Introduction

The online discussion on Female Genital Mutilation (FGM) took place on 29th October 2013. It was organised on foot of the recent European Institute of Gender Equality (EIGE) report on 'Female Genital Mutilation in the European Union and Croatia'. This report identified the need to establish a common understanding of prevalence of FGM within the EU Member States. It noted a lack of comparable data on this issue across the Member States due to a lack of harmonisation of methodologies, definitions and approaches used and due to the wide variety of information sources used to collect data and to estimate the extent of FGM at national or regional levels.

The online discussion sought to:

- Advance the development of a common EU-wide definition of prevalence of FGM.
- Explore common indicators and harmonised methodologies in the EU to determine the prevalence of FGM.

This report of the online discussion aims to support a broad dissemination of the insights and learning from the debates. It seeks to inform about progress on data collection and measurement of FGM that in turn would enhance policy development, awareness raising and other work on this issue.

This report summarises the key points made and themes explored in the online discussion. Inevitably, it is impossible to reflect fully the variety of ideas and perspectives brought forward.

Organisation of the discussion

The online discussion was organised in two separate sessions over one day:

- Session 1: The need for a common definition of prevalence of female genital mutilation.
- Session 2: Developing common indicators and methodologies to determine the prevalence of female genital mutilation and the number of women and girls at risk.

Participation

Ten people intervened in the online discussion, while there was a wider complement of participants. Contributors came from seven different Member States. Participants were drawn from academia, civil society organisations, and organisers (EIGE and Cultura Lavoro S.r.l.). Fifty-eight statements were posted by the contributors to the discussion. The discussion was in English.
Female genital mutilation (FGM) is recognised at the European Union level as a violation of the rights of girls and women. It is a form of gender-based violence involving procedures that include the partial or total removal of the external female genital organs for non-medical reasons. In all the Member States, legal provisions dealing with bodily injury, mutilation and removal of organs or body tissues are applicable to the practice of FGM and may be used for criminal prosecution. In some countries, a principle of extra-territoriality makes it possible to prosecute the practice of FGM even if committed outside of the country’s borders.

The following definitions of prevalence and incidence, drawn from the framework of EU standards applied for health statistics, served as a starting point for the online discussion in relation to definitions:

- **Prevalence** refers to the number of cases of a given phenomenon existing at a certain time expressed as the proportion of a population affected at any time in a year.
- **Incidence** is the number of new cases of a given phenomenon arising in a given period in a specified population.

The main methodological approach currently used to estimate prevalence is the ‘extrapolation of African prevalence method’: This involves gathering statistical information from national statistical offices and national census to extract data on women living in a certain Member State and originating from FGM practicing countries in Africa and using prevalence data from these countries of origin.

Beyond this assessment, it is necessary to identify data sources for enhanced information on the prevalence of FGM in the EU Member States. Administrative records, hospital and medical records, police and criminal justice records, and child protection records could be additional sources from which to gather data on the prevalence of FGM. Data from these records could serve as initial proxy indicators of prevalence and incidence of FGM at both regional and national levels.

However, many of these records are not systematically used. The existing data may not be collated centrally. Data collection may not be obligatory and access to data from such records is often restricted. As such, there is currently no reliable and comparable data on the prevalence of FGM at EU level.

EIGE’s research on FGM concluded, ‘The need for more robust data and knowledge on the practice of FGM in the EU [...] has to be addressed’. It pointed out that ‘Mapping the prevalence of this phenomenon within the EU is absolutely essential for developing effective policies and legislation, allocation of funding and evaluating the results of actions taken’.

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Summary of the discussion

Participants were encouraged to share their questions, insights, experiences and proposals in relation to the two topics with the following introductions and guiding questions. A number of overall conclusions were identified in relation to each topic and these are set out below, too.

Session 1: The need for a common definition of prevalence of female genital mutilation

Introduction:
The number of girls and women around the world who have suffered genital mutilation ranges between 100 million and 140 million. FGM is recognised as a violation of the rights of girls and women and is a particularly brutal form of violence against women and girls, involving procedures that include the partial or total removal of the external female genital organs for non-medical reasons.

