Towards a better estimation of prevalence of female genital mutilation in the European Union: interpreting existing evidence in all EU Member States

1. INTRODUCTION

Female genital mutilation (FGM) is a practice that involves all procedures to the female genitalia for non-medical reasons. The practice occurs predominantly in 27 African countries, but also outside Africa. In 22 African countries as well as in Yemen, the prevalence has been measured using a standard survey method developed by the Demographic Health Surveys (DHS) of Macro International (now ICF International). These surveys collect data from nationally representative samples of households in over 90 countries, with adult women (aged 15-49) and men in the sampled households. An FGM module is included in the Women's Questionnaire, which is part of the DHS. The DHS surveys ask female survey respondents if they have heard of FGM and then, if the answer is positive, probe for further data. Survey responses generate information on FGM prevalence rates, typologies of FGM, circumcision of daughters, and respondents’ attitudes to FGM (UNICEF, 2005). Since 2000, similar FGM prevalence data are provided by UNICEF’s Multiple Indicator Cluster Surveys (MICS) for a certain number of countries. There exist no reliable global FGM prevalence data figures for girls aged 0-15 years, and neither are data available through the DHS and MICS for prevalence in Asian countries where FGM is practised (Yoder and Khan, 2008). Due to migration, FGM became an issue in countries where it was formerly inexistent, including in European countries. The prevalence of FGM in Europe is however unknown. The European Parliament Resolution of 24 March 2009 on FGM (2008/2071(INI)) mentions that 500,000 women living in Europe have been subjected to FGM, and that each year 180,000 female migrants undergo, or are in danger of undergoing FGM. The source of these figures remains however obscure.

Providing information on the extent of FGM within countries and populations is important as it can be utilised to track progress on FGM prevention, to inform decision-making and to determine resource allocation. Ideally, the most accurate way to verify whether FGM has taken place is through a clinical
assessment of the genital area. If such data are registered accurately, they could provide clear insights into prevalence of FGM. In practice, however, such clinical assessments pose multiple logistical and ethical questions, and require specific knowledge and expertise of the clinicians performing such examinations.

2. OBJECTIVES

This paper reports on the results of the assessment of FGM prevalence in the EU, which was undertaken as part of a broader study to map FGM in the EU. The overall study was entitled “Study to map the current situation and trends of female genital mutilation in 27 EU Member States and Croatia”, and was carried out by the authors from December 2011 to December 2012 for the European Institute for Gender Equality. This study was expected to support and contribute to the future development of strategies for the elimination of different forms of violence against women, by assessing and analysing the current situation of FGM in all EU Member States. The study mapped the areas of prevalence, policy and legal frameworks, actors dealing with FGM and their approaches in all Member States and provided recommendations on data collection and policy approaches to FGM in the EU. The prevalence section of the overall study aimed at identifying and analysing all existing FGM prevalence data in all EU Member States. This paper presents these prevalence data and provides some critical reflections on estimating FGM in the EU.

3. METHODOLOGY

We defined the prevalence of FGM in any of the Member States of the EU as the number of women and girls in that country who have undergone FGM at a certain point in time expressed as the proportion of the total number of women living in the country, but originating from countries where FGM is practised. Since FGM is not performed on the native female population in any Member State, the prevalence of FGM should not be defined with respect to the total population of a country, but with respect to the female population, living in a European country, with origins in countries where FGM is practised. Girls at risk are defined as minor girls (0-18 years) that migrated from countries where FGM is common practice or who are born to parents (or one parent) who originate(s) from such countries.

A pool of native speaking researchers performed a desk research in the 28 EU countries (in 24 languages). In order to ensure the consistency of the approach across the countries, comprehensive guidelines were prepared to instruct the researchers on the national data collection, as well as templates to compile the information electronically, and a country report template to sum-
marize and reflect on the data collected. Examples of the expected deliver-
ables, based on a pilot study in Belgium and the Netherlands, were provided
and researchers were individually briefed by telephone. In addition, a
helpdesk function was established in order to assist the national researchers
during the desk research.

