

Female Genital Mutilation (FGM) Enhanced Dataset

Requirements Specification

April 2015



This information standard (SCCI2026) has been approved for publication by the Department of Health 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 Standardisation Committee for Care Information (SCCI), a sub-group of the National Information Board.

This information standard comprises the following documents:

- Specification (this document)
- implementation guidance.

An Information Standards Notice (SCCI2026 Amd 12/2014) 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 [HSCIC website](#).

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1 Introduction

Female Genital Mutilation (FGM) is illegal in the UK, as is taking a child abroad to undergo FGM, as legislated in the 2003 Female Genital Mutilation Act. It is also recognised as a form of child abuse. FGM is medically unnecessary, extremely painful and has serious health consequences both at the time when the mutilation is carried out and in later life.

The FGM Enhanced Dataset will require organisations to record and collect information about the prevalence of FGM within the female population as treated by the NHS in England. This will include if a woman is receiving treatment for any condition; it is not limited to reporting upon women receiving treatment for FGM-related conditions.

The FGM Enhanced Dataset builds on the previously implemented 1610 FGM Prevalence Dataset, providing a greater level of FGM information captured throughout various different health settings.

The NHS is in a unique position to identify those who have undergone FGM. Multi-agency guidelines and additional clinical guidance are available.

There is a programme of work, led by the Department of Health, to improve the NHS response to FGM, including the management of women's services and safeguarding of girls at risk. This standard introduces new requirements to the existing FGM Prevalence Dataset about the information that needs to be captured and shared locally about the women, and what needs to be submitted as a central return. This new information collected is needed to inform FGM Prevention programme, specifically around the following, to help the drive to eradicate the practice, and to provide services and support for women and girls who have had FGM:

- Women identified as having FGM, and specific countries of origin
- All girls and women who are at risk of having FGM performed on them
- In a given community, identify numbers of women and girls, who have undergone FGM in order to plan services.
- Providing tools to support law enforcement and identify areas of concern relating to FGM, enabling further investigations and, as appropriate, prosecutions. It should be noted, individual patient identifiable information will not be published in order to achieve this
- Reporting prevalence to other government agencies on the prevalence within a local community (this reporting will not however be at the patient level)
- To better inform the ultimate goal of moving towards existing datasets, namely;
 - Maternity Services Dataset (MSDS)
 - Children & Young People's Health Services Dataset (CYPHS)
 - Child and Adolescent Mental Health Services Dataset (CAMHS)

The FGM Enhanced Dataset will use patient identifiable information (specifically the NHS Number as the unique identifier in order to link Primary and Secondary information), moving away from anonymised data and collecting information about the specific women who have undergone FGM. This will by default, collect FGM

prevalence information within the NHS patient population receiving treatment at Acute Trusts, Mental Health Trusts and GP Practices.

Jane Ellison MP, Minister for Public Health (at the time of writing), has made improving the response to FGM one of her top priorities. There is significant public and media interest, and a new programme to implement change has now been formed to specifically help to reliably identify the prevalence of FGM within the patient population in order to support the development of FGM services nationally. In order to ensure that the FGM Prevention programme delivers the improvements where needed, with an efficient and appropriate approach, it is essential to assess the current situation within the NHS. Further to this, there will be cases where the clinician treating a woman or girl, either does not recognise FGM, or does not identify the warning signs, and therefore does not make enquiries which would confirm a diagnosis.

The programme is planning to identify good practice in the current albeit relatively few centres of excellence, and to roll this out nationally.

1.1 Purpose

The purpose of this document is to support the submission of the FGM Enhanced Dataset, through provision of strategic approaches, plans, processes and requirements in the development and implementation of this standard.

1.2 FGM Enhanced Dataset Summary

Standard	
Standard Number	SCCI2026
Standard Title	Female Genital Mutilation (FGM) Enhanced Dataset
Description	<p>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.</p> <p>Female Genital Mutilation (FGM) is illegal in the UK, as is taking a child abroad to undergo FGM, as legislated in the 2003 Female Genital Mutilation Act. FGM is medically unnecessary, extremely painful and has serious health consequences both at the time when the mutilation is carried out and in later life. Whilst there have been no prosecutions, it is believed that the practice continues both in the UK and that girls are taken abroad for the purpose of FGM.</p> <p>FGM must also be treated as child abuse.</p> <p>FGM multi-agency guidelines are accessible via this link: https://www.gov.uk/government/publications/female-genital-mutilation-guidelines</p> <p>Particular note should be given to guidelines for health professionals.</p> <p>Although the multi-agency guidelines clearly set out mandatory steps for health professionals, the stipulated action is not being taken in all cases. In addition to these guidelines, the existing FGM Prevalence Dataset mandates that FGM must be recorded within all clinical settings. This standard builds upon the 1610 FGM Prevalence Dataset.</p> <p>There is a programme of work, led by the Department of Health, to improve the NHS response to FGM, and subsequent management of women and girls as well as safeguarding girls at risk.</p> <p>This standard introduces additional requirements to those of the FGM Prevalence dataset about information that must be captured and centrally returned.</p> <p><u>Recording FGM Information</u></p> <p>The FGM information captured is needed to help provide a consistent approach to sharing FGM information locally and specifically includes the following;</p> <ol style="list-style-type: none"> 1. All clinicians, regardless of organisation type, to record in clinical notes when FGM is identified, and what type it is following clinical examination (clinical examinations will only need to be undertaken as part of a usual, routine or requested provision of care – there is no intention for every clinician to automatically undertake a clinical examination in order to record the type of FGM), using the FGM clinical codes, published in April 2014 (also detailed later in this document). This builds upon the FGM Prevalence Dataset, and clinical terminology MUST be used to record the FGM information within all settings. If any clinician is unable to do this, they must ensure referral to the appropriate specialist is undertaken, particularly in the case for children. 2. All Maternity Discharges, must include relevant FGM information identified, prior to and post-delivery of baby, informing the GP and Health Visitor of the FGM identified during the provision of care. 3. All babies born to a mother with FGM, must have the relevant FGM information recorded in the baby's patient healthcare record (GP records and PCHR Red Book) to help identify the potential risk of FGM facing the girl. <p>Where FGM is identified, all referrals made by General Practitioners MUST include FGM information when referring to relevant services where FGM may be applicable e.g.;</p> <p>Urology, Paediatric Urology, Paediatric Dermatology, Dermatology, Genitourinary Medicine, Obstetrics, Gynaecology, Gynaecology Oncology,</p>

	<p>Midwifery Service, Psychiatric Services and Mental Health – this list is not exhaustive.</p> <p>4. When FGM is identified this MUST be included within screening returns, immunisation notes and the Red Book following the birth of a child. When FGM is identified health promotion MUST also be provided. Consideration should also be given to providing the woman with the FGM Healthcare Passport in the correct language, and also providing contact numbers of community groups or charities, e.g. FORWARD.</p> <p><u>Submitting FGM Information</u></p> <p>The FGM Enhanced Dataset collection will specifically require the stated organisations to return the FGM information for each patient.</p> <p>The collection and submission of this information aims to support improvements in:</p> <ul style="list-style-type: none"> • the identification of FGM and the wider social issues that impact upon the women or girl, thus increasing public awareness and informing the development of training for clinicians • data quality by promoting more detailed recording of FGM when it is identified; and provide better evidence for potential prosecutions of those who carry out FGM • the sharing of women’s information with other referred services • alignment of prevention (through risk identification) and support for the women, identifying where support is needed most • provision of secondary use data to support aggregated detailed studies on the prevalence of FGM • informing local and cross government organisations about the prevalence of FGM, therefore supporting the ability to target specific areas for the commissioning of appropriate services, and training needs • raising awareness of the risk of FGM to women and girls, resulting in improved safeguarding measures against FGM, including early intervention by relevant organisations to reduce and work towards the eradication of FGM • the scope and quality of academic research, including the potential to support the identification of community education programmes.
Applies to	<p>Recording FGM information – all NHS funded providers</p> <p>Returning FGM information – all Acute (Foundation and Non-Foundation Trusts), Mental Health Trusts and GP Practices</p>
Release	
Release Number	Amd 12/2014
Release Title	Initial Standard
Description	The recording and submission of detailed FGM information when this is identified from within Acute, Mental Health and GP Practices
Voluntary Implementation Date	<ul style="list-style-type: none"> • 1 April 2015 to submit FGM information to HSCIC
Mandatory Implementation Date	<ul style="list-style-type: none"> • 1 April 2015 to Record and Share FGM information locally when identified • 1 June 2015 for Acute Trusts, specified GP Practices and Mental Health Trusts to Submit FGM information to HSCIC <p><i>(it is requested that from 1 April 2015 all Acute trusts continue to collect FGM information and submit via the Clinical Audit Platform)</i></p> <ul style="list-style-type: none"> • 1 Oct 2015 for all Acute Trusts, GP Practices and Mental Health Trusts to

Submit FGM information to HSCIC

1.3 Supporting Documents

Ref	Reference	Title
1	FGM Enhanced Dataset Requirements	SCCI 2026 – FGM Enhanced Dataset – Requirements Specification
2	WHO FGM Classifications	http://www.who.int/reproductivehealth/topics/fgm/overview/en/
3	FGM Multi-Agency Guidelines	https://www.gov.uk/government/publications/female-genital-mutilation-guidelines
4	CAP Registration Process	www.hscic.gov.uk/fgm
5	CAP System Specification (File Upload)	www.hscic.gov.uk/fgm
6	CAP Operational Guidance	www.hscic.gov.uk/fgm
7	FGM Enhanced Dataset: Implementation Summary	SCCI 2026 – FGM Enhanced Dataset – Implementation Guidance Summary
8	FGM Enhanced Dataset: Implementation Guidance	SCCI 2026 – FGM Enhanced Dataset – Implementation Guidance

1.4 Scope

This information standard mandates the recording of FGM information when it is identified, to better support local processes in raising the awareness of the potential risks of FGM occurring to women and girls. In addition to this, the standard also mandates the central flow of FGM information for secondary uses purposes.

The scope includes all activity undertaken by all clinical settings, and / or provided by NHS England commissioned services. This includes the following organisations which will be impacted by the implementation of this standard:

- NHS Acute Trusts (Foundation and Non Foundation NHS Trusts)
- NHS Mental Health Trusts
- General Practitioners

All NHS funded providers MUST pay regard to this information standard.

1.5 Related Standards

The FGM Enhanced Dataset will supersede the current FGM Prevalence Dataset.

The FGM Prevalence Dataset will be retired from the 31st March 2015 and will **NOT** be supported by Unify2 nor resourced to support queries.

All organisations that have submitted FGM Prevalence Data should **CEASE** to do so via Unify2 after the last submission date of 10th April 2015.

