
“ESTIMATING FGM PREVALENCE IN EUROPE. FINDINGS OF A PILOT STUDY”. RESEARCH REPORT

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1. Introduction

In 29 countries¹ the prevalence of FGM has been measured using a standard survey method developed by the Demographic Health Survey (DHS), published by MACRO, or the Multiple Indicator Cluster Surveys (MICS), published by UNICEF. In other countries, there is only anecdotal evidence as is the case for Colombia (UNFPA, 2012), United Arab Emirates (Kvello and Sayed, 2002, as cited in WHO, 2008), Oman (Mubarak, 2013), Brunei (Begawan, 2012), Iran (Südwind, 2014), Malaysia (Isa et al., 1999), Israel (Asali et al., 1995), Congo (UNHCR, 2013), Thailand (Merli, 2012) and parts of Indonesia (Budiharsana, 2004).

In Europe, the overall prevalence of FGM is unknown, as there is no standardized method to estimate the magnitude of the problem in each Member States by producing comparable and representative data.

This report provides an overview and discussion of the findings of the project “Towards a better estimation of prevalence of female genital mutilation in the European Union” (FGM-PREV). The general aim of the project was to develop a common definition on FGM prevalence and a common methodology to estimate FGM prevalence that can be used throughout the EU.

The project was funded by the DAPHNE program of the European Commission and was conducted by the International Centre for Reproductive Health at Ghent University in Belgium, the Department of Sociology of the Università degli Studi di Milano-Bicocca in Italy and the Institut National d’Etudes Démographiques in Paris. The project was implemented from November 15th, 2014 to March 15th, 2017 and was supported by a steering committee that consisted of experts in the field of FGM /prevalence studies².

¹ There countries are: Benin, Burkina Faso, Cameroon, Central African Republic, Chad, Djibouti, Egypt, Eritrea, Ethiopia, Gambia, Ghana, Guinea, Guinea-Bissau, Iraq, Ivory Coast, Kenya, Liberia, Mali, Mauretania, Niger, Nigeria, Senegal, Sierra Leone, Somalia, Sudan, Tanzania, Togo, Uganda, Yemen

² Steering committee members included: Dalila Cerejo – Portugal (principal investigator Portuguese FGM study), Marja Exterkate - the Netherlands (principal investigator prevalence study The Netherlands), Sioban O’Brien Green – Ireland (involved in prevalence studies in Ireland and in prevalence studies of EIGE), Peter Theuns – Belgium (VUB, statistician)

The project aimed at 1) mapping current prevalence studies in the EU, to analyse their definitions, methodologies and outcomes in order to identify strengths, weaknesses, opportunities and threats of these studies (the situation analysis³); 2) developing a common definition and methodology to estimate prevalence (both indirectly and directly), that would be able to produce comparable and reliable data across the EU; 3) piloting the new methodology for direct estimations in Belgium and Italy and 4) providing and disseminating a general framework for prevalence estimations for EU countries.

2. Defining FGM prevalence

Upon concluding the literature review (2015) only three national prevalence studies in the EU defined FGM prevalence. The Dutch study by Exterkate (2013, p.11) has defined FGM prevalence as ‘the percentage of new and existing FGM cases in a certain period in a certain population.’ Dubourg and Richard (2014) in their Belgian study say: ‘to estimate the number of women who have probably undergone female genital mutilation..., we calculated that girls and women born in a country where female genital mutilation is practiced were *probably already excised* or infibulated...’ (p. 5, italics in original text). Terre des femmes (2015) from Germany defines FGM prevalence as ‘all females who are of age, with their actual citizenship from a country where FGM is practiced who according to the national statistics office live in Germany’.

UNICEF (2005) describes national FGM prevalence as follows: ‘The percentage of girls and women of reproductive age (15 to 49) who have experienced any form of FGM/c is the first indicator used to show how widespread the practice is in a particular country. This indicator reflects responses by girls and women about themselves. In the 29 countries where FGM/c is concentrated, almost all girls are cut before the age of 15. Thus, prevalence data among girls and women aged 15 to 49 are considered to reflect their final FGM/c status. A second indicator of national prevalence measures the extent of cutting among daughters aged 0 to 14, as reported by their mothers. Prevalence data for girls reflect their current – not final – FGM/c

³ A full report of the situation analysis is available at request.

status, since many of them may not have reached the customary age for cutting at the time of the survey.’

EIGE (2013, p.29; also Leye et al., 2014, p.100) 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 practiced’**⁴.

In this project, 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 practiced, and their female descendants.

In 2015, the definition of EIGE has been changed to the proportion (expressed as the percentage) of girls and women who are currently residing in an EU MS and originate from or are born to mothers from countries where female genital mutilation is commonly practiced and/or are born to mothers who have undergone some form of female genital mutilation (Estimation of girls at risk of FGM in the EU Report, 2015, EIGE).

3. Indirect and direct estimations in the EU: existing studies and methodological concerns

In the framework of this project we performed a situation analysis to map existing information and data on the prevalence of FGM in the EU, to detect strengths and weaknesses of previous research through a SWOT-analysis and to produce a report that could be used to develop the methodology for estimating the prevalence of FGM in the EU. This was done through a literature review and an analysis of available data (relevant for FGM estimations) at various statistical offices.

⁴ FGM risk estimation in an EU Member State is defined as the number of minor girls (either born in, or born to mothers from FGM Risk countries), aged 0-18 years, living in an EU Member State who might actually be at risk of FGM, expressed as a proportion of the total number of girls, living in the EU country, who originate from or are born to a mother from FGM Risk countries (EIGE 2015)

From every document, we extracted the definition of FGM prevalence that had been used in the study and analysed the methodology of the research. This was done based on the principles of a SWOT -analysis. Besides this literature research, we also requested data from the national statistical offices on variables that are essential for the research on FGM. It mainly concerns information on variables such as age, nationality and ethnicity of women coming from countries where FGM is practiced, and their female descendants. Only 14 out of 28 statistical offices provided us with information. The information that we received from these 14 statistical offices shows that there is no standardized way for the presentation of data in the EU, definitions are quite different and categories of for instance age are not uniform. As a result, it is impossible at the moment to implement a uniform approach for the prevalence estimation of FGM in the EU, based on these data.

All thirteen documents included in the review referred to studies that used quantitative methods to estimate the prevalence of FGM. In two documents also qualitative data were mentioned (Andro et al, 2009; Exterkate, 2013). In only three out of thirteen documents a definition of FGM prevalence was mentioned. All documents referred to European prevalence studies that estimated indirectly the FGM prevalence in the EU member state where the research was conducted (Dorkenoo et al., 2007; Dubourg et al., 2011; Köszeghy, 2012; Exterkate, 2013; Dubourg, 2012; Macfarlane & Dorkenoo, 2014; Baillot et al., 2014; Korfker et al., 2012; Terre des Femmes, 2015; Andro et al., 2009; Farina, 2010; Farina & Ortensi, 2015; Ortensi et al., 2015).

Overview of indirect estimations of FGM in Europe

Most prevalence studies in the EU used an indirect estimation method that uses secondary sources to estimate the absolute number of women originating from a country where FGM is

⁵ SWOT is an acronym which stands for strengths, weaknesses, opportunities and threats. Strengths and weaknesses are focusing on internal factors, opportunities and threats are external. A SWOT-analysis is a tool that is well-known and frequently used in business administration and organizational psychology, but has also been applied before in for instance the field of nursing (Uhrenfeldt et al., 2014) or counseling (Leong and Leach, 2007) and in a variety of other fields. It examines at the same time internal and external factors and allows to identify important information through open-ended questions.

practiced. This absolute number is based on data retrieved from a variety of sources, including:

- a population register (Dubourg et al., 2011; Dubourg & Richard, 2014; Exterkate, 2013, Köszegehy, 2012, Terre des Femmes, 2015),
- birth register (Macfarlane & Dorkenoo, 2014; Dorkenoo et al., 2007; Dubourg et al., 2011; Dubourg & Richard, 2014; Baillot, 2014; Korfker et al., 2012),
- register of asylum seekers (Dubourg et al., 2011; Dubourg & Richard, 2014; Exterkate, 2013),
- results from a national census (Dorkenoo et al., 2007; Macfarlane & Dorkenoo, 2014; Baillot, 2014)
- or a combination of some of these data sources.

Only Korfker et al. (2012) used primary data from a retrospective nationwide survey of midwives who were asked about the total number of women they had had under their control in 2008 and who had undergone FGM.

