

# DCB2112 Amd 28/2019 FGM-IS Local System Integration Requirements Specification

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# Data Coordination Board

This information standard (DCB2112) has been approved for publication by the Department of Health and Social Care under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Change Specification
- Requirements Specification
- Implementation Guidance.

An Information Standards Notice (DCB2112 Amd 28/2019) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the [NHS Digital website](#). Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

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## Glossary of Terms

Term / Abbreviation	What it stands for
Applicable IT System	In the context of this document an 'applicable IT system' refers to any electronic information system that supports the provision of NHS funded healthcare in all clinical settings in England, including general practices, that are accessed by children. In addition, an 'applicable IT system' will use a verified NHS number to link the patient to their electronic health record. The system must also have access to the national Spine either directly or via a Spine Mini Services Provider (SMSP)
Child	A person under 18 years of age
DCB	Data Coordination Board which replaced the Standardisation Committee for Care Information in 2017
DHSC	Department of Health and Social Care
DMS	Domain Message Specification
FGM	Female Genital Mutilation
FGM-IS	Female Genital Mutilation - Information Sharing <sup>1</sup>
NHS Digital	NHS Digital is the national information and technology partner to the health and social care system. Formerly known as the Health and Social Care Information Centre (HSCIC) it was renamed in 2016.
NHS Spine	The Spine is a collection of national applications, services and directories that support the NHS in the exchange of information across national and local NHS IT systems
RBAC	Role Based Access Control
RCGP	Royal College of General Practitioners
SCRa	Summary Care Record Application
SMSP	Spine Mini Services Provider is a web client interface that allows health and care Providers to find key patient information on the NHS Spine.
The 'Service'	The FGM-IS central core component
Validated NHS number	A validated NHS number is one that conforms with the NHS Number Standard (ISB 0149 <sup>2</sup> ) and so has the correct format and passes the NHS number check digit calculation
Verified NHS number	A verified NHS number is one where the patient's identity has been cross-checked using demographic details on the Personal Demographics Service (PDS)

<sup>1</sup> <https://digital.nhs.uk/services/female-genital-mutilation-information-sharing>

<sup>2</sup> <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections>

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# 1 Overview

## 1.1 Purpose

The purpose of this document is to define an information standard for the displaying of an automatic message within all in-scope IT systems to alert relevant healthcare professionals when a child patient with female genitalia has a family history of Female Genital Mutilation (FGM).

Family history of FGM is an enabler for professionals to consider risks and become professionally curious and potentially identify further factors in undertaking their statutory duty to safeguard children. The definition of family history is a local clinical decision where FGM is known, informed by the individual personal circumstances of the child and supported by the NHS England and NHS Improvement (NHSE/I) guidance for clinicians on FGM Prevention alongside local FGM prevention protocols.

Note: All references in this document can be found in the Supporting Documents section above.

## 1.2 Background and Context

Female Genital Mutilation (FGM) is illegal in the UK, as is taking a child abroad to undergo FGM, as legislated in the Female Genital Mutilation Act 2003<sup>3</sup>. It is child abuse and a form of extreme harm. FGM is medically unnecessary, is extremely painful and leads to severe short and long term physical and psychological consequences. The UK Government is committed to preventing and ending this harmful practice which violates the rights of girls and women<sup>4</sup> <sup>5</sup>. It is the intention to eradicate FGM in this country within a lifetime.

It is estimated that approximately 103,000 women aged 15-49 and approximately 24,000 women aged 50 and over who have migrated to England and Wales are living with the consequences of FGM. In addition, approximately 10,000 girls aged under 15 who have migrated to England and Wales are likely to have undergone FGM. In the period January to March 2019, 1,990 women and girls were treated in the NHS where FGM was identified or a procedure related to FGM had been undertaken. In the same period there were 1,015 newly recorded instances in women and girls. The FGM Enhanced Dataset (SCCI2026)<sup>6</sup> is a repository for individual level data collected by healthcare providers in England, including acute hospital providers, mental health providers and GP practices and indicates the prevalence of FGM.

