



STUDY PROTOCOL

REVISED

The impact of COVID-19 on people ageing with an intellectual disability in Ireland: Protocol for a follow-up survey

[version 2; peer review: 2 approved]

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Abstract

Background: The COVID-19 pandemic and associated lockdowns have had a dramatic impact on many people, but individuals with an intellectual disability, given the prevalence of congregate living and high levels of co-morbid conditions, may be particularly vulnerable at this time. A prior initial survey of participants of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) found that, despite a majority of participants being tested, only a small proportion had tested positive for COVID-19. Furthermore, despite some reporting positive aspects to the lockdown, a similar proportion were experiencing stress or anxiety during the pandemic. The pandemic and lockdowns have continued, and it is possible that experiences and consequences have changed over time.

Aim: To explore over time and in greater depth the impact of COVID-19 and associated lockdowns and to further establish rates of infection, rates of vaccination and participants' experiences.

Methods: A structured questionnaire for people with intellectual disability participating in the IDS-TILDA longitudinal study, to be administered by telephone/video in summer 2021. Where participants are unable to respond independently, a proxy respondent will be invited to either assist the participant or answer questions on their behalf. This questionnaire will include questions from the first COVID-19 questionnaire, with extra questions assessing "long COVID" (i.e. COVID-19 lasting for 12 weeks or longer), infection control behaviours, changes in mental health, social contacts and loneliness, frailty, healthcare, and incidence of vaccination.

Impact: The results of this survey will be used to inform healthcare provision for people with intellectual disability during the latter stages

Open Peer Review

Approval Status

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version 1		
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1. **Angelo Carfi** , Università Cattolica del Sacro Cuore, Rome, Italy

2. **Yona Lunsky** , Centre for Addiction and Mental Health, Toronto, Canada

Any reports and responses or comments on the article can be found at the end of the article.

of the lockdown and into the future.

Keywords

COVID-19, frailty, healthcare, intellectual disability, mental health, lockdown, social participation, vaccination

This article is included in the [Dementia Trials](#)



[Ireland \(DTI\) and Dementia Research Network](#)

[Ireland \(DRNI\) gateway.](#)

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Author roles: **McCarron M:** Conceptualization, Funding Acquisition, Writing – Review & Editing; **Allen A:** Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing; **McCausland D:** Writing – Review & Editing; **Haigh M:** Project Administration, Writing – Review & Editing; **Luus R:** Writing – Review & Editing; **Bavussantakath FR:** Writing – Review & Editing; **Sheerin F:** Writing – Review & Editing; **Mulryan N:** Writing – Review & Editing; **Burke E:** Writing – Review & Editing; **McGlinchey E:** Writing – Review & Editing; **Flannery F:** Writing – Review & Editing; **McCallion P:** Funding Acquisition, Writing – Review & Editing

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REVISED Amendments from Version 1

We thank our two reviewers for thoughtful comments. We have made the following minor revisions to Version 1:

1. We have added information on the role of the Health Research Consent Declaration Committee and the meaning of a consent declaration from this body, with a link to their website (see Procedure, second paragraph).
2. We have added information about the settings in which people live (see Introduction, fourth paragraph).

Any further responses from the reviewers can be found at the end of the article

Introduction

The COVID-19 pandemic has had an unprecedented effect on society at large, and our understanding of this pandemic is constantly changing as research continues at a rapid pace. Besides the economic effect of ongoing lockdowns, the global death toll as of early June 2021 is estimated to be approximately 4.2 million (WHO, 2021). Although the impact of this pandemic has been devastating for many, it has been particularly severe for the more vulnerable members of society. People with an intellectual disability are an especially vulnerable group (Courtenay & Perera, 2020), and evidence from the UK and Ireland found that deaths attributed to COVID-19 occurred at a younger age for people with intellectual disability compared to the general population (Perera *et al.*, 2020). Data from an international study (with participants predominantly from the United States) indicated that the case-fatality rate was similar for people with an intellectual disability overall, but was higher for those aged 18–74 (Turk *et al.*, 2020). Apart from the threat of serious illness or death, measures employed to reduce the spread of COVID-19 have had an additional major effect on the lives of people with intellectual disability. People with an intellectual disability have missed social contacts, have had their daily lives altered by being unable to leave their homes, and have often found it hard to understand the preventative measures (Embregts *et al.*, 2020). Survey respondents in Spain reported differing conditions of support for people with intellectual disability during the COVID-19 pandemic depending on living context; for example, those in family homes relied heavily on their family for support (Navas *et al.*, 2021).