All above mentioned studies applied the so-called ‘extrapolation-of-FGM-countries-prevalence-data-method’⁶. As mentioned before in the EIGE study (2013) the extrapolation-of-FGM-countries-prevalence-data-method is a method where the FGM prevalence rate in the countries of origin (for women and girls age 15 to 49, as reported by the DHS and MICS) is multiplied by the total number of girls and women in the country of destination coming from or born to a mother originating from one of the countries where FGM is practiced, as retrieved from the different above mentioned registers. The estimation of the overall number of women who have undergone FGM in the country of destination is the sum of the estimated number of women who have undergone FGM for every country of origin.

In summary, most FGM prevalence figures in the EU are the result of this indirect estimation, i.e. a triangulation of European population data, European or national census data and data from DHS and MICS, the so-called ‘extrapolation-of-FGM-countries-prevalence-data-method’. This indirect estimation, with or without corrections, can be done regularly because the technique is cheap and not complex compared to direct estimations. At the same time, it

⁶ Some studies such as EIGE (2013) refer to the method as the ‘extrapolation-of-African-prevalence-data-method’. However, since there are countries outside of Africa such as Yemen, Indonesia and Iraq where FGM is practiced, this report will use the term ‘extrapolation-of-FGM-countries-prevalence-data-method’.

allows policy makers to have a reliable approximation of the estimated number of women and girls who have undergone FGM, to look for trends and to evaluate the impact of for instance prevention programs. However, there are several limitations to this indirect method.

Issues with indirect estimations

Firstly, the indirect estimations are based on the collection of migration related data. The UN (2001) defines an international migrant as 'any person who changes his or her country of usual residence'; a 'long-term migrant' is someone who moves to a country other than his/her usual residence for a period of at least a year and a 'short-term migrant' a person who moves for at least 3 months. However, as Johnson (2012) has stated about migration, 'a primary problem is defining exactly what measure one should use: country of birth, citizenship, "race", ethnicity, culture or migrant status.' Other research (e.g. Agyemang et al., 2012; Levecque et al.; 2012) has mentioned that there is no consensus on appropriate terms for the scientific study of health by ethnicity and that there is no universally accepted definition of 'migrant'. Many studies have focused on the diversity among immigrant populations (e.g. Brimicombe, 2007; Faist, 2009). Vertovec (2007) even referred to the variety of immigrant communities in Britain with the term 'super-diversity' because of the greater number of attributes such as age, gender, origin, language, religion.... Finally, there are different legal statuses by which immigrants can be registered (undocumented migrants, asylum seekers, adopted citizenship...). A common approach in the European Union to register migrants in such way that it provides comparable and reliable data is missing and only a uniform registration in every EU member state would allow for a reliable estimation of women coming from countries where FGM is practiced.

Secondly, even with a uniform registration, the results of an indirect estimation will always lag behind the 'real' situation because the number of migrants in Europe fluctuates from year to year. For example, Kaplan and López (2013) found in Spain an increase of 40% of women originating from countries where FGM is practiced between 2008 and 2012, corresponding to an absolute increase of 16.361 women. Macfarlane and Dorkenoo (2014) in their analysis of the evolution in the UK between 2001 and 2011 found that the total number of female migrants from 29 countries where FGM is documented had increased with more than 100.000 women in ten years. This difference was not equally distributed among all nationalities, e.g. the number of women born in Kenya and living in the UK decreased between 2001 and 2011

with almost one third (from 45.396 to 31.740) whereas the number of Somalians almost tripled (from 15.744 to 43.558). The estimated number of women and girls who have probably undergone FGM increased from 65.790 in 2001 to 137.000 in 2011.

Several prevalence studies (Exterkate, 2013; Dubourg & Richard, 2014; Farina & Ortensi, 2015; Dubourg et al., 2011) have also mentioned the need to include information about ethnicity and ethnical differences in the countries of origin. For example: 'As for the previous study (*i.e. Dubourg et al., 2011*) and other studies done at European level, we do not have data available on the ethnic origin of women. This piece of data is important for certain countries where the practice of FGM is linked to ethnic origin.' (Dubourg & Richard, 2014, p.5, italics added). Indeed, for low-prevalence countries (e.g. Uganda) or high-prevalence countries (e.g. Somalia), information about ethnical background is not essential since virtually none or almost all ethnicities will be affected by FGM (UNICEF, 2013), but in countries such as Senegal (with an FGM prevalence rate of 24,7% according to SDHS, 2014), Liberia (49,8% (LDHS, 2013)) or Mauretania (69,6% (MMICS, 2011)) there is a mix of ethnicities with some of them applying and others defying the practice. For example, data from Senegal (SDHS, 2014) show that 24,7% of the women between 15 and 49 have undergone FGM, but ethnically speaking, the prevalence varies from 1,3% (among the Wolof) to 64,4% (among the Mandingue). However, it is important to also take into consideration that the practice of FGM within an ethnicity can vary according to the country where they live. For example, the prevalence of FGM among the Peul is at 12,7% in Cameroon (CDHS, 2004), 41,2% in Benin (BDHS, 2011/12), 83,9% in Burkina Faso (BFDHS, 2010) and 99,5% in Guinea (GMICS, 2012)⁷. On the other hand the FGM prevalence of Somalians in Kenya is with 97,6% closer to the national average of Somalia (97,9%) than to that of Kenya (27,1%) (KDHS, 2008/09). As a result, only the combination of ethnicity and country of origin might result in more reliable prevalence estimations.

Another major issue with indirect estimations is how to incorporate/assess the impact of migration. Firstly, it might be that women who migrate are not representative for the women in the countries of origin. Some studies suggest that migrants tend to be more educated compared to non-migrants (Lindstrom and Ramírez, 2010; Farina and Ortensi, 2014) and that

⁷ The Peul are registered among different names according to the country: in Cameroon 'Arabe-Choja/Peulh/Maoussa/Kanuri' (CDHS, 2004), in Benin 'Peulh et apparentés' (BDHS, 2011/12) and in Burkina Faso 'Fulfuldé/Peul' (BFDHS, 2010).

they are often wealthier, younger and more urbanized than the overall national profile (UNICEF, 2005; Sipsma et al., 2012; Farina and Ortensi, 2014). Secondly, once women have migrated, their views on FGM might have changed as a result of preventive campaigns or because of fear for a strict legislation (e.g. Johnsdotter, 2002; Exterkate, 2013; UNICEF, 2013). Living in a migration context can also constitute an enabling environment to resist social pressure to perform FGM (Johnsdotter, 2003; EIGE, 2015). Or they adopt immediately the habits of the host country, like the Ethiopian Jews who gave up on FGM directly upon arrival in Israel without any signs of distress or nostalgia (Grisaru et al., 1997). Thirdly, women can migrate because they want to flee the risk of FGM, for themselves or for their daughters. In some countries in the European Union such as Belgium, FGM is considered a form of prosecution and therefore recognized as grounds to be granted refugee status (EIGE, 2013). But also the opposite has been mentioned: Somalian Bantu refugees forced their daughters to FGM shortly before their resettlement to the us because they knew that the practice was prohibited by the us legislation (Harding, 2010).

As a consequence the time that has passed between arrival in the country of destination and moment of estimation could be considered crucial in the estimation of FGM prevalence, following the idea that the longer migrants are exposed to a society where the norms are opposing FGM, the more they will be reluctant to perform FGM. However, in their study about mother to daughter transmission of FGM, Farina and Ortensi conclude: 'The number of years elapsed since migration is not a good variable to directly explain the impact of migration on a girl's risk of undergoing FGM because this information does not tell us anything about the family's interactions within their social environment, which could lead to either integration or isolation' (Farina and Ortensi, 2014, p.129).

Several FGM prevalence studies (Dubourg et al., 2011; Dubourg & Richard, 2014; Exterkate, 2013; UNHCR, 2014) have tried to incorporate information about asylum seekers. When estimating the prevalence of FGM in the European Union, it remains to be seen if it is important to take into account the proportion of asylum seekers to the total group of migrants from the 30 countries of origin.

EIGE (2013) presented the most recent estimated numbers of victims for FGM in the seven EU member states where prevalence studies have been carried out in the past (Belgium, France, Germany, Hungary, Ireland, Italy and the UK), with an estimated prevalence number between

350 and 65790. A study in the Netherlands (Exterkate, 2013) reported an estimated number of 28000 women and girls who have undergone FGM in the Netherlands. For almost all of the above mentioned countries, the estimated number of new asylum seekers who have been affected by FGM is low compared to the estimated number of potentially affected women and girls who are already registered in the official administrative records of the country of destination. This is also illustrated by table 2.

