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Estimating the costs of Female Genital Mutilation services to the NHS

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Summary

Female genital mutilation (FGM) is an illegal, extremely harmful practice and a form of child abuse and violence against women and girls. It carries serious health consequences that can blight the health and wellbeing of girls and women for the majority of their lifetimes. These include gynaecological, urological and obstetric problems alongside mental health and psychological problems. There are estimated to be 137,000 women and girls living with the consequences of FGM in England and Wales.

The World Health Organisation (WHO) defines FGM as procedures involving partial or total removal of the external genitalia or other injury to the female genital organs for non-medical reasons. WHO has classified FGM into types, detailed below.

WHO classification of FGM by Type

Type	Description
1	Partial or total removal of the clitoris and/or the prepuce (clitoridectomy). Type Ia , removal of the clitoral hood or prepuce only; Type Ib , removal of the clitoris with the prepuce.
2	Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision). Type IIa , removal of the labia minora only; Type IIb , partial or total removal of the clitoris and the labia minora; Type IIc , partial or total removal of the clitoris, the labia minora and the labia majora.
3	Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation). Type IIIa : removal and apposition of the labia minora; Type IIIb : removal and apposition of the labia majora.
4	Unclassified: All other harmful procedures to the female genitalia for nonmedical purposes, for example, pricking, piercing, incising, scraping and cauterisation.

Over recent years, the UK Government has given the issue of FGM a high priority, both in terms of raising awareness of the illegal and harmful nature of the practice and in considering the extent of health care and other needs for women who have experienced FGM. This report provides an analysis of the current health care landscape for women with FGM as well as an estimate of the costs of treatment of FGM in England and Wales. It also provides some thoughts on data collection and tariff implications for the English NHS Payment by Results mechanism.

It is not easy to estimate the costs of health care for women with FGM as there are only limited mechanisms for collecting data on such activity. Treatment for FGM is provided both in primary care and in hospital. In primary care there are mechanisms for GPs to record a patient's status as having FGM but this is more problematic in hospital. The majority of hospital treatment for FGM is provided through specialties such as gynaecology, obstetrics and urology, and recorded diagnosis and procedure codes, along with the relevant tariffs, relate to those specialties not necessarily to FGM.

It is, therefore, difficult to identify specific cases of treatment for FGM within existing data sets. The Health and Social Care Information Centre (HSCIC) has started to compile a useful data set on a quarterly basis, which identifies information on contacts that hospital, primary care and mental health providers have with women with FGM. Although this is helpful, it is not possible to identify specific forms of treatment that women receive.

In order to develop the costing analysis a mixed methods approach was adopted. The first step was to carry out interviews with service providers and commissioners to understand the care pathways for the treatment of FGM. This was followed by the use of estimates of prevalence and literature to make estimates of service costs.

Interviews with specialist providers of care and care commissioners and providers in local health economy areas in Bristol, Birmingham and North West London provided an understanding of the nature of the health services available to women with FGM. Excluding reconstructive interventions which are not routinely funded by the NHS, health care for women with FGM can be categorised into four types of treatment or intervention:

- Short-term complications are associated with women who have been cut recently, and include complications such as haemorrhage or infection;
- De-infibulation procedures are needed mainly for women with Type 3 FGM (although some women with Type 2 FGM also require de-infibulation) and are particularly important when women are pregnant. The de-infibulation procedure is relatively simple and can be carried out in community settings or hospital, but can be more complex particularly later in pregnancy;
- Longer-term complications can include obstetric complications, cysts, urinary tract infections and infertility. The difficulty in estimating the costs of these complications is that they can occur at irregular points in time and may not occur at all;
- Psychological care and support are potentially required by all women experiencing FGM, whether or not women are presenting having recently had FGM. In practice, many women do not seek care or support for mental health issues associated with FGM.

Using available incidence and prevalence data and information derived from literature on the relative risk of specific complications in women with FGM, cost estimates were made for all four categories of treatment. It is important to caveat the estimates by stating that many assumptions had to be made in establishing these estimates and there is potentially a broad margin of error in the results, due to the fact that treatment related to FGM may be unreported for many different reasons.

The cost estimates indicate that psychological problems and long-term complications make up by far the largest elements of the costs of care provided by the NHS for women with FGM. The estimated annual cost of care for women with FGM is £100 million.

Category	Total annual cost
Short-term complications	£28,000
De-infibulation	£343,000
Psychological care	£65,923,000
Long-term complications	£33,448,000
Total cost	£99,742,000

Given the uncertain nature of the estimates, sensitivity analysis was conducted to establish a likely range of the costs of FGM care. The range is broad, from a low cost of around £33 million to a high cost of £184 million.

The remit of the study asked for tariff changes to be considered, if appropriate, based on the findings of the study. The bulk of the health care costs associated with FGM are incurred in relation to psychological and long-term complications treated in both primary and secondary care. There are no specific payment tariffs in place for FGM, other than that for de-infibulation, but this does not appear to present a problem in ensuring that health care is provided for FGM.

It could be possible to establish a number of tariffs based on the groupings of conditions and treatments described in Section 3 of this paper. For example, a tariff could be established for *“haemorrhage following FGM”*, or *“urinary tract infection associated with FGM”*. The setting up of specific tariffs related to FGM could be helpful in raising awareness of FGM among clinicians and also in providing more systematic data about health care activity in response to FGM. However, other options for raising awareness of FGM and the services available to women should also be explored, particularly for psychological care where there may be considerable cultural barriers among women with FGM.

It would also be worth considering carrying out a piece of work to establish the extent to which primary care FGM codes are being used. This could be done on a longitudinal basis using data from the THIN or CPRD databases and may provide an indication of the incidence of women with FGM accessing primary care. It is particularly difficult to understand the levels of psychological care need for women with mental health problems associated with FGM. Further research would be beneficial to map out levels of current demand and provision and, specifically, unmet need.

1. Introduction

1.1. Background

Female genital mutilation (FGM) is an illegal, extremely harmful practice and a form of child abuse and violence against women and girls. The World Health Organisation (WHO) defines FGM as procedures involving partial or total removal of the external genitalia or other injury to the female genital organs for non-medical reasons [1]. WHO has classified FGM into types, detailed in Figure 1.1.

Figure 1.1: WHO classification of FGM by Type

Type	Description
1	Partial or total removal of the clitoris and/or the prepuce (clitoridectomy). Type Ia , removal of the clitoral hood or prepuce only; Type Ib , removal of the clitoris with the prepuce.
2	Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision). Type IIa , removal of the labia minora only; Type IIb , partial or total removal of the clitoris and the labia minora; Type IIc , partial or total removal of the clitoris, the labia minora and the labia majora.
3	Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation). Type IIIa : removal and apposition of the labia minora; Type IIIb : removal and apposition of the labia majora.
4	Unclassified: All other harmful procedures to the female genitalia for nonmedical purposes, for example, pricking, piercing, incising, scraping and cauterisation.

FGM carries serious health consequences that can blight the health and wellbeing of girls and women for the majority of their lifetimes. These include gynaecological/menstrual/urinary problems, childbirth/labour/pregnancy complications, mental health/psychological problems, and substance misuse/self-harm amongst others. There are estimated to be 137,000 women and girls living with the consequences of FGM in England and Wales [2] and the cost of treating these conditions across the NHS may be significant. A 2009 study in Africa by the WHO estimated that across African countries, the treatment of obstetric complications caused by FGM alone comprised 1% of all Government expenditure on women of reproductive age [3].

In 2014 the UK Government issued multi-agency practice guidelines on FGM, which aimed to provide advice on FGM and support to frontline professionals with a responsibility for safeguarding children in England and Wales [4]. In 2015 the Department of Health issued risk and safeguarding guidance on FGM which sets out some of the issues, existing guidance and the legislative framework around FGM in England and Wales. The document provides a framework for organisations to adopt to support professionals in considering the risks pertaining to FGM [5].

The Coalition Government committed to end FGM in a generation at the Prime Minister's Girl Summit in 2014, providing £3 million for a national FGM Prevention Programme between 2014 and 2016. The Conservative Government also made a commitment in its 2015 election manifesto "to work with local authorities, the NHS and Police and Crime Commissioners to ensure a secure future for specialist FGM and forced marriage units, refuges and rape crisis centres". There have been a number of important developments and events in relation to FGM over recent years:

- Since April 2015 the Health and Social Care Information Centre (HSCIC, now NHS Digital) has been collecting an FGM enhanced data set, building on prevalence data collected prior to that date. The enhanced data set includes additional fields and is extended to include mental health trusts and GP practices;
- From 31 October 2015, regulated health and social care professionals and teachers in England and Wales are required to report 'known' (visually identified or verbally disclosed) cases of FGM in under-18s to the police;
- A number of events were held on 6 February 2016 to mark the International Day of Zero Tolerance to FGM.

