

Listening and learning: discussions with women affected by female genital mutilation (FGM)

Exploring their views and experiences of deinfibulation (opening surgery) and National Health Service care

Forming part of the FGM Sister Study

2020



Developing excellence
in response to FGM and
other harmful practices



UNIVERSITY OF
BIRMINGHAM

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FOREWORD BY THE HEAD OF THE NATIONAL FGM CENTRE

The National FGM Centre (NFGMC) is a partnership between Barnardo's and the Local Government Association (LGA) to achieve a system change in the provision of services for children and families affected by Female Genital Mutilation (FGM) and other harmful practices. The NFGMC is partly funded by the Department for Education as part of its Children's Social Care Innovation Programme Project. Our evidence-informed approach to working enables us to be relevant to communities, policymakers and multi-agency frontline practitioners. Working to end new cases of FGM by 2030 is our vision and ending FGM is a value we live by.

From its inception in 2015, the NFGMC saw research collaboration and providing women with meaningful opportunities to influence research and policy as important branches of its work. Therefore, when presented with the offer to partner with the University of Birmingham FGM Sister Study, we grasped at the opportunity to be involved because of the difference the research would make to the lives of FGM survivors, the co-production element and the commitment of the research team to collaborate with the charity sector as a meaningful partner.

We are pleased to see the research coming to a conclusion, which we hope will lead to an improved understanding of the views of women, men and healthcare professionals around deinfibulation (opening surgery) and what they need from health services. The research demonstrates the willingness of women to contribute to improving services when asked, including through speaking out in their own communities. Talking about FGM is a highly sensitive topic for many women, so we thank the women for their participation.

The NFGMC will use its various platforms to share the learning from this research with women and girls affected by FGM; community organisations; professional bodies; government departments; international partners and networks and agencies with whom NFGMC works including local health (NHS trusts, GPs, public health, health visitors, school nurses), in local authorities where we deliver direct services and more widely via LGA. We hope the findings of the research are used to ultimately benefit women and girls across the world.



Leethen Bartholomew

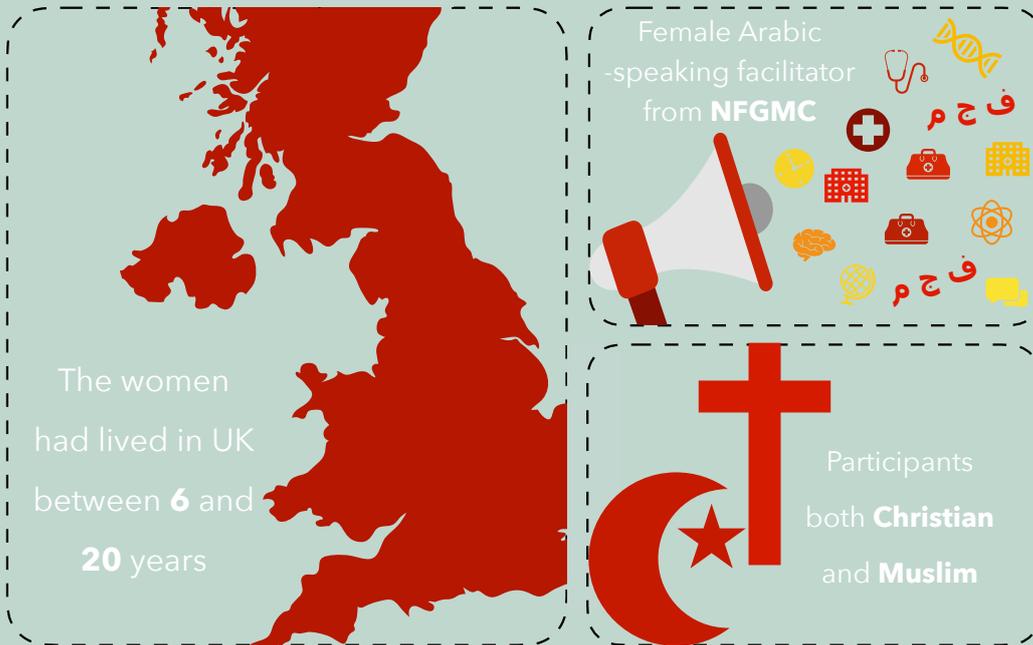
Head of the National FGM Centre

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EXECUTIVE SUMMARY

Listening and learning

Discussions with women affected by FGM



London

West Midlands



Audio Recorded



Discussions in English

Formed part of the FGM Sister Study to explore and further understand early study findings around **deinfibulation** (opening surgery) and NHS care



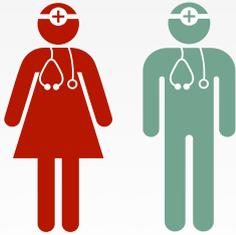


When should deinfibulation (opening surgery) take place?

"As soon as you realise that this [FGM] is no good for me, as soon as you know that it hasn't... it's got no purpose, you should have it [opening surgery] done..."

"Just do it after your wedding I would say."

"In labour, I think. Because she don't need to feel pain two times, because in the labour the same time she can do it."



Who should undertake deinfibulation (opening surgery)?

"I think it should be someone who is aware of it [deinfibulation], it's not just any procedure, any surgery, you have to understand what actually happened, how it happened, and then there's the trauma around it as well... someone who doesn't judge you"



Where should deinfibulation (opening surgery) take place?

"I think you should be given a choice, because you are the only one who knows your situation and your culture, and your background."



Who makes decisions around deinfibulation (opening surgery)?

"She has to make the decision by herself. Because no one can... there is a choice, she has to have her own choice."



Why might women have deinfibulation (opening surgery)?

"I think it's very important that they open it [vagina] up because of health reasons and as a human being too."

"I don't know if you ever can feel things the way you are supposed to feel, but at least I think you will feel like okay I am like everyone else now."



NHS FGM service provision - GP

"When you go to the GPs there is [information about] a flu jab or things like that, that is health. But FGM should be part of that as well, because it's a big community in the UK."



