NHS ENGLAND

EVALUATION OF FGM PILOT CLINICS FOR NON-PREGNANT WOMEN

Final Report

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Publication

The views expressed in this report are the authors' and do not necessarily reflect those of NHS England

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EXECUTIVE SUMMARY

Introduction

In 2019, NHS England launched a pilot scheme of eight specialist Female Genital Mutilation (FGM) clinics for non-pregnant women. These clinics provided services and support for non-pregnant women over the age of 18 who were living with the consequences of FGM. In 2022, Starks Consulting with Ecorys and Leeds Beckett University was commissioned to complete an evaluation of the pilot clinics to help inform decisions on future service delivery. The service specification[1] detailed that clinics should provide a form of tripartite support which included basic medical treatments provided by a specialist midwife or nurse; counselling for mental health concerns, and advice from a health advocate on housing or welfare needs, for example. Clinics were to be located in the community to ensure ease of access and a good local presence. Services were to be delivered independent of maternity and sexual health services and provide a sensitive and welcoming space for women.

Aims of the evaluation

The key aim of the evaluation was to determine whether the clinics improved the health outcomes of non-pregnant women with FGM. A key objective was to update the economic review that was carried out in 2021[2]. to understand whether the clinics provided opportunities for longer-term cost savings to the NHS.

Method

The evaluation adopted a mixed-modal approach that generated qualitative and quantitative data. This included interviews with all professionals involved in the delivery of the clinics; one commissioner and two voluntary organisations. Twelve women who accessed the support were purposively sampled for interviews. Quantitative data was submitted by the clinics to evidence the number of service users receiving support and the range of symptoms supported. Ethical approval was granted through Leeds Beckett University's ethics panel.

Challenges to the method

There were challenges in gathering quantitative data from clinics due to changes in data collection methods part way through the pilot. Some clinics struggled to provide data on all cases and some estimates have been used to support the cost study. The evaluation was commissioned ex-post-facto, with limited opportunity to shape data collection. No service user outcomes tool were agreed by the clinics and no permissions were in place for evaluators to contact previous service users.

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[1]

[2] Hanlon J., Hex, N. (2021) NHS England: Economic Analysis of NHS FGM Support Clinics. University of York

Data on impact was only available through qualitative interviews. These factors taken together have an impact on the robustness of the findings.

Understanding the value of the tripartite support

The significance of the health advocate role

Health Advocates were crucial to the effective running of the clinics. They supported the clinics by raising awareness of their services within local communities, contacting each service user before their appointment, and providing advocacy support as needed. Some also managed the clinic's bookings, responded to telephone and email inquiries, and helped organise the clinic diary. When health advocates became fully active, DNA rates were reduced in some clinics.

Health advocates were from similar backgrounds as the service users and understood the cultural pressures facing the women. Some advocates were themselves FGM survivors and recognised the benefit of sharing their personal experiences with the service user. This helped to engender considerable trust between the service user and the clinic.

> *"She was amazing, she understood me and I trusted her, she was so kind".* (Service User)

The significance of the specialist FGM Midwives/gynaecology consultants or nurses

Specially trained midwives or gynaecology consultants (in hospital clinics) and nurses were responsible for completing the FGM diagnosis and any further procedures such as perineal repair and de-infibulations. They provided a high level of expertise when assessing the women's health needs and agreeing on a care plan. The FGM Clinics also provide treatment for other symptoms including urinal tract infections (UTIs) menstrual problems, or thrush for example.

> *"We have to look at the woman in her entirety, explore all of her symptoms and make sure we give her the best care we can while she is with us."* (Midwife)

The second person in the room during the medical procedures was typically a second midwife or a nurse. Clinics agreed that having a second midwife supporting the procedure was most appropriate. This enabled greater opportunities for learning and knowledge transfer.

> *"I feel that I need an experienced person with me because it's complex...and if you're doing catheters all day, if you're a midwife…you will rapidly develop skills and while I feel I am skilled, I like to have someone else around when I'm doing the procedure."* (Clinic Lead)

The role of the counsellor

Speedy access to counsellors and psychotherapists was one of the most valuable forms of support for the service user. Evidence from counsellors and the women showed how valuable this support was for their recovery.

"The trauma that many of these women have gone through in their earlier life has been buried, but it manifests itself in many different ways…in their mental health, often how they feel about their sexuality, their identify…their ability to have positive relationships. (Counsellor)

Where women needed specific help with personal relationships and spoke of difficulties with sex, psycho-sexual therapists were available (in some clinics) to work with the woman around intimacy and sex. Counselling was also delivered to husbands/partners in some cases to help them understand why the woman may be struggling with intimacy. Group sessions were run by one counsellor in a clinic which helped to break down the barriers that exist in talking about FGM.

The benefits of the tripartite model of support

The tripartite support available through these clinics ensured the women who accessed the services were able to move forward more confidently with their lives.

"Being able to hold the women as a whole unit in some ways…the partnership working that we've got within the team works really well." (Psychologist)

None of the service users interviewed had spoken about their traumatic experiences to anyone prior to coming to the clinic. Professionals agreed that many women would not have accessed their clinic if the service was solely a clinical offer. The health advocate played a key role here.

"This is a challenge in itself to encourage them to talk to a professional about it… without this active engagement and support throughout their journey, they wouldn't be here…the clinic opens the door to that conversation for the first time." (Psychologist)

How the services were delivered

Clinic location

Despite the specification stating that clinics should be delivered in the community, three of the eight clinics operated from within a hospital (building on previous FGM clinical operations), and five from within community health centres or a GP surgery. The hospital sites were lead by a gynaecologist consultant with experience in delivering FGM services. Here, the model of delivery was extended to include the counsellor and health advocate.

There were no reported disadvantages to providing the clinic in a hospital setting; staff agreed it was more about providing a sensitive and welcoming environment. There was evidence that extending holistic support in a hospital allowed easy access to other gynaecology services or urology services.

In addition, hospitals could build on existing referral pathways established within hospital settings (e.g. GP referrals and gynaecology units). However, not all hospital settings were successful in generating referrals. This was in part due to logistical difficulties with health advocates not having the necessary resources (transport and expenses) to reach out to communities during the pandemic, and staff turnover in some clinics.

What was clear was that all clinics had to remain active in raising awareness of their clinics among the range of referring partners. Location, awareness raising and maintaining a welcoming environment were considered most important. A few women reported how they had had to travel long distances to reach a clinic which was off-putting.

Health advocates expressed it was easy to link in with the local community when operating from busy health and wellbeing centres. However, working from a community setting was not without challenges and one clinic was forced to relocate from the community into a hospital due to difficulties with the site (partnerships with the clinic and access to the internet).

Referrals to clinics

Clinics provided data which showed that 333 referrals were made to the clinics from September 2020-2021. In total, over two years from 2019-2021, 578 women were seen.

A key route into the service was self-referrals with 38.7% being self-referrals. A further 33.0% were referred by their GP which indicates the importance of developing strong links with GP services. The three hospital sites accounted for 60% of all GP referrals; this suggests that community sites needed to work harder to raise referrals from this route through increased publicity and partnership work; one community site received no referrals from a GP and another, just two referrals. Health advocates accounted for approximately one in ten referrals.

Clinical Interventions

Women interviewed reported that the FGM diagnosis and any clinical interventions were handled professionally and sensitively. Women appreciated the way the clinics allowed them time to discuss their needs and to ask any questions about their physical examination.

> *"They were very professional, she* [midwife] *took her time… the first consultation was two hours…I was treated very well…I was pleased with the service."* (Service User)

According to the data provided by clinics, from 2019-2021, a total of 230 de-infibulations (40%) of patients) were either completed in the clinics or women were referred to secondary care settings. No patient who had Type 3 FGM turned down the offer of de-infibulation. Most clinics performed the de-infibulations on site, but one clinic routinely sent women to a hospital where they had a general anaesthetic.

Cervical Smear Tests

Four clinics reported they offered smear tests but only two community clinics completed four tests from September 2020 to August 2021. This showed a low level of alignment with the specification which required clinics to offer smear tests. There was a difference of opinion regarding the appropriateness and value of offering women a smear test among clinic leads. What seems important when considering the original NHS specification, is that women are offered this procedure at the clinic and that they can choose whether to have a smear test.

Access to counselling

Just less than one-half of all women accessed counselling, indicating the level of need for counselling. The remainder were either not ready to access the counselling or felt they did not need it at the time. Counselling included help with trauma and, where expertise was available, psycho-sexual therapy. Counsellors provided a highly flexible service and some were able to extend their offer of counselling sessions beyond the recommended limit of six sessions where this was necessary to aid recovering. Where this was not possible due to waiting lists and capacity (two clinics operated waiting lists for counselling), women were signposted to other services.

Counselling was mainly delivered on the telephone and some sessions were delivered online. Some women would have preferred face-to-face, but there was no evidence that the sessions were less effective on the telephone. Clinics expressed challenges sometimes with language which made it difficult to communicate fully with the women. It is possible that in these cases, women did not take up the offer of counselling.

Safeguarding

Health advocates were engaged in awareness raising in their local communities to prevent further harm from FGM practices. In terms of safeguarding practices within the clinics, clinic teams reported an assumption of low risk from FGM among service user and their families. Women accessing the services were thought to have a clear understanding of the harms of FGM and their personal experiences.

> *"Women who come to our clinics have suffered and many are angry about what has been done to them. Some have left their homes to keep their children safe."* (Clinic Lead)

As a consequence clinic leads reported that prevention advice and safeguarding had to be sensitively handled with service users. In total, two children and two adults were referred to social services with safeguarding issues from September 2020 to August 2021.

Partnership working

Developing partnerships was not presented as a key feature of clinics' activities. Clinics reported a lack of time available to develop meaningful partnerships when contracted for one day per week to deliver all the services. Although health advocates did reach out to community organisations to raise awareness, there was no evidence this resulted in direct referrals. Clinics did receive referrals from GPs and other health providers which indicates an awareness of their services, but this was not the case with all clinics. One voluntary sector agency commissioned to deliver the health advocacy brought added value to the model. They provided a gateway to more awareness raising about the services and offered additional support to women via their existing services.

Sustainability

Six of the clinics indicated they will continue to provide the services and had already secured funding or were confident they would secure funding to continue with the tripartite model. Two clinics suggested they will struggle to find further funding to deliver the model (e.g. including health advocacy and counselling support). Both clinics at risk of not continuing with the model (one in a hospital setting and one community setting), stated they operated with too few referrals to justify the resource input.

Challenges and Lessons Learned

Most clinics reported challenges in establishing their service. These included: drafting operating protocols, purchasing suitable equipment, recruiting and retaining experienced staff, operating at capacity, access to necessary medicines, collating and storing case data, and supporting women for whom English was not their first language. These challenges were not present in all clinics but were reported across several clinics.

The pandemic resulted in key staff including counsellors and health advocates working from home. There was a low level of management and supervision in some clinics that impacted the health advocates in particular.

Key lessons learned were to ensure there was sufficient time allowed for the set up of the clinics. A greater consideration needed to be given to data management and sharing of information across the teams to ensure that support was meeting needs.

Impact on Service Users

Women's views of the support at the clinics were very positive. They liked the ability to self-refer and were pleased with the timely response following their initial request. Clinics treated the women sensitively and provided a high level of emotional support. Women felt listened to and understood and this helped to engender trust among the service user. The diagnosis of their FGM was an important first step in their recovery.

"Now I know this, I can move forward…this is so empowering for me to understand what has happened. Now I can begin treating myself too." (Survivor)

Women who had de-infibulations spoke of a change in their physical health but also optimism for their future, in particular with their relationships and intimacy; several women had come to the clinic in preparation for marriage.

The counselling and psycho-sexual therapeutic support had a significant impact on women's self-awareness, on their understanding of how the trauma of FGM had affected them. This was another key step forward in their recovery.

For several women, this was the start of their journey and ongoing support was going to be needed. Several suggested peer-to-peer support groups would be helpful. Clinics were considering this but had not enacted this at the time of the research.

Cost Effectiveness

The data analysis determined that the pilot FGM clinics for non-pregnant women, when considered as a whole service offer, was a cost-effective pilot, with a cost per case calculated at £1,433 across 2019-21. Calculations were based on the original clinic costs set out in the YHEC report of £51,785 per annum, and service user throughput evidenced by the clinics at 578. Clinics are estimated to have generated over £200,000 in a net benefit to the NHS between 2019 and 2021. It is calculated that, going forward, clinics need to treat at least 29 new service users per year to be cost-effective. Four clinics did not meet this threshold during the pilot due to challenges with health advocate roles, the impact of the pandemic and not being sufficiently active in raising awareness of the clinic among partners.

Conclusions

This report evidenced the positive impact on women's physical health, and emotional and mental wellbeing, and their ability to move forward with their lives. Although the sample sizes were small, without exception, women reported a very positive experience from the clinics.

The pilots delivered an overall saving to the public purse of just over £200,000. This was calculated on the actual costs of running the clinics and the number of service users receiving support. Whilst this is a moderate sum of money, these calculations were based on real savings by comparing the costs of delivering the same services in secondary care (with no FGM clinics for non-pregnant support). With an estimated cost of just over £50,000 per annum to operate a clinic, the benefits of providing these clinics are clear.

There was little evidence of the advantages of community settings; all clinics experienced a range of challenges related to set-up and referral numbers. Women seemed to be equally happy to attend hospital-based clinics or community-based clinics. What was important was the welcoming environment and the sensitivity with which the women were treated.

The clinics delivered these positive outcomes with little central coordination from NHS England to support processes or systems (e.g., data management or operating procedures) or to secure adequate training of staff.

Clinics worked hard to continue to deliver their service and were committed to delivering high-quality impactful support for survivors of FGM. There were developments in most clinics to continue operating, with six of the eight having secured some funding for further delivery.

