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Recruitment and retention in longitudinal studies of people with intellectual disability: A case study of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

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ABSTRACT

Background: Longitudinal study of people with intellectual disability and other difficult to reach populations requires specific recruitment and retention strategies to be successful.

Aims: This paper provides a case study of participant recruitment and retention for a longitudinal study of ageing among older adults with intellectual disability in Ireland.

Methods and procedures: Development and implementation of strategies to recruit and retain participants with intellectual disability aged 40+ years, for a longitudinal study comprising four data collection waves over more than a decade, are reported. Recruitment and retention outcomes are assessed alongside factors of successful implementation.

Outcomes and results: A nationally representative sample of 753 individuals with intellectual disability was recruited for wave 1 of the study. Multiple retention strategies aimed to reduce barriers to participation and create a project community and study bond, underpinned by a Values Framework and commitment to PPI. After four waves over 11 years, 87.1 % of surviving participants were retained.

Conclusions and implications: Successful recruitment and retention of people with intellectual disabilities in longitudinal studies is possible when the approach taken is personal, flexible, and innovative; participant burden is minimised; the research team is skilled and sensitive to needs of participants; and where involvement of the study population guides development and implementation of specific and bespoke strategies.

What this paper adds?

Longitudinal study of people with intellectual disabilities can support improved health and well-being when repeated measures of exposures and outcomes enables the exploration of causal inference. However, longitudinal health research designs rely on stable samples over time to support understanding of population morbidity and mortality. This paper provides a critical insight to recruitment and retention strategies developed, implemented and refined over more than a decade, and through four major waves of data

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collection – including the challenges associated with research during the COVID-19 pandemic. This paper provides a blueprint for other researchers undertaking longitudinal study of people with intellectual and developmental disability which may enhance their approaches and success for recruiting and retaining their study samples. The paper demonstrates how development of a Values Framework may underpin such strategies by guiding an inclusive ethos and driving clear Patient and Public Involvement (PPI) approaches, which proved critical to developing and implementing specific and bespoke strategies for recruiting and retaining individuals with intellectual disability. And the paper proposes a range of clear retention strategies that others may adopt, including strategies to remove barriers to participation for this population, and strategies to develop a project community and study bond among participants that stands the test of time. In doing so, the paper may help to improve understandings of how longitudinal research may be implemented over many years and multiple iterations, which will ultimately enhance our understanding of the health and well-being of people with intellectual and developmental disabilities.

1. Introduction

In health research, cohort studies assess and compare the incidence of a condition within a group of people who share the same common characteristics, for example looking at differences based on age, sex or degree of functional limitation. Many studies provide a cross-sectional insight into the nature and impact of such conditions, by, for example, identifying factors associated with increased risk. Repeated measures of the condition related exposures and outcomes enables exploration of causal inference in addition to cross-sectional associations (Rothman et al., 2008). Such longitudinal health research designs depend upon stable samples over time increase our understanding of population morbidity and mortality, including among populations with intellectual disability, as demonstrated most acutely during the COVID-19 pandemic (Bailey et al., 2021; McCarron et al., 2021).

Recruitment is concerned with how to reach the target population of a study and is critical to all types of research. However, a challenge unique to longitudinal studies is retention of study participants over multiple waves of investigation and data collection. Retention is vital to ensure the power and internal validity of longitudinal research. High attrition increases the risk of study bias, particularly if those lost to follow-up are systematically different to those retained. Such attrition can reduce the generalisability of outcomes described and statistical power to detect effects of interest (Gustavson et al., 2012). For multi-wave longitudinal studies there are the twin concerns of the representativeness of the continuing sample and having sufficient sample size for intended analyses.

This paper aims to highlight some of the challenges of recruitment and retention of adults with intellectual disability for longitudinal cohort studies. It provides a case study of retention success in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). It highlights both the challenges presented by recruitment and retention for the study, as well as the strategies implemented to maintain a sample for multiple waves of data collection over more than a decade.

1.1. Recruitment and retention in longitudinal studies

1.1.1. Recruitment

Garvey et al. (2018) suggested that multiple methods used in combination enhance success of recruitment and retention, that structured project materials and project personnel are essential components, and that non-traditional methods are also required when trying to access populations that are difficult to reach. Flakerud and Nyamathi (2000) noted that recruiters need to be trained and culturally responsive; while Chang et al. (2009) agreed cultural sensitivity was critical and suggested that peers should be trained as recruiters.

Bonk (2010) noted that some participant burdens are unique to older people, and that identifying and supporting these may more specifically help successful recruitment and retention in longitudinal studies. Potential barriers for recruiters include hearing impairments, chronic illnesses, reduced capacity to understand study information and challenges with transport. Negative publicity, institutional review boards requirements and documentation, and participant burden and concerns may all present obstacles to study recruitment. Recruitment is “an art and a science” combining communications, marketing and public relations, with methods varying according to each study, depending on location and age group. Effective communication of study purpose and objectives through dedicated and caring staff particularly underpins successful recruitment, supports informed consent and conveys what is required of participants and why they should participate (Bonk, 2010).

