Dear Colleague

Re: FEMALE GENITAL MUTILATION

This letter is to update you on developments in Scotland related to Female Genital Mutilation (FGM) and to ask that you encourage healthcare professionals in NHSScotland to **record the diagnosis and types of FGM, together with any corrective procedures, in the relevant clinical records. This includes recording in the hospital discharge summary, and coding in GP Practices.**

FGM is a hidden condition and the exact prevalence and incidence is unknown in Scotland e.g. we do not know to what extent and which communities in Scotland are affected. However, the NHS is in a unique position to identify those who have undergone FGM and those who may be at risk of FGM. As part of the strategy against gender violence, we need to understand the size and nature of the challenge. Consistently recording FGM, its type (with relevant coding in GP Practices) and any corrective procedures undertaken in clinical records (and discharge summary in hospitals), whenever healthcare professionals in NHSScotland come across an individual who has been cut, will contribute significantly to understanding the prevalence in Scotland.

To help healthcare professionals recognise the condition, some of the presenting symptoms and the services most likely to come across the condition are explained in **Annex A.** The OPCS codes (in hospital setting) and Read codes (in GP Practices) to be used are listed in **Annex C.**
In hospitals, local medical coding staff will code the diagnosis and any procedure carried out to correct FGM recorded in the clinical notes and discharge summaries and monitor the uptake of the relevant codes. ISD will be issuing a Scottish Clinical Coding Standards to coders with explicit guidance on the use of the codes by August 2014.

Background

What is Female Genital Mutilation?

FGM is mutilation of the labia majora, labia minora, or clitoris and is usually undertaken in girls under 15 years of age (ages vary from infants to older adults). There are 4 different types of FGM practised in the relevant communities, where it is known by other names such as “cutting”. To take into consideration cultural sensitivities, FGM is also referred to as female genital cutting and female circumcision. UNICEF and the United Nations Population Fund (UNFPA) currently use a hybrid term, ‘female genital mutilation/cutting’ or FGM/C.

Women and girls have been subjected to different forms of FGM as a result of different belief systems in different parts of the world for centuries. It is a practice that is fundamentally embedded in gender inequality and causes harm and suffering to millions of women and girls all over the world. Details are included in Annex A.

What is the Current and Future Legal Position?

FGM is illegal in Scotland under the Prohibition of Female Genital Mutilation (Scotland) Act 2005; and the relevant legislation in England, Wales and Northern Ireland, is the Female Genital Mutilation Act 2003. Therefore, it is illegal for anyone in the UK to circumcise or assist in the circumcision of a girl or woman\(^1\), in and outside the UK who is resident in the UK. This means that that any of the prohibited acts done outside the UK by a UK national or permanent UK resident will be an offence under domestic law and can be tried in the Scottish Courts.

An amendment to the Prohibition of Female Genital Mutilation (Scotland) Act 2005 is currently making its way through the UK Parliament within the \(^3\)UK Serious Crime Bill 2014. This change when it comes into effect in 2015, will replace the term “permanent resident” with “habitually resident”. This will ensure that a person who is not a permanent UK resident will still be able to be tried in the Scottish Courts.

What are the Implications for Adult and Child Protection?

As FGM is often carried out on minors, it is also a violation of the rights of children and is, therefore, child abuse and a child protection issue. In addition, it is considered to be a part of gender based violence against women and girls, and should be managed through existing child protection and adult protection structures, policies and procedures. It is, recognised that, in parallel, there must be a strong legal framework in place to deal with those who act illegally.

\(^1\) Sections 1-3 of the Prohibition of Female Genital Mutilation (Scotland) Act 2005
\(^2\) Section 4 of the Prohibition of Female Genital Mutilation (Scotland) Act 2005
\(^3\) Serious Crime Bill 2014
What are we doing already?

FGM is a very complex issue and requires a sensitive and co-ordinated approach. Some healthcare staff may also be personally affected by the issue. Statutory and non-statutory agencies need to work in partnership with communities to prevent FGM and support those who have had FGM, engaging with men, women and girls in order to understand, inform, and help find solutions.

Details of available resources are in Annex B.