As part of the Department of Health's FGM Prevention Programme (2014 to 2018) the Health and Social Care Information Centre (HSCIC), now NHS Digital, was commissioned to develop an FGM Risk Indication System (FGM RIS). This national IT service was viewed as an important development to support effective early intervention and ongoing safeguarding of those potentially at risk of FGM.

From August 2015, the FGM 'core service' was created. As part of the NHS National Spine it provided functionality for the Summary Care Record application (SCRa) to allow authorised

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<sup>3</sup> <http://www.legislation.gov.uk/ukpga/2003/31>

<sup>4</sup> <https://www.gov.uk/government/publications/safeguarding-women-and-girls-at-risk-of-fgm>

<sup>5</sup> <https://www.gov.uk/government/publications/multi-agency-statutory-guidance-on-female-genital-mutilation>

<sup>6</sup> <https://digital.nhs.uk/isce/publication/scci2026>

healthcare professionals to add and remove an indicator of risk of FGM for those under the age of 18 following a safeguarding assessment.

As part of the business case the Department of Health (now the Department of Health and Social Care, DHSC) included the requirement for the SCRa FGM RIS to be integrated within NHS Trust settings to reduce burden on clinician's (easing access to the flag during routine local system use) and so to, potentially, increase access to the indicator<sup>7</sup>. Local integration was included in the original version of this standard, allowing view capability of the FGM RIS 'core service'.

During 2017 the FGM Prevention Programme maintained dialogue with clinician's regarding implementation and concerns arose with regard to the risk assessment element being ambiguous. In agreement with the Royal College of General Practitioners (RCGPs) the system was changed to FGM - Information Sharing (FGM-IS), moving away from an assessment of risk to an indicator of a family history of FGM.

In most circumstances the SCRa is updated within NHS maternity settings and over 80% of maternity settings in England having received implementation support and are declaring use.

The change from Risk Identification System (RIS) to Information Sharing (IS) was made to the FGM-IS core system, via the SCRa, in March 2018. This update of the standard requirements aligns current and future locally integrated systems to the core system. In addition, mandatory requirements have been reviewed, with local integration functionality now only required in Primary Care settings. It must be noted however that the functionality may be relevant in other health care systems or settings, in which the standard may be applied on a voluntary basis in response to local decision.

Importantly, this standard only concerns local integration of the ability to view the family history of FGM indicator. The indicator will continue to be added to the Core FGM-IS system using the SCRa, in all clinical settings. A future iteration of this standard may extend local functionality to allow add, edit and remove via local system integration, but this is still under investigation.

The FGM-IS is a national system in England and the expectation to comply with local and national safeguarding frameworks will mean that professionals should use the system, as it is complementary to such frameworks. This will lead to better outcomes for those at risk of FGM in society. It will also highlight to all clinicians that they need to consider FGM as and when they provide care, as well as whether they need to take any action in this regard.

In summary, this information standard requires that in-scope local NHS applicable IT systems (see glossary) use messaging functionality to implement an automatic alert message, together with the date and time the alert was uploaded from FGM-IS core system, when a child (under 18 years old) has a family history of FGM, as recorded in the national FGM-IS core service.

This information standard is not intended to replace existing working practices and processes but aims to support them by providing additional information which is not routinely available. It supports the overall objectives of the DHSC and NHSE/I FGM prevention work. The operation of the FGM-IS is supported by a Direction<sup>8</sup> made under the Health and Social Care Act 2012.