‘You cannot eradicate such historical, rooted habits by law only. We need education of mothers and fathers. There is lots of misinformation that cutting children is good, but this is lies.’ Nawal El Saadawi, Egyptian feminist writer, activist, physician and psychiatrist.

In order to combat FGM at a European level we need prevention policies, support services and effective prosecutions. In order to advocate for legislation, policies and services we need to know the scale of the phenomenon of FGM. This is why it is so important to achieve a coherent and comparative system of data collection based on a common definition of prevalence.

The aim of this first session was to share knowledge among experts and to have a fruitful discussion in order to work towards the achievement of a common definition of the prevalence of FGM.

Guiding questions:
- What definitions of prevalence have been used until now?
- What are the pros and cons of each definition?
- What are the fundamental issues that should be taken into account to provide a definition of prevalence valid throughout Europe?
- What would you propose to use for the development of a common definition of prevalence of FGM in the EU?

Main Conclusions:
There has only been limited measurement of the prevalence of FGM in many Member States. A further issue is that measurement of prevalence that has been done in different Member States lacks comparability. Measurement of prevalence is vital in stimulating and supporting effective legislation, the development of preventative work and the provision of necessary support services. It is important that prevalence is defined and measured in a manner that ensures the evidence gathered actually serves appropriate and adequate action on the issue.

There are challenges to be met in establishing the prevalence of FGM. Data is lacking and data collection can be particularly sensitive for individuals and communities. A broad focus on prevalence is required that encompasses risk of FGM as well as actual mutilation and that offers knowledge about those who experience FGM and that can identify the experience of second and third generation women and girls whose parents originated from countries where FGM is practiced.

A multi-disciplinary approach to defining and measuring the prevalence of FGM was encouraged, involving statisticians, demographers, experts in geographic information systems and experts in FGM.

It was proposed that a broader and more general approach to measuring the prevalence of FGM at EU level could be combined with a diversity of approaches at Member State level that could take advantage of particular data sources available in different jurisdictions.
Session 2: Developing common indicators and methodologies to determine the prevalence of female genital mutilation and the number of women and girls at risk

Introduction:
On foot of exploring a shared definition of prevalence, it was important to identify indicators that would allow a calculation of prevalence. The next step was to discuss data sources that would enable these indicators to be populated and that would offer comparability among Member States.

The aim of this second session was to share knowledge among experts and to discuss data sources and indicators to measure the prevalence and incidence of FGM.

Guiding questions:
- What are the indicators that allow a calculation of the prevalence of FGM?
- What sources for data collection could allow comparability among Member States?
- What is the most effective methodology for data collection?
- How effective are the methodologies to determine the prevalence of FGM?
- What are examples of good national practices and methodologies?

Main Conclusions:
Health services could serve as key data sources in relation to FGM. Services in relation to other forms of violence against women and girls could also serve as data sources. However, it is important to support effective data collection with training and guidelines. Particular attention is required to gathering data on girls and FGM.

In-depth multi-disciplinary work could usefully be stimulated and supported to further develop indicators in relation to FGM. Particular attention is required to developing at-risk-of FGM indicators. A variety of indicators would enable cross-checking and corroboration of FGM estimates or extrapolation figures.
Session 1: The need for a common definition of prevalence of female genital mutilation

Starting Points
Three different types of starting points from which to explore ways of defining the prevalence of FGM were identified. The first type involved definitions set out for discussion at the start of the session. These were related to work in the field of health and to the recent EIGE study on FGM.

“We propose the following definitions as applied to health statistics: prevalence refers to the number of cases of a given phenomenon existing at a certain time expressed as the proportion of a population affected at any time in a year and incidence is the number of new cases of a given phenomenon arising in a given period in a specified population.” Jurgita Peciuriene

“Within the framework of the EIGE study we proposed to define prevalence 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 and originating from countries where FGM is practiced.” Catarina Arnaut

The second type of starting point from which to explore a definition of prevalence of FGM that emerged was the issue of uncertainty. Difficulties in measuring the prevalence of FGM, and doing so in a comparative manner, introduce some doubts in relation to the figures being presented. This needs some up-front acknowledgement.

