

# FGM Enhanced Dataset – Frequently Asked Questions

This document answers questions frequently asked by healthcare professionals submitting data.

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# 1 What is the FGM Enhanced Dataset?

The FGM Prevention Programme, led by the Department of Health (DH) includes projects to improve awareness, provision of services, and safeguarding of girls at risk. This has two main elements:

1. **The FGM Enhanced Dataset** - presenting a national picture of the prevalence of FGM across the NHS in England.
2. **The FGM Risk Indication System** - delivering a digital system to strengthen the safeguarding of girls at risk of FGM. For further information about this visit: <http://content.digital.nhs.uk/fgmris>

This document provides answers to frequently asked questions about the FGM Enhanced Dataset. The dataset collects information about patients who have had FGM. It builds on the FGM Prevalence Dataset, which collected data from acute trusts between 1 April 2014 and 31 March 2015.

The FGM Enhanced Dataset is an Information Standard (SCCI2026) that was published and began collecting on 1 April 2015 in Trusts and GP practices in October 2015. To read more about the FGM Enhanced Dataset Information Standard visit: [www.hscic.gov.uk/isce/publication/scci2026](http://www.hscic.gov.uk/isce/publication/scci2026).

From the data collected, it will be possible to ensure that the programme of improvements is both targeted at the areas of need, and that it is of an appropriate scale.

## 1.1 Who manages the FGM Enhanced Dataset?

The FGM Enhanced Dataset is part of the FGM Prevention Programme, NHS Digital works with NHS England to manage the data submissions. Data collection is through the NHS Digital Clinical Audit Platform (CAP). Data is used to publish quarterly and annual reports. If no cases of FGM have been identified, a 'nil return' does **not** have to be submitted

# 2 Registration Process to submit data

## 2.1 Do all trusts and GP practices need to register for CAP?

**Yes:** It is recommended that all trusts and GP practices should register to access the clinical audit platform (CAP) at NHS Digital so they are in a position to submit data promptly should FGM be identified.

## 2.2 Who should register and submit data?

It is for trusts and GP practices to decide locally who will require access to CAP, the data collection system. Registration to access CAP involves completing an FGM Enhanced dataset CAP User [Registration Form](#). This must be approved by the trust, practice or CCG Caldicott Guardian who "signs off" part C of the form and sends it from their work email address to NHS Digital at [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk)

The "sign off" is necessary because users will be able to view patient identifiable data. The Caldicott Guardian must be on the National Caldicott Guardian Register so that NHS Digital can verify that the correct person has agreed to users accessing information. You can

check who is listed for your practice by following the link <https://digital.nhs.uk/organisation-data-service/our-services>

If an organisation needs to register their Caldicott Guardian this can be done using the Caldicott Guardian/SIRO form at the above link and submitting it electronically to [Exeter.helpdesk@nhs.net](mailto:Exeter.helpdesk@nhs.net)

## 2.3 If I already have an account with NHS Digital for another audit do I still have to complete an FGM CAP registration form?

**Yes.** Each audit is different, some contain sensitive patient identifiable data while others may work so that data is imported directly from another system and data is not visible to the user. The user has to be allocated to different parts of the CAP system and we need to ensure that users are only seeing what they should be.

## 2.4 Which site code should trusts and GP's register against?

- Trust Site Codes are five digit Organisation Data Service (ODS) codes.
- GP site codes are six digits. Trust staff and GP practices with an N3 connection can search for their ODS Site Code at <https://odsportal.hscic.gov.uk/Organisation/Search>
- Trust staff should register against the trust site where they usually work. Users can only be registered at one site but can submit data on behalf of anyone at their trust.
- GP practices submitting data on behalf of multiple practices can have access if they have a different e-mail address for each "practice". A practice manager with more than 1 practice, where the practices are related, can register under 1 practice and submit data for their other practices by selecting the appropriate practice code in the *Site of treatment* field when submitting attendance information.

If an existing user moves to another trust/practice, they should notify NHS Digital and they will require a new registration to enter data for their new Trust or practice.