Pinto et al. (2018) reported on strategies for the recruitment and retention of services agencies and health service providers, which are often critical in securing access to research participants. Here, strategies beneficial to both recruitment and retention included hosting social gatherings to engage stakeholders, appealing to altruism and highlighting study benefits, offering training as an incentive, and sharing research findings. Additional recruitment strategies included minimising the study burden, establishing a key contact person at each service agency to help recruit service providers, and maintaining comprehensive records.

1.1.2. Retention

Nicholson et al. (2011) attributed their success in retaining participants to a coordinated effort by the research team and supports at clinical sites, and to project branding and a dedicated phone contact point. Bonk (2010) identified additional strategies for retaining participants as collecting excellent information at recruitment, encouraging bonding with the study through logo and mission statement, newsletters and holiday/birthday cards, monetary incentives or tokens of appreciation, providing transport, an annual social event, and periodic staff contact. In a longitudinal study of child welfare professionals, Wilke et al. (2017) achieved a retention rate of 84 % after three data collection waves through building study credibility and consistency, good communication, incentives (increasing over time) and convenience (e.g. multiple data collection sessions). While labour intensive, such efforts pay dividends in better

retention for longitudinal studies (Wilke et al., 2017).

Pinto et al. (2018) suggested specific planning to retain hard-to-reach participants and tailoring incentives in consultation with institutional review boards to support better retention. Price et al. (2016) found that most participants, in a cohort study of children and their mothers, joined for altruistic reasons; and while motivation was also associated with staying in the study, retention was associated more with demographic factors and having a positive experience in the study.

In a study of studies, Abshire et al. (2017) explored the retention strategies employed by 19 longitudinal studies with over 200 participants and a retention rate in excess of 80 %. They found that research teams were characterised by their organisation, specialisation and persistence; that they tailored strategies to their participants and adapted and innovated approaches. The most common retention strategies included study reminders, specific characteristics of the study visits (e.g., minimising burden during data collection processes), emphasising study benefits, and contact/scheduling strategies; while approaches to retention needed to be culturally sensitive.

A systematic review and meta-analysis of longitudinal cohort studies by Teague et al. (2018) identified a mean retention rate of 73.9 % (SD 20.1 %), using on average 6.2 retention strategies, across a mean duration of 4.6 study waves (4.5 years). A total of 95 retention strategies were classified in four categories: barrier reduction; community building; follow-up/reminder; and tracing. Studies using barrier reduction strategies retained 10 % more of their sample (95 % CI, (0.13–1.08); $p = .01$); however, studies using primarily follow-up/reminders strategies lost an additional 10 % of their sample (95 % CI, (–1.19 to –0.21); $p = .02$). Sample size, number of waves, study duration and the overall number of strategies employed were *not associated* with retention rates. Studies that used multiple ‘emerging’ strategies (not being identified in previous reviews), across the four types of strategy, reported higher retention rates. A higher proportion of male participants in studies was also associated with lower retention rates.

1.1.3. Using PPI to support recruitment and retention

Patient and Public Involvement (PPI) studies across a range of disciplines have highlighted several benefits for research of engaging with study populations in new ways, including supporting both recruitment and retention. As noted in Table 1 there are multiple steps throughout the research process where meaningful involvement is possible and will greatly improve a project. One of the key benefits of including persons with lived experience of the condition under investigation through PPI strategies in all aspects of the study is increasing the relevance of research among the study population, which in turn may support uptake (Boivin et al., 2018; Crocker et al., 2018), and more specifically, successful recruitment and retention.

Tomlinson et al. (2019) cited the use of PPI advisory groups to support research design including recruitment strategy and methods, using existing as well as intentionally formed PPI groups, both in-person and online. These PPI approaches helped to highlight potential study benefits to health service users, potential difficulties with recruitment and retention, and participants were also used as recruiters directly and through their networks (Tomlinson et al., 2019). McKenna (2015) demonstrated the potential for PPI to result in greater research impact for a range of studies, with user panels helping to shape the research from grant writing, recruitment strategies, supporting intervention development, and overcoming barriers. A systematic review and meta-analysis by Crocker et al. (2018) identified that patients and public involved in designing recruitment and retention strategies, developing information for potential recruits, recruitment of participants, and devising responses when recruitment was poor significantly increased the odds of patient enrolment, and resulted in a modest but non-significant improvement in retention (Crocker et al., 2018).

Table 1
IDS-TILDA attrition and retention, waves 1-4.

