Information Standards Board for Health and Social Care			
Title	ISN 1610 Female Genital Mutilation Prevalence Dataset Specification		
Document ID	ISB 1610 Amd 1/2014		
Sponsor	Flora Goldhill	**Status**	Final
Developer	Astrid Fairclough	**Version**	1.7
Author	Fairclough, Astrid	**Version Date**	20/03/2014

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ISB 1610 Female Genital Mutilation Prevalence Dataset

Standard Specification

Amendment History:

Version	Date	Amendment History
0.1		First draft for comment
0.2	7th Feb 2014	Further comments
1.0	10 Feb 2014	Final
1.1	18 Feb 2014	Appraisers comments included
1.2	20 Feb 2014	Additional inclusions following Appraisers meeting
1.3	24 Feb 2014	All but two changes made following Appraisers meeting
1.4	26 Feb 2014	Final submission for Appraisers
1.5	10 Mar 2014	Following QA
1.6	13 Mar 2014	Following Review & QA
1.7	20 Mar 2014	Comments from Board preparation meeting included

Approvals:

Name	Organisation	Version	Date
Flora Goldhill	Department of Health	1.7	20 Mar 2014

Glossary of Terms:

Term	Acronym	Definition
Female Genital Mutilation	FGM	All procedures that involve partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons – WHO definition
Office of Population Censuses and Surveys Classification of Interventions and Procedures	OPCS	Procedural classification for the coding of operations, procedures and interventions performed in secondary care settings NHS.
Read codes		Standard clinical terminology system used in general practice
SNOMED Clinical Terms	SNOMED CT	Classification of medical terms providing codes, terms, synonyms and definitions used.

Contents

1 Overview

1.1 Summary

Standard	
Standard Number	ISB 1610
Standard Title	Female Genital Mutilation Prevalence Dataset
Description	The FGM Prevalence Dataset requires organisations to record and collect information about the prevalence of FGM within the patient population as treated by the NHS in England. 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. FGM must also be treated as child abuse. There are UK government multi-agency guidelines [Ref 3]: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216669/dh_124588.pdf These guidelines will also be made available with the FGM Prevalence Standard. Particular note should be given to pages 27 – 29 of these guidelines, with respect to guidelines for health professionals. The NHS is in a unique position to identify those who have undergone FGM. There are multi-agency guidelines in place detailing what to do but there is recognition that this is not happening in all cases. There is a programme of work, led by the Department of Health, to improve the NHS response to FGM, and subsequent management of patients and safeguarding for girls at risk. This standard introduces the first requirements about information capture and a central return. The information collected is needed to inform the next stages of the FGM Prevention programme. This standard firstly instructs all clinicians, regardless of organisation type, to record into clinical notes when FGM is identified, and what type it is. The second element of the standard then instructs Acute Trusts to undertake a central return reporting upon the prevalence of FGM. The standard requires a monthly return from Acute Trusts via the UNIFY2 system. The standard also includes detail of newly published clinical codes which allow for coded entries to detail that a woman has undergone FGM and what type it is, that a patient has a family history of FGM, and that a woman has had the procedure deinfibulation. At this point, use of the clinical codes is not essential and they are included in the standard for information only, although it is worth noting that future stages of the FGM Prevention programme do plan to introduce additional requirements for NHS organisations to use these codes.
Applies to	The requirement to record FGM in clinical notes is applicable across all NHS healthcare settings. The requirement to submit the FGM Prevalence Dataset is mandatory for all Acute (Foundation and non-Foundation) Trusts, including A&E departments. Other organisations (which may include GPs) may wish to support the standard and provide an FGM Prevalence Dataset centrally. It should be noted that the standard has not had additional development to ensure it is designed to be

	suitable for other healthcare settings, but those wishing to participate will not be precluded from doing so, and can contact the team at FGM@dh.gsi.gov.uk to discuss further. It should be noted that any burden to do so must be met by the organisation concerned.
Release	
Release Number	ISB 1610
Release Title	Initial standard
Description	N/A
Implementation Start Date	1 April 2014
Implementation Completion Date	1 September 2014

1.2 Supporting Documents

Ref #	Reference	Title
1	Implementation Guidance	FGM Prevalence Dataset Implementation Guidance Final V1.0
2	DMD Change Request CR1449	NHS Data Model and Dictionary Change Request
3	Multi-Agency Practice Guidelines	HM Government Multi-Agency Practice Guidelines

1.3 Related Standards

None.

