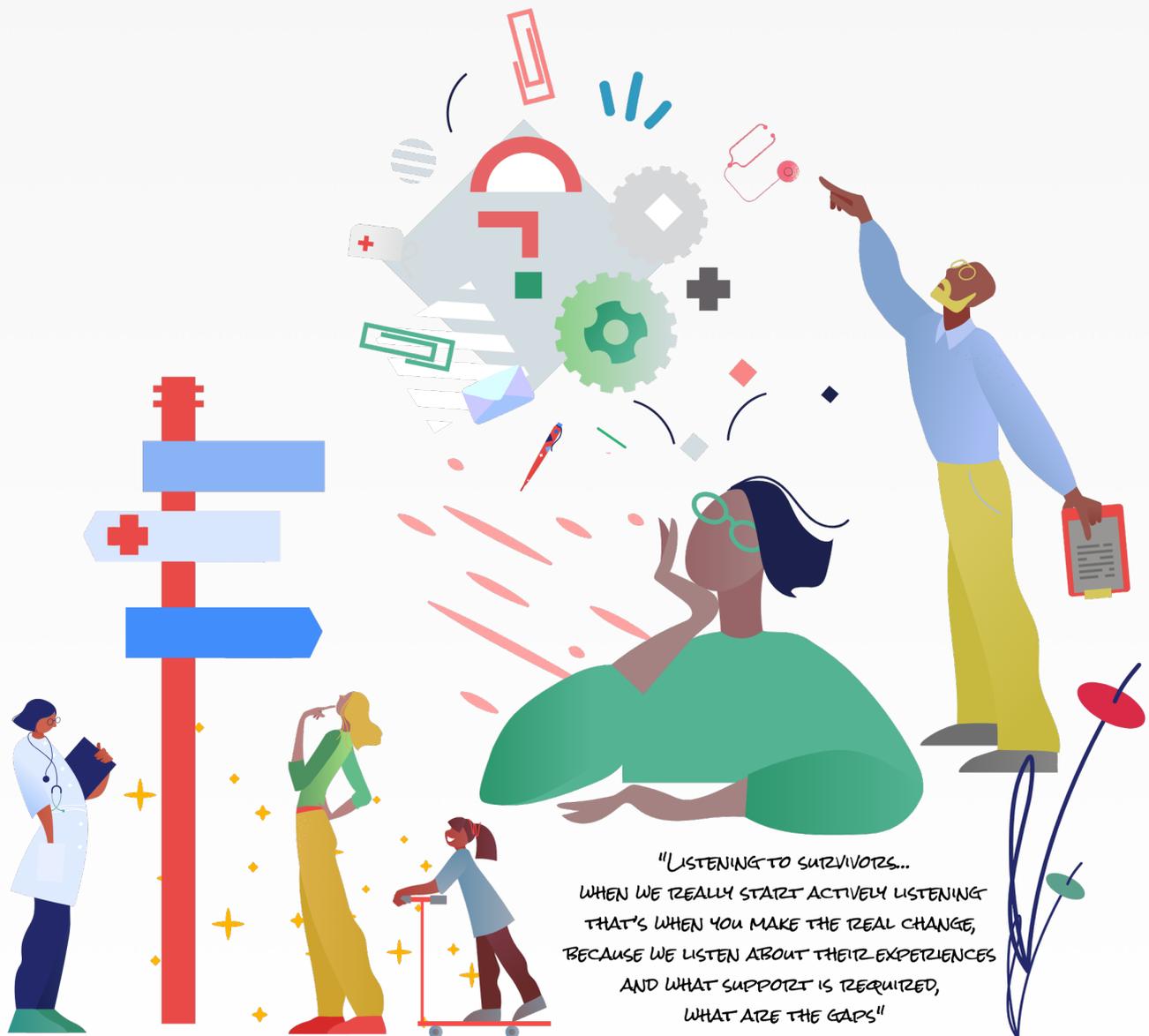


UK stakeholders working with women affected by female genital mutilation (FGM): views and experiences of deinfibulation and NHS FGM services

Forming part of the FGM Sister Study

2020



"LISTENING TO SURVIVORS...
WHEN WE REALLY START ACTIVELY LISTENING
THAT'S WHEN YOU MAKE THE REAL CHANGE,
BECAUSE WE LISTEN ABOUT THEIR EXPERIENCES
AND WHAT SUPPORT IS REQUIRED,
WHAT ARE THE GAPS"



Developing excellence
in response to FGM and
other harmful practices



UNIVERSITY OF
BIRMINGHAM

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ABBREVIATIONS

CCG	Clinical Commissioning Group
DoH	Department of Health
FGM	Female Genital Mutilation
GP	General Practitioner
NHS	National Health Service
PTSD	Post Traumatic Stress Disorder

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 is a value rather than an activity.

