



**Irish
Hospice
Foundation**

To die and grieve well wherever the place



Time to Reflect: a survey about
life, death and bereavement
during a pandemic

Every story counts. Share yours.

About Time to Reflect

Participant Information

STUDY TITLE: Time to Reflect: a survey about life, death and bereavement in a pandemic*

Study team

**Principal Investigator /
Study Lead:**

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Ms Sharon Foley, Chief Executive Officer,
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* When seeking ethical approval for this study, it was referred to as the 'Reflections on dying, death and bereavement in Ireland during the COVID-19 pandemic study'

About the study

We invite you to take part in this research study that is being carried out by Irish Hospice Foundation (IHF), a national charity focused on dying, death and bereavement in Ireland.

Before you decide whether you wish to take part, please read the information provided below carefully.

It's important that you understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

We encourage you to take your time to decide if you want to take part. If you have any questions, you can contact the study lead, Dr Helen Coughlan, at Irish Hospice Foundation. Her details are at the top of this information leaflet.

You do not have to take part in this study. You can stop your participation at any time before you submit your responses to the study team.

Why is this study being done?

We're conducting this study to better understand what people think about dying, death and bereavement in Ireland. We are particularly interested in understanding how the COVID-19 pandemic has affected people's views and experiences.

We will use findings from this study to advocate for quality care and support for people at the end of their life and for their families. We will also use findings from this study to strengthen our work to ensure that people who have been bereaved can access the support they need.

Who is organising and funding this study?

Irish Hospice Foundation (www.hospicefoundation.ie) is organising and funding this study. At Irish Hospice Foundation, our vision is that every person who experiences dying, death and bereavement gets the care and support they need when and where they need it.

Why am I being asked to take part?

Anyone aged 18 years or over who lives in Ireland can take part.

We want to hear from as many adults living in Ireland as possible. You do not have to have experienced a personal bereavement to take part. The more people who take part in this study, the better our understanding of the impact of the pandemic will be.

How will the study be carried out?

The study will take place in October and November 2021.

This study involves a short questionnaire. There is a web/online version and a paper version of the questionnaire. We expect over 1,000 people to take part.

The study is anonymous. No identifying information about you will be collected and you will not be asked to share any information that would identify you.

What will happen to me if I agree to take part?

Taking part means that you will be invited to complete either a paper or a web version of the study questionnaire. If you opt for a paper version of the questionnaire, we will send one to you to complete, along with a freepost return envelope.



The questionnaire should take around **7-15 minutes to complete**. The time it takes will depend on whether you have been bereaved during COVID and how much you share about your experiences. The questionnaire asks questions about if and how your views and experiences of end-of-life care, death and bereavement were affected by the pandemic.

There are three parts to the questionnaire.

Section A is for everyone. In this section you will be asked about your views on dying, death and bereavement during the COVID-19 pandemic

Section B is for people who experienced the death of someone close to them during the pandemic. If you did not experience the death of someone close to you during the pandemic, you will not be asked to complete this section

Section C is for everyone. In it, you will be asked some general questions about things like your age, your gender, your ethnicity, etc

For most questions, you will be asked to tick a response that best reflects your view or experiences. For some questions, you will be invited to write or type a response.

As part of the questionnaire, you will be asked about your gender, your age, your ethnicity and whether you live in a rural, town or urban location. This will allow us to understand the impact of the pandemic on different groups of people across Ireland.

What are the benefits to taking part?

You may not benefit directly from taking part in this study. However, your contribution will make a difference to end-of-life and bereavement care and support in Ireland.

What are the risks to taking part?

This study asks questions about death and loss. Some of the questions might make you feel upset. If you have experienced a recent or difficult loss in your life, taking part in this study may trigger some of the memories and emotions related to your experiences.

If you do feel upset during or after the study and are looking for support, we encourage you to phone our **Bereavement Support Line at 1800 80 70 77**. **The support line is a national freephone service.** It offers confidential listening support to anyone affected by loss, death and bereavement. It is available from 10am-1pm Monday to Friday. Some other support services and helplines are also listed at the end of the questionnaire.

Is the study confidential?

All information you provide for this study will be treated confidentially.

The questionnaire is anonymous. You will not be asked to provide any information that will identify you. That means that the study team will have no way of identifying anyone who takes part in this study.

To protect your own identity, please do not write your name or address anywhere on your questionnaire.

Each completed questionnaire will be given a code so we can analyse the information we gather. The codes will be a random sequence of numbers. We will have no way of linking a person to the code that is assigned to their questionnaire.

Some questions will invite you to write details about your views or experiences. If you choose to answer those questions, **please do not include the names or other information that might identify you or another person.**

A member of the study team will check all responses for potentially identifying information such as the names or addresses of people. To protect the identity of people and places, any potentially identifying information will be replaced with a general descriptor. For example, if you accidentally named a person in one of your answers, we will replace the actual name of the person with the word 'name' or 'relative' before we analyse the responses.