2 Health and Care Organisations

2.1 Requirements

#	Requirement [1]
1	Clinical staff MUST record in patient healthcare records when it is identified that a patient has had FGM. This applies to all NHS clinicians and healthcare professionals across the NHS. If it can be determined what type of FGM the patient has, this MUST be recorded (section 6). If it is not possible to determine the type of FGM undergone, it MUST be recorded.as type 9, 'Not Known'.
2	All data related to FGM prevalence as required by the FGM Prevalence Dataset MUST be collated at the provider (by locally agreed processes) at all Acute (Foundation and non-Foundation) Trusts on a monthly basis.
3	All data MUST be validated and analysed by providers at all Acute Trusts prior to submission to Unify2.
4	Aggregated data on counts of all data items MUST be submitted to Unify2 data collection system from all Acute Trusts on a monthly basis on or by 5th working day of the month immediately following the period of collection.
5	Aggregated data on counts of all data items MAY be submitted to Unify2 data collection system from all other healthcare settings on a monthly basis on or by 5th working day of the month immediately following the period of collection.

2.2 Conformance Criteria

#	Criteria
1	All components of the FGM Prevalence Dataset MUST be collected as specified.
2	Dataset MUST be input to the Unify2 template as made available to each Trust for a specified reporting period.
3	Centrally issued guidance and FAQs SHOULD be used to steer decisions.
4	Providers MUST apply data validation processes to assure the quality and completeness of the data prior to submission to DH.
5	Quality assurance MUST be undertaken by Information Teams to ensure that a patient is not counted twice within a submission, and therefore avoid duplicate recording of information.

[1] The key words MUST, SHOULD and MAY are defined in the information standards development methodology. They follow RFC-2119.

3 IT Systems Suppliers

3.1 Requirements

#	Requirement [2]
1	Suppliers of IT and software systems to NHS organisations MAY ensure that the clinical codes related to FGM (see section 5) can be recorded against health records.
2	Suppliers of IT and software systems to NHS organisations providing deinfibulation procedures MAY allow the use of the OPCS clinical code P07.2 or R27.2 (see section 5) to be recorded against the health record when carrying out this procedure.

3.2 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	FGM information MUST be able to be queried in order to inform the Unify2 template as made available to each Trust for a specified reporting period.
2	When submitting MUST be undertaken to ensure that FGM information for a patient is not duplicated, prior to any submission to the Information Team.
3	All components of the FGM Prevalence 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 the information standards development methodology. They follow RFC-2119.

4 FGM Prevalence Dataset definition

This following definition is taken from the NHS Data Model and Dictionary (NHS DMD) [Ref 2]:

NHS Data Model & Dictionary Label	Descriptions	Permitted values/ Format	Field specification
Organisation and Reporting Period To carry details of the reporting organisation and the reporting period			
ORGANISATION CODE (CODE OF PROVIDER)	ODS code of the A&E department, hospital or trust	ODS code of the NHS Trust / Foundation Trust, conforming to the relevant ODS specification.	3-6 characters, alphanumeric
REPORTING PERIOD START DATE	Date of the start of the reporting period	(CCYY-MM-DD)	10 characters, alphanumeric
REPORTING PERIOD END DATE	Date of the end of the reporting period	(CCYY-MM-DD)	10 characters, alphanumeric
FGM New Identifications To carry details of patients identified as having each type of Female Genital Mutilation (if known) during the reporting period. Multiple occurrences of this group are permitted, one for each FEMALE GENITAL MUTILATION AGE CATEGORY and FEMALE GENITAL MUTILATION TYPE reported			
FEMALE GENTIAL MUTILATION AGE CATEGORY	The age category for a patient identified as having undergone FGM. Type values will be 1 Under 18yrs old, 2 Over 18yrs old, 9 Not Known or Not Recorded.	1, 2, 9	1 character, alphanumeric
FEMALE GENTIAL MUTILATION TYPE	The type of FGM which the patient has been identified as having (if recorded). Type values will be 1, 2, 3, 4 and 9 (not known).	(1,2,3,4,9)	1 character, alphanumeric
PATIENTS WITH FGM FIRST IDENTIFIED TOTAL	Patients first identified as having each type of FGM during the reporting period. This will include those diagnosed/identified within the provider within the month.	COUNT	Up to 6 characters, number
FGM Active Caseload (one occurrence of this group required) The total number of patients identified as having Female Genital Mutilation before the Reporting Period Start Date, who are actively being treated on the health care provider organisations' active caseload. Multiple occurrences of this group are required, one for each FEMALE GENITAL MUTILATION AGE CATEGORY.			
FEMALE GENTIAL	The age category for a	1, 2, 9	1 character,