The desk study consisted of a systematic web-based search along with e-
m ail contacts and enquiries by phone (and, in some cases, in person) of key
institutions (such as Equal Opportunities bodies, national (gender) equality
bodies, ombudsman institutions, national human rights bodies, national min-
istries of justice, national agencies for asylum seekers, child protection agen-
cies, parliaments, police, national organisations for professionals such royal
colleges for midwives or gynecologists and finally NGOs that deal with
FGM) and individuals in order to collect and confirm all the information and
data available on prevalence, among others. The national researchers were
instructed to collect secondary data only (existing prevalence studies), as the
scope of the overall study, timeframe and budget, along with ethical and
methodological discussions around prevalence data collection on FGM, did
not allow collecting primary data (conducting studies to estimate the preva-
lence). The web-based search was performed in English and in the country’s
official language(s). Key terms such as ‘female genital mutilation’ (FGM),
‘female genital surgery’ (FGS), ‘female genital cutting’ (FGC) and ‘female
circumcision’ were suggested to guide the web-based search, together with
other terminology that may be used to refer to FGM in the different lan-
guages. Well-established scientific and academic databases were suggested to
be searched, i.e. Social Science Research Network, Sociological Abstracts,
Heinonline, Pubmed, EBSCO and Web of Science. Google Scholar was also
used. In addition, other (national) academic databases which researchers were
familiar with and had access to were used to widen the research tools in order
to increase search results related to the practice of FGM in their country.
In order to clarify the type of data and information considered to be relevant for
the scope of this study, inclusion and exclusion criteria were defined and
described in the guidelines, along with a detailed checklist of the
material/information to be collected for any prevalence estimations or other
surveys/studies to assess the magnitude of FGM in a given country, region or
city. Inclusion criteria were any documents on prevalence data on FGM, in
particular numbers of women with FGM or girls at risk of FGM in a country
(in English or local language), published from 1980 onwards. Documents that
were searched included reports by civil society organizations, health sector,
social sector, government agencies, and others; texts of criminal law on FGM,
resolutions, protocols; manuals by professionals; guidelines for professionals
by professional organizations or other agencies; national action plans; and
papers by academics. Exclusion criteria included documents on sexual and
gender based violence in general, studies that did not concern Europe or a
specific EU country, documents published before 1980 and newspapers and magazine articles.

All data collected were classified and stored in a database and 28 analytical country reports were produced by the national researchers, including a section on prevalence studies. The database contained the following information regarding prevalence data:
- Source of information (e.g. academic)
- Author(s)
- Title of document
- Year of publication
- Language of the document
- Data collection methods (how data on prevalence was collected)
- Year when data were collected
- Study population (e.g. women with FGM, girls at risk)
- Prevalence data on FGM:
  - Number of female residents from African countries/origin where FGM is performed. If available, the national researchers were requested to list data aggregated by age, ethnicity or nationality, length of stay in a country, number of daughters, age of daughters, date of birth of daughters;
  - Number of girls at risk from African countries/origin where FGM is performed. If available, data were listed aggregated by age, ethnicity or nationality, length of stay in a country, number of daughters, age of daughters, date of birth of daughters;
  - Number of non-registered female migrants from African countries/origin where FGM is performed. If available, data were listed by age, ethnicity or nationality, length of stay in a country, number of daughters, age of daughters, date of birth of daughters;
  - Number of asylum seeking women from African countries/origin where FGM is performed. If available, data were listed by age, ethnicity or nationality, length of stay in a country, number of daughters, age of daughters, date of birth of daughters;
  - Number of refugee women from African countries/origin where FGM is performed. If available, data were aggregated by age, ethnicity or nationality, length of stay in a country, number of daughters, age of daughters, date of birth of daughters.
- Aggregated data per country of origin
- Aggregated data per age
- Other aggregation
- Limitations of study
- Observations.

Based on the above mentioned data, we read and analysed all identified prevalence data and the methods used and wrote a discussion note on estimat-
TOWARDS A BETTER ESTIMATION OF PREVALENCE OF FEMALE GENITAL MUTILATION...

ing the prevalence of FGM in the EU, which was presented to and discussed by a panel of international experts (most commonly these experts were the principal investigators of the prevalence studies in various EU countries) in Paris (1 June 2012). This paper is based on that discussion note.

4. RESULTS

We identified no ongoing, systematic, representative surveys that use a harmonised approach to gather comparable data on FGM prevalence similar to the DHS or MICS surveys in the EU Member States. However, a number of countries have undertaken prevalence or other studies, aiming at understanding the extent of FGM. None of these studies and assessments generated comparable data between the Member States due to the variations in methodologies and approaches utilised.