	No. of individuals	Wave %	Deaths	Cumulative Retention (of available participants) n (%)
WAVE 1				
Wave Sample	753	100 %	35	753 (100 %)
Withdrawals	10	1.3		10 (1.3 %)
WAVE 2				
Wave Sample	708	100 %	70	708 (99 %)
Withdrawals	29	4.1 %		39 (5.2 %)
WAVE 3				
Wave Sample	609	100 %	67	609 (94 %)
Withdrawals	36	5.9 %		75 (10.0 %)
WAVE 4				
Remaining Available Sample	506	68.5 %		506 (87.1 %)
Sample Refreshment	233	31.5 %		
Total Wave 4 Sample	739	100 %		

2. IDS-TILDA: a case study of recruitment and retention in a longitudinal cohort study

This section will provide details of the IDS-TILDA study, as a case study of recruitment and retention practices in longitudinal cohort research with people with intellectual disabilities.

2.1. Overview of IDS-TILDA

IDS-TILDA was established in 2007, entering the field for the first time in 2009 to become the first longitudinal study on ageing among people with an intellectual disability to be carried out in tandem with a study of ageing amongst the general older population (Barrett et al., 2011; McCarron et al., 2011). The key aims of IDS-TILDA are:

- 1 To understand the health characteristics of people ageing with an intellectual disability;
- 2 To examine the service needs and health service utilisation of people ageing with an intellectual disability;
- 3 To identify disparities in the health status of adults with an intellectual disability as compared to TILDA findings for the general population; and
- 4 To support evidence-informed policies, practices and evaluation.

The conceptual framework underpinning IDS-TILDA spans a broad range of life domains, from physical and mental health to social inclusion and community participation (see Fig. 1).

IDS-TILDA is also guided by a Values Framework that puts people with an intellectual disability at the centre of the study. This emphasises inclusion and empowerment of people with intellectual disabilities with the ultimate aim to contribute to improving their lives. From the beginning there has been involvement of people with intellectual disabilities and their families and other carers in all aspects of the design, development, delivery, dissemination and governance of the study. These principles and practices are vital components of the study and provide the foundation for recruitment and retention efforts, as outlined later. Ethical approval for the study is granted by Trinity College Faculty of Health Sciences Research Ethics Committee (REC) and by the disability service providers who support each of the IDS-TILDA participants. Ethical approval from the service providers underpins their buy-in to the study and is another critical element of recruitment and retention, and this is reaffirmed at each subsequent wave of the study.

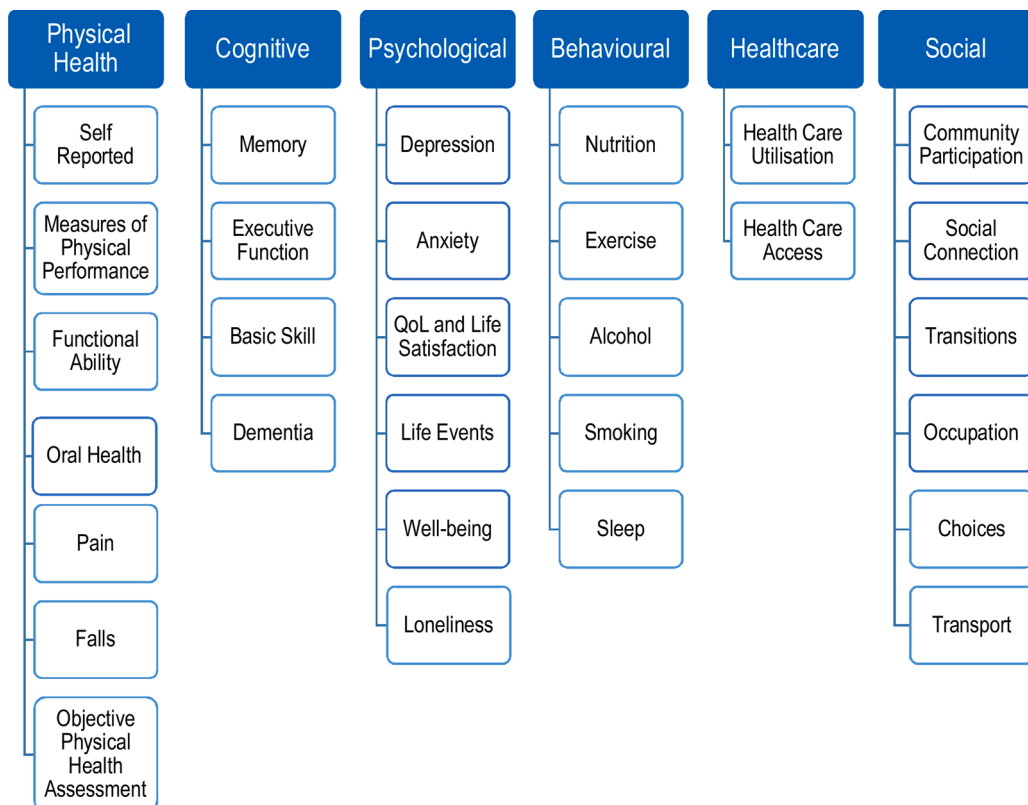


Fig. 1. IDS-TILDA Conceptual Framework.