There is a set of guidelines in place for the management of FGM, produced by the Royal College of Obstetricians and Gynaecologists and updated in 2015 [6]. The guidelines provide:

- An understanding of the short and long-term complications of FGM;
- The legal and regulatory responsibilities of health professionals;
- The principles of FGM management in obstetric and gynaecological practice.

1.2. Project objectives

The Department of Health (DH) believes that the majority of services for the FGM survivor population are either provided on a non-commissioned basis, or state that they receive significantly less funding than they believe the service actually costs to run. The DH also understands that services are finding it difficult to meet the demand and are unable to provide the range of support services they believe the patients need, in particular in relation to psychological needs.

The DH's aim for this costing work, allied with the other elements of the FGM Prevention Programme, was to provide the first real picture of, specifically, the 'cost' of FGM to the NHS. This could provide additional impetus within and outside the NHS to take the extra steps needed to act to safeguard girls and protect future generations of women from FGM.

This project was commissioned by the Department of Health in December 2015 under the PREPAREE programme (a call-off facility arrangement for fast response analysis between the Department and the University of York). The project aims to provide cost estimates for the treatment of FGM and to consider the tariff implications for the English Payment by Results mechanism. The project was

undertaken by York Health Economics Consortium (YHEC, University of York) and the Department of Health Sciences (DHS, University of York). The key stakeholders for the project are the Department of Health, the Health and Social Care Information Centre (now NHS Digital) and NHS England.

The objectives of the work are:

- To estimate the costs of procedures related to FGM within FGM NHS specialist clinics;
- To estimate the costs of procedures related to FGM across other non-specialist parts of the NHS;
- To work with NHS and ICD coding for treatments of FGM-related procedures;
- To 'spotlight' regional work in areas of high prevalence as indicated in the HSCIC published FGM NHS data official statistics;
- To inform tariff changes (if appropriate) to take forward to change the payment structures.

2. Methodology

2.1. FGM data

There are a number of dedicated health services for women with FGM in England but a lack of easily accessible data on the use of those services makes costing FGM services difficult. There is a lack of accurate and useable data in relation to treatment activity and costs for FGM in England. The health consequences of FGM are recorded as activity in relation to different hospital specialties such as gynaecology, obstetrics and urology and it is only recently that coding mechanisms have been introduced into primary and secondary care settings.

Except for the process of de-infibulation, there are no specific OPCS procedure codes that can be used to record hospital procedures related to FGM and there are limitations around ICD10 diagnosis coding for FGM. Since April 2014, clinical staff in primary care have been required to record in patient records when it is identified that a patient has had FGM. There are a number of Read and Snomed codes that record FGM history, status and de-infibulation procedures.

NHS Digital publishes an enhanced data set every three months but this has only been published since April 2015 [7]. It records contacts made by health and social care professionals with women with FGM and has some useful contextual data but some important items of data are missing, such as the type of treatment a patient has received. It is also likely that FGM incidence is understated because health and social care professionals may not complete the data set every time they see a patient with FGM, or they may be unaware of FGM issues.

Nevertheless the enhanced data set is a valuable resource in understanding the incidence of FGM. Until April 2015 prevalence data were collected in a limited form. Data are now also gathered from mental health trusts and GP practices as well as NHS acute trusts. In their aggregated form the data include:

- Total attendances;
- FGM type;
- Age at attendance;
- FGM identification method;
- Country of birth;
- Treatment function;
- Pregnancy status;
- Daughters born at attendance;
- De-infibulation.

Tables 2.1, 2.2 and 2.3 show summarised data for the first three quarters of 2015/16 (April to December 2015). This includes total numbers of new attendances, treatment function area and some data on whether a de-infibulation procedure took place, pregnancy status and whether a daughter was born on attendance.

Table 2.1: HSCIC FGM data on new attendances in England for April to December 2015

	Unknown	T1	T2	T3	T4	**T3 history	***T3 reinfibulation	Total
Q1	680	113	134	78	26	4	1	1,036
Q2	785	199	194	156	36	*	*	1,385
Q3	732	219	181	132	21	13	18	1,316
Total	2,197	531	509	366	83	*	*	3,737

* Suppressed due to small numbers.

** Current state where a woman or girl had FGM Type 3, but has since been de-infibulated.

*** Current state where a woman or girl has been closed previously, opened and is currently closed again.

Table 2.2: HSCIC FGM data split by FGM treatment function area for all attendances (England: July to December 2015)

Treatment function area	Number
Midwifery	1,221
Obstetrics	617
Gynaecology	159
Other	131
Not reported	1,751
Total	3,879

Table 2.3: HSCIC FGM data split by de-infibulation procedure, pregnancy status, and whether a daughter was born for all attendances (England: July to December 2015)

	De-infibulation undertaken	Pregnant at attendance	Daughter(s) born at attendance
Yes	62	1,587	136
No	1,431	245	1,007
Not reported	2,386	2,047	2,736
Total	3,879	3,879	3,879

What is apparent from these data is that there is a significant amount of unknown information. There is also no information on the treatment that was received by each patient and no cross-tabulation to the Type of FGM. This means that for the purpose of this costing analysis, we were unable to use the data to directly cost the services used by women with FGM.

In order to develop the costing analysis a mixed methods approach was, therefore, adopted. The first step was to carry out interviews with service providers and commissioners to understand the care pathways for the treatment of FGM. This was followed up with the use of estimates of prevalence and literature to make estimates of service costs.

2.2. Qualitative interviews

In order to gain information on the services available and the types of treatment that are provided for different types of FGM, a series of stakeholder interviews was carried out, supplemented with evidence from literature. A total of ten interviews were held with a range of individuals from specialist services and from clinicians and commissioners in local areas, to gain expert opinion and an understanding of current care pathways.

Interviews were held with providers of specialist FGM services in London and other parts of the country. Respondents included specialist midwives, a consultant paediatrician, a consultant gynaecologist and a clinical psychologist. The interviewees provided information on:

- The types of FGM seen and presenting symptoms;
- Treatments and procedures undertaken, including de-infibulation services for pregnant and non-pregnant women;
- Referral routes into the services, pathways of care and other services to which patients are referred;
- How services are commissioned and paid for;
- Access to psychological therapy services;
- Views on trends in demand, unmet need and barriers to accessing services.

In order to understand how women with FGM present to non-specialist services, interviews were held with local health economy areas with high prevalence of FGM. Bristol, Birmingham and North East London (Newham and Enfield) were selected, based on prevalence statistics. The HSCIC enhanced FGM data provide useful information on the CCG areas with highest prevalence, which informed the selection of areas in which to carry out interviews.

Respondents to local area interviews included local GPs, practice managers and a local commissioner. The interviews explored the following areas:

- How women present to services and the types of FGM they have;
- The types of interventions required, both physical and psychological;
- The care pathways for different types of patients, for initial presentation and follow-up;
- The local services available, including de-infibulation and how these are accessed by referrers;
- Views on trends in demand, unmet need and barriers to accessing services.

Semi-structured interview schedules were used, containing questions agreed with the Department of Health and other stakeholders and a summary of the discussion was sent to interviewees for comment. Thematic analysis of the interview responses was undertaken to draw out key issues.

2.3. Costing approach

The approach to costing was developed based on findings from the interviews, which provided an understanding of patient pathways. Estimates of the incidence and prevalence of FGM were used along with unit costs from publicly available national sources, to build an estimate of the costs for the treatment of FGM in England. Information from the interviews indicated four main components of care for FGM:

- **Initial treatment of FGM:** Where FGM has been performed recently there is a chance that short-term complications such as haemorrhage or infection occur. In practice, given that the vast majority of FGM procedures take place outside the UK, it is rare for NHS providers to encounter these short-term complications;
- **De-infibulation:** This treatment is mainly for women with Type 3 FGM (although some with Type 2 FGM also require de-infibulation) and is particularly important when women are pregnant. The de-infibulation procedure is relatively simple and can be carried out in a community setting or hospital, but can be more complex particularly later in pregnancy;
- **Longer-term complications:** Physical complications can include obstetric complications, gynaecological problems (e.g. cysts), urological problems (e.g. urinary tract infections) and infertility. The difficulty in estimating the complication costs is that they can occur at irregular points in time or may not occur at all;
- **Psychological care:** Psychological sequelae may occur in all types of FGM. There is a potential need for psychological support for all cases of FGM, however recent or distant the procedure.