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<sup>7</sup> <https://www.gov.uk/government/publications/services-for-women-and-girls-with-fgm>

<sup>8</sup> <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/secretary-of-state-directions>

## 2 Summary

Standard	
Standard Number	DCB2112
Standard Title	Female Genital Mutilation Information Sharing (FGM-IS) – Local System Integration
Description	<p>This information standard requires in-scope NHS funded healthcare providers to update their local applicable IT system(s) to automatically display an alert message when a patient with female genitalia under 18 years old has a family history of FGM, as recorded in the FGM-IS core service (a national Spine application). The search undertaken to display the alert is made of all genders, to cater for any patient adopting a new gender identity, and all patient records that have this flag will be displayed. This ensures all are treated fairly and no additional risk is created, as is required by the Equality Act 2010<sup>9</sup>.</p> <p>The decision to update the FGM-IS core system with a family history of FGM is a local clinical decision, informed by the individual personal circumstances of the child and supported by the NHSE/I guidance for clinicians on FGM prevention alongside local FGM prevention protocols.</p> <p>An ‘applicable IT system’ is the term used to describe those local NHS IT systems to which this standard applies and includes any electronic information system that supports the provision of NHS funded healthcare for in-scope clinical settings in England that are accessed by children. At this time, it is only mandatory for those systems working in primary care settings.</p> <p>In addition, an ‘applicable IT system’ will use a verified NHS number to link the patient to their electronic health record. The system must also have access to the national Spine either directly or via a Spine Mini Services Provider (SMSP).</p> <p>This information standard describes the integration of the FGM-IS information held on the NHS Spine within in-scope clinical settings to support the clinician with improved access to information of those under the age of 18 with a family history of FGM, which informs local safeguarding procedures.</p> <p>It supports the overall objectives of the DHSC and NHSE/I FGM prevention work in that it is expected to:</p> <ul style="list-style-type: none"> <li>• support clinicians to meet their local safeguarding responsibilities</li> <li>• support the prevention of FGM, through the provision of accurate information to all relevant care professionals</li> <li>• improve the awareness of FGM</li> </ul>

<sup>9</sup> <http://www.legislation.gov.uk/ukpga/2010/15/contents>

	<ul style="list-style-type: none"> <li>eventually help to eradicate the practice.</li> </ul> <p>This information standard forms part of the national solution across England so that whenever and wherever the child is provided with health care, a family history of FGM will be known which will lead to better outcomes for children at risk of FGM in society.</p>
Applies to	<ul style="list-style-type: none"> <li>Mandatory requirement for primary care NHS funded healthcare providers</li> <li>Optional (may implement) requirement for other NHS funded healthcare providers (local decision)</li> </ul>
<b>Release</b>	
Release Number	Amd 28/2019
Release Title	Version 2
Description	<p>Provision of an automatic alert in local NHS IT systems (applicable IT systems) when a family history of FGM has been previously recorded on the FGM-IS core service. Note that previously this alert indicated a patient's risk of FGM but following a change in the FGM-IS service this now indicates a patient's family history of FGM.</p> <p>This release makes the following changes:</p> <ol style="list-style-type: none"> <li>name change to Female Genital Mutilation Information Sharing (FGM-IS), rather than FGM RIS (Risk Indication System)</li> <li>mandatory implementation requirement for primary care only and an optional requirement for other care settings, rather than all NHS funded services being in-scope</li> <li>allows the local storage of the family history indicator if it is associated with a clear date and time stamp indicating when FGM-IS indicator was retrieved from the core FGM-IS system. Local storage, <u>which is not a mandatory requirement (or the default approach)</u>, may be used for example to record the status of the flag in historical records (the 'as at' position). <b>Notes:</b> (i) as per the initial release of this standard the indicator must only be presented up to age 18, and (ii) local storage has information governance consequences (see implementation guidance, section 7) regarding data controller. Previously local storage was not allowed.</li> <li>requirement to display FGM-IS for any patient regardless of NHS system classification of gender identity.</li> </ol>
Implementation Date	This information standard gives notice to NHS funded primary care healthcare providers in England and those that manage NHS IT system supplier contracts to achieve compliance by 31 March 2021. Implementation should commence immediately following publication of this standard.
Full Conformance Date	31 March 2021

## 2.1 Scope

### 2.1.1 In-Scope

This information standard is **mandatory** (MUST implement the requirements described in section 3) for primary care NHS funded healthcare providers in England:

- GPs and other users of primary care systems, such as practice nurses and community midwives.