2 FGM Enhanced Dataset Requirements

2.1 Healthcare Organisations

#	Requirement ¹
Recording FGM Information: All Clinicians	
1	All clinical staff MUST use FGM clinical terminology and classifications (where SNOMED CT, CTV3, Read or OPCS is supported by the system used by the clinician), when FGM has been identified that a baby girl, young girl or a woman has undergone FGM. This applies to all NHS clinicians and healthcare professionals across the NHS, and will need to be recorded within the patient healthcare record.
2	A clinician MUST record the <i>FGM Type</i> , based on what is presented in front of the clinician at that time.
3	Only when a physical examination (as part of <u>routine, usual or requested provision of care</u> for a woman) is undertaken, that when FGM has been identified, the FGM Type MUST be recorded. It is NOT required that every clinician has to perform a physical examination solely in order to populate the FGM Enhanced dataset.
4	If a physical examination is undertaken as part of routine, usual or requested provision of care for a woman, then the clinician MUST record; <ul style="list-style-type: none"> • <i>Clinical Examination</i>
5	If a physical examination is undertaken as part of routine, usual or requested provision of care for a woman, and it is the woman or girl that have outlined they have undergone FGM (or outline they've "been cut" or "circumcised"), then this MUST be recorded as; <ul style="list-style-type: none"> • <i>Self-Report</i>
6	If FGM cannot be clearly identified, then the clinician MUST record; <ul style="list-style-type: none"> • <i>FGM Type Unknown</i>, or • <i>Female Genital Mutilation</i>, when using the following clinical terminology; SNOMED CT, CTV3 or Read
7	When FGM Type 4 is identified, this SHOULD be qualified with the following FGM Type 4 qualifiers; <ul style="list-style-type: none"> • <i>Pricking</i> • <i>Piercing</i> • <i>Cauterisation</i> • <i>Incising</i> • <i>Scraping</i>

¹ Please note: the key words **MUST**, **SHOULD** and **MAY** are defined in Standard RFC-2119

8	If Type 4 is identified, but it is not possible to clearly identify the specific FGM Type 4, then <i>FGM Type 4</i> MUST still be recorded without a qualifying code.
9	<p>When FGM has been identified, the Enhanced FGM dataset MUST be recorded in one of the following ways;</p> <ul style="list-style-type: none"> • Directly within the Clinical Audit Platform which can be made available for clinicians to directly enter FGM information for a specific patient. • By recording the FGM information locally and making this available to Information Teams/ Practice managers to ensure the Clinical Audit Platform is uploaded with multiple records • Recorded directly within the patient healthcare record, and the FGM information subsequently extracted to support the upload in to CAP
Recording FGM Information: Maternity Services	
10	<p>All existing maternity discharge information sent to General Practitioners and Health Visitors MUST also include all relevant FGM information, where appropriate, when FGM or Family History of FGM has been identified; prior to, during or after the birth of a baby;</p> <p>The FGM information to be specifically included will be as follows;</p> <ul style="list-style-type: none"> • FGM Type • Confirmation that a deinfibulation procedure took place to facilitate the delivery of a birth, where applicable • Age at which the woman had FGM if specified, or confirmation of the following; <ul style="list-style-type: none"> - Under 1 - Between 1 and under 5 - Between 5 and under 10 - Between 10 and under 15 - Between 15 and under 18 - Over 18 - Didn't say - Unknown • Family History of FGM, where applicable • Confirmation that the woman has other daughter/s under 18 • Confirmation that no external female genitalia abnormalities were found at birth, following existing neonatal examinations <i>(this is not required if the new-born baby is a boy)</i> • Confirmation if an interpreter was required during the episode of care • Confirmation that the new-born baby's healthcare record has been updated to reflect FGM had been identified in the mother • Confirmation that the woman has been advised that FGM is illegal • Confirmation, that the woman has been advised on the health implications of FGM

11	<p>Upon issue of the Red Book, it is the responsibility of the midwife to populate the following section, “Are there any other particular illnesses or conditions in the mother’s or father’s family that you feel are important?”, to reflect FGM has been identified in the mother.</p> <p>This will specifically need to include the following;</p> <ul style="list-style-type: none"> • Family History of FGM • Confirmation that the baby’s mother has been advised that FGM is illegal • Confirmation that the baby’s mother has been advised on the health implications of FGM <p>Whilst it is required that the Red Book be updated with; Family History of FGM and also confirmation that health / illegality advice has been given to the parent, it will still be at the discretion of clinical or professional judgement to include this information.</p> <p>If there is an objection raised to the inclusion of this information within the baby’s Red Book, it will be for the clinician to determine if there is a potential safeguarding concern by including this information, which may mean that they choose not to include in the Red Book, or whether indeed that the objection raised needs to be considered in relation to the ongoing safeguarding concern, and whether that may require existing local safeguarding procedures to be initiated.</p> <p>As in many areas of clinical practice, the standard approach should be to include this detail within the Red Book, but if individual patient circumstances lead to the clinician making a decision to act differently, the advice is to document the new course of action within the patient’s healthcare record and consider whether there are other safeguarding actions which need to be taken</p>
12	<p>As part of the pre-natal assessment appointment, every woman MUST be asked if they have undergone FGM.</p> <p>Their healthcare record MUST then be updated with confirmation of the question being asked accompanied with one of the following responses;</p> <ul style="list-style-type: none"> • Yes • No • Not answered • Not asked
Recording FGM Information: Health Visitors	
13	<p>It is the responsibility of the Health Visitor, to update the following section within the Red Book, “Are there any other particular illnesses or conditions in the mother’s or father’s family that you feel are important?”, when applicable to do so with new FGM information. This will specifically need to include the following;</p> <ul style="list-style-type: none"> • Family History of FGM • Confirmation that the baby’s mother has been advised that FGM is illegal • Confirmation that the baby’s mother has been advised on the health

	<p>implications of FGM</p> <p>As outlined in requirement #11, clinical and professional judgement will be required where objections are raised to this, consideration for any local safeguarding actions which may be required, noting any different courses of actions taken</p>
14	<p>Where a Health Visitor identifies that there is or are sisters of a girl with FGM, it is the responsibility of the Health Visitor to inform the GP.</p>
Recording FGM Information – General Practitioners	
15	<p>On receipt at the GP Practice of the Maternity Discharge information, where FGM information has been included, the new-born baby's healthcare record MUST be updated with the following FGM information;</p> <ul style="list-style-type: none"> • Mother's Forename, Surname • Mother's NHS Number • Mother's Date of Birth • Mother's Hospital Number • Mother's FGM Type identified • Age at which the mother had FGM if known; <ul style="list-style-type: none"> - Under 1 - Between 1 and under 5 - Between 5 and under 10 - Between 10 and under 15 - Between 15 and under 18 - Over 18 - Didn't say - Unknown • Family History of FGM, where applicable • Confirmation that the new-born baby has sister/s under 18 • Confirmation that a deinfibulation procedure took place to facilitate the delivery of a birth, where applicable • Confirmation that the baby's mother has been advised that FGM is illegal • Confirmation that the baby's mother has been advised on the health implications of FGM
16	<p>On receipt at the GP Practice of the Maternity Discharge information, where FGM information has been included, the Mother's healthcare record MUST be updated with the following FGM information, identified prior to, during or after the birth of a baby;</p> <p>The FGM information to be specifically included will be as follows;</p> <ul style="list-style-type: none"> • FGM Type • Confirmation that a deinfibulation procedure took place to facilitate the delivery of a birth, where applicable

	<ul style="list-style-type: none"> • Age at which the woman had FGM if known; <ul style="list-style-type: none"> - Under 1 - Between 1 and under 5 - Between 5 and under 10 - Between 10 and under 15 - Between 15 and under 18 - Over 18 - Didn't say - Unknown • Family History of FGM, where applicable • Confirmation that the woman has other daughter(s) under 18 • Confirmation that no external female genitalia abnormalities were found at birth, following existing neonatal examinations • Confirmation if an interpreter was required during the episode of care • Confirmation that the new-born baby's healthcare record has been updated to reflect FGM had been identified in the mother • Confirmation that the woman has been advised that FGM is illegal • Confirmation, that the woman has been advised on the health implications of FGM
17	<p>On receipt at the GP Practice of any clinical notes or discharge summary information where FGM has been included, then the following MUST be included within the young girl or woman's healthcare record.</p> <ul style="list-style-type: none"> • FGM Type • Age at which the woman or young girl had FGM, if known; <ul style="list-style-type: none"> - Under 1 - Between 1 and under 5 - Between 5 and under 10 - Between 10 and under 15 - Between 15 and under 18 - Over 18 - Didn't say - Unknown • Family History of FGM, where applicable • Confirmation that the girl/ woman has sister(s) / other daughter(s) under 18 • Confirmation if an interpreter was required during the episode of care • Confirmation that the girl's parents, or the woman has been advised that FGM is illegal • Confirmation, that the girl and her parents, or the woman has been advised on the health implications of FGM
18	<p>Where FGM is identified within a General Practice, all referrals made by the</p>

	<p>GP MUST include the FGM information when referring the patient to relevant services where FGM may be applicable.</p> <p>E.g.</p> <ul style="list-style-type: none"> • Midwifery Services • Gynaecology • Gynaecology Oncology • Urology • Paediatric Urology • Obstetrics • Genitourinary Medicine • Dermatology • Paediatric Dermatology • Psychiatric Services • Mental Health Services <p><u>This list is not exhaustive</u>, and the GP must use professional judgement, about which services FGM information would be appropriate to include</p>
19	<p>It is the responsibility of the GP, to update the following section within the Red Book, “Are there any other particular illnesses or conditions in the mother’s or father’s family that you feel are important?”, when applicable to do so with new FGM information.</p> <p>This will specifically need to include the following;</p> <ul style="list-style-type: none"> • Family History of FGM • Confirmation that the baby’s mother has been advised that FGM is illegal • Confirmation that the baby’s mother has been advised on the health implications of FGM <p>As outlined in requirement #11, clinical and professional judgement will be required where objections are raised to this, consideration for any local safeguarding actions which may be required, noting any different courses of actions taken</p>
20	<p>On receipt of a notification from a Health Visitor or School Nurse that a girl under their care has a sister or sisters that are also under the same GP’s care, then the sister/s healthcare records MUST be updated to include Family History of FGM.</p>
<p>Recording FGM Information – Acute Trusts/ Mental Health Trusts</p>	
21	<p>When it has been identified in an Acute or Mental Health Trust, that a young girl or woman has had FGM undertaken, the following MUST be included within any clinical notes or discharge summary information sent to the patient’s GP. This will be in addition to any other clinical findings as part of the provision of care;</p> <ul style="list-style-type: none"> • FGM Type • Age at which the woman or young girl had FGM, if known; <ul style="list-style-type: none"> - Under 1