4.1 Existing prevalence studies

Our research has collected thirteen studies in eight EU Member States that qualify as FGM prevalence estimation studies (see Table 1). These studies were produced in Belgium (World Health Organisation, 2001; Leye and Deblonde, 2004; Dubourg et al., 2011), France (Andro and Lesclingand, 2007), Germany (Terre des Femmes, 2007), Hungary (Köszeghy, 2012), Ireland (Dhala, 2013), Italy (Ministero della Salute Italia, 2007; Degani, 2009; Istituto Piepoli, 2009), the Netherlands (Exterkate, 2013), and the UK (Dorkenoo and Morison, 2007). In all 13 prevalence studies, prevalence data on FGM from African countries and Yemen are extrapolated to the migrant female population from FGM practising countries resident in an EU country, available from general population census and national statistical offices. The African prevalence data on FGM are used from DHS and MICS or, in some cases, from the World Health Organization or UNICEF. In order to cover the total female migrant population from countries where FGM is practised, ideally other data sources should equally be taken into account, in particular to include asylum seekers, refugees, undocumented migrants and second/third generation of girls and women. This was the case in five of the identified studies, including the two from Belgium (Leye and Deblonde, 2004; Dubourg et al., 2011), and the studies from Hungary (Köszeghy, 2012), Ireland (Dhala, 2013), Italy (Istituto Piepoli, 2009) and the Netherlands (Exterkate, 2013). Two studies, in Italy (Istituto Piepoli, 2009) and the Netherlands (Exterkate, 2013), have used a mixed method approach to attempt to take into consideration the influence of migration on the practice of FGM.
### Table 1 – Overview of identified prevalence studies

<table>
<thead>
<tr>
<th>Country</th>
<th>Title of study (year)</th>
<th>Data source used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>2) female population in the foreigners register on January 1 2002 (foreigners who received permission to reside in Belgium for more than 3 months, but who did not obtain Belgian nationality)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) WHO prevalence figures 2001</td>
</tr>
<tr>
<td>Belgium</td>
<td>Estimating the number of women with FGM in Belgium (2011) (Dubourg et al., 2011)</td>
<td>1) Registered births in families from FGM risk countries in the registers of Child &amp; Family from French Speaking Community (French Community) (children aged 0-5 years born between 1998 and 2007 to women from countries from FGM countries; includes only live births)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2) Registered births in families from FGM risk countries in the registers of Child &amp; Family from Dutch speaking Community (Flemish Community) (children aged 0-5 years born between 1998 and 2007 to women from countries from FGM countries; includes only live births)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) Foreign female population in population register of National Office of Statistics (includes foreigners who obtained Belgian nationality) on January 1 2008</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4) Study from Federal Agency for the Reception of Asylum Seekers of 2009 (female asylum seekers from FGM countries, excluding all girls born after January 1 2008)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5) DHS and MICS published 31 May 2010</td>
</tr>
</tbody>
</table>

...Cont’d...
Table 1 – *Cont’d*

<table>
<thead>
<tr>
<th>Country</th>
<th>Title of study (year)</th>
<th>Data source used</th>
</tr>
</thead>
</table>
| France  | Quantitative chapter of the “FGM and disability” project, and evaluation of the needs in surgical repair (2007) (Andro A. et al., 2009; Dubourg et al., 2011) | 1) Study of Family Trajectories (supplement to population census 2004)  
2) DHS surveys (year not specified)                                                                                                                      |
2) DHS and WHO prevalence data, year not specified                                                                                                    |
| Hungary | FGM prevalence in Hungary – estimation (2012) (Kőszeghy, 2012)                      | 1) number of residents from countries where FGM is practised as of December 31, 2008; (data source not specified)  
2) number of female refugees in the past 10 years with the citizenship of countries where FGM is prevalent (data source not specified)  
3) number of women granted temporarily protected status in the past 5 years from countries where FGM is practised  
4) number of women from countries where FGM is practised residing at one of the reception centres (at the time of the study: 2011, data source not specified)  
5) DHS (not specified)                                                                                                                                  |
<table>
<thead>
<tr>
<th>Country</th>
<th>Title of study (year)</th>
<th>Data source used</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>2) Most recent DHS and MICS and WHO prevalence studies</td>
</tr>
<tr>
<td>Ireland</td>
<td>“Female genital mutilation and gender based violence”, an AkiDwa presentation to staff of the The Rotunda Hospital, Dublin, 14 September 2010 (Siddig and Xuseyn, 2010)</td>
<td>1) 2006 Population Census (female migrant population from FGM countries)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2) Data from Office of Refugee Applications Commissioner (asylum seeking women from FGM countries from April 2006 to August 2010)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) Most recent DHS and MICS and WHO prevalence studies</td>
</tr>
<tr>
<td>Ireland</td>
<td>Knowledge of General Practitioners in Ireland on Female Genital Mutilation. (2013) (Dhala, 2013)</td>
<td>1) 2011 Population Census (female migrant population from FGM countries)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2) Most recent DHS and MICS and WHO prevalence studies</td>
</tr>
<tr>
<td>Italy</td>
<td>Guidelines for Health Professionals (Ministero della Salute Italia, 2007)</td>
<td>1) 2006 Population Register (female migrant population from FGM countries)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2) DHS and UNICEF data (year not specified)</td>
</tr>
</tbody>
</table>
An overview of the absolute numbers of women/girls with FGM and those at risk, as found in the existing studies, is provided in Table 2.
### Table 2 – Figures of the most recent FGM prevalence studies in the EU (European Institute for Gender Equality, 2013)