The Scottish Government has used a multi-agency approach involving relevant agencies, professionals and communities to support children and women who are affected and to counteract the continued practice of FGM. A variety of interventions based on the “Getting it Right For Every Child (GIRFEC)” principles has been used e.g. a letter was sent by the Cabinet Secretary for Education and Lifelong Learning and Minister for Commonwealth Games and Sport (now Cabinet Secretary for Commonwealth Games, Sport, Equalities and Pensioners’ Rights) on 28 April 2014 to Head Teachers to highlight the issues related to FGM in the context of schools and the local communities. A link to the letter is attached below.


Next Steps

- In order to monitor progress in improvements in the required data collection across the health service in Scotland, ISD will use central returns to monitor the recording of the diagnosis of FGM and any procedures carried out to correct FGM, using the SMR01 (acute) and SMR02 (obstetric) datasets. There is usually a lag time of 6 to 8 weeks for the episode of care to ISD receiving the information.

- We will establish a multi-agency short life working group to propose other ways of prevention and management of FGM in Scotland.

Action

We ask that you raise awareness of FGM in NHSScotland and encourage and facilitate healthcare professionals to record the diagnosis and type of FGM, together with any procedures carried out to correct FGM, in the patient’s clinical records (this includes recording in the hospital discharge summary and coding it in GP Practices).

Thank you very much for your co-operation and willingness to help in this very important matter.

Yours sincerely

Aileen Keel

Ros Moore

DR AILEEN KEEL CBE

ROS MOORE
SOME FACTS RELATED TO FGM

The World Health Organisation estimates that more than 125 million girls and women worldwide have been cut in the 29 countries in Africa and Middle East, and around 3 million girls undergo some form of the procedure each year in Africa alone. These areas have the highest prevalence of the condition mainly among specific ethnic populations. This tradition is also widely practised in other countries due to migration.

FGM has also been documented in communities in Iraq, Israel, Oman, and the United Arab Emirates, the Occupied Palestinian Territories, India, Indonesia, Malaysia and Pakistan.

It has been estimated that over 20,000 girls under the age of 15 are at high risk of FGM in the UK each year and that 66,000 women in the UK are living with the consequences, although its true extent is unknown due to the hidden nature of the crime.

There are no clear and robust figures for the prevalence of FGM in Scotland. However, anecdotal reports suggest it is a significant issue. Although not necessarily an indication of prevalence, 2011 census data suggests that at least 2,403 girls were born in Scotland to parents from FGM practising countries between 1997 and 2011, and the number of residents in Scotland born in Africa has doubled since 2001 (Scottish Government, 2013).

In addition, whilst FGM practices are not confined to refugee populations, a report by the UN High Commissioner for Refugees found that 2,401 women from FGM practising countries sought asylum in the UK in 2011 (UNHCR, 2013). Since 2000, around 10% of people seeking asylum in the UK annually have been dispersed to Glasgow by the Home Office. Around one-third of new arrivals to Scotland have originated from countries where UNICEF estimates FGM prevalence rates to be above 75%.

It is illegal in the UK to subject a girl or woman to FGM or to assist a non-UK person to carry out FGM overseas. Whilst there have been no prosecutions in Scotland, it is believed that the practice continues in the UK, as well as girls resident in the UK being taken abroad for the purpose of FGM.

FGM is practised by families and communities for a variety of complex social and religious reasons. It reflects inequality between sexes and serves as a complex form of social control of women’s’ sexual and reproductive rights. It is often carried out in the belief that it is beneficial for the girl or woman. This then influences a girl or woman’s willingness to raise concerns or talk openly about FGM.

As FGM is mainly carried out on minors, it is a violation of the rights of the child and constitutes a form of child abuse and violence against women and girls. It also violates the rights to health, security and physical integrity of the person; the right to be free from torture and cruel, inhuman or degrading treatment, and the right to life when the procedure results in death.
**Definition**

FGM involves all procedures involving the partial or total removal of the external female genital organs for cultural or other injury to the female genital organs for non-therapeutic reasons.

According to the WHO, FGM has “no known health benefits”. It is extremely painful and traumatic and can result in immediate and long term health and wellbeing consequences. The severity and risk is related to the extent of cutting, including the amount and type of tissue that is cut and/or removed.