It is **optional** (MAY be implemented, depending on local decision) for other health care providers in England.

Note:

- An evaluation is underway regarding FGM-IS use in hospital settings, which may lead to a future mandate if there is a clear business case.
- Until this evaluation is completed NHS services will be able to use the SCRa to create, view and amend records (without local view integration).

### 2.1.2 Out of Scope

The purpose of this information standard is to integrate healthcare more closely into statutory safeguarding processes. As such, this information standard does not apply to local authorities / social care settings which already have well established processes in place.

Services accessed exclusively by adults are also excluded from this information standard as are any services that rely on anonymity for their success (such as sexual health clinics and addiction services).

The following are out of scope of the requirements of this information standard:

- Functionality of the FGM-IS core service contained within the national spine architecture. This includes the functionality available in SCRa such as the addition and removal of the FGM-IS Indicator.
- Professional safeguarding responsibilities which are guided by national and local policy; NHS funded healthcare providers are responsible for determining how the FGM-IS information will be used.

### 2.1.3 Related Standards

Ref #	Reference	Title
1	<a href="#">ISB 0149</a>	NHS Number
2	<a href="#">SCCI2026</a>	Female Genital Mutilation Enhanced Dataset

## 3 Requirements

This section describes the requirements that support this information standard. The key words **MUST**, **SHOULD** and **MAY** are used as defined in RFC2119<sup>10</sup>, namely:

- **MUST** - This word, or the terms "REQUIRED" or "SHALL", means that the definition is an absolute requirement of the specification.
- **SHOULD** - This word, or the adjective "RECOMMENDED", means that there may exist valid reasons in particular circumstances to ignore a particular item, but the full implications must be understood and carefully weighed before choosing a different course.
- **MAY** - This word, or the adjective "OPTIONAL", means that an item is truly optional.

Details of how the requirements can be monitored and measured are described in the associated conformance criteria.

### 3.1 NHS Funded Primary Care Healthcare Providers

Reference	Requirement
REQ2112-01	Providers <b>MUST</b> read the information standard Requirements Specification (this document) in conjunction with the Implementation Guidance to identify how the Standard is applicable to them.
REQ2112-02	Providers <b>MUST</b> review their IT system(s) against this information standard to identify and make any changes required to their IT systems and business processes to ensure compliance with the information standard.
REQ2112-03	FGM-IS does not replace existing safeguarding processes and procedures. NHS funded healthcare providers <b>MUST</b> review current practices to identify how FGM-IS will support existing functions and clinical practice.

### 3.2 NHS Applicable IT Systems

Reference	Description
<b>FGM-IS Query</b>	
REQ2112-04	Where the local NHS IT system uses Spine role based access codes (RBAC), the activity code B0370 "View Summary Health Records" <b>MUST</b> be used to view the FGM-IS system by appropriate users.
REQ2112-05	Where the NHS system connects to the FGM-IS Service via a Spine Mini Services Provider (SMSP) and does not use Spine RBAC, then access to the FGM-IS Service <b>MUST</b> be controlled by local system access controls mapped to the RBAC activity code B0370 "View Summary Health Records".
REQ2112-06	The FGM-IS Query message <b>MUST</b> contain a verified NHS number.
REQ2112-07	The FGM-IS Query message <b>MUST</b> contain an NHS number pertaining to a person under age 18.