From its inception in 2015, the NFGMC saw collaboration with researchers, professionals and communities as important elements of its work. Therefore, when presented with the offer to partner with the University of Birmingham on a research project, we grasped at the opportunity to be involved because of the difference the research would make to the lives of FGM survivors. The partnership with the University of Birmingham is a shining example of what can be achieved when there is an equal partnership between an academic research institution and a charity. One of the successes of this research is its co-production element, which focused on hearing the voices of stakeholders. Their contributions reflect the depths of how attuned they are to understanding the needs of FGM survivors. We thank the stakeholders for participating in the research and for their continued commitment to improving the quality of services for FGM survivors.

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 and what they need from health services. The NFGMC will use its available 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 this research is the impetus for further research that would further improve future services for FGM survivors.



Leethen Bartholomew

Head of the National FGM Centre

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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

44

13

44

1. INTRODUCTION

The FGM Sister Study is a partnership between the University of Birmingham, the National FGM Centre, Birmingham Women's and Children's NHS Foundation Trust and University Hospitals Birmingham NHS Foundation Trust.

This report is based on part of the research, which focused on a national stakeholder event held in London on the 23rd January 2020. This National Stakeholder event marked the culmination of 2 ½ years of positive research collaboration between the National FGM Centre and the core research partners. This research would not have achieved its aims without the support of the National FGM Centre as the organisation provided unique insights into engagement approaches with key stakeholders. The researchers would strongly recommend that future research on FGM is undertaken using a partnership model between academic research institutions and charities with community engagement experience.

The Stakeholder event was organised by both FGM/C experts from the National FGM Centre and FGM Sister Study researchers from the University of Birmingham. The event was divided into three main discussions facilitated by the research team. Each discussion focused on a number of questions (with a corresponding statement of early findings from the interviews undertaken as part of the FGM Sister Study) in order of importance to discuss.

The discussions are divided as follows: Discussion on-

Timing of
Deinfibulation

Knowledge, Training,
and Understanding
around FGM

NHS Provision for
FGM Survivors and
their Families

Facilitators asked each question and contextualised this by reading the corresponding statement to ground it in interview data and initial analysis. This prompted discussions at the table level to explore individuals' views about whether they agreed or disagreed with the statement and why.

Each question also contained some possible steers to facilitate discussions, which aimed to engage discussions about potential knowledge gaps and help with identifying considerations on associated research questions.

Each discussion lasted approximately 70 minutes which comprised of 35 minutes for facilitated discussion using the guide, 15 minutes to summarise main/key points and thinking about future research questions, with a whole group discussion to summarise for the remaining 20 minutes.

2. TYPES OF FGM, ASSOCIATED CONSEQUENCES AND DEINFIBULATION

The World Health Organisation defines FGM as “all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons.”

Infibulation is a term used to describe FGM WHO Type 3 where the vaginal opening is partially or completely closed. This is usually following the partial or total removal of the clitoris and the inner and/or outer labia. FGM Type 3 carries severe short and long term health consequences for the girl or woman (see Figure below).

Deinfibulation refers to the practice of cutting open the sealed vaginal opening of a woman who has been infibulated, which is often necessary for improving health and well-being as well as to allow intercourse or to facilitate childbirth [WHO February 2020].



Developing excellence in response to FGM and other harmful practices

Potential health consequences of Female Genital Mutilation

Created by the National FGM Centre with Juliet Albert (Specialist FGM Midwife)

	Type 1	Type 2	Type 3	Type 4
	<p>Type 1</p> <p>Partial to total removal of the <u>clitoral hood</u> and/or <u>clitoris</u></p>	<p>Type 2</p> <p>Partial to total removal of the clitoris and <u>inner labia</u> and/or <u>outer labia</u></p>	<p>Type 3</p> <p>Usually includes partial to total removal of the clitoris and <u>inner labia</u> and/or <u>outer labia</u>, with inner and/or outer labia <u>sewn/fused together</u> leaving a small hole.</p>	<p>Type 4</p> <p><u>Any other injury</u> to the genitalia including <u>piercing</u>, <u>scraping</u>, <u>burning</u>, <u>stretching</u> and <u>pricking</u>.</p>
Short Term	<ul style="list-style-type: none"> • <u>Infections</u> such as HIV, Hepatitis, Septicaemia and Tetanus. • <u>Pain</u> - The clitoris contains numerous blood vessels and the most nerve endings in the female body. • <u>Broken limbs</u> - If the girl was held down or restrained. 	<ul style="list-style-type: none"> • <u>Shock</u> - both physical and emotional • Excessive <u>bleeding</u> (haemorrhaging) • <u>Death</u> 		<ul style="list-style-type: none"> • Even a small prick, scrape, burn or piercing can <u>damage the nerves</u> of the genitals and cause <u>infection</u>. • Stretching labia can be painful while being carried out and uncomfortable in the long term.
Long Term	<ul style="list-style-type: none"> • Pain during sexual intercourse due to <u>scarring</u>. • It may feel tight in the clitoral area which can be very painful. • Damage to urine hole, can cause <u>incontinence</u> and <u>pain</u> when passing urine. • <u>Loss of sensation</u> which may affect sexual pleasure. 	<ul style="list-style-type: none"> • In childbirth women are more likely to suffer <u>tears</u> and <u>bleeding</u> as scar tissue may not stretch during labour. • Prone to <u>urinary and thrush infections</u>. • <u>Anxiety/Depression/PTSD/Flashbacks</u> • <u>Cysts/Fistulas</u> 	<ul style="list-style-type: none"> • Sexual intercourse and cervical smears may be difficult and painful or impossible if the opening is very small. • More likely to have <u>pain</u> and <u>blood clots</u> during menstruation • Increased risk of <u>pelvic inflammatory disease</u> • Possible <u>infertility</u> 	<p>Remember</p> <p>A small bleed or piercing of the genitalia, may not be visible many years later however the woman may remember being held down, bleeding and being in pain.</p> <p>If FGM is carried out as a baby, the woman may not remember, and may not become aware until later in life. Some women may not experience any health consequences.</p>
	Type 1	Type 2 (can include type 1 complications)	Type 3 (can include type 1 & 2 complications)	