	<ul style="list-style-type: none"> - Between 1 and under 5 - Between 5 and under 10 - Between 10 and under 15 - Between 15 and under 18 - Over 18 - Didn't say - Unknown <ul style="list-style-type: none"> • Family History of FGM, where applicable • Confirmation that the girl/ woman has sister(s) / other daughter(s) under 18 • Confirmation if an interpreter was required during the episode of care • Confirmation that the girl's parents, or the woman has been advised that FGM is illegal • Confirmation, that the girl and her parents, or the woman has been advised on the health implications of FGM
22	<p>When it has been identified in an Acute or Mental Health Trust, that a young girl has had FGM undertaken, in addition to the GP being informed of the FGM information in any clinical notes or discharge summary, this should also be sent to;</p> <ul style="list-style-type: none"> • the girl's Health Visitor if the girl is under 5 • the girl's School Nurse if the girl is over 5
Recording FGM Information – School Nurses	
23	<p>Where a School Nurse identifies that there is or are sisters of a girl with FGM, it is the responsibility of the school nurse to inform the GP.</p>
FGM Central Returns	
24	<p>From the 1st April 2015, all Acute (Foundation and Non-Foundation Trusts), Mental Health Trusts and GP Practices, MUST be able to record and submit the FGM information as defined in the FGM Enhanced dataset.</p>
25	<p>It MUST be possible to link FGM information received from General Practitioners and also from Acute/ Mental Health Trusts to avoid duplicate counting on numbers of woman identified with FGM.</p> <p>Therefore the NHS number MUST be used as the unique patient identifier for each woman.</p> <p>Information which could identify the patient will NOT be published.</p> <p>The NHS Number will only be used by HSCIC to link records between Primary Care and Secondary Care, and used to avoid the duplication of counting records twice.</p> <p>The FGM information published by HSCIC will only ever be aggregated data, (counts on numbers), and be adherent to Disclosure policy, e.g. if less than 6 patients were identified from an organisation, this number would not be published.</p>

26	<p>All Acute/ Mental Health Trusts and GP Practices, MUST use the Clinical Audit Platform template, to submit the FGM Enhanced dataset information.</p> <p>The FGM information can be submitted on a continual basis, with HSCIC determining the reporting periods.</p>
27	<p>It MUST be possible to determine the geographic region where a woman came from and also where the FGM information was collected from. This is to help identify, not just where FGM was identified, but where potential new FGM services may be required nationally, based on the geographic area of the woman's residence.</p> <p>Therefore a patient's General Practice Registration Code (Patient Registration) MUST be recorded where this is available, and the Patient's Post Code of Usual Address MUST be included in the FGM Enhanced dataset.</p> <p>The identification of the patient (NHS Number) will NOT be used in any publication of findings and will only be used by HSCIC to link records between Primary Care and Secondary Care, and used to avoid the duplication of counting records twice.</p> <p>The FGM information published by HSCIC will only ever be aggregated data, (counts on numbers), and be adherent to Disclosure policy, e.g. if less than 6 patients were identified from an organisation, this number would not be published.</p>

2.1.1 Conformance Criteria

#	Criteria
1	All (M)andatory components of the FGM Enhanced dataset MUST be collected as specified.
2	The FGM Enhanced Dataset MUST be submitted via the Clinical Audit Platform template from Acute and Mental Health Trusts for each NHS Funded provider for the specified reporting period.
3	Centrally issued guidance SHOULD be used to steer local decisions with regards to implementation.
4	All data MUST be validated and analysed by all Acute/ Mental Health Trusts and GP Practices, prior to the submission via the Clinical Audit Platform against the Data Quality conformance criteria outlined within the Data Quality section. All relevant mandatory fields MUST be completed prior to submission through CAP and CAP MUST alert the submitter where a record has not been completed.
5	Quality assurance MUST be undertaken by Acute/ Mental Health Trusts and General Practitioners to ensure that a woman's FGM information is not counted twice, within a given reporting period, unless this is done so for legitimate reasons, i.e. that a patient was identified more than once within a submitting organisation within the reporting period.

2.2 IT System Suppliers

#	Requirement ²
1	Suppliers of IT and software systems to NHS organisations MUST ensure that where SNOMED CT, CTV3, Read or OPCS is currently supported, the FGM clinical classifications and clinical codes related to FGM can be recorded against health records by Apr 2015. These codes will be the existing FGM codes as published in April 2014
2	Suppliers of IT and software systems to NHS organisations MUST ensure that where SNOMED CT, CTV3, Read or OPCS is currently supported, the new FGM clinical classifications and clinical codes related to FGM can be recorded against health records by Oct 2015. The new FGM codes will be published in April 2015 specifically; <ul style="list-style-type: none"> • History of Deinfibulation • History of FGM Type 3 These codes are detailed further within this document.
3	Suppliers of IT and software systems to NHS organisations MAY ensure that the new FGM clinical codes to be published in Apr 2015, (and detailed further within this document), can be recorded against health records from April 2015
4	Suppliers of IT and software systems to NHS organisations MAY ensure that the relevant FGM Enhanced dataset can be recorded within existing systems from April 1 st 2015.
5	Suppliers of IT and software systems to NHS organisations MUST ensure that the relevant FGM information can be recorded locally within existing systems by Dec 2015.
6	Suppliers of IT and software systems to NHS organisations MUST ensure that it is possible to extract the relevant FGM information from their systems by Information Teams or Practice Managers, enabling the update of the FGM Enhanced dataset submission to HSCIC.

2.2.1 Conformance Criteria

This section describes the tests that can be measured to indicate that the information standard is being used correctly by an IT system supplier.

#	Criteria
1	It MUST be possible to record all FGM Enhanced dataset items within the existing system
2	It MUST be possible to extract the FGM Enhanced dataset items in order to populate the Clinical Audit Platform template, for a specified reporting period.
3	All components of the FGM Enhanced Dataset MUST be identifiable, when FGM information is being collected via IT systems, to enable the appropriate queries to be run against patient records

² The key words MUST, SHOULD and MAY are defined in RFC-2119.

3 Recording FGM for Central Collection

This section outlines the requirements of the second element of the FGM Enhanced Dataset, with regards to the central submission of FGM information to HSCIC.

The intention of this section is to ensure a consistent approach nationally to the central return of relevant information when FGM has been identified, via the Clinical Audit Platform. This is a national clinical data collection tool for all relevant parties to submit FGM information to.

The main criteria for the central submission of the FGM information will be that the FGM Enhanced dataset will need to be completed as appropriate for each woman or girl when FGM has been identified and this information submitted via the Clinical Audit Platform. There are various approaches and methods that can be used to collect the relevant FGM information and the appropriate approach must be determined locally.

3.1 Audience

This section is specifically for clinicians and other healthcare workers.

3.2 General Principles

Outlined below are the general principles which collectively support the central return of FGM information:

- Every clinician from within any clinical setting may encounter a woman or girl who confirms that they have FGM. Clinicians who may not regularly encounter FGM, must still record the FGM Enhanced dataset information.
- It is NOT a requirement for every clinician to undertake an examination in order to fulfil the central return.
- A clinical examination should only be undertaken as part of a routine, usual or requested provision of care encounter.
- Where a clinical examination is undertaken, the clinician must;
 - confirm within CAP that the clinical examination has taken place
 - record the FGM Type based on what is presented to them at that time
 - record FGM Type Unknown if the Type cannot be determined.
- Where a clinical examination is not undertaken, but a woman or girl confirms that she has FGM, e.g. she's been cut, or, has been circumcised, the clinician must record this as 'Self Report':
 - If the woman or girl outlines a specific FGM Type, this can still be recorded, e.g. a woman outlines that they've been 'closed' then the clinician must record, 'Self Report' and 'FGM Type 3'
 - If the woman or girl doesn't know the FGM Type, as is often the case, then the clinician must record, 'Self Report' and 'FGM Type Unknown'.
- Where FGM Type 4 is identified, this should be further qualified if possible with one of the following five descriptions: Pricking, Piercing, Cauterisation, Incising, Scraping. If it isn't possible to further qualify the FGM Type 4, then this should still be recorded as Type 4.

3.3 Overview

There are different options available to support the central submission of FGM information from healthcare organisations. These have been defined and explored further within this section. The reason for outlining these different options is to try and accommodate the different circumstances when FGM may be identified.

These different circumstances include:

- Organisations that frequently provide care to women and girls with FGM
- Organisations that rarely see woman or girls with FGM
- Clinical settings that are not typically associated with FGM

3.4 Clinical Audit Platform (CAP)

Whilst there will be different ways in which FGM information can be recorded locally, all FGM information will ultimately be collected within CAP.

CAP is a recognised clinical collections tool used by most Acute Trusts, and is also developed, owned and supported by HSCIC. Further to this, the clinical data collected will ultimately be anonymised and used for Official Statistic publications.

It should be noted that no personal or sensitive data produced as an Official Statistic will include any patient identifiable information.

Further information about the Clinical Audit Platform can be found via the following link: <http://www.hscic.gov.uk/clinicalauditplatform>.

3.4.1 User Registration

CAP will require all necessary users, to be registered, before any submission can take place, so locally it will need to be determined whom this applies to.

It is recommended that at least one user should be someone from within an Information Team, but consideration should be given to which clinicians may require direct access to CAP also.

The registration process can be found here: www.hscic.gov.uk/fgm

3.5 Options for Central Collection

Outlined in the following sections are details of the three available options which have been introduced to support various national practices. The following options are briefly outlined below and explored further within this section:

- Direct Entry in CAP
- Collection Tools
- Existing Clinical System Development

The options for submitting information to CAP will not be limited to one per organisation. It may be for example, that specific clinicians will require access to directly record information within CAP, in addition to other clinicians in other clinical settings within the same organisation, requiring access to local tools to manually record FGM information and provide this to Information Teams.