<table>
<thead>
<tr>
<th>Country</th>
<th>Title of study</th>
<th>Year of publication</th>
<th>Number of women and girls victims of FGM</th>
<th>Number of women and girls at risk of FGM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belgium</td>
<td>Estimating the number of women with FGM in Belgium (Dubourg et al., 2011)</td>
<td>2011</td>
<td>6.260</td>
<td>1.975</td>
</tr>
<tr>
<td>France</td>
<td>Quantitative chapter of the “FGM and disability” project (Andro and Lesclingand, 2007)</td>
<td>2007</td>
<td>61.000</td>
<td>Not available</td>
</tr>
<tr>
<td>Germany</td>
<td>Statement of Terre des Femmes, - Human Rights of Women at the Public Hearing on the subject of FGM (Terre des Femmes, 2007)</td>
<td>2007</td>
<td>19.000</td>
<td>4.000</td>
</tr>
<tr>
<td>Hungary</td>
<td>FGM prevalence in Hungary, estimation (Kőszeghy, 2012)</td>
<td>2012</td>
<td>Between 170 and 350 women affected</td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td>International Day of Zero Tolerance to FGM (Siddig and Xuseyn, 2010)</td>
<td>2011</td>
<td>3.170</td>
<td>Not available</td>
</tr>
<tr>
<td>Italy</td>
<td>Quantitative and qualitative evaluation of the FGM phenomenon (Istituto Piepoli, 2009)</td>
<td>2009</td>
<td>35.000</td>
<td>1.000</td>
</tr>
</tbody>
</table>

...Cont’d...
4.2 Other assessments to quantify the magnitude of FGM

In the absence or unavailability of national FGM prevalence figures, a number of other surveys and studies were conducted in an attempt to assess the magnitude of FGM.

Such assessments were mainly surveys among health professionals: 13 studies were done in six countries, namely in Austria (Kölbl and Schlögel, 2006; Stiller, 2006), Belgium (Mager and Noriega Tontor, 2003; Leye et al., 2008; Groupement des gynécologues obstétriciens de langue française de Belgique, 2009), France (Wehenkel, 2007; Andro et al., 2009; Gynécologie Sans Frontières et al., 2009), Germany (Asefaw et al., 2007), the Netherlands (Korfker et al., 2013) and Sweden (Kangoum et al., 2004; Elgaali et al., 2005; Tamaddon et al., 2006). These studies were not nationally representative, as they were conducted among a selected number of professionals (in a region/city of the country, professionals from a certain professional organisation, etc.).

Four studies were carried out among various professionals in Italy in 2009 (Candia, 2008; Degani, 2009; Istituto Pietropolis, 2009) and in the Netherlands (Kramer et al., 2005). In Italy, the studies of 2009 also collected prevalence data. The professionals included cultural mediators, professionals working in civil society organisations, women from FGM practising communities, health care professionals, police and judiciary, and professionals from equal opportunities agencies, as well as opinion leaders for the Lazio Region. For

---

Table 2 – Cont’d

<table>
<thead>
<tr>
<th>Country</th>
<th>Title of study</th>
<th>Year of publication</th>
<th>Number of women and girls victims of FGM</th>
<th>Number of women and girls at risk of FGM</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Netherlands</td>
<td>Female genital mutilation in the Netherlands. Prevalence, incidence and determinants (Exerkate, 2013)</td>
<td>2013</td>
<td>29,120</td>
<td>40 to 50 /year</td>
</tr>
<tr>
<td>UK</td>
<td>A statistical study to estimate the prevalence of FGM in England and Wales (Dorkenoo and Morison, 2007)</td>
<td>2007</td>
<td>65,790</td>
<td>30,000</td>
</tr>
</tbody>
</table>

---

4.2 Other assessments to quantify the magnitude of FGM
the Italian study from 2009, a survey was conducted among medical doctors, cultural mediators and activists. The study in the Netherlands (2005) focused on professionals working in schools and organisations in two cities of the Netherlands. The studies were qualitative and not nationally representative.

Two surveys, one in Austria (Afrikanische Frauenorganisation in Wien, 2000) and one in Germany (Behrendt, 2011), were carried out among practising communities, and (partly) aimed at assessing the magnitude of FGM among the studied population. Both studies were qualitative among a non-representative sample of the African female population living in these countries. They were conducted in a limited study area and included only subgroups of the total population of FGM practising countries.

