Female Genital Mutilation (FGM) Enhanced Dataset, Data Quality Statement
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**Introduction**

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

The Female Genital Mutilation (FGM) Enhanced Dataset \( (\text{SCCI} \ 2026) \) replaces the earlier FGM Prevalence Dataset, prior to which there was no collection on FGM prevalence. From September 2014 to March 2015 the Prevalence Dataset collated mandatory aggregate returns of FGM incidence from acute trust providers in England.

The Enhanced Dataset is an individual level data collection of a wider range of data items than the Prevalence Dataset. Collection began on 1 April 2015 and submission was mandatory from July 2015 for acute trusts and from October 2015 for mental health trusts and GP practices. Data is collected on the NHS Digital Clinical Audit Platform.

**Relevance**

**Limitations of data collection coverage**

The FGM Enhanced Dataset collects data from acute trusts, mental health trusts and GP practices in England. It does not collect data from other settings such as sexual health, GUM and HIV clinics. It does not collect data from outside England.
Accuracy and Reliability

As a general rule, caution is advised in interpreting FGM Enhanced Dataset findings because data completeness can be low and often varies by region, submitter and data item. Caveats are noted in the descriptions accompanying the outputs in the main report.

Some comparisons, both with the earlier quarterly and annual publications of the FGM Enhanced Dataset and with other collections, including the FGM Prevalence Dataset, are possible, with caveats discussed in the 'Coherence and Comparability' section below.

The FGM Enhanced Dataset Information Standard (SCC12026) requires 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. It is therefore expected that data submitted will be accurate and reliable. All data should be validated prior to submission against the data quality criteria within the information standard.

Women and girls should only be recorded in the FGM Enhanced Dataset where they have been identified as having had FGM. When a woman with FGM has given birth to a baby girl, the baby should not be recorded in the FGM Enhanced Dataset unless the baby girl has also been identified with FGM. We are aware that babies in these circumstances have been recorded in the FGM Enhanced Dataset in error, and are working with the effected organisations to delete these records.

The number of organisations returning data for this collection may not be consistent in the early months of collection. The number and type of returning organisations is given in this publication. Any organisation could have submitted data from April 2015, but it was only mandated for acute trusts from July 2015, and mental health trusts and GP practices from October 2015. Cumulative organisation and activity figures are included in the report; as organisations may have added, deleted or amended records since the data was originally published, the figures included in time series in the current publication may not match those which were published previously.

Patient identifiable data is being collected as part of the current process to ensure data quality and to avoid duplication of records. This will remove the potential for double-counting, which was possible in the earlier FGM Prevalence Dataset, as it collected aggregated data only. Patients may be entered into the FGM Enhanced Dataset without an NHS number, but information associated with these patients will not be included in reports until they are recorded with an NHS number, to avoid double counting of patients and attendances.

Timeliness and Punctuality

Any organisation could submit data from April 2015. It has been mandatory for acute trusts from July 2015, and for mental health trusts and GP practices from October 2015.

Organisations were requested to ensure all data for the period April 2020 to June 2020 was complete in the collection system by the end of July 2020. The collection system allows updates to historic information. An initial extract was taken on 4 August 2020, and after an interval for provider data quality review and emendation, a final extract was taken on 17 August 2020, 48 days after the end of the activity period. Data was available for analysis on the same day. The date of the publication of the report was 27 August 2020, 10 days after data was available for analysis or 23 days after the initial data extract.
Accessibility and Clarity

Data is presented in charts and tables in the publication on the NHS Digital website. Downloadable versions of the charts and tables are also available in spreadsheet and csv format through the NHS Digital website, and transparency supporting data is later made available through data.gov.uk.

Links to the technical specification of the data are available through the NHS Digital website.

Coherence and Comparability

Comparability over time

The August 2020 report is the twenty-first quarterly report on the FGM Enhanced Dataset. The mandatory status of fields in the dataset is unchanged since December 2015. Comparisons to the earlier publications of the FGM Enhanced Dataset are possible, and time series data is published in annual reports on the data. However, examination of the earliest collected data should consider that engagement with the collection has increased since participation became more widely mandatory in October 2015. Coverage of data items varies over time and may often be of limited completeness and quality.

Comparison with the earlier FGM Prevalence Dataset is limited due to the difference in data item definition and collection method. The FGM Prevalence Dataset was an aggregate return from acute trusts only, whereas the FGM Enhanced Dataset collects from acute trusts, mental health trusts and GP practices, and collects patient identifiable data.

Participation data since the collection began is shown in this publication, broken-down by quarter.

The data was only a mandated collection from July 2015 for acute trusts, and for mental health trusts and GP practices since October 2015. The number and type of organisations returning data for this collection needs to be considered when interpreting the figures. The number of returning organisations is given in the publication (Table 1.1).

All figures in the report are derived from the latest available data extract, taken on 17 August 2020. This means that figures for previous quarters (e.g. numbers of newly reported women and girls) may differ from those published in earlier reports, as the FGM Enhanced Dataset is an ongoing collection, and records can be added or deleted at any time. The total number of cases in the present cohort is also likely to increase over time.

