

# Female Genital Mutilation (FGM) Prevalence Dataset

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# 1.1 Background

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## What is the FGM Prevalence Standard?

1. FGM to be recorded by all clinicians, across all healthcare settings
2. Central return of the FGM dataset from all Acute Trusts

## Why has this been implemented?

- Inform future stages of FGM prevention work
- Provide a nationally consistent standard to identify FGM prevalence
- Improve the NHS response to FGM
- Help to identify where national FGM support services are required
- Ultimately supports the safeguarding of girls at risk of FGM
- Provides relevant information across Government organisations

## When is it applicable?

- 1<sup>st</sup> April 2014: Voluntary submissions
  - 1<sup>st</sup> Oct 2014: Mandated submissions
  - 31<sup>st</sup> Mar 2015: Submission end date
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# 1.2 Overview

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Record

Clinicians:  
Always record FGM in patient's record



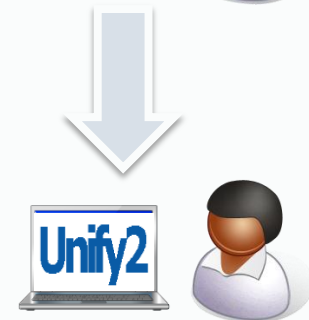
Collect

Information Teams:  
To collect and collate FGM information



Submit

Information Teams:  
To submit FGM Prevalence information



# 1.3 Implementation

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Information Teams AND Clinicians must work together to confirm local process;

- How to identify FGM and the risks of FGM
  - How FGM information will be recorded
  - How FGM information will be provided to the Information Team
  - How FGM information will be collated by the Information Team
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# 2.1 Recording: FGM Information

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- The very minimum should be the recording of ‘Female Genital Mutilation’
- FGM information captured will inform the FGM Prevalence collection

Information	Description
Female Genital Mutilation	FGM diagnosed, but specific Type is unknown
Female Genital Mutilation Type 1 - 4	Specific FGM Type diagnosed
Family History of FGM	It is made known that FGM has occurred in associated family members and/ or wider social grouping e.g. mother, aunts, guardians, cousins, non-blood relatives (in-laws)
History of FGM	A past finding or diagnosis of FGM e.g. a historic deinfibulation procedure has been observed
Deinfibulation of vulva	Deinfibulation procedure has been required
Deinfibulation of vulva to facilitate delivery	Deinfibulation procedure specifically for births

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# 2.2 Recording: Options

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FGM Prevalence dataset captured in 3 ways;

## 1. FGM Codes

- Record FGM within patient notes using FGM codes
- System and local configuration dependent  
E.g. auto-populated or drop down lists

## 2. Local FGM Collection Tool

- Record FGM within patient notes
- Manually populate FGM within existing local database/ spreadsheets

## 3. FGM Prevalence Example Tool

- Record FGM within patient notes
  - Manually record FGM information in example tool
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## 2.3 Recording: Using Codes

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FGM information recorded in the patient healthcare record, used for the FGM prevalence return

1. FGM Type 1, 2, 3 & 4
2. When the FGM Type is *'unknown'*, use code for *'Female Genital Mutilation'*

Clinical Code	Concept	Code
SNOMEDCT	Female Genital Mutilation	885761000000108
Read v2	Female Genital Mutilation	K578.
CTV3	Female Genital Mutilation	Xaad9

3. Deinfibulation procedure undertaken, when applicable
  4. FGM codes implemented locally as per system/ local configuration
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## 2.4 Recording: Deinfibulations

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Deinfibulations: Using FGM Codes:

- Deinfibulation of Vulva
- Deinfibulation of Vulva to facilitate delivery

Repeat Deinfibulations: Using FGM Codes:

- Clinician records 'Deinfibulation' in patient record
- Information Team analyst responsible for collating Repeat Deinfibulations

Historic Deinfibulations observed: Use relevant 'History of FGM' Codes

Clinical Code	Concept	Code
SNOMEDCT	History of FGM	902981000000103
Read v2	History of FGM	15K..
CTV3	History of FGM	Xab25

