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Study Title: The Digital Memories Study: Exploring how bereaved people utilise and experience the posthumous digital artefacts of their dead.

Researcher: Mórna O Connor

Healthy Volunteer's Information Sheet

I would like to invite you to take part in a research study. Before you decide whether or not you would like to take part, I would like you to understand why the research is being done and what it would involve for you. I, Mórna O'Connor (the researcher) will go through the information sheet with you if you wish and answer any questions you have. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

What is the purpose of the study?

Increasingly, people use technologies in every part of life: to work, play, shop and communicate. This means that people create digital footprints over the course of their lives, such as emails, messages, social media accounts, files on personal devices etc. Nowadays, when a person dies, these digital footprints can be left behind and encountered by bereaved people. We know little about how bereaved people use and experience this digital content left behind by loved ones.

The aim of the study is to explore how people bereaved of an individual who has left behind digital traces after death use and experience this digital content after a death. We will do this by conducting interviews with bereaved people connected to individual deaths, as well as asking them to write diaries about their experiences. The study will be based in the

Nottinghamshire area but will include participants from anywhere in the UK, as well as other countries where digital technologies are widely used.

Why have I been invited?

You may be receiving this information sheet because you have seen one of our adverts and contacted the study. It may also be that the study has been suggested to you by someone you know who is already taking part. You may also be reading the online version of this information sheet on the study website.

You are being invited to take part in the study because you have been bereaved of a person who has left behind digital traces after their death. On behalf of both myself and the research team, I would like to express my deepest sympathies for your loss.

Do I have to take part?

It is up to you to decide whether or not to take part in this research study. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect your legal rights.

What will happen to me if I take part?

The amount of time you would be involved and the frequency of your contact with the study is up to you, within a one-year maximum. You may take part as much or a little as you like over a maximum period of one year between January 2017 and April 2018. The study has four elements. Elements two, three and four are optional.

I would like to:

1. Invite participants to take part in a series of interviews (up to four) about their use and experience of the digital content left behind by the deceased. These interviews will be spread out over each participants' study period and their frequency will be negotiated with them. The minimum we ask is one interview.
2. Invite participants to map out (on paper or verbally) the network of people who have also been bereaved of the deceased.
3. Invite participants to help to recruit others to take part in the study who have also been bereaved of the deceased. This may be done by passing Study Invitation Packs to these others or by giving their contact details to the study.
4. Invite participants to keep diaries about their use and experience of the digital content left behind by their loved ones. Participants can create these diaries at any time and any frequency during the study period.

If you decide to take part in the study, I will first ask you some questions to ensure that you are eligible to take part in the study. You may then be invited to attend an interview about the digital traces left behind by your loved one and how you use and experience them. At this interview, if you are happy to do so, you will sign a consent form to indicate your agreement to take part in the study.

This interview can take place in your home, at the University of Nottingham, or other private place if you prefer. Interviews also take place over the phone or using video calling software (e.g. Skype, FaceTime). Interviews will take about an hour and the conversation will be recorded if you are comfortable with that. If you prefer, the researcher can take notes instead.

At this interview, you will be asked to map out the other people who have been bereaved of the deceased. You may do this in any way that you see fit, perhaps using the paper, sticky notes and pens that I will provide, or by talking me through this map.

At this first interview I may also ask you to give some Study Invitation Packs to other individuals who have been bereaved of the same person as you, or to direct these others to the study website, www.digitalmemories.info, where they can read about participating in the study. If it is easier for you, you may prefer to give the name and contact details of these individuals to me and I will contact them directly, mentioning that you have nominated them.

Whether or not you wish to do take part in recruitment of others, and the way you do so, is entirely up to you.

The reason behind mapping out the social group of the deceased, and speaking to multiple people in that group, is that the study aims to explore the different types of digital traces of the dead that are available to different people, as well as different people's views and perspectives on these traces. However, it is worth noting that we are also interested in exploring the experiences of individual bereaved participants. Therefore, if you would like to take part as an individual and would prefer not to recruit others, we are very much interested in speaking to you.

