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Feasibility of the Echolight Device for Bone Health Assessment among Adults with Intellectual Disability

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Executive Summary

This study evaluated the feasibility and applicability of the Echolight Radiofrequency Echographic Multi Spectrometry (REMS) device as an alternative bone health screening tool for individuals with intellectual disabilities. Traditional DXA scans, although the gold standard, are often inaccessible to this population due to mobility, behavioural, anxiety, and communication challenges. The Echolight device offers a portable, non-invasive solution that can be used in diverse settings, including people's homes and community residences. The study involved 81 participants across four service providers in Ireland, representing a range of intellectual disability severities from mild to profound. The feasibility criteria of recruitment, assessment completion, procedural adherence, and positive participant feedback were set to establish feasibility.

In total there was a 96% engagement rate, and 94% of participants were willing to recommend the screening to others. All participants said they had sufficient information to engage in the assessment which was made possible through reasonable adjustments such as easy-read information, flexible scheduling, and home-based assessments which are all critical in facilitating inclusion and ease of participation. This alternative screening method addresses the significant gap in osteoporosis detection and management evident in people with intellectual disabilities, many of whom remain undiagnosed and untreated despite high fracture risk. The Echolight device's accessibility and demonstrated acceptability mark a significant advancement in equitable healthcare provision.

Importantly, this study directly supports and aligns with the Irish Government's recently launched National Human Rights Strategy for Disabled People 2025-2030. By promoting accessible, person-centered bone health screening, this research advances the Strategy's commitments to equity, accessibility, and inclusion under pillar 4 wellbeing and health for disabled people. Implementing such innovative and tailored screening approaches is a vital step toward reducing health disparities, promoting prevention, and enhancing the wellbeing and quality of life for people with intellectual disabilities and other underserved groups.

"Inclusion is not about making room, it's about recognising that everyone already belongs"

Special Olympics 2025

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Acknowledgements

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Introduction

Introduction

1.0 Osteoporosis and people with intellectual disability, state of the science

Osteoporosis is a progressive bone disease characterised by low bone mineral density (BMD) and microarchitectural deterioration leaving bone susceptible to fragility fractures (WHO 2004). Due to the silent nature of the condition, many people are unaware of its presence until perhaps they experience their first clinical fracture (Sabri et al 2022). Dual-energy X-ray absorptiometry (DXA) is the gold standard for assessing bone density and establishing bone status, that is, the presence or absence of osteopenia or osteoporosis (WHO 2004). However, DXA does not always suit people with intellectual disability due to requirements for people to remain completely still during the assessment procedure which can be particularly challenging for individuals with intellectual disability who may experience difficulties with movement control, understanding instructions or positioning requirements that necessitate specific body alignment. This is particularly true for those with more severe to profound intellectual disability who often present with more complex comorbid conditions such as scoliosis, contractures or physical abnormalities that prevent them from lying in the correct anatomical position necessary for DXA scanning (Fritz et al 2021). Additionally, the machine itself creates significant barriers due to the physical design limitations of the scanners such as fixed table heights, lack of hoist or patient transfer or lifting options, and narrow scanning surfaces (Barrington et al 2025, Doherty et al 2020). Furthermore, the anxiety associated with unfamiliar medical environments, the inability to comprehend complex instructions, and communication difficulties often lead to non-compliance during DXA procedures, resulting in either inaccurate measurements or complete inability to perform the scan (Krahn et al 2006). This may explain the low levels of DXA uptake reported in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (Burke et al 2023a).

However new technology has been developed for the evaluation of skeletal health such as the GE Lunar Achilles [Qualitative Heel Ultrasound (QUS)] (Hans et al 2022) and more recently the Echolight REM device (Betancur et al 2025, Pisani et al 2023). Both of these offer low cost, radiation free and alternative methods for bone screening when DXA scanning is not suitable for the user. That said the QUS whilst validated by the International Densitometry Society (Hans et al 2022) is not diagnostic and has ceased production since 2024. However, Echolight

REM is more promising and has been hailed as revolutionary for both the establishment of bone quality and for its diagnostic feature (Pisani et al 2023).

1.1 Background:

Osteoporosis is a significant concern among individuals with intellectual disabilities. The prevalence is notably higher and manifests at an earlier age in this demographic due to multifaceted reasons such as comorbid health complications, extensive medication usage, and inadequate emphasis on bone health promotion throughout their lifespan (Carmeli and Imam 2014, Burke et al 2023b, Odalović et al 2023).

Osteoporosis is emerging as an issue as evidenced in the IDS-TILDA study whereby reports on the prevalence of doctor-diagnosed osteoporosis ranged from 8.1% to 19.8% across 15 years of data collection (Burke et al 2023a). However, these rates are likely underestimated when results of Wave 5 [2023] objectively measured bone health assessment are considered. IDS-TILDA indicated that 32% of participants fell within the osteoporotic range, whereas only 19% reported a doctor's diagnosis (Burke et al 2023a). Coupled with this, a further 27% were recognised within the osteopenic range (Burke et al 2023a). The probable rationale for this variance is multifaceted insofar as people with intellectual disability can present atypically resulting in osteoporosis going unrecognised which ultimately increases their risk of fracture (McNabb 2018, Winterhalder and Shankar 2022). Risk factors differ to the established risk factors in the general population (Burke et al 2024). Studies have shown factors such as poor mobility, level of intellectual disability and specific medicines impacting negatively on bone health such as antiepileptic medications or proton pump inhibitors which are highly prevalent, along with syndrome specific associations like Down syndrome and the complexity of multimorbidity (Burke et al 2024, Burke et al 2018, Vince et al 2015). All culminating in a potential increased presentation of osteoporosis and attests to the complex nature of establishing bone health among this cohort (DiStefano et al 2020, Krahn and Fox 2014). However, one of the major contributors to the condition going unrecognised is poor assessment and inequity in access to screening (Krahn et al 2006).

