



STUDY PROTOCOL

Study protocol for TILDA COVID-19 survey. Altered lives in a time of crisis: preparing for recovery from the impact of the COVID-19 pandemic on the lives of older adults [version 1; peer review: awaiting peer review]

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V1 First published: 12 May 2021, 4:51
<https://doi.org/10.12688/hrbopenres.13248.1>
Latest published: 12 May 2021, 4:51
<https://doi.org/10.12688/hrbopenres.13248.1>

Abstract

Background: Older adults are the most at-risk of contracting severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), and among the most affected by measures put in place to prevent the spread of the virus. While the full effect of the public health measures, such as social distancing and wearing masks in public spaces, implemented since March 2020 are not yet known, it is expected that they will have a severely damaging effect on physical and psychological wellbeing. The Irish Longitudinal Study on Ageing (TILDA) has been researching the lives of older adults in Ireland since 2008 with data collection conducted at two-year intervals. With an established research infrastructure, TILDA was ideally placed to examine the effect of the coronavirus disease 2019 (COVID-19) pandemic on older adults. The aim of this study is to document the lives of older adults during the COVID-19 pandemic to understand the effect of the pandemic and public health responses on their wellbeing.

Methods: Data was collected from TILDA participants via self-completion-questionnaire (SCQ). The SCQ contains ten sections that capture information on many aspects of people's lives during the pandemic including, changes in behaviour and social interactions, physical and psychological wellbeing indicators, healthcare utilisation, and exposure to SARS-CoV-2. Ethical approval was granted by the National Research Ethics Committee (NREC).

Conclusions: Research findings will be shared in a variety of formats including research reports and briefs, presentations, and academic papers. Data will be archived in the Irish Social Science Data Archive (ISSDA) and the Inter-university Consortium for Political and Social Research (ICPSR). As well as documenting the impact of the COVID-19

Open Peer Review

Reviewer Status AWAITING PEER REVIEW

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pandemic on older adults, findings from this study will provide important information to policy-makers as we respond to the damage caused by the COVID-19 pandemic.

Keywords

COVID-19, SARS-CoV-2, older adults, ageing, TILDA, public health, social gerontology, survey methodology



This article is included in the [TILDA](#) gateway.



This article is included in the [Coronavirus \(COVID-19\)](#) collection.



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Competing interests: No competing interests were disclosed.

Grant information: Health Research Board Ireland under the Rapid Response Research and Innovation Fund [COV19-2020-070]. TILDA is co-funded by the Government of Ireland through the Department of Health, by Atlantic Philanthropies, and by Irish Life PLC. *The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.*

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How to cite this article: Ward M, Clarke N, Wang M *et al.* **Study protocol for TILDA COVID-19 survey. Altered lives in a time of crisis: preparing for recovery from the impact of the COVID-19 pandemic on the lives of older adults [version 1; peer review: awaiting peer review]** HRB Open Research 2021, 4:51 <https://doi.org/10.12688/hrbopenres.13248.1>

First published: 12 May 2021, 4:51 <https://doi.org/10.12688/hrbopenres.13248.1>

Introduction

The Irish Longitudinal Study on Ageing (TILDA) has been researching the lives of older adults in Ireland since 2008. Since recruiting 8,172 community-dwelling adults aged 50 years and older for the first wave of data collection in October 2009 to February 2011, TILDA has interviewed the same participants every two years (Donoghue *et al.*, 2018; Kearney *et al.*, 2011; Kenny *et al.*, 2010; Whelan & Savva, 2013) and conducted comprehensive health assessments at waves 1 and 3 at a health assessment centre (Cronin *et al.*, 2013). The cohort of older adults that TILDA represents are both the most at-risk of contracting severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), and among the most affected by measures put in place to prevent the spread of the virus. The latter was particularly true in the early stages of the response to the pandemic when all adults aged 70 years and older and individuals with medical conditions that put them at an increased risk of severe coronavirus disease 2019 (COVID-19) infection in Ireland were required to stay at home and to limit face-to-face interactions with people from outside their own household.

As the COVID-19 pandemic took hold in Ireland in March 2020, TILDA had completed the pilot stage of wave 6 computer assisted personal interviews (CAPIs) and were preparing to pilot its physical health assessments. Government restrictions brought in to protect the population from the SARS-CoV-2 virus meant that this planned phase of the study had to be postponed. Wave 6 interviews will now be conducted via computer assisted telephone interviews (CATI) with piloting completed in early 2021 and full roll out is currently underway. The health assessment has been postponed until wave 7 (2022–2023) and is contingent on multiple factors, including the extent of COVID-19 restrictions caseload and the success of vaccine roll out at this time.

