

A specific repository for health professionals to safeguard girls against FGM

England 2014 - 2016

In brief

The Female Genital Mutilation (FGM) Enhanced Dataset is one of the action of the Department of Health's FGM Prevention Programme which is a national £3M change programme to improve the way in which the NHS responds to the health needs of girls and women who have had FGM, and to actively support prevention. This includes supporting health professionals to be confident when having discussions with women and girls. It will also help us to record and share FGM administrative data and information appropriately and to take the necessary action to safeguard girls against risk.

Girl summit and the health response to FGM in UK

Female genital mutilation (FGM) is child abuse and the Department of Health and NHS England are committed to caring for FGM survivors, protecting our girls from FGM, and preventing future generations from having to undergo FGM. On 22 July 2014, the UK hosted the first Girl Summit, aimed at mobilising domestic and international efforts to end FGM and child, early and forced marriage within a generation. The Department of Health's Female Genital Mutilation Prevention Programme in partnership with NHS England was launched at the Girl Summit, and is working on a number of FGM projects now underway across NHS settings to improve the health response to FGM.

Following publication of the Data Standard on 2 April 2014, it became mandatory for any NHS healthcare professional to record (write down) within a patient's clinical record if they identify through the delivery of healthcare services that a woman or girl has had FGM. For Acute Trusts from September 2014, it became mandatory to collate and submit anonymised aggregated data about the number of patients treated who have had FGM to HSCIC every month. The first report of this anonymised data, reporting on the data from September, was published on 16 October 2014 and is available on the Health and Social Care Information Centre website. www.hscic.gov.uk/fgm

All these data are stored in the Female Genital Mutilation (FGM) Enhanced Dataset which is a repository for individual level data collected by healthcare providers in England, including acute hospital providers, mental health providers and GP practices building on the Female Genital Mutilation Prevalence Dataset, which finished collecting data on 10 April 2015 and published on April 30th 2015. The

Reporting duty for health professionals

FGM Enhanced Dataset Information Standard (SCCI2026) was published on 1 April 2015. It has been mandatory for Acute Trusts to submit patient level data since 1 July 2015. From October 1st 2015 the following organisations have been required to have regard to the FGM Enhanced dataset standard. General Practice; Mental Health Trusts. Sexual health and GUM (Genito-Urinary Medicine) clinics, where patients do not have to provide their personal information, are out of scope but these services are nonetheless reminded of their responsibilities to share information to ensure appropriate safeguarding responses are put in place every time this becomes necessary.

In October 2015, a new professional mandatory reporting duty was introduced for all regulated professionals to report all girls under 18 with FGM to the police. The duty has been brought through the Serious Crime Act 2015 and means that whenever regulated professionals (health, social care and education) identify that a girl under 18 has had FGM, or if the girl discloses this herself, the professional must make a report to the police. In addition, GPs and mental health trusts have been mandated under the Health and Social Care Act 2012 to record FGM patient data under the FGM Enhanced Dataset. Acute Trusts have had to meet the requirements of the FGM Enhanced Dataset since 1 July 2015.

Organisations are reminded of the Department of Health's guidance *Female Genital Mutilation Risk and Safeguarding: Guidance for professionals* (2015). This guidance provides information on:

- identifying when a girl (including an unborn girl) or young woman may be at risk of FGM and responding appropriately to protect them;
- identifying when a girl or young woman has had FGM and responding appropriately to support them; and measures that can be implemented to prevent and ultimately eradicate the practice of FGM.

Data quality assessment and privacy issues

The FGM Enhanced Dataset requires organisations to record, collect and return detailed information about FGM within the patient population, as treated by the NHS in England. Data should be submitted every time the woman or girl has a procedure /treatment related to her FGM or gives birth to a baby girl, and every time FGM is identified (by a clinician or self-reported), not just the first time.

The dataset includes: patient demographic data, specific FGM information, referral and treatment information.

The data collected is sent to the Health and Social Care Information Centre (HSCIC), where it is anonymised, analysed and published in aggregate form. Personal information is only collected as part of the FGM Enhanced dataset for internal data quality assurance and to avoid duplicate counting. A woman or child's personal details will never be published in the national aggregate reports and will never be passed to anyone outside HSCIC. This work specifically will not pass any personal details to the police or social services – the collection of this data will not trigger individual criminal investigations.

With regards to the collection of patient identifiable FGM information, in common law terms an individual's explicit consent can provide the lawful basis to override confidentiality. For good reasons, that consent is not being sought in this case. A Direction has been issued to the HSCIC from Department of Health which outlines a formal legal requirement on the HSCIC to process data, and such requirements override the usual rules around common law and confidentiality, as long as:

- there is a clear explanation to a patient about what is happening to their data – what the Data Protection Act (DPA) terms as 'fair processing' and,

- a fair processing route to handle any objections to the collection Section 10 of the DPA gives individuals the right to send a formal notice to a data controller requesting they stop processing data because it will cause substantial damage or substantial distress and that this would be unwarranted.

The obligation on the data controller (HSCIC) is not to automatically accept such a notice but to respond within 21 days saying they will either accept the notice and stop the processing, or that the notice is unjustified and will not be accepted. However, due to commitments made by the Secretary of State, patient objections for FGM collections are to be treated as an automatic stop processing request. This is a policy decision that goes beyond the law's requirements.

Improvements and main benefits

The FGM Enhanced dataset focuses on two specific elements:

- the recording and sharing of FGM information locally, specifically for the provision of care;
- the central submission of FGM information when it has been identified and ultimately recorded within the Clinical Audit Platform (CAP).

The main focus on collecting FGM data from various clinical settings is to provide nationally consistent information on those women and girls who have had FGM, and to better inform the commissioning of services required.

The improvements and benefits resulting from the information standard are:

- greater understanding of the extent and issue of FGM in England;
- evidence to justify why the range of FGM support and care services needs to be commissioned;
- using the information about when and where patients with FGM are identified and treated, to support service development.

For the FGM Enhanced Dataset, the HSCIC is publishing quarterly reports based on quarterly extractions from the data collection system, which will be published as an official statistic. The first report was based on the April–June 2015 quarter. Since the health service began recording incidences of FGM for the very first time, more than 1,000 cases of FGM were recorded in just three months in the UK. For the quarter April to June 2015, there were 1,036 newly-recorded cases¹ of FGM in England, with a total of 1,159 attendances for FGM.

Contact details

Health and Social Care Information Centre's Contact Centre
1 Trevelyan Square, Boar Lane - Leeds, West Yorkshire, LS1 6AE
Telephone: 0113 397 4129
e-mail enquiries@hscic.gov.uk

Links to audio-visual materials and websites with additional information/context (if available)

<http://www.hscic.gov.uk/fgm>

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.