard	☐	4
Not answered	☐	97

Source (Adapted from IDS-TILDA)

Oral Health related Quality of Life (QoL)

QoL Question 1

Have you had (signs of) pain from your mouth in the last week? (Select best option)

Yes (as suggested verbally)	☐	1
Yes (as suggested behaviourally or physically)	☐	2
No	☐	3
Not answered	☐	97

Source (Adapted from IDS-TILDA)

Researcher prompt Oral pain suggested by behavioural signs (such as refused eating or certain food, chewing lips, pulling at face, aggression and self-injurious behaviours related to oral manipulation or function) or physical signs (swelling of cheek or gum, broken teeth, ulcers) in the last week

(OSST, Mac Giolla Phadraig et al, 2021)

QoL Question 2

Do you have any difficulty chewing? (Select best option)

No	☐	1
Yes, with some type of food	☐	2
Yes, with all types of food	☐	3
Other*	☐	4
Not answered	☐	97

*Please specify

Source (Adapted from IDS-TILDA)

QoL Question 3

How do you feel about your smile? (Select best option)

Very happy	☐	1
Happy	☐	2

Unhappy	☐	3
Very unhappy	☐	4
Not answered	☐	97

Source (Adapted from OHIP-14)

Beh Question 1

**How often do you brush your teeth or dentures (OR have them brushed)? OR
(how often do you clean your mouth/have it cleaned for you?)**

Once or more a day	☐	1
2 to 6 times per week	☐	2
Once per week	☐	3
Less than once per week	☐	4
Never	☐	5
Not answered	☐	97

Source (IDS TILDA)

Beh Question 2

What best describes the help you get from someone else to clean your teeth?

I/[He/She] clean(s) teeth without help (can include prompting, reminding, supporting)	☐	1
I/[He/She] clean(s) teeth with a little help (e.g. physical guidance, shared brushing)	☐	2
I/[He/She] clean(s) teeth with a lot of help (e.g. all brushing by carer)	☐	3
I/[He/She] do [does] not clean my/their teeth	☐	4
I/[He/She] do [does] not have any teeth to clean	☐	5
Not answered	☐	97

Source (IDS TILDA)

Beh Question 3

Do you have a mouthcare plan?

Yes	☐	1
No	☐	2
Don't know	☐	3
Not answered	☐	97

Source (Adapted from IDS-TILDA)

*Researcher prompt: A mouthcare plan is a specific document outlining a set of planned oral health behaviours on behalf of, and with, a person who needs support toothbrushing, flossing, arranging dental visits, denture care, etc.

Beh Question 4

How many times a day do you eat sweet foods or drink sweet drinks (such as biscuits, cakes, sweets, Coca-Cola, Pepsi cola, 7UP, tea with sugar etc.) between your meals? (Select best option)

Never	☐	1
Once a day	☐	2
Twice a day	☐	3
Three times a day	☐	4
Four times a day	☐	5
Five-times a day	☐	6
Six times a day	☐	7
Seven or more times a day	☐	8
Not answered	☐	97

Source (Whelton, 2007)

END SRS Question 1: Is there anything else you would like to tell us about your oral health?

End of Survey



MOSST Health Evaluation Survey v1.0
See Protocol for instructions

Participant number

Data collector code

Date

Tick if repeat
measure

1 Functional Tooth units

How many pairs of **Functional Tooth Units (FTUs)** are present? (Please circle)

0 1 2 3 4 5 6 7 8 9 1 1 1 ☐
0 1 2

Not Assessed (97)

2 Front Twelve Teeth

Are the participant's **Front Twelve Teeth** present?

No (0)

Yes (1)

Not assessed
(97)

☐
☐
☐

3 Dentures

Is the participant wearing **Dentures** now?

	No (0)	Yes (1)	Not assessed (97)
Upper (3a)	☐	☐	☐
Lower (3b)	☐	☐	☐

4 Tooth count

How Many Teeth are in each arch? (Please circle)	Not assessed
Upper arch	97
Lower arch	97

5 Cavitated Teeth

How many visibly **Cavitated Teeth** are present?

None (0)	1-2 (1)	3 or more (2)	Not assessed (97)
☐	☐	☐	☐

6 Healthy Gums

Are the **Gums Healthy**?

No (0)	Yes (1)	Not assessed (97)
☐	☐	☐

7 Oral Cleanliness

Is the participants' **Mouth / Dentures Clean**?

No (0)	Yes (1)	Not assessed (97)
☐	☐	☐

8 Comments (optional)

End of Survey