Female Genital Mutilation (FGM) Enhanced Dataset

April to June 2015, experimental statistics

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This report is of particular interest to the Department of Health in support of the FGM Prevention Programme. It may also be of interest to healthcare providers and commissioners to monitor the quality and effectiveness of services, to researchers and charities working on this subject and to members of the public.

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Executive Summary

The Female Genital Mutilation (FGM) Enhanced Dataset (SCCI 2026) is a repository for individual level data collected by healthcare providers in England, including acute hospital providers, mental health providers and GP practices.

All figures reported below relate to national level English data for FGM attendances during the quarter April to June 2015.

- There were 1,036 newly recorded\(^1\) cases of FGM reported, with 1,159 total attendances\(^2\) for FGM.
- 60 NHS trusts submitted one or more FGM attendance records. One GP practice submitted one or more FGM attendance records. Submission became mandatory for acute trusts on 1 June 2015, and becomes mandatory for GP practices and mental health trusts from 1 October 2015 onwards.
- Where the FGM type is known, type 2 has the highest incidence with 37.6 per cent.
- FGM types 1, 2 and 3 covered over 90 per cent of women and girls with a known FGM type in the cohort, with a relatively low incidence of the remaining categories (type 4, history of type 3 and type 3 – reinfibulation identified).
- There were 9 women or girls under the age of 18 at the point of first attendance, 0.9 per cent of newly recorded cases.
- Self report was the most common FGM identification method, accounting for 75.1 per cent of newly recorded cases where the means of FGM identification was known.
- 43 deinfibulation procedures were recorded. Deinfibulation was undertaken at 6.4 per cent of attendances where deinfibulation status was specified, rising to 36.8 per cent where FGM type 3 (including history of type 3 and type 3 - reinfibulation identified) was also recorded.

Definitions

\(^1\) Newly Recorded women and girls with FGM are those who have had their FGM information collected in the FGM Enhanced Dataset for the first time. This will include those identified as having FGM and those having treatment for their FGM.

‘Newly recorded’ does not necessarily mean that the attendance is the woman or girl’s first attendance for FGM.

\(^2\) Total Attendances refers to all attendances in the reporting period where FGM was identified or a procedure for FGM was undertaken. Women and girls may have one or more attendances in the reporting period. This category includes both newly recorded and previously identified women and girls.
Introduction

Female genital mutilation (FGM) refers to procedures that intentionally alter or cause injury to the female genital organs for non-medical reasons. FGM has been illegal in the UK since 1985, with the law being strengthened in 2003 to prevent girls travelling from the UK and undergoing FGM abroad.

It is important to note that if a patient is identified through the delivery of care from the NHS as having had FGM, this does not mean that she had FGM either recently or that the FGM was carried out in the UK.

This is the first report of the FGM Enhanced Dataset.

Understanding the Data

FGM datasets

The FGM Prevention Programme is a programme of work led by the Department of Health to improve the NHS response to FGM; this includes projects to improve awareness, provision of services and management of FGM, and safeguarding of girls at risk.

The earlier FGM Prevalence Dataset collected and published data from acute trusts covering the period 1 September 2014 to 31 March 2015. The FGM Prevalence Dataset collected non-identifiable aggregate data about the prevalence of FGM within the female population as treated by acute NHS trusts in England. Prior to the FGM Prevalence Dataset in 2014/15 there was no collection of the prevalence of FGM. The final report of this prevalence data can be found on the HSCIC website: FGM Prevalence Reports

The Enhanced Dataset is an individual level data collection containing a much wider range of data items than the Prevalence collection. The Enhanced Dataset has also extended collection beyond acute trusts to include mental health trusts, GP practices and community services within mental health trusts. It became mandatory for all acute trusts to collect and submit the FGM Enhanced Dataset from 1 June 2015 and will be mandatory for all mental health trusts and GP practices from 1 October 2015.

The Enhanced Dataset is an Information Standard (SCC12026) that was published and began data collection on 1 April 2015. To read more about the FGM Enhanced Dataset Information Standard visit www.hscic.gov.uk/isce/publication/sc12026. The FGM Enhanced Dataset Information Standard (SCC12026) and the Multi-agency Practice Guidelines\(^1\) require all clinicians across all NHS healthcare settings to record in the clinical notes when a patient with FGM is identified, and what type it is. This should be done as part of the clinical examination during routine provision of care.

Data is submitted to the clinical audit platform managed by the Health and Social Care Information Centre every time the woman or girl has treatment related to her FGM or gives birth to a baby girl,

every time FGM is identified by a clinician or reported by the woman and when there is a change in
the FGM type.