The qualitative interviews showed that the costs of treatment of FGM to the NHS are mainly associated with treatment of the consequences or complications of FGM, rather than treatment for FGM itself. Cosmetic surgery for FGM repair is not funded by the NHS and would usually be undertaken privately. De-infibulation procedures are relatively simple and do not incur a high cost. There is potentially a need for psychological treatment for all women with FGM. The focus of the costing work has, therefore, been on the costs of treatment of short and long-term complications and psychological care provision.

The Royal College of Obstetricians and Gynaecologists' guideline on FGM and its management provides evidence on the prevalence and epidemiology of short and long-term complications [6]. This provides data to enable calculation of estimates of incidence in any given year and thus to calculate the excess number of particular diagnoses in the population with FGM compared with those without FGM. The report states that the data sources are not always of the highest quality so the estimates are caveated but they do provide a starting point for the estimation of the costs of FGM.

3. Findings: cost estimates

The RCOG guidelines identify short-term and long-term complications relating to FGM [6]. In addition to the costs of those complications, estimates have been made of the costs of de-infibulation and of the potential cost burden relating to the need for psychological treatment for women with FGM.

3.1. Findings from interviews

3.1.1. Short-term Complications

The short-term complications of FGM are considered to be those that are an immediate and direct consequence of the FGM procedure. They include infection, haemorrhage/anaemia, urinary retention and genital swelling. Presenting symptoms may include pain, bleeding, tenderness, dysuria and slow urinary stream, nocturnal enuresis, adhesions, PTSD and urinary tract infection.

Establishing the incidence of FGM and the incidence of short-term complications is challenging. The reported statistics measure the prevalence of FGM and do not detect incident cases. Furthermore, FGM in children can be very difficult to detect, even for a specialist paediatrician. The evidence suggests that services are not seeing these symptoms and complications, or if they are, they are not being linked to FGM. This may be explained in the following ways:

- Children may have FGM abroad and only return when well;
- There may be a trend towards FGM Type 4, which is more difficult to detect;
- There is a real reduction in the number of FGM procedures.

A case file analysis study of FGM in children by Hodes *et al.* found no Type 3 FGM, some Type 2b, with Type 4 being most common (piercing/pricking) [8]. The specialist paediatric service reported seeing an increase in the number of referrals in 2013 and 2014 compared to previously, approximately 50% of which were false positives. Very few showed symptoms, such as taking a long time to pass urine.

3.1.2. De-Infibulation

All women with Type 3 FGM will benefit from de-infibulation (surgery to open a closed vagina), whether or not they are pregnant. Depending on the extent of closure, a portion of those with Type 2 can also benefit, suggested by one respondent to be approximately 30%. The experience of respondents shows that many women do not know which type of FGM they have until they undergo

an assessment by a healthcare professional, so services invariably see more women than will actually need the de-infibulation procedure.

Women who are not pregnant can benefit from de-infibulation at any time. Pregnant women need de-infibulation before a vaginal delivery is possible. This may be done up to 30 weeks into pregnancy, to allow sufficient time to heal before delivery. If pregnancy is more advanced than this, the midwife will make a care plan for the labour ward to undertake de-infibulation during labour to avoid complications or a Caesarean-section being necessary.

Services are usually provided by hospital obstetrics and gynaecology departments and the de-infibulation procedure can be performed as a day case, under a local anaesthetic. In a minority of cases, if there are complications such as scarring or psychological trauma, a general anaesthetic may be needed. De-infibulation can also be performed in a primary or community setting. There are a small number of such services with indications that more may be developed over time in areas where FGM is most prevalent. All of the service providers interviewed reported the need to provide a holistic service and not just the de-infibulation procedure, recognising the potential psychological impact that infibulation can cause. The provision of and access to psychological support was, however, described as variable.

3.1.3. Psychological Sequelae

There was a consensus from respondents that, for women who have never had the chance to speak about their FGM, all can benefit from talking through their experience with a health professional. Respondents reported that some women appear happy to talk opportunistically while in contact with services for the purposes of dealing with the physical consequences of FGM but that they are less likely to attend a mental health service. It was felt that this was partly due to cultural reasons as opposed to a lack of need. Some women are accepting of their FGM and may feel they have no need for psychological support.

Respondents reported that anxiety is common following FGM and some women have trauma memory of when the FGM was performed. Some have ongoing consequences such as family discord and longer term repercussions such as problems with self-image, self-esteem, relationships and sexual difficulties. Relatively few have a severe problem. Some features of PTSD were reported but the full disorder has a specific diagnosis and has not been diagnosed in patients accessing services from the respondents interviewed. It was reported that approximately 1 in 10 women with FGM have potential to benefit from further support for more specific problems, such as cognitive therapy for specific symptoms, psychosexual counselling and/or prescription for medication.

There appears to be a varied landscape of FGM psychological provision which includes one-to-one therapy, counselling and patient support groups, but there is a lack of consistency in specific provision for FGM across England. Services may be provided by local mental health services, not all of whom have FGM training, or there may be access to specialist psychosexual counselling with FGM expertise. The need of some women can be accommodated by local IAPT (Improving Access to Psychological Therapies) services, depending on the level of local expertise.

3.1.4. Long-Term Physical Complications

Respondents reported that most physical longer term complications are found in Type 3 and some Type 2 FGM, depending on the degree of closure. The complications mentioned most often by respondents were:

- Obstetric complications;
- Cysts – inclusion and dermoid;
- Urinary tract infections (more commonly lower);
- Infertility;
- Impaired sexual function;
- Psychological sequelae: e.g. flashbacks, PTSD.

Some of these symptoms (e.g. pelvic pain and urinary tract infections) can be common and due to other causes, such as multiple pregnancies. FGM was reported to often be an incidental finding when undertaking a vaginal examination for another reason. Indeed, FGM as the cause of longer term complications may never be picked up by clinicians if a woman does not request de-infibulation and is not pregnant.

3.1.5. Demand and Unmet Need

The pattern of demand for health services related to FGM was described by respondents as variable. Some services reported an increase in demand in the previous two years, possibly due to increased immigration and increased awareness of services, while other services reported a decrease in demand. This may be because of reduced incidence or because of the availability of specialist services in other parts of the country.

Most respondents were of the view that there is considerable unmet need and that language and cultural barriers were responsible for women not accessing services.

A more detailed framework of findings from the interviews carried out is provided at Appendix A.

3.2. Costs of short-term complications

THE RCOG guidelines refer to immediate complications associated with FGM cutting, the most common being haemorrhage, urinary retention and genital tissue swelling [6]. Other potential concerns are problems with wound healing and pain. A study by Berg *et al.* provides a range of incidence of short-term complications, from which median values have been derived [9]. Table 3.1 provides details of incidence of these complications.

Table 3.1: Incidence of short-term complications in women with FGM

Complication/symptoms	Incidence	
	Range	Median
Excessive bleeding	5-62%	32%
Problems with urination/ urine retention	8-53%	31%
Genital tissue swelling	2-27%	15%
Problems with wound healing	-	13%
Pain	-	11%

Data on the incidence of FGM cutting that occurs in the UK are sparse and it is likely that these cases are under-reported due to the criminal nature of the procedure. The HSCIC enhanced data set reported four incidences of newly-recorded FGM cases in England in October to December 2015. If that is extrapolated for a full year, 16 cases of FGM in England can be assumed, the potential for under-reporting notwithstanding.

Applying the median reported incidence values, the estimated annual costs of short-term complications for FGM are provided in Table 3.2.

Table 3.2: Estimation of costs of cases of FGM-related short-term complications

Complication	Incidence	Unit cost	NHS cost
Excessive bleeding	5	£2,938	£14,690
Problems with urination/ urine retention	5	£2,473	£12,365
Genital tissue swelling	2	£263	£526
Problems with wound healing	2	£263	£526
Pain	2	£6.73	£13
Total			£28,120

Details of assumptions made for unit costs are provided at Appendix B.

This is likely to be a very conservative estimate of the cost based on reported incidence of FGM cutting taking place in the UK. Creighton and Hodes report that there may be up to 70,000 girls under the age of 15 years who have had or are at risk of FGM in the UK [10]. If it is assumed, conservatively, that half of the girls at risk have FGM at some stage in their childhood then an annual incidence rate could be calculated as $(70,000 / 2) / 15 = 2,333$. If 10% of those girls are cut in the UK, then the numbers of girls being cut in the UK would be 233 annually. Using that value instead of 16 cases would produce an annual cost estimate of £409,498. This is a considerably higher cost than our estimate based on reported incidence of FGM in the UK and demonstrates the sensitivity of the estimate.