While the full effect of the public health measures implemented since March 2020 are not yet known, it is expected that they will have a damaging effect on the economic, social, physical, and psychological wellbeing of the population (Holmes *et al.*, 2020; Niedzwiedz *et al.*, 2021), not least older adults (Carr, 2021; McGrath *et al.*, 2020). It is critical that these consequences are identified as quickly as possible so that the most damaging repercussions can be mitigated, and the wellbeing of older adults fully restored and maintained.

When the COVID-19 pandemic reached Ireland in March 2020, TILDA was uniquely positioned to document the impact the pandemic has on the lives of older adults and with the support of the Health Research Board, TILDA surveyed its existing participants between July and November 2020. Here we describe in detail the procedures adopted by TILDA to conduct a COVID-19 specific study among older adults in Ireland. We provide details of the study aims, survey instrument, data collection procedures, ethical considerations, and study work packages.

Study aims

The overall aim of this study is to document the lives of older adults during the COVID-19 pandemic to understand the effect of the pandemic and public health responses on their wellbeing. Specifically, the study aims to:

- 1) Provide a description of the experience of COVID-19 symptomatology and testing among older adults.
- 2) Describe levels of adherence to public health guidelines intended to halt the spread of the virus.
- 3) Examine health-related, caring, and other unmet needs.
- 4) Measure change in wellbeing and examine whether this varies across groups defined by gender and other socio-demographic characteristics, socioeconomic status, coexisting conditions, and existing psychological ill-health.
- 5) Examine whether older adults experienced ageism or discrimination during the pandemic.
- 6) Describe how public health information was received and understood.

Protocol

Study design

Due to restrictions put in place in response to the COVID-19 pandemic in March 2020, it was not possible to conduct face-to-face interviews. Therefore, data was collected from participants via Self-Completion-Questionnaire (SCQ). These questionnaires were posted to the homes of existing TILDA participants and once completed, they were returned to TILDA by pre-paid post.

Sample

All existing TILDA participants, first recruited in 2009/2010, were invited to participate in the study. A total of 5,535 questionnaire booklets were posted to the participants and 3,922 aged 59 years and older of those responded, giving a response rate of 71%.

Survey instrument

The design of the SCQ was guided by three important considerations. Firstly, where possible, we included indicators and question wording that have been routinely collected over the lifetime of TILDA. By doing this, we can examine how the pandemic has changed the lives of older adults over time. Secondly, TILDA is part of the Health and Retirement Study (HRS) family of cohort studies and as such we aimed to collect information that was comparable to similar studies being conducted in other jurisdictions such as the English Longitudinal Study of Ageing (ELSA); the Health and Retirement Study (HRS); and the Survey of Health, Ageing and Retirement in Europe (SHARE). This will enable to assess the impact of policy responses to the pandemic in different contexts. Data harmonised between these and other studies will be available at a

later date from public data archives including the [Gateway to Global Aging](#). Thirdly, our choice of indicators included in the questionnaire was informed by the World Health Organisations (WHO) [COSMO toolkit](#). This toolkit provides guidance for the development of survey instruments to capture insights into changes due to the COVID-19 pandemic.

The TILDA SCQ contained ten sections that capture information on many aspects of people's lives during the pandemic. The contents of each section are summarised in [Table 1](#).

Data collection procedures

The questionnaire, participants information leaflet (ILF), and the informed consent form (ICF) are provided as extended data ([Ward, 2021](#)). [Figure 1](#) shows each step from securing ethical approval and posting the questionnaire and accompanying ILF, and ICF, to public data archiving in the Irish Social Science Data Archive (ISSDA) and the Inter-university Consortium for Political and Social Research (ICPSR). The most important considerations at each stage of this process, are data quality and adherence to data protection legislation.

Data analysis

A first research report has been published ([Ward et al., 2021](#)). This report describes the daily lives during of older adults during initial months of the pandemic, and examines how

changes participants have made to their lives have impacted on physical and mental wellbeing. The report also describes peoples' exposure to the virus as well as that of their families and friends. A number of research articles that examine in greater detail the topics captured in the survey questionnaire are currently in preparation for publication in 2021.

