



## Information Leaflet: A Case Study on Mourning, Emerging Technologies, and Public Health in Ireland

### Invitation Paragraph

We are inviting you to take part in a study about how mourning rituals in Ireland changed during the COVID-19 pandemic. We especially want to understand how new technology tools (for example, online condolence books or live-streamed funerals) affected these rituals and influenced public health. Participation is voluntary.

Before you decide if you want to take part, it is important for you to understand why the research is being done and what taking part involves.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

### What is the purpose of the study?

Our aim is to find out how mourning rituals in Ireland have changed during the COVID-19 pandemic. We will look at how new technology tools changed people's experiences of mourning and explore whether mourning has been a social or cultural factor that influenced health for individuals and communities during and after the pandemic. This research will serve to help us understand modern mourning practices in Ireland and the impact of COVID-19 and technology.

We plan to collect information relating to:

- Basic information about participants, including:
  - Name
  - Age
  - Gender
  - Religion
  - Education level
  - Occupation
  - Geographical region
  - Contact information (phone, email, address)
- We will ask questions about your personal experiences of mourning, including:
  - Mourning experiences before COVID-19



- Mourning experiences during COVID-19
- Use of technology such as online condolence books and live-streaming of funerals
- We will observe and discuss your use of technology in mourning

This research project is being conducted by Shannon Mora, a PhD researcher in the Department of Digital Humanities and Culture in the School of Languages, Literatures and Cultural Studies, Trinity College Dublin. The project forms part of her doctoral research and is expected to last until 31 March 2027.

### Why have I been chosen to participate?

We are interested in understanding the experiences of mourning before and during COVID-19 from 2020-2022, including the use of technology such as online condolence books, live-streamed funerals, or other similar tools used in mourning. You do not need to be skilled or knowledgeable in technology. We want perspectives from all individuals in Ireland.

You are receiving this leaflet because you contacted us after hearing about the study on the radio, on our project website, or through someone you know.

We plan to include around 16 people in this study, focusing on those over 50 years of age who have experienced both traditional mourning practices and any changes that happened during COVID-19.

### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information leaflet, asked to read this information leaflet and keep a copy, and asked to sign a consent form.

If you decide to take part, you are still free to change your mind at any time and without giving a reason.

Participation in this study is entirely voluntary. You may withdraw from the study at any time during the interview process and up to 90 days after the completion of this interview on or before (date): \_\_\_\_\_. To withdraw, please send a written request by email to Shannon Mora at [moras@tcd.ie](mailto:moras@tcd.ie).

Your email should include:

- Your full name
- A short note stating that you wish to withdraw from the project

After the withdrawal deadline, it may no longer be possible to remove your data, as analysis or archiving may have commenced.



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

This study involves the following stages:

### 1. Interviews and Observation

You will be invited to do three interviews about your experiences of mourning. We want to hear how you felt about changes in mourning, including any new technology tools you used (or did not use), and how these changes may have affected your health and well-being. We will record the interviews using an audio recorder. Each participant will be asked to complete a series of three separate interviews, including a pre-interview and post-interview session. We expect your involvement to include:

- Pre-interview session and consent forms: 30-45 minutes
- Three interview sessions consisting of:
  - Pre-session briefs: 10 minutes
  - Interviews: Approximately 1 hour
  - Post-session debriefs: 10 minutes
- Review of interview transcripts (optional): 2.5 hours
- Post-interview session: Approximately 1 hour

Total time commitment ranges from 9 hours to 10.5 hours.

**Permission to use your recordings:** Before we begin recording, you will need to read and agree to sign a participation agreement. This only gives us permission to record the interview and not to do anything with it. After the interview, you will be asked to sign a recording agreement. Signing this form means that you are allowing the researcher to use your interview in the ways listed. This also means that you are giving copyright of this material to the research project, on the understanding that it will not be used in a derogatory manner and that you will not be identified in any future uses of it. If you have any questions about this, please do not hesitate to contact Shannon Mora in advance of your interview. Immediately after the interview, you will be asked to sign a second consent form permitting the use of the interview.

