

FGM Prevention Programme

Understanding the FGM Enhanced dataset – updated guidance and clarification to support implementation

September 2015

Patient Consent

With regard to the collection of patient identifiable information as part of the FGM Enhanced dataset, patient consent does not need to be sought, however transparency (fair processing) is required.

See the HSCIC 'Female Genital Mutilation Enhanced Dataset – Information Governance Statement', http://www.hscic.gov.uk/media/18125/FGM-Enhanced-Dataset-IGStatement/pdf/FGM_Enhanced_Dataset_IG_Statement.pdf, for an explanation of the legal basis for this.

Fair processing and the right for patients to object

All NHS organisations are bound by a range of responsibilities to maintain patient confidentiality and respect the wishes of patients; under the Data Protection Act this is called 'fair processing'.

To meet the requirement to provide a 'fair processing' notification to patients, clinicians should give the patient the FGM leaflet "More information about FGM" (2015). This is available to order online, free of charge in English and ten other languages.

Organisations can also download copies from NHS Choices [<http://www.nhs.uk/Conditions/female-genitalmutilation/Pages/Introduction.aspx>]

Giving the patient this leaflet fully meets the requirement for 'fair processing' and this action alone is sufficient. There is no requirement to discuss the FGM dataset in detail, or to ask a patient for explicit consent to collect their information, although clinicians will need to answer any questions that a patient has and know to whom they might need to refer the patient for additional information.

Clinicians should always discuss, if they have not previously, the illegality of FGM in the UK, and the many negative health consequences of the practice with the patient.

Fair processing objection route

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.

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 information to HSCIC). If the objection is not raised at this point, and the patient's information is submitted, she can still choose to contact HSCIC at a later date to raise an objection at the following website: <http://www.hscic.gov.uk/media/14700/Preventing-the-use-of-yourinformation-for-health-andor-social-care-purposes->

other-than-directcare/pdf/Preventing_Use_of_Your_Information_Form.pdf, the objection will be automatically enforced and the patient's data will be removed from the dataset.

If the objection is raised with HSCIC, they do not automatically have to accept this request and remove the information. However, due to commitments made by the Secretary of State for Health, patient objections for FGM data collection must always be treated as an automatic 'stop processing' request. This is a Government policy decision that goes beyond the law's requirements.

Similarity to other NHS datasets

There are other examples across the NHS where the approach used for the FGM Enhanced dataset is already in place to collect patient information without explicit consent from individual patients. One such example is the collection of information for commissioners, which supports the ongoing cycle of commissioning health services. Within this, explicit patient consent is not obtained but it is clear how patients can object and remove their information. For more information please see: <http://www.england.nhs.uk/ourwork/tsd/data-services/>