3.3. De-infibulation costs

De-infibulation can be provided in a primary or community setting under a local anaesthetic in some circumstances. It is provided in secondary care under general anaesthetic if the procedure is likely to be more complicated, for example if there is scarring from multiple FGM. It is applicable for the following types of FGM:

- Type 1: Not required;
- Type 2: Required in some cases (estimate from one clinic is 30% of cases);
- Type 3: All will benefit from de-infibulation. It is necessary for vaginal delivery in pregnancy;
- Type 4: Not required.

For secondary care procedures, Hospital Episode Statistics (HES) provides details of the numbers of de-infibulation procedures carried out in 2014/15, using two OPCS codes:

- P07.2: De-infibulation of vulva: all procedures – 95;
- P27.2: De-infibulation of vulva to facilitate delivery: all procedures – 81.

It is not possible to separately identify the cost of de-infibulation from a delivery cost so it has been assumed that the same costs will be used for both OPCS codes.

The PbR has tariffs for combined elective and day case procedures and also non-elective procedures. The non-elective tariff for lower genital tract minor procedures (MA22Z) is £996. Applying this tariff to the hospital activity gives a total cost of £175,296, if it is assumed that elective procedures are paid using a similar tariff value. Additional to this, it has been assumed that there will be one GP visit as a follow up. The costs of this non-hospital follow-up care are estimated as: 176 x £65 (GP patient contact lasting 17.2 minutes – PSSRU Unit costs of health and social care 2015 p177) = £11,440.

From interview responses, it is known that de-infibulation procedures are also carried out in community settings. In order to estimate the numbers of de-infibulation procedures carried out annually, the HSCIC enhanced data set was reviewed. This provides the reported number of de-infibulation procedures carried out each quarter but there are a significant amount of patient contacts where there is no record of whether or not de-infibulation took place. In the third quarter (2015/16) report, 33 attendances were reported as including de-infibulation with 802 recorded as de-infibulation not having taken place, indicating that de-infibulation occurs in around 4% of attendances. If that rate is applied to the attendances where this was unreported (1,403) there would be an additional 58 de-infibulation procedures recorded, giving a total of 91. The same estimate was made based on data for the other two quarters and a total for the year was extrapolated (323).

If the hospital procedures (176) are subtracted then that allows an estimate of a further 147 de-infibulation procedures, which took place outside hospital. Community de-infibulation service models are variable and it is therefore challenging to derive a cost per de-infibulation procedure in a community setting. One community-based service has an approximate cost in the region of £1,000, based on the contract value and the estimated number of de-infibulations per year. If that value is applied to the activity, then a further community cost of £147,000 can be derived, along with additional GP follow-up costs of $147 \times £65 = £9,555$. Table 3.3 provides a summary of the cost estimates for de-infibulation.

Table 3.3: Estimation of annual costs of de-infibulation

Procedure	Incidence	Unit cost	NHS cost
Hospital de-infibulation	176	£996	£175,296
Related follow up care	176	£65	£11,440
Non-hospital de-infibulation	147	£1,000	£147,000
Related follow up care	147	£65	£9,555
Total			£343,291

3.4. Psychological care costs

Interview respondents indicated that all women suffering FGM potentially need psychological care. Not all women access care for a number of different reasons. Although some women do require psychological care as a result of FGM, it is difficult to estimate the number due to a lack of data.

An NSPCC report on estimating the costs of child sexual abuse in the UK has provided some unit costs and estimates of likely incidence of psychological problems but these are not specific to women with FGM [11]. Instead literature specific to FGM was searched for and estimates of incidence of psychological problems that relate to FGM were found. They mostly come from small pilot studies and have wide confidence intervals but are FGM specific. Data on prevalence of psychological conditions were obtained from a household survey of adult psychiatric morbidity in England [12] and data on the impact of depression, anxiety and post-traumatic stress disorder (PTSD) were obtained from case study reports [13, 14]. Estimates of excess numbers of women with FGM suffering from psychological and mental health problems were calculated by applying the prevalence for the whole population and for the population with FGM and then computing the difference (Table B2 – Appendix B).

The costs of psychological complications were derived from National Institute of Health and Care Excellence (NICE) guidelines. The NICE guideline on depression suggests an average cost of antidepressant treatment of £435 [15]. It has been assumed this form of treatment would be used for mild to moderate depression with more intensive psychological therapy treatment used for women suffering from more serious psychological problems such as PTSD. The NICE guideline on social anxiety disorder reports an annual cost per patient of £609 [16]. There is very little evidence on the costs of PTSD but NICE guideline CG26 provides an estimate of £825 for ten treatment sessions [17].

The estimated additional incidence of psychological and mental health problems among women with FGM was used with the estimated unit costs to provide an overall estimate of the costs of treating these problems to the NHS. Table 3.4 provides details.

Table 3.4: Estimate of costs of excess cases of FGM-related psychological problems

Complication	Excess cases	Unit cost	NHS cost
Depression	42,470	£435	£18,474,450
Anxiety	28,359	£609	£17,270,631
PTSD	36,579	£825	£30,177,675
Total			£65,922,756

There is wide variation in confidence intervals relating to the reported incidence of some problems. To provide a form of sensitivity analysis, the upper and lower confidence interval values were used to estimate the costs of high and low incidence. The parameters are provided in table B2 in Appendix B. Table 3.5 shows the impact of applying different values to the costs of psychological problems associated with FGM.

Table 3.5: Upper and lower estimates of the costs of psychological problems associated with FGM in England and Wales

Complication	Upper cost estimate	Lower cost estimate
Depression	£24,672,330	£12,157,380
Anxiety	£32,288,571	£2,252,691
PTSD	£51,652,425	£8,702,925
Total	£108,613,326	£23,112,996

It should be stressed that these costs may not represent all of the mental health and psychological costs related to FGM. For example, there may be excess costs associated with alcohol and substance misuse that we have been unable to quantify. It is also recognised that this estimate may overstate the actual cost to the NHS as many women may not seek treatment for their problems and it is understood, through interviews, that there are significant levels of unmet need. The estimated cost of psychological problems (£66 million) assumes that there is no unmet need and the actual costs may well be toward the lower end of the costs in Table 3.5. Nevertheless, it is important that the full potential costs of psychological care are included in the overall estimate of the costs of FGM care. If Government efforts to raise awareness of FGM are successful, the need for additional psychological care services may be acknowledged and addressed.

3.5. Long-term complication costs

A rapid evidence assessment, based on the long-term complications identified in the RCOG guidelines identified three main groups of complications in relation to the gynaecological, obstetric and psychological effects of FGM. Table 3.6 gives details of the type of complications identified.

Table 3.6: Long-term complications of FGM

Complication area	Description	Detail
Gynaecological	Genital scarring	Keloids
		Cysts
	Urinary symptoms	Infection
		Kidney impairment and possible kidney failure
		Fistula and urethral strictures
	Menstrual difficulties	Painful and prolonged periods
	Genital infection	Bacterial vaginosis
		Herpes simplex type 2
	Infertility	Infertility
	Infection	HIV
Hepatitis B		
Hepatitis C		
Pain	Pain	
Obstetrics	Obstetric complications	Prolonged labour
		Obstetric tears
		Caesarean Section
		Instrumental delivery primi
		Instrumental delivery multi
		Obstetric or post-partum haemorrhage
		Difficult delivery
		Episiotomy
		Obstetric fistula
		Perinatal death
		Extended maternal hospital stay
		Low birth weight (<2,500g)
		Stillbirth or early neonatal death
Infant resuscitation		
Psychological effects	Psychological complications	Anxiety and depression
		Dyspareunia, apareunia & impaired sexual function
		Post-traumatic stress disorder

The papers were found through a targeted literature search and are detailed in the following sections for each individual complication. They provide some estimates of the increased risk of these complications in the population of women with FGM. In England and Wales there are estimated to be 136,858 women born in countries where FGM is practised who have had FGM [2]. Estimates of the excess numbers of women with FGM suffering complications were calculated by applying prevalence for the whole population and for the population with FGM and then computing the difference (Table B3 – Appendix B).

In calculating the proportion of non-FGM women suffering a particular complication in any given year, whole population statistics were used. These will include women with FGM, but the assumption was made that women with FGM account for only a small proportion and will have negligible effect on the estimate.