### 2. Transcription

We will type up the interview's audio recordings word for word. We will use a secure online service for typing up the interviews, which follows data protection rules in the European Union.

### 3. Review of Transcripts

After the interviews are typed up, we will send you the text so you can check it. You can remove anything that identifies you or anything else that you feel uncomfortable sharing. You can also set any conditions you want for future use of the interview.

### 4. Storing and Maintaining the Data

#### Original Recordings and Transcripts

- We will keep your original recordings and original transcripts in a secure online system and on a secure computer drive that only the researchers can access, for 5 years.
- These documents will be identifiable as your data and will not be de-identified.
- We will use a secure online service for typing up the interviews, which follows data protection rules in the European Union.



### **Consent Forms and Contact Information**

- Your consent forms will be stored in a locked filing cabinet for 5 years.
- We will store your personal details and contact information in a separate secure online system and on a secure computer drive that only the researchers can access for 5 years.
- These documents will be identifiable as your data and will not be de-identified. These documents will not be shared with anyone outside of the research team.

### **De-identified Recordings and Transcripts**

- The de-identified interview recordings and transcripts will be stored until we finish studying the information and place it in a safe archive for future research.

### **What are the benefits of taking part?**

We hope the results of the study will help us to understand technology use during mourning and how mourning has changed in Ireland. There will be no direct benefits to participants, however, by sharing their thoughts, feelings, and knowledge during interviews, participants will contribute to the historical record of a major event during their lifetime, which provides an opportunity for empowerment. The interview process will provide time and space for participants to reflect on their experiences, which could result in increased self-awareness and understanding of their mourning rituals.

### **What are the possible disadvantages and risks of taking part?**

Discussing or reliving memories of death and loss could evoke feelings of guilt, regret, anxiety, or shame, introducing psychological discomfort. Participants might also feel distressed upon reviewing the transcripts during post-interview sessions or dissemination. To mitigate any negative emotional impact, especially considering that individuals who are mourning may be considered a vulnerable population, I will implement the following measures:

- The interviewer will offer or insist on taking breaks if conversations become difficult.
- During the pre-and post-interview sessions participants will be given the opportunity to set any boundaries for the interviews and will be reminded at each meeting they can stop recording at any point during the interview process.
- In the event of the interview triggering an emotional event, the interviewer will stop the session and advise you to contact someone you trust, such as a friend or family member, or contact a professional counsellor if you continue to feel upset. You can also talk to your GP or other trusted supports for further support.
- Here are some bereavement resources which you can also contact for support:  
Throughout the island of Ireland:
  - **Samaritans**  
Samaritans have volunteers on duty 24 hours a day, seven days a week, on the free phone helpline number 116 123 and email [jo@samaritans.org](mailto:jo@samaritans.org)



In Republic of Ireland only:

○ **Irish Hospice Foundation**

They provide a free Bereavement Support Line, in partnership with the HSE, is there if you're grieving and need comfort, connection and support right now. It is a national freephone service, 1800 80 70 77, available from 10am to 1pm, Monday to Friday. They also offer bereavement events, workshops, and leaflets.

In Northern Ireland only:

○ **Cruse Bereavement Support**

Volunteers are trained in all types of bereavement. Call 0808 808 1677 for support.

### Will my participation in this study be kept confidential?

Your privacy is important to us. Your personal information will be stored securely in a secure online system and on a secure computer drive that only the researchers can access, for up to 5 years in Trinity College Dublin.

Your audio files and interview transcripts will be securely stored. Your interview transcripts will be shared with select third parties who comply with data protection regulations in the European Union.

The information you provide will be pseudonymised before being shared publicly. This simply means we will use a name that is different from yours, and we will remove information which could be used to identify you. After the interviews are de-identified, they may be shared with the public and the scientific community.

