



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. This co-design workshop is part of that process. We want to figure out, together with you, what kinds of social support and what services should be included, what technology should be used (existing apps or social media services, new tools, online forums, etc.), and how the solutions should be designed.

Why have I been invited to take part?

You have been asked to take part because you have experienced at least one miscarriage, and have indicated that you might be interested in our study when we reached out to you either on the Facebook groups of the previous study in which you were involved, through one of our charity partners, or through a leaflet.

Do I have to take part?

No, 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 sheet to keep and be 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.

What will happen if I take part?

If you agree to be in the study, a researcher will take you through a one-on-one co-design workshop, which consists of a series of interactive activities that are designed to help us understand what support around miscarriage people access, how they access it, and to whom they turn for support. We will use a variety of techniques, which may include sharing your experiences of what has and has not worked for you in the past; sorting concepts into groups; commenting on prototypes that others have designed or suggesting your own designs. The researcher will be experienced in working on sensitive topics, and there will also be a note-taker. You are free to take a break from the workshop at any time; we will provide a safe and welcoming space where you can do so.

We would like to audio record the workshop, and video record only the materials on the table during the workshop, and take photos of any feedback, post its, designs, or other artefacts that you produce. However, we will not do so if you feel uncomfortable with it.

The workshops will take at most two hours. We will compensate you for your time with a £20 One4All voucher, but unfortunately, we do not have the funds to pay for child care.

We will analyse the results of all activities to determine how could address the support needs of women who have miscarried, and to gather ideas about how to design such technology.

In order to protect your privacy, we will not reveal any names or directly identifying information from your contributions in the workshop. You may choose to allow the use of quotations in publications or presentations of this work. We will also anonymise all notes, drawings, and paper prototypes that you agree to leave with us after the workshop.

Should you agree to be audio recorded, the resulting audio data will be transcribed by a GDPR compliant transcription service and fully anonymised by the researcher with assistance from her supervisors. Should you agree to being video recorded, the resulting video data will be annotated. Any photos that you allow the researchers to take will be annotated and, if they contain text, transcribed. Any identifying information will be anonymised.

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 patients 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?

While in the workshop, the risks are:

- Emotional distress from discussing sensitive topics
- Being hurt by insensitive comments

You are completely free to choose the extent to which you participate in the workshop. You can leave the workshop or take a break from the discussion at any time, and choose to stop and skip any activity that makes you feel uncomfortable. We will provide a quiet room for those who wish to take breaks. While we will do everything we can to minimise distress, you may also experience unexpected strong emotions as a result of the discussions.

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 if there are any problems?

If you have a concern about any aspect of this study please contact Prof Helen Pain helen.pain@ed.ac.uk who will do their best to answer your questions.

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

You can stop taking part in the workshop at any time, and you do not have to give us a reason why. We can delete all your information from the study, if you wish. Leaving the workshop will not result in any penalty or loss of benefits to which you are entitled.

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 any research notes, transcripts, annotations, and photos 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. The 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. You may choose to allow the use of quotes or images from your contributions to the discussion in publications or presentations of this work. 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/>>

Sponsorship has been obtained.

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 Informatics Research Ethics Panel at <inf-ethics@inf.ed.ac.uk>

