

Data Provision Notice

for the FGM Enhanced Dataset

Information Asset Owner:

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Background

The Health and Social Care Act 2012 (the Act) gives the Health and Social Care Information Centre, now known as **NHS Digital** and hereafter referred to by this name, statutory powers, under section 259(1), to require data from health or social care bodies, or organisations that provide health or adult social care in England. Data will be required, where it has been Directed to establish an information system by the Department of Health (DH) or NHS England (NHSE).

When a direction is received, NHS Digital can issue a Data Provision Notice to the appropriate providers of the required data who are then legally required, under section 259(5) of the Act, to provide the data in the form, manner and period specified below.

This Data Provision Notice is for data required to support a direction from DH to NHS Digital for the collection of data in relation to the treatment of patients with female genital mutilation (FGM) in the NHS.

These data are being collected to ensure that adequate information is available to support the commissioning and planning of services. The work forms part of the FGM Prevention Programme, a wider change programme aiming to improve the NHS response to FGM and actively support prevention.

Purpose of the collection

DH needs specific information about patients with FGM being treated across the NHS to support the provision of appropriate services to meet the needs of women and girls who have FGM.

In 2014/15 NHS Digital collected data on a monthly basis from acute trusts to produce an aggregated number of people at each trust with FGM. This specific data reports are published on NHS Digital's website [here](#).

From 1 April 2015, the requirement was extended to include; additional organisations, further information and to transfer the collection on the Clinical Audit Platform. The collection is also now at an individual patient level in order ensure data quality and to identify when an individual patient is being treated across multiple healthcare sectors and providers. However the final report is published at aggregate level only.

The data collection will support improvements in:

- the quality and safety of NHS services available to women and girls with FGM
- the availability of NHS FGM prevalence data at a national level
- information sharing with partners agencies and local / cross government organisations at an aggregate level. Supporting joined up multi-agency working to tackle FGM across all sectors

On 1st April 2015 the Standardisation Committee for Care Information (SCCI), published the FGM Enhanced Dataset. The requirements and implementation guidance for this standard are available from: <http://content.digital.nhs.uk/isce/publication/scci2026>.

This Data Provision Notice is being issued retrospectively and is applicable to data requested from 1st April 2015.

The collection of data and publication of reports will continue until 31 March 2020. It will be for DH to confirm if this collection will be undertaken beyond that time, in conjunction with key stakeholders.

Benefits of the collection

DH launched the FGM Prevention Programme in 2014, in partnership with NHS England. The programme highlighted the need for information to support the commissioning of services, as the scope and needs of the patients are little understood. This aggregate data will be used by NHS England with partner agencies, to inform FGM prevention strategies, and support the commissioning of services for women and girls with FGM. Specifically this data collection will help to:

- Reduce the risk of services being commissioned based on anecdotal evidence
- Enable commissioners to identify where patient services are required to improve local patient outcomes
- Reduce the risk of insufficiently commissioned, poor quality services
- Improve the overall quality of NHS FGM prevalence data at a national level

Legal basis for the collection, analysis, publication and dissemination

NHS Digital has been directed by DH under section 254 of the Health and Social Care Act 2012 to establish and operate the FGM Information System for the collection and analysis of the information specified for this service.

A copy of the Directions supporting this notice is available from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/427336/fgm.pdf

This information is required by NHS Digital under section 259(1) of the Health and Social Care Act 2012.

In line with section 259(5) of the Act, all Acute and Mental Health Trusts (Foundation and Non-Foundation) and General Practices in England must comply with the requirement and provide information to NHS Digital in the form, manner and period specified in this Data Provision Notice.

This Notice is issued in accordance with the procedure published as part of NHS Digital duty under section 259(8).

The FGM Direction outlines a formal legal requirement on NHS Digital to process data, and such requirements override the usual rules around common law and confidentiality, as long as:

- a) 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,
- b) a 'fair processing' route to handle any objections to the collection.

Fair Processing

To meet the requirement to provide a *'fair processing'* notification to patients, health professionals should give the patient the FGM leaflet "More Information About FGM". This is available to order online, free of charge in English and eleven other languages. Organisations can also download copies from NHS Choices: <http://www.nhs.uk/fgm>

Giving the patient this leaflet fully meets the requirement for 'fair processing'. There is no requirement to discuss the FGM dataset in detail, or to ask a patient for explicit consent to collect their information. The patient is free to opt out of sharing their data (see below), and some clinicians may choose to explain this, as well as the benefits of sharing the information. If taking this approach, the patient information leaflet and the NHS Digital website contain information to support such discussions. Health professionals should also discuss the illegality of FGM in the UK and the many negative health consequences of the practice with each patient.

Objection Handling

There are two stages at which, if a patient raises an objection after having received the *'fair processing'* notification, their objection will be considered and acted upon. These together form the *'fair processing'* objection route.

1. If a patient raises an objection within the care delivery setting (i.e. within the GP surgery or the hospital), the local organisation must consider this objection within their own processes, and ensure they record within the healthcare record the outcome of this decision (i.e. whether or not to disclose any information to NHS Digital).
2. If the objection is not raised at this point, and the patient's information is submitted, they can still choose to contact NHS Digital at a later date to raise an objection using the following email address: enquiries@nhsdigital.nhs.uk.