2.2. Population and sample

IDS-TILDA includes people with an intellectual disability living in the Republic of Ireland who are aged 40 years and above. The original study sample was age stratified and drawn randomly and anonymously from the National Intellectual Disability Database (NIDD), recruiting a study sample of 753 participants for wave 1. Consent to participate in the study was sought, in the first place, directly from all individuals with intellectual disability using accessible materials. Where there was a reduced capacity to give informed consent, proxy consent to participate in the study was sought from a family member or legal guardian. The wave 1 sample included 285 self-consenting participants (38 %), with proxy consent provided for 468 individuals (62 %) who were considered to lack the capacity to provide fully informed self-consent, and for whom a letter of agreement/consent to participate was obtained from a family member/guardian. For both self- and proxy-consented individuals, participation was also underpinned by a system of process consent during data collection, which sought to reaffirm that participants were happy to continue in the study. For waves 2 and 3, consent to continue was reaffirmed in writing with existing participants. A similar approach in wave 4 was supplemented by additional measures for two key reasons. First, a sample refresh was undertaken to recruit new study participants, requiring ethical approval from new service providers and an original study consent from newly recruited participants. Second, new regulations governing data protection, the General Data Protection Regulations (GDPR), came into force within the European Union in 2019. This entailed revision of study protocols, including a requirement to obtain a 'Consent Declaration' to allow the inclusion of individuals with intellectual disability who lacked the capacity to give informed consent.

The original sample recruited at wave 1 comprised 8.9 % of the total eligible population in Ireland and was demographically and geographically representative of the target population within the NIDD, sample characteristics that it would be important to retain through individual retention strategies. The sample was 45 % male and 55 % female; aged 41–90 years (mean age 54.7 years); 24 % had a mild ID, 46 % moderate ID, 24 % severe ID, and 5 % profound ID (with 5 % unverified). Around 40 % lived in 52-week residential care centres, with a further 5.3 % in other residential centres (i.e. 45.3 % in 'institutional' or 'congregated' residential care settings); around one-third (34.1 %) lived in community group homes with other individuals with intellectual disability; 5 % lived independently or semi-independently; and 11 % lived at home with their families (McCarron et al., 2011).

2.3. Data collection

IDS-TILDA undertakes data collection in three-year cycles and has reported key findings from each wave every three years since 2011 (Burke et al., 2014; McCarron et al., 2017; McCarron et al., 2020; McCarron et al., 2011). There are three core components to data collection:

- A face-to-face interview with participants using a Computer Assisted Personal Interview (CAPI) system – this was adapted using remote video interviewing following the outbreak of COVID-19 during wave 4 data collection;
- A self-completed Pre-Interview Questionnaire (PIQ);
- The IDS-TILDA Health Fair of objective health assessments – carried out every second wave.

Participants with intellectual disability may be supported to take part in all core components of the study by a person who knows them well (a minimum of six months), and by use of proxy respondent to answer on their behalf where required. Additional components to IDS-TILDA depend on eligibility, including:

- A Carers Questionnaire for family carers, and
- An End-of-Life Questionnaire carried out with family or other carers of participants who have deceased since the previous wave.

It was recognised that the multiple data collections and the length of protocols all posed potential challenges to individual retention. A key strategy was the involvement of people with intellectual disabilities themselves in the training of field workers/interviewers as well as close cooperation with providers, key workers and the person with an intellectual disability themselves on the scheduling of interviews including breaking interviews into shorter sessions if needed.

2.4. Attrition and retention

From the original sample of 753 participants, 247 individuals (32.8 %) were lost to attrition by the end of wave 4 data collection, eleven years later (2009–2020). This left a total of 506 participants which was 67.2 % of the original sample at wave 1 (Table 1). Of the 247 individuals who were lost to the study over the first four waves, over two-thirds were deceased (69.6 %, 172/247), with less than a third of attrition due to withdrawal of participants (30.4 %, 75/247). Overall, just 10 % (75/753) of the original sample withdrew from the study during the first four waves. When the 172 deaths are excluded, the 506 original participants remaining at Wave 4 represents 87.1 % (506/581) of those who were still alive at this point. A sample refreshment exercise recruited an additional 233 new participants at wave 4, bringing the overall sample back up to 739.

An additional complication to retention and sample refreshment efforts during Wave 4 arose with the outbreak of the COVID-19 pandemic in March 2020, bringing ongoing sample refreshment and data collection efforts to a temporary halt. Following ethical approval, data collection and recruitment resumed using remote methods (telephone and video conferencing). The recruitment of the 233 new participants, and indeed the retention of existing participants during this time, was further aided by a series of online

webinars hosted by the IDS-TILDA team for the intellectual disability community in Ireland, in addition to the regular engagement activities (see below). A follow-up COVID-19 survey conducted in May-August 2021 identified the further retention of 92.3 % (n = 682) of Wave 4 participants following this extremely challenging period.