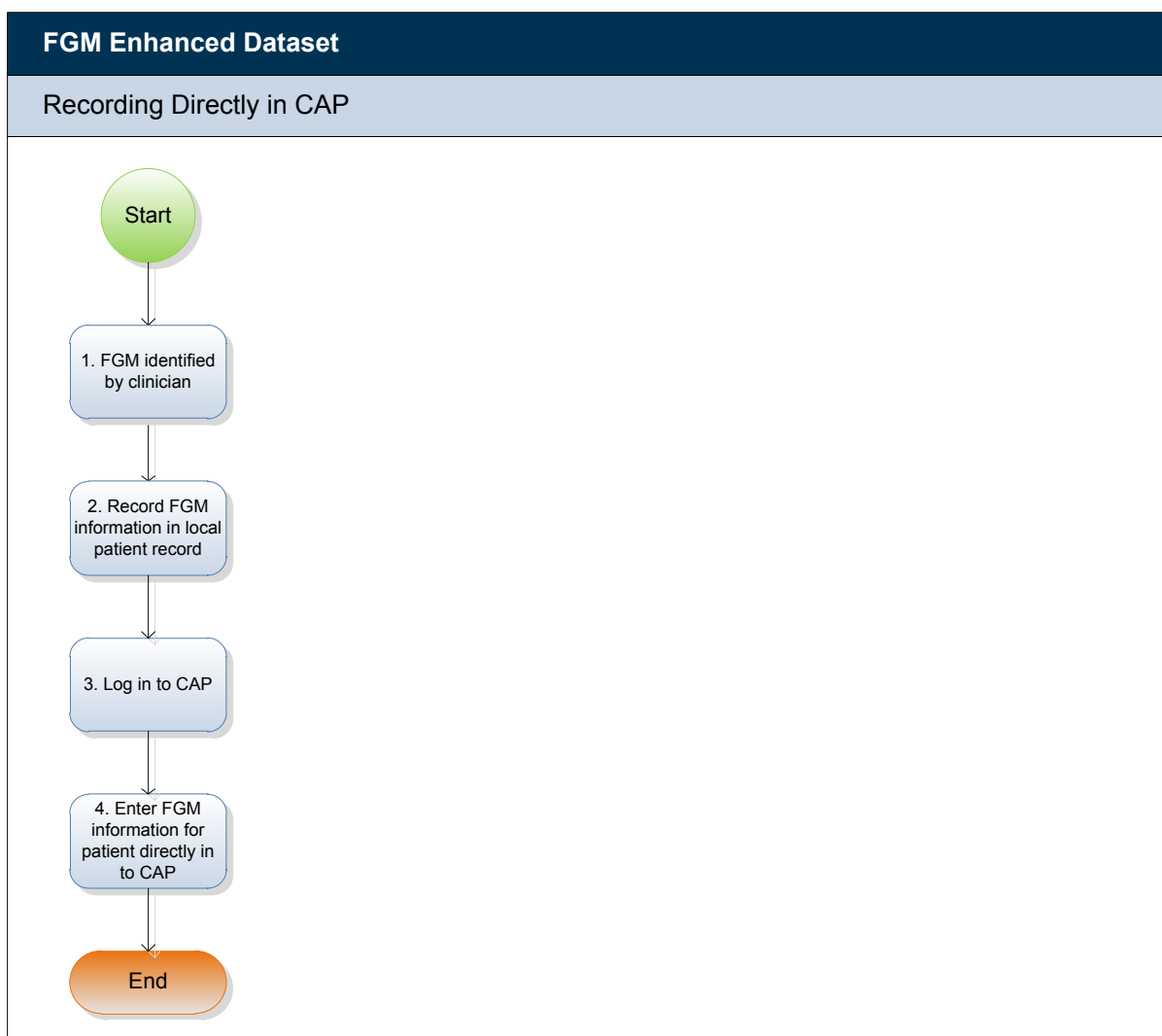
3.6 Direct Entry in CAP

When a woman or girl is identified as having FGM, it will be possible for registered clinicians to directly access and record the relevant FGM information for a woman or girl. CAP also include validation criteria and will display relevant formats or lack of, when applicable, in relation to what information can and should be collected.

CAP has also been developed to support the ability for a clinician to be able to see which other clinicians and organisations have recorded FGM information for a woman or girl.

Further details relating to entering information within CAP are provided in the CAP Operational Guidance document.

3.6.1 Process



3.6.2 Process Steps

The following steps support the process for how the FGM information is to be recorded directly within CAP.

It will need to be determined locally which clinician's would require access to directly enter FGM information within CAP.

Step	Description
1	<p>FGM identified by clinician:</p> <p>This process is initiated from the first identification of FGM being undertaken. Whilst it is acknowledged the difficulties in identifying the differences in FGM Types, this process follows, from where the identification of any FGM Type, as a result of direct routine questioning during history-taking /or has been disclosed by a patient, or, has been discovered by chance during the delivery of healthcare.</p>
2	<p>Record FGM information in Patient Record:</p> <p>Relevant information must always be recorded within the patient's healthcare record when FGM has been identified. Clinical codes must be used where and when these are available within local systems.</p>
3	<p>Log into CAP:</p> <p>This will require previous CAP registration to have been approved for the relevant clinician, and once access has been confirmed, the clinician will be able to directly create a new - or update an existing – patient record.</p>
4	<p>Enter FGM directly within CAP</p> <p>The forms used within CAP will highlight which FGM information must be populated and also provide the opportunity to include optional and required FGM information too.</p>

3.7 Collection Tools

There are two main ways in which the relevant FGM Enhanced Dataset items can be captured using local tools. These include;

1. Use of local collection tools
2. Use of the FGM CAP system specification

It will be for each organisation to determine which method will be the most suitable and to ensure that:

- clinicians know how they can access these tools and where they will be stored locally
- if they are to be printed and used as part of a consultation, clinicians can access them at the right time
- it is understood locally how these will be made available to the information teams or practice managers

3.7.1 Local Collection Tools

The local collection tools can be categorised in two further ways:

3.7.1.1 Electronic Records

Where existing electronic are tools used (e.g. spread sheets / databases) to record FGM information, these will require modification to ensure they can capture the required FGM Enhanced Dataset items. The collection of the required FGM Enhanced data will follow existing FGM information capturing processes, but with the addition of the additional FGM information collected.

With any modification of existing forms, it will still be possible to include additional FGM information for local purposes, so long as the FGM Enhanced data can still be recorded as a minimum.

3.7.1.2 Paper Forms

Locally it may be determined that paper forms are the best medium for collecting FGM information. Whilst this is not recommended, this may still be a preferable option for an organisation, and relevant guidance is, therefore, included here for completeness.

Where either electronic tools or paper forms are used, one obvious drawback is that drop down lists of e.g. Countries, or, Organisations which are displayed in CAP, may of course not be easily replicable within those local tools. It is recommended therefore, that in the development of any local tool, details of the clinician and their contact details should also be included, to support the circumstances when the information recorded needs to be reconfirmed.

Further to the above, local units will need to determine how and when the FGM information captured within these tools will be made available to the Information Team analysts or Practice Managers. This could be, for example, by:

- Providing direct access to local tools on shared drives that analysts would also have access to
- Securely emailing the tool to the relevant analyst

- Physical retrieval of paper form or printed version of the tool

3.7.1.3 Records Management: NHS Code of Practice

All patient information recorded locally must continue to adhere to the safe and secure storage and maintenance of patient records policies, as outlined in the Dept. of Health's Records Management: NHS Code of Practice Part 1 & Part 2 <https://www.gov.uk/government/publications/records-management-nhs-code-of-practice>

3.7.2 CAP System Specification

To support the entry of information into CAP, the FGM CAP system specification will also be available (retrievable via the FGM CAP webpage). This tool can be used in conjunction with electronic local data sources to support the transposing of all relevant FGM information into the correct format. The system specification also allows for the capture and recording of one or multiple women's/ girl's information to support the bulk upload of the FGM information.

The FGM CAP system specification can be used in the following circumstances:

3.7.2.1 Replace existing collection tools

Instead of using local tools, the FGM CAP system specification can be used to completely replace any existing collected tools used to record FGM information.

The benefit of this approach is that all relevant fields for CAP have already been defined in terms of content, expected values, and formats, and further to this, existing processes used to populate spread sheets can continue, albeit the FGM Enhanced Dataset may include additional information to what is currently recorded.

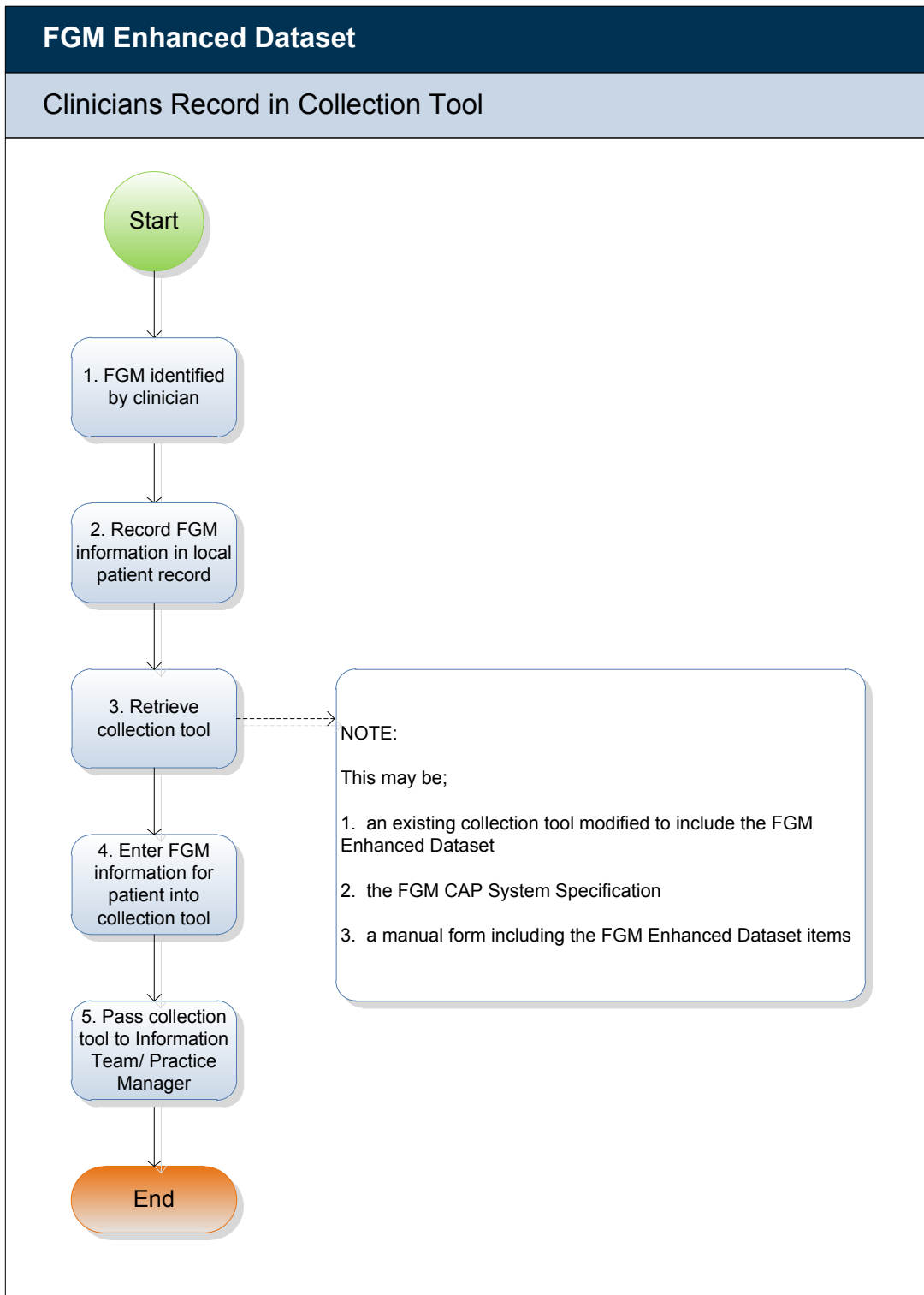
The system specification can also be populated with details relating to one or many women or girls and therefore supports bulk upload of these women / girl's FGM information in to CAP.

