**Information for potential participants:**

This information sheet will explain what the ‘Death Before Birth’ research project is about including its aims and purpose; invite you to participate in the study; and explain what participation will entail. Its purpose is to enable you to make an informed decision about whether you wish to participate.

**What are the aims of the research?**

The full title of the project is: ‘Death Before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth.’

The overall aim of the research project is to examine the law surrounding the disposal of the remains of pregnancy and the ways in which it is interpreted, and to examine the language used by people who have experienced pregnancy loss or stillbirth, and those who support them.

A key aim for the current project phase is to investigate how women make sense of their experience of termination due to fetal anomaly, and how they made choices regarding the disposal of the remains of pregnancy. A second aim is to talk to people who have supported the same women as a partner, friend or family member and to hear from them about their experiences.

Our main partners for the ‘Death Before Birth’ project are: The Human Tissue Authority; SANDS; the Miscarriage Association; Ante-natal Results and Choices. In addition to representatives from each of these agencies, our stake-holder board includes Rick Powell, National Secretary of Federation of Burial and Cremation Authorities (FBCA) and Jessica Read, Chair of the Local Supervising Authority Midwifery Officers’ Forum UK (LSAMO).

The research will take us 2 years in total. Other aspects of our work involve talking to midwives and funeral directors, and to staff who work at our partner agencies to support women through pregnancy loss or stillbirth. We hope that our findings will not only inform future revisions of the Human Tissue Authority Guidance on the Disposal of Pregnancy Remains, but will also support the work of our partner agencies in future communications with bereaved families. In doing so, we hope that our research will contribute to better support for people who have experienced pregnancy loss and to better public understanding about the choices and decisions that are made by bereaved families.

**Why are we asking you to participate?**

We would very much value your reflections about your experience of termination due to fetal anomaly and about how you made choices e.g. about commemoration.

**How would we like you to participate?**

We would like to invite you to an interview lasting about 90 minutes with a member of our research team.

We will arrange to meet you in a quiet place, e.g. in your home or in a private room in your town/city or elsewhere if you would prefer that. If you would prefer to talk via skype or telephone we can arrange that. We appreciate that we are asking you to give up your time but hope that you will find the discussion interesting.

**How will we conduct the interview?**

We realise that telling us about your experiences may cause a range of emotions. If you would like to take a break at any point in the interview, please say so. If you feel that you want to stop the interview entirely, you may do so – just tell the researcher.

At the close of the interview, we will provide contact details for relevant support agencies in case you wish to talk to someone about any feelings or issues that you may be concerned about – either on the same day as the interview or in the days after the interview has taken place.

**How will we use the interview data in our research programme?**

All the data collected from you will be treated as confidentially as is practical. All participants will chose a pseudonym and your real name will not be used when reporting or presenting the research for publication. However, we cannot entirely remove all identifying information from the transcript when storing or quoting from your data, since aspects of your experience may be recognisable **if** someone connected to you chooses to take part in the second phase of our study.

Once the interview has been transcribed you will be sent a copy that you can review and amend if you wish. Amendments should be made and communicated to the research team within 2 weeks of receipt of the transcript. You will also be asked to select any sections of text that you would prefer to be taken out of the version that will appear in the electronic repository. (You may also choose for the transcript not to be deposited in an e-repository)

The interview data will be used to inform our analyses. It is possible that we will use short quotations from the interview in presentations, publications and reports arising from the project. Some of these publications will be for an academic audience but others will be aimed at our partner agencies, stakeholders, and their clients. Reports and guidelines may be posted on public-facing websites.

With your permission, a copy of the interview transcript or part of the interview transcript (with sections that you have selected taken out) will be placed in an electronic repository. This will occur shortly after the project funding ends (31 August 2018). We will check with the University of Birmingham (UoB) research data management experts if existing UoB research data services are ESRC (Economic and Social Research Council) compliant. If so, data will be deposited at the UoB, if not, we will deposit with the UK Data Service as recommended by ESRC. The data will be viewable by other authorised researchers but personal data will be removed. No personal data (such as an email address) will be attached to the transcript.

**Participation is entirely voluntary but we very much hope that you will take part.**

You have the right to withdraw completely from the project. Before the scheduled interview you can withdraw by contacting the member of the research team who has been in contact with you to arrange the interview. You may take a break or stop the interview entirely during the interview if you wish: just let the interviewer know that you would like a break or that you no longer wish to take part in the study. After the interview, and before you receive the interview transcript for checking, you can contact the interviewer or the Project Lead (Danielle Fuller) to withdraw. We will send you the transcription for review, allowing you 2 weeks to do so. It will not be possible to withdraw data from the interview once you have reviewed and approved the interview transcript. Before that point, if you withdraw, your interview data will be removed from the study in its entirety and will be destroyed.

**Contacts**

This is a research project funded by the Economic and Social Sciences Research Council (UK). The project’s home is the University of Birmingham where the Principal Investigator, Dr Danielle Fuller ([d.fuller@bham.ac.uk](mailto:d.fuller@bham.ac.uk)) is based. If you have any concerns or questions, please do not hesitate to contact her. If you would prefer to contact someone at arms-length to the project, please contact: Sheena Robertson ([s.a.robertson@bham.ac.uk](mailto:s.a.robertson@bham.ac.uk)) who is the Manager of the Research and Knowledge Transfer Team, College of Arts and Law, University of Birmingham.

**Thank you very much for taking part in this research project.**