NHS Health FGM services in general

"It's [FGM] got different names in different countries.... I had no idea absolutely that it was even called FGM."

"I feel unfair they [healthcare professionals] are target[ing] special groups.... sometimes that make you feel unhappy actually."

THE FGM SISTER STUDY

The FGM Sister Study is one of the **UK's largest** qualitative studies exploring the views of FGM survivors, male partners and healthcare professionals on the **timing of deinfibulation** (opening) surgery and NHS FGM service provision.

You can find out more about the study by:

Following us on Twitter: **@FGMSisterStudy** or **@drlauraljones**

Or you can email the lead researcher on L.L.Jones@bham.ac.uk

The study ran from May **2018** to September **2020**

In partnership with **Barnardo's National FGM Centre**, healthcare professionals and a group of women who have been affected by FGM

Following the interviews, we looked at what the participants had told us and discussed our early findings with FGM survivors and a range of different stakeholders involved in supporting survivors and their families across the UK

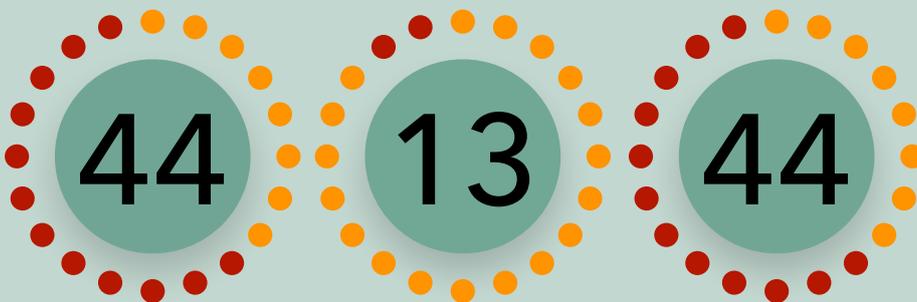


The study is funded by the National Institute for Health Research (NIHR) Health Technology Assessment

INTERVIEWED:

101 people about their views on when deinfibulation should take place and how NHS FGM services can best be delivered

44 were FGM-survivors, **13** male partners of women affected by FGM, and **44** healthcare professionals caring for FGM-survivors and their families



1. INTRODUCTION

This is a report of two discussion groups facilitated by the National FGM Centre (NFGMC) in November and December 2019. A total of ten women affected by female genital mutilation (FGM) and who had experience of FGM in their community took part in the discussions. The report is part of a wider piece of research by the University of Birmingham on the timing of deinfibulation (opening) surgery and the FGM care received from the National Health Service (NHS). The purpose of the discussion groups was to explore the findings from the interviews to see if those taking part in the face-to-face discussion groups agreed with them, and if there were other comments or insights which should be considered.

The two groups met at locations in London (four women took part) and the West Midlands (six women took part). Group members were invited by staff at the National FGM Centre to join one of the discussion groups. All the women needed to be able to speak and understand some English as the group discussions took place in English, and the explanatory documents about the study were written in English. The purpose of the research was outlined to them individually, and each one signed to say they agreed to join the discussion group and have their views shared anonymously as part of the study.

Both groups were facilitated by a female, Arabic-speaking NFGMC staff member who provided interpretation of specialist terms if needed. The University of Birmingham researchers provided the facilitator with a discussion guide which had been drawn up based on the initial findings from the research. She interpreted this flexibly depending on the direction of the discussion, while making sure the key topics were covered. The groups lasted between one and a half and two hours and the women each received a shopping voucher as thanks for taking part.

The groups were recorded, with the permission of all those involved, and the discussion transcribed. The women provided basic details about themselves including country of birth; how they had been affected by FGM and, if so, the type and whether they had been deinfibulated; number of children; age; faith; relationship status; employment and housing status; and citizenship.

All 10 women had been affected by FGM. The three women who had experienced type three FGM had been deinfibulated.

The **ten** women were born in Eritrea, Saudi Arabia, Somalia (n=4), Sudan (n=3), and Zambia.

Eight of the women described their faith as Muslim, and **two** as Christian.

The women were between **18-24** years and **50-54** years, and had lived in the UK between six and twenty years. Four were British citizens.

Five were working part or full-time and **one** was a student.

All of the women were **renting accommodation** except the **student** who was living with family members. **Eight** of the women had a partner, **one** was single and **one** was separated.

Two women did not have children, and the remaining **eight** women had 32 children in total between them.

