



THE UNIVERSITY
of EDINBURGH

Participant Information Sheet

Together for Change: Towards eHealth Tools for Supporting Miscarriage

You are invited to take part in a research study. To help you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are a team of three researchers: Mrs Mona Alqassim, PhD student at the School of Informatics, University of Edinburgh, and her supervisors Dr Maria Wolters and Prof Helen Pain.

In our research, we want to design solutions for supporting women who are experiencing or have experienced a miscarriage. In particular, we are interested in meaningful ways to use technology (apps, social media, etc.) to do so.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I take part?

If you agree to be in the study, you will be invited to look at situations when you would like to receive support during a miscarriage experience: Who should be giving you support, at what time, where would you like to receive support, where would you like to access support, how would you like to receive support, how would you alert the person to your needs, what support do you need? You will see cards that relate to

each of these categories, and we ask you to sort them into groups that are meaningful to you.

No demographic information will be collected. The only potentially identifying information will be your Prolific Academic ID, to ensure payment. Initially, all of your answers will be stored on password protected servers outside of the European Union run by Optimal Workshop, Ltd. After the data have been collected, they will be stored on safe, password-protected cloud servers managed by the University of Edinburgh, UK.

In order to protect your privacy, we will not reveal any names or directly identifying information from your contributions in the online card sorting. Only the team of investigators will have access to the original data set. These are Dr. Maria Wolters and Prof. Helen Pain who are academic members of staff at the University of Edinburgh and Mrs Mona Alqassim, who is a PhD candidate at the University of Edinburgh.

What are the possible benefits of taking part?

There are no direct benefits to you taking part in this study, but the results from this study might help to improve the healthcare of women who have experience miscarriage in the future.

The results of this study may be used for the future development of a new app or platform. While your participation in this study will not entitle you to benefit financially from this, we will aim to ensure that the developer is a non-profit, community oriented business.

What are the possible disadvantages of taking part?

When you consider the cards, you may feel emotional distress from memories evoked by some of the cards. Remember that you are completely free to choose the extent to which you participate in the online card sorting. You can stop taking part at any time and without giving a reason. Here are some relevant sources of support:

Miscarriage Association:

<https://www.miscarriageassociation.org.uk>, Helpline 01924 200 799,
info@miscarriageassociation.org.uk

SANDS Stillbirth and Neonatal Death Charity:

<https://www.sands.org.uk>, Helpline 0808 164 3332
helpline@sands.org.uk

For further links, see <https://copingwithpregnancyloss.com/support/>

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

You can stop taking part in the card sorting at any time, and you do not have to give us a reason why. We will delete all your information from the study, if you wish. Your decision whether or not to participate in this study will not affect your current or future relations with The University of Edinburgh. Once you withdraw from the study, your data will not be used in any further publications and for any further research.

What happens when the study is finished?

After the end of the data collection, we will keep the card sorts that you have created for at least five years to ensure that we have enough time to analyse it, and to write it up for publication.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. While your original card sorting data will be stored on a server in the US, where Optimal Workshop is registered, afterwards, all data will be stored on password protected, secure servers in the UK or on password-protected, encrypted research laptops. Only the research team will have access to your data. We will prepare reports, presentations, and publications about the data collected while preserving your anonymity at all times.

What will happen to the results of the study?

This study will be written up in Mrs Alqassim's PhD thesis, and submitted to academic journals and conferences. We will also share our findings with charities.

You will not be identifiable from any published results.

We will inform you of any publications through the study web page <https://blogs.ed.ac.uk/mona-alqassim/>.

Who is organising and funding the research?

The study is being funded by the Alan Turing Institute Seed Funding Grant "Generating Health Data" to Dr Maria Wolters and a PhD scholarship awarded by the Saudi Arabian Government to Mrs Mona Alqassim.

Who has reviewed the study?

Ethics certification documents for this study, including the participant information sheet and consent form, have been reviewed by the Informatics Ethics Panel of the University of Edinburgh, and the document have been certified as complete and correct (298-1819/7).

This study builds on the results of an earlier study conducted on Facebook, which can be accessed here: <https://blogs.ed.ac.uk/mona-alqassim/arc-study/>

Researcher Contact Details

If you have any further questions about the study please contact Mrs Mona Alqassim at 0131 651 1768 (weekdays, 9am-5pm) or by email at mona.alqassim@ed.ac.uk.

Independent Contact Details

If you would like to discuss this study with someone independent of the study please contact Dr Robin Hill, r.l.hill@ed.ac.uk

Complaints

If you wish to make a complaint about the study please contact the Psychology Research Ethics Committee at psych-ethics@ed.ac.uk