The full dataset contains 30 data items including: patient demographic data, specific FGM
information, and referral and treatment information. The full dataset is outlined here:
http://www.hscic.gov.uk/media/18370/FGM-Enhanced-
Dataset/xls/FGM_Enhanced_Dataset_v1.1.xls. The reasons for collecting these data items are
given in the Standardisation Committee for Care Information (SCCI) FGM specification document:

Given the sensitive nature of the subject matter, we have adopted a cautious approach to FGM
reporting. Consequently only the headline counts have been reported in this inaugural publication.
The quality and completeness of the other items in the data collection are being reviewed. We are
planning to publish data involving a wider range of items in future reports, once further data have
been collected and the quality of the new data items is established.

Comparing outputs from the Prevalence and Enhanced
Datasets

For the FGM Prevalence Dataset, ‘newly identified’ cases and ‘active cases’ were determined
locally and submitted for analysis.

With the FGM Enhanced Dataset, newly recorded cases are presented in this report. These
women and girls are newly recorded in the FGM Enhanced Dataset, which began collecting on 1
April 2015, but may have been previously identified by the health provider as having FGM and may
have been included in the FGM Prevalence Dataset.

The concept of ‘active’ cases is not included in this publication as FGM information is added
whenever it is identified and there is no way to record if a woman is still under the care of an
organisation in the database system.

In the FGM Prevalence Dataset, a patient would have been counted more than once if they had
attended more than one hospital trust. In the FGM Enhanced Dataset, because the data is
collected at patient level, it is not possible to double count the patient.

The FGM Enhanced Dataset will be reported on a quarterly basis. The FGM Prevalence Dataset
was reported on a monthly basis for the seven months it was collected.

Further information

The Data Quality Statement accompanying this report provides further information on the
publication and data. The technical standard for the dataset provides further information on the
collection.²

² Information standard for the Female Genital Mutilation Enhanced Dataset
http://www.hscic.gov.uk/isce/publication/scci2026
Results

This report presents the results of the Female Genital Mutilation Enhanced Dataset collection for the first time. Results for the first three months of collection (April - June 2015) are shown. For this first report data is only presented at a national, England, level. Future reports will contain further breakdowns of the data including geographical information.

Suppression of small numbers

A risk assessment has been carried out as to the possible identification of women and girls from the publication of this data. Suppression procedures are in place to manage this risk. National data is not suppressed, but when data below this geographical level is presented it will undergo primary suppression to obscure numbers between 0 and 4. Where an aggregate figure would enable the calculation of a suppressed number between 0 and 4, an additional number greater than 4 will also be suppressed. This is known as secondary suppression. Only national data is presented in this first report, so no suppression has been applied.
Number of submitting organisations

This table shows the number of organisations submitting attendance data in the collection period, broken-down by organisation type. Submission was only mandated for acute trusts from June 2015 and will not be mandated for GP practices and mental health trusts until October 2015.

Table 1.0: Number of organisations in England submitting attendance data, April to June 2015.

<table>
<thead>
<tr>
<th>Submitting organisation¹ type</th>
<th>April 15</th>
<th>May 15</th>
<th>June 15</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS trust</td>
<td>38</td>
<td>44</td>
<td>47</td>
<td>60</td>
</tr>
<tr>
<td>GP practice</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>39</strong></td>
<td><strong>44</strong></td>
<td><strong>47</strong></td>
<td><strong>61</strong></td>
</tr>
</tbody>
</table>

¹ The organisation that submitted the Attendance record.

61 organisations submitted one or more attendance records during the reporting period. With the exception of one GP practice, all submitting organisations were NHS trusts. The number of GP practice submitters is likely to rise when submission by GP practice becomes mandatory on 1 October 2015.

There are 241 NHS trusts in England³, although not all trusts would be expected to have an instance of FGM in the reporting period. For comparison, 76 NHS trusts reported one or more FGM care contacts in the final three months of FGM Prevalence reporting (January to March 2015)⁴. There are about 8,000 GP practices in England⁵.

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³ NHS trusts recorded as active on 1 April 2015 in the Organisation Data Service (ODS) trust reference table extracted on 28 August 2015 [http://systems.hscic.gov.uk/data/ods/datadownloads](http://systems.hscic.gov.uk/data/ods/datadownloads).
⁵ GP Practices recorded as active on 1 April 2015 in the ODS GP Practice reference table extracted on 28 August 2015 [http://systems.hscic.gov.uk/data/ods/datadownloads](http://systems.hscic.gov.uk/data/ods/datadownloads).