2.5. Recruitment strategies

IDS-TILDA faced several challenges in recruiting its sample, many of which were unique to this particular population. These included:

- Finding the target population of older adults with intellectual disabilities;
- Identifying the stakeholders – who would be critical in supporting study participation;
- Target population not accustomed to getting post and personal information sent to them directly, with lack of opportunity and personal autonomy;
- Communication difficulties – much of the population had limited verbal and written competence, and lower capacity to understand information;
- Consent issues – when capacity to understand study information and provide informed consent is an issue for much of this population;
- Access issues – for adults living in formal residential care or with family;
- Dependence on gatekeepers, staff and family caregivers;
- Additional potential burden on family and support staff to support participation.

To overcome these challenges, the IDS-TILDA recruitment strategy included a range of key tools and approaches (Table 2).

The combination of these strategies, along with a strong degree of resilience and persistence by a skilled and dedicated team, ensured successful recruitment of a nationally representative sample of older adults with intellectual disabilities for wave 1 of IDS-TILDA.

2.6. Retention strategies

The retention rate of 87.1 % of surviving participants (excluding deaths) reported above for IDS-TILDA, through four waves of data collection over an 11-year period, is high for a longitudinal study (Teague et al., 2018). The success of participant retention in IDS-TILDA is owed to the combination of multiple retention strategies broadly categorised under three specific approaches:

- 1 Reducing barriers to participation
- 2 Creating a project community and study bond
- 3 Values framework and PPI

2.6.1. Reducing barriers to participation

A wide variety of strategies were developed throughout the course of IDS-TILDA aimed at reducing potential barriers to participation, not only for the target population, but also for other key stakeholders including family carers, support services and care staff (Table 3).

Table 2

Recruitment strategies used.

Developing a road map for the study.
Identifying potential barriers to interview completion progress.
Weekly team meetings to review progress and identify new barriers.
Communication with the various stakeholders using a multi-pronged approach, with different approaches for:
<ul style="list-style-type: none"> • People with intellectual disabilities • Family members and staff caregivers • The gatekeepers • Management and people with influence to validate the importance of the study
Being culturally sensitive and knowing your population:
<ul style="list-style-type: none"> • Peers as recruiters • Utilising interpersonal contacts within the sector • Face-to-face relationships and targeted “roadshow” presentations • Getting buy-in from staff and gatekeepers • Giving back to all partners with presentations, events, and dissemination materials
Multiple follow-ups by phone and re-sending materials as required.

Table 3
Retention strategies used to reduce barriers.

<p>Accessible study materials including Easy to Read information booklets, consent forms and appointment cards, using pictorial cards to assist understanding. Using non-clinical interview settings that were more homelike and relaxed. Avoiding clinical words such as ‘tests’. Advisory Groups to ensure the interview style is appropriate and materials/questions are understandable. Study participants and other people with intellectual disabilities assisting with the training of field workers. Alternative methods of data collection. Anonymity of participants. Avoiding any financial costs to participants, for example proving stamped addressed envelopes, and eliminating travel costs. Consistency in research staff. Partial data collected through Pre-Interview Questionnaire (PIQ) to reduce the length and burden of the face-to-face interview. Extended data collection window and second or third visit if necessary, to reduce participant burden. Flexibility from field workers in scheduling, regarding venue, day and times, including availability at evening time and weekends. Hiring, systematic training (3–5 days) and continuous support of field workers. Pre-pilots and pilot testing of protocols and new measures. Pre-testing the prioritising and the placing of the questions and the order of survey items to ease completion. Sensitivity to participant fatigue. Option for participants to “rest” a data collection wave if necessary. Providing IDS-TILDA contact person details and phone number for participants and supporters.</p>
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2.6.2. Creating a project community and study bond

The creation of a connection with the study for participants, family members and support services was an additional critical element in maintaining buy-in from all stakeholders and in sustaining high retention rates over multiple study waves (Table 4).

2.6.3. Values Framework and PPI

Both of the approaches outlined above are critically underpinned by an IDS-TILDA Values Framework, which in turn guides the PPI strategies that are vital to the success of the study. The Values Framework sets out the fundamental principles and ethos of the study (Fig. 2).

This framework creates the inclusive environment and culture in which PPI strategies bring the voice and leadership of people with intellectual disability to the heart of the study, tying all efforts of recruitment and retention together.