The following recommendations are offered to help deliver improved services.

- **Recommendation One**: NHS England to draft an operating procedure template for clinics to complete to ensure compliance and consistency with the model of care.
- **Recommendation Two:** each clinic to ensure teams are supplied with adequate IT, telephone and other equipment required to carry out their duties.
- **Recommendation Three**: each clinic to ensure sufficient time for management and oversight of the clinic is incorporated into the monthly resources.
- **Recommendation Four:** each clinic to ensure regular line management and supervision arrangements for multi-agency teams.
- **Recommendation Five:** prior to clinics operating, design a secure data storage database that can be held online that will allow shared access for each clinic member.
- **Recommendation Six:** to understand whether services are meeting users' needs, ensure that views from service users are collected.

- **Recommendation Seven:** Clinics should ensure that staff is sufficiently trained and confident in offering smear tests so patients accessing the clinics have a choice as to whether they receive the service.
- **Recommendation Eight:** clinics should consider the opportunities and implications on their resources of delivering peer-to-peer support groups, and to factor in sufficient time/resources for establishing and sustaining the groups.
- **Recommendation Nine:** clinics to ensure adequate time and resources are committed to raising awareness of the service to increase referral numbers.
- **Recommendation Ten:** clinics to consider the diversity of languages spoken by potential service users and ensure all information leaflets and services can be available equally to all women.

1 INTRODUCTION, CONTEXT AND AIMS OF THE STUDY

Introduction and context

1.1 FGM is a practice which causes permanent injury to female genital organs for non-medical reasons, is recognised internationally as an act of violence against women and girls, and was made illegal in the UK in 1985. The practice is primarily carried out on young girls and it is estimated that over 200 million girls and women are alive today who are suffering as a result of FGM (World Health Organisation, 2022). Global migration from areas where FGM is practiced means that FGM is now a worldwide health concern[3].

1.2 Currently, in the UK, survivors of FGM who are pregnant are provided with peri-natal support to help with their pregnancy and in preparation for the birth. However, outside of this pilot, there are limited services accessible for non-pregnant women to help deal with the, often long-term, physical and psychological illnesses caused by their FGM. Some existing FGM services have extended support for non-pregnant women, but without sufficient evidence of impact, this remains a fragile offer.

1.3 Research has highlighted how survivors suffer from gynaecological, urological and obstetric problems, as well as long-term mental health and emotional problems[4]. There is emerging evidence backed up by the findings from this study, of the profound effect of FGM on women's sense of identity, self-esteem, personal relationship and family life[5].

1.4 It is estimated that treating survivors of FGM, costs the NHS between £33 million to £184 million (giving a midpoint estimate of £100 million). Therefore, minimising the costs by treating symptoms early is a major driver for the NHS[6].

[3]UNICEF. Female genital mutilation/cutting: A global concern - UNICEF DATA. New York: United Nations Children's Fund, 2016

[4] Utz-Billing, and K. Kentenich (2008) 'Female genital mutilation: an injury, physical and mental harm.' Journal of Psychosomatic Obstetrics & Gynaecology, 2008, 29 (4)

[5] O'Neill,S. and Pallitto, C. (2021) 'The Consequences of Female Genital Mutilation on Psycho-Social Well-Being: A Systematic Review of Qualitative Research'. Qualitative Health Research 2021, Vol. 31(9) 1738–1750

[6] Hex N, Hanlon J, et al. Estimating the costs of Female Genital Mutilation Servicers to the NHS. May 2016. University of York and King's Fund.

1.5 In 2019, NHS England launched a pilot scheme of eight specialist Female Genital Mutilation (FGM) clinics to provide services and support for non-pregnant women who were living with the consequences of FGM. In 2022, Starks Consulting with Ecorys and Leeds Beckett University was commissioned to complete an evaluation of the pilot clinics to help inform decisions on future service delivery.

FGM Pilot Clinics Service Offer

1.6 Clinics were provided with funding from NHS England to provide a model of tripartite support tailored to the needs of non-pregnant women with FGM who were over the age of 18. This model of support included access to basic medical treatments from a specialist midwife or nurse, access to specialist counselling, and advice and support in other areas such as welfare or housing delivered through an experienced health advocate. The service specification[7] drawn up by NHS England stated that women should expect to receive the following:

- Health care that includes assessment of needs, FGM diagnosis, simple de-infibulation with local anesthetic (where needed), cervical smear testing
- Access to consultant gynaecology and urology for assessment and treatment if required
- Safeguarding assessments and personal education about FGM, consequences and illegality, exploring attitudes and perceptions
- Access to a specialist counsellor (up to six sessions)
- Access to an FGM health advocate providing advice and support
- Referral to other Third Sector specialist support as needed.

1.7 The service specification[8] also recommended that clinics follow the quality assurance standards set out by the 2018 NHS England FGM Recommendation for Commissioners. This recommended considering the following aspects of delivery:

- Location of the clinics to be in a community setting such as a local GP surgery, a community centre or a health centre

[7] NHS England (2018) Service Specification Clinics for non-pregnant women who have undergone female genital mutilation
[8] Ibid

- Good access to transport links to support women who may travel out of the area to reach a clinic
- Sensitivities around the naming of clinics and any contact with service users to ensure access to, and use of the services, remains confidential. This included maintaining independence from other services including maternity and sexual health clinics
- Staffing should include specialist midwives/gynaecology nurses, with oversight from a consultant, as well as the health advocate and counsellor(s).

Aims of the Evaluation

1.8 The key aim of the evaluation was to determine whether the clinics improved the health outcomes of non-pregnant survivors of FGM. Within this overarching aim, key evaluation objects were identified:

- Determine whether the pilot services adhered to the original service specifications and where there may be deviations, to understand which specifications are crucial to improving the health and well-being of service user
- Explore the importance of the clinics being in a community setting
- Provide an understanding of the dynamics played by having a health advocate and a counsellor involved in the service and how this benefits service users
- Update the economic review that was carried out in 2021[9] to provide an estimate of the longer-term cost savings to the NHS by providing support to non-pregnant women with FGM.

1.9 Findings from the evaluation will contribute to a greater understanding of the physical and mental harm to women caused by FGM and evidence of service users' experiences when interacting with the clinics. It also provides an estimate of any longer-term cost savings to the public purse by providing support earlier in an FGM survivor's lifetime.

1.10 NHS England requested recommendations which could help support service delivery as well as decisions on the future commissioning of services for survivors of FGM. These are offered in the concluding section.

[9] Hanlon J., Hex, N. (2021) NHS England: Economic Analysis of NHS FGM Support Clinics. University of York

Method

1.11 An evaluation framework (see **Appendix A**) was agreed upon with NHS England that set out the key question areas. These included:

- **Clinical services and operations:** delivering against the specification; referrals; capacity; support, and partnerships developed
- **Service-user experiences:** Service users' views of the service and impact on their health and wellbeing
- **Cost-effectiveness:** evidence of potential cost savings of the clinics.

1.12 All research tools including interview topic guides and the performance survey were agreed upon by NHS England.

1.13 The evaluation adopted a mixed-modal approach that generated qualitative and quantitative data.

1.14 Qualitative data included 42 (primarily by telephone, one clinic was visited) semi-structured interviews with:

- Ten clinical staff including three consultant gynaecologists, One General Practitioner, seven FGM specialist midwives/nurses
- Two clinic management/administrative staff
- Eight health advocates
- Seven psychotherapists/counsellors
- Two third-sector service leads involved in delivering support
- One clinical commissioner.

1.15 Twelve interviews were completed with service users who were all survivors of FGM. Service users were selectively sampled through the clinic staff. This was considered to be more appropriate due to the highly sensitive nature of the interviews.

1.16 Quantitative data generated through the collection and collation of performance data from each clinic showing how many women accessed the services, service users' symptoms at the time of accessing support, clinical interventions received including medical (e.g. diagnosis and de-infibulation), therapeutic services and advocacy support. This data was collected using an online survey and/or Excel spreadsheet completed by clinics.

1.17 The evaluation was given ethical approval through Leeds Beckett University ethics procedures. The following practices were adhered to ensure ethical rigor:

- Informed consent: written or verbal consent was obtained from all participants in the interviews
- Clinic monitoring data was pseudonymised before being sent to the research team
- Safeguarding: given the sensitive nature of the topic being researched, attention was paid to risk reduction in data collection, with sensitive handling of service user and onward referral available should further support be required
- Confidentiality and anonymity: no personal identifying information has been used in reporting the data
- Secure information management: maintained through password-protected university systems.

Challenges with the evaluation

1.18 The evaluation was commissioned in May 2022 and the fieldwork with the clinics began in June 2022. Pilots began delivery in 2019 and NHS England requested data to be collected on each service user. However, the extent of information requested was considerable, and clinics struggled to complete all data entries. It was agreed that the data request would be reviewed by NHS England. However, this exercise was not completed. As a consequence, the data that clinics generated was inconsistent: some clinics continued to complete the original data request, and some clinics completed data requested by their Trust or Clinical Commissioning Group.

1.19 To address the inconsistencies in data collection a questionnaire was designed that required the clinics to review their case data and report on key aspects of service delivery (e.g. referrals received, clinical interventions delivered), counselling and other support delivered and service user symptoms. This exercise was a challenge for some clinics due to a lack of capacity to support this request as the data required input from midwives, counsellors, and health advocates. Data for the cost study was provided by seven clinics and some data was missing. Therefore, estimates have been used to calculate the overall cost-benefit.

1.20 No outcomes data collection methods were agreed upon at the start of delivery which would have evidenced outcomes and impact on service users, and service users' views on the quality of the service were not routinely gathered by clinics. In addition, no protocols were put in place to enable the evaluators to contact service users via email or telephone. To access service users' views on their support, clinical staff (midwives, counsellors and advocates) were asked to contact the women. The sample, therefore, is not a random sample of service users and findings may not be representative of all service users' experiences.

2 THE SIGNIFICANCE OF THE TRIPARTITE SUPPORT

Introduction

2.1 This section of the report provides a narrative of the significance of the specialist roles operating within the clinics. One of the key requirements of the FGM pilot clinics for non-pregnant women was to ensure they received holistic support tailored to their needs.

"Survivors must feel that an FGM clinic is a service where their needs will be put first, and where they will be treated with dignity and respect. An effective FGM clinic will not simply provide services, but will help an individual understand what FGM is and what happened to them."[10]

2.2 The section looks in detail at the benefits of the tripartite support delivered through the health advocate, midwife/gynaecologist, and counsellor/psychotherapist.

2.3 Support for each service user in the clinics took similar pathways:

- The health advocate was the initial point of contact and was active in supporting the woman throughout her attendance at the clinic. Advocates were part of the initial assessment where additional needs such as housing, welfare needs, or support with refugee status, for example, were identified.
- A specialist midwife/gynaecologist completed the FGM diagnosis and performed any clinical procedure as required (e.g. de-infibulation). They also assessed for any ongoing health care needs or complications which may need a referral to a gynaecology unit.
- If the women consented to receiving counselling, counsellors and/or psycho-sexual therapists supported the women further to help them understand any impact on their mental health, emotional well-being and personal relationships.

[10] NHS England (2016) Non-Pregnant FGM Clinics Specification: Clinics for non-pregnant women who have undergone female genital mutilation

2.4 The input from each role was not necessarily sequential; some women accessed counselling support before any clinical intervention and continued with counselling after the clinical procedure. Some women did not access any counselling. What seemed important was that the service flexed to the needs of the women. Each of these supporting roles is explored in more detail below.

The role of the Health Advocates

2.5 Health advocates were crucial to the effective running of the clinics once the patient had contacted the service. They contacted each patient prior to their appointment, and provided advocacy support as needed. Some also managed the clinic's bookings, responded to telephone and email inquiries, and helped organise the clinic diary.

2.6 Many clinics spoke about the high rate of service users who did not attend (DNA) appointments, particularly at the start of the pilot operations.

"Before our health advocate started to call the woman on the day of their appointment, we had high numbers of DNAs, now they are reduced to next to nothing." (Specialist midwife)

2.7 Clinics learned they had to be much more proactive in supporting the women to attend appointments to minimise the rate of DNAs. Where this approach was adopted, health advocates called the women the day before their appointment and on the day of their appointment. Some advocates accompanied the woman to the clinic where there was a high risk of non-attendance and where this was practical due to their close location to the clinic. They were often the first person to meet the woman on arrival at the clinic, provided reassurance, and helped to settle any nerves.

2.8 Four health advocates were employed by a third-sector organisation (which was commissioned to support the clinic with the health advocacy role) that had links with the target community. The other four were employed by a health trust or directly by a GP running a clinic.

2.9 Most health advocates were from similar backgrounds as the service user and understood the cultural pressures facing the women. Some of the advocates were themselves FGM survivors and recognised the benefit of sharing their personal experiences with the service user. This helped to engender considerable trust between the service user and the clinic.

"She was amazing, she understood me and I trusted her, she was so kind". (Service User)

2.10 Clinics reported that language barriers could be a problem when communicating with women. In many cases, health advocates with their shared heritage and language skills including Arabic and Somali were successful in minimising the language barriers and helped to ensure that service users fully understood the procedure and the support they could access.

2.11 Some health advocates also played a part in raising awareness of the harms of FGM and delivered awareness-raising sessions about their services to organisations which included general information about FGM, and what services they provided. FGM advocates evidenced a high level of commitment to their role and to ending FGM.

