

Female Genital Mutilation Prevention Enhanced Data Set

**Proposal for a Secretary of State Direction to Support
Collection of Data for the Female Genital Mutilation
Prevention Data Set**

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Background

The Department of Health (DH) is leading a programme of work, to improve the NHS response to Female Genital Mutilation (FGM) and the subsequent management of patients and safeguarding for girls at risk of FGM. The development of the FGM enhanced dataset is part of this wider Programme of work and will provide a vital element.

This enhanced dataset is intended to replace the existing standard – ISB 1610 FGM Prevalence Dataset which was implemented in April 2014 and is due to be retired at the end of March 2015. This new standard proposes to extend the data to flow nationally including personal data in the form of an NHS number, and will in time be a mandated return from all Acute Trusts, Mental Health Trusts and NHS Primary Care Providers in England.

The collection is to be supported by a Ministerial Direction provided from DH to HSCIC.

Supporting the DH and NHSE FGM Prevention Programme

HSCIC as a recognised ‘safe-haven’ for data is best positioned to provide high quality data collection and reporting from NHS funded primary and secondary care providers in England in a legal and ethical way to understand patterns of FGM on a national and regional footprint and support improvements in patient care and support led by DH and NHS England (NHSE).

The data is to be collected using the HSCIC Clinical Audit Platform (CAP) and will include the following sensitive data: NHS number, Date of Birth, Name, No. of daughters under 18 and FGM identification (including type of FGM). Identifiable data items such as NHS number and name will be used for Quality Assurance of data at HSCIC and stripped out; Date of Birth will be used to enable an “age at encounter” data field and stripped out. HSCIC will not share any patient identifiable information with any external partner organisation.

The data will be published as an official statistic by HSCIC, following the normal rules of statistical release. Management reports with no patient identifiable data will be provided to the FGM Prevention Programme at DH and NHSE to enable the continuation of the prevention work and to guide policy and commissioning decisions.

Issues Under Consideration

A Secretary of State Direction is provided to establish the legal basis for extracting, processing and reporting this data. DH will further support in coordination with the HSCIC FGMP Programme team in issuing fair processing notices to comply with the Data Protection Act. This is included in an FGM patient information leaflet which is being provided to all Acute Trusts, Mental Health Trusts and Primary Care Providers in England by DH. NHSE FGM Prevention Programme team will form the central point of contact in cooperation with the HSCIC Clinical Audit Support Unit to manage patient objections and queries under the fair processing notice.

All of these processes and resources will be in place before extractions commence.

It is the DH’s intention that this data should start to flow from April 2015. The standard is due for final approval by SCCI on 25th March.

Actions Required of the Board

The purpose of this paper is to brief the Board about this project and to ask them to agree the Secretary of State direction.