# 3 What is the legal basis for collecting patient identifiable data without consent?

## 3.1 Do I need to get consent from the woman or girl?

Explicit consent is not required because the collection is being undertaken under Directions from the Department of Health (DH). To read the Directions visit:

<https://www.gov.uk/government/organisations/health-and-social-care-information-centre/about/our-governance#directions>

FGM information will be submitted to the FGM Enhanced Dataset; women and girls should be advised of this. DH has provided a patient leaflet in several languages for this purpose, which can be ordered by visiting: <http://www.nhs.uk/Conditions/female-genital-mutilation/Documents/2905942-DH-FGM-Leaflet-English.pdf>

## 3.2 What if women and girls do not want their information used?

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 processes<sup>1</sup>, and ensure they record within the healthcare record the outcome of this decision (i.e. whether or not to disclose information to NHS Digital).

If the objection is not raised at this point, and the patient's information is submitted, she can still choose to contact NHS Digital at a later date to raise an objection by contacting [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk). The objection will be treated as an automatic 'stop processing' request and the patient's data will be removed from any publication. This is a Government policy decision that goes beyond the law's requirements.

## 3.3 Should historical cases be entered?

Only cases where FGM was identified or treatment relating to FGM occurred on or after 1 April 2015 can be submitted to the FGM Enhanced Dataset, regardless of when the original procedure of FGM took place. If data is submitted historically organisations must ensure that the woman has been informed about the data collection as part of Fair Processing.

# 4 Who can submit and view the data?

## 4.1 Which organisations submit data?

The FGM Enhanced Dataset requires clinicians in acute trusts, mental health trusts and GP practices to record in the patient notes and submit data to NHS Digital when patients with FGM are identified, including the type of FGM.

Community services within mental health trusts can participate.

Sexual Health and Genito-Urinary Medicine clinics are excluded but the legal obligation to appropriately share information with their safeguarding teams still applies.

## 4.2 Can trusts and GP practices outside England submit data?

**No.** The FGM Enhanced Dataset Information Standard (SCCI2026) only applies to services commissioned by NHS England and the data collection system has been designed accordingly.

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<sup>1</sup> GP Practices: Information Governance Toolkit Requirement version 14:  
<https://www.igt.hscic.gov.uk/RequirementsList.aspx?tk=6&Inv=2&cb=b691a5f2-bca5-498f-9f6e-9da34ef99728&sViewOrgType=4&sDesc=General%20Practice>

Mental Health and Acute Trusts: Information Governance Toolkit Requirement version 14:  
<https://www.igt.hscic.gov.uk/RequirementsList.aspx?tk=6&Inv=2&cb=73785ee3-ff0d-4759-bea1-2a8258295494&sViewOrgType=5&sDesc=Mental%20Health%20Trust>

### 4.3 If I did not create a record in CAP can I delete it?

**Yes.** Any person with access to CAP for FGM can delete a record if it was created by someone from the same organisation.

### 4.4 Can I delete a record I created?

**Yes.** You can delete a Patient, Attendance or FGM Record that you created by going into the Record Tree page and clicking on 'Delete Record'. You must delete the records in the following order: FGM, Attendance and Patient.

The screenshot shows the 'Record Tree' for a patient. At the top, the patient's details are displayed: NHS Number: 222 222 2222, Date Of Birth: 01/06/2000, and Name: TEST test. Below this, a 'Record Tree' section contains a list of records:

- Patient: 222 222 2222** (Folder icon) with options: Edit record, Delete Record, Add Attendance
- Attendance: Care Contact date: 01/06/2015** (Document icon) with options: Edit record, Delete Record
- FGM: FGM Type 3 - Re-infibulation Identified** (Document icon) with options: Edit record, Delete Record
- Attendance: Care Contact date: 03/10/2016** (Document icon) with options: Edit record, Delete Record, Add FGM
- Attendance: Care Contact date: 01/11/2016** (Document icon) with options: Edit record, Delete Record, Add FGM

### 4.5 Who can view the data?

Users can submit and view data for patients seen at different organisations. CAP only allows a registered user to enter a full NHS number to view a record. Users must enter an exact NHS number for a patient and a result will only be returned if that patient is already in the database.