The disproportionate effect of this pandemic has led to relevant stakeholders advocating for priority for vaccinations to be given to people with intellectual disability (Hotez *et al.*, 2021). Notwithstanding the ongoing rollout of vaccinations, at time of writing lockdown restrictions continue in Ireland, and the pandemic may have effects that persist well beyond the end of any societal restrictions. Given existing challenges in planning for long-term care for many adults with intellectual disability,

the COVID-19 pandemic has further added to the vulnerability of this cohort.

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008 to study ageing in a representative sample of people with intellectual disabilities in Ireland aged 40 and older. With the onset of the COVID-19 pandemic and the associated lockdown in mid-March 2020, all data collection for Wave 4 of IDS-TILDA, which was ongoing at that time, was suspended. However, ethical approval was obtained in May 2020 to complete Wave 4 data collection by remote interviewing (by phone/video) rather than face-to-face and for the addition of a supplemental COVID-19 survey to investigate the impact of the pandemic and lockdown on the IDS-TILDA participants.

This initial IDS-TILDA COVID-19 survey, conducted between May and September 2020, found no deaths from COVID-19 among participants (McCarron *et al.*, 2020; McCarron *et al.*, 2021). Seven hundred and ten participants completed the COVID-19 questionnaire, out of 739 enrolled in Wave 4, a 96% response rate. Participants were aged over 40, with all levels of intellectual disability represented. Fifty percent lived in a community group home, 17% lived independently or with family, and 33% in residential care. A majority (62.4%) had been tested for COVID-19, although only 10% reported COVID-19-like symptoms and only 2.5% tested positive. These findings were despite high rates reported of chronic conditions associated with worse outcomes for COVID-19, including cardiovascular disease and diabetes. Of those participants who tested positive or had symptoms, over three-quarters had a plan in place to manage self-isolation according to guidelines, although one third were unable to comply with these guidelines. Most participants (58%) indicated there had been positive aspects to the lockdown (for example, trying new activities, more rest and relaxation), but 55% indicated they had experienced stress/anxiety, with most common reasons being not being able to do usual activities, not being able to see family/friends and fear of contracting COVID-19. The full report (including an accessible version) is available at: <https://idstilda.tcd.ie/wave4/launch.php>

There is a need for additional data collection. Ireland has had an extended, restrictive lockdown since January 2021, although a national vaccination program has been progressing, with over 1.4 million people in Ireland having received at least one vaccine dose at the time of writing. It is important to understand the impact of extended lockdown and the experience of vaccination for individuals ageing with an intellectual disability by repeating the questions from the first survey, and asking additional questions on mental health consequences, changes suggesting increased frailty and/or “long COVID”, and access to and experience of vaccination. The questions intended to be asked are an opportunity to gather data that is comparable

to questionnaires being completed with other populations and in other countries.

Protocol

Ethical approval

Ethics approval has been received from the National Research Ethics Committee (Application number: 20-NREC-COV-050-AMEND-2).

Participants

The National Intellectual Disability Database was originally used, with support from the Health Research Board, to anonymously recruit a representative sample of adults with an intellectual disability aged 40 years or older for IDS-TILDA. For Wave 4 the sample was refreshed from the same source (McCarron *et al.*, 2020). The sample for this follow-up survey will again consist of participants in Wave 4. At time of writing, 725 participants from the original Wave 4 sample of 739 are surviving, and all will be invited to take part in the second COVID-19 survey.

Survey development

Existing questionnaires on the impact of the COVID-19 pandemic were consulted in the preparation of the current survey. The research team obtained feedback from the IDS-TILDA Scientific Advisory Committee and drew on work with international collaborators including the T21RS (Trisomy 21 Research Society) group (<https://www.t21rs.org/covid-19/>). The research team also consulted with the Steering Committee at IDS-TILDA, who provided feedback that was incorporated into the survey. As public and patient involvement (PPI) remains central to IDS-TILDA, a consultation session on the proposed questions was held with adults with intellectual disability. The adults, members of the Inclusive Research Network, provided perspectives of their lived experience of the pandemic which informed aspects of the protocol. The questionnaire is openly available at the following link: <https://idstilda.tcd.ie/data/datacollectiontools/>

Measures

The questionnaire (see Survey development for link to the full questionnaire) will contain the following sections:

1. Health and COVID-19

Items gathered will include a rating of overall health (Likert scale, adapted from TILDA's COVID-19 survey; Ward *et al.*, 2021); five items from the "physical health problems" section of the Epidemic-Pandemic Impacts Inventory (EPII; Grasso *et al.*, 2020); symptoms of COVID-19 and their duration; frequency of COVID-19 testing and results of tests (from first IDS-TILDA COVID-19 questionnaire; McCarron *et al.*, 2020, updated for more recently identified symptoms of COVID-19 and "long COVID", i.e. COVID-19 lasting longer than 12 weeks); and contact with others who had COVID-19 (adapted from TILDA's COVID-19 survey).