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Counts of total attendances and women and girls newly recorded in the FGM Enhanced Dataset

Newly recorded women and girls with FGM are those who have had their FGM information collected in the FGM Enhanced Dataset for the first time. This will include those identified as having FGM and those having treatment for their FGM. These women and girls are newly recorded in the FGM Enhanced Dataset, which began collecting on 1 April 2015, but may have been previously identified by the health provider as having FGM and may have been included in the FGM Prevalence Dataset.

Table 2.0: Number of attendances in England submitted for the period April to June 2015.

This table shows the number of women and girls newly recorded in the FGM Enhanced Dataset and the total FGM attendances by month.

<table>
<thead>
<tr>
<th>Month of attendance for FGM</th>
<th>Newly recorded&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Total attendances&lt;sup&gt;2&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>April 2015</td>
<td>298</td>
<td>318</td>
</tr>
<tr>
<td>May 2015</td>
<td>323</td>
<td>378</td>
</tr>
<tr>
<td>June 2015</td>
<td>415</td>
<td>463</td>
</tr>
<tr>
<td>Total</td>
<td>1,036</td>
<td>1,159</td>
</tr>
</tbody>
</table>

<sup>1</sup> Women and girls first recorded in the FGM Enhanced Dataset during the reporting period. This will include those identified as having FGM.

<sup>2</sup> Women and girls may have one or more attendances in the stated period. This includes both newly recorded and previously recorded women and girls. An attendance will be when a woman or girl with FGM has had treatment for her FGM or given birth to a baby girl, or when FGM has been identified.

In all, 1,036 women and girls were newly recorded in the FGM Enhanced Dataset during the reporting quarter. Reported cases of FGM rose by over one third between April and June 2015, which reflects the policy change that made acute trust submission mandatory on 1 June 2015.

For comparison, information on 1,675 newly identified women and girls was submitted in the final three months of FGM Prevalence reporting (January to March 2015)<sup>6</sup>. As noted in the ‘Understanding the Data’ section, caution is advised when comparing Enhanced and Prevalence

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Female Genital Mutilation (FGM) Enhanced Dataset: April - June 2015, experimental statistics

outputs. For example, double counting may have occurred in the FGM Prevalence Dataset, but is impossible in the Enhanced collection; and the cases newly recorded in the enhanced dataset may have been previously included in the FGM Prevalence Dataset.

The following table shows the number of women and girls newly recorded in the FGM Enhanced Dataset by the type of FGM identified.

Table 2.1: Number of newly recorded women and girls in England by FGM type, April to June 2015.

<table>
<thead>
<tr>
<th>FGM type</th>
<th>Type 1</th>
<th>Type 2</th>
<th>Type 3</th>
<th>History of type 3</th>
<th>Type 3 – reinfibulation identified</th>
<th>Type 4</th>
<th>Unknown</th>
<th>Not reported</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>113</td>
<td>134</td>
<td>78</td>
<td>4</td>
<td>1</td>
<td>26</td>
<td>661</td>
<td>19</td>
<td>1,036</td>
</tr>
<tr>
<td>England</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

i. Women and girls first recorded in the FGM Enhanced Dataset during the reporting period as having undergone FGM. This will include those identified as having FGM.

ii. Categories of FGM type are defined in the definitions box below right.

Not Reported = When no FGM type (including Unknown) has been submitted.

98.2 per cent of newly recorded women and girls had an FGM type submitted, although the majority were reported as Unknown (65.0 per cent). Where the FGM type was known, type 2 had the highest incidence with 37.6 per cent. Types 1, 2 and 3 covered over 90 per cent of known FGM types, with a relatively low incidence of the remaining known categories.

The four FGM types defined by the World Health Organisation (http://www.who.int) are:

- **Type 1**: Partial or total removal of the clitoris and/or the prepuce (clitoridectomy).
- **Type 2**: Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision).
- **Type 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 4**: All other harmful procedures to the female genitalia for non-medical purposes, including pricking, piercing, incising, scraping and cauterization.

