



Department
of Health



Health & Social Care
Information Centre

FGM Prevention Programme

Understanding the FGM Enhanced dataset –
updated guidance and clarification to support
implementation.

September 2015

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The Department of Health's FGM Prevention Programme is a national £3M change programme to improve the way in which the NHS responds to the health needs of girls and women who have had FGM, and to actively support prevention. This includes supporting health professionals to be confident when having discussions with women and girls. It will also help us to record and share FGM information appropriately and to take the necessary action to safeguard girls against risk.

In October 2015, a new professional mandatory reporting duty will be introduced for all regulated professionals. In addition, GPs and mental health trusts will be mandated under the Health and Social Care Act 2012 to record FGM patient data under the FGM Enhanced Dataset. Acute trusts have had to meet the requirements of the FGM Enhanced Dataset since 1 June 2015.

Mandatory reporting¹ of FGM:

New professional duty to report all girls under 18 with FGM to the police:

This new mandatory reporting duty will commence in October 2015. The duty has been brought through the Serious Crime Act 2015 and will mean that whenever regulated professionals (health, social care and education) identify that a girl under 18 has had FGM, or if the girl discloses this herself, the professional must make a report to the police.

Mandatory Reporting does not replace general safeguarding responsibilities: professionals must still undertake any safeguarding actions as required, usually beginning with a discussion with their local safeguarding lead to identify an appropriate course of action. Organisations are reminded of the DH's guidance ['Female Genital Mutilation Risk and Safeguarding: Guidance for professionals' \(2015\)](#).

FGM Enhanced Dataset

The following organisations are required to have regard to the FGM Enhanced dataset standard from October 2015:

- General Practice
- Mental Health Trusts
- Acute Trusts (mandatory since 1 July 2015)

Sexual health and GUM (Genito-Urinary Medicine) clinics, where patients do not have to provide their personal information, are out of scope, but these services are nonetheless reminded of their responsibilities to share information to ensure appropriate safeguarding responses are put in place every time this becomes necessary.

The data collected is sent to the Health and Social Care Information Centre (HSCIC), where it is anonymised, analysed and published in aggregate form. Personal information is only collected as part of the FGM Enhanced dataset for internal data quality assurance and to avoid duplicate counting. A woman or child's personal details will never be published in the national aggregate reports and will never be passed to anyone outside HSCIC. **This work specifically will not pass any personal details to the police or social services - the collection of this data will not trigger individual criminal investigations.**

¹ For further information: <https://www.gov.uk/government/news/crime-prevention-minister-announces-mandatory-reporting-of-fgm>

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The improvements and benefits resulting from the information standard are:

- Greater understanding of the extent and issue of FGM in England;
- Evidence to justify why the range of FGM support and care services need to be commissioned;
- Using the information about when and where patients with FGM are identified and treated, to support service development. This might be to improve multi-agency working, for example if used by Local Safeguarding Children's Boards, by commissioners or other settings.

Complying with the FGM Enhanced Dataset does NOT mean that a professional will have met their professional requirements as set out in the new mandatory reporting duty. Organisations should take care to ensure this message is clear when implementing the FGM Enhanced Dataset, and that all local procedures and policies reflect all responsibilities across these areas.

Patient Consent

With regard to the collection of patient identifiable information as part of the FGM Enhanced dataset, patient consent does not need to be sought, however transparency (fair processing) is required.

See the HSCIC 'Female Genital Mutilation Enhanced Dataset – Information Governance Statement', http://www.hscic.gov.uk/media/18125/FGM-Enhanced-Dataset-IG-Statement/pdf/FGM_Enhanced_Dataset_IG_Statement.pdf, for an explanation of the legal basis for this.

Fair processing and the right for patients to object

All NHS organisations are bound by a range of responsibilities to maintain patient confidentiality and respect the wishes of patients; under the Data Protection Act this is called 'fair processing'.

To meet the requirement to provide a 'fair processing' notification to patients, clinicians should give the patient the FGM leaflet "More information about FGM" (2015). This is available to order online, free of charge in English and ten other languages. Organisations can also download copies from NHS Choices [<http://www.nhs.uk/Conditions/female-genital-mutilation/Pages/Introduction.aspx>]

Giving the patient this leaflet fully meets the requirement for 'fair processing' and this action alone is sufficient. There is no requirement to discuss the FGM dataset in detail, or to ask a patient for explicit consent to collect their information, although clinicians will need to answer any questions that a patient has and know to whom they might need to refer the patient for additional information.

Clinicians should always discuss, if they have not previously, the illegality of FGM in the UK, and the many negative health consequences of the practice with the patient.

Fair processing objection route

There are two stages at which, if a patient raises an objection after having received the 'fair processing' notification, their objection will be considered and acted upon. These together form the 'fair processing' objection route.

If a patient raises an objection within the care delivery setting (i.e. within the GP surgery or the hospital), the local organisation must consider this objection within their own

processes², and ensure they record within the healthcare record the outcome of this decision (i.e. whether or not to disclose information to HSCIC).

If the objection is not raised at this point, and the patient's information is submitted, she can still choose to contact HSCIC at a later date to raise an objection at the following website: http://www.hscic.gov.uk/media/14700/Preventing-the-use-of-your-information-for-health-and-or-social-care-purposes-other-than-direct-care/pdf/Preventing_Use_of_Your_Information_Form.pdf, the objection will be automatically enforced and the patient's data will be removed from the dataset.