Types of FGM

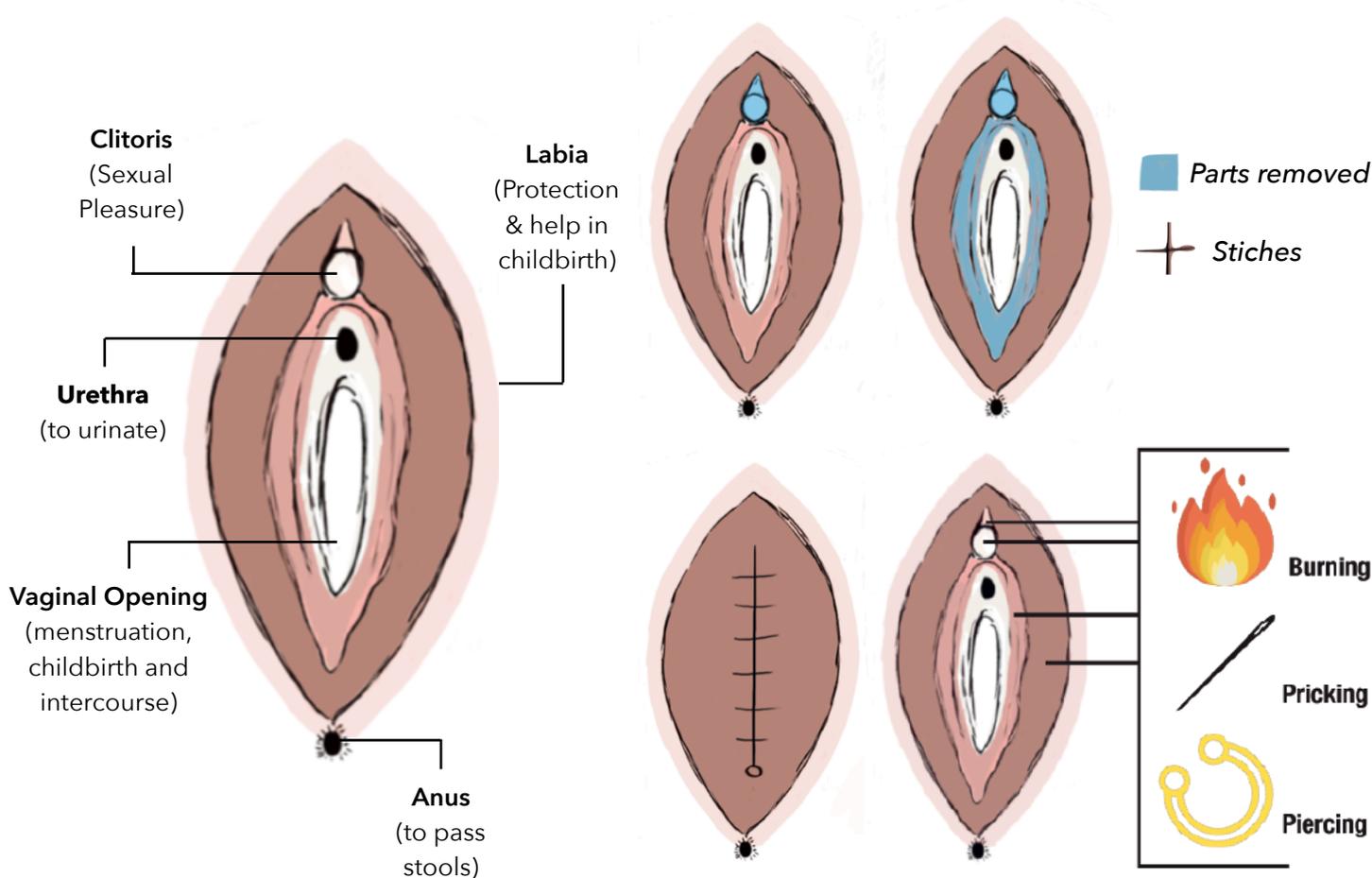
With the agreement of the group, the facilitator started by explaining FGM and its definition:

“Female genital mutilation (FGM) includes all procedures that involve the partial or total removal of external genitalia or other injury to the female genital organs (such as stitching of the labia majora or pricking of the clitoris) for non-medical reasons”

(World Health Organisation, 2018)

The facilitator then outlined the “four types” of FGM. The London group thought that Type 3 was less common now than in the past and that Type 1 was the most common in their community now.

The use of the diagrams below, and a model of the female genital organs, enabled the facilitator to ensure that all those in both discussion groups were aware of the four types, rather than only the types practiced in their community, and also what was meant by “**deinfibulation**”.



This was important as some of the women described their own or other family members’ experiences of being partially opened when younger in their home country for health reasons:

“My sister who is younger than me couldn’t wee even, and she got ill, inflammation and got difficult to wee, and they took her, mummy and daddy... took her back to the doctor, and they gave her space for the wee.”

“She was struggling as well since she was child, she was struggling to pass urine, so she came back again to the lady what she has done, it’s like midwife you know what I mean? She open a bit, cut a bit, make it wider.”

The study defined deinfibulation as:

“Deinfibulation is a surgical procedure that reverses infibulation by opening up the closed genital scar tissue in a girl or woman who has undergone type 3 FGM. It is often necessary for improving health and wellbeing as well as to allow intercourse or to facilitate childbirth”¹

Examples such as those outlined above by the women in the discussion groups were not always the same as what was meant by deinfibulation in the research study. This demonstrates that there may be misunderstandings within the FGM affected communities about what is meant by deinfibulation.

¹ “Care of girls and women living with female genital mutilation: A clinical handbook”, World Health Organization, 2018

2. FEEDBACK FROM THE DISCUSSION GROUPS

The two discussion groups talked about a number of key issues which the researchers had interpreted during their research. These are now described in the sections below in turn. It is not possible to draw any firm conclusions from the comments alone, but they do provide information about the range of views held by community members affected by FGM and some suggestions for further work.

Theme 1: Deinfibulation

The first theme which the discussion groups considered was the timing of deinfibulation and matters directly associated with the deinfibulation process.

1. When is the right time for a woman to have deinfibulation?

The women within each groups found it difficult to reach an agreement about the best time for a woman to have deinfibulation. Their responses were often influenced by the personal experiences of the woman or family members. It was also highlighted that the decision may have consequences for the woman which could potentially put her at risk in some cultures. For example, one woman said that she believed the "Right time" was "Anytime", but explained how FGM and deinfibulation is regarded among her community:

"The thing is many people don't know about it [deinfibulation] and other people as well they fear to go even to hospital to open it [vagina]. Some people feel ashamed. And some people also think that it's [FGM] a normal thing, it's in their head that oh this is a way of our life, like there's nothing bad in it...When they find you open they say you are touched before me...it is more than that they think you have done something, you are not a girl, you are not a virgin so he kick you out of his house, and your family will be ashamed, all that."

Overall, there were four key times which were identified. Firstly, as soon as a girl or woman wishes to take the step, whether or not they are in a relationship:

"As soon as you realise that this is no good for me, as soon as you know that it hasn't... it's got no purpose, you should have it done, as soon as you realise, you've got that information, you should have it done. I think you don't need to wait any longer."