"I love this work, I feel empowered to make a difference….this is a barbaric practice, we must stop this, it's so important we put an end to it for all our sakes." (Health Advocate)

The role of the specialist FGM Midwives/gynaecology consultants and nurses

2.12 Specially trained midwives or gynaecology consultants and nurses were responsible for completing the FGM diagnosis and any further procedures such as perineal repair and de-infibulations. Clinics also provided treatment for other symptoms that women may be experiencing including urinal tract infections (UTIs) menstrual problems or thrush for example. Where further gynaecological needs were identified referrals were made to secondary services. Where FGM clinics were operational in hospitals, these could be supported by the gynaecological consultant who was also the FGM clinic lead.

2.13 In the community clinics, specialist midwives were recruited to carry out the medical procedures. All midwives/gynaecologists were trained and specialised in FGM. They provided a high level of expertise when assessing the women's health needs and agreeing on a care plan.

"We have to look at the woman in her entirety, explore all of her symptoms and make sure we give her the best care we can while she is with us." (Midwife)

2.14 Clinics were required to operate with a second person in the room during any diagnosis or medical procedure. This person was, in most clinics, a midwife or nurse who supported the specialist midwife/gynaecologist with the clinical procedures. They organised the equipment and medical tools/syringes and provided emotional support for women.

"I am a second pair of eyes for identifying the anatomy…and very much there for the woman, hold her hand, talking to them… as a comforter." (Nurse)

2.15 Clinic leads agreed that a second midwife or nurse who had experience in performing de-infibulations was the most effective form of support. This enabled greater opportunities for learning and knowledge transfer.

"I feel that I need an experienced person with me because it's complex...and if you're doing catheters all day, if you're a midwife…you will rapidly develop skills and while I feel I am skilled, I like to have someone else around when I'm doing the procedure." (Clinic Lead)

The role of the counsellor

2.16 The NHS specification stipulated that the clinics should provide up to six counselling sessions to support the service user in dealing with the mental and emotional traumas associated with FGM. The provision of six sessions included access to trauma counselling and in some clinics, access to psychosexual therapy.

2.17 Speedy access to this level of specialist support was one of the most valuable forms of support for the service user. Clinics and commissioners reported that there was a gap in local services for psycho-sexual therapy and that without the specialist support provided through NHS England, service users could be waiting for over a year for this type of support.

2.18 All counsellors had, or had developed over the period of the pilot, a good understanding of the difficulties experienced by women affected by FGM.

"The trauma that many of these women have gone through in their earlier life has been buried, but it manifests itself in many different ways…in their mental health, often how they feel about their sexuality, their identify…their ability to have positive relationships. (Counsellor)

2.19 Where women needed specific help with personal relationships and spoke of difficulties with sex, psycho-sexual therapists were available (in most clinics) to work with the women around intimacy and sex. This included digital work around preparing for sex and a lot of counselling before and after medical procedures to help prepare them for how sex with their partner would feel.

"We try and make it a therapeutic appointment, and to help make them heal". (Psychotherapist)

2.20 Realising the importance of supporting women with their relationships, one psychologist reported how she had opened her sessions up to service users' partners. Below is an account provided by the psychologist as to why she had chosen to do this.

Involving partners in therapy

"A client who attended the clinic reported difficulties with sex because of her FGM. It was very painful, so she went through a process of trying all the time, to the point where she was getting really traumatised. This resulted in her first marriage breaking down. She did marry a second time but disclosed in therapy that she was really worried that this relationship was also going to break down, due to her fear around sexual intercourse. I diagnosed vaginismus and I also learned that her husband was putting a lot of pressure on her because he did not understand her difficulties. After discussions with the survivor it felt helpful to invite her husband to a session where they could focus on a joint understanding of each other's needs. We shared information about how the trauma had affected his wife and her husband was more empathetic towards her and they talked about how the FGM affected her. The outcome was that the couple were able to have sex without the woman feeling traumatised, and her self-confidence also grew. There was a lot that she learned about herself…she became more confident with her own body." (Psychologist)

The value of holistic support for service users

2.21 Professionals working in the clinic recognised the strength of the model of support for women suffering from FGM.

> *"Being able to hold the women as a whole unit in some ways…the partnership working that we've got within the team works really well."* (Psychologist)

2.22 The model was about professionals working together to put the women's needs at the centre of their service offer.

> *"…it's about the women, the patient has to feel they're in control of it and you've got to be respectful of that and respectful of what they've been through." (Nurse)*

2.23 Professionals agreed that many women would not have accessed their clinic if the service was solely a clinical offer. The roles of advocate in engaging women in the clinic and the support from the counsellors were an essential aspect of support.

> *"This is a challenge in itself to encourage them to talk to a professional about it… without this active engagement and support throughout their journey, they wouldn't*

be here…the clinic opens the door to that conversation for the first time."

(Psychologist)

2.24 Working together as a team also provided a vital source of support to each specialist working at the clinic. Most of the clinics operated only one day a week, or one day every two weeks, and therefore, it was important that each worker felt supported in their role.

2.25 The success of the tripartite model on service effectiveness was not guaranteed, however. There was some evidence that the more successful clinics in terms of the number of referrals and lower rates of DNAs, had a more effective team dynamic.

"… we are our own little support network, the three of us… but we do it even though we only see each other every two weeks properly. We always meet up and have a quick catch-up so that we update each other as to where we are and what we're doing…it's so easy to lose track when you don't see each other on a regular basis."

(Psychologist)

2.26 Where there was clear leadership and active managerial support for staff, supported with good information sharing, clinics appear to have worked more effectively. Where this was lacking, the impact on professionals was somewhat negative, rather than positive (see Section Four for more details on the challenges and lessons learned).

Summary

2.27 The section detailed the significance of the three roles as set out in the NHS specification and their unique contribution to the FMG clinic for non-pregnant women. The health advocate provided that one-to-one engagement and support which engendered trust in the service; the specialist midwife and nurses provided the clinical expertise in treating women with FGM and the counsellors delivered sessions tailored for women's mental health needs. Despite some challenges in delivering the holistic care explored in the following sections, the individual roles and responsibilities played a key part in delivering good outcomes for their service users.

3 CLINICAL OPERATIONS AND SERVICES

Introduction

3.1 This section of the report describes how the clinics operated and how effectively they delivered against NHS England's service specification. It draws on evidence from interviews with clinic staff, service user, and the performance data completed by the clinics.

3.2 Key aspects of the clinics' functions including processes and procedures are considered in this section including:

- Clinic location
- Referrals
- Assessment and diagnosis
- Clinical Interventions
- Access to counselling and health advocacy
- Partnership working
- Sustainability

Clinic Location

3.3 Three of the eight clinics operated from within a hospital and five from within community health centres or a GP surgery. The three hospital clinic leads had been delivering services to women with FGM before the launch of the pilot. However, prior to the NHS funding, their service offer was predominantly an offer to pregnant women. This pilot funding allowed the clinic leads to extend their services to non-pregnant women and to recruit an additional health advocate and counsellor.

3.4 Extending the hospital provision enabled these clinics to build on the specialist knowledge and expertise of clinical staff gained over many years, as well as maintain the pathways of referral and support established within hospital settings (e.g. GP referrals and gynaecology units).

> *"I can also refer the women on to other services such as continence of bladder or women's health physio if they require a scan or another gyne clinic".* (Nurse)

3.5 There were no reported disadvantages to providing the clinic in a hospital setting; staff agreed it was more about providing a sensitive and welcoming environment. One hospital-based clinic had relocated from a community setting due to issues with the location, a poorly designed room and no access to the internet.

"Location isn't the most important thing. Delivering in the community is cheaper than in outpatients. But in terms of numbers, it doesn't make a difference. It's more about reputation, having the right lighting…having the right equipment…women know who we are…there is trust in a hospital. People feel cared for". (Clinic lead, hospital)

3.6 Location, awareness of the service and accessibility was considered most important. One clinic lead in a hospital was concerned there was a general lack of awareness of their service and that some women found it difficult to find their clinic. A few women reported how they had had to travel long distances to reach the clinic which was off-putting.

3.7 Five of the clinics were in community settings including GP surgeries, or health and wellbeing centres. All reported that their sites provided a good level of access and service to the women who needed it. Clinics reported the location of their clinic was an advantage due to it being in a community setting, near bus routes and with free parking. Advocates expressed it was easy to link in with the local community when operating from busy health and wellbeing centres.

"There are good links with the community that I can build on, people know the clinic, it's just easy to develop those relationships as we're a local service." (Health Advocate)

Referrals to clinics

3.8 Service user data was collated for the period September 2020-2021 to support the cost effectiveness study. **Table 3.1** shows that 301 new service users were seen in the clinical settings for the period 2020-2021, but that a greater number of referrals were made (333). Some Service users were yet to be seen.

3.9 Data provided by the clinics shows that a key route into the service was self-referrals with 129 (38.7%) being self-referrals. This shows the importance of promoting the services to the wider community. A further 110 (33.0%) were referred by their GP which shows the importance of developing strong links with GP services. Other NHS routes (12.3%) included Genito-Urinary, Maternity and Mental Health Services.

Table 3.1: Referrals received 2020-2021

	Referral Route								
Setting	**Self**	**GP**	**Other NHS**	**VCOs**	**CJS**	**Other**	**Social Care**	**Totals**	**Total %**
Hospital	42	46	6	5	4	1	1	**105**	**31.5%**
Hospital	7	10	12	6	0	0	1	**36**	**10.8%**
Hospital	6	10	4	2	0	0	0	**22**	**6.6%**
Sub Total	***55***	***66***	***22***	***13***	***4***	***1***	***2***	***163***	***48.9%***
Community	20	2	4	0	4	0	0	**30**	**9.0%**
Community	25	10	4	19	0	0	0	**58**	**17.4%**
Community	3	0	11	5	0	0	0	**18**	**5.7%**
Community	13	18	0	0	0	5	0	**36**	**10.8%**
Community	13*	14*	0	0	0	0	**0**	**27**	**8.1%**
Sub Total	***74***	***44***	***19***	***24***	***4***	***5***	***0***	***170***	***51.1%***
Totals	**129**	**110**	**41**	**37**	**8**	**6**	**2**	**333**	**100.0%**
Total %	**38.7%**	**33.%0**	**12.3%**	**11.1%**	**2.4%**	**1.8%**	**0.6%**	**100%**	

Source: Clinic survey data
* One community clinic was unable to provide a breakdown of their data and these are estimated.

3.10 The three hospital sites received a greater number of referrals from GPs, accounting for 60% (n=66) of all GP referrals, which suggests that community sites needed to work harder to raise referrals from this route; one community site received no referrals from a GP and another just two referrals. One service had spent considerable resources searching GPs' contact details and sending out leaflets to raise awareness of their service which had resulted in increased referrals.

3.11 There were a few accounts of women asking their GP for support with their FGM and the GP not knowing where to refer them to.

> *"I had had conversations about my FGM with my GP, but nothing was done. I had assumed I couldn't get any help."* (Service user)

3.12 One community clinic suggested that there was a need for more training of GPs to increase awareness of their service, but more generally to develop confidence among GPs in identifying a need and making the necessary referral.

3.13 One hospital site struggled to get the volume of referrals they were expecting which was thought to be due to the location of the hospital and the wide geographical area it was serving.

3.14 Promoting awareness of the clinics among local communities and services was an important aspect of ensuring continued referrals. This was particularly the case following the Covid-19 epidemic, when some clinics were closed, or continued to deliver counselling online.

"A key lesson learned is that when you set up the community out of the hospital – the key thing is the community engagement. They won't come to it unless they build trust with the community" (Clinic lead).

3.15 Some clinics were more active in this exercise, one featuring in a national newspaper[11], and producing campaign leaflets and teaching resources.

3.16 Where health advocates were recruited through voluntary organisations this helped to promote awareness of the service and resulted in 11.1% of referrals. Some advocates struggled to generate referrals, where links with the community were less well established.

3.17 Any barriers to accessing services at the clinics were kept to a minimum with referrals being reviewed and accepted each week. Referrals were permitted as self-referrals via the telephone phone, email or in person (drop-in), or from any professional. Women who had found out about the service online (via the NHS website, or Google search and finding a local clinic site) valued the ability to contacted self-refer to the clinics.

"I the clinic one day, and the next day I had an appointment for one week [sic]. This was so good for me to get help so quickly." (Service User)

Clinical Interventions

Assessment and FGM diagnosis

3.18 Most clinics completed the initial assessment of need and FGM diagnosis at the first appointment and any clinical procedure at the second appointment. One clinic delivered the assessment of need, diagnosis and any clinical procedure at the same time, making the service very efficient for both service users and staff.

"We do all our engagement work on the telephone and then book an appointment for the clinical procedure. This keeps their travelling down and maximises our time as specialists in the clinic." (Midwife)

3.19 Women interviewed reported that the initial assessment and diagnosis were handled sensitively. They appreciated the way the clinics allowed them time to discuss their needs and to ask any questions about their physical examination.

[11] https://www.theguardian.com/global-development/2021/aug/25/im-one-of-them-the-fgm-survivor-providing-a-lifeline

"They were very professional, she [midwife] took her time… the first consultation was two hours…I was treated very well…I was pleased with the service." (Service user)

"..they asked me about my experience, and they examined me, and let me know what type I had…they offered me the counselling. They were very respectful…very gentle and understanding…this put my mind at ease." (Service user)

3.20 Following the assessment and diagnosis, clinic leads agreed a plan with the woman based on her FGM type and assessment of other needs including support for mental health and advocacy.

De-infibulations, perineal repair

3.21 Following diagnosis, clinical procedures were performed for the women as necessary to reduce any pain or to carry out a de-infibulation. In 2020-2021, a total of 73 (22 per cent of all women seen) de-infibulations were completed. A further 14 women were referred to secondary care for the procedure due to concerns or complications with the procedure. A total of 230 women (40% of all patients) received a de-infibulation either in the clinics or in secondary care settings as a result of attending the FGM clinic. All the women who attended the clinic and were diagnosed with a Type 3 FGM had, or were referred for a de-infibulation.