3. PARTICIPANTS

A total of 30 participants took part in the workshop. Participants consisted primarily of professionals involved in supporting girls and women with FGM including some seeking deinfibulation, with further representation from policy making, police and safeguarding (chart 1).

The majority (93%) of the workshop participants identified as female and 7% as male.

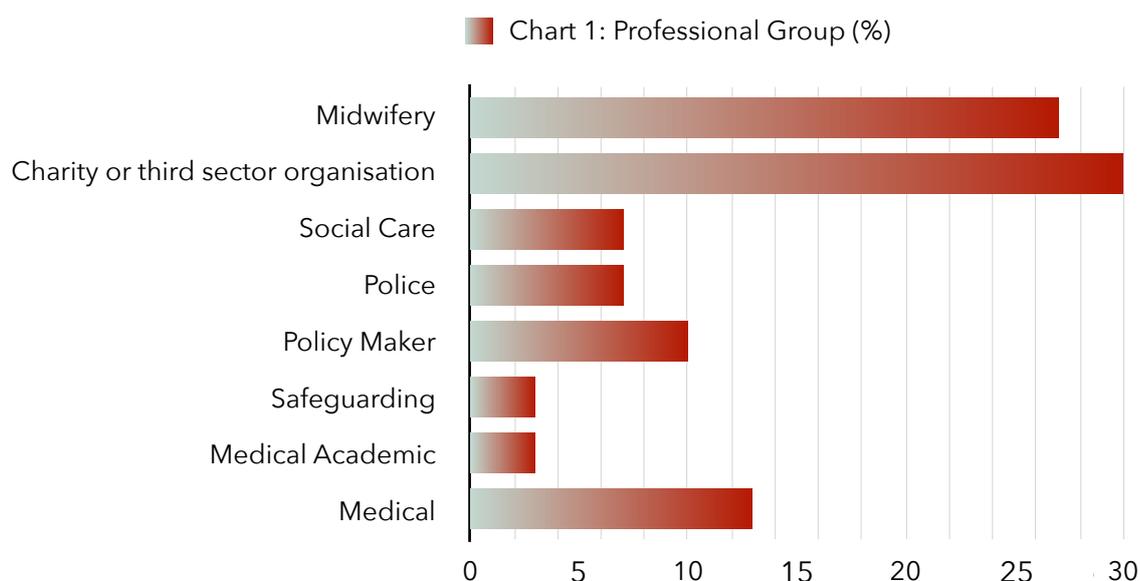
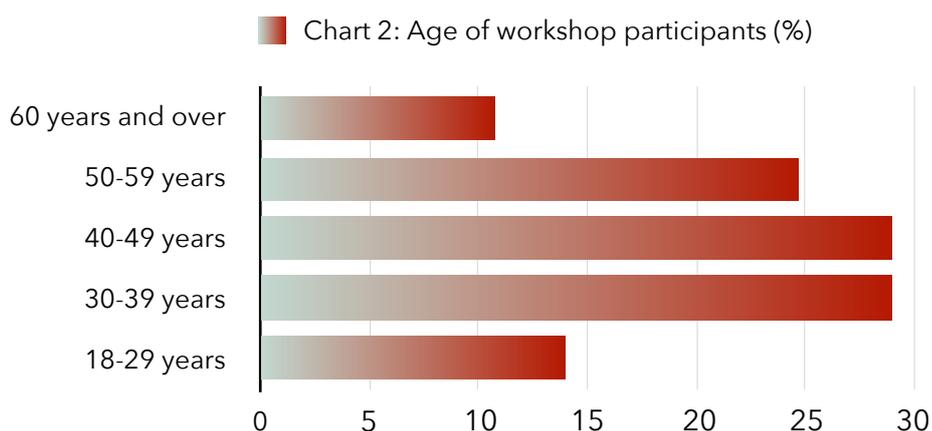


Chart 2 shows the ages of the participants with 60% being over 40 years and 13% being under 30 years old.