For some women this is the time when the greatest degree of personal choice can be exercised: *"You have to come voluntarily...you have the option to go in".* This was compared to during labour: *"NHS the only time they can, interfere that's when in labour."*

Secondly, other women linked the decision with marriage and believed deinfibulation should be done at this time:

"I would say before marriage or after marriage, because then she can enjoy herself, because it will be a pain. So yes, it will be a pain, it might be easier to have one pain in labour, but what about after your wedding? Probably until they get pregnant then that's another pain isn't it? So, you might as well just do it after your wedding I would say."

A third alternative was to arrange deinfibulation during pregnancy (antenatally) before labour started. This was offered at 20 weeks in some hospitals, but was not a popular choice.

Finally, the fourth choice was to have deinfibulation during labour: *"In labour, I think. Because she don't need to feel pain two times, because in the labour the same time she can do it."*

This option was not supported by some of the women: *"Complications could happen as well during labour because of that, you might not need to go through if you have done it before and healed from it, and then now you are dealing with a different issue"*.

Overall, after lengthy discussions, the London discussion group considered that deinfibulation should be carried out before marriage, but the West Midlands discussion group did not reach a common conclusion.

2. Who should carry out the deinfibulation?

The women talked about traditional deinfibulation practices where it can be carried out by the woman's husband after the marriage took place:

"When you are marrying the man has to find out that you are like this and they start up after that. Yeah, he open it up, not you."

"Different parts of Somalia do it different ways, because some parts they open the girls three days before the marriage, still she is not healed, she can get infection and all this, and pain and some parts they don't, they let the man do the job."

However, neither group advocated this today. When the groups were asked this question, the discussion centred not only on the person's professional qualifications, but also their gender and knowledge of FGM:

"I don't care about [who is] looking at me as long as it's a professional and they know they are doing their job. But it felt more normal and to even discuss things like that and freely it just felt yeah I can chat with you because you're a woman and you know how I feel, and I think that impacts on other ladies as well because you think right okay but gynaecologists having more experience than midwives I think they will be the best more suitable to do such things."

Some women were less concerned about the gender: *"You just trust and it doesn't matter if it's male or female."*

Another woman said that it was very important that the person carrying out deinfibulation had a sensitive understanding of what it meant psychologically to have this procedure:

"I think it should be someone who is aware of it, it's not just any procedure, any surgery, you have to understand what actually happened, how it happened, and then there's the trauma around it as well, the person needs to be able to speak to whoever the surgeon or the doctor is and have that confidence oh this person understands me, this person knows what I am talking about, where I am coming from, and they can go through the... just how I feel. I can't go to any doctor, yes if you have a broken arm you can do to the doctor and you know what they are doing, but it's a different procedure, very private, and there's a lot of stigma around it as well, so you want someone who doesn't judge you, someone who doesn't go oh look at that, you know what I mean?... It should be someone professional who know what they are doing, but someone who is familiar with the whole procedure as well."

3. In what setting should deinfibulation take place?

With this group of women, there was no one healthcare professional which was preferred over another, and it was recognised that a midwife or gynaecologist could carry out deinfibulation, depending on the circumstances.

There are a number of locations where deinfibulation can take place, such as in a community setting or a hospital. The facilitator talked with the women about these options to find out their views about which they would prefer.

The discussion groups were strongly in favour of a hospital setting:

"I think it's hospital...Hospital. Just in case....More equipment. Hospital is more prepared for that. And professional. They got what they called...the necessary equipment. Operation rooms, supporting, if when they have consult, they have a nurse, they have following up after that. If anything, happen complication after that bleeding...Hospital is more preferable."

When asked about where in the hospital the deinfibulation should take place, there was general agreement that for pregnant women it should take place in maternity, with midwives available to provide support.

However, it was recognised that if a woman was not pregnant or married, then the maternity department at a hospital or an antenatal clinic was not the ideal setting as:

"They [community] might say she is hiding something": "I think should be outpatients, because then you can have any ward or whatever but then you have still got your follow-ups and you still, it could be a minor surgery, a day surgery in out, but then at least I think it should be done as outpatients then everybody can go, and then obviously if you are pregnant then yes maybe then the maternity ward because you've got more support of the midwives."

Again, the importance of providing a flexible response, and giving women a choice, was emphasised:

"I think you should be given a choice, because you are the only one who knows your situation and your culture, and your background. So, if you feel you are most comfortable in the maternity or you feel I can't be seen in that area therefore I prefer another ward I think it should be left up to you, because you are the best person to decide."

No-one mentioned a GP surgery as a suitable place. There was some discussion about the most suitable location for non-pregnant women, but in general the hospital was still preferred:

"Whether you are pregnant or not you are going through same experience, pregnancy is different, but this procedure is the same experience for everyone, we go back to that day where you were on that table probably, and you feel exactly the same way if you're pregnant or not, the trauma happened the same as it happened to a non-pregnant woman. But when you are pregnant obviously you have other things to worry, that's on top of it. But I think they both should go to hospital."

4. Why is deinfibulation important?

Both discussion groups were asked what were the benefits of deinfibulation and why it was important. This question was answered throughout the group discussion and no-one expressed the view that women with FGM Type 3 should not have deinfibulation. However, in families and communities where FGM may not be talked about, it was often not a subject which could be raised with other, particularly older, family members.

One of the women in the London discussion group spoke about why she thought deinfibulation was important, both for the woman herself and also for the next generation:

"I think it's very important that they open it [vagina] up because of health reasons and as a human being too. You have been done something that is not right, it should [not] be like that. Eventually this person is going to be a mum too, so you will have to know what's right, what's wrong, and you know that something wrong is done to you. I think it's very important that you get the help and more knowledge about that you should open it, even for your own health."