In Austria, in 2011, the Ministry of Internal Affairs published the number of asylum applications, specifying those requested on the ground of FGM (Muck et al., 2011). In France, the “Office de Protection des Réfugiés et Apatrides” published in its annual report 2009 and 2010, an overview of numbers of asylum seekers, including the female population granted subsidiary protection on grounds of FGM (Office Français de Protection des Réfugiés et Apatrides, 2011; Office Français de Protection des Réfugiés et Apatrides, 2013). Figures for both years are based on data of the agency for refugees and stateless persons. These figures are nationally representative.

Two studies (Belgium and UK) looked into the number of registered newly born girls. The 2007 study in Belgium looked at girls born in a family originating from a country where FGM is practised and residing in the French-speaking community (Office de la Naissance et d’Enfance (ONE), 2007). In the UK, the study estimated the number of maternities (registered live or still births) to women with FGM, by applying prevalence rates of African countries from which these women originated, to the birth registration data in each of the four years from 2001 to 2004, which allowed assessing a trend over time. The same study was repeated in 2007 (Roy et al., 2011).

One study in Belgium extrapolated African prevalence data to the number of women in asylum centres in Belgium coming from countries where FGM is practised, to estimate the proportion of women in the asylum centres that could have been subjected to FGM (Jaoui, 2009).

Some countries collected and published numbers of women coming from countries where FGM is practised. This is the case for Denmark (Danmarks statistik, 2011), France (Institut National de Statistique et des Etudes Economiques, 2013), Germany (Binder et al., 2005), Spain (Grande and Hernández, 2013; Grupo Interdisciplinar para la Prevención y el Estudio de las Prácticas Tradicionales Perjudiciales, 2006; Kaplan and López, 2013; Kaplan, 2002) and the Netherlands (Exterkate, 2011), among others. Numbers of asylum seeking women from countries where FGM is practised in Denmark were also provided, as well as the number of daughters (0-18 years old) with origin in countries where FGM is performed (Danmarks statistik, 2011).
5. DISCUSSION

In the EU Member States there are no ongoing, systematic, representative surveys that use a harmonised approach to estimate the FGM prevalence similar to the DHS and MICS surveys. Some Member States and regions have used a variety of other data sets to collate data and formulate national or regional FGM estimates, which aim to gain insights into the extent of the practice of FGM. However, these have not generated comparable data between the Member States due to the variation in methodologies and approaches used. With the existing prevalence studies and surveys, a number of issues emerged, which could be taken into consideration when designing future prevalence studies.

5.1 Girls at risk of FGM

One of the critical data gaps in relation to FGM prevalence estimates and data collection to date in EU Member States is the lack of information and numbers of girls at risk of FGM and girls who have undergone FGM (both within the EU and in counties of origin prior to arriving in the EU). Only a few EU countries have attempted to approximate FGM prevalence in girls aged less than 18 years, notably Belgium, Italy and UK. This lack of information is critical, as it is unlikely that the needs of minor girls are met and protection of girls at risk of FGM is prioritized, in the absence of accurate data.

The estimation of girls at risk is complex, for a number of reasons. Registered live births of girls to women from countries where FGM is practised can be considered a first indication of risk but are not systematically noted in hospital records. Another risk indicator might be the female residents born to a mother or a father that originates from countries where FGM is practised. However, the problem here is to assess the level of risk of being subjected to FGM of these second and third generation girls, as the parent might have changed attitudes towards FGM (Johansen, 2006), or might come from an ethnic group that does not perform FGM. Methods are needed here to assess whether or not second and third generation girls are still at risk. Finally, in order to have an accurate number, undocumented female minors from countries where FGM is practised, should equally be taken into account, using methods for hard-to-reach populations, such as capture-recapture method (Powell et al., 2004).

5.2 Limitations of census only data

There are a number of limitations using the ‘extrapolation-of-African-prevalence-data method’ from census figures to calculate FGM prevalence in EU
Member States. For instance, census data sometimes lack disaggregation by African country of origin, by country of birth, and length of stay in a country. Furthermore, in order to have a representative sample of the female population affected by FGM, it is paramount to include female asylum seekers, refugees and undocumented migrants, who may not appear in national census figures.

Ethnicity is often a more useful indicator of FGM than nationality, but it is not routinely included in census data figures; for instance, estimations on the Kurdish population (who also practise FGM) are hard to collect since they belong to different nationalities (Iraq, Turkey, etc.). Moreover, in some EU Member States (for example France), collecting and utilizing data on ethnicity is not possible for legal and ethical reasons.