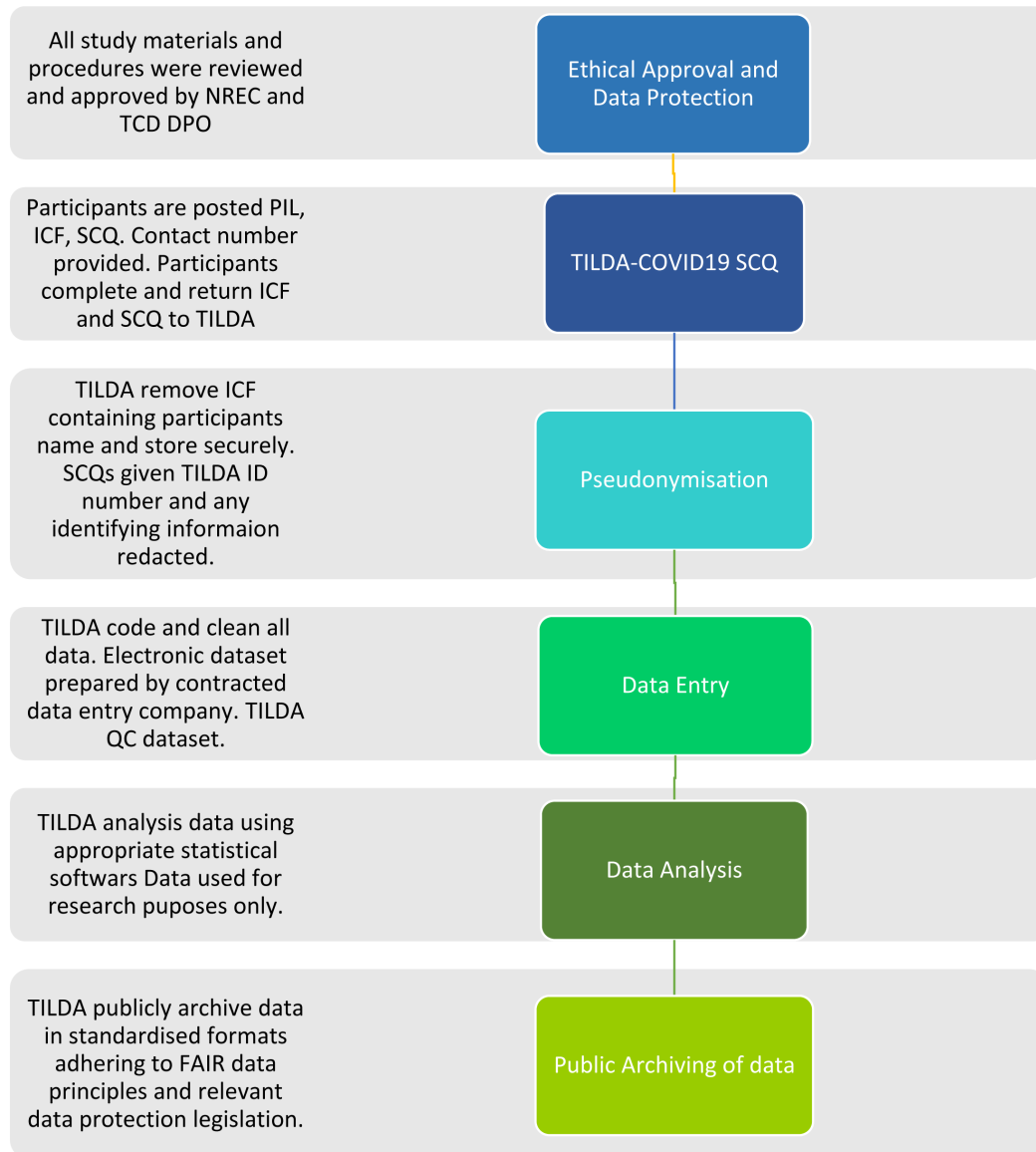
Within the TILDA study team, data analysis is conducted using Stata/MP 14.2 or later ([StataCorp, 2015](#)). Public data files will be made available in the most commonly used quantitative analysis formats (SPSS/Stata/SAS/R).

Ethics and data protection

Ethical approval for the wider TILDA study is granted for each wave of data collection by the Faculty of Health Sciences research Ethics Committee at Trinity College Dublin (Wave 6 REC Ref: 190407). TILDA adheres to the guidelines set out in the 1964 Helsinki declaration and its later amendments. The TILDA COVID-19 study was granted ethical approval from the National Research Ethics Committee (NREC) in June 2020: NREC Application number: 20NREC-COV-030-2. In addition to the SCQ, participants were posted a participant information leaflet (PIL) and informed consent form (CIF) to read and sign. The participant information leaflet and consent form were reviewed and approved by the Trinity College Dublin Data Protection Officer in addition to NREC. Fully

Table 1. Content of the TILDA COVID-19 SCQ.