Along with presenting risk factors, diagnosis is often times, dependent on bone mass t-score from DXA, which is recognised as the gold standard (WHO 2004). As previously alluded to, DXA does not always suit people with intellectual disability (Finlayson et al 2019). Research

from the IDS-TILDA study indicates inadequate attendance for diagnostic DXA screening with Power (2023) identifying limited engagement in DXA screenings particularly evident among those with severe/profound intellectual disability. Power (2023) noted that only 14% of those with severe/profound intellectual disability could effectively participate. This alarming discrepancy results in an 86% unavailability for essential bone screening, despite the high risk for developing osteoporosis and the multiple complex health status of those with severe/ profound intellectual disability. Literature echoes these findings, attributing the challenges to physical abnormalities, behavioural issues, and communication barriers all of which make it difficult for an accurate scan to be conducted, leading to potentially underdiagnosis and delayed treatment (Srikanth et al., 2011; Burke et al., 2019; Finlayson et al., 2018). The suboptimal access to bone health screenings within this population along with limitations of DXA for people with intellectual disability demonstrates it is not always a feasibly diagnostic tool to use amongst this population and further increases the potential risk of future fracture. This disparity underscores the critical need for accessible and feasible bone screening methods to diagnose, manage and treat osteoporosis.

1.2 Echolight REMS and justification for the study

Echolight REMS stands as an innovative technology that can address this disparity, utilising Radiofrequency Echographic Multi-Spectrometry (REMS) to measure bone mineral density (Adami et al 2020, Cortet et al 2021). Echolight REMS is a non-ionising, portable technology that uses ultrasound-based analysis to assess BMD at key skeletal sites, such as the lumbar spine and femoral neck, with a diagnostic accuracy comparable to DXA (Pisani et al., 2021). Unlike DXA, it does not require individuals to lie still on a scanning table or be exposed to radiation, making it more suitable for individuals with physical or cognitive limitations, autism, behavioural support needs, or sensory sensitivities (Zambito et al 2025). The feasibility of Echolight REMS in populations with intellectual disability is particularly promising. Its portability allows the device to be used in familiar, community-based settings such as day services or residential care environments, reducing the need for travel to hospital-based radiology departments. The scan itself takes only a few minutes and is painless, quiet, and requires minimal cooperation thus facilitating assessments even among those who might be unable to tolerate other forms of screening.

A presentation was made to the Irish Osteoporosis Society (IOS) in October 2023 highlighting the potential of Echolight as a viable alternative screening device for individuals with intellectual disabilities, who face challenges accessing DXA screening. The IOS considered this possibility favourably however noted without a feasibility study they would not include alternative screening in their recommendations. Therefore, the need for a feasibility study to establish the potential for a more feasible and accessible bone screening pathway, was necessary among people with intellectual disabilities The European Society for Clinical and Economic Aspects of Osteoporosis, Osteoarthritis and Musculoskeletal Diseases (ESCEO) and the Food and Drug Administration (FDA) have approved Echolight as a viable bone health diagnostic device but there is currently no research assessing its feasibility in people with intellectual disabilities.

1.3 Rationale for the Study:

This feasibility study therefore sets about establishing the user friendliness, flexibility, acceptability and practicality of using the Echolight REMS device as an alternative accessible bone health screening tool for people with intellectual disability. Having an alternative accurate device for bone screening for people with intellectual disability would contribute to

- Improvement of bone health assessment
- Reduction in the risk of fracture and subsequent negative mobility consequences
- Reduction in costs both personal and financial
- Improvement in prevention, management and treatment of osteoporosis
- Aligning with the rights of those with disability to accessible assessment

The integration of the Echolight screening device presents an opportunity to revolutionise bone health assessments for individuals with intellectual disabilities, and the establishment of the device's feasibility holds multifaceted benefits, transcending mere diagnostic capabilities. It will of course improve bone health assessment, particularly for those who are unable to access DXA, those with mobility compromise, people with severe/ profound intellectual disability, those with multiple complex health need, anxiety or challenging behaviours issues, those who are anatomically challenged, those with communication challenges and those who are unable to tolerate conventional procedures. The promise of recognising the Echolight REM technology as a viable screening assessment for bone health

among people with intellectual disability could potentially lead to nationwide implementation for this high-risk cohort, allowing for the prompt initiation of treatment plans and interventions. Having a tool that can detect and diagnose osteoporosis early could potentially mitigate the risk of fragility fractures, the deleterious consequence of osteoporosis. The current economic burden stemming from the cost of fractures and subsequent rehabilitation programs among individuals with intellectual disabilities, service providers, and the state, is substantial (Whitney et al 2022, Frighi et al 2022, Ispsen et al 2024). The implementation of Echolight holds the promise of alleviating this burden by reducing the incidence of fragility fractures through early detection and intervention. This proactive approach not only ensures better health outcomes but also mitigates the need for avoidable hospital visits. This not only translates into economic savings but also fosters a more holistic and supportive societal framework that prioritises the well-being and health outcomes of individuals with an intellectual disability. Subsequently the personal costs, pain and suffering, are avoided.

Beyond diagnostic benefits, the integration of this device advances the rights of people with intellectual disabilities (Irish Statute Book, Disability Act 2005). It aligns with Article 25 of the UN Convention on the Rights of Persons with Disabilities and with the Irish Disability Act (United Nations, UN 2006), which emphasise the right to the highest attainable standard of health without discrimination. Ensuring equitable access to screening through technologies like Echolight represents reasonable adjustment under these frameworks, enabling earlier identification of osteoporosis and timely initiation of management strategies. Accessible bone health screening inherently aligns with international human rights standard and, by fostering inclusivity and offering reasonable adjustments to a marginalised group timely access to diagnostic procedures and subsequent therapeutic interventions are ensured. The implementation of the Echolight REMS device could also have the benefit of streamlining waiting times in bone health assessment healthcare delivery, facilitating early detection and interventions ultimately mitigates the risk of fragility fracture occurrence.

The completion of this feasibility study holds the promise of recognising the Echolight REMS device as a viable and accessible bone screening device for individuals with intellectual disabilities. It offers a tremendous opportunity to address longstanding barriers in osteoporosis screening for people with intellectual disability. This alternative bone health screening device presents the potential of improving equitable health outcomes for a

population too often left out of preventative health initiatives. Adopting this technology, with appropriately adjusted and supported methods, has the potential to lead to better health outcomes, lower fracture risk, and a more inclusive healthcare system that truly meets the needs of all ensuring timely access to assessments and empowering early interventions.

1.4 Aim and Objectives:

The overall aim of the project is to comprehensively evaluate the applicability and feasibility of using an alternative bone health assessment system, namely the Echolight REM. To achieve this aim, the team subdivided the overall aim into two specific objectives as follows:

1.4.1 Objectives

- To engage over 70% of participants in an adapted screening process.
- To address any issues immediately to ensure reasonable adjustments
- To establish participants opinions on the supports and information before the scan and, their opinion following completion of the scan.
- To evaluate suitability across different levels of intellectual disability.