3.22 The lowest number of de-infibulations carried out by a clinic in 2020-2021 was three, and the highest was 38 which shows considerable variation. Six clinics performed fewer than ten de-infibulations in 2020-2021. One clinic did not perform any de-infibulations, preferring to send the women to the local hospital for the procedure, where this was completed under a general anaesthetic.

3.23 Although the referral to the hospital was said to work smoothly, and without delay, it was unclear why this clinic did not feel it appropriate to undertake a de-infibulation without a general anaesthetic and only in a hospital setting. This reduced the cost-effectiveness of the clinic (See Section Six on Cost Effectiveness for more detail) and may suggest a training need.

3.24 Both hospital clinics and community clinics reported good links with secondary health care services, stating that referrals for further support were picked up quickly without a re-referral back to the GP. Sixteen women were referred for secondary health care services during 2020-2021.

Cervical smear tests

3.25 Four clinics reported they offered smear tests but only two clinics completed four tests from September 2020 to August 2021. Clinics reported referring women for smear tests to other specialist clinics also. However, this shows a low level of alignment with the specification which required clinics to offer smear tests.

3.26 There was a difference of opinion regarding the appropriateness of offering women a smear test among clinic leads. One clinic that offered and completed two smear tests considered it an important offer due to many women presenting at the clinic never having had a smear test.

"… this is hugely important and particularly to prevent cervical cancer. Women know they need to have a smear and it's very difficult to access this if they feel embarrassed. Most won't have had a smear because of their experience." (Clinic lead)

3.27 Part of the challenges reported with a smear test was the cost of getting the samples tested due to the geographical spread of service users accessing the clinics; many women travelled out of their area to access FGM clinics. Therefore, the tracking of payment for smear test results would involve contacting multiple GPs, resulting in a heavy administrative burden on the clinics. One clinic had arranged with a Foundation Trust to provide the results of the screening free of charge as they were fully supportive of the clinic and saw the merits of doing so.

Access to counselling

3.28 From the period September 2020 to August 2021, an estimated 163 (49% of all women seen) accessed some form of counselling or therapeutic support. For some women, two or three counselling sessions were sufficient to help them talk through their feelings and any concerns. For others experiencing longer-term trauma, six sessions were not enough; some women had self-funded further therapy.

"If you have an old-time problem it takes a long time to overcome. Eight to ten sessions is not enough" (Service User)

"I think six is really very minimal for the kind of work that we do… because we might open the conversations and then and the woman's going through the trauma and then suddenly this is the end, it just feels like, they're not being held appropriately." (Counsellor)

3.29 Some clinics reported extending the sessions beyond six weeks if they could do so. Some counsellors stayed in touch with the women and offered their services at a later date should the women need to return. Some clinics signposted the women on to further services.

3.30 Two clinics reported operating a short waiting list for counselling services due to high demand and the infrequency of the service offer.

"..the waiting list is because we give them six sessions, but the clinic only runs every other week. So in a month I only see Service user twice. So I can only get a few women through at that rate." (Counsellor)

3.31 Counsellors provided a highly flexible service where women could have sessions weekly or monthly depending on their wishes. Some women received counselling before any clinical procedure to help them mentally prepare, and further sessions were continued post-procedures.

3.32 Due to Covid and changes in working practices, sessions were delivered mainly via the telephone, and a few via online calls (e.g. Zoom). Very few women had attended counselling face-to-face. Three women reported they would have preferred face-to-face support but were happy to receive the support over the telephone. There were additional challenges mentioned with language and it was reported that some women had turned down support due to this barrier.

3.33 Not all clinics provided psycho-sexual therapy, this was only available where there was expertise to deliver it. It appears to have been a valuable offer where this was made available for women.

Safeguarding

3.34 To protect girls and women from future harm health advocates reported being engaged in awareness raising about the harms and illegality of FGM to local community groups, and voluntary organisations. One clinic reported delivering awareness raising with local schools to safeguard younger children against FGM. This was not a key feature of all clinics, however, due to capacity issues.

3.35 Clinical leads reported an assumption of low risk from FGM among service users and their families. This was due to service users' recognition of the harms of FGM and their personal experiences.

"Women who come to our clinics have suffered and many are angry about what has been done to them. Some have left their homes to keep their children safe." (Clinic Lead)

3.36 As a consequence clinic leads reported that prevention advice and safeguarding had to be sensitively handled with service users. Specialists spoke about how they asked about any safeguarding issues concerning other people or family members who may be at risk from FGM. They also spoke about issues relating to domestic abuse. In total, two children and two adults were referred to social services with safeguarding concerns from September 2020 to August 2021.

Partnership working

3.37 Developing partnerships was not presented as a key feature of clinics' activities. Clinics reported a lack of time available to develop any meaningful partnerships when contracted for one day per week to deliver services. Although health advocates did reach out to community organisations to raise awareness, there was no evidence this resulted in referrals. Data shows that some clinics received referrals from GPs, voluntary organisations and other health services, but it was unclear how regularly these referrals were made.

3.38 One voluntary sector agency commissioned to deliver the health advocacy brought added value to the model. They provided a gateway to more awareness raising about the service, and offered additional support to women via their existing services. One such organisation in London had built a strong profile with their local community and was able to provide additional support to women as needed.

Figure 3.1: Benefits of close partnerships with voluntary organisations

A women's and family centre based in London already worked with the Somali community and were themselves a multi-cultural workforce working with women in the community. "*Through our work, we discovered a real need to speak out about FGM and the practice, and local women started to come forward to talk about it".*

The organisation offered other services that women from the clinics could access: they had a women's group called Conversation Café which focused on wellbeing issues and women were could join this group. They had another programme focused on supporting vulnerable women who had no recourse to funds, and they helped those in need get access to clothing, food and other immediate needs (such as a pushchair). They also made referrals to local authorities' Early Help support where needs were more complex.

Sustainability

3.39 Clinics were provided with funding to help to develop a funding strategy to sustain their services beyond the life to the pilot. Six of the clinics indicated they will continue to provide the services and will find the funding through CCGs of health trusts.

> *"It's a really small amount of money for each CCG. We've used estimates of prevalence across the… and linked to health inequalities in each area to calculate contributions. This worked well".* (Commissioner)

3.40 Where clinics were located in the hospitals, the Health Trusts were continuing to pay for the lead clinicians and midwives and solutions to continue funding counselling and health advocacy were being considered.

3.41 Two clinics suggested they would struggle to find further funding to deliver to the specification. Both clinics at risk of not continuing with the model (one in a hospital setting and one community setting), reported operating with too few referrals to justify the resource input.

Summary

3.42 This section detailed how the clinics delivered their services in both the hospital setting and the community setting. There were advantages and disadvantages in both models, although community clinics reported access to the clinics was easier and advocates reported it was easier to reach out to communities.

3.43 However, referrals were higher among hospitals and the number of GP referrals was higher among hospitals. Although these figures were skewed by one hospital that was very well established it does indicate clinics needed to prioritise raising awareness of their service, particularly post-pandemic. Partnership working was not a key feature of the clinics due to time constraints, although there was an example of good partnership working in one clinic where a voluntary sector organisation was commissioned to deliver the advocacy role.

3.44 Clinics delivered the key services including diagnosis and de-infibulation, although one clinic routinely sent all de-infibulations to a secondary care setting. Only two clinics provided smear tests, with only four being trained. There was a difference of opinion as to whether smear tests should be offered in these clinics.

3.45 Data showed that nearly one-half of all women accessed counselling and that this was mainly delivered online or via telephone, which most women were happy with. Funding for the clinics was secured for six clinics, although there was some uncertainty in the medium term over funding for the advocacy role in some clinics. A further two clinics reported they would struggle to justify longer term resource commitment with the current rate of referrals.

4 CHALLENGES AND LESSONS LEARNED

Introduction

4.1 Clinics reported challenges in delivering the FGM pilot clinics for non-pregnant women. This section of the report looks at the challenges and lessons learned from the pilot clinics.

Establishing the service

4.2 Establishing clinical operations was a challenging period for most clinics. Clinic leads reported they felt that they were *'left to get on with it'* without any real support or managerial oversight.

4.3 Two clinics operated with a project manager who provided support for the initial set-up and recruitment phase, but other leads were responsible for finding the space, hiring or purchasing equipment, and drafting and agreeing on operating protocols. There were no templates provided to assist this process. Each clinic, therefore, spent time drafting and agreeing on their own protocols. Two clinics reported delays in opening their service by six months due to difficulties in getting the service started.

4.4 Some clinics reported difficulties in purchasing the right equipment including the right beds and in getting access to the necessary drugs to perform the clinical interventions. Although the midwives had a midwifery exemption, they were not able to use this in the FGM clinic as they were not performing standard midwifery services.

"This is a bit of a challenge, this is the only downside of being in the community, but at the moment I do have stock in my clinic". (Midwife)

4.5 There were also some limitations regarding the space they had managed to secure for the service. Clinics reported it was preferable to have two rooms, one for clinical operations and one for health advocacy and counselling, although this would no doubt come at additional costs. The cost of hiring space varied across the community clinics from £100 per month to £830 per month.

4.6 **Lesson Learned:** Clinics need sufficient time and personnel to help establish the clinic, hire equipment and draft protocols. Future commissioning of services needs to consider the space within the clinic venues, access to the necessary medicines and purchase of IT and other necessary equipment.

Generating referrals

4.7 Five clinics reported their services to be under-utilised due to Covid-19 due to low numbers of referrals and the rate of DNAs. Some clinics saw no women over a two-week period. In some clinics, the health advocates were less successful in generating referrals. This was considered to be more challenging in London where clinics had to compete for clients and where women had to travel a long distance to reach the clinic. There were also concerns over a lack of profile and awareness of the clinic.

"Women will have difficulty finding our services, the level of advertising of our clinic is too low. (Clinic Lead)

4.8 Health advocates, responsible for engaging with the community reported time constraints. Most were funded for two days per week. Some health advocates struggled with poor or no computer equipment and no expense budgets to travel to organisations.

4.9 **Lesson Learned**: the success of the clinics relied on generating referrals, whether they be self-referrals, referrals from GPs through health advocates or voluntary and community organisations. This function needed resources assigned to this specific task including the creation of a webpage, production of leaflets, phone calls or visits to potential referrers and supervision and review of health advocates' capacity to continue to raise awareness.

Management of the clinics

4.10 Clinic leads (midwife/gynaecology consultant) took on the role of managing the service. This included agreeing to the operating protocols, managing the team, and managing referrals and caseloads. For busy health specialists who had additional roles outside of the clinics, their capacity to carry out this role was limited and many reported catching up on administrative tasks in their own time. This is an extract from one interview with a midwife in a community clinic.

"The allocated time of 7.5 hours every 2 weeks for the clinic lead and the therapist is not enough given the number of referrals, as well as the administrative side of the work: 7.5 hours just covers my time in the clinic at the moment, not the time to manage the referrals, the phone calls to women, the need to organise interpreters and do onward referrals as well:" (Clinic Lead)

4.11 Another clinic lead reported that she did not have the time to take on the management of staff at the clinic.

"We did have someone who was helping to sort out the computers and everything but he has gone. So there is very little management of the team. I did not and cannot commit to managing the team (health advocate and counsellor)." (Clinic lead)

4.12 Time constraints on clinic leads restricted the team's capacity to come together, review cases, and supervise staff. Some staff struggled in their roles and there was a level of turnover reported among nurses, midwives and health advocates. Turnover of staff resulted in a lack of capacity among some clinics during the pilot period and a loss of momentum.

4.13 For two advocates interviewed, delivering their role was not altogether a positive experience.

"I was given a laptop and wasn't able to use it outside of the clinic…I had no phone line, no operational manager…sometimes I am doubting…am I in the right team, to be honest, I am also losing my passion.' (Health Advocate)

"I am finding it difficult in my role, I don't know who to go to when I'm struggling." (Health Advocate)

4.14 Where counselling services were commissioned externally, this was often delivered remotely and as a relatively separate offer. Two clinics struggled to report how many women had accessed counselling services. Some women did express they felt the service was a little disjointed.

"I never got a clear sense about what I was being referred for; I had met so many different doctors, all based in London…I felt like a little passed from service to service." (Service User)

4.15 **Lessons Learned:** managing the clinic with all the administrative functions takes considerable time and cannot be completed by a midwife working one day per week who is also carrying out the assessment, diagnosis and clinical interventions. There needs to be sufficient time allowed for the supervision and management of staff and for teams to review cases, particularly where aspects of the service are delivered by an externally commissioned service.

Recruiting and retaining experienced staff

4.16 Several clinic leads reported issues with recruiting and retaining staff including midwives, psycho-sexual therapists and health advocates. One clinic lost a midwife, a health advocate and the psychologists all during the pandemic; another clinic reported constant challenges in recruiting a midwife who specialised in FGM.

"Short staffing of midwifery is a real challenge. One woman was gong to start then didn't and someone came for a while and left….it's not an easy subject to work with. We just haven't found anyone who has the emotional capacity to do this". (Clinic Lead)

4.17 Recognising the gap in skills, one of the specialist consultants delivered training for midwives to work with women with FGM. This was not delivered as part of the pilot but helped to ensure that the midwives recruited were sufficiently skilled and felt confident to carry out their role. Two midwives reported completing training in their own time, including how to complete smear tests for women with FGM.

4.18 **Lesson Learned:** Moving forward, this aspect of training would need to be considered to ensure there is capacity in the system to support the clinics and any increase in the number of women requesting support.