Table 1: Estimated number of new asylum seekers who have been affected by FGM compared to the estimated number of women and girls that have potentially undergone FGM who are already registered in the official administrative records of the country of destination

	Year of publication	Estimated number of women and girls potentially affected by FGM (EIGE, 2013)	Estimated number of female applicants (14-64) potentially affected by FGM in 2014	% of new applicants compared to the existing population of women and girls affected by FGM
Belgium	2011	6260	626	10%
France	2007	61000	1928	3%
Germany	2007	19000	4269	22%
Hungary	2012	350	121	35%
Ireland	2011	3170	12	0%
Italy	2009	35000	763	2%
UK	2007	65790	1254	2%
The Netherlands	2013	28000	968	3%

Particularly for high prevalence countries in the EU, the number of asylum seekers from one of the 30 countries where FGM is practiced, compared to the existing population remains marginally low between 0% and 3%. Only for Hungary (with a very low absolute prevalence number), Germany (where the estimation dates back from 2007) and Belgium, the proportion of new asylum seekers to the existing population is considerable.

Given the low number of asylum seekers on the total number of migrants from the 30 countries where FGM has been documented, the importance of including asylum seekers as a separate group in a prevalence study is limited.

Corrections on indirect estimations

Finally, some studies tried to find some corrections to approximate FGM prevalence of migrants starting from prevalence data in practicing countries. Ortensi et al. (2015) corrected the FGM figures as presented by DHS and MICS based on migration characteristics such as age, wealth, education and level of urbanization of the migrants in their country of origin. They justified their corrections with the hypothesis that migration is a selective process, the so-called 'selection hypothesis'. Moreover, since data concerning FGM prevalence for girls under 14 were only available in the DHS of Egypt, Farina and Ortensi (2015) applied the FGM prevalence rates of women aged 15-19 to girls 10-14, following the assumption of Yoder et al. 'that the FGM/c prevalence of girls aged 10-14 is equally prevalent of those aged 15-19, which yields a slightly high estimate' (Yoder et al., 2013, p 194).

Andro et al. (2009), on the other side, and working in the French context, where more second generation women are present, made their estimation on the base of women's age at the arrival. After applying the extrapolation-of-FGM-countries-prevalence-data-method, they calculated an interval based on three hypotheses: (a) only women who were born in the country of origin and who arrived after the age of 15, (b) only women who were born in the country of origin and (c) all women who originated from a country of origin where FGM is practiced. They conclude that the second ('medium') hypothesis is most likely to correspond with reality.

Exterkate (2013) applied corrections on the results of the indirect estimation justified by theoretical arguments as well as the outcome of additional qualitative research. The first correction is based on the age of girls and women in the countries of origin and destination and regional differences regarding the practice of FGM in the countries of origin: in most DHS and MICS studies, FGM prevalence figures are given for the age group between 15 and 49 (with the exception of Egypt and Togo where prevalence for girls 0-14 is also known). However, the majority of the girls undergo FGM before the age of 15, as shown by table 1, with the median age for undergoing FGM in the 29 countries where FGM is documented ranging between 1 and 14. Exterkate (2013) used the median age for undergoing FGM, as reported by DHS or MICS, to estimate the prevalence of FGM among girls 0 – 14, based on their age of arrival. Dubourg et al. (2011) estimated the FGM prevalence for women aged over 50 by taking the FGM prevalence figures for the women aged 45-49 and applying these to the entire 50+ cohort.

Exterkate's second correction relates to FGM prevalence figures per province or region, as given by the DHS and MICS (Exterkate, 2013). In most countries of origin the variation between the different regions is substantial. For example, in the southern region of Senegal 69,4% of women have undergone FGM, whereas only 6,3% of women in the central region have been subjected to FGM (SDHS, 2014). In Kenya the differences are even bigger: 0.8% of the women in the Western province have undergone FGM compared to 97,5% in the Northeastern province bordering Somalia (KDHS, 2008/2009). Because the registration system for migrants in the Netherlands also encodes birthplace in the country of origin, it was possible to apply regional, rather than national prevalence figures to estimate the prevalence of FGM in the Netherlands.

After both corrections, Exterkate invited respondents who were selected through a local NGO, to take part in focus group discussions. Based on the outcome of these focus groups, the result of the study were then presented as an interval, presuming that the 'real' prevalence will be somewhere between a calculated minimum and a maximum (Exterkate, 2013). This interval was a statistical estimation where the maximum meant that there was no influence of migration whatsoever (and the practice continued at the same rate in Europe as in the countries of origin) and the minimum meant that after migration the attitudes and behavior towards FGM had completely changed (and nobody had changed FGM status after arrival in the country of destination). She added qualitative data to give insights into motives, cultural habits and reasons for (dis)continuity of the practice after migration. Based on the results of qualitative research methods, she argues that the 'real' prevalence is closer to the minimum than to the maximum, saying that some or most but not all migrants have changed their attitudes and behavior towards FGM.

Issues related to national surveys in Europe on FGM using direct methods

Even if indirect estimation has some advantages (easy to perform, not costly), it does not really say anything about FGM in emigration countries. Indirect estimations are projections of what the number of women with FGM would be in the hypothesis that migrants share perfectly the average national profile of their non-migrants co-nationals. For the same reason, repeated estimates based on indirect studies cannot show any trends about FGM in the country of destination. On the contrary, they are just the combination of the effect of FGM prevalence

trends in the countries of origin and of the trends in migration flows in the country of immigration, sometimes combined with trends of acquisition of citizenships that tends to reduce the number of foreigners.

The combination of social, economic, ethnical and geographical selection of migration flows can result in a community prevalence far from those observed in the country of origin. For these reasons, to have a more accurate estimation that can be used to better target prevention measures, policymaking and training of health specialists, a direct estimation is preferable.

A prevalence survey on fgm in a migration context must overcome many challenges, which are discussed in detail below.

Composing a representative sample

In a survey on FGM, the issue is to sample an elusive or hard-to-reach population with no suitable sampling frame. By elusive populations we mean populations for which - by virtue of their characteristics, or as consequence of the lack of suitable sampling frames, or for difficulties in obtaining the required information, adequate samples cannot be defined, drawn or implemented using the normal procedures of general population sampling. Such problems arise when no frame, or at best very partial frames or lists, are available for sampling, or when many units are not available or willing to participate in the survey. We may also include in this group surveys conducted on what may be considered 'normal' populations, but which are subject to serious problems of under-coverage or of non-response in particular cases. These may result from the nature of the individuals to be interviewed, from the type of information sought in the survey, or the particular conditions under which the survey is conducted (ILO, 2014; Kish, 1991). Such problems appear in a wide variety of surveys, including surveys on fgm.

Surveying fgm must overcome the primary problem of locating the target population as the migrant population is made also of irregular stayers, newcomers and people characterized by high levels of mobility.

In the field of population studies some methods used to study migrants irrespectively of their legal status and produce a representative sampling have been successfully developed.

Examples are the Centre Sampling (Baio et al. 2011) or the capture-recapture method (Rivest and Baillargeon, 2014) but these methods are not appropriate to study fgm.

Sample surveys on general topics on immigrants have also been performed by national statistic institutes but these studies usually rely on sampling from official registry and therefore reach only a selected subpopulation of immigrants leading to an overrepresentation of some categories (such as for example mixed couples) raising some question on the representativeness of the samples obtained according to this method. Moreover not all Member States have list of residents or any means of reliably locating the study population.

Defining the sample in a survey on FGM has to overcome the following issues:

- Communities where FGM occurs in an EU country have different sizes. Some small communities may be quite difficult to be interviewed. The target population may be characterized by uneven distributions or patchy concentrations on the territory of the EU country. Depending on the patterns of distribution – and on whether information is available on these patterns before sample selection – it may become difficult, or even impossible, to obtain good samples for the population of interest using normal procedures (ILO, 2014). The costs of locating such populations are substantial and can exceed usual interviewing costs.
- A complete list to draw a statistical sample is missing.
- The target population is very mobile and also consists of undocumented, unregistered and naturalized (i.e. invisible to registers/statistics on foreign resident) refugees and newcomers.
- Fluid population definitions: We need to define first generation women born in at-risk countries (migrant, regardless of their age at arrival) and second generation women born in European countries and with a EU nationality (with at least one of her parents born in an at-risk country). However, a common approach is missing in defining generations and citizenships (see par. 3). The collection of data to identify descendants is similar to minorities-related-data. This data on ethnic origin/race is classified as sensitive and is rarely collected in official statistics. Therefore, adequate samples cannot be defined, drawn or implemented using the procedures of general population sampling.

- The collection of migration related data is not standardized in EU. There are different legal statuses by which immigrants can be registered (undocumented migrants, asylum seekers, adopted citizenship...). A common approach is missing to allow for a reliable estimation of women coming from countries where FGM is practiced.

As a consequence is impossible to carry out a randomized household sampling to investigate fgm (Behrendt, 2011).