In order to assess changes over time, FGM prevalence estimation studies need to be repeated on a regular basis, using the same methodology. This is currently not happening. FGM prevalence rates from African countries also change over time and these changes need to be reflected in figures used by EU countries to calculate FGM prevalence. Countries may utilize varying definitions of “at risk” and “prevalence” in their attempts to calculate FGM data.

Census data may also not be recent and consequently may not reflect changes in migrant populations in a country.

In addition, census data do not take into consideration the influence of migration on the practice of FGM. The length of stay by migrants in a country, the reasons for migration (possibly to avoid FGM), ethnicity and inter-generational repetition of cultural norms such as FGM are not reflected in census data. As a result, mixed methods research to assess the influence of migration on FGM might be useful. Two countries have attempted to take this effect into consideration (the Netherlands and Italy), but the methodology to assess the causal link between the influence of migration and changes in prevalence needs further elaboration to clarify an appropriate research design suitable for application in multiple EU Member States, including tools and methodologies and cognisance of ethical and potentially legal considerations. Whilst the current FGM prevalence estimates from Member States using census data should be recommended as initial data on the issue, further work is required to develop, refine and enhance the ‘extrapolation-of-African-prevalence-data-method’ using census figures.

5.3 Non-systematic data collection

One of the emerging issues from this study is that data collection is usually not obligatory.

This results in non-systematic data collection. If data collection is not required by policies, protocols, guidelines, or professional standards, systematic, routine, on-going data collection is not viable. The lack of aggregations of existing records, which are dispersed in a variety of databases across various
sectors and departments (like hospitals, police, child protection, asylum system, etc.), presents another challenge. Although a number of records or potential data sources are kept in a variety of locations, few (if any) efforts are made at national level to collate and examine the data to provide a more accurate picture of the prevalence of FGM.

Multi-sectoral and multi-agency collaborative efforts are required to gather the most comprehensive records and data on a country-by-country basis in relation to FGM. At the same time, the use of different software platforms and tools by services and professionals to collate patient and client data is another challenge. There may be variations between data gathering systems in relation to technical, privacy and security (data protection) issues and settings which make it difficult to integrate existing databases and merge data arising from them and with potential cost, resource and training implications. As a result of these issues, the gap for examining somewhat comparable data sets and statistics with a view to FGM prevalence widens across the EU Member States and remains a challenge.

5.4 Lack of funding and monitoring of data collection

Accurate FGM prevalence data and figures are important to plan services and training and target resources. However, few authorities or states have taken the initiative to set aside resources to measure the extent of FGM. The EU countries that have done so are Belgium, France, Italy and the Netherlands. In these countries, such studies were commissioned by the Ministry of Health (Belgium, France, Italy and the Netherlands) or the Department of Equal Opportunities (Italy). Adequate resources are also required to update data collection systems to include FGM codes and nomenclatures, in particular in medical and hospital settings.

Surveillance and monitoring of data collection is also important to reaffirm the importance of correct and consistent data entry and collection. When there is no authority to monitor the data collection on a routine basis, it may not be given the priority needed and data gaps or inaccurate data could emerge. In the absence of on-going monitoring and quality control checks, staff may not be motivated to enter and collect data as required to achieve robust statistics and comparable findings.

5.5 A baseline and an enhanced FGM prevalence estimate

In the study, we proposed to distinguish between a baseline and an enhanced FGM prevalence estimate, for those countries who wish to obtain a more accurate picture of national FGM prevalence. In order to estimate baseline prevalence, census data from national statistical offices can be used.
These data should, as a minimum, be disaggregated by country of origin, by sex and by age. Other data sets that can be used to calculate and extrapolate the baseline prevalence include the DHS and MICS prevalence rates for African countries and Yemen. It is important to use the most recent and up to date DHS and MICS data for these calculations. For some EU countries, possible extra indicators can be utilized in order to calculate an enhanced FGM prevalence estimate and to generate more precise data on FGM and the population affected. In addition to country of origin, sex and age data collected for a baseline estimate of FGM, elements of the following data could be collected for an enhanced estimate: place of birth; place of residence; age of arrival to the EU country; age when FGM was performed; type of FGM; country of birth; country of origin of mother and father; age when FGM is usually performed in the country of origin; length of residence in an EU country; and ethnicity. Moreover, populations not generally represented in censuses should equally be taken into consideration, in particular non-documented migrants, asylum seekers and refugees. However, these indicators will need further discussion and examination, as well as a robust and inter-Member State transferrable definition and methodology to produce an enhanced prevalence FGM estimate model at a country level.

5.6 Potential of administrative data records

The study identified a number of administrative records that could be used to provide information on FGM, including hospital/medical records, child protection records, asylum records, and prosecution records. Data from these records could act as a proxy indicator of prevalence and incidence of FGM at both regional and national levels and also indicate whether states are adequately responding to the practice.