Reliable estimates of the additional incidence of FGM related cases are not available for all complication types. Some evidence was found for the following:

3.5.1. Urinary Tract Infection

Car estimated that urinary tract infections (UTI) affect up to 15% of women a year [18]. Berg *et al.* estimated the risk ratio comparing FGM to non-FGM was 3.01 (1.42, 6.38) [9].

The majority of UTI cases can be treated through antibiotic treatment. It was assumed that a small proportion (10%) of cases would be treated in hospital. Table B4 in Appendix B provides details of the calculation of the costs of these two forms of treatment.

3.5.2. Dyspareunia

Osborn *et al.* estimated that the prevalence of dyspareunia among women aged 34-39 was 8% [19]. Berg *et al.* found the risk ratio for FGM/non FGM was 1.53 (1.20, 1.97) [9].

The causes of dyspareunia are varied and in the case of FGM-related dyspareunia may be a result of physical or psychological injury or both. There is, consequently, no standard treatment for FGM-related dyspareunia. It has been assumed that some form of anxiety treatment could potentially be applicable for cases of dyspareunia and that half the cases could be treated pharmacologically with the rest receiving a form of cognitive behavioural therapy (CBT). It was assumed that a course of citalopram would be prescribed for four months with two GP visits and for CBT, 12 sessions would be required costing £70 (based on median values provided in NHS Choices website). Table B4 in Appendix B provides details of the calculation of the costs of these two forms of treatment.

3.5.3. Bacterial Vaginosis

Berg *et al.* estimated that the odds ratio for bacterial vaginosis between women with and without FGM was 1.68 (1.28, 2.22) [9]. Bradshaw *et al.* found that in a cohort of Australian women 11.8% had bacterial vaginosis [20].

Clinical guidelines indicate that bacterial vaginosis is treated appropriately with antibiotics. A single visit to a GP was also assumed. Table B4 in Appendix B provides details of the calculation of the costs.

3.5.4. Obstetric Complications

In 2013 there were estimated to be 10,355 maternities to women with FGM which accounted for approximately 1.5% of all maternities (England and Wales) [21].

Caesarean section

HSCIC figures show that 25% of deliveries were by caesarean section [21]. Berg *et al.* reported that the odds ratio comparing FGM to non FGM was 1.6 (1.33, 1.91) [9]. The costs of Caesarean section were derived as a weighted average from NHS Reference Costs (Table B4, Appendix B).

Instrumental deliveries

Berg *et al.* found no significant difference between multiparous FGM women and multiparous FGM in the odds of having an instrumental delivery [9]. However there was a significant rate for first time mothers. The proportion of instrumental deliveries (primi) is 58.8% (HSCIC, 2014-15 maternity statistics). Berg estimated the odds for primi women (comparing FGM to non FGM) to be 1.56 (1.32, 1.86) [9]. The costs of instrumental deliveries were derived as a weighted average from NHS Reference Costs (Table B4, Appendix B).

Long labour

Berg *et al.* found the odds of prolonged labour comparing FGM to non FGM women was 1.49 (1.01, 2.19) [9]. HSCIC report that 10.19% of deliveries involved a prolonged labour [21]. The costs of long labour, obstetric haemorrhage, obstetric tear and episiotomy were all assumed to relate to a form of assisted delivery with some form of post-partum intervention. The costs of these complications were derived as a weighted average from NHS Reference Costs (Table B4, Appendix B).

Obstetric haemorrhage

Berg *et al.* found the odds of obstetric haemorrhage comparing women with FGM to those without were 1.91 (1.012, 2.19) [9]. Post-partum blood loss was defined as ≥ 500 ml. In Europe the proportion of women experiencing this amount of blood loss was 13.5% (Calvert *et al.*) [22].

Obstetric tear

Berg *et al.* found the odds of experiencing an obstetric tear comparing FGM to non FGM women was 1.39 (0.99, 1.95) [9]. HSCIC 2014/15 maternity statistics reported perineal laceration in 41.18% of all maternities [21].

Episiotomy

Berg *et al.* estimated that the risk ratio for episiotomy was 1.38 (1.14, 1.67) [9]. NHS maternity statistics for 2010-11 published by HSCIC found that 15% of women had an episiotomy [23].

Table 3.7 summarises the costs of excess cases of FGM related long-term complications for those complications where there was available evidence. There was no useful evidence in relation to a number of important long-term complications so it was not possible to estimate costs for excess cases of:

- Cysts;
- Kidney impairment and possible kidney failure;
- Infertility;
- HIV;
- Hepatitis B;
- Hepatitis C;
- Perinatal death;
- Stillbirth;
- Infant resuscitation.

It is likely, therefore, that the costs of long-term complications associated with FGM are understated.

Table 3.7: Estimate of costs of excess cases of FGM-related long-term complications

Complication	Excess cases	Unit cost	NHS cost
UTI (antibiotic)	37,237	£66.5	£2,476,261
UTI (hospital)	4,137	£2,473	£10,230,801
Bacterial vaginosis	8,494	£94	£798,436
Dyspareunia (pharmacological)	2,877	£134	£385,518
Dyspareunia (CBT)	2,877	£970	£2,790,690
Caesarean Section	1,036	£3,941	£4,082,876
Instrumental delivery (primi)	1,056	£2,913	£3,076,128
Long labour	395	£3,457	£1,365,515
Obstetric haemorrhage	984	£3,457	£3,401,688
Obstetric tear	810	£3,457	£2,800,170
Episiotomy	590	£3,457	£2,039,630
Total			£33,447,713

There is wide variation in the reported incidence of some complications, depending on which study is being used. To provide a form of sensitivity analysis, the upper and lower confidence interval values were used to estimate the costs of high and low incidence. The parameters are provided in Table B3 in Appendix B. Table 3.8 shows the impact of applying different values to the costs of long-term complications associated with FGM.

Table 3.8: Upper and lower estimates of the costs of long-term complications associated with FGM in England and Wales

Complication	Upper cost estimate	Lower cost estimate
UTI (antibiotic)	£6,641,555	£491,967
UTI (hospital)	£27,442,881	£2,032,806
Bacterial vaginosis	£1,442,336	£412,096
Dyspareunia (pharmacological)	£734,320	£183,580
Dyspareunia (CBT)	£5,315,600	£1,328,900
Caesarean Section	£5,714,450	£2,447,361
Instrumental delivery (primi)	£4,888,014	£1,870,146
Long labour	£3,512,312	£0
Obstetric haemorrhage	£9,129,937	£0
Obstetric tear	£6,022,094	£0
Episiotomy	£3,581,452	£715,599
Total	£74,424,951	£9,482,455

4. Conclusions

4.1. Levels of incidence and prevalence

Data on incidence and prevalence of FGM are sparse and the quality of the data may be patchy. This may be for a variety of reasons including lack of awareness of FGM among clinicians, or patients not presenting specifically with FGM.

It is particularly difficult to understand the rates of FGM happening in England and the UK. It is estimated that 50% of FGM is performed between the age of 0 years and 5 years with the remainder occurring between 5 years and 15 years of age [24]. The City University paper of 2015 reported that in 2011 in the UK, 10,000 girls under 15 years had undergone FGM and came from FGM practising communities [2]. Creighton and Hodes reported that a further 60,000 girls were born that year to mothers from FGM practising communities, meaning there are a possible 70,000 girls under age 15 years who have had or are at risk of FGM in the UK [10].

This would appear to indicate a rising population of girls at risk of FGM in the UK but this is uncertain. The difficulty in trying to quantify the cost of FGM to the NHS is that many of the costs are hidden due to a lack of reporting. The majority of paediatricians are unlikely to see children who are acutely unwell due to FGM. Haemorrhage, infection and sepsis are common acute complications attributable to FGM and can be life-threatening but there are no reports of such acute presentations in the UK. The reasons for this may include:

- A reduction in incidence;
- Children being sent back to their countries of origin for FGM and only returning if well;
- Access to medical treatment for complications within practising communities;
- A trend towards less invasive types of FGM with less tissue damage and lower acute risk to the child (Type 4).

These were cited as possible reasons for a huge disparity between estimates of prevalence of paediatric FGM cases and the number of cases coming to the attention of statutory health services, identified by Hodes in 2016 [8]. The study also found a significant number of children (15%) had undergone FGM when under 1 year of age which concurs with the global trend of FGM occurring at an increasingly younger age. This reduces the chance of the child remembering or being aware that the practice has taken place and adds to the difficulty of reporting prevalence and being prepared for longer-term complications.