Forty three percent of workshop participants identified as British European with strong representation from a wide range of other ethnic origins (chart 3).

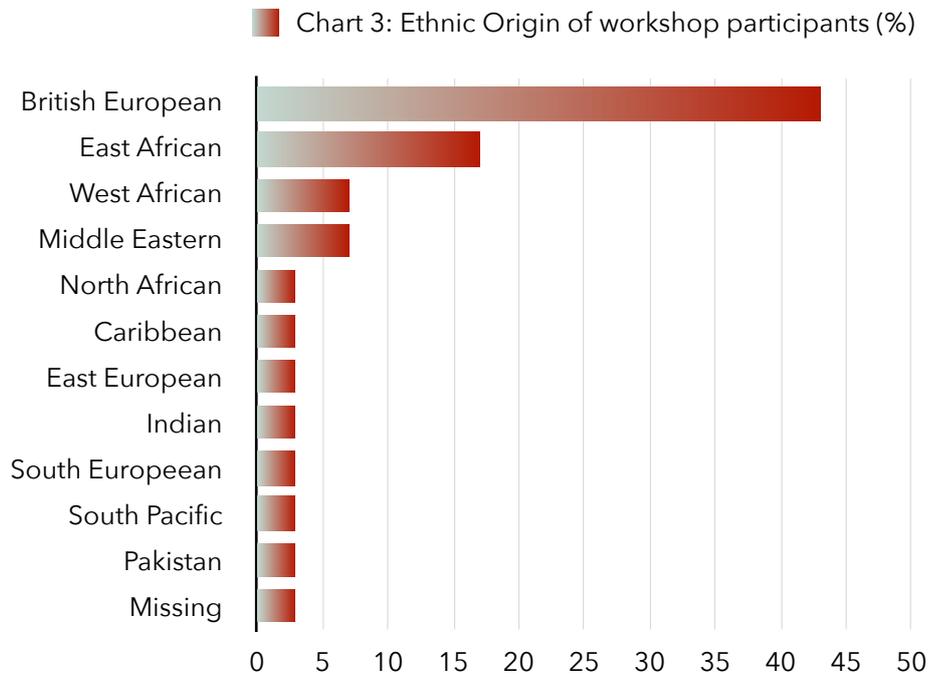
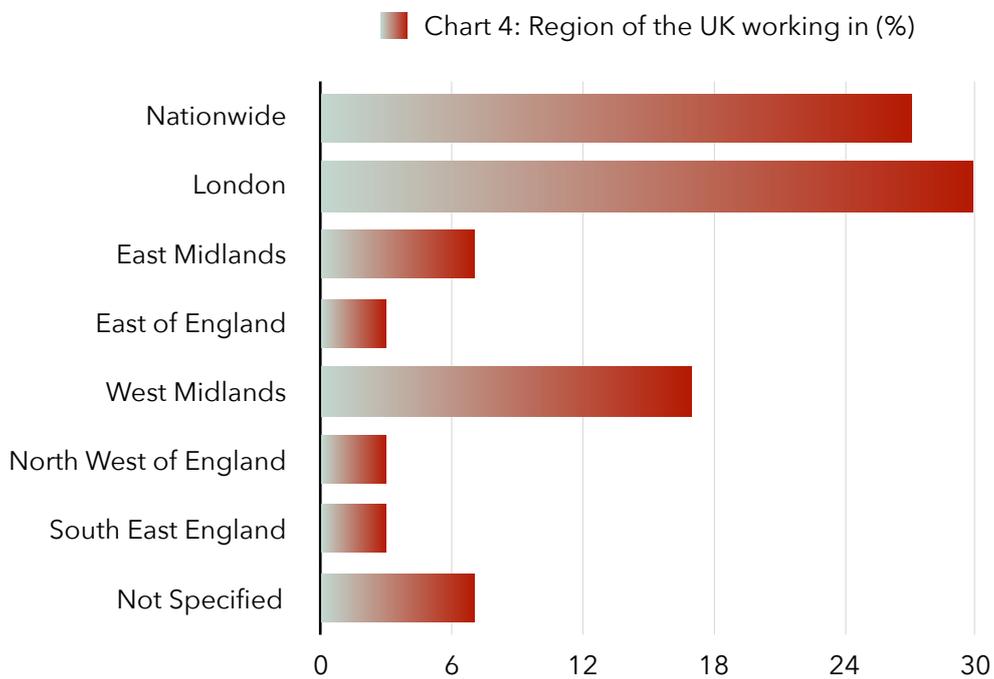


Chart 4 shows the regions in which the workshop participants work. The highest number of participants were from London and the West Midlands with representation also from across the other regions.



