

Title of Study: Digital Goodbyes: Meaning-making, connection and disconnection at the End of Life During COVID-19

Thank you for your interest in the project and for reading the information below to understand more about it. Please contact me if you have further questions.



Principal Researcher:

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Would you like to share your experiences during the COVID-19 pandemic?

My name is Annabel Howell, and I am doing a PhD study as part of the COVID-19 and University of Hull sponsored and funded research project Digital Goodbyes: Meaning-making, connection and disconnection at the End of Life During COVID-19.

I'm inviting you to take part in this study if:

- Someone close to you died during the pandemic and you were unable to be with them in person, and you had to say goodbye using technology such as video calls
- OR you were previously a healthcare worker during the pandemic, who helped someone say goodbye to a loved one using digital technology.

What is the purpose of the study?

My study is about how people used technology such as phones, laptops or tablets to stay connected at the end of life during the pandemic- and what those experiences meant to them.

I want to understand:

- What these moments were like for you
- How you made sense of them
- And how they affected your grief, your emotions and your process of saying goodbye.

Your story can help us learn more about digital technologies and how they can support people in difficult times, how they could supplement being in person in certain circumstances- and how it may affect grieving and closure when someone dies.

About the Research and Your Participation:

Who is doing the research?

My name is Annabel Howell, and I am a PhD student at the University of Hull. I'm part of a research group looking into people's experiences of the COVID-19 pandemic. My study focuses on how people said goodbye to loved ones using technology such as phones, laptops or tablets when they could not be in person, and what those moments meant to them. I will be looking at this from the view of someone close to those who died, or healthcare professionals who worked previously during the pandemic, who helped someone.

You can find out more about the project at: <https://www.hull.ac.uk/research/centres/social-and-psychological-approaches-to-research-in-health-and-care>

Who can take part?

You can take part in this study if you are aged 18 or over and:

- Lost someone close to you during the pandemic and had to say goodbye using technology
- OR you were a healthcare worker (and are no longer working in NHS or NHS funded facilities) during the pandemic, who helped someone say goodbye using a phone, tablet or other digital method.

What does taking part involve?

If you choose to take part, you'll be invited to an online information session about the research and any questions regarding the process lasting 30-60 minutes. The 1:1 online interview asking you about your experiences will usually last 60 -90 minutes, though can be shorter if you wish and feel you have said what you want to say. We'll choose a day and time that suits you. In the interview, I'll ask about your experiences of using technology to say goodbye during the pandemic. You'll be encouraged to share your thoughts and feelings and what the experience meant to you.

Questions I might ask are:

- Can you tell me what happened?
- Can you describe what happened when you had to say goodbye?
- Can you tell me how you said goodbye?
- Have you used technology in this way, before the pandemic? How?
- How did that make you feel and think?
- How did you feel after?
- Can you tell me about your grief?

The interview will be recorded and typed up (transcribed) with your permission. Once the anonymised transcription is completed, the recording will be deleted. I'll also keep a personal research journal to help reflect on what I learn from your stories.

Why is this research important and what are the benefits of taking part?

By sharing your experiences, both good and bad, you can help us understand:

- What worked, and what didn't when people said goodbye using technology
- How digital goodbyes affected people's grief and healing
- How we can improve care for others in the future, especially when people are separated by distance

Some people may also find that talking about their experiences helps them to feel heard and supported. This will be a safe space for you to share your feelings, if you wish to.

Your privacy and information:

The project has been approved by the University of Hull's Faculty of Health Sciences, following strict ethical rules. Your name and any identifying details will be kept private, and any data related to you will be anonymised. Your data will be protected in line with GDPR regulations and the Data Protection Act 2018. Everything you share will be stored securely by the University.

The University of Hull is the data controller which means they take responsibility for ensuring the safety of your data. If you chose to withdraw within the timeframe, any data related to you- your personal contact details, any recordings or transcriptions, will be erased. The results of the study in terms of themes and anonymised quotes will be part the PhD being awarded. The results may be published in this anonymised way later. For more information please visit: <https://www.hull.ac.uk/asset-library/docs/data-protection-policy.pdf>

Can I change my mind?

Yes. You have the right to:

- Say no to taking part
- Stop the interview at any time
- Withdraw from the study up to one month after your interview. After that, your interview will be part of the research findings and so cannot be removed.

If you are unhappy with the process:

You can either speak my supervisor Jo Bell j.bell@hull.ac.uk or on 01482464687 who will explore any concerns. Alternatively, you can contact fh-s-ethicssubmissions@hull.ac.uk

What are the risks of taking part?

Talking about loss and grief can be emotional. Grief varies in the moment. If you feel upset during the interview, we can pause, stop or rearrange for another day. Your health and wellbeing are our priority. Please feel free to ask for support at any point - from me, from your loved ones or from a professional service. This can either be through the helplines described below or through other services if you wish. If you are already accessing support and are concerned, we can of course discuss this in the initial meeting, to ensure your wellbeing.

Helplines:

Cruse Bereavement Support

Tel: 08088081677

Email: support@cruse.org.uk

Website: www.cruse.org.uk

Bereavement Support Scotland Tel: 0808101011 Email: helpline@sfad.org.uk