"There needs to be a stronger plan for the education of nurses and key partners". (Clinic Lead)

Supporting women whose first language was not English

4.19 Engaging women whose first language was not English presented challenges for clinics. Many reported having to rely on Google translate during text exchanges to communicate details of the appointment.

4.20 Some clinics used external interpretative services to help communicate information. However, this was not without problems, particularly where interpreters offered were male. This was felt to be inappropriate given the sensitive nature of the clinics.

"If the women come from Somalia, it's easier for me to engage with Somalian women, but if they are from West Africa, it's more difficult, there is less of a relationship and understanding between the health advocate and the women.

4.21 **Lesson Learned:** any future commissioning of services needs to consider the range of languages spoken by potential service users and identify potential translators prior to establishing the services. Publication materials need to be translated into multiple languages to ensure target communities are reached.

Managing and sharing FGM service user data

4.22 Clinics reported not knowing how to manage service-user records, where to store the information and struggled to share service-user data across the team. Clinic specialists stored service user data on different computers depending on their role as clinicians, counsellors or advocates. One clinic began its services without any systems in place for recording and storing data. This created challenges in terms of managing appointments, reviewing the services and ensuring the support delivered met the needs of women.

"If someone can tell us how they manage all this data storage then that would be really helpful as we've struggled". (Clinic Lead)

4.23 **Lesson Learned**: data management systems needed to be agreed prior to clinics beginning to operate. A centrally designed and managed data storage system would have enabled teams to share data and for data to be collated centrally to understand the performance of clinics.

Summary

4.24 Most clinics reported challenges in establishing their service. These included: drafting operating protocols, purchasing suitable equipment, recruiting and retaining experienced staff, operating at capacity, access to necessary medicines, collating and storing case data, and supporting women for whom English was not their first language. These challenges were not present in all clinics but were reported across several clinics.

4.25 The pandemic resulted in key staff including counsellors and health advocates working from home which impact the effectiveness of the tripartite support in some clinics. There was a low level of management and supervision in some clinics that impacted the health advocates in particular.

4.26 Key lessons learned were to ensure there was sufficient time allowed for the set up of the clinics. A greater consideration needed to be given to data management and sharing of information across the teams to ensure that support was meeting needs.

5 IMPACT OF THE CLINICS ON SERVICE USERS

Introduction

5.1 The women who had accessed support from the clinics were interviewed to understand the impact on their physical as well as mental and emotional well-being. This section tells their stories as survivors of FGM. It describes how FGM affected their lives, the progression they have experienced since attending the clinic, and the potential longer impact the clinics had made on their overall mental and physical well-being.

5.2 Data presented here was generated from interviews with professionals and with twelve FGM survivors. Names have been given to the service users, who in this section, are referred to as survivors; these are not their real names to protect their anonymity.

Impact of FGM on women's mental and physical wellbeing

5.3 For most women, the memory of their FGM experience was still vivid despite the event being many years ago. The women interviewed were in their twenties, thirties and forties and were still dealing with mental, physical and emotional scars left by FGM.

"I have physical symptoms, the area is very sensitive and I suffer from psychological trauma." (Survivor)

5.4 Many women remained unaware of the extent of the problems caused by their FGM often until they were married and when they were unable to have sex with their husband, sometimes leading to further abuse and ultimately divorce. Some survivors had denied the impact of their FGM for many years before seeking support from the clinic, and others did not link their health problems to FGM.

"I had FGM when I was young, but I dismissed it and later realised it was affecting me mentally…not confident in myself and affected my relationships." (Survivor)

5.5 A few women expressed how FGM had affected their confidence more generally to go out and enjoy making friendships.

"I didn't grasp the concept that something had been taken away from me…I didn't know what this was, I always felt isolated and secluded… I was quite hesitant to have sex and was quite closed off and timid and frightened…" (Survivor)

Women's experiences of the FGM Clinics for non-pregnant women

Women's experience of the diagnosis and clinical interventions

5.6 Many women who came to the clinics came because they wanted a greater level of understanding of how their FGM had affected their physical and mental well-being. Survivors described wanting to understand their ongoing health issues with painful menstruation, frequent urinary tract infections, and painful intercourse.

"I knew something wasn't right, but because I didn't talk to anyone, I couldn't compare my experiences. When I had the opportunity to seek help about all of this, I was so pleased." (Survivor)

5.7 Some survivors sought support from the clinics as they were preparing for marriage or had recently been married and were wanting to make sure the relationship was a success. They were pleased to have had a speedy response from the clinic and received the diagnosis and clinical intervention without any delays.

5.8 Receiving the diagnosis of what FGM type they had and what support was available was, according to the women, the start of their recovery.

"Now I know this, I can move forward…this is so empowering for me to understand what has happened. Now I can begin treating myself too." (Survivor)

5.9 The case below shows how quickly and smoothly women reported receiving their diagnosis and treatment and how this helped them move forward.

Figure 5.1: Case study one

Rana* aged 27, recently got married but her husband was yet to arrive in the country. *"I had FGM since I was a child and it's difficult to access services in my country...it's hard to seek help and there is a lot of social stigma regarding the problem".* (Rana) Rana was trying to deny the issues of the impact of FGM, but she stated it was difficult *"…we are not allowed to have sex without getting married, but there were difficulties…I was avoiding trying to get married. So I got married late…but there was pain…I suffered a lot."* Rana searched on Google and found the clinic. *"I sent an email to the clinic and they responded immediately on the same day. I went the next day to have the appointment."* The clinic went into a hospital as an outpatient. She was happy going to the hospital.

"They were very supportive at the clinic, the care was wonderful. I was alone in the UK and I have no relatives here. I came by myself. I didn't feel that I was alone, all the staff were very supportive they took me to a private room and they asked for a history and they gave her a medical examination…I had the de-infibulation…I had been worried about it and it was in my own mind for ages, but it was so relieving to have this done.".

Rana said she had a lot of thoughts and feelings on her mind for a very long time. She had experienced painful menstruation (dysmenorrhea) and had many urine infections. She was offered counselling but she said she did not feel she needed it.

Rana said the de-infibulation and her experience at the clinic have been life-changing.

"The results were even more better than what I imagined, it's life-changing you know, I thought it would be with me all my life. But it's so quick and I was so grateful that I found these people."

5.10 Women reported feeling the team provided a responsive and supportive environment.

"I felt listened to at the first appointment in [name of clinic], *and able to trust staff."* (Survivor)

"Everything was carried out perfectly for me personally… a lot of support and greeted with a lot of understanding and care. I am very grateful." (Survivor)

5.11 There was no evidence that their experience was affected by attending the clinics in the hospital. What seemed clear was that the environment was welcoming and that women felt they could trust the staff.

"I didn't mind it being in a hospital…they understand the background I come from. They were very informed, and I would say educated about the history of the survivors." (Survivor)

Women's experiences of counselling and psycho-sexual therapeutic support

5.12 Not all of the women interviewed wanted counselling; some like Rana were satisfied with the diagnosis and de-infibulation procedure. However, nearly one-half of all women who had accessed the clinic, received counselling or psycho-sexual therapy to help them recover.

"The most important thing was the psychotherapy because I knew that I might be having PTSD and that's why I'm not able to have sexual intercourse…this is what I need to work on" (Survivor)

5.13 The case below shows how important this offer of support was to the women.

Figure 5.2: Case study two

Aged thirty-one, Casho had experienced Type 2 FGM in Somalia. She arrived in the UK for a forced marriage. She sought support from a women's African organisation, where workers took her history. She disclosed her FGM and was advised to attend the clinic.

Casho attended the clinic, received her diagnosis and was recommended to attend some counselling sessions. She spoke with the therapist over the telephone whilst at her initial assessment of need and opted to receive therapy. Once she started to attend the therapy sessions, she felt able to open up, disclosing and discussing her experiences of abuse. She described the importance of the therapist's knowledge and skills which helped make her feel at ease talking, despite never having spoken to anyone about it before.

"The therapy allowed me to see my experiences in a new perspective, and to discuss all sorts of issues around sex and sexuality. I had suffered from depression prior to seeking support from the clinic, and the therapy really helped with this."

Casho received twelve sessions altogether and was recommended to seek further support from her GP who prescribed her medication to help with her depression.

She said she would recommend the service to other people if she knew they needed it.

"This has been amazing for me, if I can help others by telling them about the clinic I will.".

5.14 For most women, the six sessions were sufficient, but for some women who were traumatised and had buried their thoughts and feeling for many years, six sessions were considered insufficient. As stated previously, some clinics provided more sessions where this was felt necessary for the woman's recovery and where they had the capacity to do so.

> *"I wasn't improving, so she [therapist] gave me more time…it made a big difference and I realised that it was ending after that."* (Survivor)

5.15 One woman spoke of the benefits to her of accessing group counselling sessions.

> *"We had group counselling…virtual on Zoom. We did about twelve sessions. We all had gone through FGM…this really helped. The first session people were a bit shy, but by the end of the sessions we all got to know our backgrounds and what people's experiences were."* (Survivor)

Women's experience of support from the Health Advocate

5.16 The support from the health advocate was referenced in the interviews in terms of their journey to the clinic and the feelings of being supported that emanated from their experience. As has been mentioned in previous sections, the health advocate played a key role in engaging the women and in making them feel the clinic was designed specifically for their needs and to support them in their recovery.

"She was very kind, very caring and listened to me. She made me feel relaxed and looked after me while I was at the clinic." (Survivor)

5.17 Although there were accounts provided by the health advocates themselves of linking in with other services to provide essential items and food parcels, these were not evidenced from the interviews with women.

Outcomes and impact of attending the clinic

5.18 Women spoke of the benefits of holistic support and a range of positive outcomes including:

- Health improvements
- Increased self-confidence and feelings of empowerment
- Improved mental wellbeing
- Improved relationships

Health Improvements

5.19 Women reported improvement in their physical health, with reduced pain during menstruation and an end to urine infections. The specialists who understood their symptoms and how they related to FGM helped deliver longer-term health outcomes.

[If it wasn't for this clinic] I would still be the same…I have been through a lot, and I used to be crying thinking that I would be like this for the rest of my life, but I got rid of my vaginismus." (Survivor)

5.20 Women spoke of having a better experience during menstruation and being able to use tampons more effectively which helped them to feel cleaner. They spoke of connecting with their body for the first time instead of feeling alien to it.

"I feel like I am beginning to understand myself as a woman now." (Survivor)

5.21 Although very few women had a smear test, a few did speak that they would now feel more confident ingoing for a smear test. This was partly due to having had a de-infibulation, but also due to the support they had experienced from the health professionals and feeling more confident with their bodies..

"Now I know that they understand, I feel more confident talking about it with my doctor." (Survivor)

Increased self-confidence and feelings of empowerment

5.22 Others described how they felt empowered with the knowledge of FGM and how their symptoms related to it. They felt more able to look after themselves when they had completed their therapy sessions; they felt more positive from being heard and more connected to others.

"The benefit has been amazing. Very pleased with it. There are so many women out there that suffer in silence and if I can encourage them to speak about it it's been worth it..." (Survivor)

5.23 Several women spoke about how the FGM clinics were a source of empowerment against the violence that had been done to them. For the first time, they felt supported by a community that was openly dealing with FGM.

"I feel like I am undoing all the wrong that was done to me, this is me beating back from all the hurt." (Survivor)

Greater confidence in relationships and intimacy

5.24 Greater confidence in relationships and intimacy was frequently reported. One woman spoke about how she had come to terms with her own sexuality as a result of feeling more confident with her body and her emotions.

"Having this therapy has helped me explore my emotions and to admit what I feel and to come to terms with my bi-sexuality." (Survivor)

5.25 Women reported feeling more confident with sex and having got a sex life for the first time as a direct result of the clinical intervention, the knowledge gained about their body, and the psycho-sexual therapeutic support.

"…I am now able to touch myself.. and to be aware of how my own body feels…I feel less shame about this and in a much better place". (Survivor)

"…after like a year and a few months I was able to have normal sexual intercourse after working on my brain and you know my thoughts… I spent years and years trying and it was impossible [prior to the clinic support]*."* (Survivor)

Improved mental wellbeing

5.26 Women experienced improved mental well-being as a result of accessing holistic support from the clinic. Women reported the significance of having a service of professionals who were there for them and had time to listen to their stories and support them with their physical and mental well-being. Many spoke about feeling a sense of weight being lifted from their shoulders.

"I had twelve sessions...the impact of this support opened me up to my whole experience…the FGM and abuse from my family…they helped me cope with my depression." (Survivor)

Figure 5.3: Case Study Three

Leila had been married before, and during her relationship, she didn't feel normal but tried not to focus too much on this especially when her marriage ended. She then wanted to get married again, so she went to her GP because she was worried about her FGM affecting her relationship again.

She was successfully referred to a clinic for a check where she had a diagnosis and was informed she had Type 1 FGM. This happened to her when she was around 12 years old.

Leila reported that the female worker she saw was, *"very kind and gentle."* Her physical examination at her first appointment lasted just five minutes. She was offered a cervical smear test but did not need one as she had already had one.

She agreed to have therapy and met the therapist once at the clinic and then continued with her sessions on the telephone. The therapist spoke Arabic which Leila said was very helpful. *"…she helped me remember stuff…it was really helpful to talk to her…she understands very well, and she knows more about our culture and why this happens."* (Leila)

The therapy helped Leila talk through her trauma, to understand her relationship difficulties and helped improve her mental well-being. She had eight sessions which she was very grateful for but for Leila was not enough and she sought help from another organisation to continue her therapy.

Ongoing needs

5.27 Several women admitted to having ongoing support needs. Some women admitted to feeling bitter about how their family had inflicted pain on them and how their community had allowed this to continue. This was still affecting their identity and self-esteem.

5.28 Some women still felt unable to talk to their families about it for fear of burdening them with their shame and suffering.