Another woman spoke about a conversation she had had with a friend in her home country, and the positive effects on her friend's life of choosing deinfibulation:

"We and her are discussing it she was like, "I wish I had done it [deinfibulation] a long time ago, I suffered through the wedding, I suffered through my marriage, and then now I am pregnant and I am still suffering," and she had to do it [deinfibulation] I think a month or two months before having the baby and then go back again to delivery. But luckily, she had a normal delivery but after that she was like no, she had the options of do you want us again to do it, but obviously she was like no, leave it..."No halfway no quarter just leave it I don't want any stitching anymore," and she had got three kids now and so for the next two she had a normal delivery, no pain, she was like, "No I enjoy myself more now." "

The diaspora communities have regular contact with their home countries and changing practices overseas can help to change minds in England about deinfibulation as well as vice versa.

5. Who should make the decision about deinfibulation, and who should be included?

As part of understanding the views of the women affected by FGM about deinfibulation, the FGM Sister Study wanted to understand the process of making the decision and who is involved in makes this decision. For example, should it be the woman alone, or in conjunction with her partner or other family members or with healthcare professionals.

Some members of the West Midlands discussion group were very clear that it should be the woman herself:

"You should decide by yourself."

"Exactly, you decide yourself because you are going to be cut..."

A woman from the London group told the facilitator:

"I went to the doctor by myself to open... My mum never know that."

“ So, you made the decision to go yourself to actually have it opened? (facilitator)

“Because I have learnt about the health so I find that difficult and the problems, so I went to the doctor.”

Another member of the group agreed:

“She has to make the decision by herself. Because no one can...there is a choice, she has to have her own choice.”

For many women this was not a decision which could be shared with their mother, particularly if the mother had arranged for her daughter to have FGM in the first place:

“ So, you didn't tell your mother? (facilitator)

“Because she will get very angry, I will be...I don't want to annoy my mum, because it's a job she has done for me, so if I say I have...she would be happy...to keep my mum happy I never told her, even I have had c-section for two of my kids I never told her to keep her happy. I am not wanting my mum to worry about me.”

The group recognised that to act alone the woman would need to be quite confident and independent. A young girl might feel she needed support from female family members and they might have an influence on the decision-making. If she did not have this support, a young woman might not feel able to go ahead:

“It depends how old you are...you will not go through it on your own. If you let's say you decide to do it when you're 16 you want your mum to go, “Yeah I am okay with it go and do it.” But if she says no, you are more likely to say okay I am not going to do it, because my mum said no, and she's not happy. I would rather make my mum happy; I think I would have done that. I would look at my mum and go she said no, okay, I am not doing it.”

One of the women in the London discussion group thought that in some families, but not all, attitudes were changing and as a result 16-year olds might face a range of responses:

“But sometimes nowadays mums do understand the implication, 16 years old now you think she can have a conversation because that mum herself is not that older generation where she goes, no way, where maybe some mums still do prefer now wait for your husband or things like that, but I think the woman should be... because as

a girl you get a lot of support from mum, and you want that. But I know some mums obviously wouldn't give you certain things, they will support you in getting married or doing this or having a baby, but when it comes to culture stuff, they might say no that's our culture, are you stepping out of the culture? Are you becoming westernised?"

Education and better understanding of the procedure and its benefits were thought to be key, both for the young woman and for her family:

"A lot of mums don't really understand, they are just stuck in that oh if my girl hasn't gone through what I have gone through she's not going to have the good life, husband, children, a proper home. There's just that stigma around it. Oh, your husband don't want you if you have this, and because that's how she feels obviously she wants what's best for her daughter but she doesn't understand the complications as well. She might understand if she thinks it's worth it."

Women who were married faced different circumstances, and then some women thought that the husband should be part of the decision-making, particularly if the woman was pregnant:

**“ So, if a woman is pregnant do you think her husband should have a say?
(facilitator)**

"Yes, because the marriage is something like we are meant to be doing like accompany, it's sharing...it's life sharing. So this is your husband, you are sharing the child with you, so you have to have a say as well, you have to discuss with him, though you are not following everything that is good for your life, so he has to have his say in Islam, in our culture, some people follow him. But in Islam also we have to discuss about what we are doing for our lives, for our children, even if you are pregnant you cannot decide whatever you want, we have to discuss with him that..."

Another woman felt strongly that even when she was married, it was the woman's decision, and that the husband's role was to provide support:

"I think it's personal, I don't think he has that decision, he can... confide with him, speak to him and get the support maybe okay I am going to do this, I want you to help me, support me, understand, but I don't think the decision is... nothing to do with him. You just tell I have gone through this; he wasn't there when it was done to you."

Another woman explained that the conversation is not always an easy one to have: *"Sometimes if I said I want to do, my husband say no you're not doing that; you could be in trouble."*

She did not outline what "in trouble" might mean.

Others thought that if both men and women were better informed about FGM, then the husband would understand the benefits of deinfibulation:

"I think it's down to education. If you give both...obviously you become aware, and then you pass on the education to your husband. I don't think he will have that hesitation to even say to have an issue to whether it should even be...who should decide. As much as...as long as you've got that education you no longer want to remain like that. As soon as education comes you don't want to stay anymore you know what I mean?"

The person or people the women thought should be involved in the decision to go ahead with deinfibulation depended on the age and circumstances of the woman at the time when she wanted to take this step. There was no one answer to this question. Interestingly, their discussions were all in relation to family members with no discussions of the role of healthcare professionals in decision making around deinfibulation.

3. FEEDBACK FROM THE DISCUSSION GROUPS THEME 2: NHS PROVISION

Theme 2: NHS Provision

The second theme which the discussion groups considered was the FGM care from the NHS which had been received by the women.

1. Views on care services available

The women were asked about their views on the NHS services available to survivors of FGM. A woman in the London discussion group explained that it should not be assumed that women affected by FGM know about the NHS, and what can be provided by GPs and other services:

"I know now, I am aware of it now. But when I done mine [deinfibulation] years ago I had gone through researching myself, I was talking to [a friend] about it. I have gone Googling myself and research. I wasn't aware of the NHS; I didn't even know whether my GP will know about it. So, I have done myself of I need to do this but how do I go about it? Just research it on the internet."