If the objection is raised with HSCIC, they do not automatically have to accept this request and remove the information. However, due to commitments made by the Secretary of State for Health, patient objections for FGM data collection must always be treated as an automatic 'stop processing' request. This is a Government policy decision that goes beyond the law's requirements.

Similarity to other NHS datasets

There are other examples across the NHS where the approach used for the FGM Enhanced dataset is already in place to collect patient information without explicit consent from individual patients. One such example is the collection of information for commissioners, which supports the ongoing cycle of commissioning health services. Within this, explicit patient consent is not obtained but it is clear how patients can object and remove their information. For more information please see: <http://www.england.nhs.uk/ourwork/tsd/data-services/>

Implementation Timetable

All mental health trusts and general practices have to introduce the FGM Enhanced Dataset by 1 October 2015. This means that organisations must have developed a method to capture the required information from 1 October, and must ensure that they submit their first return no later than 31 January 2016.

Change to dataset validation

The Standardisations Committee for Care Information (SCCI), will shortly be issuing an amendment to the dataset. This will be communicated through the formal HSCIC update process, but GP practices do not receive these updates. Organisations should note that the validation of the data item 'How FGM was identified' will be changed. The data item was previously 'Required' and has now been changed to 'Optional'.

This change will be reflected in the online materials and a corrigendum will be issued alongside the information standard: <http://www.hscic.gov.uk/isce/publication/scci2026>

GP data template

All GPs should complete the CAP registration process in preparation for submitting the dataset: http://www.hscic.gov.uk/media/16099/FGM-User-Registration-Form/doc/FGM_User_Registration_Form_v1.2.doc.

² GP Practices: Information Governance Toolkit Requirement 13-212:

<https://www.igt.hscic.gov.uk/RequirementQuestionNew.aspx?tk=422477393778945&Inv=2&cb=12e8a681-d0fe-42f3-86bb-77c7a1aa2336&sViewOrgType=4&reqid=2686>

Mental Health and Acute Trusts: Information Governance Toolkit Requirement 13-202:

<https://www.igt.hscic.gov.uk/RequirementQuestionNew.aspx?tk=422477393778945&Inv=2&cb=0d155ce9-5eed-4a36-8951-fab0649f5a6b&sViewOrgType=5&reqid=2678>

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Additional clinical codes will be published on 1 October 2015; see Annex for the pre-release details of these codes.

With the introduction of the new codes, organisations are reminded that they can now create their own template locally within their GP records system to support the collection of this information. We are working to ensure that templates are available for the major systems from 1 October 2015 to allow the recording of FGM information, with a mechanism to support the extraction and submission of this data from 1 December, in order that the first return can be submitted no later than 31 January 2016.

Please note that the data extraction process may still require some administrative input locally, as it may not be possible to fully automate this process. Further details will be released in due course.

Annex – new clinical codes to support FGM Enhanced Dataset

The following tables outline the new requested clinical terminologies supporting the FGM Enhanced Dataset.

Whilst the values outlined below are expected to be taken forward, these will not be formally published (via existing publication routes) until Oct 2015. As such, these will still be subject to change until that time.

Read v2 Term	Read v2
No family history of female genital mutilation	122S.
Discussion about illegality of female genital mutilation	67DQ0
Discussion about health implications of female genital mutilation	67DQ1
Country in which patient underwent female genital mutilation	15L..
H/O: female genital mutilation under 1 year of age	15K1.
H/O: female genital mutilation between 1 and under 5 years of age	15K2.
H/O: female genital mutilation between 5 and under 10 years of age	15K3.
H/O: female genital mutilation between 10 and under 15 years of age	15K4.
H/O: female genital mutilation between 15 and under 18 years of age	15K5.
H/O: female genital mutilation at 18 years of age or over	15K6.
H/O: female genital mutilation type 3	15K0.

CTV3 Term	CTV3 Code
No family history of female genital mutilation	Xacuf
Discussion about illegality of female genital mutilation	Xacyl
Discussion about health implications of female genital mutilation	XacyJ
Country in which patient underwent female genital mutilation	XadFY

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H/O: female genital mutilation under 1 year of age	XacuW
H/O: female genital mutilation between 1 and under 5 years of age	XacuX
H/O: female genital mutilation between 5 and under 10 years of age	XacuY
H/O: female genital mutilation between 10 and under 15 years of age	Xacub
H/O: female genital mutilation between 15 and under 18 years of age	Xacud
H/O: female genital mutilation at 18 years of age or over	Xacue
H/O: female genital mutilation type 3	Xabx2

SNOMED CT Fully specified Name	SNOMED CT ID
No family history of female genital mutilation (situation)	977651000000105
Discussion about illegality of female genital mutilation (procedure)	979461000000100
Discussion about health implications of female genital mutilation (procedure)	979481000000109
Country in which patient underwent female genital mutilation (observable entity)	988761000000109
History of female genital mutilation under 1 year of age (situation)	977471000000103
History of female genital mutilation between 1 and under 5 years of age (situation)	977491000000104
History of female genital mutilation between 5 and under 10 years of age (situation)	977511000000107
History of female genital mutilation between 10 and under 15 years of age (situation)	977571000000102
History of female genital mutilation between 15 and under 18 years of age (situation)	977611000000106
History of female genital mutilation at 18 years of age or over (situation)	977631000000103
History of FGM Type 3	941261000000104