

Participant Information Sheet for Parents Accessing the Stillbirth Stories Website (Version 1.0, 26/07/2017)

Evaluation of Stillbirth Stories

Does the opportunity to listen to the clinical and personal experiences of parents whose baby was stillborn and clinicians who work with these families offer positive benefits for other bereaved parents, their families and friends?

We are approaching you to ask if you would like to take part in this study because you have accessed the Stillbirth Stories website.

Before you decide, 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 and discuss it with others if you wish. Ask 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?

The death of a baby before or shortly after birth affects approximately 1 in every 250 pregnancies in the UK. Many studies show that the death of their baby has a profound and enduring effect on parents' psychological and social wellbeing. More recently, it has become apparent that stillbirth also has a significant impact on those caring for bereaved parents. However, the confidence and emotional response of professionals caring for families whose baby is stillborn is little considered or researched. The purpose of this project is to determine whether listening to the Stillbirth Stories archive helps bereaved parents – and their families and friends – by listening to the experiences of other bereaved parents and clinicians caring for families.

Why have I been chosen?

We are inviting you to take part because you clicked on a link in the Stillbirth Stories website.

Do I have to take part?

It is up to you whether or not to take part. If you decide to take part you will be asked to give your consent in the online questionnaire.

What happens to me if I do take part?

If you agree to take part we will ask you to complete a questionnaire to determine your views on the website and its archive. The questionnaire will take about 15 minutes to complete. All of the data will be anonymised so no-one will be able to identify you.

What are the possible disadvantages of taking part?

The research team recognise that participation may bring up difficult and distressing memories for some of the participants. **If you need to access additional support you can contact the Sands helpline by phone: 0808 164 3332 or by email: helpline@sands.org.uk (Monday to Friday: 9.30am – 5.30pm, Tuesday and Thursday evenings: 6pm – 10pm) or Tommy's helpline 0800 0147 800 (Monday to Friday 9.00 – 5.00 pm).**

What are the advantages of taking part?

The study will not benefit you directly but the information we get from this study will help improve the Stillbirth Stories website and develop training and support for professionals who care for families who have experienced a stillbirth or neonatal death.

Will my taking part in this study be kept confidential?

Study data may only be looked at by the research team and authorised individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, for monitoring and auditing purposes. All study information will be handled in the strictest of confidence, and stored in locked filing cabinets in locked offices with swipe card access required, or in password protected files on firewalled NHS or University servers.

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

You can withdraw from the study at any time if you wish without giving a reason by not continuing to complete the questionnaire. However, once you have clicked to submit the questionnaire you can no longer withdraw your data from the study.

What will happen to the results of the research study?

We will use this information to develop the Stillbirth Stories website and training resources. The results will be presented at relevant meetings and will be published in journals read by doctors and midwives. We will also display posters at St Mary's Hospital. You will not be identified in any of our results. Research data generated by the study will be held for 15 years, but items such as contact details will be deleted as soon as the study ends.

What happens when the research study stops?

Study recruitment is expected to last approximately 3 months, when data is complete the results will be analysed. The information will be used to develop the Stillbirth Stories website and how the archive can be used to train midwives and doctors.

What if there is a problem?

If you have a minor complaint then you need to contact the researcher(s) in the first instance. Please contact Dr Alexander Heazell, on phone 0161 701 0889 or by email alexander.heazell@cmft.nhs.uk. If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact the **Research Governance and Integrity Manager Dr Clare Griffin on phone 0161 701 2690 or by email clare.griffin@cmft.nhs.uk**.

Who is organising and funding the research?

This research is being carried out by the Maternal and Fetal Health Research Centre, St Mary's Hospital. The project is funded by the Wellcome Trust.

Who has reviewed this study?

This study has been reviewed and given a favourable opinion by the Health Research Authority. If you would like any further information please contact Dr Alexander Heazell, Professor of Obstetrics on 0161 701 0889 or alexander.heazell@cmft.nhs.uk.

Thank you for taking the time to read this information sheet. Please keep it for your records.