She outlined how useful it is for the GP to have information available about FGM services and for this to be communicated sensitively:

"So you go to your GP because you have a headache or you have a pain somewhere, you don't go because something happened years ago that you have in the back of your mind this might be an issue but the GP shouldn't deal with this, or something like that. The first contact with NHS would be your GP, and if your GP is aware of it and they have leaflets or even if the doctor has brought it up saying well if you ever want to talk about that or if you want to know a bit more information there is a leaflet here, just take it home, and then you know okay my GP knows about it. I go home and read about it, I come back and say yeah you know what I want to discuss a bit more about this. But I think there should be a bit more... when you go to the GPs there is (information about) a flu jab or things like that, that is health. But FGM should be part of that as well, because it's a big community in the UK."

Another woman in the London group said that she wanted emotional support to be available as well as services to address the physical effects of FGM:

"They need to have emotional support, though we are strong women we need more support, but not to say FGM as well as the Social Services involved to the families most of them are talking about the FGM, while some families are not doing the FGM, they just arrived asking, that question is also hard in the community, and making them to give you a gap. We need them to have a good approach towards the families when they are assessed, when they are in assessment. They need to have a professional support and emotional support during the assessment."

This support includes listening when: *"There is a problem that's not involving with FGM"* and not immediately asking *"What do you think about the FGM?"*

2. The FGM Pathway

Another woman in the West Midlands group said that while NHS services may not be known and understood by some women with FGM, others may not even know they have experienced FGM. Health and social care professionals should be aware of this when talking about the "FGM Pathway":

"The midwife will ask you have you had FGM done, sometimes they just ask on paper, you are not even aware that you've had, because it's got different names in different countries. I remember the social worker years back when my daughter was only two years old, she asked me, "Do you plan to do FGM on [her]?" I had no idea absolutely that it was even called FGM, and even anything like that."

“ So even when you gave birth your midwife didn't talk to you about it? (facilitator)

"No, absolutely. When I gave birth to my last son that's when I was asked have you had FGM done, that's all, but for my two children nothing was mentioned."

This woman was aware that FGM occurs widely in many different countries, not just in Africa, and thought that all women should be included in questions about FGM:

"The only thing I am just wonder sometimes I feel unfair they are targets special groups. Because now I know there are some people in Europe, they have it, but sometimes I feel concentrated, just mean that people come

from Africa, so sometimes that make you feel unhappy actually."

The West Midlands group identified the GP as the initial point of contact for most women:

"I think because most of the times especially when you have got children, most of the places you go to is the GP. I think those are the people who are on the ground, you can't just go to the hospital, you go through your GP. So, I think that's where it should start from, and just like you have been saying making them aware, even the nurses and everybody them making them aware and giving them the signs, and just giving them an education, because that's where we go mostly."

There was also a discussion in both groups about the need for mental health services for women who have had FGM to be included in the "FGM pathway".

"Mental health itself is a stigma, it's a taboo to talk about it. A lot of communities with mental health, obviously the trauma comes under the mental health, and someone to talk about mental health itself: with our community that's another case, a whole other subject where "mental health? No, no, no, everyone is fine." "

In response to a question from the facilitator whether the language of "mental health" was appropriate, one woman suggested *"emotional support, empowering women, wellbeing support" would be more helpful terms.*

Some women identified the need for sexual help services, which specifically recognised some of the problems which women may experience as a direct result of FGM:

"I have no feelings. But I am here two years or three years with a man I don't want him, I am not feeling... if you are living a long-time illness you have to adapt it and accept it, I accept it. But some women if the husband left, she think that because of the FGM, it's effect."

3. The importance of information and knowledge

The West Midlands group discussed the importance of women and girls being provided with information about the options they have regarding health care and the choices open to them. In particular, the women did not all know that deinfibulation can take place at different times in their life, with different implications and consequences: *"That's the first time I hear they have three options"*

Another advised that professionals and community organisations should be wary of assuming that all affected women and families are well informed:

"We might think the community is getting educated, whereas there are a lot of people who need this information." And "I don't think that a lot of information... sometimes you are struggling when I have to start... you have to look and research. Sometimes you never know how to start from..."

It was also emphasised that understanding and acting on information is a process and does not happen immediately:

"If she is in denial then it's better that she gets more information about it [deinfibulation], because if you're scared of something you wouldn't do straight away, I am going to open it. You need to know because this has been normal for you for so many years it's a part of your life. You're not going to think it's wrong unless someone tells you, even if you don't want to do it. I am sure there's people that don't want to do it, why would I open it? But at the same time, it's lack of knowledge, lack of information, they don't know what they are really going through."

Similar discussions took place in the London group:

"It depends every household isn't it? Some households don't discuss about it [FGM]. So maybe that girls can get the information from somewhere else and bring that to home and discuss. Maybe mum and dad never want to discuss about it before, but now they are open to it plus their daughter wants to from a young age. I think accessibility is quite important."

Overall, the London group thought that deinfibulation, as a procedure and an option for women, was more widely known and discussed than in the past:

"I think a lot of people are on-board. Some are not obviously. I think some are, because I have seen a lot of groups of Somali mums and Somali women talking about, and I think talk about it first as the beginning. As long as you're actually aware of the situation that it opens up doors and opportunities and what to do about it and discussions, and a lot of people are discussing. Like mums are talking about it, well there is people who still obviously don't want to."

The participants in both groups thought that a good way of communicating with women and girls about FGM and their health was: *“To do more workshops in our community”* similar to the ones offered by the National FGM Centre.

4. Barriers to community engagement about health

An important aspect of the research was to ask the two discussion groups what they thought the barriers are that prevent women from using health services. Six different barriers were talked about. Once identified, the means of addressing them can be incorporated into service design and delivery. Some of these conversations are included in this section.