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# 2.5 Recording: Collection Tool

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Record FGM within patient clinical record

Populate example tool/ extract FGM information from local tool:

- Department (Treatment Function Area)
- Month of collection
- Unique patient identifier
- Date of birth
- Date FGM identified
- FGM Type identified (1, 2, 3, 4 or 9 when unknown)
- Who completed the return
- Date of the return
- Number of deinfibulation procedures performed within the reporting period
- Number of repeat deinfibulation procedures performed

Manually collected, and provided to the Information Team

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# 3.1 Collecting: FGM Codes

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Information Team's collecting and collating when FGM codes are used;

## Collect

- Run queries using the FGM Codes against electronic patient records
- Identify the associated unique patient identifiers
- Identify the associated date of birth
- Identify the treatment function area where FGM was identified in
- Create list of all FGM cases locally identified

## Collate

- Use the unique patient identifier to confirm;
    - Active Cases (if the patient has had FGM identified previously)
    - Newly Identified Cases (no previous FGM records)
    - Repeat Deinfibulations (where Deinfibulation was previously recorded)
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## 3.2 Collecting: Collection Tools

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Information Team's collecting and collating when using local collection tools;

### Collect

- Obtain FGM information from all departments
- Create list of all FGM cases identified

### Collate

- Use the unique patient identifier to confirm;
  - if the patient has had FGM identified previously = Active Case
  - if the patient has not had FGM identified previously = Newly Identified
  - if the patient has had Deinfibulation recorded previously = Repeat Deinfibulation

# 3.3 Recording & Collate Overview

An overview of the FGM data to be captured and those responsible for doing so

FGM Data Item	Clinician using Local Tool	Clinician using FGM Codes	Collated by Info Team	Submitted to Dept. of Health
Treatment Function Area	✓	✗	✓	✓
Month	✓	✗	✓	✓
Unique Patient Identifier	✓	✗	✓	✗
Date of Birth	✓	✗	✓	✗
Date FGM Identified	✓	✗	✓	✗
FGM Type (1,2,3,4 or 9)	✓	✓	✓	✓
Form Returned By	✓	✗	✓	✗
Date Returned	✓	✗	✓	✗
Deinfibulation	✓	✓	✓	✓
Repeat Deinfibulation	✗	✗	✓	✓

# 4.1 Submissions: Process

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Information analyst, to collate findings and submit FGM information into Unify2

- FGM Data Collection & Management
    - Under DCT Home Page, click FGM
    - FGM Form >>
    - FGM Part >>
    - Click on FGM Link
  - Data
  - Sign off
    - View Manage
    - Select Collection Type: DCT
    - Select Collection Name: Relevant Month
    - Select Type of View: Collection View
    - Search
    - Click on FGM Text Link
    - Click on Sign Off
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# 4.2 Submissions: Data

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Unify2 is the Department of Health system used to submit FGM information

Information Team analyst completes 3 sections within Unify2

- Section 1 Newly Identified;
    - Number of Children identified by FGM Type
    - Number of Adults identified by FGM Type
    - Total number of patients identified by Type
  - Section 2 Active Caseload
    - Number of Children previously reported on
    - Number of Adults previously reported on
    - Total Number of all patients
  - Section 3 Treatment Function Area
    - Treatment Function Area where FGM was identified
    - Number of Deinfibulations and Repeat Deinfibulations
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# 4.3 Submissions: Timescales

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- Implemented (Voluntary start)
    - Locally recorded FGM information since 1<sup>st</sup> April
    - Trust submissions began from 1<sup>st</sup> May
  - Completion: (Mandatory start)
    - Locally recorded FGM information from 1<sup>st</sup> Sept
    - Trust submissions to DH beginning from 1st Oct
  - End Date:
    - Locally recorded FGM information from 1<sup>st</sup> March
    - Trust submissions to DH ending in April 2015
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## 4.4 Submissions: Collection Periods