This complicates the task of trying to provide an accurate estimate of the cost burden of FGM to the NHS.

4.2. Cost estimates

The lack of accurate data on the incidence of FGM means that significant caveats must be placed on the cost estimates in this report. Many assumptions have been used and there is potential that costs could be overstated or understated. For example, it was not possible to quantify the costs of all potential long-term complications and there may well be a shortfall in the number of reported cases of short-term complications related to FGM. There is also considerable variation in the reported incidence of some complications and there is reported unmet need for psychological care.

The cost data show that the bulk of the health care costs associated with FGM related to psychological and long-term complications. Table 4.1 provides a summary of the costs estimated in this study.

Table 4.1: Estimated annual costs of FGM in England and Wales

Complication category	Complication type	Estimated cost
Short-term complications	Excessive bleeding	£14,690
	Urination/ urine retention	£12,365
	Genital tissue swelling	£526
	Problems with wound healing	£526
	Pain	£13
Sub total		£28,120
De-infibulation	In hospital setting	£186,736
	In community setting	£156,555
Sub total		£343,291
Psychological problems	Depression	£18,474,450
	Anxiety	£17,270,631
	PTSD	£30,177,675
Sub total		£65,922,756
Long-term complications	UTI (antibiotic)	£2,476,261
	UTI (hospital)	£10,230,801
	Bacterial vaginosis	£798,436
	Dyspareunia (pharmacological)	£385,518
	Dyspareunia (CBT)	£2,790,690
	Caesarean Section	£4,082,876
	Instrumental delivery (primi)	£3,076,128
	Long labour	£1,365,515
	Obstetric haemorrhage	£3,401,688
	Obstetric tear	£2,800,170
	Episiotomy	£2,039,630
Sub total		£33,447,713
TOTAL		£99,741,880

The overall estimate of the cost burden of FGM to the NHS in England and Wales is £100 million per year. However, this could be as low as £33 million or as high as £184 million if sensitivity analysis is applied. The wide variation in potential costs is a result of the difficulty on accurately estimating the levels of incidence of complications associated with FGM. Table 4.2 provides details of the sensitivity analysis applied to the cost estimates.

Table 4.2: Sensitivity analysis of cost estimates

Complication	Upper cost estimate	Lower cost estimate
Short-term complications	£409,498	£28,120
De-infibulation	£343,291	£343,291
Psychological problems	£108,613,326	£23,112,996
Long-term complications	£74,424,951	£9,482,455
Total	£183,791,066	£32,966,862

4.3. Tariff considerations

The remit of the study asked for tariff changes to be considered, if appropriate, based on the findings of the study. Feedback received throughout the interview process for this study has indicated that the bulk of the health care costs associated with FGM are incurred in relation to long-term complications and psychological problems treated in both primary and secondary care. There are no specific payment tariffs in place for FGM, other than that for de-infibulation, but this does not appear to present a problem in ensuring that health care is provided for FGM in relation to physical health complications. Most long-term complications are paid for using tariffs relating to gynaecology, obstetric and urology specialties in hospital. In primary care, patients are treated routinely and there is no need for a specific tariff.

There is potentially an argument for a specific tariff for treatment of psychological and mental health problems related to FGM. Our estimates indicate that the potential cost burden of treatment for these problems is high largely due to high levels of incidence among women with FGM. The interviews carried out indicate that there is potentially a high level of unmet need among women with FGM, some of which may be cultural and some because of a lack of recognition of the need among health care professionals. The establishment of a form of tariff for psychological treatment of the effects of FGM could raise awareness of these problems and help to address unmet need but alternatives also need to be considered.

There is also a question of whether there is any value in establishing some form of PbR tariff for other FGM complications, other than the existing tariff for de-infibulation. There are some immediate problems with this, specifically; the nature of the treatment and therapy received by women with FGM is so variable that it would be difficult to come up with a single tariff. It could be possible to establish a number of tariffs based on the groupings of conditions and treatments described in section 3 of this paper. For example, a tariff could be established for *“haemorrhage following FGM”*, or *“urinary tract infection associated with FGM”*.

The setting up of specific tariffs related to FGM could be helpful in providing more systematic data about health care activity in response to FGM. While this is potentially attractive, there could be some logistical problems in establishing new tariffs. While there are Read and Snomed codes set up for use in primary care, ICD10 codes for FGM could be more difficult to use. They are currently set up to operate on a 6 digit code basis and so coding systems would need to be able to accommodate that approach. One potential solution to this could be to add FGM as a secondary diagnosis code but this is limited by ICD being an international system.

The DH and HSCIC could consider setting up additional healthcare resource group (HRG) codes for FGM to reflect specific forms of treatment, such as *“treatment for UTI for women who have undergone FGM”*. This could form the building blocks for the development of alternative tariffs for the treatment of FGM. However, apart from improving the quality of data it is not clear that this would result in any improvements in health care for women with FGM, or that it would necessarily improve awareness among clinicians and other service providers.

The DH and HSCIC should consult on and explore further the potential for the establishment of more specific FGM tariffs, bearing in mind the logistical challenges involved, and they should also explore alternatives to raising awareness of FGM. For example, consideration needs to be given to whether the establishment of tariffs for psychological care for women with FGM would address unmet need or whether there are more effective ways of raising awareness among patients and clinicians about these problems and the services available. Given that providers have not reported that the tariff payment system is causing problems in ensuring that women with FGM can access health care, it may be that the creation of new tariffs is not the best option for raising awareness. In terms of improved data reporting on the use of resources for FGM-related health care, the DH and HSCIC should explore further development of the existing data capture methodology for the enhanced FGM data set reported quarterly by HSCIC.

It would also be worth considering carrying out a piece of work to establish the extent to which primary care FGM codes are being used. This could be done on a longitudinal basis using data from the THIN or CPRD databases and may provide an indication of the incidence of women with FGM accessing primary care. It is particularly difficult to understand the levels of psychological care need for women with mental health problems associated with FGM. Further research would be beneficial to map out levels of current demand and provision and, specifically, unmet need.

4.4. Overall conclusions

Our research has shown that there is a high cost burden associated with the health consequences of FGM for a relatively small population of women and girls. National health bodies such as the Department of Health, NHS England and the Health and Social Care Information Centre have done well to raise awareness of the issue of FGM and it is encouraging to see Government commitment to continue this agenda.

Treatment of health complications and problems associated with FGM occurs mainly within mainstream health settings, with some additional specialist provision. The tariff payment system appears to operate reasonably well in relation to most physical health complications with women

receiving treatment within existing specialties. There may be an argument for the development of more specific tariffs as a means of generating better data on the incidence of FGM but other options for raising awareness of FGM and the services available to women should also be explored.

There is a need for greater awareness and information on the psychological and mental health effects of FGM as this is the area of higher cost burden and is also the area of health care where there is likely to be the highest level of unmet need. As awareness of FGM increases among health professionals it is vital that all necessary services are made available to women who have suffered from FGM.

References

1. WHO. Eliminating female genital mutilation. An interagency statement – OHCHR, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCR, UNICEF, UNIFEM, WHO. 2008.
2. Macfarlane, A. J. & Dorkenoo, E. (2015). Prevalence of Female Genital Mutilation in England and Wales: National and local estimates. London: City University London in association with Equality Now.
3. Bishai D, Bonnenfant Y-T, Darwish M, Adam T, Bathija H, Johansen E, Huntington D. Estimating the obstetric costs of female genital mutilation in six African countries. *Bulletin of the World Health Organization* 2010;88:281-288.
4. HM Government. Multi-agency Practice Guidelines: FGM. 2014.
5. Department of Health. Female Genital Mutilation Risk and Safeguarding – Guidance for professionals. March 2015.
6. Royal College of Obstetricians and Gynaecologists. Female Genital Mutilation and its management. Green-top Guideline No. 53. July 2015.
7. Health and Social Care Information Centre. Female Genital Mutilation (FGM) - October 2015 to December 2015 Experimental Statistics. March 2016.
8. Hodes D, Armitage A, Robinson K, Creighton SM. Female genital mutilation in children presenting to a London safeguarding clinic: a case series. *Arch Dis Child* 2016;101:212–216.
9. 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.
10. Creighton SM, Hodes D. Female genital mutilation: what every paediatrician should know. *Arch Dis Child* 2016;101:267–271.
11. Saied-Tessier A. Estimating the costs of child sexual abuse in the UK. NSPCC 2014.
12. Adult psychiatric morbidity in England, 2007 Results of a household survey. HSCIC (statistics for women).
13. Kizilhan JI. Impact of psychological disorders after female genital mutilation among Kurdish girls in Northern Iraq. *Eur. J. Psychiat.* vol.25 no.2 Zaragoza abr.-jun. 2011
14. Behrendt A, Moritz S. Posttraumatic Stress Disorder and Memory Problems After Female Genital Mutilation *Am J Psychiatry* 2005; 162:1000–1002.
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.
16. National Collaborating Centre for Mental Health. Social anxiety disorder – recognition assessment and treatment. National Institute for Health and Care Excellence (NICE) Clinical Guideline 159. 2013.
17. National Collaborating Centre for Mental Health. The management of PTSD in adults and children in primary and secondary care. National Institute for Health and Care Excellence (NICE) Clinical Guideline 26. 2005.