A. What is “normal”?

The West Midlands group said that some women (and men) did not know what “normal” female genital anatomy is. This was partly because of different practices at the time of childbirth in the woman’s country of origin. As a result, these women did not know about deinfibulation and its benefits:

“ People that don’t actually know that you can have this procedure (deinfibulation) done? (facilitator)

“In my country because when they got the birth just do it for you.”

“ And they stitch you back up, don’t they? (facilitator)

“Yeah, and you have to put it back again.”

“ So, you don’t even know that it can stay open? (facilitator)

“No...you have to stitch you back. So, he doesn’t know what the normal...”

“Number [type] three actually they have to do that, they have to back again because it stitched for a long time, when they cut it, it feels strange and not like normal, so they put it back usually in my country.”

B. Lack of services for non-pregnant women

A number of NHS clinics for non-pregnant women were established in 2019, but not all the women were aware of them. If a non-pregnant woman wants to be deinfibulated, the discussion groups both identified some of the barriers she faces. These included the language used:

"Don't say antenatal, no Somali would attend..."

“ Just to have it available, so anywhere the hospital...? (facilitator)

"Yeah, hospital, clinics. Say FGM support service."

There were concerns about the conclusions that community members might draw if a non-pregnant woman was seen in an antenatal clinic:

"You might see people that you don't want to be seeing going to places like that, that is in their own problems themselves so people are very scared to go to... straight away they will think okay they came here for abortion or that's what they do, or they came out doing an abortion if someone sees you coming out."

These factors all influenced what women thought would be the best solution for non-pregnant women:

“ What do you suggest, a neutral setting? (facilitator)

"I think the hospital, especially maybe where it's only women and no pregnancy, everything that has to do with section of women."

“ How about gynaecology do you think that might be better for non-pregnant women? (facilitator)

"Yeah, non-pregnant woman they would like to keep it discrete, don't want the whole world to know or be seen maybe, or scared to even be seen. So, you can go to a gynaecologist for anything, it doesn't have to be that, it can just be a natural check, so it's safe to say."

C. FGM as a taboo subject

FGM is often not talked about openly among women, or in families or communities. It is “hidden in plain sight” and this makes it more difficult to make changes in practices within families or elsewhere. This was explained by two of the women who took part in the discussion groups:

“We write about that’s your privacy, you should not speak anyone about your privacy what everything... it’s something just you have to feel shame when talk to about it, so that could be part of education, part of culture you come from, and woman grown they think that’s the normal because they are not awareness about... because when she is grown she see that, she doesn’t know how it look normally.”

and:

“This matter is a taboo thing. You wouldn’t even want to speak about. I don’t mind speaking about it, but there’s women that’s scared to say something because things like, what are people going to do, everyone else how are they going to think about me. This is something that a lot of people think is the right thing to do, so I am going against it.”

D. Need for education for women, particularly from survivors

A topic which came up, time and again, was the need for education and information, including by community members who had experience of FGM:

“If you have the education, if the education comes in the community and then they will know...If you don’t know, you don’t know, how can you just get up and go for something that you don’t know? But if that information reaches you and says oh this practice is very bad, and these are the reasons, and this is what you could be going through, when that awareness comes, and then people will bring themselves forward because what it is with this FGM it’s you who knows what you have gone through. If somebody who has gone through it reaches out and says the reason why you have been having this infections it could be A, B, C, D, and then you agree with it, automatically you be a witness to yourself to say oh yeah that makes sense, you know what I mean?”

This was echoed by another participant:

"We should get people to be more part of things like this, more Somali people. Even if the awareness is there it's not going to help if people are not taking part that actually for example been through it, knows the health problems and everything and knows about what the religion says about it and everything. I think people like that should be part of this awareness too, to be taken more serious I think..."

E. Lack of Education for men

Both groups considered it important to educate men about FGM, as well as, women:

"Most of the time getting the man involved will be very important so they know this is being done for them."

"Most of our community leaders are men."

““ Do you think they [men] are involved in talking about the implications [of FGM] or talking about deinfibulation? (facilitator)

"Not that much. I think it's mostly amongst themselves, the men amongst themselves."

Men's attitudes can prevent women from having deinfibulation:

"I think we have to educate the men also, because in my country sometimes men say I am not going with woman without FGM because they have been educated like that, all those things in mind, woman she is not going to be a virgin if she has not had that, woman she is not a clean woman if she not had that. But I think when you educate them properly, when we see what woman she is going through, see that, I think they are now thinking..."

The London discussion group agreed:

"The virginity thing is a whole other case. I think that's a bigger problem with again not just the Somali community, with a lot of communities when it comes to virginity, what virginity is exactly. I think men themselves should be educated about it..."

F. Attitudes towards mental health

One member of the London discussion group explained that mental ill-health was often regarded as a symptom of spirit possession in their community:

"In Somali communities when they hear mental health they don't think about emotions, they don't think about depression, they don't think about mental health straight away, they think that this person is possessed, that this person has jinns or something like that, they don't really believe that drugs can do that or emotions, situations that you have been through...Trauma, all of that is not mental health in a Somali community, it's more like you hear mental health, okay this person is crazy, or this person is possessed."

Another woman agreed:

"Somali woman if they hear that they have got a mental health [illness] and go to that hospital no one will trust her again, that's our problem, that's what we are talking about nowadays, because mental illness is something can be cured, can be healed. But if the community are criticising you and you know that you lost the confidence, and if you are hurting, heart is broken, you can never call...we need more empowerment as long as the cultural diversities, our main problem because in our country the person get a mental illness until they die..."

4. RECOMMENDATIONS FROM WOMEN AFFECTED BY FGM ABOUT HOW SERVICES CAN BE IMPROVED

Both groups had ideas about how to improve the NHS services provided to women and girls affected by FGM. They argued in favour of the benefits and importance of listening to women who were actual and potential patients, and asking them how to develop services to meet their needs. Deinfibulation is potentially a big decision for a woman and: *“She needs someone to speak to her and support her.”*

This includes professionals:

“I think all the professionals should be aware and they should be told...I know they are busy people, just take time to explain on there have you had FGM done, FGM is this and that, and that, you are aware, or do you know anything about, instead of just asking have you had FGM done, do you know anything about FGM, and then maybe just explain a little bit so that somebody is able to answer whether...to know. Because if it's called another thing you won't know, you will straight away say no and just dismiss it.”