<sup>10</sup> <http://www.ietf.org/rfc/rfc2119.txt>

REQ2112-08	The FGM-IS Query message <b>MAY</b> contain an NHS number pertaining to a male if the patient, under the age of 18, has female genitalia.
REQ2112-09	The process to query the FGM-IS service <b>MUST</b> be done automatically once the patient's demographics have been checked and their NHS number confirmed. As such, there will be minimal impact on the user.
REQ2112-10	The local NHS IT system <b>MUST</b> undertake an FGM-IS Query for patients satisfying the above criteria, at the following 'Significant Events': <ul style="list-style-type: none"> <li>• when a patient registers at a GP practice (once the patient's NHS number has been verified)</li> <li>• at the beginning of any episode of unscheduled care (where the patient can be identified and their NHS number can be verified) if appropriate to the setting</li> <li>• at all clinical appointments including outpatient (if appropriate to provider / scope of implementation)</li> <li>• prior to in patient admission and discharge (if appropriate to provider / scope of implementation) .</li> </ul>
REQ2112-11	The FGM-IS Query message is fully defined in the FGM-IS Domain Message Specification (DMS) <sup>11</sup> . The FGM-IS DMS <b>MUST</b> be used to implement the FGM query message. The information in the query message ensures the following can be determined: <ul style="list-style-type: none"> <li>• the patient to whom the query applies (NHS number)</li> <li>• that it is a FGM query</li> <li>• who sent the request</li> <li>• when the FGM query was sent</li> <li>• where the FGM query was requested from.</li> </ul>
<b>FGM-IS Response</b>	
REQ2112-12	Where a current FGM family history for a patient exists on FGM-IS, the applicable IT system <b>MUST</b> automatically alert the user to this.
REQ2112-13	Following the retrieval and confirmation of a patient record including a verified NHS number, there <b>MUST</b> be no further specific action required by a user in order to be alerted if the patient has a family history of FGM.
REQ2112-14	The format of the FGM-IS alert message will be determined locally. However, it <b>MUST</b> include the date and time the FGM-IS flag query was requested (supplied in the FGM-IS response message) and it <b>MUST</b> be displayed within the correct patient's record ensuring that there can be no confusion as to which patient the FGM alert message is associated.
REQ2112-15	The FGM-IS alert message <b>MUST</b> be presented in such a way that it cannot be missed by a user.
REQ2112-16	If the FGM-IS response message indicates that no family history exists for the patient, or where an error is returned, there <b>MUST NOT</b> be a message displayed to the user.
REQ2112-17	If the FGM-IS response message returns an error, there <b>MUST</b> be a mechanism for reporting the error to appropriate staff (e.g. The Information Technology department).

<sup>11</sup> <https://data.developer.nhs.uk/fhir/fgm-v2-draft-d/Chapter.1.About/index.html> **Note:** This will be updated to reflect move to FGM-IS.

REQ2112-18	<p>The FGM-IS Response message is fully defined in the FGM-IS Domain Message Specification (DMS). The FGM-IS DMS <b>MUST</b> be used to understand the information contained in the message in order to implement this information standard. The information in the response message ensures it can be determined:</p> <ul style="list-style-type: none"> <li>• Whether or not a family history of FGM exists for the patient on FGM-IS</li> <li>• Whether an error has occurred and if so, details of the error</li> <li>• If a family history of FGM exists for the patient, the date and time the assessment was undertaken</li> <li>• When the response was sent from Spine.</li> </ul>
REQ2112-19	<p>Local systems <b>MUST NOT</b> be enabled to store the FGM-IS indicator once the patient is over the age of 18. FGM-IS indicator data held locally <b>MUST</b> be deleted for those over this age.</p>
REQ2112-20	<p>Local systems <b>MAY</b> store the FGM-IS indicator if it is presented with the date and time it was retrieved from the core FGM-IS service and it is updated each time the patient record is accessed.</p>

### 3.3 Conformance Criteria

This section describes the tests that can be measured to indicate that the information standard is being used correctly by NHS funded healthcare providers and their local IT system suppliers.

Reference	Criteria
CNF2112-01	Primary care NHS funded healthcare providers <b>MUST</b> conform to this information standard by 31 March 2021.
CNF2112-02	NHS IT applicable systems may only gain access to the FGM-IS by going through the Common Assurance Process (CAP) or via an accredited SMSP.
CNF2112-03	FGM-IS access is governed by appropriate role-based access control and is permitted to authorised users only.
CNF2112-04	FGM-IS is embedded into existing processes and working practices to clinicians statutory safeguarding duties.