Domain	Contents
Preventative behaviours & precautionary measures	Usual daily activities; social distancing; adherence to preventative hygiene behaviours; change in behaviours; living arrangements; access to outdoor spaces.
Social contacts, activities & health behaviours	Face-to-face contacts; contact by phone, email etc.; smoking; alcohol consumption; physical activity; food affordability.
Health and well-being	Eye colour; self-rated physical health; self-rated mental health; life satisfaction; UCLA loneliness measure (Russell, 1996); CES-D8 depression scale (Radloff, 1977); CASP-12 quality of life (Hyde et al., 2003); Ryff Purpose in Life sub-scale (Ryff, 1989); PSS-4 Perceived Stress Scale (Cohen et al., 1983); GAD-7 Anxiety Scale (Spitzer et al., 2006); sleep patterns; quality of relationships.
Economic well-being	Employment situation; receipt of pandemic unemployment payment; income; household spending; household expenses; savings; general financial situation.
Caring	Caring for others; receipt of state services; help received.
Healthcare utilisation	Healthcare needs; unmet healthcare needs; telephone and online healthcare appointments; medications; health supplement use.
Information sources	News sources, frequency and level of trust; understanding of government guidance; knowledge of COVID-19.
Ageism & discrimination	Perceived ageism; experience of ageism; agreement with cocooning policy.
COVID-19 exposure and testing	Concern with COVID-19; symptoms and diagnosis of COVID-19
Two free text questions	(1) How would you describe the general impact that the COVID-19 pandemic has had on your life during this period? (2) What is it that you are most looking forward to do once COVID-19 ends?



Notes: PIL: Participant Information Leaflet; ICF: Informed Consent Form; SCQ: Self-Completion Questionnaire; GDPR: General Data Protection Regulation; DPO: Trinity College Dublin Data Protection Officer.

Figure 1. Description of TILDA COVID-19 study data collection procedures.

informed written consent was requested of all participants wishing to participate in the study. Participants have been part of TILDA for over ten years and are very familiar with the consent process. Once returned, SCQs were coded with a unique TILDA serial identification number and do not contain any personal identifying information such as name or home address. If a participant provides any identifying information, for example, by naming an individual or organisation, this too is redacted prior to data analysis. This study adheres to General Data Protection Regulation (GDPR) and Health Research Regulations (HRR) and has numerous safeguarding measures in place to protect participants.

Data sharing will be in line with participant consent and relevant codes of conduct and legislation. TILDA also set up a direct contact number for participants to contact should they have had any questions or concerns.

Data availability

The data generated by this study will be made publicly available in the second quarter of 2021. This is in accordance with the requirements of the Health Research Board’s data sharing policy. Data will be shared according to the FAIR data research principles to ensure data is findable, accessible, interoperable and reusable. The TILDA COVID-19 SCQ dataset will

be made publicly available in accordance with established TILDA data sharing processes that adhere to European Union and national data protection regulations (GDPR and HRR). The data file, codebook, and accompanying documentation will be made available via the Irish Social Science Data Archive (ISSDA, University College Dublin) alongside existing public [TILDA data files](#). The fully pseudonymised public dataset will also be made available via the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan and the Gateway to Global Aging for the purpose of long-term data storage and dissemination. International researchers and educators from within and outside the European Economic Area can apply to access this data for teaching and research purposes. Again, individual identifiers will not be included in these datasets and data will be shared in line with participant consent and relevant data protection legislation. Contractual arrangements will be put in place prior to any data transfers.

Description of work packages

The study is organised around four work packages. Work Package 1 (May – October 2020) includes questionnaire design, data collection and preparation. Work Package 2 (October – January 2021): the rapid dissemination of a research report describing the altered lives of older adults and the consequences of the COVID-19 pandemic for the wellbeing. Work Package 3 (January – August 2021): In WP3, data generated by the COVID-19 project will be linked with 10-years of TILDA data previously collected across five waves from these same participants. This will enable us to examine how the pandemic has altered the lives of older adults by comparing their status during the pandemic to that of the preceding ten years. Finally, Work Package 4 (January – March 2021) involves the preparation of the COVID-19 SCQ data for public archiving. Data sharing will adhere to FAIR (Findable, Accessible, Interoperable and Reusable) principles, and will be in line with participant consent and GDPR.

Study status

Data collection took place between July and November 2020. A research report describing the main findings from the data was published in January 2021 ([Ward et al., 2021](#)) and a number of research articles are currently in preparation. As described above, publicly accessible data files containing the data collected in this study are currently being prepared.

Conclusion

The data generated by the study will be further enriched by linking it to the ten years of data previously collected by TILDA. As such, this study will truly provide a comprehensive record of the extent to which the lives of older adults in Ireland have been altered by the COVID-19 pandemic. We hope that this information will prove useful in efforts to mitigate the harmful repercussions of the pandemic among older adults' and contribute to our recovery. We also hope that this protocol may prove useful to other researchers' efforts to conduct research with older adults during the pandemic and beyond.

Data availability

Underlying data

No data are associated with this article.

Extended data

Harvard Dataverse: TILDA COVID-19 study. <https://doi.org/10.7910/DVN/UJCWIT> ([Ward, 2021](#)).

This project contains the following extended data:

- TILDA COVID SCQ - Information sheet.pdf
- TILDA COVID SCQ - Questionnaire and consent.pdf

Data are available under the terms of the [Creative Commons Zero "No rights reserved" data waiver](#) (CC0 1.0 Public domain dedication).

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