

Participant Information Sheet



Study Title: Evaluation of a Web-Resource to Support Families and Friends Bereaved During COVID-19 and Beyond

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Ethics/ERGO no: 63208

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You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

We are a research team in the School of Health Sciences at the University of Southampton in the United Kingdom. We are inviting you to participate in a study focused on supporting those bereaved during the COVID-19 pandemic (due to COVID or any other reason). In partnership with a wide range of experts, we have developed a web-resource to help support individuals with their bereavement, taking a family-focused approach. Although the web-resource has been developed during the restrictions of COVID-19 the content is designed to have relevance beyond this specific context.

Many people manage their bereavement with the help of family, friends, and informal support networks. During COVID-19 this has been restricted, social distancing and limitations imposed upon funerals have prevented the support often provided through families and friends coming together. All of this can make it difficult for people to make sense of what has happened and to gain support to help them with their loss and grief. Therefore, the web-resource is focused on bereavement experience in the context of the family and close social networks (including friends, neighbours and any others who are important), to promote communication, and reflect on ways to manage grief collectively.

The study is now focused on evaluating the web-resource with members of the public and bereavement professionals who would like to access it and feedback experiences of using it via a one-off interview. You will be able to access the web-resource which includes information and activities to support bereavement. The web-resource has been designed so that you can move about it to those areas you find most useful. There is no obligation to complete the interview after accessing the web-resource, however we would value your thoughts about the resource and your experience of using it. This will enable us to refine the resource for future use by others.

This study was approved by the Faculty Research Ethics Committee (FREC) at the University of Southampton (Ethics/ERGO Number: 63208).

Why have I been asked to participate?

You have been asked to take part because you are a:

- member of the public who has experience of bereavement of a relative, friend, neighbour or someone who is important to you, from any cause, from the beginning of 2020
- bereavement professional who has supported anyone who has experienced a bereavement since the beginning of 2020

You will have been invited to participate via adverts through bereavement organisations, social media, carer groups, BBC local radio and local newspapers.

We are aiming to recruit up to 40 participants for this part of the study.

What will happen to me if I take part?

Taking part will involve accessing the web-resource www.familiesinbereavement.org.uk at a time convenient to you and then taking part in a one-off interview, which should take approximately 45 minutes of your time. The interview will take part at a time convenient to you and occur via telephone or video call (MS Teams) whichever you would prefer. The interview will be recorded to enable the discussion to be transcribed for analysis.

If you are interested in taking part please contact the researchers using the details at the top of this information sheet. They will be pleased to answer any further questions you may have about being involved.

If you agree to take part you will be asked to sign a consent form, stating that you have read this information sheet and have had the opportunity to ask questions.

Are there any benefits in my taking part?

If you decide to take part in this study, you will not receive any direct benefits; however, you may find that accessing the resource is beneficial to you and your family or your clients.

Are there any risks involved?

There is a possibility that taking part in this study could cause you some psychological discomfort and/or distress because you are considering bereavement. If this happens, please contact the research team (contact details above) who can signpost you to appropriate sources of further support.

What data will be collected?

The questions in the interview will cover your experience of accessing and using the web-resource. The questions will focus around: how accessible and easy to use you found the resource, how appropriate and relevant you found the content, and how beneficial (useful) you found the resource and why. In addition, if you are a member of the public you will be asked for some demographic information – your relationship to the person who died, if bereavement was a result of COVID or other condition, and when the bereavement occurred. If you are a bereavement professional you will be asked about the sector you work in and your role.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential. Once transcription of the interview has been obtained the recording will be destroyed. Any potentially identifiable details such as names will be removed from the data at the point of transcription.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check

that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Personal data that includes your contact details (phone number and/or email address) will be stored electronically in a password protected file, within a secure folder (only accessible by the research team) on the University of Southampton secure servers. These personal data will be destroyed at the end of the study.

Electronic copies of the consent forms will be stored separately from non-identifiable interview data. These data (the transcripts), will be given codes (participant numbers) to reduce the risk of identification. All data and study-related documentation will be stored in secure folders (only accessible by the research team) on the University of Southampton secure servers.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part. If you would like to take part or discuss potentially taking part please contact the research team via the contact details on the top of page 1.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. If you would like to withdraw please contact the research team (contact details on page 1).

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you.

Where can I get more information?

Please contact the research team using the contact details at the top of page 1 if you have any questions at all.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions (contact details on page 1).

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/Is/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Data will be anonymised, and therefore the research data will not be able to be traced back to an individual.

Thank you for reading this information sheet and considering taking part in this research.