Collection	Local Collection Period (Clinicians)	Unify2 Submission Open Date (Information Team)	Unify2 Submission Closing Date (Information Team)	Voluntary/ Mandated Submission
<b>Dates</b>	1 <sup>st</sup> – 31 <sup>st</sup> Jul 2014	1 <sup>st</sup> Aug 2014	8 <sup>th</sup> Aug 2014	Voluntary
	1 <sup>st</sup> – 31 <sup>st</sup> Aug 2014	1 <sup>st</sup> Sept 2014	5 <sup>th</sup> Sept 2014	Voluntary
	1 <sup>st</sup> – 30 <sup>th</sup> Sep 2014	1 <sup>st</sup> Oct 2014	10 <sup>th</sup> Oct 2014	Mandated
	1 <sup>st</sup> – 31 <sup>st</sup> Oct 2014	1 <sup>st</sup> Nov 2014	7 <sup>th</sup> Nov 2014	Mandated
	1 <sup>st</sup> – 30 <sup>th</sup> Nov 2014	1 <sup>st</sup> Dec 2015	5 <sup>th</sup> Dec 2015	Mandated
	1 <sup>st</sup> – 31 <sup>st</sup> Dec 2014	1 <sup>st</sup> Jan 2015	9 <sup>th</sup> Jan 2015	Mandated
	1 <sup>st</sup> – 31 <sup>st</sup> Jan 2015	1 <sup>st</sup> Feb 2015	6 <sup>th</sup> Feb 2015	Mandated
	1 <sup>st</sup> - 28 <sup>th</sup> Feb 2015	1 <sup>st</sup> Mar 2015	6 <sup>th</sup> Mar 2015	Mandated
	1 <sup>st</sup> – 31 <sup>st</sup> Mar 2015	1 <sup>st</sup> April 2015	10 <sup>th</sup> April 2015	Mandated

# 4.5 Submissions: Findings

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High level findings to date on voluntary submissions (approx.);

- 30% of all Acute Trusts submitting returns
- 8% of all Acute Trusts provided positive findings
- 27% of all Acute Trusts in London have submitted responses
  - Of which 50% have provided FGM information

To be taken forward, from July 2014;

- Detailed analysis of data submitted
  - Quality assurance on data
  - Trust engagement to support uptake
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# 5. Organisations

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## FGM Prevalence Standard;

- All Clinicians within any healthcare setting must record FGM when it is identified
  - Only Acute Trusts to return FGM information centrally
  - Other healthcare settings can return FGM information if they wish
  - Communicating guidance for clinicians in other healthcare settings will become available
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# 6 FGM Reporting

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On-going development, to review FGM Prevalence reports and publications

Examples:

- Newly identified cases (month on month)
- FGM type prevalence
- All active cases (child, adult, totals)
- Number of deinfibulations (including any repeats identified)
- Regions of increasing/ reducing prevalence

Not an exhaustive list

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# 7 Considerations

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- Considerations for new FGM Terminology and Clinical Classifications
    - History of Deinfibulation as a clinical finding
    - FGM Type 4 sub-qualifiers; Pricking, Piercing, Incision, Stretching, Cauterisation
    - *Repeat Deinfibulation (rejected)*
    - *FGM Type 09 – ‘Unknown’ (rejected)*
  - ICD-10 5<sup>th</sup> Edition: Personal History of Female Genital Mutilation will be available from 1<sup>st</sup> April 2015
  - Alternative submission tool instead of Unify2
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# 8 Next Steps

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- Quality assurance on submissions
  - Detailed analysis on findings
  - Development of reports for wider publication
  - Enhancing the FGM dataset and standards for post April 2015, e.g.
    - Family History of FGM, Daughters, Country/ Region of Origin, Other healthcare settings
  - Testing value of FGM reports
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Questions?

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# Further Information/ Contacts

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FGM Prevalence Dataset Documentation:

[http://www.isb.nhs.uk/documents/isb-1610/amd-01-2014/index\\_html](http://www.isb.nhs.uk/documents/isb-1610/amd-01-2014/index_html)

- Standard Specification
  - Dataset Definition
  - Terminology & Clinical Classifications
- Implementation Guidance

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Cross Government Programmes

- FGM Prevention Programme
- Child Protection Information Sharing Service

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