## 5 What data will be collected?

The full dataset contains 30 data items including: patient demographic data, specific FGM information, referral and treatment information.

Whenever, FGM is identified/newly recorded either through clinical examination or self-reported by the woman or girl it should be documented in the clinical notes.

“Newly recorded” does not necessarily mean that the attendance is the first for FGM.

If a woman or girl has already been identified and reported to the FGM Enhanced Dataset as having FGM, a new Attendance record and/or FGM Record will need to be created if:

- the woman or girl is having treatment relating to her FGM (Attendance Data)
- the woman gives birth (Attendance Data)
- there is a change in her FGM Type (FGM data)

Where the clinician is unsure about the type of FGM, type ‘Unknown’ should be recorded.

Genital piercings are included because the World Health Organisation currently defines all female genital piercings as a form of FGM. The data item FGM Type 4 Qualifier allows users to specify that the FGM was a piercing. Labiaplasty and genital tattoos are not included.

## 5.1 Are all data items mandatory?

**No.** 9 of the 30 data items are mandatory. However, 19 are required and trusts and GP practices are encouraged to submit as much information as possible.

In the CAP Patient Record:

- Patient forename and surname, date of birth and post code are mandatory.
- NHS Number is required, if not available a Local Patient Identifier should be provided
- Provider Organisation Code must be provided if NHS Number is not available.

In the Attendance Record:

- Care Contact Date is mandatory.

In the FGM Record:

- FGM Activity Identified (FGM Type) is mandatory

## 5.2 Why is patient identifiable data collected?

The main reasons for collecting patient identifiable data is to ensure the quality and usefulness of the data:

- NHS Number and Date of Birth (DOB) are used to uniquely identify the woman or girl within the dataset, ensuring the correct data is entered against the correct record; this prevents double counting. Also, where users do not have an NHS Number available, the date of birth (DOB), Local Patient Identifier and Provider Organisation are used to uniquely identify the woman or girl until the NHS Number can be entered.
- Only records with an NHS Number will have their data included in the quarterly and annual reports.
- Date of birth is also used to identify where girls are under 18 years of age.
- Name is only collected to avoid data entry errors by users when moving in and out of records (i.e., users can see at a glance whose record they are in). It is not collected or used for any other purpose.
- Postcode is collected to enable more detailed analysis and reporting of a geographical nature (for example, Clinical Commissioning Group).

No patient identifiable information will ever be published, and to prevent individual patient identification small numbers of aggregated numbers will be suppressed in reports.

## 5.3 How will data be collected and recorded?

Trusts and GP practices are encouraged to introduce methods of collection and issue clear instructions on how and where to record FGM within their own systems and consider how best to support teams, through either additional professional training or guidance.

For further information about how to collect and record the data, please see the CAP Operational Guidance at:

[http://content.digital.nhs.uk/media/22978/FGMCAPOperationalGuidanceEnhancedDatasetv15/pdf/FGM\\_CAP\\_Operational\\_Guidance\\_Enhanced\\_Dataset\\_v1.5.pdf](http://content.digital.nhs.uk/media/22978/FGMCAPOperationalGuidanceEnhancedDatasetv15/pdf/FGM_CAP_Operational_Guidance_Enhanced_Dataset_v1.5.pdf)

## 5.4 Are there templates for collecting the FGM Enhanced Dataset?

**Yes:** There is an example data collection pro-forma available within the Operational Guidance, section 1.7 and 6.1.3, which can be found at

[http://content.digital.nhs.uk/media/22978/FGMCAPOperationalGuidanceEnhancedDatasetv15/pdf/FGM\\_CAP\\_Operational\\_Guidance\\_Enhanced\\_Dataset\\_v1.5.pdf](http://content.digital.nhs.uk/media/22978/FGMCAPOperationalGuidanceEnhancedDatasetv15/pdf/FGM_CAP_Operational_Guidance_Enhanced_Dataset_v1.5.pdf)

Organisations can create their own if they wish.

