Thank you for taking time to read this information sheet and for considering taking part in the FGM Sister Study.

All reasonable travel expenses will be covered if you take part in a face to face interview or a discussion group away from your usual place of work.

What if there is a problem?
If you are not satisfied with any aspect of the way in which you have been approached or treated during the course of this study, then please first speak to the researchers (our contact details are on the front cover of this information sheet).

If you wish to complain formally then you can contact the University of Birmingham Sponsor Representative:

Dr Sean Jennings
University of Birmingham, Research Support Group, Room 119 Aston Webb Building, Edgbaston, Birmingham, B15 2TT

📞 0121 415 8011
✉️ researchgovernance@contacts.bham.ac.uk

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**Female Genital Mutilation:**

A qualitative study exploring the views of survivors, male partners and healthcare professionals on the timing of re-opening (deinfibulation) surgery

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What is FGM/C?
FGM/C is a practice that involves changing, altering or removing part of a girl or woman’s external genitalia without a medical or health reason. Across the world, more than 200 million girls and women are affected by FGM/C, with 137,000 living with the consequences of FGM/C in England and Wales. The World Health Organisation has identified four different types (types 1, 2, 3 and 4) of FGM/C with Type 3 (which involves creating a seal over the vaginal opening) being the most severe.

What is re-opening (deinfibulation) surgery?
Girls and women who have experienced type 3 FGM/C may need to have a small operation to re-open their vaginal seal, known as re-opening (deinfibulation) surgery.

What will I have to do if I take part?
You can take part in two ways; Firstly, you can choose if you would like to take part in a one to one interview or in a discussion group with a small number of other healthcare professionals. Interviews will take around 60 minutes and discussion groups around 90 minutes. Interviews can be take place in a private room at your place of work, at the University of Birmingham or by telephone. Discussion groups will take place in an appropriate location. These discussions will be audio recorded to allow (1) the researcher(s) to pay full attention to what you are saying and (2) the research team to do further analysis at a later date. Secondly, if you agree to take part in an interview or discussion group, you may be given the opportunity to take part in a national stakeholder meeting after the results of the study have been analysed. If you agree to take part in the national stakeholder meeting, you will be sent a summary of the results of the study. At the meeting, you will be asked to discuss the results of the study with other people involved in the delivery of FGM/C care (e.g. healthcare professionals, policy makers, commissioners) and give your views on the conclusions we have reached. The whole group will be asked to comment on what should change around FGM/C health care practice and what is the best time for re-opening (deinfibulation) to take place.

Will what happen to any information that I give?
The audio-recording of the interview/discussion group will be used to produce a typed record of the discussion, known as a transcript. This transcription will be done by a specialist transcription company who will sign an agreement to keep your data confidential and stored securely. The transcript will be anonymised, that is all identifying details such as names and locations will be changed to preserve confidentiality. We will analyse the anonymised transcripts as part of our research.

The University of Birmingham will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Birmingham and regulatory organisations may look at your research records to check the accuracy of the research study. The NHS organisations and third sector organisations who may approach you about taking part in the study, with your permission, will pass your contact details to the University of Birmingham. The only people in the University of Birmingham who will have access to information that identifies you will be people who need to contact you, for example, to invite you to participate in the study or to audit the data collection process.

The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Birmingham will keep identifiable information about you until the main results of the study have been published, after this time, identifiable information will be safely destroyed. Anonymised data will be stored securely at the University of Birmingham for at least ten years after the end of the study. You have the right to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting Dr Laura Jones (L.L.Jones@bham.ac.uk; 0121 414 3024).

Can I decide not to carry on with the study?
If you decide to take part in the study but then change your mind, you will be free to withdraw for up to two weeks after the interview/discussion group.

Can I decide not to carry on with the study?
If you decide to take part in the study but then change your mind, you will be free to withdraw for up to two weeks after the interview/discussion group without giving a reason (although we will appreciate it if you tell us why you change your mind).

What will happen to the results of the study?
When the results of the study are known, we will run an event to discuss them with key stakeholders in FGM/C service provision. You may be invited to attend this event. We will also share the findings via our website (www.birmingham.ac.uk/fgmsisterstudy) and will publish the overall findings of the study in health journal(s), for consideration by the National Institute for Health and Clinical Excellence (NICE). Please note that you will not be identifiable in any study related report.

Who has organised and reviewed the research?
This study has been funded by the National Institute for Health Research (NIHR) (HTA: 16/78/04). It is organised, managed and coordinated by the University of Birmingham, and data will be collected and stored by this institution. The study is sponsored by the University of Birmingham. The FGM Sister Study has been reviewed by the North West Greater Manchester East Research Ethics Committee. Additionally, the study will be supervised on a regular basis by a Study Management Group and a Study Steering Group.