At this first interview, the diary element of the study will also be explained to you by me, Mórna. If you want to take part you can choose to keep your diary using the online, audio or paper-and-pen methods. If you choose the online method, you will invited via email to the secure online diary space. You will then be able to submit diary entries about the digital traces left behind by your loved one, how you use them and any thoughts about, or experiences you have, with them. You will also be given a diary guide to help you if you are unsure what to write about.

You can submit entries to your online diary space whenever and as often as you like during the study and there is no limit to the amount you can write. Other participants in the study will not be able to see what you write; your online diary space is only visible to you and the research team. You can also email, audio record or hand write your diary entries if you would prefer. I will explain what to do for each of these options. Remember that you can change your diary-keeping method (e.g. from online to audio) at any time. You can also withdraw from the diary element of the study at any time without giving a reason and without it impacting your participation in the interview element of the study.

I may contact you to remind you about the diary element of the study, with no less than four weeks between reminders and a maximum of ten reminders over your time in the study. I will also offer to send you a copy of your diary entries at the end of the study.

After your first interview, I will contact you for up to three further interviews. You do not have to take part in all four interviews if you do not wish to, the minimum I ask is one interview. Should you decide against coming for an interview, I will not contact you about subsequent ones unless you tell us otherwise.

These other interviews would also be on the topic of your experience with the digital artefacts left by the deceased. The reason for these serial interviews on the same topic is to explore the phenomenon under study over time.

At the end of your study journey, you will exit the study. You can then request a copy of all the diary entries you submitted to the study. If you wish, I will send you a summary of the study findings and you can visit the study website, www.digitalmemories.info, for information and updates on the study. At the end of the study, you may also be invited to a findings sharing event attended by other participants and interested parties. Whether or not you wish to receive information or attend events after the study is entirely up to you.

Expenses and payments

Unfortunately expenses are not available for participating in this study.

What are the possible disadvantages and risks of taking part?

Some people may find talking and writing about a deceased loved one, and what they have left behind, upsetting. The researcher who talks with you will be experienced in discussing sensitive topics with research participants.

Another possible disadvantage is that you may recognise or be recognised by others in your group in the published study findings. We will make every effort to make you anonymous in all study publications, by changing your name and any other identifying information in your interviews and material you submit to the study. However, if others in your group know you have taken part in the research it is possible that they will still recognise your account in the study's publications. You may also be able to recognise the accounts of others in your group in published study material.

What are the possible benefits of taking part?

For some people, it may be good to talk and write about the dead. In other research studies like this, people report that taking part can be a positive experience.

The information we get from your participation in this study will help us to understand what it is like to be bereaved of a person who has left behind digital artefacts after their death. Little is known about this phenomenon and studies like this one will help us to understand what those who die in our digital age are leaving behind, and what the views and perspectives are of their bereaved. This information may have relevance for bereavement support services, online service providers and estate and willing services as they cope with death and bereavement in the digital age.

The overall benefit of the study will be that you will be involved in a project that will further our understanding of this new phenomenon.

What if there is a problem?

If you have a concern about any aspect of this study, you should contact me, Mórna O'Connor, and I will do my best to answer your questions. My contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH, United Kingdom. Email: louise.sabir@nottingham.ac.uk.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about you which leaves the University will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in interviews and diary entries is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you wish, you can request a copy of your diary entries up to the point of your withdrawal. Should you wish, data collected up to the date of withdrawal can be erased, or you may opt to have it used in the study.

What will happen to the results of the research study?

The materials produced in the study will be studied in detail and used in writing a thesis for an educational qualification (PhD) for one of the research team (Mórna O'Connor). This thesis will be published online and material from it will also be published in articles submitted to academic journals and conferences in order to share the findings with others. A summary of the findings may also be published on the study website and presented at a findings sharing event held at the end of the study.

Direct quotes from your interviews and diary entries may be used in these publications and presentations, but you will not be identified in any of these.

The material produced by you in the study may also be published in an online store of study data so that other researchers can use it for other academic studies. You would not be identifiable in any of this material. If you wish, you may opt out of this without impacting your participation in the study.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is funded by The Vice Chancellor's Scholarship for Research Excellence.

Who has reviewed the study?

All research in the University of Nottingham is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Medicine and Health Sciences Research Ethics Committee, University of Nottingham.

Further information and contact details**Researcher:**

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