Female Genital Mutilation (FGM) prevalence dataset

Data Quality Note

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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, researchers and charities working on this subject and to members of the public.

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Introduction

The Female Genital Mutilation (FGM) prevalence dataset (ISB 1610) is a monthly return of data (mandated from 1st September 2014) from acute hospital providers in England. It is an aggregated return of the incidence of FGM including women being treated or seen (Active Cases) and newly identified patients within the reporting period.

This information is being collected to gain a national picture of the prevalence of FGM to support the Department of Health’s (DH) FGM Prevention (FGMP) Programme.

Female genital mutilation (FGM) comprises all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons.
Relevance

Limitations of data collection coverage

Under the ISB 1610 Standard Clinical staff must record in patient healthcare records when it is identified that a patient has undergone FGM. This applies to all NHS clinicians and healthcare professionals across the NHS.

However, the requirement to submit the FGM Prevalence Dataset is only mandatory for Acute (Foundation and non-Foundation) Trusts, including A&E departments.

Other organisations (which may include GPs) may wish to provide an FGM Prevalence Dataset centrally. It should be noted that the dataset standard has not had additional development to ensure it is designed to be suitable for other healthcare settings.

The data is an aggregate collection from individual trusts. If one trust sees a new case and the same patient is also seen for the first time by a separate trust that patient will be recorded as a new case twice. Similarly if a patient is recorded in the active caseload of more than one trust they will be counted multiple times. To overcome this would require identifiable information for each patient to be submitted centrally (for example NHS number or name, date of birth and home address). An enhanced FGM dataset is being considered that would contain identifiable data and would allow for these challenges to be addressed.

Coverage of data collection in the publication

The first publications of this dataset will not report all of the data collected. Initially the data in the reports will be limited to active caseload and newly identified cases for England and for the four commissioning regions of England.

We are planning to publish data broken down by the additional factors collected during 2015. The quality and completeness of these factors in the data collection are not yet known for the mandated collection. Provisional data would suggest that there may be issues that will require further analysis before the full data can be published. This analysis is planned during spring 2015, with publication of the additional elements as soon afterwards as possible.

In addition to that being published data is collected on:

- Age category (Under 18 years old/Over 18/Not known or not recorded)
- Type of FGM (for a full description on FGM types see the technical specification signposted to below)
- Activity treatment function code – the specialised service within which the patient is being treated or has been referred to.
- Total number of care contacts within reporting period
- Number of patients undergoing ‘deinfibulation’ procedure (Deinfibulation is a surgical technique to reverse the closure of the vaginal opening after infibulation (one type of FGM)).
- Number of patients undergoing ‘repeat deinfibulation’ procedure

As the data is collected at hospital trust level it could be reported at this lower level.

For full details of the data please see the technical specification here:
Accuracy and Reliability

This is the first collection of data on FGM in this format. With nothing to compare it to directly it is difficult to estimate its proximity to the unknown true value.

As this is data collected from hospitals other sources of hospital data are the most likely place to find a comparison. Hospital Episode Statistics (HES), a detailed set of hospital data, is limited in this regard however. The current classification of FGM within ICD10 (the diagnosis codes used in HES) is associated with other conditions, and therefore cannot be used to specifically identify FGM patients.

There are studies of FGM available but they do not provide a comparable figure to estimate the proximity of the statistics presented here to an unknown true value.

- 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, Britain or the UK.
- A report published by the Foundation for Women’s Health, Research and Development (FORWARD) in collaboration with The London School for Hygiene and Tropical Medicine and The Department of Midwifery, City University estimated the prevalence of FGM in England and Wales [http://www.forwarduk.org.uk/download/96](http://www.forwarduk.org.uk/download/96). This applied prevalence figures of FGM in their home countries to migrants to England and Wales. It, and previous estimates, omitted second generation women born in the UK who may have undergone FGM. Assumptions were also made that the prevalence within migrant groups were the same as in the country of origin.

Timeliness and Punctuality

The first mandated collection of this data covers September 2014. The publication of this data was on the 16th October 2014. Future monthly publications are initially planned to be within a month or two of the end of the collection period.

Accessibility and Clarity

Initially the data in the reports will be limited to Active Caseload and Newly Identified cases for England and for the four commissioning regions of England.

Data is presented in a table on the HSCIC website. Downloadable versions of the table in spreadsheet and csv format are also available through the HSCIC website.

Web links to the technical specification of the data are available through the HSCIC website and are available here: [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)
The key elements of the data collection are presented alongside the table on the HSCIC website.

**Coherence and Comparability**

**Comparability over time**
The first publication of this data is 16 October 2014. It is a monthly collection of data and publication, so future reports will allow comparisons over time.

**Comparable with other sources**
As stated above, direct comparison with HES is not possible. This data may however help inform interpretation of HES data.

**Comparability across regions**
Data is presented for the four commissioning regions of England. However, no figure is presented for the population (children and women) at risk of FGM. These numbers may vary between regions so this limitation needs to be considered when comparing regional data.

**Trade-offs between Output Quality Components**
The requirement to submit the FGM Prevalence Dataset is only mandatory for all acute (Foundation and non-Foundation) trusts, including A&E departments. There is a programme of work, led by the Department of Health, to improve the NHS response to FGM. This is the first data collection requirement. The information collected is needed to inform the next stages of the FGM prevention programme.

As detailed above, we are not initially reporting all of the data collected. Once more mandated data has been collected, analysis of the additional elements will inform what is published and how. This analysis is planned in the spring of 2015, with publication of the additional elements to be made available as soon after this analysis as possible.

Limited, high level numbers are available now to ensure some data is available in a timely manner following the initial mandated collection of this data.
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, to improve the NHS response to FGM. The information collected is needed to inform the next stages of the FGM prevention programme.

The HSCIC 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 enquires@hscic.gov.uk (please include ‘FGM’ in the subject line). Alternatively you can call our contact centre on 0300 303 5678 or write to HSCIC, 1 Trevelyan Square, Boar Lane, Leeds, LS1 6AE.

Performance, Cost and Respondent Burden

The data collection used in this publication is required to support the DH led programme of work on FGM. As discussed above this is due to the lack of data elsewhere.

It is collected under the Review of Central Returns (ROCR) license ROCR/OR/2231/001MAND and standard - ISB 1610 FGM Prevalence Dataset.

As part of the Health and Social Care Act 2012, HSCIC has a statutory responsibility to seek to minimise the burden of data collections on the NHS. The HSCIC has a duty to make recommendations to the Secretary of State for Health 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 Burden Advice and Assessment Service (BAAS) which takes over many of the functions of the Review of Central Returns (ROCR) programme. Further information can be found here: http://www.hscic.gov.uk/baas.

The Information Standards Board for Health and Social Care (ISB) approved information standards for implementation in English health and care. For further information please see the Information Standards section of the HSCIC website: http://systems.hscic.gov.uk/data.

Confidentiality, Transparency and Security

Providers are required to apply data validation processes to assure the quality and completeness of data prior to submission centrally. Quality assurance is required to be undertaken by submitting information teams to ensure that a patient is not counted twice within a submission, and therefore avoid duplicate recording of information. However, if in doubt as to whether the patient has been included in this return during previous reporting periods, they should be included again.

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; National data will not be suppressed, but at commissioning region numbers of 1 to 5 will be. This will be reviewed when the content of the report changes or annually if sooner.