Once registered, users can submit data directly into CAP one record at a time or they can use the file upload system.

The CSV file specification can be found within the Excel Dataset file on the right hand side of the webpage at <http://content.digital.nhs.uk/fgm>

The **Reference data tab** tells you which numeric values to put in.

- Users can create templates for the three file types by referring to the CSV file specification, which can be found within the Dataset file at <http://content.digital.nhs.uk/fgm>
- GP practices that are able to run a report from their clinical system will need to upload the 3 file types to the clinical audit platform. These must be uploaded in the following order
  - Patient
  - Attendance
  - FGM
- Some clinical information systems have created templates to collect the data for example SystemOne (guidance available in notifications).

**NOTE: If a practice only has a few submissions it is probably easier to submit data manually.**

## 5.5 Does a new Patient Record need to be created every time a woman or girl attends?

**No.** A Patient record only needs to be created once (when FGM is identified – whether that is by self-report or through clinical examination). Subsequent attendances should be added to the record. You should search for a patient record by entering the NHS number. Local identifiers can be used until the NHS number is known.

## 5.6 How are FGM Types defined

**Female Genital Mutilation (FGM) is a procedure where the female genitals are deliberately cut, injured or changed, but there's no medical reason for this to be done.**

**HOWEVER, Cosmetic (plastic surgery; Labiaplasty) and Gender Reassignment surgery ARE NOT forms of FGM.**

### 1. (Cosmetic) Labiaplasty is not considered FGM

A **labiaplasty** is a plastic surgery procedure to reduce the size of the labia minora – the flaps of skin either side of the vaginal opening. Some women consider having a **labiaplasty** because they don't like the look of their labia, or because the labia cause discomfort.

### 2. Gender reassignment surgery is not considered FGM

Gender reassignment surgery is a term used to describe multiple medical and/or surgical treatments related to alleviating gender dysphoria (**Dysphoria** is a state of mental discomfort or suffering)

**PLEASE NOTE:**

3. **Decorative piercings (as adult, and consented) should be included in the collection of FGM data and submitted to NHS Digital; details below:**

Vaginal piercings **ARE** classed as (FGM), under NHS rules. Therefore, any woman whose clitoris or labia has been pierced – even if it was entirely her own decision - will be seen as an act of FGM.

Piercings come under FGM Type 4 as: “All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization.”

- **Type 1:** Often referred to as **clitoridectomy**, this is the partial or total removal of the clitoris (a small, sensitive and erectile part of the female genitals), and in very rare cases, only the prepuce (the fold of skin surrounding the clitoris).
- **Type 2:** Often referred to as **excision**, this is the partial or total removal of the clitoris and the labia minora (the inner folds of the vulva), with or without excision of the labia majora (the outer folds of skin of the vulva).
- **Type 3:** Often referred to as **infibulation**, this is the narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora, or labia majora, sometimes through stitching, with or without removal of the clitoris (clitoridectomy).
- **Type 4:** This includes all other harmful procedures to the female genitalia for non-medical purposes, e.g. pricking, piercing, incising, scraping and cauterizing the genital area.

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

## 5.7 Does a new Attendance Record need to be created every time a woman or girl has treatment?

**Yes:** A new Attendance Record must be created every time the woman or girl has treatment related to FGM and if FGM type has changed that should be recorded too. There could be multiple Attendance Records. The Care Contact date is a mandatory field and if this is not completed the data will not be submitted for analysis.

Attendance Records do not need to be submitted in chronological order; historical data can be submitted (but not from before April 2015) and will not overwrite previously submitted records unless the Care Contact Date is the same.

## 5.8 Should all visits/attendance to maternity services be recorded

**Yes.** If the FGM is treated/discussed as this will indicate the level of attendance and the services required to support these women.

## 5.9 What happens if a woman or girl has more than one attendance on the same day?

The data collection system will only allow one Attendance Record to be created per individual, per care contact date.