MUTILATION AGE CATEGORY	patient identified as having undergone FGM. Type values will be 1 Under 18yrs old, 2 Over 18yrs old, 9 Not Known or Not Recorded.		alphanumeric
NUMBER OF PATIENTS WITH FEMALE GENTIAL MUTILATION ACTIVE CASELOAD TOTAL	Patients identified as having a history of any FGM TYPE prior to the reporting period and still being actively seen/treated for FGM-related conditions or any other non-related condition. Note does not include those patients within NUMBER OF PATIENTS WITH FGM FIRST IDENTIFIED IN REPORTING PERIOD (i.e. identified within this reporting period)	COUNT	Up to 6 characters, number
Number of Contacts by Treatment Function Code (Multiple occurrences of this group permitted, one per TFC) To carry details of total patient contact activities for each ACTIVITY TREATMENT FUNCTION CODE that patients with Female Genital Mutilation are being seen/treated under, during the reporting period. Multiple occurrences of this group are permitted, one for each ACTIVITY TREATMENT FUNCTION CODE. Note: for TREATMENT FUNCTION CODES where there have been no CARE CONTACT activities undertaken for the active caseload or newly-identified PATIENTS during the REPORTING PERIOD, there is no requirement to report a zero value for that TREATMENT FUNCTION CODE			
ACTIVITY TREATMENT FUNCTION CODE	The TFC is recorded to report the specialised service within which the patient is treated the patient is being treated under or has been referred to if not yet seen	TFC as per the NHS Data Dictionary (Recorded to report the specialised service within which the patient is treated).	3 characters, alphanumeric
PATIENTS WITH FEMALE GENITAL MUTILATION CARE CONTACTS TOTAL	Total number of care contacts of any type recorded for any patient within the reporting period (NUMBER OF PATIENTS WITH FGM FIRST IDENTIFIED IN REPORTING PERIOD and NUMBER OF PATIENTS WITH FGM ACTIVE CASELOAD)	COUNT	Up to 6 characters, number
DEINFIBULATIONS TOTAL	Number of FGM patients undergoing a patient procedure of 'deinfibulation' during the reporting period	COUNT	Up to 6 characters, number
REPEAT	Number of FGM patients	COUNT	Up to 6 characters,

DEINFIBULATIONS TOTAL	undergoing a patient procedure of 'repeat deinfibulation' during the reporting period. X – Number of repeat deinfibulations not known		number

5 Terminology and Clinical Classifications

The following details are taken from the UK Terminology Centre, and are intended for information only. The UKTC records should be used as the definitive specification for the clinical codes as used in the UK.

The publication of these codes will allow for coded entries to detail that a woman has undergone FGM and what type it is, that a patient has a family history of FGM, and that a woman has had the procedure deinfibulation.

At this point, the clinical codes are included in the standard for information only; organisations are not required to take action.

It is worth noting that future stages of the FGM Prevention programme plan to introduce additional requirements for NHS organisations to use these codes. Therefore if any organisation wishes to take steps to introduce the routine use of the clinical codes when record FGM in clinical records, and appropriate situations, this is welcomed. To discuss plans with the programme team, if required, please contact FGM@dh.gsi.gov.uk.