## 4 Operational Use

### 4.1 Viewing FGM-IS

Patient / parent consent is not required to view the FGM family history indicator held on the FGM-IS core service. The FGM-IS project is an important part of supporting child protection and safeguarding by facilitating the sharing of FGM family history information with other relevant health professionals. It is accepted that information sharing is vital to safeguarding and promoting the welfare of the child. A key factor identified in many serious case reviews has been a failure by practitioners to record information, to share it, to understand its significance and then take appropriate action.

The FGM-IS core service has the capability for applicable IT systems to share information when a child has a family history of FGM.

The use of the FGM-IS local integration system should be used to provide the NHS healthcare worker with an opportunity, and additional relevant information, to apply local processes and safeguarding procedures related to FGM. Local processes could include further assessment as to whether the child is currently at risk of FGM. Conversely it should not be assumed that if no message is displayed the child does not have a family history of FGM, and local processes and safeguarding procedures should still be utilised. Access to FGM-IS information is a local clinical decision.

The notification that a patient record is flagged should appear as ribbon on the screen rather than as pop-up box and the ribbon should have the option to be closed by the clinician viewing the record.

The notification that the patient record is flagged must only appear when accessed during a consultation/episode of care, not when the record is used to book an appointment or any other administrative tasks.

### 4.2 Safeguarding Procedures and Processes

FGM is child abuse and as such, professionals have a statutory obligation under national safeguarding protocols, for example, 'Working Together to Safeguard Children'<sup>12</sup> to protect those under 18 years of age.

NHS funded healthcare providers will already have local safeguarding protocols and procedures for helping children and young people who are at risk of or facing abuse. These should include sharing of information with multi-agency policies and procedures, consistent with those developed by their previous Local Safeguarding Children Board or the current Local Area Partnership. This information standard does not replace existing safeguarding processes.

It is strongly recommended that NHS funded healthcare providers review their current processes, if they have not already done so, to include handling cases where FGM is alleged or known about or where there is a potential risk of FGM identified. FGM-IS integration is not intended to replace existing working practices and processes but aims to support them. NHS funded healthcare providers will need to determine locally how FGM-IS integration will be

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<sup>12</sup> <https://www.gov.uk/government/publications/working-together-to-safeguard-children--2>

used with their existing processes and ensure processes and procedures are updated accordingly.

## 4.3 Service Management

It is expected that existing arrangements to support access to Spine services and communicate service outage will be applicable.

## 4.4 Data Quality and Information Governance

The NHS England FGM Prevention Board will monitor the use of both the SCRa and the integrated FGM-IS systems on a quarterly basis. This review will examine how the flag is being created, changed and viewed by health setting; this will allow them to identify any trends that may require national intervention.

At a local level it is expected that the audit of the FGM-IS information will be undertaken in line with the general audit of local systems. This should include, as a minimum, regular verification that the staff who are accessing the record in any form have the appropriate authorisation to do so; and to identify any trends that may cause alarm (e.g. too many creations, or deletions).

It is also expected that local FGM Prevention partnerships have a role to play in monitoring the use of the system and maintaining appropriate use.

If the MAY requirement REQ2112-20 is used to store information on the local system, then it should be noted that the system owner becomes the data owner for that stored data. Therefore, the local organisation must take appropriate action under General Data Protection Regulation (GDPR) to include updating fair processing notices, and ensuring the information is used for clinical purposes only internal to the organisation that owns it.

## 4.5 Issues and Maintenance

To support the implementation of this information standard supporting documentation, including an implementation guide, are available. Any persistent issues should be fed back to the standard's developers. Feedback will be used by the developers for future development and to improve implementation of the standard. Send feedback to [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk) (please include 'FGM-IS information standard' in subject line).