The majority of participants reported that the prevalence of FGM was high in the region in which they worked; 13% reported it as low and 27% were unsure of the prevalence in their region..

4. SUMMARY OF THE DISCUSSIONS

This section summarises the views expressed in the four discussions on different aspects of FGM and includes quotes from workshop participants.

A. Timing around deinfibulation

The first discussion focused on practical aspects of deinfibulation, specifically when it should happen, who should perform it, where it should take place, and who is important in the decision-making process.

When should deinfibulation happen?

There was a strong feeling among participants that deinfibulation should happen when it is right for any individual woman and that she should be encouraged and supported in making her decision. For some this might mean during labour, for others prior to first sexual encounters, or as part of antenatal care.

It was agreed that it is a complex decision for any woman to take:

'It is about the woman's choice because she may choose to have the procedure, but that procedure may be during pregnancy, it may be before pregnancy, it will depend upon her personal circumstances as to her readiness for deinfibulation to take place if indeed she is ready, and that will include not just the readiness in terms of her lifespan but also in terms of the actual timing of the procedure, whether it be weekday, weekend, so forth'.

From a clinical point of view, some participants thought:

'It might be better outside of pregnancy, so that people who might have had complications, they might have had fertility problems, actually have that opportunity before them'.

Others saw advantages to deinfibulation being part of antenatal care as this is a time when strong relationships are often developed between health care professionals and the pregnant woman, and deinfibulation is just one of the services from which women can benefit during pregnancy. This was summarised by one participant:

'I think what was interesting for me hearing was about the continuity of care that actually if it's [deinfibulation] done in the antenatal period that relationship can be built up from the clinic and that clinician and all the rest of it, whereas if it's done in labour you get whoever is on at that time so that was interesting!'

Some felt they would like to provide guidance on the safest time for deinfibulation but identified: *'A lack of evidence to be able to advise appropriately about that safety element'*.

Who should do the deinfibulation?

The discussion on who should perform deinfibulation was approached from two slightly different but complementary perspectives.

Initially, the focus was on the requirements of the individual carrying out the procedure and the need for them to be a *'Specialist in deinfibulation'* having undergone specific training in deinfibulation. Such clinicians will usually, but not always, be midwives. The key criteria are that within their scope of practice they: (a) have the expertise to carry out the deinfibulation procedure, (b) be *'Working within a referral pathway with consultant obstetricians'* who can manage *'Complex obstetric gynae problems'*, and (c) be able to provide the appropriate psychological care. There was a strong focus on the need for someone performing deinfibulation: *'To have a deeper level of understanding as to the journey of the woman'*. As summarised by one participant: *'I keep coming back, it's about trauma, the women deserve better, they don't deserve to be re-traumatised and they deserve safety and quality care'*.

Therefore, when considering the needs of an individual woman the focus was on the highly skilled, trained health care professional specialist in deinfibulation. However, at the same time there was a call for all midwives to have the skills to perform deinfibulation: *'Because say in labour a woman shows up and has type three [FGM], no one else can do it...'*. As explained:

'They are the person who is going to be called, and there have been situations where people have then had to do a caesarean section because no one knows how to deal with that sort of FGM. So at least if there was an expectation at the same time as trainees are being trained to repair episiotomies and tears, that there is expectation that actually this [deinfibulation] is part of your remit and this is the standard thing that you have to all learn how to do....and it becomes integrated into that curriculum'.

These two perspectives are brought together by one participant who explained:

'...Those who do it [deinfibulation] have the duty to ensure that every time you do it [deinfibulation] they should be asking a trainee or a midwife or a nurse to come and do it with them so they get the physical but also you can model what good psychological holistic support looks like for that woman in care. So, for me it's not just can they cut, can they suture safely, it's actually do they have the deeper holistic approach of care to this woman, can they recognise PTSD when it's happening? How would they manage that in an acute situation, whether it's in labour or whether it's antenatal or a non-pregnant deinfibulation?'

Where should deinfibulation take place?

The key factors for women in relation to where deinfibulation should take place were clinical safety, comfort and confidentiality. Maternity services, FGM clinics and hospital all provided clinical safety; however, hospitals appeared to be the most favoured places: *'Because you could be at the hospital for any reason'*. As summarised by the facilitator for unmarried women, going to a maternity service, or an FGM clinic might be difficult and *'Being seen as an unmarried woman in a maternity setting by someone in the community was worse than being seen in an FGM clinic'*.

Participants talked about women having choice about where to go for advice and treatment on deinfibulation; however, they were also aware about the limitations of services and wanted choice to be available: *'But without compromising on provision or the quality'*.

Who is important in the decision to be deinfibulated?

All participants agreed that the most important person to be involved in decision-making about deinfibulation was the woman and that ideally there should be a two-way relationship with a health care professional with whom she has been in conversation.