Some of the counts in the publication use ‘newly recorded’ women and girls as the cohort. In this context ‘newly recorded’ with FGM means 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. For example, an initial attendance for FGM may have occurred before the start of collection (1 April 2015). In that instance, the first attendance entered onto the data collection system would be classed as a newly recorded attendance.
Comparability with other sources

Number of cases

In addition to the FGM Prevalence Dataset (discussed above), other sources of hospital data may also be used to find a comparison. Hospital Episode Statistics (HES), a detailed set of hospital data, is of limited use for this purpose. The current classification of FGM within ICD10 (the diagnosis codes used in HES) is also associated with other conditions, and therefore cannot be used to specifically identify patients with FGM; however there is the capability to compare numbers of deinfibulations recorded in HES against instances reported as part of the FGM Enhanced Dataset.

There are other studies of FGM available, though results are not directly comparable with the figures in the FGM Enhanced Dataset:

- A study by UNICEF [Female Genital Mutilation/Cutting: a statistical overview and exploration of the dynamics of change (2013)] looked at prevalence in countries where FGM is more prevalent. It did not include England, Great Britain or the UK.
  - UNICEF published [Female Genital Mutilation/Cutting Country Profiles (2016, updated 2020)] which present statistical information on FGM within 31 countries where it is prevalent.

- A report published by City University London and Equality Now [Prevalence of Female Genital Mutilation in England and Wales: National and local estimates (2015)] estimated the prevalence of FGM in England and Wales and every region and local authority area. This applied age specific prevalence rates of FGM in their countries of birth, to migrant women living in England and Wales and enumerated in the 2011 census. It also used birth registration data, to estimate the number of maternities and girls born in FGM-practising countries and living in each local authority area. As there are no data about the overall prevalence of FGM among women born in the UK, they could not be included in these figures. The estimates used the assumption that the prevalence of FGM among women who migrated is the same as that among all women in their country of birth and the limitations of this are discussed. The report includes text, data tables and interactive maps: Maclaren A, Dorkenoo E. [Prevalence of Female Genital Mutilation in England and Wales: National and local estimates]. London: City University London and Equality Now, 2015.
Assessment of User Needs and Perceptions

This data has been collected and presented as part of the programme of work, led by the Department of Health and Social Care (DHSC), to improve the NHS response to FGM.

NHS Digital is keen to gain a better understanding of the users of this publication and of their needs. Your feedback is welcome and may be sent to enquiries@nhsdigital.nhs.uk (please include ‘FGM’ in the subject line). Alternatively you can call our contact centre on 0300 303 5678 or write to NHS Digital, 1 Trevelyan Square, Boar Lane, Leeds, LS1 6AE.

Feedback we receive on quarterly and annual reports informs changes to the design of later reports.

Performance, Cost and Respondent Burden

Aggregated data from the data collection used in this publication is required to support the DHSC led programme of work on FGM.

As part of the Health and Social Care Act 2012, NHS Digital has a statutory responsibility to seek to minimise the burden of data collections on the NHS. NHS Digital has a duty to make recommendations to the Secretary of State for Health and Social Care on how reductions in the burden could be achieved.

These responsibilities have led to the development of a new burden methodology and the launch of the Challenging Burden Service (CBS), which has been followed by the Data Standards Assurance Service (DSAS) acting on behalf of the Data Coordination Board (DCB) and taking over many of the functions of the Review of Central Returns (ROCR) programme.

The data is collected under Standardisation Committee for Care Information (SCCI) Technical Standard, SCCI 2026.
Confidentiality, Transparency and Security

As noted, patient identifiable data is being collected as part of the current process to ensure data quality and to avoid duplication of records. Patient identifiable information is held securely and with restricted access and will not be released from NHS Digital to other parties.

The FGM collection has been introduced under a Direction issued by the Department of Health and Social Care under the Health and Social Care Act 2012. This means that explicit consent for the information to be collected and its purpose is not required; but as part of good clinical practice and compliance with the Data Protection Act 1998 women should be provided with both verbal and written information about the collection when in contact with healthcare professionals.

Women and girls are advised that information about their FGM will be collected by NHS Digital. There is a patient information leaflet, available in several languages, to explain this to the patient. These can be ordered by visiting Health Publications.

The Directions issued to NHS Digital, as the Health and Social Care Information Centre (HSCIC), for this collection can be read on gov.uk, as the FGM Directions 2015.

Individuals are able to request that their information is removed from the dataset. At the initial contact they will be given information about how they can request that their information is removed.

Sexual health, GUM and HIV clinics do not need to submit FGM information to NHS Digital but the responsibilities for safeguarding children and vulnerable adults remains.

It is expected that through the introduction of the FGM Enhanced Dataset, all organisations will continue to follow existing NHS codes of practice in regard to patient confidentiality, information security management, record management and other legal obligations.

A risk assessment has been carried out as to the possible identification of patients from this publication. Suppression procedures are in place to manage this risk.

- All counts of people or attendance are rounded, including national totals. Numbers between 1-7 are rounded to 5 and all other numbers are rounded to the nearest 5.
- Zeroes are shown unsuppressed.
- Percentages are calculated using rounded numbers. This can lead to misleading figures when dealing with small numbers so where the denominator is less than 20, the percentage is suppressed.
- Other calculations, such as averages, are rounded to the nearest whole number.

To support the FGM Enhanced Dataset implementation, a Privacy Impact Assessment has been undertaken, to help identify privacy risks, to support action to mitigate those risks prior to any collection, sharing, retention or analysis of FGM information.