Another member of the discussion group commented:

“I don't think the health professionals understand at all. I feel there is still more education, those nurses and the midwives, how to go about it, how to ask questions and just reach out to you.”

Other women who have undergone deinfibulation are important sources of support:

“I think also coming to other women who had their experience and giving them the assurance to say that you had that done, we are the same and we are going to support you, this is your new normal, embrace it, enjoy it because this is the way you are meant to be.”

Community members and support groups were also important and influential communicators:

“We are the most people affected the FGM have to participate and take part with it...They need to take a part, all the community leaders as well as the religious leaders need to take part. They take a part but they need to do more orientation.”

One way of doing this suggested by a member of the West Midlands group was “community champions”:

“They could organise something in the community, even a smallest gathering in your house just to educate each other. Once in a month you go and maybe if there are barriers to culture, have one culture in one house, and other one, and the way it goes like that, because even when new people come you embrace them and teach them what you have learnt and how to integrate.”

The women also added that modern technology should play its part:

“We cannot do door to door, but we use social media and all that.”

The West Midlands group felt that more should be done to provide support to women after deinfibulation has taken place. This was essential for the woman herself:

“Especially with this operation because you think it’s put you back for memories. Some people I know they say they get back the pain and how we don’t like that, because after operation two or three days they have a lot of pain, no ibuprofen working they said, when she got passed urine she still have difficult to pass urine and bring a lot of these memories.”

A woman from the London discussion group highlighted that the pain experienced after deinfibulation can be mental as well as physical. Women wanted emotional support as well as access to the procedure:

“The whole procedure when you are going through it, it may leave a trauma, as an adult still dealing with it, and you need that emotional support before you reopen... even try to discuss, because as a child you know what happened and you never discussed it with mum or anybody, and all of a sudden now you know you have a complication, you go to your doctor and the doctor will straight away maybe say to you okay this is the procedure we do, go to this hospital, read up, see you. No one talks about it at all, how do I feel, that’s the trauma we have been left with, I feel embarrassed, scared and pain, and all of the things that happen when you are young are still there.”

This will also include support to help her when dealing with the reaction of family members:

“When you talk with the family, they ask why you do that? Why you done that? This is not happening like that. So, she feel like she do something wrong and she started asking, do I do something wrong? Because still she does not have more information about why she have that. So should the more explaining, the more supporting after the operation, she have to put through like you say a group or counselling, to talk about that’s normal, you feel pain, there are other people, because she is still that in her mind she is look like that’s the normal.”

Health and social care services are working increasingly together to provide an integrated response to patients and service users. However, women in both discussion groups were concerned that **“Social Services”** were being seen negatively by affected women:

“Social Services are a part of NHS, if they hear that, if you tell them that you call for help, they will tell you “they will collect my kids”. That’s another problem we are suffering from, we need more understanding about the system, we need more help to the woman affected...”

and:

“Most of the people from my community they expose for FGM through the schools, because when you try have holiday and go for injection and stuff like that they are saying to you immediately Social Services and stuff, the way you expose it I think it’s very negative.”

These comments link back to the discussions about the continuing need for information and education around what services are available for both women and girls, and the earlier statements about all professionals, from whatever background, taking care and: *“the language that the professional is speaking, or the time available.”*

Things to remember about the discussion groups

The two discussion groups described in this report provided a rich source of information about the views of woman affected by FGM regarding deinfibulation and NHS services. The face to face conversations among the women provided an opportunity for concerns and opinions to be raised through the debate between the women which may not always occur in individual interviews.

The groups were potentially limited by the requirement that all participants spoke some English, although the use of an Arabic-speaking facilitator enabled the discussion to be more inclusive than would have been the case without her presence. The facilitator was also from an affected community, and this knowledge appeared to help the women feel more able to be open.

The use and choice of terminology did not appear to prevent the women from expressing themselves. Neither “deinfibulation” nor “opening surgery” were used during the group discussions by the women. The term “deinfibulation” is used throughout the report and by the facilitator to distinguish this surgery from the opening which some women experienced as children.

There is no suggestion that it is possible to generalise from the comments made by the women who participated in the discussion groups. The reasons for this include: the small size of the sample; women were only included from five countries where FGM is practised; no women were spoken to with Type 3 FGM who did not have deinfibulation.

However, the views and opinions of the women who spoke about their experiences do provide extremely useful information about the variety of perspectives of community members affected by FGM, and suggestions for further work.

KEY TAKE HOME MESSAGES FROM THE FGM SISTER STUDY TEAM



There was no clear agreement about when deinfibulation should take place but the London group did suggest **before marriage**



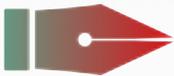
Deinfibulation should be done in a **hospital** by somebody who is **knowledgeable about FGM** and the procedure



The key for healthcare professionals is to **listen** to women when supporting them



Women, men, communities and healthcare professionals need **better awareness** and **knowledge** around FGM



Survivors can play a role in **education** around FGM



Women who have had deinfibulation can play an important role in **supporting other women** who might be thinking about having surgery



Women need to know what services are available so that they can make the right **choices for themselves**



Women, families and communities all need to be **included in the development** of new services



Women need **emotional support** as well as access to deinfibulation services



Services for non-pregnant women need to be in **neutral locations** such as in gynaecology and **not in maternity**

Acknowledgements

The University of Birmingham and the National FGM Centre would like to thank all the women who took part in these discussion groups to help us understand their views on deinfibulation and health care services. We hope that, as a result, services in future will be better able to meet the needs of all women and girls affected by FGM.

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Developing excellence
in response to FGM and
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