**Example for names:** Your real name is Mary and we use Linda in the transcripts and analysis.

**Example for identifiable information:** If you describe your employer during the interview, we will remove that reference from the transcripts and remove it from any recordings before they are made available to the public.

By law, we must report anything we accidentally discover about serious harm or illegal activities, in line with Irish law and Trinity College Dublin policy.

### What will happen to the results of this research?

While the information from this study will be disseminated, your identity will be confidential. We will use a different name when discussing your information.

The information from this study may be used in the following ways:

- Public talks or lectures.



- Printed publications (books, journals); audio or video (cassettes, DVDs, CD ROM, USB keys); or online (websites).
- Public reference purposes in libraries, museums and archives.
- Use in schools, universities, colleges and other educational establishments, including use in a thesis, dissertation or similar research.
- Use on radio, television or social media.
- Use in apps for smartphones / tablets / laptops and computers.
- Publication worldwide on the internet.

### What do I do if I have any further questions?

If you have any questions or concerns regarding your participation in the study please ask the researcher that gave you this information leaflet for further information. They will be happy to answer any questions that you may have.

Shannon Mora can be contacted by email at [moras@tcd.ie](mailto:moras@tcd.ie).

THANK YOU

## Data Protection Information

Data Controller	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 Ireland Email: <a href="mailto:dataprotection@tcd.ie">dataprotection@tcd.ie</a> Website: <a href="http://www.tcd.ie/privacy">www.tcd.ie/privacy</a>



### What is the lawful basis to use my personal data?

Information will only be used for this research study which aims to develop, improve our understanding of how mourning practices were impacted during COVID-19 and with the use of technology. The legal basis for processing your personal data is Article 6(1)(e) of the EU General Data Protection Regulation (GDPR). The legal basis for processing your sensitive personal data is Article 9(2)(j) GDPR.

We collect your personal data for the purpose of creating a historical record that will help people understand these issues for many years. This is allowed by law for work done in the public interest. When your interview is finished, we will ask you to sign a Recording Agreement giving us permission to include your interview in the project archive. By signing, you agree that we can keep your contact details safely as part of the project. We will not share these details with anyone else, unless the law requires it (for example, if we have to prove who made the recording or show that you gave permission). We will only use your name, address, phone number, or email to contact you if we need to check details about the interview or tell you about important changes to the project.

This is permitted under Article 6 GDPR, which allows us to collect data where processing is necessary for the performance of a task carried out in the public interest. When the interview is completed, you will be asked to sign a Recording Agreement to give us permission to include your interview as part of a project archive. If you do so, you are agreeing that we can permanently retain and securely store your personal contact details as part of the project. These details will not be shared with anyone unless we are obligated to do so for legal purposes, such as evidencing ownership or demonstrating a valid Agreement. Your personal data (address, email address, phone number) will only be used by the project team to follow up with you about issues relevant to the recording agreement, to seek clarification or further details about aspects of the recording and to update you if any of the project terms and conditions change significantly.

### What are my rights in relation to your use of my personal data?

You are entitled to request any of the rights below unless it would make it impossible or very difficult to carry out the research study:

- The right to access to your personal data;
- The right to receive a copy of your personal data;
- The right to ask us to restrict our use of your personal data;
- The right to ask us to correct inaccurate information about you; or



- The right to ask us to delete your personal data.

You are entitled to object to any further processing of the information we hold about you (except where it is de-identified).

You can exercise these rights or learn more about data protection in relation to this study by contacting the PI, Shannon Mora, at [moras@tcd.ie](mailto:moras@tcd.ie) or the Trinity College Data Protection Officer (contact details above).

Please note that these rights relate to data which could identify you (personal data). If your data has been anonymised, we will not be able to access or delete it as we will have no way of being able to link the data to you.

If you are unhappy with how we have used your personal data, you can raise a concern with the Data Protection Commission via their online form -

<https://forms.dataprotection.ie/contact> - or contact the Commission at:

Data Protection Commission

21 Fitzwilliam Square South

Dublin 2

D02 RD28

Ireland

<https://www.dataprotection.ie>