2. Responding to COVID-19

Questions will establish if the participant moved from their home as a result of COVID-19 concerns; was there a plan to manage self-isolation; did hospitalisation/admission to intensive care (first IDS-TILDA COVID-19 questionnaire), household quarantine, and/or limiting of physical closeness with loved ones occur (from "physical distancing and quarantine" section of EPII); and whether participant received accessible information and how easy it was to understand on a four-point Likert scale (new items).

3. Infection control behaviours

Personal responses to improve infection control will be assessed using five items (e.g. "did you wash your hands more frequently than usual") (adapted from TILDA's COVID-19 survey).

4. Mental health during COVID-19 pandemic and lockdown

As well as asking for a rating of overall mental health (Likert scale, adapted from TILDA's COVID-19 survey), other items will address causes of stress/anxiety (first IDS-TILDA COVID-19 questionnaire); anxiety (GAD-7; Spitzer *et al.*, 2006, and Glasgow Anxiety Scale; Mindham & Espie, 2003); loneliness (UCLA loneliness scale; Russell *et al.*, 1980); depression (PHQ-9; Kroenke *et al.*, 2001); and whether the participant was able to access supports for mental health (new item).

5. Contact with others

Established items will ask for information on contact with family/friends in person; in writing or via technology (adapted from IDS-TILDA Wave 4); reduced hours of work/day service (adapted from "work and employment" section of the EPII); arguments/physical conflict at home (adapted from "home life" section of the EPII); and social activities ("social activities" section of the EPII).

6. Life events

Data will be gathered on major life events and level of stress caused (none/a little/a lot; adapted from Hermans & Evenhuis, 2012, and IDS-TILDA Wave 4 study); death of a person close to participant due to COVID-19 (Hatton, personal communication).

7. Positive aspects of the COVID-19 period

A series of questions will investigate positive aspects experienced during the COVID-19 period (adapted from first IDS-TILDA COVID-19 questionnaire and EPII).

8. Frailty

Standardized questions will gather information on changes in strength; mobility; falls; weight; new diagnoses (adapted from SARC-F, Woo *et al.*, 2014; and FRAIL scale items, Morley *et al.*, 2012).

9. Impact of COVID-19 on healthcare utilisation

Healthcare utilization questions will ask about appointment cancellations; whether health practitioners are usually seen once

a year, and whether this occurred since the pandemic began (adapted from TILDA COVID-19 questionnaire); information on new healthcare appointments (based on consultation with Inclusive Research Network); changes in medication and health supplements (adapted from TILDA COVID-19 questionnaire).

10. Vaccinations

A new area for data gathering, questions will address whether easy read information was received and how easy it was to understand; whether vaccine was received; which vaccine; date(s) of dose(s); what it means to the individual to have received the vaccine; side effects reported and their duration; location where vaccine was received and its convenience and whether someone known to participant accompanied them; and willingness to receive the vaccine (if vaccine has not been received) and, if not, the reason why not (new items).

11. Final questions

Open-ended questions will seek insights on the general impact of the pandemic on the individual's life and about their most anticipated activity following the end of the pandemic (new items).

Procedure

Building on the first IDS-TILDA COVID-19 survey and previous waves of the longitudinal study, field researchers will be trained to administer the survey sensitively and consistently. Following information on the background to IDS-TILDA and the COVID-19 survey, they will be instructed on their roles and responsibilities. They will be given training in the use of the survey software. Training on re-affirming consent, maintaining confidentiality and data protection will be provided, as well as instruction on what to do if there are serious concerns about a participant's mental health. The field researchers will be given the opportunity to roleplay the survey to practice its administration.