Taking into account the migration context

In order to have a methodology that can yield comparable data among EU countries, another major obstacle needs to be considered, i.e. the varying migration flows among EU Member States ((Van Mol and de Valk, 2016). These migration flows are influenced by the national context of each country and historical/colonial aspects. In the rankings of European receiving countries, France, the United Kingdom and Germany were for long-time the 3 primary countries of destination. Presently, sub-Saharan migrants tend to reach a wider range of destinations, with a less marked preference for the former colonizing countries. With this redistribution of sub-Saharan flows, new receiving countries have emerged in Europe. Southern European countries (Spain, Italy and, to a lesser extent, Portugal and Greece) and Northern European countries (Norway, Sweden) are now more frequent destinations for migrants leaving sub-Saharan Africa. In a socio-demographic perspective, these variations in historical migration frameworks lead to different population structures for this group, depending on national context. Two patterns could be noticeable in EU: former receiving countries with an ancient presence of sub-Saharan families (i.e. a part of the target population is settled for long-time, with heterogeneous social-networks, with descendants born in the EU) and new receiving countries where most of the population are newcomers, with specific social-networks.

In this pilot study we had to deal with the fact that Belgium and Italy are countries of different demographic size and in at a different point in their recent history of migration.

The demographic size is quite important once we have to discuss the sample size. A sample of 200-300 women can in fact be a quite high sampling fraction in small contexts and therefore more difficult to be reached in Belgium than in Italy.

The migration history of the country under analysis is also important. In our case we dealt at the same time with Belgium, an older country of immigration, with a higher number of second generation girls and Italy a more recent country of immigration with few second generation already aged 18 and over. Moreover, at the moment of the fieldwork Italy was also affected by relevant flows of refugees from fgm countries. The presence of different flows has to be accounted both in the sample design and in the common questionnaire in order to ensure comparability.

Introducing the sensitive topic of FGM during interview

FGM is a form of violence against women which is anchored in social organization in countries of origin and is often clashing with the norms in the receiving country. Surveys on FGM using interviews aim to conduct research with women who may have experienced traumatic events, who know that these practices are penalized and who often talk about it for the first time. Moreover, FGM could be hidden or taboo for a part of the target population while awkward and uncomfortable for the part of the people who abandoned the practices.

Several issues must be considered to guarantee respect for the interviewees. It will be essential to inform participants on the study goals and objectives, to control the potential risks associated with the study and to be sure of the beneficence for participants. Protecting privacy and confidentiality and respect for the integrity of respondents is crucial.

Hence, one of the main challenges that surveys on FGM have to deal with is the fact that FGM is a sensitive topic to talk about. For instance Andro et al. (2009) mentioned the fear for stigmatization because of the confrontation with the norms in the country of destination. Moreover, legislations⁸ might prevent respondents from speaking out: 'In countries where

⁸ FGM is banned by the law in the following African countries: Benin (2003); Burkina Faso (1996); Central African Republic (1996, 2006); Chad (2003); Cote d'Ivoire (1998); Djibouti (1994, 2009); Egypt (2008); Eritrea (2007); Ethiopia (2004); Ghana (1994, 2007); Guinea (1965, 2000); Guinea Bissau (2011); Kenya (2001, 2011); Mauritania (2005); Niger (2003); Nigeria (1999-2002, multiple states); Senegal (1999); Somalia (2012); South Africa (2000); Sudan (state of South Kordofan 2008, state of Gedaref 2009); Tanzania (1998); Togo (1998); Uganda (2010); Zambia (2005, 2011) Outside of Africa, FGM is banned in: Australia (6 out of 8 states between 1994-2006); Austria (2002); Belgium (2000); Canada (1997); Colombia (2009); Cyprus (2003); Denmark (2003); France (Penal Code, 1979); Italy (2005); Luxembourg (on mutilations only, not specifically on 'genital' mutilation, 2008); New Zealand (1995); Norway (1995); Portugal (2007); Spain (2003); Sweden (1982, 1998); Switzerland (2005, 2012); United Kingdom (1985); United States (federal law 1996, 17 out of 50 states between 1994 and 2006) – (UNFPA, 2015)

FGM/c has been the target of campaigns or legal measures prohibiting the practice, mothers may be reluctant to disclose the actual status of their daughters for fear of repercussions' (UNICEF, 2013, p.25). FGM is not a topic that is generally talked about in the practicing communities, as has been noticed by previous qualitative research as well: 'Only some one-to-one (or very small peer-group) talks about the subject may happen among a mother and daughter (e.g. about the 'value' of being cut), among young mothers or young mothers-to-be (about medical issues), among sisters or cousins, or within a couple' (EIGE, 2015, p.89). In the same study some men even declared that it was the first time they ever spoke about FGM.

When introducing the topic, in most countries of origin respondents to DHS are asked a suggestive question: 'Have you ever heard of female circumcision?'. If the answer is 'no', interviewers are encouraged to probe with a question like: 'in some countries, there is a practice in which a girl may have part of her genitals cut. Have you ever heard about this practice?'. It is important to mention that these questions are only asked at the end of the survey, e.g. in the Kenyan DHS (KDHS, 2008-09) FGM is the thirteenth and last chapter of the questionnaire. This gives interviewer and interviewee some time to build up trust and to start talking about FGM in a general, abstract way. As Andro et al. (2009) have mentioned, the challenge is to make sure that female respondents do not feel uncomfortable regarding these extremely difficult questions.

Another way to introduce the subject is through the use of local terminology. In some countries of origin such as Liberia, the researchers of the DHS decided to eliminate any direct reference to FGM because of the sensitivity of the topic. Instead, the question was introduced indirectly and respondents were asked whether they had been initiated into a women's secret society such as the Sande (LDHS, 2007; LDHS, 2013). The results were used as a proxy for the estimation of the number of women who were subjected to FGM since membership of the secret society requires that a woman is subjected to FGM.

Andro et al. (2009) have emphasized the importance of a thorough selection, training, and follow-up of interviewers, which is deemed crucial to the success of the interview, and they stressed the importance of female interviewers who speak the same language as the interviewees. This has been confirmed by other research such as Exterkate & de Jager (2011), who emphasize to use facilitators from the same ethnic background as the participants in focus groups. They also point out that an important kind of response bias often present in these focus groups is social desirability. Women might alter their answers in order to match

the answer they think the interviewer is looking for or what they think is the right answer. The interviewee might also deny that she has undergone FGM to avoid stigmatization or even legal consequences. To address this crucial point Farina (2010) relied on a team of carefully selected and trained interviewers from the communities under study.

After paying attention to all these sensitivities, Andro et al. (2009) report an unexpectedly low number of drop-outs or refusals, which has been confirmed by other research such as EIGE (2015) and Farina (2010). It means that FGM is a subject that can be talked about if it is done by the right person in a respectful, non-offensive way and that, as a consequence, respondents are willing to address the issue with little or no reluctance and that their answers will be reliable. Some researchers even mention that many interviewees express the need to break the silence around FGM with their participation in the research. It is for instance mentioned by Andro et al. (2009) and confirmed by other qualitative research: 'The focus group discussions triggered requests for follow-up discussions, declarations of interest to participate in further research on the subject, as well as expressions of interest from other people to participate... (indicating that participants had been positive in their feedback about the discussions)' (EIGE, 2015, p.90).

Limitations and biases of self-reported data

The assumption that cut women have an accurate awareness of their status, is not always verified. Several studies where women's self-reported status was compared with the findings of clinical examinations by healthcare practitioners, reveal discrepancies between the two (Yoder et al., 2004; Morison et al., 2001; Klouman et al., 2005; Snow et al., 2002; Andro et al., 2010). Researchers attribute these differences to two main factors: firstly, some women, who underwent FGM at very young ages, are not fully aware of their status, and secondly, some types⁹ of FGM do not necessarily cause a visible alteration of the external genitalia and are not diagnosed by clinical examination. Qualitative researches have also revealed that it is

⁹ The WHO distinguishes four different types of FGM (WHO, 2008): Type I: Partial or total removal of the clitoris and/or the prepuce (clitoridectomy). Type II: Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision). Type III: Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the inner or outer labia, with or without excision of the clitoris (infibulation). Type IV: All other harmful procedures to the female genitalia for non-medical purposes.

common for women to discover their FGM status only when they become sexually active, and in some cases only when they give birth (Andro et al., 2010).

Exterkate (2013) indicated that 'information bias may occur, since women as well as clinicians may incorrectly report women's FGM-status. Clinically examined FGM may also not be 100% reliable, since the mildest forms may not easily be recognizable.' Elmusharaf et al. (2006) compared reported and examined types of FGM and found that some girls or women who reported to have undergone clitoridectomy actually had been infibulated. Based on the findings of several other studies Yoder et al. (2013) concluded that 7-10% of women inaccurately reported their FGM status. This means that the use of self-reported data does not necessarily lead to better or worse results compared to data from medical examinations and that there is sufficient ground for calculating FGM-prevalence based on self-report studies (Yoder et al., 2004; UNICEF, 2013; Farina and Ortensi, 2015).