1.5 Conclusion

Osteoporosis is an issue for people with intellectual disability. Detection and access to appropriately adjustable screening services appear to contribute to this issue. Echolight REMs technology offers a solution to this however its feasibility, acceptability and a reasonably adjusted method to conduct and engage people with intellectual disability has not been established. This study aims to address this, the following chapter presents the study design and methods to address the aim and objectives of this study.

Methods

Methods

2.0 Introduction

Having robust and well-designed methods is essential to all research projects to ensure the validity and reliability of the findings (William, 2024, Coleman 2022). A solid methodological framework strengthens the credibility and ensures the conclusions are based on sound evidence therefore enhancing the impact and applicability of the overall research. In this study careful consideration and consultation with experts including those with lived experience of intellectual disability adds to the robustness of the overall study.

2.1 Study Design

A comprehensive and multi-dimensional methodology approach was incorporated to collect data using qualitative narratives, quantitative metrics, clinical outcomes, and stakeholder perspectives. This involved a process-effectiveness design through a phased approach to establish the feasibility of the Echolight REM device to enable screening assessment with people with intellectual disability. This study design enabled assessing the efficiency and impact of the assessment process to ensure the most effective practices were employed that would lead to the desired outcome i.e., that the process of establishing bone health using the Echolight REMs device would ensure sufficient reasonable adjustments and that the screening process would be acceptable to people with intellectual disability.

2.2 The Phased Process

The project unfolded in four meticulously planned phases, beginning with 1). Refining the study design and Public and Participant Involvement (PPI). 2). Preparation and recruitment which involved liaising with the service providers, developing the survey and accessible materials, devising the reasonable adjustments for the Echolight REM procedure, ethics and supported decision-making preparations, along with planning logistics for data collection. 3). Data collection in the field. 4) Data analysis, involving the PPI contributors, preparing summaries and reports. Overall ensuring this phased approach aligned with the team's inclusive research principles ensuring collaboration and participant empowerment.

2.2.1 Refining the study design

Initially the team liaised with the PPI panel from the Trinity Centre for Ageing and Intellectual Disability (TCAID). This ensured the PPI panel informed the study priorities and design early

and contributed to the relevance and accessibility of what the study was about and how it was being conducted. Co-produced research, making sure the research materials and methods were developed collaboratively, promotes inclusivity and ensures all stakeholders get practical value from being involved in the research (Hewitt et al 2023). At this stage collaborative decisions were made regards participant profile, services to invite and establishing a gatekeeper approach to contacting potential participants. The following participant inclusion criteria was confirmed.

Participants: The team aimed at including adults across all levels of intellectual disability. Therefore, the inclusion criteria encompassed:

- Adults aged over 18 years
- People with a diagnosis of an intellectual disability
- All levels of intellectual disability [mild, moderate, severe or profound]
- People of all ethnicities
- In receipt of services in the participating service providers.

Service Invitation and gate keeper process: In total four services from across Ireland were invited to participate in the study. This provided the team with a diverse range of service models. The services were across Ireland thus providing variation of geographic location and the spread also captured a broad spectrum of service user experience from a variety of health service locations. The involvement of multiple providers ensured the team include people with different levels of intellectual disability from mild to severe/profound. Representing this variation, particularly those with complex needs, ensured that the research reflected the complexity and varied supports and expertise needed to engage participants, and the contributions needed from community to residential settings, overall enriching the study's outcomes and its impact and relevance. Each service involved confirmed a gatekeeper for the study which supported the team to access service sites, provided invaluable advice on times, locations and ethical procedures and supported the research team with logistics and concerns including reducing disruption to the service users whilst promoting their inclusion in the research. Overall, the Gatekeepers facilitated effective access to the participants by endorsing and vetting the research which contributed to the building of trust between the researchers and service users and ensured ethical standards were maintained.

2.2.2 Preparation and Recruitment

The team developed pre and post survey questionnaires following extensive literature review, PPI collaboration and expert consultation. These concise pre and post questions would establish the baseline knowledge of participants, their needs and experience of assessment, their expectations and concerns and provide us with contextual information about demographics to ensure the study objectives were answered. These questionnaires were developed as easy read and also reviewed by our PPI panel for content, flow and accessibility and to make sure the team would be able to establish change in attitude, and satisfaction with the experience. Overall, they would be pivotal in providing valuable feedback on experience, how the process could be improved and overall evaluate the impact of the bone health assessment using the Echolight REM device. The questionnaires would enable comparative insights to emerge. It was essential for the team to have a strong integration of reasonable adjustments at every stage of the study from facilitating questions, to explaining procedures, to obtaining ethics, to providing results in easy read form, this encompassed the comprehensive accessible participation methodology embedded in the study.

Comprehensive Accessible Participation Approach: From the initial consultation with the PPI panel the team integrated their opinion throughout the study to ensure the inclusionary principles were operationalised. The PPI panel, involving people with an intellectual disability advised on modifications to the project protocol and reviewed all material for accessibility and relevance to the project. The team's underpinning philosophy was an emancipatory philosophy which replicated the approach team members held for the engagement of people with intellectual disability in the research objective health measures in the IDS-TILDA study, see elsewhere for further details (Burke et al 2020). The PPI panel reviewed all easy-to-read accessible materials including the information booklet, consent form, appointment card, result card, pre -scan questionnaire and post evaluation survey and provided their expert by experience opinion on the effectiveness of all the accessible material. This approach ensured that the project aims, objectives, and the purpose of data collection was conveyed to all prospective participants in a transparent manner. Accessible and easy read materials were important to include appropriately as inclusion ensured maximum accessibility of materials. This ensured sufficient information was available for the person with an intellectual disability to empower them to make their own informed decisions regards their involvement in the

study, their understanding of the assessment procedure and reinforced with them opportunities to ask and get answered any questions they may have. To that end a total communication approach (e.g., using LÁMH), augmented communication tools, role play, and the implementation of reasonable adjustments were employed to ensure optimum understanding and participation was achieved. All questions in the survey questionnaires and procedural steps in the implementation of the Echolight REM screening had supporting pictorial representation.

Following the completion of their participation in the study, each individual received their results on an easy-to-read result card, if there were any anomalies identified this was highlighted with the participant and they were advised to note this with their GP. This clear and transparent approach ensured the participant knew what was expected.