All participants will be contacted and their participation requested. Participants will either complete the survey by themselves, with help from someone who can assist them in answering the questions, or a proxy will respond on their behalf where the participant is unable to respond to the questions themselves. Consent will be reaffirmed verbally with participants before the survey begins. Written consent/assent was previously obtained for all participants to take part in Wave 4 of IDS-TILDA. A system of process consent will be in place, whereby the field researchers will check at regular intervals during the interview whether the participant is happy to continue participation, and will be alert to signs that the participant may not wish to proceed with further questions. The participants will be reminded at the outset that they are not obliged to answer any specific questions they do not wish to, and can withdraw from the interview at any point. A consent declaration was obtained from the Health Research Consent Declaration Committee (HRCDC) to facilitate the inclusion of individuals with intellectual disability. The HRCDC deals with situations where obtaining consent may not be possible, and the public interest of conducting the research outweighs the

need for the explicit consent of the participants. The granting of a consent declaration from this committee means that the consent of the individual is not required for the obtaining and use of their personal information for the health research concerned (see <https://hrcdc.ie/about-us/>). Easy read materials will be developed to assist participants in responding to the questions. Pilot testing with a research assistant with intellectual disability has indicated that the survey should take approximately 45–60 minutes to complete. The survey will be conducted via telephone/video call, and interviewers will enter the survey data into a software system.

Data analysis and statistical plan

Descriptive statistics will be calculated to describe the effects of the COVID-19 pandemic on the IDS-TILDA participants. Significance testing will help determine the level of differences between the first and second questionnaires where items are in common.

Dissemination plan

A report will be prepared on the results of this survey, similar to that which described the results of the previous survey (McCarron *et al.*, 2020). Updates will be provided to relevant stakeholders including the Department of Health. Results of this survey will also be published in academic journals, presented at academic conferences, and included in a webinar presentation on COVID-19 and people with intellectual disability offered by the authors.

Discussion

Among the key findings of our first survey, conducted from May–September 2020, were that most participants had been tested for COVID-19 but very few tested positive, there were no reports of participant mortality due to COVID-19, and a slight majority of participants reported positive aspects of the lockdown, but a similar proportion reported feeling stress/anxiety. The results of this second survey are likely to enhance our understanding of the impact over time of the COVID-19 pandemic and associated lockdowns on people ageing with an intellectual disability in Ireland. The survey will enhance our knowledge of infection control behaviours, the impact of the lockdown on social interaction and loneliness, and risk factors such as frailty and stressful life events. This survey will probe in greater depth about physical and mental health, as well as the level and nature of healthcare utilisation during the pandemic. The findings of this second questionnaire will be further enriched by information gathered on vaccination, including rates of vaccination, which vaccines are being employed, and what it means for people ageing with an intellectual disability to have received the vaccine. There are already similar research efforts underway in other countries and it will be important to compare findings as well as identify issues that have been unique to Ireland.

Notwithstanding the progression of vaccination, there may also be long-lasting effects of the pandemic and associated lockdowns, whether through “long COVID” or the psychosocial consequences of long periods of isolation from family or

friends and the disruption of daily life including day services and social activities. The findings here will provide a first picture of such experiences of people with intellectual disability in Ireland, and will inform rehabilitative models to support people post-lockdown, as well as informing the rebuilding of services (e.g. whether an increasing engagement with communication technology can be used to enhance healthcare provision and reduce loneliness). The first survey already provided an evidence base for the prioritisation of vaccinations for people with an intellectual disability in Ireland. Although some lockdown measures are currently being lifted in Ireland, the possibility that more restrictive rules may later be introduced (e.g. due to new strains of the coronavirus) cannot be ruled out, and so planning for future lockdowns is required. At time of writing, planning is underway for Wave 5 of IDS-TILDA, which will include an opportunity to gather more detailed information on the health and well-being of participants who

experienced the pandemic and to further assess the long-term consequences of the pandemic.

Study status

Data collection is currently underway for this study. We anticipate that data collection will be complete by the end of August 2021.

Data availability

No participant data are associated with this article.

Acknowledgements

This research would not be possible without the ongoing commitment of people with intellectual disability and their support staff and carers. We would like to acknowledge the commitment of our funders: the Department of Health and the Health Research Board, Ireland.

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Open Peer Review

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Reviewer Report 18 October 2021

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 **Angelo Carfi** 

Centro Medicina Dell'Invecchiamento, Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Università Cattolica del Sacro Cuore, Rome, Italy

Nothing to add.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Medical care of adults with Down syndrome and other intellectual disabilities

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 21 September 2021

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 **Yona Lunskey** 

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This is a very timely protocol, building off a unique cohort study of older adults with intellectual disabilities. The authors provide a strong justification and overview for their study, which is essentially a more in depth follow-up of the pandemic experience of a well studied group of adults in Ireland. They select several key topics: vaccination experience, Long COVID symptoms, and physical and mental health of aging adults. Each of these are important, and not well covered by the studies focused on the earlier stages of the pandemic. Furthermore, other studies tend to focus on younger adults and children, and few studies include the perspective of adults with ID, based on such a large cohort.