5.6.1 Hospital/medical records

Existing hospital and/or medical records that have the potential to collect data on FGM consist of patient registers, maternity registers, child health registers and school health registers. In some countries, hospital and/or medical records already contain information about FGM. This is for example the case in Belgium, France, Ireland, the Netherlands, Portugal, Sweden and the UK. In some countries, the data collection tools for these records are relatively new and will need to be evaluated in time. Limitations exist especially with the potential under-recording of FGM due to a lack of knowledge of FGM amongst health professionals to properly register the varied types of FGM. Limitations also exist due to a lack of adequate nomenclature or codes for recording FGM incidence and type. The general lack of availability of admin-
istrative recording systems for out-patients in medical/hospital settings and the lack of data from primary care settings or from general practitioners further restrict the possibility of a comprehensive picture. When women are asked to self-disclose FGM to a health professional, this can lead to more challenges such as women not wanting to disclose their status, women not recognising the terms used by health care professionals to describe FGM and/or typologies, health professionals not having the skills to correctly ask women about FGM and an inadequate or lack of training of health professionals on FGM, and a lack of competencies in dealing with multiculturalism. Health professionals have a particular role to play in terms of care and treatment for women who have undergone FGM.

Rigorous data collection on health care and complications related to FGM (including maternal and neonatal deaths, de-infibulation, surgical repair and reconstruction, and post-natal care in patients with FGM) should allow for both FGM prevalence data collection and insights into recommended clinical care pathways and patient outcomes.

5.6.2 Child protection records

In the EU28, child protection systems, registers and processes are in place to protect children from child abuse and neglect. These systems could also be used for collecting numbers of girls at risk or who have already been subjected to FGM and all investigations with regard to cases of girls at risk or having undergone FGM. However, very few countries in this study - only France, the Netherlands, Spain and the UK - documented such recording systems or records of investigations or interventions regarding child protection and FGM. Given the nature of FGM and the importance of child protection mechanisms and responses, this would suggest a concern for Member States in terms of lack of data available or of data collection tools.

5.6.3 Asylum records

A statistical overview prepared by UNHCR estimated that 8,809 female asylum applicants in the EU aged 14-64 may have been affected by FGM in 2011, i.e. 61% of the total 14,440 girls and women from the same age group originating from FGM-practising countries who sought asylum that year in one of the 27 Member States included in this study (Croatia only became a Member State on the 1st of July 2013 and was not included in this study). FGM asylum countries most likely to be affected by FGM in 2011 were Sweden, France, Italy, the UK and Belgium (United Nations High Commissioner for Refugees, 2013). Information on numbers of claims introduced and granted or rejected for international protection in EU Member States on the basis
of FGM is however lacking. Only Belgium, France, Italy (through regional commissions) and Luxembourg have some mechanisms to collate this data and only Belgium has a department that monitors asylum applications by claimants based on fear of FGM. As a result, there is limited data available across Member States on the number of cases where international protection was requested, granted or rejected in relation to FGM.

5.6.4 Prosecution records

By February 2013, 9 EU countries (Austria, Belgium, Cyprus, Denmark, Ireland, Italy, Spain, Sweden and the UK) have put specific legislation in place with regard to FGM but it still remains a challenge to obtain data on numbers of reports of suspected or performed FGM to police, numbers of investigations, outcomes of investigations and numbers of court cases as there are no central registration systems to provide such information. France prosecutes FGM under a non-FGM specific criminal law provision (harm to bodily integrity causing permanent mutilations) and more than 40 court cases relating to FGM have occurred, most of them before criminal jurisdictions (Assize Court). The opportunity for other countries to learn from its jurisprudence is possible but has not been fully realised yet, due to lack of collation, analysis and publication of the French expertise.

In conclusion, despite the potential of various administrative records to assist and enhance FGM data and prevalence across EU Member States, there remain considerable shortcomings and barriers. Many of the records are not systematically used, existing data are not collated centrally and access to data from such records is often restricted or extremely limited. In order to develop these records for FGM data collection, considerable training will be needed for the professionals involved, enhanced data compilation systems, software and tools may be required and specific relevant codes or nomenclatures identified and developed.