However, if the specification is amended to support any additional FGM information required locally for example, these changes will result in the file being rejected from being uploaded as these will not be expected by CAP.

3.7.2.2 Provided to system suppliers or other local data sources

The system specification has been specifically designed to support an upload to CAP, and can be made available to system suppliers to support the capture of the relevant FGM information and subsequently used to populate CAP automatically. This would require that the relevant FGM information can be appropriately obtained from those systems and this would require engagement with the supplier to ensure that the necessary work was undertaken.

3.7.3 Process



3.7.4 Process Steps

The following steps support the process outlining how the FGM information is to be recorded within a local collection tool.

Step	Description
1	<p>FGM identified by clinician:</p> <p>This process is initiated from the first identification of FGM being undertaken. Whilst it is acknowledged the difficulties in identifying the differences in FGM Types, this process follows, from where the identification of any FGM Type, as a result of direct routine questioning during history-taking /or has been disclosed by a patient, or, has been discovered by chance during the delivery of healthcare</p>
2	<p>Record FGM information in Patient Record:</p> <p>Relevant information must always be recorded within the patient's healthcare record when FGM has been identified. Clinical codes must be used where and when these are available within local systems</p>
3	<p>Retrieve Collection Tool:</p> <p>The collection tool should be retrieved by the relevant clinician, in order for them to populate this with FGM information.</p> <p><u>Note:</u></p> <p>It should be fully understood locally where this tool is located locally and how this can be accessed, and may be one of the following, dependent on which method is the most appropriate locally:</p> <ul style="list-style-type: none"> • a modified existing collection tool • the FGM CAP system specification • manual forms
4	<p>Enter FGM information for patient into Collection Tool:</p> <p>All relevant FGM Enhanced Dataset items must be recorded where applicable, for each woman / girl</p>
5	<p>Pass Collection Tool to Information Team / Practice Manager:</p> <p>On completion of the information for each patient, this should be made available to the information team or practice manager, dependent on the clinical setting.</p> <p>The following will need to be determined locally;</p> <ul style="list-style-type: none"> • The mechanism to be used to ensure the Information Team / Practice Manager can receive the collection tool, e.g. emailed, physically provided, direct access • The frequency for when the collection tool is provided to the Information Teams or Practice Managers, e.g. following each identification, on a specified day each month/ quarter

3.8 Existing Clinical Systems Development

This approach is the third option available to support the collection of relevant FGM information, and involves the development of existing clinical systems.

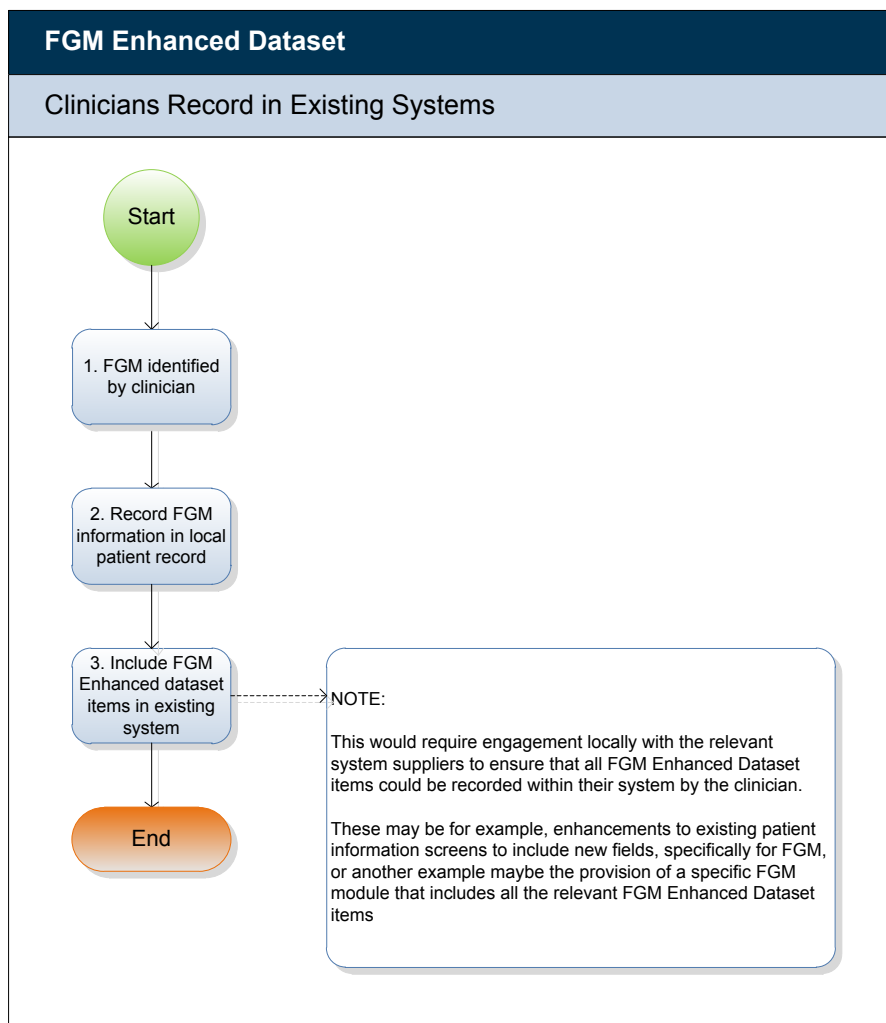
This approach will require the development of existing clinical systems, which must, as the minimum requirement, be able to support the recording of the FGM Enhanced Dataset. As an example, this may be to include additional fields within existing patient clinical records, or to include a specific FGM module, aligned to an existing system.

It should be noted that the development options outlined above, are only examples, for potential development within existing systems and organisations should engage with their suppliers to determine how the FGM information can be recorded within those existing systems.

The CAP FGM System Specification will be available and can be used both by existing system suppliers and to support the population of CAP with the relevant FGM information.

This specification outlines the content, values and appropriate formatting to support the population of CAP.

3.8.1 Process



3.8.2 Process Steps

Step	Description
1	<p>FGM identified by clinician:</p> <p>This process is initiated from the first identification of FGM being undertaken. Whilst it is acknowledged the difficulties in identifying the differences in FGM Types, this process follows, from where the identification of any FGM Type, as a result of direct routine questioning during history-taking /or has been disclosed by a patient, or, has been discovered by chance during the delivery of healthcare</p>
2	<p>Record FGM information in Patient Record:</p> <p>Relevant information must always be recorded within the patient's healthcare record when FGM has been identified. Clinical codes must be used where and when these are available within local systems</p>
3	<p>Include FGM Enhanced Dataset Items in Existing System:</p> <p>Where the local system has been developed to support the relevant FGM Enhanced Dataset information, the clinician who identified FGM should be able to directly enter the FGM information, according to the woman's or girl's circumstances</p>

4 FGM Information for Central Collection

4.1 Dataset Summary

The table below provides a summary of the FGM Enhanced Dataset information that is required to be collected within the Clinical Audit Platform.

M/R/O	DATA ITEM NAME
	HEADER
R	ORGANISATION CODE (CODE OF PROVIDER)
	PATIENT DETAILS
R	NHS NUMBER
O	LOCAL PATIENT IDENTIFIER
R	PERSON BIRTH DATE
M	POSTCODE OF USUAL ADDRESS
M	FORENAME
M	SURNAME
R	COUNTRY OF BIRTH
R	COUNTRY OF ORIGIN
O	REGION OF COUNTRY OF ORIGIN
R	GP PRACTICE REGISTRATION CODE
	ATTENDANCE DETAILS
M	CARE CONTACT DATE
R	REFERRING ORGANISATION TYPE
R	REFERRING ORGANISATION CODE
R	SITE CODE OF TREATMENT
R	TREATMENT FUNCTION AREA
R	PREGNANCY STATUS INDICATOR
M	FEMALE GENITAL MUTILATION (IDENTIFICATION)
R	FGM FAMILY HISTORY
R	NUMBER OF DAUGHTERS UNDER 18
R	ADVISED ON THE HEALTH IMPLICATIONS OF FGM?
R	ADVISED ON THE ILLEGALITIES OF FGM?
R	DAUGHTER/S BORN AT THIS ATTENDANCE
O	COUNTRY OF BIRTH OF THE BABYS FATHER
O	COUNTRY OF ORIGIN OF THE BABYS FATHER
	FGM DETAILS

M	FGM ACTIVITY IDENTIFIED
O	FGM TYPE 4 QUALIFIER
R	AGE RANGE WHEN FGM WAS UNDERTAKEN
R	COUNTRY WHERE FGM WAS UNDERTAKEN

- (M)andatory: These data items **MUST** be included. Failure to submit these items will result in the rejection of the submission
- (R)equired: These data items **SHOULD** be reported where they apply. Failure to submit these items will not result in the rejection of the submission but they may affect the derivation of national indicators or national analysis
- (O)ptional: These data items **MAY** be submitted on an optional basis at the submitter's discretion

4.2 Dataset Descriptions

M/R/O	DATA ITEM NAME	DATA ITEM VALUES	DATA ITEM DESCRIPTION
HEADER			
R	ORGANISATION CODE (CODE OF PROVIDER)		<p>This SHOULD be included, where available.</p> <p>This will be required where there is an organisation submitting the FGM information on behalf of another provider. Confirmation of the submitting organisation and the provider organisation need to be recorded when applicable.</p>
PATIENT DEMOGRAPHICS			
R	NHS NUMBER	N/a	<p>This SHOULD be included, where available.</p> <p>The NHS Number will be required to submit a record in CAP. Without the NHS Number the record will not be included within any statistics.</p> <p>If no NHS Number is present, then a Local Patient Identifier MUST be included.</p> <p>Whilst CAP will validate that the NHS Number is in the correct format, it will not immediately verify that this is the correct NHS Number for the patient.</p> <p>However, where an NHS Number is not included, this will be highlighted within a data quality report from within CAP, outlining to the submitting organisation that a correct NHS Number is required for that patient.</p> <p>It is anticipated that it will be the Information Teams that will have access to the data quality reports, and in order for the submission to be completed, the correct NHS Number will need to be sought and included for that record.</p>
O	LOCAL PATIENT IDENTIFIER		<p>This MAY be included even if the NHS Number is available. However, if the NHS Number is not present, then the Local Patient Identifier MUST be included, to help the submitting organisation identify which record requires an NHS Number.</p>
R	PERSON BIRTH DATE	<ul style="list-style-type: none"> DD-MMM-YYYY 	<p>This SHOULD be included and used in part to verify the correct patient.</p>