18. Car J. Urinary tract infections in women: diagnosis and management in primary care. *BMJ*. 2006;14:332(7533):94-97.
19. Osborn M, Hawton K, Gath D. Sexual dysfunction among middle aged women in the community. *Br Med J (Clin Res Ed)*. 1988;2:296(6627):959-962.
20. Bradshaw CS, Walker J, Fairley CK, Chen MY, Tabrizi SN, Donovan B. Prevalent and incident bacterial vaginosis are associated with sexual and contraceptive behaviours in young Australian women. *PLoS ONE* 8(3):e57688.
21. HSCIC NHS Maternity Statistics – England. 2014/15.
22. Calvert C, Thomas SL, Ronsmans C, Wagner KS, Adler AJ, Filippi V. Identifying regional variation in the prevalence of postpartum haemorrhage: a systematic review and meta-analysis. *PLoS ONE* 7(7):e41114.
23. HSCIC NHS Maternity Statistics – England. 2010/11.
24. UNICEF. Female Genital Mutilation/Cutting: A statistical overview and exploration of the dynamics of change. July 2013.

Appendix A

Mapping and Understanding the Services Provided

	Type 1 FGM	Type 2 FGM	Type 3 FGM	Type 4 FGM
Description (WHO definition, 1995)	Clitoridectomy: partial or total removal of the clitoris Few symptoms? Difficult to identify	Excision: partial or total removal of the clitoris and labia minora, with or without removal of the labia majora	Infibulation: narrowing of vaginal opening by creating a seal from the labia minora and labia majora, with or without removal of the clitoris	Other: all other harmful procedures to genitals for non-medical reasons e.g. pricking, piercing, scraping, cauterising. Can be very hard to identify type 4.
Symptoms / complications: short-term (at the point of FGM been done)	<p>Short-term complications:</p> <ul style="list-style-type: none"> • Infection; • Haemorrhage/anaemia; • Urinary retention; • Genital swelling. <p>From evidence so far, services are not seeing these symptoms/complications. Adult services report seeing cases where FGM has been done in 'country of origin'. Children suspected of being taken out of the country and not returning until 'well'.</p>			
Symptoms / complications: longer term	<p>Most physical longer term complications are found in Type 3 and some Type 2 depending on degree of closure. Can be categorised as follows: obstetric; gynaecological; psychological.</p> <p>These may include (<i>italics indicate complications mentioned most often by services</i>):</p> <ul style="list-style-type: none"> • <i>Obstetric complications (may result in C-section if not picked up in time);</i> • <i>Cysts – inclusion and dermoid;</i> • <i>UT infections (more commonly lower UT);</i> • <i>Infertility;</i> • <i>Impaired sexual function;</i> • <i>Psychological sequelae: e.g. flashbacks, PTSD;</i> • Bladder and vulval calculi; • Menstrual difficulties; • Genital scarring; • Genital infections – pelvic inflammatory disease; • HIV and Hep B. <p>Presentation of complications:</p> <ul style="list-style-type: none"> • Pregnant women – usually identified antenatally by midwifery team when booking in for maternity services (via screening questions). If missed early on, may come to light further into pregnancy; • Non-pregnant women: EITHER self-refer requesting support/assessment and/or de-infibulation (if type 3). 			

	Type 1 FGM	Type 2 FGM	Type 3 FGM	Type 4 FGM
	<p>OR present with complications arising from FGM.</p> <p>Complications may never present or be picked up by clinicians – especially in older women.</p> <p>Somali women – pelvic pain and UTIs can be common but can be other causes e.g. multiple pregnancies.</p>			
Services required for FGM	<p>Initial assessment (women not always aware of which FGM type they have)</p> <p>Psychological *</p> <p>Nothing specific physically identified</p>	<p>Initial assessment (women not always aware of which FGM type they have)</p> <p>Psychological *</p> <p>Some can benefit from de-infibulation but depends on severity (approx. 30%)</p>	<p>Initial assessment (women not always aware of which FGM type they have)</p> <p>Psychological *</p> <p>All may benefit from de-infibulation.</p> <p>Pregnant women will need de-infibulation before vaginal delivery. May be done up to 30 weeks (ideally between 22 – 30 weeks, no later so time to heal). If later – make a care plan for the labour ward. May end up having C-section.</p> <p>Non-pregnant women – can benefit at any time from de-infibulation. Many request it just before marriage.</p> <p>De-infibulation can be provided in primary / community setting under a local anaesthetic.</p> <p>Need secondary care/GA if more complicated e.g. scarring from multiple FGM.</p>	<p>Initial assessment (women not always aware of which FGM type they have)</p> <p>Psychological *</p> <p>Nothing specific physically identified</p>

	Type 1 FGM	Type 2 FGM	Type 3 FGM	Type 4 FGM
Services required for physical complications / symptoms	Nothing identified	For other complications listed above: <ul style="list-style-type: none"> • Urology; • Gynaecology; • Fertility. E.g. excision of inclusion/dermoid cysts	For other complications listed above: <ul style="list-style-type: none"> • Urology; • Gynaecology; • Fertility. E.g. excision of inclusion/dermoid cysts	Nothing specific identified. Depends on what has been done – not often identified in clinic.
* Psychological services	<p>All can benefit from talking through with a health professional - some may do so opportunistically but attendance at a mental health service is less likely, partly due to cultural reasons not because there is no need. Some women are accepting of their FGM.</p> <p>Anxiety is common. Some have trauma memory of when FGM was performed. Some have on-going consequences e.g. family discord and longer term repercussions such as problems with self-image, self-esteem, relationships and sexual difficulties. Relatively few have a severe problem. See some features of PTSD but the full disorder has a specific diagnosis and has not been reported by respondents. Approximately 1 in 10 have potential to benefit from a further support for more specific problem e.g. cognitive work for specific symptoms.</p> <p>Varied picture of provision includes one-to-one therapy and/or counselling, patient support groups. Some provided by local mental health services, not all with FGM training, or may have access to specialist psychosexual counselling with FGM expertise. Some cases can be accommodated by IAPT services; some may need more specific services e.g. psychosexual counselling and/or prescription.</p>			
Children (under 18s)	<p>Can be very difficult to detect, even for specialist paediatrician!</p> <p>Children sometimes identified as part of safeguarding assessments, via identifying FGM in other female family members, concerns by the school, or worried GP.</p> <p>Specialist service is seeing an increase in numbers. Approximately 50% are false positives, with referrals to the clinic resulting from increased anxiety about FGM.</p> <p>Study (Hodes et al, 2015) found no type 3 but some type 2b. Type 4 is most common (piercing/pricking).</p> <p>Very few have had symptoms e.g. taking a long time to pass urine. A few have been abused. Presenting symptoms may include: pain, bleeding, tenderness, dysuria and slow urinary stream, nocturnal enuresis, adhesions, PTSD, recurrent UTI.</p> <p>Discussion points: move towards type 4 FGM with less tissue damage; FGM performed at very early age; medicalisation of FGM.</p>			