2.6.4. Overview

The dynamic use of these many components has combined to create an overall retention strategy and also required investment in an ongoing effort executed by a skilled and committed team. It is difficult to rank the methods outlined above by importance based on an objective assessment of their impact on recruitment and retention. At the same time, we believe that what really counts is the cumulative effect of multiple methods and consistent efforts over time, underpinned by a genuine commitment to inclusion of the study population. As such, the importance of individual strategies may vary depending on the specific context of each study. Both recruitment and retention strategies are underpinned by the establishment and continuous maintenance of participant contact details and related information, for example details of supporting family members or support staff which are critical for this population. This enables the efficient tracing of participants from one wave to the next of the longitudinal study.

3. Discussion

High quality data is essential to underpin evidence-based healthcare policy (Committee on the Future of Healthcare, 2017) and practice (Portney, 2020). The benefits to healthcare of longitudinal studies lie in their ability to support causal inference through the

Table 4
Retention strategies used to create a project community and study bond.

<p>Establishing a Scientific Advisory Committee and Steering Committee. Appointing study patrons with an intellectual disability. Branding – study logo, colour and materials – reflecting involvement of people with intellectual disabilities through design competitions. Study branded gifts: IDS-TILDA pens, keyrings, water bottles, bags, wristbands. Non-financial Incentives: IDS-TILDA Certificate of Participation. Accessible dissemination of study findings, including use of videos featuring actors with intellectual disabilities, accessible Easy to Read reports, and infographics. Christmas/Easter card design competitions. Keeping in touch through newsletters and holiday cards. Educational events. Reporting study impact to participants and supporters to highlight continued relevance and the importance of participation. Celebrating success through periodic events, such as report and video launches, providing opportunities to meet other participants and caregivers. Photographic exhibition featuring work submitted by people with intellectual disabilities. Visibility of and opportunity to meet the Principal Investigator. Ongoing public communication through media coverage, IDS-TILDA website and social media including Twitter. Connecting with participants and their supporters through a series of webinars during the COVID-19 19 pandemic. An overall and shared Values Framework which underpins a PPI strategy placing the voice of people with intellectual disability at the heart of the study.</p>
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Fig. 2. Values Framework underpinning the IDS-TILDA study.

temporal order of exposures and outcomes of conditions (Rothman et al., 2008), thereby offering critical insights into morbidity and mortality patterns and to possible preventative measures and treatments. The value of ongoing longitudinal studies of this nature was also highlighted during the COVID-19 pandemic (Bailey et al., 2021; McCausland et al., 2021). During this period, IDS-TILDA was able to use its prior multiple waves of health data to inform policy debate in Ireland which raised the risk status and vaccine priority given by policymakers to older adults of with intellectual disability, and the standing infrastructure was rapidly mobilised to support a supplementary survey on the impact of COVID-19 among this population (McCarron et al., 2020).

Most critically, realisation of these benefits of longitudinal studies requires that, once sufficient numbers are recruited, participants are then retained within the samples to support the types of in-depth analyses required (Gustavson et al., 2012). How challenges and strategies in recruitment and retention were addressed in the IDS-TILDA longitudinal study provides insight to successful approaches for difficult to reach and retain groups such as people with intellectual disabilities.

Regarding recruitment, many of the key strategies employed by IDS-TILDA mirror those of other successful studies. Use of multiple methods enhances successful recruitment (Garvey et al., 2018). More specifically IDS-TILDA is an example of developing a road map and dynamically identifying and responding to potential barriers to progress; adapting communication about the study to the needs of different stakeholders, recognising that the same approach is not suitable to all (Bonk, 2010); being culturally sensitive, knowing your target population and responding to their needs (Chang et al., 2009; Flaskerud & Nyamathi, 2000); and having a skilled and dedicated team that is persistent and resilient, using excellent administrative data to follow-up and track (potential) participants (Pinto et al., 2018). Innovation and non-traditional methods were also successful (Garvey et al., 2018).

The utilisation of different types of participation, including self-reported, supported and proxy-reported interviews, facilitated the inclusion of people with intellectual disability of all ranges of ability. This was underpinned by a system of process consent, which reaffirms willingness to continue in what capacity individuals are able to do so. A flexible approach also allows for different types of participation (i.e., self, supported, or proxy) between different sections of the overall research protocol – facilitating greater or lesser direct involvement depending on participants' preferences. The provision of different options in this way also provides for adapted levels of participation in circumstances where an individual's ability to participate may deteriorate over time – for example, with the onset and advance of dementia.

Regarding retention, again IDS-TILDA combined multiple strategies to successfully maintain its sample over four waves of data collection, when assessed beside the 73.9 % average retention in longitudinal cohort studies reported by Teague et al. (2018), especially considering that IDS-TILDA maintained high retention levels over a much longer period – 11 years compared with the mean duration of 4.5 years reported by Teague et al. Nonetheless, refreshment of the IDS-TILDA sample after the first three waves was considered prudent when anticipating the statistical power required to perform multivariate analyses across different subgroups within the sample and the desire to maintain representativeness of the sample. The measures used aimed at barrier reduction for participants; and creating a study community and bond were also identified in a recent review and meta-analysis by Teague et al. (2018). Barrier reduction was particularly associated with the best retention outcomes, a strategy also supported by others (Abshire et al., 2017). Community building and study bonding have also been cited by other studies as a successful element of retention (Bonk, 2010; Wilke et al., 2017).