This contrasts with Female Genital Cosmetic Surgery (FGCS) which refers to non-medically indicated cosmetic surgical procedures which change the structure and appearance of the healthy external genitalia of women, or internally in the case of vaginal tightening. FGCS is different from FGM in that is it a voluntary request by an informed adult (at least over 18 years old) who must be advised on the range of normality and lack of an evidence base for the surgery. In the NHSScotland FGCS is covered by the Adult Exceptional Aesthetic Referral Protocol and should only be considered for women with a functional impairment confirmed by an appropriate specialist.

**Classification of FGM (2008)** – The WHO/UNICEF/UNFPA joint statement classified FGM into 4 types with subdivisions following 10 years of experience (details can be accessed through the link below):

http://www.who.int/reproductivehealth/topics/fgm/overview/en/#

- **Type I – Clitoridectomy**: partial or total removal of the clitoris (a small, sensitive and erectile part of the female genitals) and/or the prepuce (the fold of skin surrounding the clitoris).
- **Type II – Excision**: partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (the labia are the 'lips' that surround the vagina).
- **Type III – Infibulation**: 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.
- **Type IV – Other**: all other harmful procedures to the female genitalia for non-medical purposes, e.g. pricking, piercing, incising, scraping and cauterising the genital area.

Type IV comprises a large variety of procedures which does not remove tissue from the genitals. They are generally less associated with harm or risk than Types I, II, III, where genital tissue is removed.

**Immediate Risk to Health and Welfare from FGM can include:**

- Severe pain
- Excessive bleeding
- Emotional and psychological shock (exacerbated by having to reconcile being subjected to the trauma by loving parents, extended family and friends)
- Infections, including tetanus and blood-borne viruses (including HIV and Hepatitis B and C), ulcers, abscesses, genital infections

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4 This definition is from the Royal College of Obstetricians and Gynaecologists paper on *Ethical considerations in relation to female genital cosmetic surgery*, October 2013

• Difficulty in passing urine
• Injury to adjacent tissues, including repeated FGM
• Fracture or dislocation as a result of restraint
• Damage to other organs

The Long-Term Health Implications of FGM can include:
• Chronic vaginal and pelvic infections with damage to the reproductive system, including infertility
• Difficulties with menstruation
• Difficulties in passing urine and chronic urine infections, leading to renal impairment and possible renal failure
• Excessive scar tissue (keloid) and unintended labia fusion, neuromas and cysts formation
• Sexual problems such as pain during sex and psychosexual problems such as low libido
• Complications in pregnancy and labour, particularly in Type III
• Danger to the newborn e.g. higher rate of neonatal death
• Psychological consequences, including a number of mental health problems such as depression, anxiety and sexual dysfunction; post-traumatic stress disorder
• Substance misuse and/or self-harm
• Increased risk of HIV and other sexually transmitted infections
• Death during childbirth

Some of the Psychological and Mental Health Problems
• FGM is an extremely traumatic experience for girls and women, which stays with them for the rest of their lives.
• Young women receiving psychological counselling in the UK report feelings of betrayal by parents, incompleteness, regret and anger.
• The results from research in practising African communities are that women who have undergone FGM have the same levels of Post Traumatic Stress Disorder (PTSD) as adults who have been subjected to early childhood abuse, and that the majority of the women (80 per cent) suffer from affective (mood) or anxiety disorders.
• The fact that FGM is ‘culturally embedded’ in a girl’s or woman’s community appears not to protect her against the development of PTSD and other psychiatric disorders.
RESOURCES FOR MANAGING AND PREVENTING FGM

Some of the principles for all agencies in relation to identifying and responding to girls (and unborn girls) and women at risk of, or those who have experienced, FGM and their parent(s) are that:

- The safety and welfare of the child is paramount.
- All agencies act in the interests of the rights of the child as stated in the UN Convention on the Rights of the Child (1989).
- It is considered to be a part of gender based violence
- FGM is illegal in Scotland.
- Accessible, acceptable and sensitive health, education, police, social care and voluntary sector services must underpin interventions.

The aim of the engagement with families and communities is to eradicate the practice from Scotland entirely, by preventing FGM and supporting those girls or women who have been cut, as well as others in the community, including men.