Another under-reporting bias may be linked to legislative changes in certain countries. A reluctance to report having undergone FGM in an environment where the practice has been banned has been observed in African countries where data have been collected on different dates. In at-risk countries, from the mid-2000s, when the campaign against FGM was intensified, several surveys recorded decreases in the prevalence of FGM in some age groups, which did not seem to reflect real declines but were rather the result of under-reporting by the women surveyed (UNICEF, 2013). Such under-reporting is even more likely in migration contexts, particularly in surveys of migrants' descendants with origins in an at-risk country. It is difficult for women born or raised in EU to report having undergone FGM and even more difficult for them to report FGM performed on their daughters. It is therefore important to consider the legal contexts in which the questions on FGM are asked, to adapt the survey protocols.

4. Methodology for indirect estimations of FGM prevalence in the EU

An indirect method, based on a triangulation of population data and/or census data and data from DHS and MICS, the so-called 'extrapolation-of- FGM-countries-prevalence-data-method', gives an appropriate estimation of the number of women who have potentially undergone FGM. Depending on the situation, the extrapolation could be done based on the raw FGM percentages as mentioned in the DHS, or a correction based on age, wealth, level of education and urbanization (Farina & Ortensi, 2014) could be applied or it might be possible to opt for an interval with a minimum and a maximum (Exterkate, 2013; Andro et al.,2009).

We have applied the indirect method to all EU Member States and Norway and Switzerland, in order to provide an estimation of the total number of first-generation girls and women in Europe who have undergone FGM. The method applies the extrapolation-of- FGM-countries-prevalence-data-method by 5-year interval to the results of the 2011 European census. Estimations provided for this study follow the standard for baseline estimation proposed by EIGE. To assure comparability between countries in the foreign-born female population, enumeration data from European censuses have been used. Following the 2011 census, all the National Statistical Institutes of the European Union have released data based on harmonized statistical classifications and definitions. This exercise resulted in complete and comparable statistics that are publicly available (<https://ec.europa.eu/CensusHub2>). Variables of interest for this study were sex (female), age (5-year age groups), place of birth (countries where FGM is practiced) and residence-nations (1 of the 28 countries of the EU, or Norway or Switzerland).

The possibility of producing comparable data on FGM in Europe depends highly on a uniform registration system across countries, which is currently lacking. The use of census data gave us the possibility of overcoming this major limitation of population data. In order to estimate the prevalence of FGM in the countries of destination from each country of origin we relied on the same extrapolation-of- FGM-countries-prevalence data-method as used previously, as already explained above. Prevalence figures for 29 of the 30 countries of origin were provided by DHS and MICS¹⁰. For Indonesia, data were based on an estimation made by UNICEF. Since the

¹⁰ These surveys have been conducted since the 1990s at regular intervals in more than 50 countries around the world. In the 29 countries where FGM is documented a module gathers information on FGM.

data of the European census concerned 2011, we have utilised the DHS/ MICS for the countries of origin in the year closest to 2011.

The methodology (described in Van Baelen L et al, 2016) follows, the methodology of, among others, Yoder et al., using the DHS and MICS prevalence figures in the countries of origin and applying them to immigrant females in the destination country. We applied the specific FGM prevalence figures in the countries of origin for each 5-year age category between 15 and 49 to the corresponding group living in the European country. FGM prevalence data had to be calculated for the age categories under 15 and above 49, as women in the age group between 15 and 49 were the sole DHS/MICS survey respondents. Based on the assumption that 40 years ago there were little or no FGM prevention campaigns and the fact that in most countries FGM prevalence figures differ only slightly between the age categories 40–44 and 45–49, for women above 50 years, we have used the prevalence rate of the 45–49 cohort. For girls under 15 years, no direct data were available either, but given the decreasing FGM prevalence data for most countries in the lower age categories and the fact that some of the girls might have arrived long before they had reached the median age for undergoing FGM in their country of origin, we estimated only the FGM prevalence rate for girls between 10 and 14 and assumed that it corresponded to the prevalence rate for the 15–19 cohort. It means that for some countries of origin for the age category between 0 and 10, there might be a slight underestimation, while for the category 10–14, there might be in some cases an overestimation. Results are presented in section 6 of this report.

This methodology and its application have been published in *The European Journal of Contraception and Reproductive Health Care*. To link to this article please go to <http://dx.doi.org/10.1080/13625187.2016.1234597>.

5. Methodology for direct estimations of FGM prevalence in the EU: the pilot study

The rationale behind the method proposed in the pilot study was to try to reduce as much as possible some of the biases mentioned above. The choice of countries to pilot the

methodology was initially France and Italy. However, given the limited time frame of the project (two years), and the unexpected and unanticipated long period for obtaining ethical clearance in France (minimum six months with no guarantee for a positive outcome), France was dropped as pilot country and replaced by Belgium, as Italy is a new country of migration and Belgium is similar as France, an 'old' country of migration. The method was thus piloted in Italy and Belgium. The methodology was carefully designed and extensively discussed by all project partners and the steering committee members. The design of the pilot studies was based on the results of the situation analysis, discussions with project partners and steering committee at the first (Gent, July 2015) and second (Paris, October 2015) face-to-face meetings, and was further refined during skype meetings.

Target population

Due to the issues related to obtaining ethical clearance for conducting research on FGM among minors, we decided to include only adult women (at least 18 years old) in our survey. As it was not possible to cover all the 30 communities considered at risk of FGM, 8-10 communities were selected for direct estimation according to the size of the female community living in the country where the survey was to be carried out.

Accordingly, the target population for our direct estimation was defined as:

- (1) Women from selected FGM country living in the host country with (8-10 nationalities, according to the national ranking, see detail in the next sections)
- (2) With at least one parent born in an FGM country
- (3) Age ≥ 18
- (4) Both legally resident and undocumented migrants (random)

Mixed method of TLS and RDS

The methodology tested for the pilot survey was a combination of Time-Location Sampling (TLS) and Respondent-Driven Sampling (RDS).

Time-Location Sampling is useful for collecting information on a hard-to-reach population by sampling locations where persons of interest can be found, and then sampling those who attend (Leon et al., 2015). A list is drawn of these places and of the days at which they are visited (place/time pairs). Persons in the time-location pairs are sampled.

The principle of Respondent-Driven Sampling is the use of a probability snowball sample (Heckathorn, 1997). “Seeds” interviewees receive 2 to 3 coupons after the interview, which they give to acquaintances (regardless of their social network size). These persons call the interviewers to be interviewed in turn. They have to be linked to their recruiter (with a number on the coupon) and become in turn recruiters. Some questions aimed at assessing the number of people the respondent knows within the target population (Personal Network Size) are also required to perform estimations based on this method.

The integration of two sampling methods allows researchers to reach women who do not frequently use the facilities chosen for the interviews. The mixed method is implemented by interviewing some women following a TLS approach and then asking them to become “seeds” according to the RDS procedure and refer other members of the target population (using coupons and incentives where possible). All women are asked questions about their Personal Network Size to ensure the possibility to apply RDS.

The fieldwork started as a typical TLS sampling and then included a final passage to allow interviewees to become recruiters.

An exhaustive list of facilities visited by the target population was defined in both countries. Depending on the structure of this population and on the national situation, the type of facility could vary. For example, the population coverage by medical facilities differs in the EU countries and some other places could be more efficient to reach the target population. Possible places might include health services, asylum centres, NGOs, places of worship, ethnic shops, amusement places, shopping centres, etc. The number of facilities varies according to the concentration/segregation of the target population in the country/region. Ideally, the data collection should be simultaneous to avoid double-counting. We suggest to select at least 30 facilities and to collect 50 interviews in each facility.

After the preparation of the TLS centres’ sampling frame, coordinators have scheduled meetings with all the staff to explain the objectives and the protocol of the survey. Each interviewer was carefully trained about the survey protocol and the questionnaire.

In Italy, every woman coming in the facility was contacted using a contact form¹¹. In Belgium, women were approached by the interviewer and directly asked about the inclusion criteria. If she was in the target groups, the interviewer explained the aim of the survey, the interview length, and collected the informed consent of every interviewee. Every migrant or descendant women from a target group who agreed to be involved in the survey will be interviewed.

To allow the passage to an RDS sampling at the end of the questionnaire, the interviewer asked the interviewed woman to take 2 (in Italy) or 3 (in Belgium) coupons with her ID Questionnaire Number written on it, and to give them to two/three other concerned women respectively. Only in Belgium primary and secondary incentives¹² were provided to ease RDS recruitment. Women were eligible to incentives in case a woman from their network contacted the researchers to be interviewed.