Ethics: Ethics was applied for and granted by Trinity College Dublin Faculty Ethics Committee level 3 and all participating Service Providers ethics committees. A robust data protection assessment was conducted by the team which was reviewed and approved by the data protection office in TCD and those in the Services involved. As people with severe and profound intellectual disability would be involved in the study who may not have the ability to provide unsupported explicit consent, the team applied to the Health Research Consent Declaration Committee seeking a consent declaration. This was granted by the secretariat following careful review of application and consideration. Once all these aspects were in place the team were able to approach the Services involved and plan the data collection process. From inception through to development, and roll out of the study, the team rigorously adhered to all fundamental research ethical principles, including confidentiality, non-maleficence, veracity, beneficence, respect for persons (autonomy), and justice, ensuring the highest ethical standards were maintained throughout the research process.

Data Collection Logistics: Full details of the project were sent to the gatekeeper including easy-to-read accessible materials for dissemination to potential participants. This included an accessible cover letter, consent form and participant information booklet. Participants were given time to consider the information, minimum one week. Contact details of the project team were available on the participant information booklet, should a potential participant have any questions or further queries. This process ensured that prospective participants were informed about the project, could ask questions, and provide voluntary consent before their

involvement in the research. The consent process was reiterated on the day of their appointment, at this point a copy of the record of consent was provided to the participant for their own records. The team also wanted to encourage as many to participate as possible to be involved therefore appointment times were flexible to accommodate participants individual needs. Appointments were arranged to facilitate later times, or quieter periods of the day to minimise sensory overload allowing for a calmer environment or to accommodate participants work commitments or additional complex needs. Longer appointment times were also allocated to accommodate participants pace, reducing pressure, and allowing for breaks if required.

2.2.3 Data Collection

The research nurse underwent comprehensive training and certification on the use of the Echolight REM device. This ensured that the accuracy, reliability and credibility of the data collected was assured and errors and biases were minimised. This also enabled a comprehensive development of a standardised procedure. The team were then able to apply the principles of inclusion and person centredness to the procedure and integrate these into the overall process and adapt it to suit people with intellectual disability to ensure reasonable adjustments were made to promote engagement. One of the greatest benefits of the Echolight REM device is the fact that it is portable. The person with intellectual disability was able to have the screening in their own home, if preferred. Frequently attending an acute or primary care setting for any type of screening can be challenging particularly for those with more severe intellectual disability. Completing the procedure within a familiar environment, either in a person's home, day service or other service setting of choice, ensured there was a conducive environment which was familiar, private, respectful, and significantly minimised stress for the person, enhancing their comfort and reducing anxiety. The team developed a pre and post questionnaire to complement the overall process. This enabled them to capture both quantitative information, eg demographic profile of those participating, feasibility data eg number of successful completions and also qualitative data, opinion and comments from the participants. These tools were reviewed by experts and those with lived experience of intellectual disability.

Echolight REM Technology: The Echolight REM device is a non- invasive technology, free of ionizing radiation used to assess bone density and fracture risk (Echolight Medical 2025). The

scanning procedure is painless and less demanding in terms of patient positioning, time of scan and offers the convenience of being portable, compared to conventional DXA scan. In total the scan takes around two minutes. The assessments generate a report instantly and incudes all parameters most commonly used in diagnosis of osteoporosis such as BMD, T-score, Z-score and it also includes an independent assessment of the internal bone structure which provides a fragility index and body composition (Betancur et al 2025).

Echolight REM procedure: Two research nurses conducted the field data collection. Both were Registered Nurses in Intellectual Disability (RNID) who had extensive experience of supporting people with all levels of intellectual disabilities including those with communication challenges. To mitigate against potential sensory sensitives such as touch sensitivity issues or anxieties, participants were encouraged to hold the probe used and feel the conductive gel used during the ultrasound examination on the back of their hand prior to scanning. Participants were encouraged to have the support of a familiar person such as a family member, support worker, carer, or friend with them. The presence of this support person helped ally any fears, provided reassurance and encouraged participants to relax during the screening. The procedure took approximately 2 minutes. All explanations were supported with easy read materials and a total communication approach to support the individual's style of communicating was adopted. Screening took place in a familiar place of the persons choosing, full consent was obtained from the participant firstly and full explanations were given using the easy read material. The team knew that using these reasonable adjustments and ensuring a person centred approach would lead to greater success.

2.2.4 Data Analysis

A mixed methods approach was employed, combining both quantitative and qualitative data to obtain a comprehensive understanding of participant experiences and evaluation outcomes. Quantitative data were analysed using IBM SPSS software. Descriptive statistics were generated to profile the participants, calculate participation rates, satisfaction rates, and provide an overall evaluation rating of their experience. This allowed for a clear summary of key metrics related to the study population and their feedback and supported the establishment of feasibility. Qualitative data from open-ended responses were analysed using a thematic analysis approach, following the Braun and Clarke (2006) framework. Participants' opinions on their experience, their likelihood to recommend the scan, and their suggestions

for improvement were systematically coded to identify key themes. This qualitative analysis added contextual depth and rich insight into participants' views, complementing the quantitative results. By integrating quantitative summary statistics with qualitative thematic findings, the mixed methods approach enabled a robust evaluation of the scan experience, facilitating richer interpretation and actionable recommendations.

2.6 Feasibility Criteria

When considering the criteria for this feasibility study the team defined a number of key factors to ensure the study was well structured, yielded meaningful results and measured what was expected. This criteria included

- Recruitment rate
- Completion rate
- Adherence to the procedure
- Participant feedback

Recruitment rate: For this pilot feasibility study, a target sample of 100 participants was set. This would ensure reasonably precise estimates with a 95% confidence interval. The team aimed at achieving minimum 70 participants which is generally viewed as sufficient to enhance feasibility. This also ensured a practical approach within resource constraints.

Completion rate: A 70% success rate threshold to complete the full assessment including the pre and post questionnaires, the Echolight REM screening and providing their opinion on the overall procedure.

Adherence to the procedure: People of all levels of intellectual disability, over the age of 18 years in receipt of services with the four participating service providers were invited to participate. The total procedure included their expression of interest, providing informed consent/ assent via carer or family member in line with the HRCDC, completing the pre-interview questionnaire, completing the bone density screening and providing their experience and opinion post screening through the post-interview questionnaire.

Participant feedback: Would be captured by the research nurses and transcribed into their pre and post questionnaires where allowance for opinion was facilitated. These vignettes and comments were then transcribed into excel for analysis.