			Where this is not known for any reason, then the default value of 01/01/1900 must be included, but the date of birth should always be sought where possible.
M	POSTCODE OF USUAL ADDRESS	N/a	This MUST be included and used in part to verify the correct patient.
M	FORENAME	N/a	This MUST be included and used in part to verify the correct patient.
M	SURNAME	N/a	This MUST be included and used in part to verify the correct patient.
R	COUNTRY OF BIRTH	<ul style="list-style-type: none"> • Name of Country – (see Appendix) • Unknown – Patient Not Asked • Unknown – Patient Asked but not Answered • Unknown – Not Specified • Other Country – Not Listed 	<p>This SHOULD be included by the clinician (where available).</p> <p>This will help to provide confirmation of where the woman or girl was born. The list of relevant countries will be available from within CAP, including the following default values if the woman doesn't, won't or can't specify. The full list of Countries is available within the Appendix section of this document.</p>
R	COUNTRY OF ORIGIN	<ul style="list-style-type: none"> • Name of Country • Unknown – Patient Not Asked • Unknown – Patient Asked but not Answered • Unknown – Not Specified • Other Country – Not Listed 	<p>This SHOULD be included by the clinician (where available).</p> <p>This will be the name of the country that the woman or girl deems themselves to have originated from.</p> <p>If from more than one country (e.g. a mixed heritage background) then the country of origin should be the one that the woman or girl states themselves, to be the most pertinent.</p> <p>The list of relevant countries will be available from within CAP and will include the default values if the woman, doesn't, won't or can't specify. The full list of Countries is available within the Appendix section of this document.</p>
O	REGION OF COUNTRY OF ORIGIN	<ul style="list-style-type: none"> • Name of Region of Country • Unknown – Patient Not Asked • Unknown – Patient Asked but not Answered • Unknown – Not Specified • Other Region – Not Listed 	<p>This MAY be included by the clinician, (if available).</p> <p>Confirmation of the region within the country of origin determined.</p> <p>If no Country of Origin has been outlined, then the Region of Origin can't be included.</p> <p>If the Country of Origin is UK, then the Region of Origin is not required.</p> <p>The list of relevant regions will be available from within CAP, including the default values if the woman, doesn't, won't or can't specify. The full list of Regions is available within the Appendix section of this document.</p>

M	GP PRACTICE REGISTRATION CODE	<ul style="list-style-type: none"> • GP Practice Registration [ODS Code] • Not Registered - Eligible • Not Registered - Recently Entered Country • Not Registered - Unknown / Unable to Confirm 	<p>This MUST be included by the clinician.</p> <p>Where a patient does not have a GP Practice Registration Code, one of the default values must be included.</p> <p>If the GP Practice Registration code is not included, then this will be highlighted within the data report, and it will be necessary to include the specific code of the patient's GP Practice or include a default value.</p>
ATTENDANCE DETAILS			
M	CARE CONTACT DATE	<ul style="list-style-type: none"> • DD-MMM-YYYY 	<p>This MUST be included.</p> <p>This will be the date when the encounter with the woman or girl took place.</p>
R	REFERRING ORGANISATION TYPE	<ul style="list-style-type: none"> • 01 – GP Practice • 02 – NHS Organisation • 03 – Self Referral • 04 – School • 05 – Voluntary Sector • 06 – Local Authority • 07 – Police • 08 – Justice Service • 09 – Immigration Centre • 10 – Religious Organisation • 11 – Other • XX – Not Stated 	<p>This SHOULD be included, where available.</p> <p>The type of organisation the woman or girl was referred from should be included; if this was a GP Practice or other NHS organisation, then the organisation code should be populated within the Referring Organisation Code field.</p>
R	REFERRING ORGANISATION CODE	<ul style="list-style-type: none"> • GP Practice Registration [ODS Code] • NHS Organisation [ODS Code] 	<p>This SHOULD be included by the clinician, (if available).</p> <p>The Referral Organisation Code indicates the code of the referring organisation type where the referral has been made from.</p> <p>The list of referring organisations will be available from within CAP.</p> <p>If the referral is from a General Practice or other NHS organisation, the associated code for that GP or NHS organisation will need to be included.</p> <p>The GP Registration Practice codes (including Not Registered) and NHS Organisation codes will be available within a drop list for the clinician to directly record within CAP.</p>

			<p>Notes:</p> <ul style="list-style-type: none"> • 03 – Self Referral (e.g. walk-ins) • 04 – School: (e.g. primary, secondary, colleges, other educational establishments) • 05 – Voluntary Sector: (including charities, victim / survivor groups, etc.) • 06 – Local Authority (including, children or adult) • 08 – Justice Service (e.g. prison, young offender’s institutes, sexual assault referral centres, etc.) • 10 – Religious Organisation (e.g. church, mosque, prayer group, etc.)
R	SITE CODE OF TREATMENT	<ul style="list-style-type: none"> • NHS Organisation [ODS Code] 	<p>This SHOULD be included (if available). The Site Code of Treatment will be the code of a specific clinic or hospital within a wider organisation. The full list of these Site Codes will be available within CAP.</p>
R	TREATMENT FUNCTION AREA	<ul style="list-style-type: none"> • Treatment Function Area Code as per data dictionary 	<p>This SHOULD be included by the clinician, (where available). The Treatment Function Area options will be available from within CAP. The full list of these options is available within the Appendix section of this document.</p>
R	PREGNANCY STATUS INDICATOR	<ul style="list-style-type: none"> • Yes • No • Unknown • Not Stated 	<p>This SHOULD be included by the clinician, (where available). One of the Values should be selected from within CAP.</p> <p>Notes:</p> <ul style="list-style-type: none"> • Yes (<i>the woman or girl is pregnant</i>) • No (<i>the woman or girl is not pregnant</i>) • Unknown (<i>it was not qualified either way</i>) • Not stated (<i>the patient was asked but no response was provided</i>)
M	FEMALE GENITAL MUTILATION (IDENTIFICATION)	<ul style="list-style-type: none"> • Self-Report • On Examination 	<p>This MUST be included by the clinician. This will outline how FGM was identified, and one of the Values must be selected from within CAP.</p> <p>Notes:</p>

			<ul style="list-style-type: none"> • Self-Report (<i>where the woman or girl outlined they have FGM</i>) • On Examination (<i>only when a physical examination, as part of routine, usual or requested provision of care for a woman is undertaken</i>).
R	FGM FAMILY HISTORY	<ul style="list-style-type: none"> • Yes • No • Unknown • Not Stated 	<p>This SHOULD be included by the clinician (where available). FGM has been identified in other family members to the woman or girl (e.g. mother, sisters, aunts, grandmothers, cousins etc.) or, their wider community group (e.g. guardians, in-laws, wider social group). This is not an exhaustive list and may include;</p> <ul style="list-style-type: none"> • New-born baby girls, where FGM has been identified in the mother. • Adult women who have older female relatives with FGM. <p>It is acknowledged that confirming if FGM has been undertaken in other family members will not be easy to determine, but this will help to determine any future potential risk of FGM occurring to a woman or girl. One of the Values should be selected from within CAP.</p> <p>Notes:</p> <ul style="list-style-type: none"> • Yes (FGM has been identified in the immediate or wider family) • No (FGM has not been identified in the immediate or wider family) • Unknown (the question was not asked) • Not Stated (the question was asked but no clear response was provided)
R	NUMBER OF DAUGHTERS UNDER 18?	<ul style="list-style-type: none"> • 0 – 20 (Integer) • Unknown – Not Specified 	<p>This SHOULD be included by the clinician (where available). Confirmation that the woman or girl already has daughters under 18 is required. One of the Values should be selected from within CAP.</p> <p>Notes:</p> <ul style="list-style-type: none"> • 0 – No daughters • 1 – 20 daughters can be recorded • Unknown - Not Specified (the question was asked but no clear response was provided)

R	HAS THE PATIENT BEEN ADVISED ON THE HEALTH IMPLICATIONS OF FGM?	<ul style="list-style-type: none"> • Yes • No • Unknown – Not Specified 	<p>This SHOULD be included by the clinician. One of the Values should be selected from within CAP.</p> <p>Notes: All health professionals should be aware of FGM and its health implications. They should also understand what actions are required when they encounter a child or woman who has had, or is at risk of, FGM. Examples of short term health implications, include; Severe pain, Shock, Bleeding, Wound infections including tetanus and gangrene, Blood-borne viruses such as HIV, hepatitis B and hepatitis C, Inability to urinate, Injury to vulval tissues surrounding the entrance to the vagina, Damage to other organs nearby such as the urethra and the bowel. This list is not exhaustive. Examples of long term health implications, include; Chronic vaginal and pelvic infections, Abnormal periods, Difficulty passing urine and persistent urine infections, Kidney impairment and possible kidney failure, Damage to the reproductive system including infertility, Cysts and the formation of scar tissue, Complications in pregnancy and newborn deaths, Pain during sex and lack of pleasurable sensation, Psychological damage including low libido, Depression and anxiety, Flashbacks during pregnancy and childbirth and the need for later surgery to open the lower vagina for sexual intercourse and childbirth. This list is also not exhaustive and sometimes, FGM can also cause death.</p>
R	HAS THE PATIENT BEEN ADVISED ON THE ILLEGALITIES OF FGM?	<ul style="list-style-type: none"> • Yes • No • Unknown – Not Specified 	<p>This SHOULD be included by the clinician. One of the Values should be selected from within CAP.</p> <p>Note: FGM is a crime in the UK. Even if someone is taken overseas for the mutilation, it is still a crime in the UK if the mutilation is done by a UK national or permanent UK resident. It is also a crime if a UK national or permanent resident assists or gets a non-UK national or permanent resident to carry out the acts overseas on a UK national or permanent</p>

			resident.
R	DAUGHTER/S BORN AT THIS ATTENDANCE	<ul style="list-style-type: none"> • Yes • No 	<p>This SHOULD be included by the clinician.</p> <p>Confirmation that a baby girl was born as part of the attendance.</p>
O	COUNTRY OF BIRTH OF THE BABYS FATHER	<ul style="list-style-type: none"> • Unknown – Patient Not Asked • Unknown – Patient Asked but not Answered • Unknown – Not Specified • Other Country – Not Listed 	<p>This MAY be included by the clinician (if available).</p> <p>Confirmation of the country of birth of the baby’s father.</p> <p>The list of relevant countries will be available from within CAP and will include the default values if the woman doesn’t, won’t or can’t specify.</p> <p>The full list of Countries is available within the Appendix section of this document.</p>
O	COUNTRY OF ORIGIN OF THE BABYS FATHER	<ul style="list-style-type: none"> • Unknown – Patient Not Asked • Unknown – Patient Asked but not Answered • Unknown – Not Specified • Other Country – Not Listed 	<p>This MAY be included by the clinician (if available).</p> <p>The list of relevant countries will be available from within CAP and will include the default values if the woman, doesn’t, won’t or can’t specify.</p> <p>The full list of Countries is available within the Appendix section of this document.</p>
FGM DETAILS			
M	FGM ACTIVITY IDENTIFIED	<ul style="list-style-type: none"> • FGM Type 1 • FGM Type 2 • FGM Type 3 • History Of FGM Type 3 • FGM Type 3 - Re-infibulation Identified • FGM Type 4 • FGM Type Unknown • Deinfibulation Undertaken to facilitate delivery • Deinfibulation Undertaken 	<p>This MUST be included by the clinician.</p> <p>Only when a physical examination (as part of routine, usual or requested provision of care for a woman) is undertaken, can the FGM Type be confirmed.</p> <p>It is NOT required that every clinician has to perform a physical examination solely in order to populate the FGM Enhanced Dataset.</p> <p>One of the Values must be selected from within CAP.</p> <p>Where FEMALE GENITAL MUTILATION (IDENTIFICATION) outlines Self Report, an FGM Type MAY be recorded.</p> <p>Where FEMALE GENITAL MUTILATION (IDENTIFICATION) outlines On Examination, one of the values MUST be recorded.</p> <p>Notes:</p> <p>History Of FGM Type 3:</p> <ul style="list-style-type: none"> - Where the woman or girl has previously had FGM Type 3 but has also since had a Deinfibulation procedure as part of her treatment, then this MUST be recorded when identified.