Activities should also include seeking the support of other influential leaders in the relevant communities, who can challenge the deep-rooted cultural beliefs and practices.

Healthcare professionals share a responsibility with other partner agencies for identifying and responding to the care and wellbeing needs of girls and women with FGM or at risk of FGM, including helping to raise awareness of the issue. All decisions or plans should be based on good quality assessments and be sensitive to the issues of race, culture, gender, religion and sexuality; and should avoid stigmatising the girl or woman affected, or the practising community. Further information is available from the Principles supporting the guidelines from Multi-agency Practice Guidelines: Female Genital Mutilation, HM Government 2011 which can be accessed through the link below.

Female genital mutilation: multi-agency practice guidelines

The National Guidance for Child Protection, which is used by all children’s services such as education, includes a section on FGM. If there are concerns that a child may have been subject to, or may be at risk from, FGM, this becomes a child protection matter and the updated National Guidance provides advice particularly at Part 4, paragraphs 512-518 in the link below.

http://www.scotland.gov.uk/Publications/2014/05/3052/0

There are a number of existing resources which colleagues may find helpful to raise awareness of and respond to potential cases of FGM. The UK Home Office has produced a leaflet ‘Female Genital Mutilation – The Facts’ which may provide a helpful introduction to the issue. It is available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/261326/FGM_leaflet.pdf

The Scottish Government funds the Women’s Support Project to develop resources for use in training and education – these are available at www.womenssupportproject.co.uk/vawtraining/content/femalegenitalmutilation/277,234

Education Scotland has worked with partner agencies and Education Authority to produce a short supported PowerPoint presentation, which is available for use by authorities and staff in schools and early years settings and can be accessed through the attached link.
Information Governance
Collecting and sharing information appropriately is essential to provide safe and effective healthcare.

The NHSScotland Code of Practice – Protecting Patient Confidentiality (link provided below) should be read with the healthcare professional’s regulatory organisation’s guidance on confidentiality such as those given below. If healthcare professionals are unsure about the law or their responsibilities relating to protecting personal identifiable information, senior colleagues, the individual’s regulatory or professional body or the defence organisation may be able to help. The local information governance expert for NHS Boards is the Caldicott Guardian or the Data Protection Officer.


The General Medical Council’s (GMC) 0-18 years: guidance for all doctors sets out the duties and principles for doctors related to children from 0-18 (particularly paragraphs 42-52 in the link below). In it, the GMC explains that “it is guidance, not a statutory code, so you must use your judgment to apply the principles to the various situations you will face as a doctor, whether or not you hold a licence to practise and whether or not you routinely see patients. You must be prepared to explain and justify your decisions and actions.”


GMC’s guidance on Confidentiality (2009) sets out the principles of confidentiality and respect for patients’ privacy that doctors are expected to understand and follow. See link below.

http://www.gmc-uk.org/static/documents/content/Confidentiality_-_English_0414.pdf
CODES FOR FGM

OPCS Classification of Interventions and Procedures (OPCS) v 4.7

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<tr>
<td>R27.2</td>
<td>Deinfibulation of vulva to facilitate delivery</td>
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P07.2 – This is a more general code which would be typically used in acute care and would be recorded on ISD’s SMR01 (Inpatient and Day Case) records in Scotland

R27.2 – This is a specific code for obstetrics and would therefore be restricted to use in obstetric care and would typically be recorded on ISD’s SMR02 (Obstetric) records in Scotland

The above 2 codes, which are to be recorded when patients are admitted to have these types of repair, came into effect in April 2014 in Scotland and ISD will be producing guidance note for coders on these codes and sending the Scottish Clinical Coding Standards by August 2014.

The current classification of FGM within ICD10 is associated with other conditions and therefore not deemed to be appropriate for the data to contribute to the FGM prevalence.

Read Codes

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Women and girls may present elsewhere in the NHS where FGM might be identified which could enable coding and recording of the condition and type e.g. at cervical smear screening, family planning and Genito Urinary (GU) clinics, travel clinics, paediatrics, urology, gynaecology, mental health services, A&E staff, Scottish Ambulance Service and GP Practices.