2.7 Conclusion

Overall, this study uses a robust approach to participant recruitment and data collection to ensure feasibility and methodological rigor. People with life experience of intellectual disability [PPI panel] were key in guiding the team in the development of the overall protocol, research design and the implementation of reasonable adjustments. The team were guided by the emancipatory philosophy underpinning the study and the procedures implemented were selected to provide robust, reliable feasibility metrics while maintaining ethical standards. These methods provide a strong basis for the subsequent analysis and interpretation of the study results.

Results

Results

3.0 Introduction

Following analysis, the key findings are presented from the feasibility study, focusing on recruitment and participant profile, preliminary feasibility outcome and overall participant ratings of the screening along with the qualitative data summarising the opinion and comments from participants.

3.1 Demographic characteristics of participants

Overall, 63.1% (n=53) of participants were female, with the majority of participants between the ages 40 – 64 years (62%, n=52). In total 43.2% of the women (n=30) reported having gone through or going through the menopause with a mean age onset 50 years. Full demographic details can be seen in table 1.

Table 1: Demographic profile (N=84).

Characteristic		Frequency (*n*)	Percentage (*%*)	Total
Sex	Female	53	63.1	84
	Male	31	36.9	
Age	<40 years	17	20.2	84
	40- 49 years	26	31.0	
	50 – 64 years	26	31.0	
	65 years+	15	17.9	
Level of ID*	Mild	24	29.6	81
	Moderate	35	43.2	
	Severe/Profound	22	27.2	
Cause of ID	Down syndrome	22	26.2	84
	Non-Down syndrome	62	73.8	
Menopause	Yes	30	35.7	
	No	22	26.2	
	N/A Male	31	36.9	
Mean age at menopause**		50.27 years (n=15, SD± 5.22, range 38 – 58 yrs)		

**missing obs. n=3*

***n=12 did not know age at menopause; n=1 missing ob.*

3.2 EchoLight Feasibility of Screening

In total out of the target sample size of 100 participants, 84 initially consented to take part in the study, representing an 84% recruitment rate. Ultimately, 81 participants completed the full assessment, as three individuals withdrew on the day of participation (see table 2 below). This completion rate supports the feasibility of the study's sample size and recruitment strategy of engaging at least a 70% participation rate. A small proportion (19.8% n=16) of participants expressed their anxiety prior to the assessment with all participants feeling reassured following engagement with the research team. One support staff noted "*he often finds it difficult to engage with diagnostics, it was good that he received the easy to read 7 days in advance so we could regularly talk him through and show him the pictures*". Participants themselves reported some anxiety when they remarked '*I was a little bit worries as I never had my bons checked before, I will now make sure to get my bones checked when needed*", another noting "*the nurses reassured me and gave me extra time during the appointment…"*. Many others had support from their carers' and the opportunity to discuss the appointment prior to arriving "*I wasn't a bit worried about the scan, we talked about it with my friends in the day services before coming to the appointment*". Having the information beforehand in an accessible format, having the support of their carers', the opportunity to ask questions and discuss prior to appointment, and providing extra time, supported participation and eased anxiety as evidenced in these quotes. Another aspect that emerged around anxiety prior to the assessment was location and time of assessment. Over 95% (n=81) reported the time suited them, many had busy schedules and reported that "morning appointment suited as I have activities in the afternoon", with another number noting that the scan was in their own home which also suited as many did not want to leave their home. This is evidenced by the following "*..it was great to have the scan completed in their own home which greatly helped to alleviate their anxiety*". Overall, participants noted that they were provided enough information to make a choice, and everything was explained well by the nurse. The following quote demonstrates this sentiment, *"It was much easier than going to the hospital to have it done, I would do the scan again.".* The majority noted that the scan was easy to do (96.3%, n=78) '*I liked everything, it was quick and easy to d*o", another noting "*it was grand, it didn't hurt*". However, 4.9% (n=4) noted some discomfort which was followed through by the nurses. It emerged early in the study that the gel felt too cold, adjustments were made by the nurses to let the participant experience the gel on their hand to take that initial cold shock away. This

reasonable adjustment addressed this issue. Overall, the vast majority of participants (93.8%, n=76) said they would recommend the assessment to a friend, "*I would tell my friends to get their bones checked", "it is good to know if your bones are healthy*" "*I would tell my friends that it wasn't sore or scary*". A support worker noted that "*Participant was previously unable to have a bone scan as they couldn't lie still for 15 minutes, we were unaware that she had osteoporosis*".

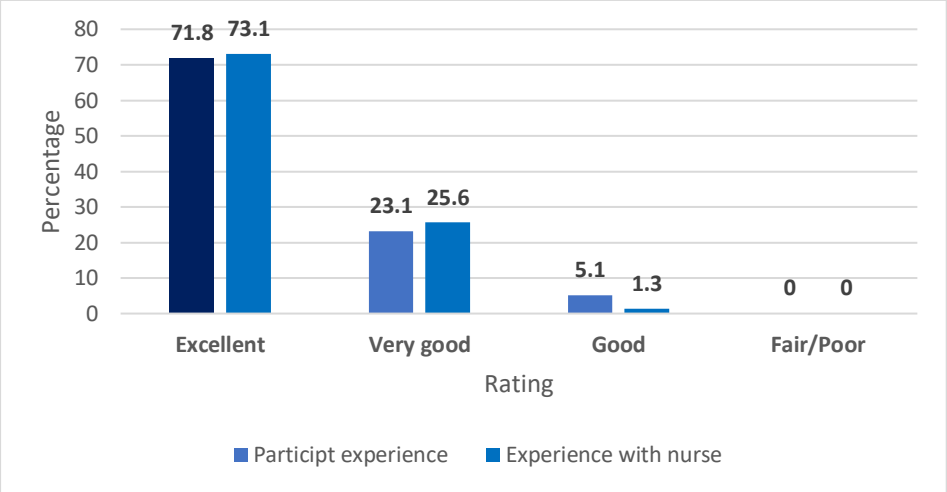
Table 2 Echolight (EL) Scan Participant Evaluation

Evaluation Question		n	%
Completed Echolight (EL) scan	Yes	81	96.4
Were you worried about the EL scan	Yes	16	19.8
Enough information to make a choice	Yes	81	100
Did the appointment time suit	Yes	81	96.4
Explained well by the nurse	Yes	81	100
Time given to ask to questions & get all answered	Yes	69	85.2
Was the EL scan easy to do?	Yes	78	96.3
Did you experience discomfort?	Yes	4	4.9
Would you tell your friends about the EL scan?	Yes	76	93.8