			<p>FGM Type 3 - Re-infibulation Identified</p> <ul style="list-style-type: none"> - Where a re-infibulation event has been identified (i.e. has historically been deinfibulated following FGM Type 3, but has since been 'closed' again, then this MUST be selected. It is acknowledged that this may not be easily identifiable, but if identified through consultation, this can be recorded here. <p>FGM Type 4:</p> <ul style="list-style-type: none"> - Where a FGM Type 4 has been identified, this can be qualified by using the FGM Type 4 Qualifier Code. If it is not possible to identify the specific FGM Type 4 condition, then FGM Type 4 MUST still be recorded. <p>FGM Type Unknown:</p> <ul style="list-style-type: none"> - This MUST only be used when it cannot be clearly identified which FGM Type the woman or girl has been subjected to.
O	FGM TYPE 4 QUALIFIER	<ul style="list-style-type: none"> • FGM Type 4 Pricking • FGM Type 4 Piercing • FGM Type 4 Scraping • FGM Type 4 Incising • FGM Type 4 Cauterisation 	<p>This MAY be included by the clinician (if available). Where FGM Type 4 has been selected, this can be further qualified if possible, by selecting one of the Values within CAP.</p>
R	AGE RANGE WHEN FGM WAS UNDERTAKEN	<ul style="list-style-type: none"> • Under 1 • Over 1 and under 5 • Between 5 and under 10 • Between 10 and under 15 • Between 15 and under 18 • Over 18 • Didn't Say 	<p>This SHOULD be included by the clinician (where available). The Age Range when FGM was undertaken should try to be obtained.</p> <p>Example: Under 5 would include those patients up to and including 4yrs and 364 days.</p>
R	COUNTRY WHERE FGM WAS UNDERTAKEN	<ul style="list-style-type: none"> • Name of Country • Unknown – Patient Not Asked 	<p>This SHOULD be included by the clinician (where available). The Country where FGM was undertaken should try to be obtained, and when / if identified, this should be recorded using the Values outlined</p>

		<ul style="list-style-type: none">• Unknown – Patient Asked but not Answered• Unknown – Not Specified• Other Country – Not Listed	<p>within CAP. The list of relevant countries will be available from within CAP and will include the default values if the woman doesn't, won't or can't specify. The full list of Countries is available within the Appendix section of this document.</p>
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4.3 Additional Dataset Notes

Whilst the Dataset items will be included within CAP and - where relevant - different values will be displayed to the user, where local collection tools are used. Outlined below are additional notes to inform:

- the user as to how the information requested can be recorded, and
- information teams / practice managers as to how this information can be sought for eventual inclusion within CAP.

4.3.1 NHS Number

This should always be sought where possible for inclusion within CAP as the primary identifier of the patient.

Without the NHS Number, a record can still be created within CAP but the record will not be used for reporting purposes and will therefore trigger an entry in the Missing Key Field report within CAP, highlighting the missing NHS number. The correct NHS Number must be sought and the record updated.

4.3.2 Person Date of Birth

This will be used to help verify the patient, but also to help confirm whether the record is for an adult or a child.

If for any reason the date of birth is unknown this needs to be recorded as the default value of 01/01/1900 within CAP.

4.3.3 Countries

Where possible, the “Country” fields should be populated. Clearly, every clinician will not know every country nor immediately have available a list of all possible countries that can be populated within a local collection tool. However, this information should be made available where possible.

If possible, “Country” information (i.e. for patient demographics, or to record where the FGM was undertaken) should be sought from the woman or girl, and recorded. When a local collection tool is used, attempts should be made to record these details, and when provided to the Information Teams / Practice Managers, this information should – where possible – be transposed into CAP.

Similar attempts should be made for the “Region of Country of Origin”, but - again - it is fully acknowledged that this will not always be easy to:

- a) initially obtain from the patient,
- b) record appropriately
- c) transpose to CAP by information teams

Whilst there are lists of Countries and Regions outlined within the Appendix of this document, it is for each organisation to determine how they could use these, if at all. Accordingly, completion of this information i.e. specifically for Region of Country, is Optional.

The list of countries outlined within CAP are aligned to ISO3316:
http://www.iso.org/iso/home/standards/country_codes.htm

4.3.4 Organisations

All healthcare organisations in England, including General Practices, have associated organisation codes.

Within CAP, it will be possible to search for the relevant healthcare organisation and select this as appropriate. However, if a local collection tool is used, the name of the organisation should be sought if not immediately available, and included. Any locally recorded organisation information will require the Information Teams / Practice Managers to search and select the appropriate organisation within CAP.

4.3.5 Number of Daughters Under 18

Where possible, confirmation whether a woman or girl has daughters under 18 should be sought.

This will include circumstances where the encounter leading to the recording of FGM information has included a birth of a daughter.

4.3.6 History of Type 3

History of Type 3 indicates the identification of a woman or girl who has historically been 'closed' (had Type 3) and subsequently been 'opened' (deinfibulated). This is still FGM, and needs to be recorded as History of FGM Type 3.

As the clinician needs to record what is presented to them, where it is known that the woman or girl had historically had FGM Type 3, then this must be recorded as History of Type 3, and not FGM Type 3, in order to provide the historical context of the FGM identified.

5 Collecting FGM Information

This section outlines the collation processes in relation to appropriately populating CAP with the FGM information recorded by clinicians.

How FGM information is recorded by clinicians will impact on how the FGM information can be collected locally by Information Teams or Practice Managers. As such, the methods for collection will directly relate to how the FGM information was initially recorded, i.e.:

- Direct entry in CAP by a clinician
- Use of collection tools locally
- Development of an existing clinical systems

5.1 Audience

This section is specific for Information Teams and Practice Managers.

5.2 Direct entry in CAP

Where clinicians have direct access to record FGM information within CAP, as long as all required elements have been included, no additional input will be required by the Information Team, as the FGM information will have been submitted directly by the clinician. However, where there is missing information, the Missing Key Field report would highlight the data that is required before the record within CAP can be used for reporting purposes.

It is recommended that, in addition to any clinicians that may have access to CAP, an Information Team analyst and / or Practice Manager should also have access to CAP. This will be to ensure that any records highlighted within the Missing Key Field report can be updated and successfully used for reporting.

5.3 Collection tools

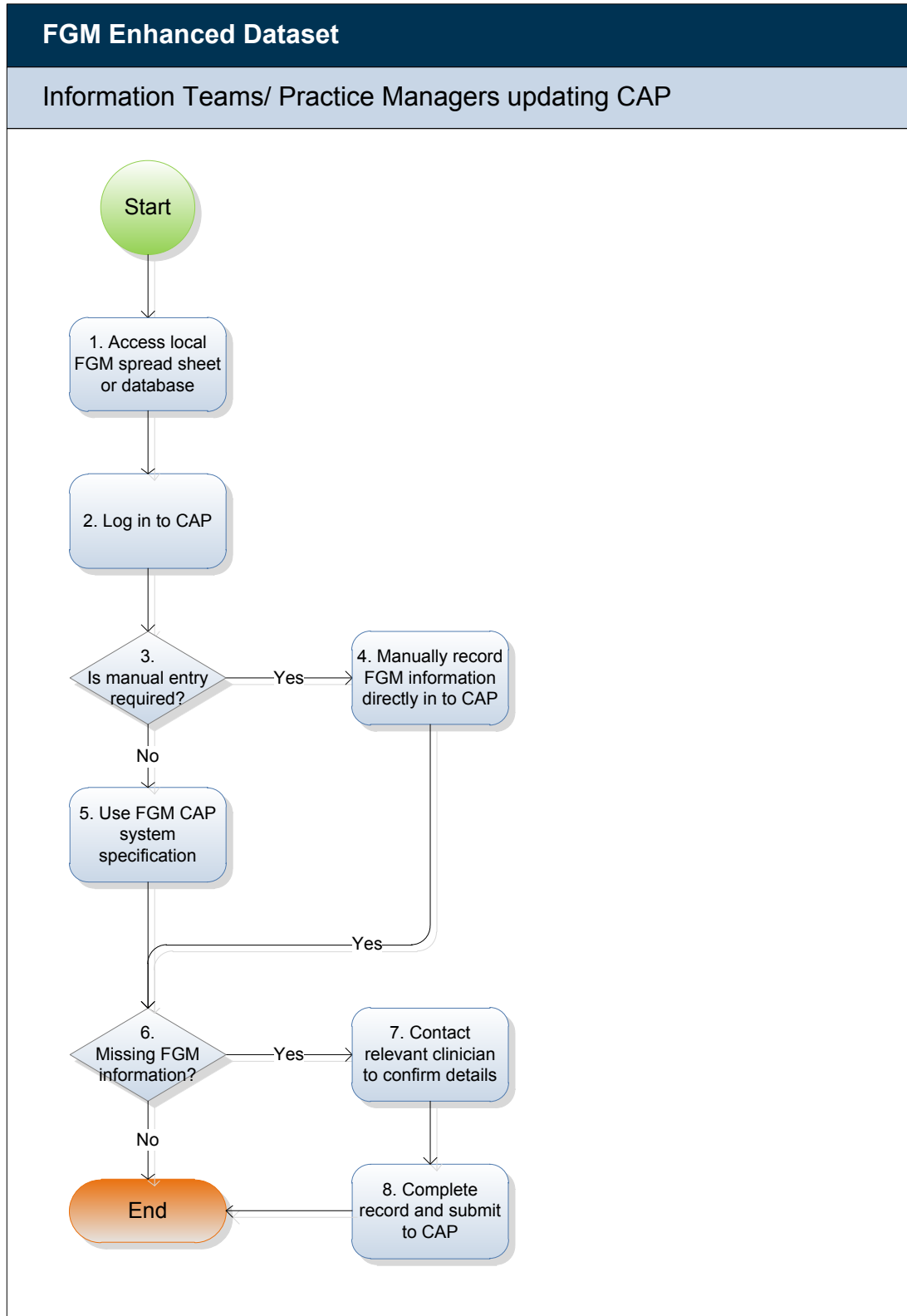
Where FGM information has been recorded within local collection tools, consideration must be given to how this will best be shared with the Information Teams or Practice Managers locally, in order for final entry into CAP to be undertaken.