The use of adapted methods and remote interviewing to complete Wave 4 following the outbreak of COVID-19 highlights another

means by which barriers to participation may be reduced when it is not physically possible to reach participants. While physical distance for rural participants is not a significant issue in a small country like Ireland, this use of remote methods may also, post-COVID-19, assist recruitment and retention efforts for geographically difficult to visit participants in larger countries.

Several other retention strategies used support previous findings from several studies (Abshire et al., 2017; Bonk, 2010; Wilke et al., 2017). The usefulness of study branding and identity reflects similar outcomes in other successful studies (Nicholson et al., 2011; Teague et al., 2018). The persistent efforts of a dedicated study team in tracking, keeping in touch and supporting participants has also been identified by several other studies (Abshire et al., 2017; Bonk, 2010; Nicholson et al., 2011; Wilke et al., 2017). The combining of a number of different strategies, from minimising participant burden of interview duration to recruiting and training only knowledgeable and dedicated fieldworkers, and the creation of a positive overall experience may also have been critical in engendering continued participation in the study, as found previously by Price et al. (2016).

For IDS-TILDA, that these strategies were rooted in a Values Framework emphasised inclusion, empowerment and affecting positive change in the lives of people with an intellectual disability. This Values Framework provided the basis for the multiple PPI strategies employed throughout the study that proved so critical to successful recruitment and retention – from inclusion in governance structures, development of research questions, accessible materials, and inclusive dissemination methods. The experiences in IDS-TILDA is a demonstration of recommendations elsewhere that including persons with intellectual disability in all aspects of the study is beneficial to recruitment and retention in research (Boivin et al., 2018; Crocker et al., 2018).

4. Conclusions

The lessons learned from over a decade of the IDS-TILDA study indicate that, once the fundamental principles are in place (as in the Values Framework), successful recruitment and retention of people with intellectual disabilities is possible in longitudinal studies. The personal touch matters in these studies, flexibility is needed, innovation is rewarded with success, and minimising participant burden is critical to retention. The research team and fieldworker training are critical as these are the people who will create a lasting impression with participants. High public visibility by the Principal Investigator also creates and sustains a connection with participants and support agencies. One size does not fit all in retention strategies for people with intellectual disabilities and it is likely the same holds true for other hard to reach and hard to retain populations such as persons with substance use, mental health and homelessness issues. Involvement at all levels of representatives of populations being researched helps guide the development and successful implementation of specific and bespoke retention strategies that work.

CRedit authorship contribution statement

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References

- Abshire, M., Dinglas, V. D., Cajita, M. I. A., Eakin, M. N., Needham, D. M., & Himmelfarb, C. D. (2017). Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC Medical Research Methodology*, 17(1), 30.
- Bailey, T., Hastings, R. P., & Totsika, V. (2021). COVID-19 impact on psychological outcomes of parents, siblings and children with intellectual disability: Longitudinal before and during lockdown design. *Journal of Intellectual Disability Research*, 65(5), 397–404. <https://doi.org/10.1111/jir.12818>
- Barrett, A., Savva, G., Timonen, V., & Kenny, R. A. (2011). Fifty-Plus in Ireland 2011: First results from the Irish Longitudinal Study on Ageing (TILDA). *The Irish Longitudinal Study on Ageing*.
- Boivin, A., Richards, T., Forsythe, L., Grégoire, A., L'Espérance, A., Abelson, J., & Carman, K. L. (2018). Evaluating patient and public involvement in research. *BMJ*, 363, Article k5147. <https://doi.org/10.1136/bmj.k5147>
- Bonk, J. (2010). A road map for the recruitment and retention of older adult participants for longitudinal studies. *Journal of the American Geriatrics Society*, 58, S303–S307.
- Burke, E., McCallion, P., & McCarron, M. (2014). *Advancing years, different challenges: Wave 2 IDS-TILDA*. https://www.tcd.ie/tcaid/assets/pdf/Wave_2_Report_October_2014.pdf.
- Chang, M.-W., Brown, R., & Nitzke, S. (2009). Participant recruitment and retention in a pilot program to prevent weight gain in low-income overweight and obese mothers, 2009/11/21 *BMC Public Health*, 9(1), 424. <https://doi.org/10.1186/1471-2458-9-424>.
- Committee on the Future of Healthcare. (2017). *Sláintecare Report*. Houses of the Oireachtas. <https://assets.gov.ie/22609/e68786c13e1b4d7daca89b495c506bb8.pdf>.
- Crocker, J. C., Ricci-Cabello, I., Parker, A., Hirst, J. A., Chant, A., Petit-Zeman, S., ... Rees, S. (2018). Impact of patient and public involvement on enrolment and retention in clinical trials: Systematic review and meta-analysis. *BMJ*, 363, Article k4738. <https://doi.org/10.1136/bmj.k4738>
- Flaskerud, J. H., & Nyamathi, A. M. (2000). Collaborative inquiry with low-income Latina women. *Journal of Health Care for the Poor and Underserved*, 11(3), 326–342.
- Garvey, R., Pedersen, E. R., D'Amico, E. J., Ewing, B. A., & Tucker, J. S. (2018). Recruitment and retention of homeless youth in a substance use and HIV-risk reduction program. *Field Methods*, 30(1), 22–36.
- Gustavson, K., von Soest, T., Karevold, E., & Røysamb, E. (2012). Attrition and generalizability in longitudinal studies: Findings from a 15-year population-based study and a Monte Carlo simulation study. *BMC Public Health*, 12(1), 918.
- McCarron, M., Haigh, M., & McCallion, P. (2017). *Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland, Evidence from the First Ten Years of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)*. <https://www.tcd.ie/tcaid/assets/pdf/wave3report.pdf>.
- McCarron, M., McCausland, D., Allen, A., Luus, R., Sheerin, F., Burke, E., McGlinchey, E., Flannery, F., & McCallion, P. (2020). *The impact of COVID-19 on people ageing with an intellectual disability in Ireland*, 65(10), 879–889. October 2021 <https://www.tcd.ie/tcaid/assets/pdf/wave4idstildareport.pdf>.