3.3 Echolight participant evaluation.

In total 81/84 participants completed the evaluation questionnaire following their scan and overall, the majority rated their overall experience of engaging in the procedure as excellent or very good (94.9% n=74) with the remaining reporting their experience as good (5.1%, n=4), see figure 1. No participant rated their experience as fair or poor. The following quotes provide supporting evidence of their overall experience of doing the screening and that of the procedure, "*It was good because people with an intellectual disability never get an opportunity to do research or do something like this, it was nice*", "*I found it good that the scan was done in my own bedroom at home because I worry when I have to go to the hospital".* The vast majority rated the nurse's performance during the appointment as excellent (73.1%, n=57), very good (25.6%, n=20) or good (1.3%, n=1) which is evidenced by the following vignettes: "*I wasn't rushed or hurried and the nurses took time to answer questions during my consent*", "*the nurses were very patient an with me, I felt comfortable enough to ask questions*

and I was given plenty of time I didn't feel rushed", "*I had 2 lovely nurses for my scan, I had enough time and the nurses were lovely to me".*



n=4 did not answer all questions
n=2 DNK

Figure 1 Evaluation of participant experience

Similarly, the majority were extremely happy or very happy to have gotten the scan done (95.9 %, n=76), see figure 2, with the remaining 3 participants noting they were happy with the scan being done. This is evidenced when one supporter noted "*it was brilliant to have an accessible alternative screening method, it is very accessible for people with ID*" and a participant noted "*it is important to get your bones checked to see if they are healthy. It would be great to have the scan done in the community and not have to go to hospital to queue and have it done, this was much quieter and relaxed, I was happy*".

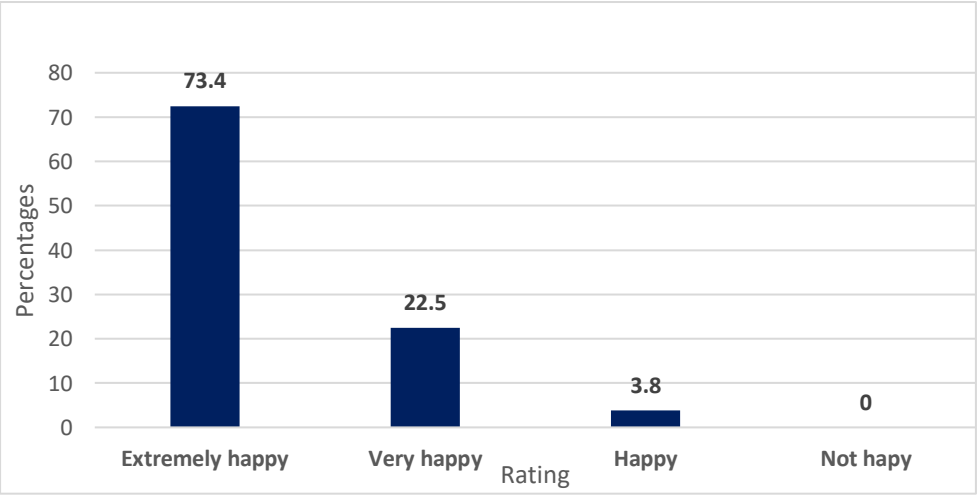


Figure 2 Rating their satisfaction in getting the scan done.

3.4 Overall opinion on screening with the Echolight REM

The final question of the evaluation explored the overall opinion of the participants on their experience doing the scan, what they felt were the best aspects, what could be changed or done differently and what they thought was good or bad about the Echolight REM device and getting the scan done. There were a total or 38 responses which were thematically analysed using the Braun and Clarke framework. The emerging themes can be viewed in figure 3.

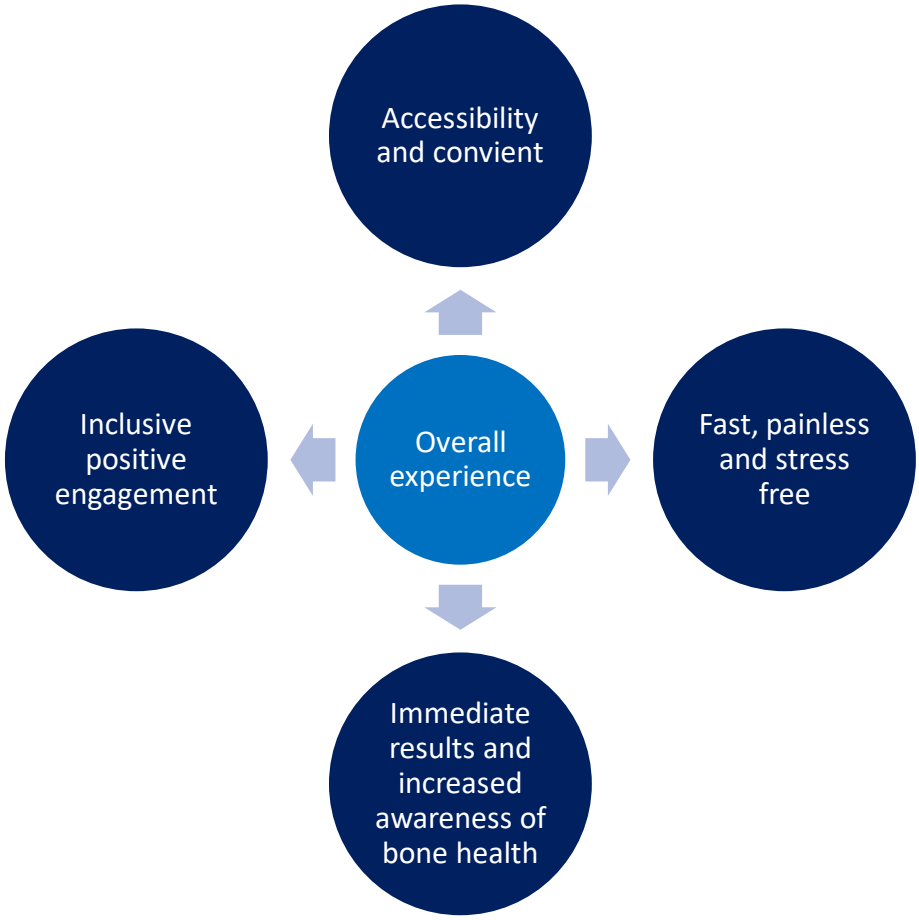


Figure 3: Participant opinion, emerging themes

Theme 1: Accessibility and convenient

Participants reported how easy and portable the device was compared to the traditional hospital based DXA scans. The fact that they could do it in their own home or in the community setting was greatly valued as it reduced the stress, the travel time and there were no long waiting times. In fact, the participants reported that there would be no need to go to the hospital which was beneficial as sometimes these settings can be overwhelming or inaccessible. Participants noted that their assessments in the acute setting could sometimes

end in failure particularly if they had difficulty lying still, or as staff noted, particularly for those with more severe/profound intellectual disability the Echolight REMS method however was far more feasible. Supporting evidence includes vignettes from both participants and support staff/family:

“Brilliant that we didn’t have to access acute/general services for a bone scan.”[participant]

“The Echolight scan was an easier option than DXA for people with ID.”[Staff]

Theme 2: Fast, painless and stress-free experience

Overall participants found that the simplicity and speed of the procedure highlighted the major benefits. A number of participants were delighted that it only took 2 minutes which made it easier for them to stay focused on what was happening, and they did not feel stressed. The majority noted that it was painless however there were a couple who felt that the gel was too cold and gave them a bit of a shock when applied, this was recognised early in the study and remedied with reasonable adjustments. Overall, they felt assured by the way the nurses explained what was happening and by their calm approach. This theme is evidenced by the following quotes:

“It was pain-free and very quick.” [participant]

“The scan was only 2 minutes, so he could engage easily with the procedure.”[staff/family]

“I wasn’t rushed at all, I liked it.” [participant]

"The gel felt a bit cold." [participant]

"Testing and feeling the gel on the hand before doing the scan helped, it was not as much of a shock when applied during the scan." [participant].

Theme 3: Immediate results and increased awareness of bone health

Participants were delighted to receive their results on the same day, being allowed to take home their results so that they could share it with their doctor. This made them feel more informed about their bone health. Several participants learned for the first time that they had poor bone health, increasing their awareness and giving them a sense of being able to engage in proactive health management. The following quotes exemplify the sentiments of this theme:

"It is important to have your bones checked, the scan was really quick and gives instant results."[participant]

"I got my results on the day to bring home to show my doctor." [participant]

"Without this device, she would have been unaware that she had osteoporosis." [staff/family]

"The nurses were patient and the environment was relaxed, [participant] was previously unable to have a bone scan, couldn't lie still for 15 minutes. [Participant] was unaware that she had osteoporosis." [staff/family]

"Don't need to lie in an exact position for the scan, it was ok if he moved slightly. The nurse was able to move the probe if he moved position. Results were given instantly"[staff/family]

Theme 4: Inclusive positive engagement for people with intellectual disability

The participants and supporters with them expressed appreciation for being able to be involved in the study. They were delighted with the accessibility of the scan which they saw as a positive for people with intellectual disability especially those who had previously been unable to engage in such healthcare procedures. Having the option for an alternative diagnostic device, especially for those who struggled with attendance at DXA, was extremely positive for the health of those with intellectual disability. Support staff and participants acknowledged the supportive approach by the nurses conducting the scanning and felt that their clear communication, use of accessible material and overall encouragement was inclusive. They felt that being able to do the scan in a familiar environment contributed to the overall positive experience. The following quotes support the sentiments in this theme:

"It was good because people with an intellectual disability never get an opportunity to do research or do something like this."[participant]

"I was happy with everything, it was efficient" [participant]

"The Echolight enables people with intellectual disability to have a bone scan if they cannot comply with DXA." [staff/family]

"[Participant] was very nervous before the scan but gradually you can see she became more relaxed throughout the procedure."[staff/family]

3.5 Conclusion

Overall, the Echolight REMS scan was perceived as an innovative, stress-free, and valuable healthcare option, particularly for individuals who had previously struggled to access bone health assessments. Providing a medical procedure that is supported by easy-to-read, accessible information plays a crucial role in facilitating understanding and reducing anxiety for individuals with intellectual disabilities. Allowing ample time for discussion prior to the assessment helps build familiarity and trust with the process, which can be instrumental in promoting cooperation and comfort. Additionally, making reasonable adjustments such as granting extra time, allowing the participant to see, feel and touch the gel and equipment during appointment and offering the option to complete the screening in the person's own home further supports a positive and accommodating environment. These modified approaches not only enhance the overall experience for individuals with intellectual disabilities but also contribute significantly to the success and accuracy of the assessment itself. By prioritising clear communication, personalised support, flexibility and alternative methods, healthcare providers can ensure that bone health screening are both accessible and effective for this population. Ultimately our goal is to achieve equity in healthcare by ensuring that people with intellectual disability have equal access to preventative services like bone screening, timely diagnosis to prevent disease and effective treatment to promote healthy bones and prevent fracture. Through this feasibility study we aimed to demonstrate that the Echolight REMS was suitable and acceptable for people with intellectual disability. The results show that the future is bright, Echolight REM presents an alternative diagnostic assessment to detect osteoporosis and thus address the health disparity that exists when those who need screening cannot avail of it. Overall fostering an alternative method of bone screening that is inclusive, person centered and adaptable, improves quality of life and long-term outcomes for people with intellectual disability.

Conclusion and Recommendations

Conclusion and Recommendations

4.0 Beyond the state of the science

Osteoporosis and osteopenia [poor bone health] are critical and under recognised concerns among people with intellectual disabilities, with prevalence rates reported to range from 8.1% to as high as 79% in various studies. For example, the IDS-TILDA study (N=753) found that only 8.1% had a diagnosed osteoporosis condition, yet only 18.6% had ever undergone bone mineral density testing (DXA), indicating significant underdiagnosis (Burke et al 2024). Smaller, focused studies report even higher rates of osteoporosis and osteopenia, with some populations, particularly those in long-term residential care or on certain medications showing rates up to 89% (Burke et al 2024). Despite this elevated risk, bone health screening remains substantially underutilised, with less than half of high-risk individuals undergoing DXA scans, and many fractures going undetected until after clinical events (Burke et al 2024). This gap in early osteoporosis detection is compounded by challenges in accessing traditional bone health assessments, which require the person to cooperate with specific positioning and stay still for a period of time, aspects which can be difficult for people with intellectual disability to manage compounded often with mobility difficulties. These barriers highlight the urgent need for alternative, accessible, and inclusive screening approaches.

Addressing this critical gap, the present study evaluated the feasibility of using the Echolight Radiofrequency Echographic Multi Spectrometry (REMS) device as an innovative alternative to traditional DXA screening. The study spanned diverse demographic groups and settings from day services and community residences to individuals' homes and the study included people across all levels of intellectual disability (mild, moderate, severe to profound). Grounded in an emancipatory philosophy that prioritised inclusion, public and patient involvement, and reasonable adjustments, this study demonstrated that the Echolight REMS device is a feasible and flexible tool for bone health screening among those with intellectual disability.