Sampling

The sample size was the result of a priori decision. For this pilot study we had the possibility of performing a maximum of 1,500 interviews in each country where the survey will be performed.

Sample structure

When dealing with studies including different groups, stratification is advisable as we are dealing with different expected prevalence rates. Stratification refers to partitioning the population before sample selection: within each origin, a sample is selected separately (independently). In so far as the strata represent relatively homogeneous groupings of units, as in the case of country of origin in our study, the resulting sample is made more efficient by ensuring that every statistical unit from each group is appropriately represented in a controlled way. Control through stratification also reduces the risk of getting a poorly distributed sample by chance. Apart from statistical efficiency, stratification is convenient in the study of FGM because data are required separately for sub-divisions of the population (i.e. estimation by country of origin) in order to meet the goals of our project (producing estimates

¹¹ The contact form asks for place of birth, age, mother and father place of birth, and provides a unique ID Questionnaire number as well as the name/address and code of detection place

¹² The woman who brought the researches in contact with new participants received for each new contact (maximum 3), a coupon of 12,50 euro for the website Bol.com. Primary incentives for everyone Handsoap

based on this survey for some communities and testing the reliability of indirect estimations). Stratification also permits flexibility in the choice of the design separately for each part of the population with different sampling requirements and challenges.

In the case of the pilot study selecting an a priori number of nationalities was useful in order to:

- a) Optimizing the process of selection of interviewers, by citizenship/country of origin (communities).
- b) Having a minimum/optimum number of cases for every community involved. This is key in the process of estimation and in the control of the precision of estimate. In fact too few cases do not allow the possibility of making an estimation of the prevalence in a community or may not guarantee the reliability of this estimate. It also guarantees the possibility to make comparisons with overseas communities and DHS data from countries of origin.
- c) Making the sample design more statistically efficient by allowing a higher sample for strata where the expected proportion of FGM is closer to 0.5.

Even if involving women from all practicing country would be the optimum solution, covering all communities and at the same time ensuring an appropriated sample size at the community level, is a very difficult task. This is also because some communities are scarcely present in some EU member states, including Italy and Belgium.

The process of choosing the communities involved and allocating the number of interviews in the survey should comply with research priorities and statistical criteria.

In our study the allocation of the number of interviews was defined as a two-step process:

- The selection of communities (i.e. choosing strata)
- The allocation of the number of interviews for each community

The communities included were chosen according to the following criteria:

- a)** Inclusion of the biggest communities (according to data about women presence)

- b)** Ensuring a chosen margin of error and a confidence level for estimation
- c)** Including communities that are known from literature to be particularly different from the country of origin overall profile

Point a) ensures that the main communities are included. Point b) determines the appropriate sample size for estimating the proportion of mutilated women in each community i to within a specified margin of error.

The size of our sample dictates the amount of information we have and therefore, in part, determines our precision or level of confidence that we have in our sample estimates. An estimate always has an associated level of uncertainty, which depends upon the underlying variability of the data as well as the sample size. The more variable the population, the greater the uncertainty in our estimate. Similarly, the larger the sample size, the more information we have and so our uncertainty reduces. According to our survey we want to estimate a proportion with a given level of precision (we suggest a margin of error below 10%) and a 95% confidence interval¹³.

Point c) allows for the incorporation of previous qualitative or quantitative results.

For the pilot study, the appropriated sample size n_i for each community i was calculated as follows:

$$n_i = \left(\frac{z_{\alpha/2}^2}{m^2} \right) p_i(1 - p_i)$$

Where:

- W_i is the number of women in each community i according to Eurostat data
- p_i is the expected proportion of women with FGM according to DHS/MICS data
- $z_{\alpha/2}$ is the critical value of the Normal distribution at $\alpha/2$ (e.g. for a confidence level of 95%, α is 0.05 and the critical value is 1.96)

¹³ The confidence interval for a proportion p is $p \pm z \sqrt{\frac{p(1-p)}{n}}$

- $m = z_{\alpha/2} \sqrt{\frac{p(1-p)}{n}}$ is the margin of error, is the level of precision we required. This is the range in which the true proportion is estimated to be and should be expressed in percentage points (e.g., $\pm 10\%$).

According to these criteria the following community were selected in the pilot study

- Italy: Egypt, Nigeria, Senegal, Cote d'Ivoire, Burkina Faso, Eritrea, Ethiopia, Somalia, Cameroon, Ghana
Belgium: Cameroon, Guinea, Ghana, Cote d'Ivoire, Ethiopia, Nigeria, Senegal, Togo, Iraq, Indonesia

For the pilot study we implemented a dynamic allocation of the sample. A first number of interviews were allocated in order to ensure a chosen level of precision and confidence level (step 1), while a certain number of interviews remained not allocated at the beginning of the fieldwork. When all interviews scheduled for a given community according to step 1 were performed, the prevalence of women in each community according to results of interviews allocated in step 1 was computed. The remaining number of interviews is allocated according to prevalence observed in interviews allocated in step 1 for each community.

In Belgium, from the countries where FGM is practiced a selection was made of the ten most prevalent nationalities (Cameroon, Nigeria, Ivory Coast, Senegal, Togo, Ethiopia, Indonesia, Iraq, Guinea and Ghana), representing 78.8% of the total number of women coming from one of the 30 countries where FGM is practiced who were living in Belgium on January 1st 2015¹. From these ten countries Indonesia, Iraq, Guinea and Ghana were excluded: the first two because it would require a separate set of TLS-organizations and interviewers, the last two to allow a good mix of countries with low and high FGM prevalence figures according to DHS and MICS.

Final estimation of the prevalence

When primary data on prevalence of FGM are available for a selected number of communities the final estimation of the prevalence for the country should be based on a combination of

direct and indirect estimation. To comply with the age structure of DHS/MICS and Eurostat data it may be convenient to consider 5 years age spans and extend the direct estimation based on women aged 18 and over also to women aged 15-17. In doing this an estimate for girls and women aged 15 and over will be produced.

- Let $P_{x,x+4,j}$ be the number of women aged $x,x+4$ from practicing community j not included in the survey ($x>14$)
- Let $m'_{x,x+4,j}$ be the prevalence for women aged $x,x+4$ according to last DHS/MICS data for countries j not included in the survey
- Let P_i be the number of women aged 15 and over from practicing community i included in the survey
- Let \bar{m}_i be the prevalence estimated for women aged 15 and over (from the survey) for communities i
- The estimated number of mutilated/cut women aged 15 and over is calculated as:

$$\bar{P}^m = \sum_{j,(x,x+4)} m'_{(x,x+4),j} P_{(x,x+4),j} + \sum_i \bar{m}_i P_i \quad (x>14)$$

Questionnaire

The questionnaire was based on self-reported FGM status. The Italian questionnaire includes several sections aimed at identifying the determinants of continuation of the practice other than the prevalence. The FGM section is placed at the end of the interviews thus the interviewer had time to gain her trust. We have used three different formulations for “excision” to be sure that women understood what we were talking: Are you excised? Have you been cut? Are you purified? Very few women refuse to answer all questions related to FGM knowledge, practice, and opinions. For example refuse to respond to the questions: “Do you know if FGM has happened to you?” is 0.9%; “Do you think that this practice should be continued?” is 1.2%. The question “Have you ever heard of FGM?” is ever lower (0.3%).

The Belgian questionnaire started with a section on demographic data, followed by a section on African cultural practices that are prevalent in Belgium and find their origin in Africa. These questions first concerned the presence of cultural practices in the country of origin. The questions were specifically on birth rites, rites of passages for boys and girls, marriage traditions and funeral rites. These questions served as an introduction to the subject and to gain trust, before the inquiry after knowledge about and experience with FGM followed. Women were, as in the Italian questionnaire, asked whether they had heard about the

practice, if they themselves were excised, cut or purified and if their daughters were excised, cut or purified. After this part, they were asked about the continuation of cultural practices, including FGM, in the same way, another way or not all in the Belgian context. Only one in 57 women refused to answer the questions on FGM. Compared to the Italian survey, the Belgian one was more limited in number of questions and length of interview time.

Recruitment and training for interviewers

The small number of refuses also depends on recruitment and training of interviewers.

In the Italian pilot study, interviewers have been selected from an existing group working for Regional Observatory operating from 15 years as well as from personal knowledge of cultural mediators even in different regions of Italy. Among 40 candidates 23 have been selected from communities under study or that have access to these communities to avoid gatekeeper opposition. All, but one were female. The high number of interviewers allows reaching women with a different background, also controlling some background characteristics of interviewers as being first/Second Generation; old/young; old/new migrant. In short, a notable number of interviewers reduced the interviewer – distortion effect. All interviewers are from practicing countries. This choice has been crucial because they could be insiders of the networks of their community, even informal and unknown by the researcher. They used common language and codes during the interview. All interviewers have been trained, and a handbook has been prepared. The survey has been carried out in a high number of places to improve the quality of the survey reducing the selection of nationalities since some attend only certain places. The coordinator of the fieldwork had the responsibility to control the job of interviewers, i.e. primarily controlling the first 10/15 questionnaires to be sure that the mandate has been fully understood.