If submitting via CSV file an Attendance Record with the same NHS Number and Care Contact Date as an existing Attendance Record will overwrite the data in the existing Attendance Record (though populated fields are never overwritten with blanks).

If submitting manually, users will be alerted if they try to submit an Attendance Record with the same NHS Number and Care Contact Date as an existing Attendance Record. A user should only overwrite the data in the existing Attendance Record if the attendance occurred later in the day than the existing attendance.

## **5.10 If a woman or girl self-reports FGM and a clinical examination confirms FGM during the same attendance, what should be recorded?**

Confirmation of the FGM Type following a clinical examination should be recorded in this instance. Clinical examination confirmed FGM takes priority over both self-reporting and referral.

## **5.11 What reports are available within the data collection system?**

There are three different reports available to users from within CAP.

1. System reports
2. Missing Key Field Report
3. Under 18s Report

See the CAP Operational Guidance for further information

[http://content.digital.nhs.uk/media/22978/FGMCAPOperationalGuidanceEnhancedDatasetv15/pdf/FGM\\_CAP\\_Operational\\_Guidance\\_Enhanced\\_Dataset\\_v1.5.pdf](http://content.digital.nhs.uk/media/22978/FGMCAPOperationalGuidanceEnhancedDatasetv15/pdf/FGM_CAP_Operational_Guidance_Enhanced_Dataset_v1.5.pdf)

## **5.12 What if I have a question about submitting to the dataset?**

Email the contact centre at NHS Digital at [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk)

## **6 Is the mandatory reporting of under 18 yr. olds to the police the same as submitting their data to the enhanced dataset?**

**No.** The mandatory reporting of under 18's is a separate duty under the Serious Crime Act 2015 to report to the police. Further information/resources about the mandatory reporting is available from: <https://www.gov.uk/government/publications/fgm-mandatory-reporting-in-healthcare>

The data relating to under 18's still needs to be submitted to CAP.

## **6.1 What happens when trusts or GP practices submit data on girls who are under 18?**

CAP has the capability to capture where a girl under 18 has been identified with FGM. Whilst the organisation should have already considered safeguarding responsibilities; the trust or practice should run a report on under 18's using the report function in CAP to check the accuracy.

## **7 Are private patients included?**

Private patients seen in an NHS healthcare setting should be included

## **8 What do we do when somebody says they have FGM but medical examination has confirmed they do not have FGM?**

While self-identification is considered to be sufficient for the contact to be considered eligible for inclusion into the collection (medical confirmation of the FGM is not a requirement), individuals who are medically identified as not having undergone FGM not should not be returned

## **9 When is data submitted?**

### **9.1 How often must trusts and GP practices submit?**

Extracts from the data collection system, on which the reports are based, will be taken a month after the end of each quarter. For example, the data for the April - June quarter will be taken on 31<sup>st</sup> July so trusts and practices will have until that date to ensure their data has been correctly entered. Trusts and practices can run an extract in CAP to quality check the data that has been submitted. These reports should be run prior to data deadlines to ensure the quality of the data.

Annual submissions and reporting dates can be found at

<http://content.digital.nhs.uk/article/7523/Health-professionals-and-NHS-organisations>

### **9.2 What is done with the data?**

NHS Digital will publish quarterly and annual reports based on quarterly extractions from the data collection system; these will be published as an official statistic – experimental statistic (these are official statistics undergoing evaluation). Reports can be found at the following link [FGM reports](#).

No patient identifiable information will ever be used within any publications. Also, NHS Digital does not share patient identifiable data for example with the police.

### **9.3 What shall I do if I want more information than is published in the reports?**

NHS Digital will review all requests for unpublished data on a case by case basis.

Individuals or organisations with a request for FGM Enhanced Dataset information should call the contact centre at NHS Digital on 0300 303 5678 or email [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk).

## 10 What if I have a question that is not answered here?

For further information please:

- visit the FGM Prevalence Dataset webpage at <http://content.digital.nhs.uk/fgm>
- contact the NHS Digital contact centre on 0300 303 5678
- Email: [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk) (please put 'FGM' in the subject field of your email).