"I can't talk to my children about it, I don't feel it's appropriate for them to know how I have suffered, but it does make things difficult for me sometimes to keep this a secret." (Survivor)

5.29 Some women had deeper issues that needed further treatment and spoke of how their enjoyment of sex had been taken away from them.

"I can get so angry about this still, I know why now at least, but I am still so upset and angry." (Survivor)

5.30 Some reported they would like to be part of a group of women with similar experiences. This idea was being talked about in the clinics but none had enacted any peer-to-peer support groups at the time of the research.

"I would have liked more peer support from other women who had experienced the same thing as me." (Survivor)

"I would have liked to have a group of women to talk about it, but it's never really got off the ground. It's time constraints but I'm sure women would come." (Survivor)

"I think speaking to other people, especially for like, for other people with more severe types, it would have been beneficial." (Survivor)

5.31 A few women raised the issue of reconstructive surgery to help them recover and to achieve more enjoyment during sex.

"I am in a better place but I am still on my journey… until I have the reconstruction I won't feel right about it. I have wanted to do this for years. There is a fear of the pain, but this will be nothing compared to what was done." (Survivor)

Summary

5.32 Women's views of the support at the clinics were very positive. Clinics treated the women sensitively and provided a high level of emotional support. Women felt listened to and understood and this helped to engender trust among the service user. Women who had de-infibulations spoke of a change in their physical health but also optimism for their future, in particular with their relationships and intimacy; several women had come to the clinic in preparation for marriage.

5.33 The counselling and psycho-sexual therapeutic support had a significant impact on women's self-awareness, on their understanding of how the trauma of FGM had affected them. This was another key step forward in their recovery.

5.34 For several women, this was the start of their journey and ongoing support was going to be needed. Several suggested peer-to-peer support groups would be helpful. Clinics were considering this but not had enacted this at the time of the research.

6 COST-EFFECTIVENESS OF FGM CLINICS

INTRODUCTION

6.1 This chapter presents a high-level cost-benefit review of the FGM Clinics. The review aimed to:

- Assess the cost-effectiveness of the FGM clinics
- Understand where and how greater levels of cost-effectiveness are achieved across the clinics.

6.2 The context for the review is that support for women who have experienced FGM is estimated to cost £100 million across England and Wales[12], with nearly all costs relating to psychological care and long-term complications from FGM[13]. This puts budgetary strains on an already stretched service. However, good preventative support and support for victims of FGM will reduce the need for more costly services longer-term.

6.3 A previous review of the costs of the clinics had been undertaken by York Health Economics Consortium (YHEC) in 2019-20[14]. Primarily, this study intended to update the previous cost review with 2020-21 data generated from the survey of clinics[15]. This included:

- The number of new service users
- The symptoms they experienced (Urinary tract symptoms/urinary tract infections Recurrent thrush; Menstruation problems (e.g. blood clots stuck behind scar); Per Vaginal (PV) discharge; Problems with urination or urine retention (e.g. enuresis, dysuria, increased frequency of urination, haematuria); Fistula; Dyspareunia or problems with sexual function[16]; Psychosexual problems
- Mental health problems: mild, moderate or severe[17].

[12] Hex N, Hanlon J, et al. (2016) Estimating the costs of Female Genital Mutilation Servicers to the NHS. University of York and King's Fund.
[13] York Health Economics Consortium (2021) Economic Analysis of NHS FGM Support Clinics
[14] Ibid (2021)
[15] There may be mode effects given that the previous study included data from centrally obtained management information; this cost study relied solely on a survey (albeit where information may be have obtained from the management information for each clinic).
[16] E.g. pain around genitalia, difficult or painful sexual intercourse, genital bleeding during intercourse, sexual intercourse not possible, reduced sexual sensation, reduced sexual satisfaction, reduced sexual desire.
[17] Mild: e.g. mild depression. Moderate: Anxiety, flashbacks, panic attacks, sleeping disturbances, nightmares. Severe: Post Traumatic Stress Disorder, eating problems, obsessive compulsive thoughts or behaviours, substance misuse, behavioural problems, self-harm, suicide attempts.

- The number of Type 3 service users receiving de-infibulations through the clinics
- The number of Type 3 service users receiving de-infibulations through secondary care facilities.

CLINIC COSTS

6.4 The costs of delivering the clinics were calculated by YHEC (2021) and included:

- Staffing: midwife, advocate, counsellor/mental health, manager, administration, consultant time
- Training and supervision for staff: supervision, cervical smear and STI training, training/recruitment costs
- Room rental
- Consumables
- Equipment: IT equipment and phones, other equipment (e.g. examination couch)
- Travel and expenses
- Mental health charity overhead.

6.5 The YHEC report found that the average annual cost per clinic after offset costs, was **£51,785[18].**

6.6 A cost per case was calculated at **£1,433** by dividing the estimated costs of the eight clinics (£51,785 x 8 clinics x 2 years) by the total number of service users seen over 2019-2021 across all eight clinics (578 service users).

Estimating the potential benefits or cost savings of the clinics

6.7 Cost savings are achieved by FGM clinics when they prevent a need for more costly interventions. A hypothetical counterfactual is presented in the tables below where the same number of service users do not have access to FGM clinics (**No FGM Clinics**), and so would need to seek alternative treatment options from non-clinic settings.

[18] The average annual cost per clinic per clinic was based on the five pilot clinics (Blossom, Calabash, Hibiscus, Summerfield, WAHA) because the three other sub-pilot clinics (Bristol Rose, Primrose, Sunflower) received funding for additional posts only and so do not reflect the full running costs of the clinics.

6.8 The cost savings primarily arise from the clinics treating the following symptoms and complications more cheaply than non-clinic treatment:

- Presenting symptoms
- Infibulation (by treating with de-infibulation)
- Long-term obstetric complications.

6.9 The survey of clinics gathered evidence of the numbers of women treated in the clinics and experiencing **symptoms** for 2019-2021. The unit costs and treatment framework set out in the YHEC report (2021) (see Appendix B and Appendix C1 respectively in this report) were then applied to the new symptoms data[19]. The framework was informed by expert clinicians from the clinics and outlined which symptoms could be treated by the FGM clinics and which would need to be referred elsewhere: for example, to a psychological service to treat mental health problems, or to urology to treat a fistula or urination problem.

6.10 Over the two-year period 2019-2021, 578 women were seen. **Table 6.1** summarises the costs of treating all symptoms for one year (2020-2021) and for both years 2019-2021. This is shown as being treated at the FGM clinics ("FGM clinics") and compared with the counterfactual of without FGM clinics ("No FGM clinics"). The calculated cost savings from the different pathways (or 'net benefits') are shown in red (with a 'negative cost' being a 'positive benefit').

Table 6.1: Summary of treatment costs for presenting symptoms for FGM clinics and No FGM clinics

Clinics Delivery Year	Analysis	FGM clinics	No FGM clinics	Difference
2020-21 (n=301)	Cost per cohort	£202,231	£373,027	-£170,797
2020-21 (n=301)	Cost per Service user	£672	£1,239	-£567
2019-21 (n=578)	Cost per cohort	£298,512	£646,269	-£347,758
2019-21 (n=578)	Cost per Service user	£516	£1,118	-£602

6.11 The table shows that clinics provided £347,758 net benefit in 2019-21 compared with non-FGM clinics, which includes £170,797 of net benefit from 2019-2021. In other words, the clinics have treated presenting symptoms £347,758 more cheaply than would have been possible had there been no FGM clinics in the last two years. The saving per service user equates to £602 per service user. The detail behind the calculations in **Table 6.1** is provided in Appendix C2.

[19] Unit costs were not uprated for inflation or otherwise adjusted, to maintain consistency with the YHEC analysis.

6.12 **Table 6.2** details the cost savings of performing the **de-infibulations** in the clinics for one year (2021) and for both years (2019-2021) and compared to secondary care settings. In the absence of FGM clinics, it is assumed that all de-infibulations would be carried out in a hospital, either as an outpatient procedure or day case for more complex cases. For cases treated in a hospital, this study uses the YHEC report assumption that 90% of cases are outpatient (with a unit cost of £221 for an outpatient procedure in a hospital, or absorbed as part of the FGM clinic cost where treated) and 10% of cases are complex (with a unit cost of £1,178 for a day case procedure).

Table 6.2: Summary of de-infibulation costs for FGM clinics and No FGM clinics

Delivery year	Analysis	FGM clinics	No FGM clinics	Difference
2020-21 (n=88)	Cost per cohort	£17,971	£31,673	-£13,702
2020-21 (n=88)	Cost per Service user	£60	£105	-£45
2019-21 (n=230)	Cost per cohort	£22,763	£78,821	-£56,058
2019-21 (n=230)	Cost per Service user	£39	£136	-£97

6.13 Again, it is apparent that treating Type 3 cases that require de-infibulation was more cost-effective in a clinic than in a hospital setting (by assuming this would be carried out by a midwife as opposed to a consultant in a hospital), to the value of £13,702 in 2020-21 (£46 per service user) and £56,058 over 2019-21 (£97 per service user). The detail behind **Table 6.2** is provided in Appendix C3.

6.14 In addition, long-term obstetric complications from FGM, if left untreated and/or in the absence of FGM clinics for non-pregnant women, can cause complications during pregnancy. These complications will have associated costs from dealing with them, including access to gynaecology, psychological and urology services.

6.15 On the other hand, treating women in the FGM clinic avoids long-term obstetric complications for women who become pregnant. Therefore, the costs of long-term complications for women treated in the FGM clinic are £0.

6.16 **Table 6.3** presents the costs of long-term obstetric complications for women treated in an FGM clinic and assuming the same cohort was not treated in a clinic. The difference between the costs is the cost savings. This analysis has used the YHEC (2021) report assumption (based on an external study[20]) that 50% of the women with Type 3 FGM and having de-infibulation (in a clinic or secondary care) would become pregnant in the future.

Table 6.3: Summary of obstetric complication costs for FGM clinics and No FGM clinics

Delivery year	Analysis	FGM Clinics	No FGM Clinics	Difference
2020-21 (n=44)	Cost per cohort	£0	£241,606	-£241,606
2020-21 (n=44)	Cost per Service user	£0	£803	-£803
2019-21 (n=115)	Cost per cohort	£0	£631,470	-£631,470
2019-21 (n=115)	Cost per Service user	£0	£1,093	-£1,093

6.17 Table **6.3** shows substantial cost savings for FGM clinics, of £241,606 (£803 per service user) in 2020-21 and £631,470 across 2019-21 (£1,093 per service user) due to having dealt with the symptoms prior to pregnancy. The detail behind Table 6.3 is provided in Table E in Appendix C4.

6.18 It is possible that there may be other long-term complications, such as kidney problems, infertility, HIV, hepatitis and perinatal death[21], which may understate the cost savings presented here.

Summary of the cost-effectiveness of FGM clinics for non-pregnant women

6.19 The costs per case of the FGM clinics and the costs of treatment per case are presented below to understand any potential savings *per case*. The net benefit is the difference between the costs of the FGM clinics and the costs of no FGM clinics.

[20] Berg RC, Underland V, Odgaard-Jensen J, Fretheim A, Vist GE. Effects of female genital cutting on physical health outcomes: a systematic review and meta-analysis. BMJ Open 2014;4:e006316.

[21] Hex N et al. Estimating the costs of female genital mutilation (FGM) services to the NHS. November 2016.

6.20 **Table 6.4** takes the cost per case identified earlier for treating in an FGM clinic (£1,433) or not (£0) for 2019-21. It then compares these with the costs per case, as outlined above, for treating symptoms, carrying out de-infibulations and avoiding long-term obstetric complications within and without FGM clinics (£556 and £2,347 respectively). The overall costs per case of a service user treated in an FGM clinic were £1,989 (clinic cost per case and the cost of the treatment). Had the same service user not been treated in an FGM clinic, the costs would have been £2,347 per case. Therefore, treating service users in an FGM clinic has led to a cost saving of £358 per case between 2019 and 2021.

Table 6.4: Cost per case, 2019-21

Delivery years 2019-21	**FGM Clinics**	**No FGM Clinics**
Number of cases	578	578
Clinics' costs per case	**£1,433**	**£0**
Treatment costs per case		
Presenting symptoms	£516	£1,118
De-infibulation	£39	£136
Long term obstetric complications	£0	£1,093
Total treatment costs per case	**£556**	**£2,347**
Net cost per case (clinic costs + treatment costs)	**£1,989**	**£2,347**
Net benefit per case (Difference between FGM clinics and No FGM clinics)	**-£358**	

6.21 Applying the figures in Table 6.4 to all of the service users seen over the two years of operation of the clinics (578 service users), a cost saving of over £206,000 is estimated (**Table 6.5**), at a cost per case of £1,433.