The flexibility to deliver home-based assessments supported by easy-read information and tailored communication resulted in a remarkable engagement rate of 96%. The majority of participants expressed satisfaction, with 73% reporting they were extremely happy and no participants reporting dissatisfaction. Additionally, 94% confirmed they would recommend the screening to a friend, underscoring the acceptability and success of this alternative

approach. The overall aim to comprehensively assess the applicability and feasibility of this alternative screening system was achieved, meeting predefined criteria including recruitment, completion, adherence, and positive participant feedback. This represents a significant advancement in accessible bone health assessment for people with intellectual disabilities, providing a practical pathway to address the documented health inequities in this vulnerable population and aligns with the current governments aims of the new National Human rights Strategy for Disabled People 2025-2030 (Department of Children, Disability and Equality 2025).

4.1 Strengths and Limitations

The screening procedure was well-received and worked effectively, demonstrating feasibility and acceptability within the intellectual disability population. The fundamental emancipatory principles applied within the study, the inclusion of a PPI consultation process prior to the study, ensured accessibility and consideration of the unique needs of participants with intellectual disabilities. Further, the use of home-based and flexible screening approaches along with the easy-read explanatories helped reduce participant anxiety and improved engagement, supported by strong nurse-patient communication and reasonable adjustments, fostering positive experiences and successful assessments. Additional strengths of the study include the fact that the data collected provides valuable insights to address gaps in bone health screening and promote equitable healthcare access for this vulnerable cohort.

With consideration to the breath of the study the team considered the sample size as relatively small and confined to participants from only four services, limiting the generalisability of findings. A fact that needs to be further explored and addressed. However, it has to be said that the restriction to a limited number of sites was driven by practical constraints such as cost, time, and resource availability. The screening was conducted by only two nurses, indicating a need for training more healthcare professionals to scale the service effectively. While inclusionary, there is always the possibility that the study may have missed individuals with more profound disabilities or greater health complexities due to recruitment or assessment barriers. Reliance on newer screening devices still requires further validation within this cohort compared to standard DXA testing, acknowledging technological and diagnostic limitations.

4.5 Implications for Practice

The portable, non-invasive bone screening device (Echolight REMS) offers a feasible alternative to traditional DXA scans for individuals with intellectual disabilities who face challenges with standard bone density tests due to mobility, anxiety, anatomical or behavioural difficulties. Opening an alternative avenue for improved bone health for all people with intellectual disability. However, it must be accompanied with reasonable adjustments. Implementation of accessible screening technologies in community or home settings allows for reasonable adjustments, including flexible timing, easy read information beforehand and supportive environments significantly improve participation rates and reduce anxiety. This bodes well for bone health as it enables early and accurate identification of osteoporosis or osteopenia in people with intellectual disabilities and enables timely referral for treatment, potentially reducing fracture risk and associated morbidity. An area that does need attention is access to such devices. Currently the device used in the study is the only one operational in Ireland, therefore further investment is needed, training healthcare providers in the use of these newer technologies and in communication strategies tailored to intellectual disability populations is essential which will ultimately optimise the quality of assessments and the persons overall experience. All healthcare providers, not only within the intellectual disability field, need to consider integrating accessible bone screening into routine health checks for not only adults with intellectual disabilities but all adults as the silent epidemic of osteoporosis grows. This will ensure the promotion of equity in healthcare access, supports prevention strategies, and contributes to improved long-term health outcomes and quality of life in this vulnerable population and beyond.

4.6 Future Research

Future research should focus on scaling up the current feasibility study to a full clinical trial that evaluates the effectiveness and reliability of the Echolight REMS bone screening device in a larger and more diverse population of individuals with intellectual disabilities, whilst also incorporating their level of fracture risk. Expanding the sample size and including participants from multiple geographic regions and service providers will enhance the generalisability of findings and provide more comprehensive evidence.

Recommendations for scaling up include

- Investing, training and employing additional healthcare professionals to administer the screening device to meet increasing demand and ensure consistent service delivery.
- Incorporating long term follow-up to assess the impact of bone health screening on clinical outcomes such as osteoporosis diagnosis, fracture prevention, and treatment adherence.
- Incorporating and analysing participants level of fracture risk to achieve a more comprehensive bone health assessment.
- Comparing Echolight REMS results with standard DXA scans where possible to validate the accuracy and diagnostic value of the device specifically among those with intellectual disability as this is the first time people with intellectual disability have been included in such a study.
- Developing and testing protocols for routine implementation of accessible bone health screening within standard health assessments for adults with intellectual disabilities.

Including people with intellectual disability in such research is critical to establish evidence-based, accessible bone health screening pathways that address current healthcare disparities and improve prevention and management of osteoporosis for this vulnerable cohort. This will contribute to enhanced health equity, wellbeing, and quality of life for this underserved population. These recommendations are aligned with ongoing healthcare priorities and current governmental strategy for disabled people. The recommendations stemming from the study highlight an urgent need recognised by experts and patient advocates alike to provide tailored, feasible, and effective bone health screening alternatives beyond traditional DXA scanning

4.7 Final thoughts

The Echolight REM bone screening device has demonstrated strong feasibility as an accessible, non-invasive alternative to traditional DXA scans for individuals with intellectual disabilities,

overcoming many practical barriers to assessment. It was seen in this study that employing reasonable adjustments which included easy-read accessible information, flexible scheduling, supportive communication, and offering home-based screenings ensured true inclusion and fostered a positive, anxiety-reducing experience for participants. The study's success in engaging people with intellectual disability through alternative screening methods in accessible environments, highlights the critical importance of improving healthcare equity and accessibility, which aligns directly with the goals outlined in Ireland's recently launched National Human Rights Strategy for Disabled People 2025-2030. While promising, further research and development are needed to expand the device's applicability to all levels of disability and to explore its transferability to other groups, such as older adults and individuals with physical disabilities who also face challenges accessing conventional bone density testing. This work reinforces the importance of the current governments thinking to ensure to have a cross-government and whole-of-health approach to reduce health disparities, promote preventive care, and fulfil the Disability Strategy's commitments to provide accessible, person-centered healthcare, ultimately contributing to the improved health, wellbeing, and quality of life of people with intellectual disabilities and other underserved populations.

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