In the Belgian pilot study, 15 interviewers were recruited through common job recruitment channels. All 15 interviewers were trained, but only seven have actually done interviews. They were hired as volunteers and received a fee for each completed interview. Because of the target group and the specificity of the subject, preference was given to women of African origin, who were fluent in French or English. Both women with a background from countries where FGM is practiced as from countries where FGM does not occur were selected. Among the interviewers were also two women without an African background. This choice was made to

avoid bias through socially desirable answering in different directions. The selected interviewers were all women between 21 and 40 years old. The interviewers received training on the issue of FGM, the methodology used in this study and communicating about sensitive issues. During the training they also practiced interviewing skills. Following this training, the interviewers conducted their first interviews together with the trainer and received one-to-one feedback on improving their interviewing approach.

6. Findings from the direct estimations pilot studies in Belgium and Italy: lessons learned

One among the first aims of this pilot study was to make an effort in order to test a methodology able to limit some of the bias typical of surveys on hard to reach populations. For these reasons, a survey methodology “as statistical as possible” was implemented, i.e. a combination of TLS and RDS, as detailed in section 5. Findings from the piloting in Italy indicate that TLS and RDS are both survey design methodologies that are too rigid in order to make a survey on FGM.

Limits of TLS methodology when applied to FGM surveys

The main limitation of TLS is that it requires an exhaustive list of centres and it also requires that for the centres in the list to be always open and accessible to interviewers in order to allow the casual extraction of time and venue where the interviewer can be addressed. If such a methodology can be suitable for some hard to reach populations and some related typologies of centres (e.g. sex workers and clients and night clubs), it proved unfit for an FGM survey. Venues of interest to survey women from FGM communities are for example not always open and accessible. On the contrary the coordinator should be aware of opening hours in order not to waste time sending interviewers when such centres are not open.

Moreover not all centres are accessible. Sometimes the permission to send an interviewer is denied by those who are responsible for them. FGM may appear a topic too sensible to be enquired. Centres of interest are also selected by nationality: there are centres that are attended by a high number of women of some communities, while at the same time are not

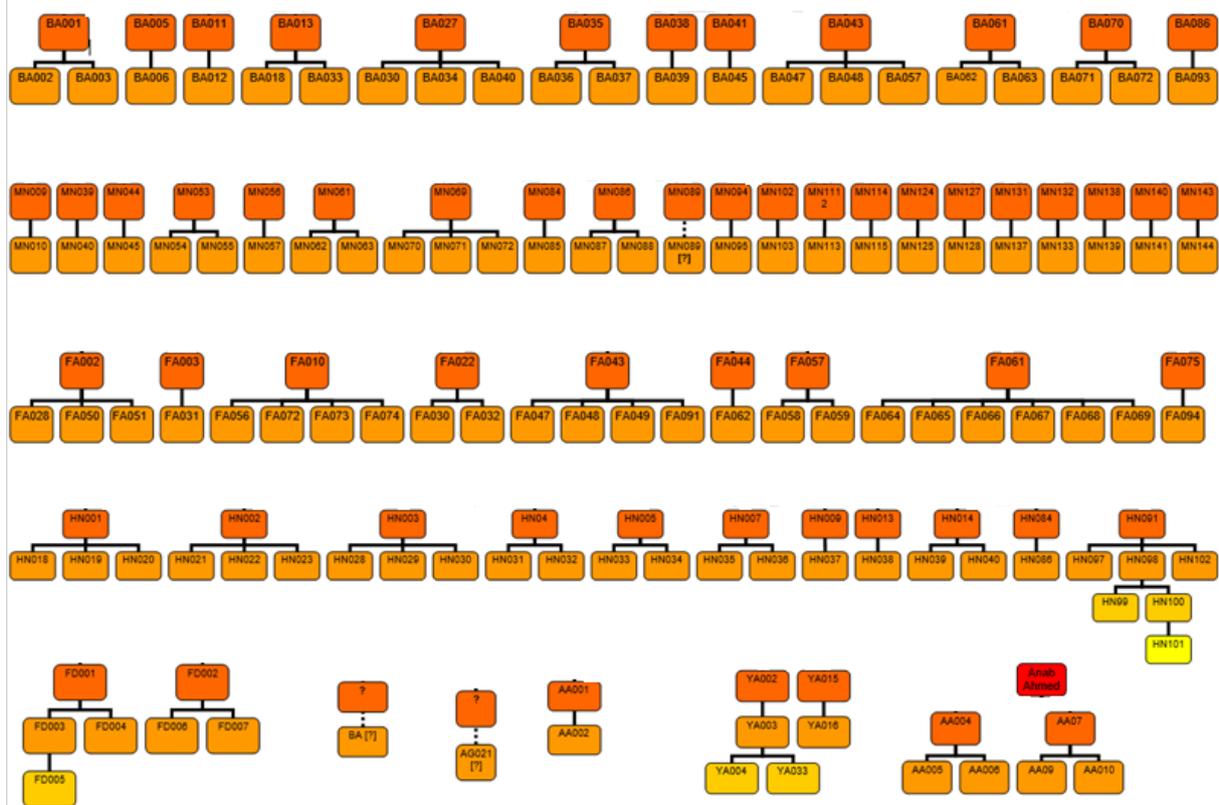
attended at all by women from other communities. Gatekeeping by those in charge of centres or by communities themselves can heavily limit the free access to centres. Especially in Belgium, gatekeepers turned out to be a major limitation in reaching the target population. The experience with this pilot study suggest that using (only) a casual extraction of time and location is not realistic as it implies a considerable amount of time in extracting and replacing venues that are not accessible or are not accessible in the hour selected. Both experiences from the field in Italy and Belgium turned soon to a facility-based sampling that allowed the interviewers to attend centres at right time and day when they were accessible.

The second common experience earned from the fieldwork is that there are plenty of informal locations that are unknown to the researcher(s) but that are well known to the interviewers. Examples in this sense are parks, parties, wedding, female meetings in private houses, festivals, meeting for religious celebrations.

Limits of RDS methodology when applied to FGM surveys

Respondent-driven sampling (RDS), combines "snowball sampling" with a mathematical model that weights the sample to compensate for the fact that the sample was collected in a non-random way. The experience of this pilot study however tells us that RDS showed to be quite difficult to handle for interviewers. Sometimes recruited women showed up without having the card with the code of the recruiter. The lack of incentives for women recruited was an additional limit for Italy. On the other hand, the use of incentives in Belgium did not result in a higher number of women participating in the RDS chains. RDS has also the limit that is not fit to model some typical situations of the fieldwork (e.g. a group of friends interviewed in the same centre). The map of recruitment chains for the Italian field also shows that in the few cases where a recruitment chain began, it rarely proceeded to further recruitments.

Figure 1 – Recruitment chains FGM-PREV Survey Italy



These findings suggest a very high cost of contact with the RDS method. Another limitation arose from the determination of the Personal Network Size. If the target population is very peculiar (e.g. sex workers, drug injectors) it's quite easy for an interviewee to determinate the Personal Network Size. Feedbacks from interviewers were unanimous in reporting difficulties in assessing the Personal Network Size and resulted in low reliability of answers. As a result the % of RDS was too low (8,5%) to be used to produce estimations and it's hard to think of RDS as the main/only method for an FGM survey. Previous experiences suggest that snowball sampling could be used instead of RDS as a less rigid option to contact women that so not attend centres.

Stratification of the sample and dynamic allocation of interviews

Stratification of the sample proved to be a valid solution to deal with multiple communities. Selecting a limited number of communities helped the coordinator of the survey in the choice of interviewers (mainly co-nationals) and dealing with difficulties. For example, in the Italian field problems arose in recruiting Ethiopian interviewers and interviewee did not affect the rest of the sample. The dynamic allocation of the sample, i.e. the use of the prevalence found

halfway on the field to inform the second part of the fieldwork also proved a helpful instrument to improve precision.