We are using SurveyMonkey for the web version of the study. It is important to note that there is always some level of risk to privacy and anonymity when using the internet. We have taken every measure we can to protect your anonymity. That means no identifying data about you will be collected via the Survey Monkey platform. Details about your computer IP address will not be collected. You can get more details on the security and privacy settings on SurveyMonkey at:

https://help.surveymonkey.com/articles/en_US/kb/How-do-I-make-surveys-anonymous

Voluntary participation

Participation in this study is completely voluntary. You do not have to take part.

If you do take part, you can choose not to answer some of the questions. If you begin the web version of the questionnaire, you can opt out at any time before you submit your responses by closing your browser.

Data protection and usage

We will be using your questionnaire responses as part of our research on the impact of the COVID-19 pandemic on people's views and experiences of dying, death and bereavement.

This study follows best practice in relation to data protection. This means that all data that are collected for this study will be stored securely and confidentially by Irish Hospice Foundation. As this is an anonymous study,



it does not fall under the General Data Protection Regulations (GDPR). The study is also in compliance with all ethical requirements. Ethical approval for this study has been granted by the Research Ethics Committee of Royal College of Surgeons in Ireland (RCSI).

The only people who will have access to the survey information are people who are part of the study team. Along with the team members named on this information leaflet, we (Irish Hospice Foundation) may employ one or more researchers to analyse the data collected for this study. The information we collect will be stored in digital format. That means it will be inputted into a spreadsheet and stored on a secure server within Irish Hospice Foundation.

If you complete a paper version of the study, your survey will be stored in a locked filing cabinet in the offices of Irish Hospice Foundation. Someone from the study team will transfer your responses into the computer file. This is to make sure that your information can be analysed with the rest of the study responses. Digital study files and completed paper surveys will be held securely at Irish Hospice Foundation for a period of five years. After that, they will be destroyed.

Because the study is anonymous, it will not be possible to withdraw your survey information once you have completed the web version or posted in a paper version.

If you take part in the study and later contact a member of the study team, your participation in the study will no longer be anonymous. However, we will still be unable to connect you with your survey responses because the survey is anonymous.

Consent to future uses

The information (data) we collect from you may be used for additional research that we conduct within the five years following this study. For example, we may wish to do more in-depth analysis of the data we have or to combine the data from this study with a later study to compare findings across time.

By participating in this survey, you are also agreeing that we may include your anonymous questionnaire responses to share our study findings. Ways we might share our findings include reports, journal articles, press releases, teaching and other presentations. We may also use creative ways of translating study findings. For example, we might combine some of the free text responses to create animations that capture people's experiences.

When we share findings from the study in reports or in other types of outputs, we may include direct excerpts from some of your free text survey responses.

Where can I get further information?

If you have any questions about the study or if you need any more information now or at any time in the future, please contact, Dr. Helen Coughlan at Irish Hospice Foundation, Morrison Chambers, Dublin 2.
E: helen.coughlan@hospicefoundation.ie **T:** 01 679 3188.

If you want to learn more about Irish Hospice Foundation and our work, you can visit our website at www.hospicefoundation.ie.

For more information about this survey, go to www.hospicefoundation.ie/timetorelectsurvey. A link to a print version of the questionnaire is available there. You can also request information or a paper copy of the questionnaire by emailing timetorelect@hospicefoundation.ie.

To complete the survey online, please go to www.surveymonkey.com/r/IHFtimetorelect.

Support

We understand that issues around dying, death and bereavement are sensitive. Taking part in a study exploring these issues may cause you to feel upset. Here are details of some of services that may be able to offer you support if you need it:

IRISH HOSPICE FOUNDATION BEREAVEMENT SUPPORT LINE

www.hospicefoundation.ie

Freephone: 1 800 80 70 77

Our Bereavement Support Line is a national freephone service that is available from 10am to 1pm, Monday to Friday. It provides a confidential space for people to speak about their experiences or to ask questions about the death of someone in their lives. When you phone, a trained volunteer will listen to you and provide you with emotional support. They will also try to direct you to practical support if you need it. The support line can also be used by people in work settings who want information about how to support a bereaved colleague.

BEREAVEMENT INFORMATION HUB

www.bereaved.ie

The bereavement information hub is part of the information provided by Irish Hospice Foundation. Here you will find information and resources about all aspects of grief and bereavement.

ALONE

www.alone.ie

COVID-19 helpline number for older people: 0818 222 024

ALONE provides a number of support services for older people. These include their Befriending support service for older people who are isolated and feeling alone. They also have a helpline for older people who are concerned about the pandemic.

TEXT 50808

www.text50808.ie

Text number: 50808

Text 50808 is a free text support service for people who are in distress or struggling with their emotional or mental health. Trained volunteers are available 24/7 to provide support, including support for people in crisis.

COUNSELLING IN PRIMARY CARE

www.hse.ie

Counselling in Primary Care is a free HSE counselling service for people aged 18 and over who hold a medical card. People can access up to 8 counselling sessions in their local health centre. Referrals can be made through a GP.

IRISH ASSOCIATION FOR COUNSELLING & PSYCHOTHERAPY (IACP)

www.iacp.ie

The IACP is an umbrella organisation for qualified and accredited counsellors and psychotherapists across Ireland. You can search for therapists in your area on the website.





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