It was recognised that for many women, especially those who might have recently arrived in the UK, conversations around such personal issues were unfamiliar. As one participant explained:

'[They] aren't used to making decisions around any part of their bodies, they weren't involved in the decision about FGM, they were surprised to be involved in the decision around deinfibulation, so they defer...the women I work with will often turn to their sisters who have knowledge from their sisters and mothers.'

Conversely, some women appeared to be pro-active and assertive in relation to their bodies, with one participant explaining that:

'The younger women that I see are coming forward because they wish to take back control and that has largely been through interaction with social media and education'.

The same range of opinions was expressed when talking about the role of men in decision-making. On the one hand participants explained that: *'Husband is important, quite often a woman will turn to her husband say what do you think?'*. Whilst others stressed the value of men being informed or educated: *'It's about telling the man what he might be doing if the woman doesn't go and have her deinfibulation before her wedding night, it's about educating the man'.*

Whilst recognising the value of involving men, workshop participants wanted to avoid this being interpreted as an expectation that a woman has to seek permission from either her husband or male family member before going ahead with deinfibulation. As explained by one participant:

'The risk of doing that [involving men] badly could be that we set an expectation that a man has to be asked for permission. That would be the furthest end of that spectrum, but it is one which we need to make sure we don't travel'.

B. Knowledge, training, and understanding

This discussion was concerned with those people working with FGM-affected communities, what knowledge was important, how they can be supported in acquiring and maintaining this knowledge.

There was some disquiet around the use of the terminology of FGM-affected and FGM-practising communities with some feeling that: *'There will be a portion of the UK that feel that's not relevant to us, yet it is very relevant even if they have got one patient on their GP list who may be affected'*. They went on to say that local communities: *'Found it stigmatising that they have got many issues, diabetes, cancer care, lots of things happening, and yet they're stigmatised with this label FGM-affected or FGM-practising'*.

“ What knowledge is important for people working with FGM-affected communities?

There were some areas of knowledge which participants felt were important for people working with FGM-affected communities should have; however, they felt that understanding communities and the attitude of people working with communities were essential elements.

Knowledge of the law was considered to be important although as one participant said: *'There needs to be more psychological and emotional knowledge rather than leaning more towards the legal'*. There was also a call to: *'Treat FGM as a rights issue and an issue around safeguarding children, as well as an issue that can affect people medically'*, in order to be able to provide a professional service.

There seemed to be a call for different types of knowledge acquisition for activists and clinicians, whilst recognising that an activist could also be a clinician. It was suggested that activists could benefit from more exposure to the evidence base from high quality research studies, as explained here:

'The significant work that academics, government, however much we criticise them, clinicians, social care people are doing, because if you take training for instance academics and others have come together and people have agreed that the evidence says this is what we would pass on.'

Conversely, clinicians were being invited to: *'Acquaint themselves with all the issues around FGM, the variety of nuances, and what support they can offer'.*

When talking about the attitude of people working with FGM-affected communities, there was considerable agreement. Listening to communities, recognising that all communities are different and non-sensationalising FGM were three recurring themes as highlighted in the following quotations:

'...Listening to survivors....that they should be shaping our support services rather than [us] coming with a top down approach. So, when we really start actively listening that's when you make the real change, because we listen about their experiences and what support is required, what are the gaps.'

'...You have to be careful how you approach someone....Nigerians can be different to Sierra Leone is different, Somalians are different, every culture is not just...culturally we are all so different, how we react to things we're different and how we see things we're different, and within that culture every family is different, every individual is different.'

'There's something for me around non-sensationalising the issue.....you have made them the other, we're talking about everyday people, everyday lives, that just happen to be affected by this one particular issue. So, things around in training, in education, not using graphic images and graphic videos of girls screaming and things like that, because we wouldn't do it for anything else or we shouldn't do it for anything else. It's about empowerment and not seeing this group of people or these women as the other, as something sensational or something different.'

How can we support people working with FGM-affected communities to gain core knowledge?

Participants felt that:

'There needs to be training but rather than specifying specifically you need to know this, this and this it's about the way in which that training is undertaken' with 'Using women's journeys' and 'The terminology of how women are talked about being really important'.

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There was a call on the one hand for specialist training whilst on the other hand there was a call for FGM to be seen as an issue which does not require specialist support:

'We don't want to repeatedly have FGM as 'othered' so people feel that they have to have special training... actually should be embedded into the organisation the same way you would have knowledge around gender-based violence as a wider thing.'

These perspectives were not seen as mutually exclusive but each valuable in their own way. FGM champions: *'Particularly trying to get things up and established and embedded'* were also seen as valuable, in the same way that sepsis champions have been.

What are the current barriers and facilitators to supporting people working with FGM-affected communities gaining and maintaining knowledge?