Persons Consulted

There is an obligation on the part of NHS Digital to consult with (as set out in in section 258 of the Health and Social Care Act 2012):

- (a) the person who gave the direction or made the request
- (b) representatives of other persons who the Centre considers are likely to use the information to which the direction or request relates
- (c) representatives of persons from whom any information will be collected, and
- (d) such other persons as the Centre considers appropriate.

Following receipt of this direction NHS Digital has consulted with the following persons:

Organisation / Group	Including (but not limited to)
Professional Groups	Royal Colleges (of GPs, Nursing, Midwifery, Obstetricians & Gynaecologists, Paediatrics and Child Health)
ALBs	NHS England

Leading clinicians	FGM specialist working as midwives, nurses, counsellors, gynaecologists, obstetricians, GPs, paediatricians
Patient / community groups and survivors	Including those working nationally, locally, grassroots community organisations, campaigning survivors
NHS service providers	NHS acute trusts, mental health trusts, CCGs, including representatives from information teams
Subject Matters Experts	Internally to NHS Digital and DH, including information governance, security, data protection act, communications, policy, commissioning, analysts.

Please note that the consultation referenced in the table above was included as part of a wider agenda including topics relating to efforts to end FGM and the wider FGM Prevention programme. However, all included discussion or presentation on the aims and plans of the FGM Enhanced Dataset data collection.

Scope of the collection

The scope of the collection is limited to the following organisations in England:

- Acute Trusts (Foundation and non-Foundation)
- Mental Health Trusts (Foundation and non-Foundation)
- General Practices

The following organisations will be out of scope of the collection and therefore are not required to submit data to NHS Digital:

- Sexual Health Clinics
- Genitourinary Medicine (GUM) Clinics
- Community Health Trusts.

Form of the collection

The data items included within the FGM Enhanced Dataset should be obtained during the standard delivery of patient care where it is identified that patient has had FGM. The data collection does not require professionals to ask additional questions about FGM beyond those necessary for the patient's treatment.

The collection includes some individual level personal confidential data, however this is not released by NHS Digital; the personal details are required to validate the data, ensuring data quality and identifying duplication where individual patients are being treated across different healthcare sectors and providers.

The detailed data specification and implementation guidance for the FGM Enhanced Dataset SCCI2026 can be found here <http://content.digital.nhs.uk/isce/publication/scci2026>

Manner of the collection

Data is submitted to NHS Digital via the Clinical Audit Platform (CAP). Data submission dates are flexible, but must be undertaken within a quarterly reporting period.

Details of how to register and submit your FGM data is available here
<http://content.digital.nhs.uk/fgm>

General practices can also learn more about the availability of central templates within GP systems that facilitate the submission of data to NHS Digital via this [link](#)

Period of the collection

The collection of the FGM Enhanced Dataset began on 1st April 2015 and is mandatory for all organisations in the scope.

Reporting is quarterly and organisations have a month to submit their data before the extract for the report is taken. For example, the deadline for the April-June quarter is 31 July.

Reporting Period	Submission Deadline	Provisional Publication Date
April - June	31 July	September
July - September	31 October	December
October - December	31 January	March
January - March	30 April	June

This DPN will be reviewed in three years from the publication of this notice or sooner if changes are required to the collection.

Further Information and Support

Further information about the FGM Enhanced Dataset including access to the published reports is available from

<http://content.digital.nhs.uk/fgm>

If you have any further queries in relation to the collection of the FGM Enhanced Dataset, then please contact enquiries@nhsdigital.nhs.uk.

Burden of the collection

Steps taken by NHS Digital to minimise the burden of collection

To minimise the burden it imposes on others, in line with sections 253 (2a) and 265(3) of the Health and Social Care Act 2012, NHS Digital has an assessment process to validate and

challenge the level of burden incurred through introducing new information standards, collections and extractions.

In order to minimise the burden of this collection, NHS Digital is using the Clinical Audit Platform (CAP). CAP is an easy to use data submission tool which is intuitive and needs no specific training. It can accept information either through a web portal or by a file upload to suit the organisations preference.

Data can be recorded directly in CAP or via CSV file uploads.

More details on CAP are provided here: <http://content.digital.nhs.uk/clinicalauditplatform>

NHS Digital has also arranged for GP system suppliers to provide FGM data collection templates through their existing systems and guidance on the production of FGM reports, which can be used to support the submission of FGM data via CAP.

Detailed burden assessments (DBA) are carried out by the Burden Advice and Assessment Service (BAAS) who report the findings and recommendations as part of the overarching SCCI process. SCCI is the committee that oversees the development, assurance and acceptance of information standards, data collections and data extractions for the health and social care system in England.

Detailed burden assessment findings

An initial burden assessment was carried out in January and February 2015 to support the review of the information standard by SCCI.

This found that a full Detailed Burden Assessment (DBA) was recommended to be scheduled when details of the new dataset have been defined, and pilot testing is underway.

Assessed costs

The associated burden of the data collection as assessed in February 2015 is:

Burden on providers	£1.6m	
Set up costs for the data collection	£0	
Other costs of the data collection	£357k	This annual figure includes costs for the development of the collection, collecting and analysing the data and subsequent publication.

Help us to identify inappropriate collections

NHS Digital's Burden Advice and Assessment Service (BAAS) offers a Collection Referral Service which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

For more details and information on how to refer a collection, please visit: <http://www.digital.nhs.uk/article/6183/Collection-Referral-Service>

More about the Burden Advice and Assessment Service can be found at:
<http://digital.nhs.uk/baas>

For further information

www.digital.nhs.uk

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