PARTICIPANT INFORMATION LEAFLET HEALTHCARE PROFESSIONALS

fgm SISTER STUDY

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

Lead Researcher: Dr Laura Jones
fgmsisterstudy@contacts.bham.ac.uk
0121 414 3024 / 07790 374806 / 07790 374808
@FGMSisterStudy
www.birmingham.ac.uk/fgmsisterstudy

All reasonable travel expenses will be covered if you take part in a face to face interview or a discussion group away from you 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

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

National FGM Centre – Developing excellence in response to FGM and other harmful practices
University Hospitals Birmingham NHS Foundation Trust
Believe in children Barnardo's
NHS National Institute for Health Research
University of Birmingham | Institute of Applied Health Research

FGM Sister Study – Participant Information Leaflet (HCPs)
IRAS ID: 235256
v1.0 11th June 2018

Key Study Summary

Why have I been invited to take part?
You have been invited to take part because you are a healthcare professional who currently or has previously (within 5 years) been involved in the delivery of care or services to women who have experienced female genital mutilation, also known as female genital cutting (we will use the term FGM/C from now on in this information leaflet).

What is the purpose of the study?
The aim of this study is to explore and understand FGM/C-survivors', their male partners' and healthcare professionals' preferences for the timing of deinfibulation and their views on how NHS services can best be delivered to meet the needs of FGM/C-survivors and their families.

Do I have to take part?
Taking part is voluntary. If you decide to take part, you will be asked to sign a consent form but you will be free to withdraw up to two weeks after the interview/discussion group.

What are the benefits of taking part?
This research may not directly benefit you, but what you tell us may help us to better understand the perspectives of healthcare professions who provide care to FGM/C-survivors and their families. We hope this will improve FGM/C care in the future. We also hope that we will be able to provide healthcare professionals with guidance on when it is most appropriate to carry out re-opening surgery (deinfibulation) and what care is required at this time.

What are the risks of taking part?
There are no physical risks to taking part in this study. However, interview/discussion group may cause you to think and talk about things that are upsetting. If this happens, we will ask you if you want to stop and have a short break, or if you want to stop completely.

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.

What will 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. Your rights 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).

Will my taking part be kept confidential?
Yes. All information which is collected about you during the course of the research will be kept strictly confidential.

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.