6. CONCLUSION

Prevalence studies are important tools to inform policy making. The absence of information on FGM prevalence appears to be a conspicuous gap, particularly the impossibility to capture and analyse the trends and changes in relation to national FGM prevalence figures over time. The main reasons for this gap are the lack of studies on the subject, the non-use of administrative datasets that could be valuable to collect data to produce FGM prevalence information and the complexity of calculating accurate up-to-date FGM prevalence figures. The lack of funding, agreed working definitions, expertise and common methodologies may also be factors. National statistical institutes
could play an important role in contributing to the knowledge on FGM in Member States by utilising and sharing the data they collect, in particular population censuses data. This census data will need to be disaggregated by country of origin, as well as sex and age and will need to be collected on a regular basis. Additional data to formulate enhanced FGM prevalence estimates may also be available from national statistical institutes. Eurostat might play a role in supporting the development and piloting of data collection tools and common methodologies and approaches across EU Member States in terms of FGM data. Based on the collated data from Member States, it could also calculate FGM prevalence estimates among the asylum seeking population in the EU.

The willingness of countries to learn from each other and share data collection tools, methodologies and expertise should be harnessed. It is important to note that experience exchange among countries preceded the development of some data collection tools, for example in Ireland with the Ethnic Identifier and the Irish FGM prevalence studies which were based on the UK prevalence study and the Dutch prevalence study which was partly based on a broad consultation with experts from Europe and further afield.

References

AFRIKANISCHE FRAUENORGANISATION IN WIEN (2000), [Studie zu Weiblicher Genitalverstümmelung in Österreich: Die Anwendung der Female Genital Mutilation (FGM) bei MigrantInnen in Österreich Wien], Afrikanische Frauenorganisation in Wien, Wien.


1 The Ethnic Identifier is a data collection tool used by the Irish Health Service Executive to collect information on patient ethnicity in various health care settings through its use on patient charts and admission forms. It is based on Irish Census ethnicity question from the 2006 and 2011 Censuses.

2 This is an FGM prevalence study based on the ‘extrapolation-of-African-prevalence-data-method’ but with additional qualitative research to assess influence of migration on FGM.


BINDER U., GRUBER F., KULIK K. (2005), [Studie zu weiblicher Genitalverstümmelung], Terre Des Femmes e. V., Tübingen.


DANMARKS STATISTIK (2011), Annex 1. A - Female immigrants and descendants in Denmark with origin where FGM is performed (divided by origin). B - Female immigrants and descendants in Denmark with origin where FGM is performed (divided by age). Annex 2. A - Females at risk of FGM in Denmark - divided by origin. B - Females at risk of FGM in Denmark - divided by age. Annex 3 - Asylum seeking women in Denmark with origin where FGM is performed. www.statistikbanken.dk.


TOWARDS A BETTER ESTIMATION OF PREVALENCE OF FEMALE GENITAL MUTILATION...


GROUPEMENT DES GYNECOLOGUES OBSTETRICIENS DE LANGUE FRANÇAISE DE BELGIQUE (2009), [Croyances, traditions et délivrances des soins médicaux], Groupement des Gynécologues Obstétriciens de langue Française, Liège and Eupen.


GYNECOLOGIE SANS FRONTIERES, GROUPEMENT REGIONAL DE SANTE PUBLIQUE PAYS DE LA LOIRE, RESEAU SECURITE NAISSANCE (2009), [Enquête Régional Pays de la Loire sur les Violences Faites aux Femmes], Gynécologie Sans Frontières; Réseau Sécurité Naissance, Nantes.

INSTITUT NATIONAL DE STATISTIQUE ET DES ETUDES ECONOMIQUES (2013), [Recensement de la population]. http://www.insee.fr/fr/themes/

ISTITUTO PIEPOLI SRL (2009), [Valutazione quantitativa e qualitativa del fenomeno delle mutilazioni genitali in Italia], Istituto Piepoli for the Ministry for Equal Opportunity, Presidency of the Council of Ministries, Rome.

JAOUI S (2009), [Femmes excisées ou à risque d’excision dans les structures d’accueil en Belgique], Fedasil, Brussels.

JOHANSEN R.E.B. (2006), Experiences and perceptions of pain, sexuality and childbirth. A study of Female Genital Cutting among Somalis in Norwegian Exile, and their health care providers, University of Oslo, Faculty of Medicine, Oslo.


MINISTERO DELLA SALUTE ITALIA (2007), [“Linee Guida destinatione alle figure professionali sanitarie nonché ad altre figure professionali che operano con le comunità di immigrati provenienti da paesi dove sono effettuate le pratiche di mutilazione genitale femminile per realizzare una attività di prevenzione, assistenza e riabilitazione delle donne delle bambine già sottoposte a talie pratiche. Art. 4 - Legge n. 7 del 2006”], Ministero della Salute Italia, Rome.


WEHENKEL M. (2007), [“Dépistage et prévention des mutilations génitales féminines et de leurs complications en médecine générale”]. PhD in Medicine General Medicine, Université Pierre et Marie Curie (Paris 6) - Faculté de Médecine Saint Antoine, Paris.