The barriers identified included inadequate funding, a lack of consistency of local actions, a lack of accountability and a lack of a support structure for frontline staff. In addition, participants talked about establishing the right balance between being appropriately sensitive to the feelings of communities and providing clear, authoritative information. There was a suggestion that some professionals shy away from having difficult conversations and giving direct information, as shown in the following quotations:

'...We forget to look at the thing that is our responsibility as professionals to do, like mandatory reporting, because you get doctors saying they don't want to do that, and we're focusing on the flowery bit, that's a serious business and we really need to come to it from the context in which the abuse happens, and sometimes I don't hear that when people talk, I really don't hear that.'

'...The flowery part is the part that we who haven't had FGM think that we should be offering these people. We feel sorry that we are almost talking to them about the law, we feel sorry that we are almost saying if you do this to your child you will be arrested by the Police. We feel so sorry that we are having to intervene, and I hear that so often that one of my biggest worries is what I have written, to listen to the academics rather than all the people on the ground.'

'...I get you about sensitivity and I don't think the people who work with women and girls are insensitive, but there has to be an element of objectivity. There has to be an element of you the professional are non-judgemental, and you are sensitive.....you listen to the women they want us to give them straightforward direct information.....I don't believe that I should give women any other information other than that which you have proven to work, and you deliver it in a way that people like NICE and other people have said you should do it.'

C. NHS provision for FGM survivors and their families

This discussion explored three questions relating to the NHS care provision for FGM survivors and their families.

What is good about current NHS FGM care provision?

Participants reported that: *'There is a groundswell of increased knowledge about FGM'*, that the increasing demand is recognised and that the care available to survivors and their families has improved considerably in recent years with new schemes being piloted in different clinics.

Healthcare professionals delivering services for FGM survivors were noted for their commitment and were described as being: *'Really passionate about what they do'*.

Additional positive features identified included newly commissioned FGM clinics which complement existing services, the integration of psychological services with FGM clinics, self-referrals *'Even though self-referral isn't necessarily available in every area'* and:

'Leadership from NHS prevention programmes that [has] raised awareness amongst commissioners, so we've been able to commission certain services that we may not have been able to commission five years ago'.

What is challenging about current NHS FGM care provision and how can we improve it moving forward?

Lack of funding was identified as a major issue and also the over-reliance on a small number of dedicated professionals, leaving significant gaps when they were not available.

Time for counselling was identified as a challenge as explained by one participant: *'Allocation of professional time whether it be for a professional counsellor or counselling as part of that professional relationship'*.

An additional challenge was the range and variety of services that were difficult to keep track of, as described by one participant: *'They [FGM services] are so different from one place to another what's available, one place to another is so varied'*. The suggested solution was: *'better networking and sharing the models of care'*. However, another participant pointed out that there is a shortage of data, saying: *'We don't know what we don't know because we don't have the data necessarily'*.

Different services are commissioned by different agencies, which participants felt added to the complexity of services. One participant explained:

'FGM falls between two things....basically FGM will be commissioned by CCGs, whereas sexual assault work which involves many of the...say for example paediatricians, it's commissioned by NHS England. So it falls between the two'.

Another participant then added: *'Then there's sexual health clinics which is where teenagers go is commissioned by local authorities'*. Although it appears that when an FGM service was established in a sexual health clinic it was unsuccessful.

Two additional complex challenges were discussed in greater detail, namely supporting non-adults and balancing the need to create safe spaces and complying with mandatory reporting requirements. These two issues are closely linked.

There was general agreement that young people (under 18) were increasingly more aware of the issues around FGM, but it was unclear: (a) where they might go for support and guidance and (b) how professionals balance their priorities for support, as demonstrated in the following dialogue.

'...If you look at the NHS Digital quarterly report it is said that there are kids who have had FGM, but also we don't know if we have got 13, 14, 15 year olds who are desperately wanting to see a doctor, talk to somebody.'

'...and I've got someone else now who has looked at posters in the accident and emergency and has decided that actually she would like to be seen. So, I think young people are becoming more aware of it. I don't think they would necessarily know where to go or whether they need to see anyone.'

'[Young people] are very much aware about FGM. My concern is where do those 13 to 15 year olds go, the Top Shop generation or H&M generation, where do they go to get advice? They can't go and walk into anybody's clinic because the clinic is setup, and actually that might be such a nice or interesting nugget of individuals that we don't know about, they do not appear in a statistic.'

'We have to phone the Police, don't we?'

'Sorry?'

'We have to phone the Police.'

'Well I think that should not be the first thing we think about. I think the first thing we think about, that I am talking about, is you could document statistics or I suppose my concern was about their health and wellbeing, that you have got this group of girls and secondly is it because you have to phone the Police that we are not going to encourage them to turn up, we are not going to phone the Police, there are ways of doing these things. I think it's around safeguarding, and I don't want to go into that, I am just concerned those numbers that could really direct us as to what we need to do next in terms of service provision.'