5.1 Publication of codes

As at the 1 April 2014, the following clinical codes will be published;

5.1.1 Readv2

Proposed Concept	Read v2	Release Date
Family History of Female Genital Mutilation	12b..	01.04.14
History of Female Genital Mutilation	15K..	01.04.14
Female Genital Mutilation Type 1	K5780	01.04.14
Female Genital Mutilation Type 2	K5781	01.04.14
Female Genital Mutilation Type 3	K5782	01.04.14
Female Genital Mutilation Type 4	K5783	01.04.14
Deinfibulation of vulva	7D045	Existing Concept
Deinfibulation of vulva to facilitate delivery	7F1B5	01.04.14

5.1.2 CTV3

Proposed Concept	CTV3	Release Date
Family History of Female Genital Mutilation	Xab24	01.04.14
History of Female Genital Mutilation	Xab25	01.04.14
Female Genital Mutilation Type 1	Xab2E	01.04.14
Female Genital Mutilation Type 2	Xab2F	01.04.14
Female Genital Mutilation Type 3	Xab2G	01.04.14
Female Genital Mutilation Type 4	Xab2H	01.04.14
Deinfibulation of vulva	XaPs4	Existing Concept
Deinfibulation of vulva to facilitate delivery	XaaoP	01.04.14

5.1.3 SNOMEDCT

Proposed Concept	SNOMEDCT	Release Date
Clinical Finding		
Female Genital cutting	429744008	
Female genital mutilation	885761000000108 [UK]	
Female Genital Mutilation Type I - World Health Organisation classification	903121000000105 [UK]	01.04.14
Female Genital Mutilation Type II - World Health Organisation classification	903141000000103 [UK]	01.04.14
Female Genital Mutilation Type III - World Health Organisation classification	903161000000102 [UK]	01.04.14
Female Genital Mutilation Type IV – World Health Organisation classification	903181000000106 [UK]	01.04.14
Situation with Explicit Content		
Family history of FGM (female genital mutilation)	902961000000107 [UK}	01.04.14
History of FGM (female genital mutilation)	902981000000103 [UK]	01.04.14
Procedure		
Deinfibulation of vulva	442290007	Existing Concept
Deinfibulation of vulva to facilitate delivery	893721000000103 [UK]	01.04.14

5.1.4 OPCS Classification of Interventions & Procedures (OPCS-4) v 4.7

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

5.1.5 ICD10

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 Prevalence Dataset.

5.2 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 appropriate to their provision and/or system to record when a patient has had FGM.

A further Information Standard is planned, in which there will be additional requirements in relation to patient records of FGM. It is likely that this will include requirements to use the codes whenever entering details of FGM within patient records systems.

For this reason, providers wishing to familiarise themselves with the codes at an earlier date are encouraged to do so.

6 Types of FGM

The following details are taken from the UK Terminology Centre, and are intended for information only. The UKTC records should be used as the definitive specification.

When diagnosing and categorising type of FGM, the World Health Organization (WHO) definitions should be used (http://www.who.int/reproductivehealth/topics/fgm/overview/en/) wherever categorisation is possible:

- **Type 1:** Partial or total removal of the clitoris and/or the prepuce (clitoridectomy).
- **Type 2:** Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision).
- **Type 3:** Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation).
- **Type 4:** All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization.

When the category cannot be ascertained, for whatever reason, FGM should still be recorded in the clinical notes, using the value ‘Type 9: Not known’.

Records carrying ‘Type 9: Not Known’ are to be included in the dataset return.

7 FGM High Level Process Flow

Below is an outline of the high level process with regards to roles and responsibilities to collate FGM information when it is identified, and the submission process to the DH.

FGM Return: High Level Process				
Step	Clinical Staff	Information Teams	Department of Health	Note
1	Identification of FGMType during clinical encounter			Clinical engagement, guidance and communications will be available to support health professionals to identify the different types of FGM
2	Record FGM data as part of clinical encounter			1. To determine locally the tools that will be used to support the recording of FGM, when it is identified. E.g. example collection tool as per the Appendix 2. To ensure all clinical areas record FGM when it is identified and deinfibulations and repeat deinfibulations
3	Submit local tool to Information Team			Determine locally the frequency of submitting FGM collections to the Information Team. E.g. immediately whenever FGM is identified, or provided weekly from each department
4		Collate FGM Information & Quality Review		1. To ensure all departments are submitting 2. Applying the relevant Treatment Function Codes 3. Confirming the patient numbers within the relevant reporting period (active or new cases) 4. Data quality to avoid/ limit any potential duplicates
5		Submit via Unify2		Submit monthly report via Unify2 for the given month
6			Retrieve FGM Return	DH analysts to retrieve the FGM Return details
7			FGM Reports	DH to compile relevant reports to outline FGM prevalence nationally