I particularly appreciated the inclusion of an advisory to select the measures and topics covered, and the various steps to ensure informed consent including "process consent." Some clarification on what the Health Research Consent Declaration Committee does would be helpful.

It would also be helpful to include a little bit more information about how health and social services are structured in Ireland and more detail on the IDS TILDA cohort. To contextualize findings, it would be good to know the types of congregate care there, and the proportion of people in the cohort who live in such settings. Low rates of COVID-19 in the cohort may be a reflection of overall rates in Ireland, or on the level of care and support available to people in the IDS-TILDA study relative to other adults with ID. Representativeness of the sample would be important to discuss in any reports based on this protocol.

With regard to measurement, it would be good to describe which measures designed for the general population have been adapted for people with ID (e.g., EPII, GAD-7, UCLA Loneliness scale). It would also be helpful to explain how analyses of self reported experiences will be conducted separately from when an informant responds to the items on behalf of someone with a disability.

There will be important lessons to learn from results of this wave of the IDS-TILDA study, relevant to other jurisdictions. I look forward to reading results when they are available.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Intellectual disability, health

I confirm that I have read this submission and believe that I have an appropriate level of

expertise to confirm that it is of an acceptable scientific standard.

Author Response 07 Oct 2021

Andrew Allen

We thank this reviewer for their positive appraisal of the article and for their approval.

This reviewer has noted a number of possible additions/changes that could benefit the protocol paper, and we believe these have indeed improved the quality of this protocol. We quote the comments and outline our responses below.

"Some clarification on what the Health Research Consent Declaration Committee does would be helpful."

We have added information on the role of the Health Research Consent Declaration Committee and the meaning of a consent declaration from this body, with a link to their website (see Procedure, second paragraph).

"It would also be helpful to include a little bit more information about how health and social services are structured in Ireland and more detail on the IDS TILDA cohort. To contextualize findings, it would be good to know the types of congregate care there, and the proportion of people in the cohort who live in such settings. Low rates of COVID-19 in the cohort may be a reflection of overall rates in Ireland, or on the level of care and support available to people in the IDS-TILDA study relative to other adults with ID. Representativeness of the sample would be important to discuss in any reports based on this protocol."

This is a valid point about settings in which people live. We have added the information to the introduction, fourth paragraph. As noted on pages 4 and 5, the IDS-TILDA sample as a whole is representative of people with intellectual disability aged 40 or over in Ireland.

"With regard to measurement, it would be good to describe which measures designed for the general population have been adapted for people with ID (e.g., EPII, GAD-7, UCLA Loneliness scale)."

Measurements or questions designed for the general population were not directly edited for accessibility. However, easy read materials for the overall questionnaire were developed, in consultation with the Inclusive Research Network, to assist people with intellectual disability in completing the survey (see Procedure, second paragraph). It is also the IDS-TILDA practice to pilot instruments and easy read materials with individuals with intellectual disability to ensure these accessibility steps are sufficient.

"It would also be helpful to explain how analyses of self reported experiences will be conducted separately from when an informant responds to the items on behalf of someone with a disability. "

We will look at overall trends in the data from the whole sample; we will also compare self-reported to proxy responses for key variables (e.g. anxiety or depression), similar our

analysis of the data from the first phase (McCarron *et al.*, 2020).

Competing Interests: None.

Reviewer Report 13 September 2021

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The manuscript outlines the methodology by which the second wave of a survey dedicated to assessing the impact of the Covid-19 pandemic on adults with intellectual disabilities will be conducted. The topic is of great interest as the impact of the pandemic on this often overlooked segment of the population has been extremely heavy.

The proposed methodology has many strengths:

- It is based on the experience of a very long running longitudinal study called IDS-TILDA.
- It has a longitudinal design.
- It has a holistic approach to the person with ID and investigates multiple domains impacted by the pandemic.
- I believe this methodological approach can serve as a useful example and incentive for other similar studies, and I anticipate that the data from this research will be extremely informative.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Medical care of adults with Down syndrome and other intellectual disabilities

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 07 Oct 2021

Andrew Allen

We thank this reviewer for their positive appraisal of the article and for their approval.

As there are no issues to be addressed reported by this author, we have not made any corresponding changes to this study protocol.

Competing Interests: None.