Table 2 – Dynamic allocation of interviews - FGM-PREV Survey Italy

	<i>Interview</i>	<i>reached</i>	<i>prevalence on-the-field according to the first step result</i>	<i>Minimum to be reached with second step</i>	<i>Lowest number reached in first step</i>	<i>Additional minimum in the second step interviews</i>	<i>Final</i>	<i>Minimum reached</i>
Egypt	50	yes	43,9%	95	no	45	306	Yes
Nigeria	72	yes	70,3%	80	no	9	167	Yes
Senegal	71	yes	35,5%	88	no	16	142	Yes
Cote d'Ivoire	91	yes	13,6%	45	yes		115	Yes
Burkina Faso	70	yes	74,7%	73	no	2	244	Yes
Eritrea	54	yes	52,7%	96	no	42	134	Yes
Ethiopia	73	no		0	no		20	No
Somalia	50	yes	67,5%	84	no	34	131	Yes
Cameroon	50	yes	17,5%	55	no	5	65	Yes
Ghana	50	Yes	9,0%	31	yes		54	Yes
Total	632			648			1378	

The pilot survey FGM-PREV resulted in very interesting methodological results that will prove useful for anyone willing to perform a prevalence study in a member state.

Preparation of the fieldwork

The preparation of the fieldwork has proven to be a crucial element in the success of the survey in Italy, and the main barrier to a successful implementation in Belgium. Given that in Italy, previous collaborations for surveys existed, helped in conducting the survey in a timely

manner. In Belgium, the go ahead to start with the fieldwork was only given at a very late stage, the lack of previous contact persons and associations that can provide access to locations, demanded a lot of time to assure their collaboration. Moreover, the team in Italy could rely on an adequate number of skilled interviewers from communities under study or professional interviewers that had access to these communities, stemming from their previous survey. In Belgium, this work also had to be done from scratch, and proved to be very time consuming, resulting in gatekeeping from community members.

Number of interviews and reliability of the estimation

The dynamic allocation of interviews proved a useful instrument to adjust promptly - while still performing the interviews - the allocation of the questionnaires to each community. This is particularly important when the prevalence found in the field is different from that obtained from DHS/MICS, to control the margin of error.

The pilot study allocated the interviews to each community on the base of statistical considerations. Of course our sample was not randomly selected: this suggest that a sample size that can be adequate under the assumption of a randomly selected sample should be considered as a minimum when these conditions are not met. In research on FGM, the statistical criteria should be integrated with other considerations, especially the variation of prevalence among areas or ethnic groups in the country of origin. It is advisable for countries with a high internal variation to provide higher subsamples even in the case of a very low expected prevalence.

7. Recommendations for future FGM Prevalence studies in countries of migration

- *Choice between indirect or direct method*

Direct estimation of FGM prevalence among FGM practicing communities in the diaspora is possible and advisable. However, the variation in the number of women from FGM practicing countries in the EU Member States (countries with high and countries with low prevalence), demands a different approach when estimating FGM prevalence. Decisions on the use of a particular method (indirect or direct estimation), may be taken for a variety of

reasons (budgetary, political, scientific, ...). Hence why we suggest using an indirect estimation for countries with low prevalence of women from FGM countries, and a direct estimation for countries that have a high prevalence of women from FGM risk countries.

- *Longitudinal approach*

Surveys should be developed in such way that they can be used to perform longitudinal research, i.e. to allow a similar survey to be conducted at regular intervals, in order to measure changes in profiles of migrants and their attitudes towards FGM, the perpetuation or abandonment of the practice in the subsequent generations. Such a longitudinal approach will require sufficient resources at regular intervals.

- *Use a combination of facility based and snowball sampling*

Surveying immigrants without sampling frames requires the implementation of alternative field methods. According to our experience from the pilot studies in Italy and Belgium, a combination of facility based and snowball sampling is the best way to perform a survey on FGM. Facility based sampling means the use of formal and informal centres where women can be met as starting point. In order to get in contact with women who do not attend such centers, snowball sampling can be used, asking women who were met in formal and informal centres, to put the interviewer in contact with other women eligible for the interview.

- *Preparation of fieldwork*

As the method requires access to centres where women from FGM practicing countries can be contacted and interviewed, researchers should take as much time as possible to establish positive contacts with grassroots organisations, community based organisations, associations, authorities or institutions in charge of centres. It's important to share the aims and goals of the study with the organisations and additionally assure compliance with ethical guidelines and assure respectful dissemination of results. It's very important to win their trust and willingness to collaborate in order to have access to their community centres, otherwise unknown to the researchers. A sufficient number of interviewers should also be available. Having a large team helps to control for interviewer's bias¹⁴. As different

¹⁴ Examples are a partiality of some interviewers towards a preconceived response based on the structure, phrasing, or tenor of questions asked in the interviewing process or questions laced in ways that can influence respondents and distorts some outcome of the interview.

interviews can have access to different informal centres of aggregation, having a large number of interviewers indirectly helps in reaching as many ethnic networks as possible.

- *Choice and training of interviewers*

Interviewers should be recruited among the communities relevant to the study. Interviewers outside these communities can be used but should have specific skills in the field of migration and should have skills in contacting hard-to-reach populations. It is recommended to have as many interviewers as possible (ideally more than 2 from each community) in order to control interviewer bias and selection on ethnic base (e.g. an interviewer might be contacting more co-nationals of the same ethnic group). Interviewers from these communities can aid in evaluating the usefulness and accessibility of formal and informal centres where women can be met.

- *Multicentre approach*

To conduct a national survey that can produce representative data, it is useful to include as many centres as possible in the respective country (as far as possible from each other) in order to catch as many different local networks as possible for each community. Using a multicentre approach will enhance representativeness at the national level.

- *Coordinator*

It is key to enrol a coordinator with specific experience in this complex field including the knowledge of different networks of communities, and to have a big number of professional and trusted interviewers. The coordinator must be able to organize and manage the hard-to-reach population surveys.

- *Choice of main FGM practicing communities*

Even if involving women from all practicing countries would be the optimum solution, covering all communities and at the same time ensuring an appropriated sample size at the community level is a very difficult task. This is also due to the fact that some communities are very scarcely represented in some EU member states. We suggest focusing on the biggest communities present in the country where the survey is carried out and/or the communities with the highest expected prevalence of FGM accordingly to DHS/MICS survey data in the country of origin or other information about overseas communities. We suggest the researchers should use the best data available to make a hypothesis about prevalence. The

dimension of the community should be evaluated on the basis of population register ranking, or any other register of foreign population available.

- *Use stratification in sampling design*

Each community selected should have a defined minimum subsample. As women are not selected randomly, it is important to provide a larger sample than that would be adequate to estimate a proportion with a given level of precision according to a binomial distribution and random sampling.

- *Use dynamic allocation of sample*

Using the prevalence data obtained halfway the study, can help to correct the allocation of interviews while still on the field. We therefore recommend a dynamic allocation of the number of interviews to ensure the same margin of error.

- *Questionnaire*

- Introduction of the subject: When starting the interview, one should start with some brief introductory questions to establish a certain level of trust before inquiring about the FGM status. Leave women free to express variable degree of (un)certainly about their FGM status.
- Opportunities for registering supplementary information: When a questionnaire is used, respondents often provide supplementary, but relevant information on the subject. While designing the questionnaire, room for this information should be foreseen.
- The pilot survey: As part of the fieldwork coordinator should take as much time as possible to make pilot survey in order to a) to assess the quality of the questionnaire particularly on dictionary adopted, register, and sequence of the sections. b) to have a feedback from the interviewers on the potential difficulties when taking the questionnaire and amend if this is the case.
- Self-reported FGM Status: Women's knowledge about the FGM Status is not always according to the WHO typology of FGM (the 4 types with subtypes). The use of the DHS-typology might be better to use in a survey for direct estimation. It is therefore also advisable to provide flexibility to women to express variable degrees of (un)certainly about their FGM status.

- *Language*

In countries where multiple languages are spoken, interviewers should be selected on their knowledge of relevant languages. If possible multilingual interviewers should be preferred. Interviews in dialect or mother tongue should be allowed if they increase the confidence between interview and interviewer.

- *Provide sufficient resources*

When conducting a direct estimation, it is paramount to allocate sufficient funding to ensure that data collection and analysis are done in a scientific robust way. Direct estimations require resources for, at least:

- Salaries for interviewers (at least 2 interviewers per FGM practicing community)
- Salary for coordinator of the fieldwork
- Salary for data input and data cleaning
- Salary for data analysis
- Incentives for respondents
- Transport costs for conducting interviews and for supervision moments with coordinator
- Print costs for questionnaires or tablets for e-interviews
- Translation costs for questionnaires

Sufficient time allocation is equally important. Time should be calculated for:

- Field preparation, which includes obtaining access to the field, gaining trust from communities
- Recruiting interviewers: an outstanding team of interviewers is necessary, consisting of a high number of skilled interviewers or that have access to the communities (to avoid gatekeeping), preferably multi-linguistic.
- Recruiting fieldwork coordinator: with previous experience in conducting surveys among hard-to-reach populations
- Training of interviewers
- Piloting of interviews
- Conducting survey and analysis of data

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