8. Appendix

8.1 Example FGM Tool Instruction Sheet

The following worksheet outlines the 1st worksheet from the example FGM Collection Tool, which provides an overview of the process to collect FGM information locally within the Trust and provide this to the Information Team.

FGM Collection - INTERNAL Return	
Purpose:	This spread sheet is to inform the Information Team of all new cases of FGM identified within the patient population, and the number of deinfibulations carried out each month.

ALL Clinics		
Process:	1	Whenever a patient is first identified in this clinic as having had FGM, whoever writes the clinical notes (which must record that she has FGM and the type where possible) is also to include the patient details on this form.
	2	At the end of the month, a nominated individual must submit the form to the Information team on [to be locally determined in line with local suitability]
	3	This process is to be followed every month for all patients.

Please note:	1	The FGM Definitions listed are those to be used when completed the spread sheet and when recording type in the clinical notes.
	2	All midwives, doctors and healthcare practitioners in the team must be informed of the new process and asked to comply.
	3	If in doubt as to whether the patient has been included in this return during previous reporting periods, **they should be included again**. Repeat identifications are **not** an issue.
	4	If it is not possible to identify the type of FGM, it should be recorded under 'Type 9: Other'.

Clinics Performing Deinfibulations		
Process:	1	At the end of the month, a nominated individual should review activity during the period to obtain a COUNT of the number of deinfibulations and reinfibulations completed during the month.
	2	That nominated individual is to complete the collection sheet and return to the Information Team on the first working day of the following month.

8.2 Example FGM Tool_FGM New Patients Collection

The following worksheet outlines the 2nd worksheet from the example FGM Collection Tool, which provides the first of the two main collection templates, to support the collection of FGM information locally within the Trust.

Department:	*e.g. Maternity*	*If Treatment Function Code is known, this should be entered here*
Month:	*e.g. March*	*Reporting period is each calendar month.*

Unique Patient Identifier	Date of Birth	Date FGM Identified	FGM Type Identified (1, 2, 3, 4 or 9)	
e.g. 123 456 7890	*CCYY-MM-DD*	*CCYY-MM-DD*	*3*	*One activity per line.*

Form returned by:		
Date returned:		

Please complete and return the spread sheet in accordance with the instructions on the front page to infoteam@emailadress by COP on 1st working day of each month.

8.3 Example FGM Tool_FGM DeInfibulations Collection

The following worksheet outlines the 3rd worksheet from the example FGM Collection Tool, which provides second of the two main collection templates, to support the collection of FGM information locally within the Trust.

Department:	*e.g. Maternity*
Month:	

Reporting period is each calendar month.

	Deinfibulation	Repeat Deinfibulation
Number of procedures performed in the department in the reporting period (Month)		

Form returned by:	
Date returned:	

Please complete and return the spread sheet in accordance with the instructions on the front page to infoteam@emailadress by COP on 1st working day of each month.

8.4 Example FGM Tool_FGM Definitions

The following worksheet outlines the 4th worksheet from the example FGM Collection Tool, which provides the WHO definitions of the FGM Types, to support healthcare workers identify the relevant FGM Type.

Definitions		
FGM Type Identified	1	Clitoridectomy: partial or total removal of the clitoris (a small, sensitive and erectile part of the female genitals) and, in very rare cases, only the prepuce (the fold of skin surrounding the clitoris).
	2	Excision: partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (the labia are "the lips" that surround the vagina).
	3	Infibulation: narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the inner, or outer, labia, with or without removal of the clitoris.
	4	Other: all other harmful procedures to the female genitalia for non-medical purposes, e.g. pricking, piercing, incising, scraping and cauterizing the genital area.
	9	Not known

Source:	http://www.who.int/reproductivehealth/topics/fgm/overview/en/