Where local tools, e.g. spread sheets have been used to record the relevant FGM information, there are two approaches that can be used to transpose the information into CAP. These include:

- Using the FGM CAP system specification to ensure that the information contained within the local spread sheets is automatically transposed and then the FGM CAP system specification saved within CAP, and ultimately populating all the women's and girl's records automatically.
- Manually transposing each local record and updating CAP manually. This is not recommended but is outlined here for completeness as it may be deemed locally to be the most applicable method.

Where local paper forms are used, then the information contained in the forms will need to be manually recorded within CAP. Again, this is not recommended but, outlined here for completeness if deemed locally, to be the most applicable method.

5.3.1 Process



5.3.2 Process Steps

Step	Description
Information Teams / Practice Managers Updating CAP	
1	<p>Access local FGM spread sheet or database:</p> <p>It will need to be determined how the Information Teams or Practice Managers will obtain the relevant spread sheets, paper forms or access to local databases.</p>
2	<p>Log into CAP:</p> <p>This will require previous CAP registration to have been approved for that clinician, and once access has been confirmed, the clinician will be able to directly create or update a new or existing record for a patient.</p>
3	<p>Establish whether manual entry is required.</p> <p>Where manual forms have been used locally to record the FGM Enhanced Dataset items, it is likely that CAP will need to be manually updated directly.</p> <p>If Yes, go to step 4.</p> <p>If No, go to step 5.</p>
4	<p>Manually record FGM information directly in to CAP:</p> <p>This will require access to CAP in order to manually re-record the FGM information from local manual forms.</p>
5	<p>Use FGM CAP System Specification:</p> <p>Access the FGM CAP system specification which will be available via the Clinical Audit Platform FGM web page. Once retrieved, the FGM information from local tools can be transposed and saved to the FGM CAP System Specification, which is then saved within the CAP FGM web page.</p>
6	<p>Establish whether any FGM information is missing.</p> <p>This will be highlighted within the Missing Key Fields Report within CAP and will highlight the missing FGM information. If there is missing FGM information, go to step 7.</p> <p>If there is no missing information identified from an uploaded file, end the process.</p>
7	<p>Contact relevant clinician to confirm missing details, and where possible obtain these and edit the relevant patient record.</p>
8	<p>Complete record and submit to CAP.</p>

5.4 Existing Clinical Systems Development

The FGM CAP system specification can be used by clinical system suppliers to extract the relevant FGM information and submit this directly to CAP. This can include one or many women's or girl's records and also, and where there has been any missing FGM information, that is required as part of the upload, this will trigger the creation of a Missing Key Field report, highlighting the specific missing information.

Further details of how to use the FGM CAP system specification are available in the CAP Operation Guidance.

5.5 Missing Fields Report

These reports will be visible from within CAP for each submitting organisation. Each report will highlight the records that have, for whatever reason, not included specific FGM information. Details of the Missing Fields Report will be available within the FGM CAP System Specification.

As an overview however, where a patient record has been included within the Missing Key Field report, the reasons why the record has been included here will require appropriate amendment or updating, before a woman or girl's record can be included for reporting purposes.

5.6 Submission Frequency

Whenever FGM is identified in a woman or girl, the relevant information should be entered into CAP in order to ensure the necessary, continual submission of data.

The 'extract period' will be defined by CAP, but it is anticipated that this will initially include all records received with attendance dates between 1st April 2015 and 30th June 2015 and then ongoing on a quarterly basis with an annual report also to be provided.

Depending on the method for collecting FGM information locally, it is recommended that to ensure that any records resulting in the creation of a Missing Key Field report should be worked on to complete the record, as soon as possible. Any records that are not submitted or completed for the extract period will not be included within any reporting.

6 Information Governance

The Health and Social Care Information Centre (HSCIC) no longer needs to apply for Section 251 support when directed or requested to collect person confidential data. This is set out in Sections 254 and 255 of the Health and Social Care Act 2012.

However, all data providers must still ensure compliance with the fair processing requirement of the Data Protection Act 1998. To meet these requirements, data providers must make information and guidance available to patients and/or their legal guardians to inform them that their data will be used for secondary uses purposes.

As a result, the proposed changes for the FGM Enhanced Dataset Information Standards Notice (ISN) do not require Confidentiality Advisory Group (CAG) approval. A Privacy Impact Assessment has instead been carried out in relation to the collection of FGM information on behalf of the FGM Prevention Programme.

Although the HSCIC is permitted to collect, hold and process patient-identifiable FGM information under the Health and Social Care Act 2012, it is obliged to ensure that there is a legal gateway in place before sharing this data with third parties.

It is not intended that patient-identifiable data will be shared with other parties. Such activity would require explicit patient consent, Section 251 support under the NHS Act 2006, or another statutory gateway.

It is intended however, that the FGM information collected and disseminated using the Clinical Audit Platform will support the publication of patient-anonymised Official Statistics.

6.1 Patient Consent

As the FGM Enhanced Dataset will be underpinned as a result of Department of Health directions, this will require *no explicit patient consent* to be sought in order to collect this information and subsequently share this with HSCIC.

However, each patient where FGM information has been identified by a healthcare organisation, must inform each woman or girl as to how and what will happen to the information being recorded, and further to this, where an objection to this is made each organisation must ensure it understands the fair processing procedures outlining where a woman can contact to make an objection to this information being recorded and sent to the HSCIC.

6.2 Fair Processing Procedure

To support an objection made by a woman or girl with regards to the use of their data, the specific FGM Enhanced Dataset route to object will be clearly outlined from the following web address: <http://www.hscic.gov.uk/yourinfo>.

Further to this, leaflets will be available to all health organisations that will provide the woman or girl with further information about the use of their information, referencing the following;

- The Data Protection Act 1998 governing the processing of personal data held on computer systems and other formats
- The information that is being collected

- Why the information is being collected
- Compliance to national standards around data security and confidentiality as outlined: <http://systems.hscic.gov.uk/infogov/confidentiality>
- The right to object to confidential information being shared, as outlined above

This leaflet will be produced and made available from the DH in due course.

6.3 Privacy Impact Assessment

To support the FGM Enhanced Dataset implementation, a Privacy Impact Assessment has been undertaken, to help identify the privacy risks of what is being proposed, to support the action required to mitigate those risks prior to any collection, sharing, retention or analysis of FGM information.

6.4 Management of Patient Information

It is expected that through the introduction of the FGM Enhanced Dataset, all organisations will continue to adhere to existing NHS Codes of Practice with regards to patient confidentiality, information security management, NHS records management and legal obligations as outlined from:

<http://systems.hscic.gov.uk/infogov/codes>

Further to this the implementation of the FGM Enhanced dataset must not infringe on these policies and it will be for local healthcare organisations ensure that these codes of practice are maintained.

7 Terminology and Clinical Classifications

The following details are taken from the UK Terminology Centre, and are intended for use by all NHS systems. The UKTC records should be used as the definitive specification for the clinical codes as used in the UK. The publication of these codes has allowed for coded entries to detail findings in relation to FGM.

At this point, the clinical codes are included in the FGM Enhanced information standard, and are to be used from April 2015.

7.1 Publication of codes

The following clinical codes were published in April 2014;

7.1.1 Read v2

Proposed Concept	Read v2
Female Genital Mutilation	K578.
Family History of Female Genital Mutilation	12b..
History of Female Genital Mutilation	15K..
Female Genital Mutilation Type 1	K5780
Female Genital Mutilation Type 2	K5781
Female Genital Mutilation Type 3	K5782
Female Genital Mutilation Type 4	K5783
Deinfibulation of vulva	7D045
Deinfibulation of vulva to facilitate delivery	7F1B5

7.1.2 CTV3

Proposed Concept	CTV3
Female Genital Mutilation	Xaad9
Family History of Female Genital Mutilation	Xab24
History of Female Genital Mutilation	Xab25
Female Genital Mutilation Type 1	Xab2E
Female Genital Mutilation Type 2	Xab2F
Female Genital Mutilation Type 3	Xab2G
Female Genital Mutilation Type 4	Xab2H
Deinfibulation of vulva	XaPs4
Deinfibulation of vulva to facilitate delivery	XaaoP

7.1.3 SNOMED CT

Proposed Concept	SNOMED CT
Female Genital cutting	429744008
Female Genital mutilation	885761000000108 [UK]
Female Genital Mutilation Type I – WHO classification	903121000000105 [UK]
Female Genital Mutilation Type II - WHO classification	903141000000103 [UK]
Female Genital Mutilation Type III – WHO classification	903161000000102 [UK]
Female Genital Mutilation Type IV – WHO classification	903181000000106 [UK]
Family History of FGM (female genital mutilation)	902961000000107 [UK]
History of FGM (female genital mutilation)	902981000000103 [UK]
Deinfibulation of vulva	442290007
Deinfibulation of vulva to facilitate delivery	893721000000103 [UK]

7.1.4 OPCS-4 Classifications, Interventions & Procedures v4.7

Deinfibulation of vulva	P07.2
Deinfibulation of vulva to facilitate delivery	R27.2

7.1.5 ICD-10

Note that the current classification of FGM within ICD 10 is associated with other conditions, and therefore not deemed appropriate for the data extraction in support of the FGM Enhanced Dataset.

7.2 Use of terminology and classifications

All healthcare providers of NHS funded care, including independent sector and social enterprise / voluntary organisations are able to use the above clinical codes or narrative appropriate to their provision and / system to record when it is identified that a woman or girl has FGM.

7.3 Future Development

To provide greater clarity in the support of recording FGM, there are a number of proposed SNOMED CT concepts which are due for publication by April 2015.

These include the following new concepts;

- History of Deinfibulation
- History of FGM Type 3

These new concepts will help clinicians to provide a greater level of granularity when recording when historical deinfibulations have been identified or, when historical FGM Type 3's have been identified.

7.3.1 ICD-10 5th Edition

The ICD-10 5th edition is due to be published on the 1st April 2016.

Personal history of female genital mutilation	Z91.7
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The description above from the ICD 5th edition means that if the patient healthcare record documents that the woman has had female circumcision or female genital cutting or any of the four FGM Types then this code is the correct code to use.

Examples:

Healthcare Record 1	Documents that the patient has had a female circumcision – the coder will assign Z91.7
Healthcare Record 2	Documents that the patient has had genital cutting – the coder will assign Z91.7
Healthcare Record 3	Documents that the patient has FGM type 2 – the coder will assign Z91.7
Healthcare Record 4	Documents that the patient has FGM but the type has not been specified – the coder will assign Z91.7

Whilst this does not detail the specific FGM type identified, there will be further development work in this area, but it is not currently expected that this will be available until a later date (approx. 2017-18), aligned to global agreement on the inclusion of more granular information.

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