Why is this study being done?

The Irish Longitudinal Study on Ageing (TILDA) is the most comprehensive study of adults aged 50 years and over, ever undertaken in Ireland. In early 2020, the world experienced the global pandemic of Coronavirus (COVID-19). This pandemic has directly affected the lives of everyone in Ireland; particularly those over 50 years old. We believe it is vital that the lived experience of the over 50s in Ireland is collected and documented. It is important this information leads to new policy developments and changes in society which may minimise any negative effects of COVID-19. We hope to examine:

- health-related, caring, and other social needs;
- measure changes in wellbeing and
- examine whether older adults experienced ageism or discrimination as a result of COVID-19.

We will do this via your participation in a Self-Completion Questionnaire (SCQ).

We hope that you will take part in this SCQ and contribute to our understanding of the experience of growing older in Ireland, particularly during the COVID-19 pandemic.

Why have I been invited to take part?

We are very interested in looking at how the situations and experiences of adults aged 50 years and over in Ireland have changed due to COVID-19. Each TILDA participant is invaluable, and your continued support has contributed hugely to the success of the TILDA study so far.

Do I have to take part? Can I withdraw?

We rely on voluntary participation and therefore, the success of the study depends on your goodwill and co-operation. However, participation is voluntary. If you do not wish to participate in this COVID-19 specific piece of research, simply do not return the SCQ. We will be in touch again in the coming months to invite you to take part in TILDA Wave 6 (standard data collection & health assessment).

What will happen if I decide to take part?

Self-Completion Questionnaire

Please read this information leaflet and sign the accompanying consent form. The Consent form must be signed to allow us to use the information you provide in the SCQ. Simply complete the SCQ and post it back to TILDA in the stamped addressed envelope provided.

Are there any benefits to taking part in this research?

By participating in TILDA-COVID 19, you are helping to highlight the effect COVID-19 has had on people aged 60+ in Ireland. TILDA's mission is to make Ireland the best place in the world to grow old. Your experience of COVID-19 can help shape Ireland's response in the future.

Are there any risks to me or others if I take part?

You may find the topics raised in this questionnaire to be distressing or upsetting. While we appreciate it may be difficult for you to answer some questions, please try your best. We hope your input will provide TILDA with important information to help us understand how Covid-19 has affected you and people aged 60+ in Ireland. Please contact one of the support helplines provided at the end of this leaflet if you feel this may be of benefit to you.

There is always a potential risk of a data breach when any information is collected. This study has been reviewed by TCD data protection office and he risk of such a data breach is deemed as low. A stamped address envelope is provided to minimise the risk of a data breach.

Will I be told the outcome of the study?

TILDA uses your data along with more than 6,000 other people's data. It is unlikely any specific finding will relate to you personally. We present the findings from TILDA through public media, at public talks, scientific conferences and in scientific journals, both nationally and internationally. Your identity is not disclosed in any publication or presentation. Please look out for our reports on the television, radio and in newspapers.

Data Protection

What information about me (personal data) will be used as part of this study?

We collect information on your experience of life during the COVID-19 pandemic. Data becomes more useful the longer we store it as it shows changes over time.

For this reason, we will store the data we collect about you indefinitely. Further information about how we manage your data is available in the TILDA Privacy Notice, available on www.tilda.ie.

Who will access and use my personal data as part of this study?

TILDA COVID-19 is carried out by the TILDA research team at Trinity College Dublin.

Your privacy is important to us. The information you provide is held securely in Trinity College Dublin.

Identifiable information: Only the TILDA research team (TCD) have access to your identifiable data (name, address, date of birth).

Coded data: This is where we replace your name with a study ID number. Any other national or international research groups (universities and hospitals) working with TILDA receive Coded Data.

We also archive coded data in The Irish Social Science Data Archive (ISSDA) so that other research teams can learn from it too. This archive does not contain any identifying information about you.

TILDA uses third parties for specific study related tasks: These include;

- An Post
- Custodian Printing
- SeefinDM Data Management
- Iron Mountain File storage

What is the lawful basis to use my personal data?

This research is in the public interest. We also ask for your consent as this is health research.

What are my rights?

You can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is held anonymously)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and have it transferred to another data controller
- The right to request deletion of your data

If you withdraw your consent for participation, we will no longer contact you to collect any new information. We may keep any information we have collected up until this point.

You can exercise these rights by contacting TILDA or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie.

Website: www.tcd.ie/privacy.

If you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland.
Website: www.dataprotection.ie.

Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the COVID-19 National research ethics committee, set up by the Department of Health to conduct research in Ireland on COVID-19.

Who is organising and funding this study?

TILDA COVID-19 is funded by the Health Research Board. Some staff in the TILDA research team also use this CODED data for obtaining academic qualifications.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying people to take part in the study.

Future Research

Will my personal data be used in future studies?

TILDA is an ongoing study started in 2009. It hopes to run far into the future. With your consent, we will use your data

to answer lots of different questions about ageing in Ireland. This COVID-19 data will provide important information about your experience of the COVID-19 pandemic. We hope this research will continue for many years.

Further Information

Will I be contacted again?

We will contact you to remind you to return the self-completion questionnaire. TILDA hopes to recommence Wave 6 data collection in the coming months and so we will be in touch with you to book your home interview.

Who should I contact for more information?

If you have any concerns or questions, you can contact:

TILDA: Phone: 01 896 2509
Email: tilda@tcd.ie

Data Protection Officer: Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy

Thank you for your participation in TILDA COVID-19

The Irish Longitudinal Study on Ageing (TILDA)
Trinity Central
152-160 Pearse St
Dublin 2
D02 R590
Republic of Ireland
tilda@tcd.ie

If you are affected by any of the issues raised in this questionnaire or are looking for information on COVID-19 (coronavirus) please contact:

ALONE COVID-19 support line (Monday to Friday, 8am-8pm): 0818 222 024.

The **Age Action Information Service** is available Monday to Friday, 9.30am – 5pm, 01 4756989.

COVID Community Response is a national support helpline for individuals and organisations seeking assistance from their local community during the COVID-19 pandemic. You can text or call the numbers below to request assistance through available volunteers. COVID Community Response: TEXT: 086 180 0256 or CALL: 021 237 7809.

Family Carers Ireland will answer carers' specific queries: 1800 24 07 24.

The **Health Service Executive (HSE)** helpline, which you can call Monday to Friday: 8am - 8pm, and Saturday and Sunday 9am – 5pm. Phone: 1850 24 1850 Phone: 041 6850300.

The **Irish Hospice Foundation** have a Bereavement Support Line that aims to provide connection, comfort and support in these exceptional times. This service can be contacted by freephone 1800 80 70 77 from 10am to 1pm, Monday to Friday.