- McCarron, M., McCausland, D., Luus, R., Allen, A., Sheerin, F., Burke, E., McGlinchy, E., Flannery, F., & McCallion, P. (2021). The impact of coronavirus disease 2019 (COVID-19) on older adults with an intellectual disability during the first wave of the pandemic in Ireland [version 1; peer review: 1 approved with reservations]. *HRB Open Research*, 4(93). <https://doi.org/10.12688/hrbopenres.13238.1>
- McCarron, M., Swinburne, J., Burke, E., McGlinchy, E., Mulryan, N., Andrews, V., Foran, S., & McCallion, P. (2011). *Growing older with an intellectual disability in Ireland 2011: First results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing*. <https://www.tcd.ie/tcaid/assets/pdf/idstildareport2011.pdf>.
- McCausland, D., Luus, R., McCallion, P., Murphy, E., & McCarron, M. (2021). The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland. *Journal of Intellectual Disability Research*. [https://doi.org/10.1111/\(ISSN\)1365-2788](https://doi.org/10.1111/(ISSN)1365-2788)
- McKenna, H. (2015). Perspectives: Patient and public involvement and research impact: A reciprocal relationship. *Journal of Research in Nursing*, 20(8), 723–728. <https://doi.org/10.1177/1744987115619803>
- Nicholson, L. M., Schwirian, P. M., Klein, E. G., Skybo, T., Murray-Johnson, L., Eneli, I., ... Groner, J. A. (2011). Recruitment and retention strategies in longitudinal clinical studies with low-income populations. *Contemporary Clinical Trials*, 32(3), 353–362.
- Pinto, R. M., Witte, S. S., Wall, M. M., & Filippone, P. L. (2018). Recruiting and retaining service agencies and public health providers in longitudinal studies: Implications for community-engaged implementation research. *Methodological Innovations*, 11(1), 2059799118770996.
- Portney, L. G. (2020). *Foundations of clinical research: Applications to evidence-based practice* (4th ed.). F.A. Davis.
- Price, S. M., Baetz, R. A., Adams, S., Li, T., Brenner, R. A., Park, C. H., & Lo, A. (2016). Participant retention in a longitudinal study: Do motivations and experiences matter? *Survey Practice*, 9(4), 2805.
- Rothman, K. J., Greenland, S., & Lash, T. L. (2008). *Modern epidemiology*. Lippincott Williams & Wilkins.
- Teague, S., Youssef, G. J., Macdonald, J. A., Sciberras, E., Shatte, A., Fuller-Tyszkiewicz, M., ... Hutchinson, D. (2018). Retention strategies in longitudinal cohort studies: A systematic review and meta-analysis. *BMC Medical Research Methodology*, 18(1), 151.
- Tomlinson, J., Medlinskiene, K., Cheong, V. L., Khan, S., & Fylan, B. (2019). Patient and public involvement in designing and conducting doctoral research: The whys and the hows, 2019/08/16 *Research Involvement and Engagement*, 5(1), 23. <https://doi.org/10.1186/s40900-019-0155-1>.
- Wilke, D. J., Radey, M., & Langenderfer-Magruder, L. (2017). Recruitment and retention of child welfare workers in longitudinal research: Successful strategies from the Florida Study of Professionals for Safe Families. *Children and Youth Services Review*, 78, 122–128.