The FGM Enhanced Dataset includes three additional categories relating to FGM Type 3:

- **History of Type 3**: Current state where a woman or girl had FGM Type 3, but has since been deinfibulated.
- **Type 3 - Reinfibulation Identified**: Current state where a woman or girl has been closed previously, opened and is currently closed again.
- **Unknown**: When the FGM category could not be ascertained. It is acknowledged that even for experienced healthcare workers who frequently see women and girls with FGM it can still often be difficult to determine the type of FGM that had been undertaken.
Table 2.2: Number of newly recorded women and girls in England by age group, April to June 2015.
This table shows the newly recorded women and girls by age group. The data is grouped by whether the woman or girl was under 18 at their first recorded attendance for FGM. Age is classed as Not Known where the date of birth is invalid or not recorded.

<table>
<thead>
<tr>
<th>Age at attendance for FGM</th>
<th>Under 18</th>
<th>18 and over</th>
<th>Not known&lt;sup&gt;ii&lt;/sup&gt;</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>9</td>
<td>1,026</td>
<td>1</td>
<td>1,036</td>
</tr>
<tr>
<td>England</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<i>Women and girls first recorded in the FGM Enhanced Dataset during the reporting period. This will include those identified as having FGM.</i>

<i>Not Known = no valid date of birth submitted, so unable to calculate age at attendance.</i>

A valid data of birth was submitted for almost all newly recorded women and girls in the reporting period (99.9 per cent). 99.1 per cent of newly recorded women and girls were aged 18 or over at the point of their first recorded attendance, with 0.9 per cent aged under 18.
Table 2.3: Number of newly recorded women and girls in England by how the FGM was identified, April to June 2015.

This table shows the newly recorded women and girls by how the FGM was identified.

<table>
<thead>
<tr>
<th>FGM identification method</th>
<th>National</th>
<th>England</th>
<th>Self report</th>
<th>On examination</th>
<th>Other clinician</th>
<th>Other or unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>557</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>182</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>294</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1,036</td>
</tr>
</tbody>
</table>

i. Women and girls first recorded in the FGM Enhanced Dataset during the reporting period. This will include those identified as having FGM.

ii. Self report = the woman or girl said they had FGM at this attendance.
    On examination = a clinical examination at this attendance led to the identification of FGM.
    Other clinician = a referral has been made stating that FGM has been identified.
    Other or unknown = the method of identification does not map to one of the above categories or is unknown.

71.6 per cent of women and girls had confirmation of the how the FGM was identified (self report, on examination or other clinician). Self report was the most prevalent means of identification, covering 75.1 per cent of known submissions.

**Definitions: FGM identification method**

The FGM can be identified in a number of ways:

- **Self Report**: the woman or girl said they had FGM at the attendance
- **On Examination**: a clinical examination at the attendance led to the identification of FGM.
- **Other Clinician**: a referral has been made stating that FGM has been identified
- **Other or Unknown**: the method of identification does not map to one of the above categories or is unknown
Deinfibulation procedures undertaken

Deinfibulation is the surgical procedure to open up the closed vagina of FGM type 3. Table 3.0 shows the number of deinfibulation procedures undertaken during the collection period. Because deinfibulation may occur at any attendance, this table looks at total attendances in the reporting period, not just for newly recorded women and girls. To ensure that all deinfibulation procedures are captured, the table below looks at all attendances, not just women and girls reported with FGM type 3. Women and girls with an unknown FGM type (and where types 1, 2 or 4 have been reported) are therefore included.

Table 3.0: Number of deinfibulation procedures undertaken in England, April to June 2015.

<table>
<thead>
<tr>
<th>Deinfibulation procedures undertaken?</th>
<th>Yes</th>
<th>No</th>
<th>Not reported</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>43</td>
<td>626</td>
<td>490</td>
<td>1,159</td>
</tr>
<tr>
<td>England</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

i. Women and girls may have one or more attendance during the reporting period. Includes both newly recorded and previously recorded patients. An attendance will be when a woman or girl with FGM has had treatment for her FGM or given birth to a baby girl, or when FGM has been identified.

57.7 per cent of total attendances for FGM had confirmation of whether or not deinfibulation was undertaken. 43 deinfibulation procedures were recorded. Deinfibulation was undertaken at 6.4 per cent of attendances where deinfibulation status was specified, rising to 36.8 per cent where type 3 (including history of type 3 and type 3 reinfibulation identified) was also specified.

Definitions:

Infibulation or FGM type 3 is the 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 [http://www.who.int].

Deinfibulation is the surgical procedure to open up the closed vagina of a woman or girl with FGM type 3. Deinfibilation is often undertaken to facilitate delivery during childbirth.

Reinfibulation is where a woman or girl has been closed previously (infibulated), opened (deinfibulated) and is currently closed again (reinfibulated).
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