Table 6.5: Total costs and cost savings per Service user 2019-2021

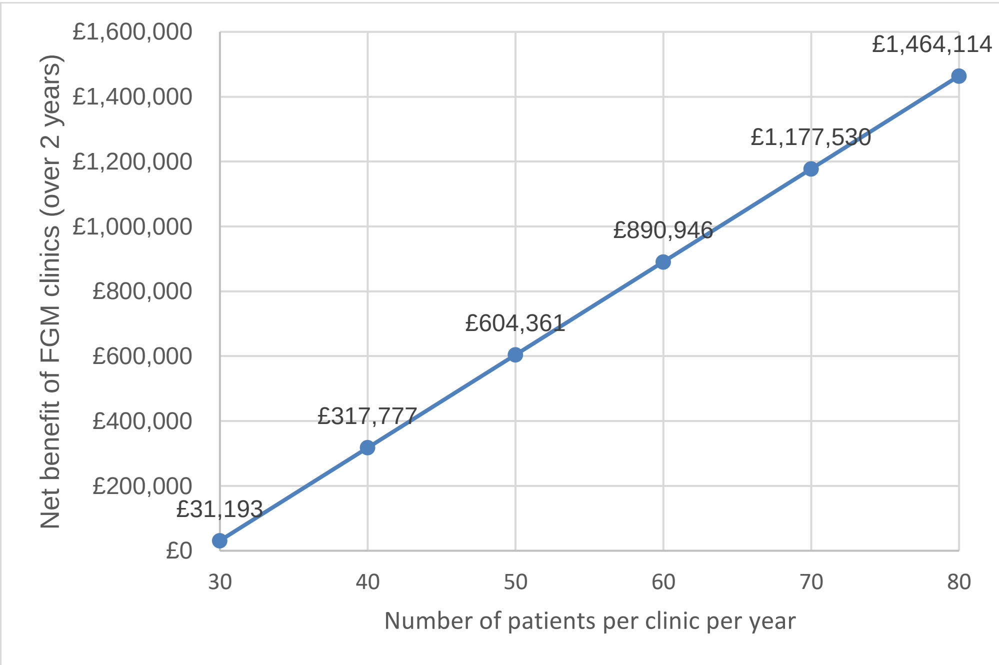
2019-21	**FGM Clinics**	**No FGM Clinics**
Clinic costs	**£828,560**	**£0**
Treatment costs		
Presenting symptoms	£298,512	£646,269
De-infibulation	£22,763	£78,821
Long-term obstetric complications	£0	£631,470
Total treatment costs	**£321,275**	**£1,356,561**
Net costs (clinic costs + treatment costs)	**£1,149,835**	**£1,356,561**
Net benefit of FGM clinics (difference between FGM clinics and No FGM clinics)	**-£206,726**	

6.22 At the estimated levels of benefits, the FGM clinics would provide a net benefit as long as the cost per case was lower than £1,791. The largest potential saving comes from avoided long-term obstetric complications.

6.23 An FGM clinic with an average annual cost of £51,785 would need to see 29 or more service users per year to be cost-effective compared to the counterfactual of no FGM clinics operating (£51,785 ÷ £1,791 = 28.9 service users). It is worth noting that, during the period of the study (2019-20), the number of women seen, and de-infibulations carried out were significantly reduced due to the restrictions of Covid-19.

6.24 Survey data also highlights that clinics were operating below full capacity and five of the eight clinics treated fewer then 29 service users suggesting they were not cost-effective. For all clinics to be viable economically, more service user needs to be seen. Thereafter, when the number of service users increased beyond 29, this will increase the level of efficiencies across the clinics. This relationship is shown in Figure 6.1.

Figure 6.1: Project net benefits of FGM Clinics for non-pregnant women



6.25 The graphs show how by increasing the number of service users seen the net benefits (cost savings) also increase. Were clinics to reach an average of 50 service users a year, this would deliver an overall net benefit of £604,361 per year from the eight clinics. Were they to reach 80 service users per year, this would deliver a cost saving of £1,464,114 per year. This would be achievable with the clinics operating as they currently do with two clinical days per month and seeing four service users each day.

Summary

6.26 In summary, this analysis has determined that the pilot FGM clinics for non-pregnant women when considered as a whole service offer, was a cost-effective pilot. With a cost per case calculated at £1,433 across 2019-21 based on the original costs set out in the YHEC report, and with service user throughput evidenced by the clinics at 578, clinics are estimated to have generated over £200,000 in a net benefit to the NHS between 2019 and 2021.

6.27 The analysis presented shows that treating symptoms, providing de-infibulation and preventing long-term obstetric complications are more cost-effective in an FGM clinic than in a hospital. However, clinics have to be sufficiently cost-effective to cover the costs of establishing and running a clinic, since the model assumes that treatment of FGM otherwise is covered within the costs of existing services and, therefore, does not attract any additional set-up and delivery cost.

6.28 There are benefits to operating at scale since the cost of the clinics is relatively fixed, so when referrals and service user numbers increase, the cost per service user reduces.

6.29 As with the previous study, there are some limitations with the data and, as a result, the analysis does rely on some assumptions, which creates some uncertainty in the results. As a result, sensitivity analysis was undertaken for the previous study, to adjust various assumptions. All assumptions made the analysis more conservative, therefore reducing the cost-effectiveness of the clinics (i.e., fewer net benefits). At its extreme, in the case of no long-term obstetric complications arising from future pregnancies, the clinics are a net cost, but no complications seem unlikely and counter the evidence from previous studies[22]. It should also be noted that, as in the YHEC report, this analysis does not consider secondary outcomes such as quality of life or subjective well-being gains for women, which would likely improve the cost-effectiveness of the clinics further.

[22] Berg RC, Underland V, Odgaard-Jensen J, Fretheim A, Vist GE. Effects of female genital cutting on physical health outcomes: a systematic review and meta-analysis. BMJ Open 2014;4:e006316.

7 CONCLUSIONS AND RECOMMENDATIONS

Introduction

7.1 This section draws from the evidence presented in the report to consider the implications for sustaining and extending the number of FGM clinics for non-pregnant women across the UK. NHS England is currently reviewing the service specifications to ensure that it is fit for purpose and based on the experiences of the pilot clinics. This research will help to shape that specification and also provide lessons learned and considerations for future delivery.

Conclusions

7.2 This report evidenced the positive impact on women's physical health, emotional and mental well-being, and their ability to move forward with their lives. Although the sample sizes were small, without exception, women reported a very positive experience from the clinics. They gave accounts of how the diagnosis and clinical interventions had alleviated their physical symptoms. Crucially, they gave accounts of how the counselling and/or psycho-sexual therapeutic support had helped them to come to terms with the trauma they had experienced over many years and how that trauma had sometimes manifested itself in anger, depression and difficulties with relationships. The role of the advocate was crucial in getting the women engaged and present at the clinics for appointments. Evidence shows that the tripartite support delivered through this pilot resulted in positive and potentially long-lasting change for survivors of FGM. For some survivors, there was an ongoing need for further counselling.

7.3 The pilots delivered an overall saving to the public purse of just over £200,000. This was calculated on the actual costs of running the clinics and the number of service users receiving support. Whilst this is a moderate sum of money, these calculations were based on real savings by comparing the costs of delivering the same services in secondary care (with no FGM clinics for non-pregnant support). In addition, no estimates were included for any longer-term savings in mental health support that many women would have required (without the additional counselling intervention delivered through this model). Therefore, these calculations are conservative. In addition, future services would very likely not be operating during a pandemic and the number of service users accessing the clinics would be greater, reducing the cost per service user and bringing greater net benefits to the public purse. With an estimated cost of just over £50,000 per annum to operate a clinic, the benefits of providing these clinics are clear.

7.4 Any extension of the FGM clinics for non-pregnant women needs to draw on the challenges experienced by the clinics and the key lessons identified in this study.

7.5 Turning to the key features of the service specification[23],: there was little evidence of the advantages of community settings; all clinics experienced a range of challenges related to set-up and referral numbers. Women seemed to be equally happy to attend hospital-based clinics or community-based clinics. What was important was the welcoming environment and the sensitivity with which the women were treated. This was equally apparent in both clinic settings. The key was to ensure that potential service users, professionals and relevant community groups knew of this service, and that staff operating in the clinics had sufficient time and expertise and could work together to deliver the services. There were some lessons learned regarding team working, management and supervision of the multi-agency team that need to be considered moving forward.

7.6 There was a difference of opinion regarding the need to offer smear tests to service users. Four clinics said they did offer this service, but only four smear tests were completed by two clinics. What seems important is that conversations are held with women regarding the need for them to receive smear tests in the future, and to ensure they felt confident in accessing this service. Training for administering smear tests was spoken of by two midwives who reported completing this in their own time, which may be a reason for the lack of tests being completed. There were also costs associated with getting test results which need to be considered by clinics.

7.7 The clinics delivered these positive outcomes with little central coordination from NHS England. Clinic leads (midwives, nurses or gynaecologists) came together and formed a support network, where experiences and lessons learned regarding clinic operations were shared. But this appears not to have been backed up by any support with processes or systems. For example, no standard template to help draft operating procedures, and crucially no IT database where clinics could gather and hold consistent data. With the right expertise and a little resource input at the start of the pilot, a system for holding the data on the internet could have been designed that enabled all team members in each clinic to view and add case data.

[23] NHS England (2018) Service Specification Clinics for non-pregnant women who have undergone female genital mutilation

7.8 This lack of systems and any central coordination was felt by clinic leads and their team, and comments such as 'we were just left to get on with it' crystalise their experience.

7.9 There was also no attention given to generating feedback from service users, and no real consideration of the requirements needed to deliver a pilot evaluation.

7.10 Having said all the above, clinics worked hard to continue to deliver their service and were committed to delivering high-quality impactful support for survivors of FGM. There were developments in most clinics to continue operating, with six of the eight having secured some funding for further delivery. The following recommendations are delivered to help deliver improved service delivery.

Recommendations

7.11 **Recommendation One**: NHS England to draft template operating procedures for clinics to complete to ensure compliance with the model of care detailing: clinical care pathway, governance arrangements, access to medication by midwives, data storage arrangements, referrals to the service, safeguarding procedures and audit arrangements.

7.12 **Recommendation Two:** each clinic to ensure teams are supplied with adequate IT, telephone and other equipment required to carry out the duties.

7.13 **Recommendation Three**: each clinic to ensure sufficient time for management and oversight of the clinic is incorporated into the monthly resources secured to operate the clinic. Two days per midwife per month was an insufficient amount of time to manage the clinic and deliver the clinical interventions. This will help the overall performance of the clinics.

7.14 **Recommendation Four:** each clinic to ensure regular line management and supervision arrangements for multi-agency teams are factored into the delivery of services. This is particularly important for health advocates who may be working in a clinic setting for the first time and may feel unfamiliar with terminology and clinical practices.

7.15 **Recommendation Five:** prior to clinics operating, design a secure data storage database that can be held online that will allow shared access for each clinic. This should enable reports to be pulled off showing details on referrals, interventions delivered and exit routes for survivors (e.g., any further signposting to other services). This will help commissioners understand the performance of the clinic.

7.16 **Recommendation Six:** to understand whether services are meeting service-users' needs, ensure that views from service users are collected. This could be a simple online or telephone survey distributed to service users to get their feedback on their experiences. This can be designed using any free apps available on phones or online. Review the data every quarter. Permission should be requested to enable any follow-up of service user views.

7.17 **Recommendation Seven**. Clinics should ensure that staff is sufficiently trained and confident in offering smear tests so patients accessing the clinics have a choice as to whether they receive the service.

7.18 **Recommendation Eight:** clinics to consider the opportunities and implications for delivering peer-to-peer support groups on their resources and factor in support for establishing and sustaining the groups.

7.19 **Recommendation Nine:** clinics to ensure adequate time and resources are committed to raising awareness of the service. This should include online (e.g., bespoke website page and social media) as well as leafleting to local health, mental health and community centres. The role of the health advocate in developing partnerships is paramount and a plan for contacting relevant partners should be agreed upon.

7.20 **Recommendation Ten**: consider the diversity of languages spoken by potential service users and ensure all information leaflets and services can be delivered equally to all women.

APPENDICES

Appendix A: Evaluation Framework

Area of investigation	Key Questions
1. Clinical Services	a) Did the clinic agree a service delivery plan with the NHS? What are the key performance indicators? How do you monitor these, and any lessons learned. b) Have the clinics operated as planned with the range of holistic services being offered to patients (clinical support/interventions, 6 x counselling sessions, advocacy). c) If not, why not? d) What other services have been provided and why?
2. Clinical Operations	a) **Publicising the offer**: How have the clinics publicised their service? b) **Referrals:** How does the clinic receive referrals? Has the number of referrals changed since the launch of the pilot? If so, why? How accessible is the clinic to all patients in need? Are there any restrictions and, if so, for what reason? c) **Capacity:** Is the clinic operating to capacity? What restricts that capacity? If not, why not? Can they meet demand, and do they operate waiting lists? Were they able to estimate take-up and was this accurate? **d) Interventions delivered:** - **Medical**: what is the range of medical interventions that have been delivered? How many of the range of interventions have been delivered? - **Counselling**: how many patients have accessed counselling support. On average, how many counselling sessions per patient were accessed? - **Advocacy support**: what types of support are delivered through advocacy support? How are needs determined? How many patients have accessed advocacy support? - **Patient interactions:** how many times have patients accessed to support and over what period? What limits this?

Area of investigation	Key Questions
	- **Safeguarding:** how many safeguarding issues have arisen since operating? How are these concerns identified? How robust are relationships with children's services (e.g., speed and nature of response) - **Onward referrals:** how do clinics exit the women from their service? What onward referrals/requests for support in the community have they made? **e) key successes, challenges and lessons learned from the FGM clinic models of operation? Considering the following:** - Estimating capacity - Referrals for support and engagement of patients - Patients' holistic support needs and flexibility of services offered
3. Engagement in FMG prevention and support	a) What are the key lessons learned with regard to raising awareness of the clinic and the support offered by local partners and community groups? Do advocates feel they have improved local knowledge around this with partners and in the community and if so, how? b) How/how well do they engage with the target population? c) How/are clinics able to develop trusted relationships with communities and patients?
4. Partnership Working	a) Who are the key partners the clinics need to work with in order to deliver their services? b) Have the clinics developed new partnerships since delivering their services? If so, in what areas/sector and for what purpose? c) What has facilitated partnership integration? d) Has the clinic experienced difficulties with partner engagement? If so, why and what impact has this had on their service offer?
5. Patient experiences	a) **Engagement:** How did the patient hear about the clinic? What brought them to the clinics/symptoms? b) **Needs:** How was their experience of FGM affecting them physically or/and mentally? Over what period of time? Did the service offer identify other support needs?