	Type 1 FGM	Type 2 FGM	Type 3 FGM	Type 4 FGM
How commissioned and remunerated	<p>Specialist services: range of commissioning models found so far:</p> <ol style="list-style-type: none"> 1. Clear service specification identifying components of service and prices – may include just the assessment and de-infibulation procedure (with referral required for psychological support). Some services also include integrated psychological support. One service describes a ‘episode of care’ as including - first appointment, de-infibulation if required, follow-up appointment and clinical psychology input; 2. Midwifery led service which is integrated into maternity services and not separately commissioned, (some will see out of area patients and re-charge home CCG); 3. Psychological services via local provision – not specifically commissioned for FGM. <p>‘FGM clinics’ tend to be accessed in a number of ways: self-referral, GP referral (direct) or to referral management service if this approach is used by local commissioners, GP referral to gynae OP and then onwards to the FGM clinic.</p> <p>Some specialist services will see patients from out of area and re-charge (although not always clear on how this happens and whether it is always done).</p> <p>Services for physical complications (FGM may not be detected as cause):</p> <ul style="list-style-type: none"> • Outpatient tariffs for relevant specialities – urology, gynaecology. <p>Procedure codes exist for:</p> <ul style="list-style-type: none"> • De-infibulation not in labour (P07.2); • De-infibulation in labour (R27.2). 			
Demand and unmet need	<p>Picture of demand is very variable:</p> <ul style="list-style-type: none"> • Some services seeing increase in demand, speculate that this is due to increased immigration and increased awareness of services; • Some seeing decrease in their service, speculated to be due to availability of other services in other parts of the country. <p>Experience shows that majority of Somali women have FGM, so prevalence in local community can be estimated but not all will need or seek services.</p> <p>Demand from women for psychological support is not high.</p> <p>The services are often asked to provide reports for immigration/criminal justice system on whether FGM is present and type of FGM.</p> <p>Some expect there is lots of unmet need, particularly in non-Somali communities e.g. Indonesia, India, Egypt.</p>			
Barriers	<p>Stigma – services require anonymity of location (e.g. in a hospital outpatient clinic or a GP practice/community clinic).</p> <p>Language/literacy.</p> <p>Lack of awareness – community and health/social care professionals.</p> <p>Stigma surrounding mental health needs (‘mad/crazy’).</p>			

Appendix B

Cost Estimate Calculations

Short-term complications

A number of assumptions were made about the unit costs of short-term complications.

It was assumed that excessive bleeding would require a hospital admission. As the type of admission or the severity of the presenting symptoms are uncertain, a weighted average cost was calculated based on the NHS Reference costs for 2014/15 for lower genital tract procedures. Table B1 below provides details of the calculation of the assumed weighted average cost for excessive bleeding.

Table B1: Weighted average cost for excessive bleeding

Complication	HRG code	Description	FCEs	Total cost (£)	Weighted average cost (£)
Lower genital tract procedures	MA01Z	Complex Open, Upper or Lower Genital Tract Procedures	267	£1,382,657	
	MA02A	Very Major Open, Upper or Lower Genital Tract Procedures, with CC Score 4+	694	£4,471,347	
	MA02B	Very Major Open, Upper or Lower Genital Tract Procedures, with CC Score 2-3	1,832	£8,632,552	
	MA02C	Very Major Open, Upper or Lower Genital Tract Procedures, with CC Score 0-1	4,089	£16,253,372	
	MA03C	Major Open Lower Genital Tract Procedures with CC Score 3+	802	£2,486,336	
	MA03D	Major Open Lower Genital Tract Procedures with CC Score 0-2	6,015	£15,468,832	
	MA04C	Intermediate Open Lower Genital Tract Procedures with CC Score 3+	875	£2,172,113	
	MA04D	Intermediate Open Lower Genital Tract Procedures with CC Score 0-2	8,633	£17,319,534	
Total			23,207	£68,186,743	£2,938

The costs of treatment for urine retention were also assumed to relate to a hospital admission and the same cost was applied as for UTI treatment for long-term complications (Table B4).

It was assumed that problems with genital tissue swelling and wound healing would be dealt with in an outpatient setting. The costs of treatment were, therefore, estimated as £133 for treatment in a gynaecology outpatient clinic (NHS Reference Costs, 2014/15) plus two GP visits at £65 per visit.

The costs of treatment for pain were assumed to relate to a prescription for co-codamol for mild to moderate pain. The BNF tariff for a course of co-codamol tablets is £6.73.

Psychological and mental health complications

Table B2: Calculation of excess cases of FGM-related psychological and mental health complications

Complication	% experiencing complication		FGM population size*	Number experiencing complication		Excess cases
	Non-FGM	FGM		If non-FGM rate	If FGM rate	
Depression	2.6	33.6 (23, 44)	137,000	3,562	46,032 (31,510, 60,280)	42,470 (27,948, 56,718)
Anxiety	5.3	26 (8, 44)	137,000	7,261	35,620 (10,960, 60,280)	28,359 (3,699, 53,019)
Post-traumatic stress disorder	3.3	30 (11, 49)	137,000	4,521	41,100 (15,070, 67,130)	36,579 (10,549, 62,609)

* England and Wales (95% Confidence interval).

Long-term complications

Table B3: Calculation of excess cases of FGM-related long-term complications

Complication	% experiencing complication		FGM population size*	Number experiencing complication		Excess cases**
	Non-FGM	FGM		If non-FGM rate	If FGM rate	
Urinary tract infection	15	45 (21, 96)	137,000	20,550	61,924 (28,770, 131,520)	41,374 (8,220, 110,970)
Dyspareunia	8	12 (10, 16)	137,000	10,960	16,714 (13,700, 21,920)	5,754 (2,740, 10,960)
Bacterial Vaginosis	12	18 (15,23)	137,000	16,166	24,660 (20,550, 31,510)	8,494 (4,384, 15,344)
Caesarean	25	35 (31,39)	10,355	2,589	3,624 (3,210, 4,038)	1,036 (621, 1,450)
Instrumental delivery (primi)	59	69 (65,75)	10,355	6,089	7,145 (6,731, 7,766)	1,056 (642, 1,678)
Long labour	10	14 (10,20)	10,355	1,055	1,450 (1,036, 2,071)	395 (-20, 1,016)
Obstetric haemorrhage	14	23 (12,39)	10,355	1,398	2,382 (1,243, 4,038)	984 (-155, 2,641)
Obstetric tear	41	49 (41, 58)	10,355	4,264	5,074 (4,246, 6,006)	810 (-19, 1,742)
Episiotomy	15	21 (17, 25)	10,355	1,553	2,143 (1,760, 2,589)	590 (207, 1,036)

* England and Wales (95% Confidence interval).

** Confidence intervals may not be symmetrical.

Table B4: Estimated costs of long-term complications

Complication	HRG 4 digit code	Description	FCEs	Total cost (£)	Weighted average cost (£)
Urinary tract infection (antibiotic treatment)	n/a	Antibiotic treatment with amoxicillin – £1.50 (average cost: BNF) Consultation with GP - £65 (17.2 minutes – PSSRU 2015)	n/a	n/a	66.50
Urinary tract infection (hospital treatment)	LA04	Kidney or urinary tract infection	160,748	412,676,560	
	LA09	General renal disorders	26,925	58,645,483	
	LB16	Urinary incontinence or other urinary problems	11,022	20,804,240	
	LB19	Ureteric or bladder disorders	1,896	4,626,225	
	LB37	Miscellaneous urinary tract findings	1,406	2,922,896	
	LB57	Urethral disorders	598	1,349,586	
Total			202,595	501,024,990	2,473
Dyspareunia (pharmacological treatment)	n/a	Cost of 4 month course of citalopram: £1.02 (cost of 28 day course: BNF) - £4.37 2 GP consultations - £130	n/a	n/a	£134
Dyspareunia (CBT treatment)		Cost of 12 sessions of CBT at £70 per session - £840 2 GP consultations - £130			£970
Bacterial vaginosis (antibiotic treatment)	n/a	Antibiotic treatment with metronidazole – £29 (average cost: BNF) Consultation with GP - £65 (17.2 minutes – PSSRU 2015)	n/a	n/a	94
Caesarean section	NZ50	Planned Caesarean Section	49,729	169,206,014	
	NZ51	Emergency Caesarean Section	89,021	377,670,251	
Total			138,750	546,876,265	3,941
Instrumental delivery	NZ40	Assisted delivery (AD)	7,243	19,139,793	
	NZ41	AD with epidural or induction	18,568	56,057,211	
Total			25,811	75,197,004	2,913
Long labour / Obstetric haemorrhage / Obstetric tear / Episiotomy	NZ42	AD with epidural & induction or post-partum surgical intervention	28,393	96,145,778	
	NZ43	AD with epidural or induction and post-partum surgical intervention	2,358	8,354,230	
	NZ44	AD with epidural, induction and post-partum surgical intervention	4,079	15,889,929	
Total			34,830	120,389,937	3,457

Source: NHS Reference Costs 2014/15.

P **R** **↙** **P**artnership for
E **P** **A** **R**esponsive
L **R** **E** **P**olicy
↘ **R** **E** **A**nalysis and
↗ **R** **E** **R**esearch