'I absolutely agree and I really do think that there are a group of girls that we could really offer something to.'

Several questions are raised here. Firstly, what kind of numbers of young people are seeking advice and guidance on FGM, or would benefit from such advice if it was accessible? Participants have come across such young people and sense that there may be many more, if the services were in place.

Secondly, where can young people go for support as they may be unlikely to feel comfortable accessing an antenatal clinic and may not want to be seen to be visiting an FGM clinic, or booking an appointment with their GP? To date, some participants have been working in schools

with teachers, although from September 2020 it will be mandatory for schools to teach about FGM.

Thirdly, how do professionals, balance creating a safe confidential space for young people to talk about FGM and meeting the mandatory reporting requirements? This was summed up by one participant: *'Sometimes it was challenging to have a confidential space but also be aware that there is mandatory reporting and safeguarding issues as well, and that sometimes can feel difficult'*. Participants felt that the police were: *'very willing to work with us to make things work'*.

The discussion was highly animated around the involvement of the police with many different interpretations of mandatory reporting and the challenge being summed up as: *'So, I think while there is still a legal requirement for mandatory reporting it does make it very difficult for everybody'*.

What other services would help FGM survivors?

Time was limited to discuss this question; however, the strongest call was for enhanced peer support. One participant described the peer support group facilitated by Save our Sisters, saying:

'They have a peer support group that meets for FGM survivors group, PTSD, maybe not particularly around the FGM specifically but how they made their journey to the country, war zones etc, other issues, and there's a large network within [place] of women of all age groups who support each other, not just for FGM, FGM is part of it, but it's to reduce socialised emotion, make friends, support each other. It's got a multi-layered approach, but that's just one element of it. It seems to work quite well because it is not just about FGM'

5. RECOMMENDATIONS

Recommendations for further research



To better understand the **risks** and **benefits** of deinfibulation at different times



To explore the needs and experiences of young people in relation to FGM

Recommendations for service development/clarification



An increased awareness of the range and **scope of services** for survivors of FGM and their families.



Mapping the support available for those working with communities affected by



Clarification on how to comply with the **mandatory reporting requirements** and safeguarding procedures in relation to FGM whilst also maintaining safe spaces and ensuring confidentiality, where appropriate.



Extending non-FGM specific services, like PTSD counselling and support, to **include survivors of FGM and their families.**

6. SUMMARY & CONCLUSION

This report is based on a national stakeholder event held with a wide range of professionals working across the UK. The collaboration between the core FGM Sister Study researchers and the National FGM Centre ensured that the aims of the workshop were achieved. The Stakeholder event saw a number of professionals from a range of backgrounds participating in roundtable discussions which focused on the timing of deinfibulation; knowledge, training and understanding of the topic and health care provisions for FGM survivors and their families.

Participants generally felt that the timing of a deinfibulation was a complex matter for a woman to decide on and stressed the importance of recognising women have choice and agency over their bodies. The need for providing professionals with guidance on the timing of deinfibulation is something that was echoed by most. There was a general consensus that deinfibulation must be undertaken by a trained health professional with knowledge of what it means to take a holistic approach to caring for FGM survivors. A health setting was seen as the most appropriate place to undertake a deinfibulation but there was preference for a hospital setting. Whilst it was recognised that both the FGM survivor and the healthcare professional are equally important in deciding on a deinfibulation, it was recognised that for some women an approach based on reciprocity would be a new experience, whilst for other women having agency to make such decisions would not be problematic. The importance of engaging with men featured in the narrative of some stakeholders as they recognised that some women would seek the advice of their partner when deciding on if and when to be deinfibulated.

When working with communities, stakeholders felt that using the right terminology is important as failure to do so could lead to communities feeling stigmatised. Stakeholders noted that those working in this arena must have knowledge of the law but also needed to be versed in the psychological and emotional aspects of FGM. There was a unanimous agreement that those working on FGM must listen to communities and this empathetic approach must be at the heart of working with women.

The barriers preventing adequate intervention with FGM-affected communities cited by stakeholders indicated that more resources are need along with a more uniformed approach based on evidence that it works. There is also a need for frontline staff to be supported to ensure

that they develop confidence and there is accountability in the system. These are perennial issues which require a targeted sustain approach and action plan to overcome.

Stakeholders recognised the dedication of healthcare professionals and the increased knowledge of FGM across the sector. Whilst there was acceptance that care and support provisions have increased over time, there was still a lack of funding and psychological services. The fragmented approach to commissioning also led to the needs of women being ignored and that the needs of children and young people must also be considered. Mandatory reporting requirements was seen as a possible barrier to engage with young people and presented challenges with providing them with safe spaces to discuss clinical matters.

The views of the stakeholders provided rich data on a little researched topic. It is hoped that the findings for this research will work towards influencing positive professional practice and better outcomes for women.

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