Area of investigation	Key Questions
	c) **Support:** what medical support has the patient received? When was this received? What other support (counselling or/and advocacy) was the patient offered and did they engage in? if not, why not? What was the quality of the support received? d) **Relationships:** Did the patient feel they were listened to? Did they develop trusted relationships with practitioners in the clinics? Have they had any ongoing support from the clinic or peer-to-peer support? e) **Outcomes:** What is the outcome and impact of that support (e.g., improved physical health, mental well-being, confidence, resilience). What difference have the advocates and counsellors made to the outcomes?
6. Cost-effectiveness	a) What is the cost of running each clinic and how does this differ across the sites? b) What is the most cost-effective model? (e.g., considering clinic size, throughput, interventions, location? c) What are the potential costs avoided in providing FGM services to non-pregnant women? d) What is the perceived benefit of having clinics in the community? (e.g., level engagement, partnerships, throughcare)

Appendix B: Unit Costs

Unit costs	Value	Source
Treat in FGM clinic	£0	Assumption
GP appointment	£39	Unit Costs of Health & Social Care 2020 (PSSRU) General Practitioner - unit costs per patient contact lasting 9.22 minutes
Antibiotics for UTI	£1.5	Antibiotic treatment with amoxicillin – £1.50 (average cost: BNF)
Refer to Gynaecology	£152	National Tariff Outpatient Attendance Gynaecology 2019/20
Refer to Urology	£138	National Tariff Outpatient Attendance Urology 2019/20
Refer to Sexual Health	£169	PSSRU Consultant-led (Multi-professional) non-admitted, face to face, first
Cost of 12 sessions of CBT at £70 per session	£840	From 2016 report. It has been assumed that some form of anxiety treatment could potentially be applicable for cases of dyspareunia with half the cases receiving a form of cognitive behavioural therapy (CBT).
Refer to Psychological Service: depression	£470	£435 from ref in old report - 15. National Collaborating Centre for Mental Health. The treatment and management of depression in adults. National Institute for Health and Care Excellence (NICE) Clinical Guideline 90. 2010
Refer to Psychological Service: anxiety	£658	The NICE guideline on social anxiety disorder reports an annual cost per patient of £609 [16]
Refer to Psychological Service: PTSD	£891	There is very little evidence on the costs of PTSD but NICE guideline CG26 provides an estimate of £825 for ten treatment sessions [17]
De-infibulation cost: simple	£221	National schedule of NHS Costs V2 MA22Z Minor Lower Genital Tract Procedures Outpatient
De-infibulation cost: complex	£1,178	National schedule of NHS Costs V2 MA22Z Minor Lower Genital Tract Procedures Day Case
Total de-infibulation cost simple hospital procedure + GP appointment)	£260	Calculated from other unit costs
Total de-infibulation cost (complex hospital procedure + GP appointment)	£1,137	Calculated from other unit costs
Caesarean delivery: Weighted average of cost of NZ50 Planned Caesarean Section and NZ51 Emergency Caesarean Section	£4,257	Taken from 2016 report and uprated to 2020
Instrumental delivery: Weighted average of NZ40 Assisted delivery (AD) and NZ41 AD with epidural or induction	£3,147	Taken from 2016 report and uprated to 2020
Long difficult labour: Weighted average of NZ42 AD with epidural & induction or post-partum surgical intervention and NZ43 AD with epidural or induction and post-partum surgical intervention and NZ44 AD with epidural, induction and post-partum surgical intervention	£3,734	Taken from 2016 report and uprated to 2020

Appendix C: Detailed Cost Tables

Appendix C1: Costing framework for assumed treatment options for different symptoms

Symptom in case tracker	**FGM clinics**		**No FGM clinics (all FGM Types)**
	If FGM Type 3 and resolved by de-infibulation	**If not FGM Type 3**	
No symptoms	N/A	N/A	N/A
Urinary tract symptoms/urinary tract infections	Treat in FGM clinic: incorporated in FGM clinic cost	Refer to GP: General Practitioner appointment plus treatment with antibiotics	Refer to GP: General Practitioner appointment plus treatment with antibiotics
Recurrent thrush / Menstruation problems (e.g., blood clots stuck behind scar) / PV discharge	Treat in FGM clinic: incorporated in FGM clinic cost	Refer to gynaecology: Gynaecology outpatient appointment plus GP appointment in 50% of cases (to facilitate referral)	Refer to gynaecology: Gynaecology outpatient appointment plus GP appointment in 50% of cases (to facilitate referral)
Problems with urination/urine Retention: enuresis, dysuria, increased frequency urination, haematuria Fistula	Treat in FGM clinic: incorporated in FGM clinic cost Refer to urology	Refer to urology: Urology outpatient appointment plus GP appointment in 50% of cases (to facilitate referral)	Refer to urology: Urology outpatient appointment plus GP appointment in 50% of cases (to facilitate referral)
Dyspareunia/sexual function: pain around genitalia, difficult or painful sexual intercourse, genital bleeding during intercourse, sexual intercourse (per vagina) not possible, reduced sexual sensation, reduced sexual satisfaction, reduced sexual desire	Treat in FGM clinic: incorporated in FGM clinic cost	Refer to sexual health: Sexual outpatient appointment plus GP appointment in 50% of cases (to facilitate referral) plus course of CBT for 50% of patients	Refer to sexual health: Sexual outpatient appointment plus GP appointment in 50% of cases (to facilitate referral) plus course of CBT for 50% of patients
Mental health mild: Depression	Treat in FGM clinic: incorporated in FGM clinic cost	Treat in FGM clinic: incorporated in FGM clinic cost	Refer to psychological service: Cost of treatment of depression in adults plus GP appointment in 50% of cases (to facilitate referral)
Mental health moderate: anxiety, flashbacks, panic attacks, sleeping disturbance, nightmares	Treat in FGM clinic: incorporated in FGM clinic cost	Treat in FGM clinic: incorporated in FGM clinic cost	Refer to psychological service: Cost of treatment of social anxiety disorder plus GP appointment in 50% of cases (to facilitate referral)
Mental health severe: PTSD, eating problems, obsessive compulsive thoughts or behaviours, substance misuse, behavioural problems, self-harm, suicide attempts	Refer to psychological service: Cost of treatment of PTSD (NICE) plus GP appointment in 50% of cases (to facilitate referral)	Refer to psychological service: Cost of treatment of PTSD plus GP appointment in 50% of cases (to facilitate referral)	Refer to psychological service: Cost of treatment of PTSD plus GP appointment in 50% of cases (to facilitate referral)

Appendix C2: Treatment costs for presenting symptoms for FGM clinics and No FGM clinics

2020-21	**NUMBERS**			**COSTS**				
	FGM clinic		**No FGM clinic**	**FGM clinic**		**No FGM clinic**		**Difference**
Symptom category	**Type 3****	**All other exc Type 3****	**No FGM clinic**	**Type 3**	**All other exc Type 3**	**Total**	**No FGM clinic**	**Difference**
UTI: urinary tract symptoms, recurrent UTIs	32	78	110	£0	£3,184	**£3,184**	£4,551	-£1,367
Thrush*	18	45	63					
Problems with menstruation (e.g. blood clots stuck behind scar)*	37	89	126	£0	£45,218	**£45,218**	£69,531	-£24,313
PV discharge*	20	47	67					
Problems with urination/urine retention: enuresis, dysuria, increased frequency urination, haematuria	32	79	111	£0	£12,385	**£12,385**	£17,580	-£5,194
Fistula	0	1	1	£42	£0	**£42**	£145	-£102
Dyspareunia/sexual function: pain around genitalia, difficult or painful sexual intercourse, genital bleeding during intercourse, sexual intercourse (per vagina) not possible, reduced sexual sensation/satisfaction/desire	47	115	162	£0	£69,925	**£69,925**	£98,619	-£28,695
Mental health mild: Depression	25	60	85	£0	£0	**£0**	£41,574	-£41,574
Mental health moderate: anxiety, flashbacks, panic attacks, sleeping disturbance, nightmares	28	68	96	£0	£0	**£0**	£65,187	-£65,187
Mental health severe: eating problems, obsessive compulsive thoughts or behaviours, substance misuse, behavioural problems, self-harm, suicide attempts, PTSD	24	58	82	£20,058	£51,418	**£71,476**	£75,841	-£4,365
			TOTALS	**£20,100**	**£182,130**	**£202,231**	**£373,027**	**-£170,797**
				PER PATIENT		**£672**	**£1,239**	**-£567**

2019-21	**NUMBERS**			**COSTS**				
	FGM clinic		**No FGM clinic**	**FGM clinic**		**No FGM clinic**		**Difference**
Symptom category	**Treatment option 1****	**Treatment option 2****	**No FGM clinic**	**Type 3 only**	**All other exc Type 3**	**Total**	**No FGM clinic**	**Difference**
UTI: urinary tract symptoms, recurrent UTIs	41	88	129	£0	£3,593	**£3,593**	£5,337	-£1,744
Thrush*	26	52	78					
Problems with menstruation (e.g. blood clots stuck behind scar)*	92	130	222	£0	£52,318	**£52,318**	£86,086	-£33,768
PV discharge*	21	51	73					
Problems with urination/urine retention: enuresis, dysuria, increased frequency urination, haematuria	49	110	159	£0	£17,273	**£17,273**	£25,182	-£7,908
Fistula	3	1	4	£476	£0	**£476**	£579	-£102
Dyspareunia/sexual function: pain around genitalia, difficult or painful sexual intercourse, genital bleeding during intercourse, sexual intercourse (per vagina) not possible, reduced sexual sensation/satisfaction/desire	187	223	410	£0	£135,801	**£135,801**	£249,592	-£113,792

Mental health mild: Depression	32	93	125	£0	£0	**£0**	£61,138	-£61,138
Mental health moderate: anxiety, flashbacks, panic attacks, sleeping disturbance, nightmares	54	130	184	£0	£0	**£0**	£124,942	-£124,942
Mental health severe: eating problems, obsessive compulsive thoughts or behaviours, substance misuse, behavioural problems, self-harm, suicide attempts, PTSD	27	75	101	£22,568	£66,482	**£89,050**	£93,414	-£4,364
			TOTALS	**£23,044**	**£275,467**	**£298,512**	**£646,269**	**-£347,758**
					PER PATIENT	**£516**	**£1,118**	**-£602**

*To avoid double counting, the number assumed to be referred to gynaecology was only 'Problems with menstruation'.

**In 2019-20, data on the numbers of symptoms per Type 3 and non-Type 3 cases was available, but in 2020-21 this was not available. 29% of total cases in 2020-21 (i.e., the figures under "No FGM clinic" in the 2020-21 table above) were Type 3 cases. The number of patients experiencing the listed symptoms in 2020-21 has been allocated 29% to Type 3 and 71% to non-Type 3. For the 2019-21 table, these estimates have been added to available data for 2019-20.

Appendix C3: De-infibulation costs for FGM clinics and No FGM clinics

2020-21		***Number in cohort***		***Cohort costs***		
Number of referrals	**Location of deinfibulation**	**FGM clinic**	**No FGM clinic**	**FGM clinic**	**No FGM clinic**	**Difference**
Base case: n=88	FGM clinic	73	0	£0	£0	£0
	In hospital	15	88	£17,971	£31,673	-£13,702
	Totals	**88**	**88**	***£17,971***	***£31,673***	***-£13,702***
			PER PATIENT*	***£60***	***£105***	

2019-21		***Number in cohort***		***Cohort costs***		
Number of referrals	**Location of deinfibulation**	**FGM clinic**	**No FGM clinic**	**FGM clinic**	**No FGM clinic**	**Difference**
Base case: n=230	FGM clinic	200	0	£0	£0	£0
	In hospital	19	219	£22,763	£78,821	-£56,058
	Totals	**219**	**219**	***£22,763***	***£78,821***	***-£56,058***
			PER PATIENT*	***£39***	***£136***	

* Based on total in cohort, not just those deinfibulated.

Appendix C4: Obstetric complication costs for FGM clinics and No FGM clinics

2020-21				
Number of Type 3 in cohort (Base case)	88			
% Having pregnancy	50%			
Number having pregnancy	44			
Complication	**%**	**Number**	**Unit cost**	**Cost**
Caesarean Section	35%	15	£4,257	£65,558
Instrumental delivery (primi)	69%	30	£3,147	£95,543
Long difficult labour: long labour*	14%	6	£3,734	*£0*
Long difficult labour: Obstetric haemorrhage*	23%	10	£3,734	*£0*
Long difficult labour: Obstetric tear*	49%	22	£3,734	£80,505
Long difficult labour: Episiotomy*	21%	9	£3,734	*£0*
			TOTAL COHORT COST	**£241,606**
			COST PER PATIENT**	**£803**

2019-21				
Number of Type 3 in cohort (Base case)	230			
% Having pregnancy	50%			
Number having pregnancy	115			
Complication	**%**	**Number**	**Unit cost**	**Cost**
Caesarean Section	35%	40	£4,257	£171,344
Instrumental delivery (primi)	69%	79	£3,147	£249,714
Long difficult labour: long labour*	14%	16	£3,734	*£0*
Long difficult labour: Obstetric haemorrhage*	23%	26	£3,734	*£0*
Long difficult labour: Obstetric tear*	49%	56	£3,734	£210,411
Long difficult labour: Episiotomy*	21%	24	£3,734	*£0*
			TOTAL COHORT COST	**£631,470**
			COST PER PATIENT**	**£1,093**

* To avoid double counting the cost, only the proportion with obstetric tear are included in the number for 'long difficult labour'.

** Based on total in cohort, not just Type 3 FGM.