“The question isn’t how we define the ‘prevalence of FGM’ but rather how we should call the numbers we are able to publish: estimated prevalence? Possible acceptance? Lowest likely amount of protectable girls and women who need our support?” Katharina Kunze

“There is a need to be clear that existing figures can only be estimates.” Elise Petitpas

A final type of starting point for this work of defining the prevalence of FGM was the importance of having data, even imperfect data on prevalence. Measurements of prevalence are a vital stimulus for action on the issue of FGM and an important evidence basis from which to design and assess interventions.

“In Ireland we have utilised the numbers estimated to progress legislation, support prevention work and develop services. It was imperative to have some national data to get traction on the issue of FGM.” Siobán O’Brien Green

Approaches
Specific approaches to defining and measuring prevalence in both Ireland and Germany were described. These reflected the extrapolation-of-African-prevalence-data-method.

“We can access statistics about how many women from foreign countries live in Germany at the moment (‘illegal’ residents and those with newly gained citizenship status are excluded). We take those numbers and calculate prevalence by the percentage of FGM prevalence in the different countries.” Katharina Kunze

“In Ireland we used a very simple model developed in the UK by FORWARD(…) The definition we used was (…) Total number of women from FGM practising countries aged 15-44 and resident in Ireland (who completed the census).” Siobán O’Brien Green

There are difficulties with this approach. The Irish experience reflected many of these.

“This statistical extrapolation-of-African-data-method has many limitations (…) not everybody may complete the census and additional factors such as ethnicity may not be available for analysis. Also census data may not respond fast enough to new population shifts.” Siobán O’Brien Green
A broader challenge was identified in relation to the calculation and presentation of the prevalence of FGM. This was the challenge to ensure that the evidence gathered actually serves to stimulate action on the issue. There are dangers that the data can be presented in forms that actually undermine a real assessment of the seriousness of the issue.

“The publication of estimated prevalence of FGM with regard to the entire female population of a country and of a continent is an issue of concern. The percentages are so low in the EU that it will not be comparable with DHS survey in the country of origin and can be counter-productive to adequate decision-making in line with international obligations.” Elise Petitpas.

Finally, a broader approach to establishing the prevalence of FGM was suggested that would encompass a range of different factors. This presentation of prevalence would deepen the understanding of FGM and provide a more expansive evidence base to inform policy and programmes to address FGM.

“Some experts working with END FGM Campaign have identified three elements to the development of European-wide research on FGM prevalence […] We need information […] on the risk of being mutilated and the prevalence rate in countries of origin […] on the number of affected migrant women living in Europe and who they are (e.g. geographical location, ethnicity) […] and on second and third generation women and girls who were born in Europe from parents originating from countries with high prevalence.” Elise Petitpas.

“We would like to be able to include answers to questions about the communities in Germany like: How many families support the continuation of FGM? How many men won’t marry an uncut woman? How has the prevalence of FGM changed among the communities? Which factors contribute to a cultural change? Which factors contribute to a continuation?” Katharina Kunze

Issues

The overarching issue in relation to defining and measuring the prevalence of FGM is the lack of work that has been done on this issue in many Member States and in the lack of comparability between the approaches taken in the different Member States.

“Measuring the prevalence of FGM poses many challenges. Only a few countries in the EU have made efforts to estimate the prevalence of the phenomenon and all of them have used different methodologies.” Catrina Arnaut

Deficits in knowledge about, and data on, migrant communities lie at the heart of the difficulties in assessing the prevalence of FGM. There are also issues to be addressed in much of the data that is personally sensitive and, in the current context for migrant communities, particularly sensitive for whole communities.

“There is little knowledge available on the health, wellbeing and use and need of health services of migrants in Finland […] Therefore the Migrant Health and Wellbeing Study (Maamu study) was carried out in 2010-2102 […] The target groups of the study were Russian, Somali and Kurdish origin adults in Finland […] The study included questions on FGM […] 70% of Somali women and 32% of Kurdish women who answered the questions had been circumcised.” Seija Parekh

“The question how to define ‘prevalence of FGM’ is difficult because we usually don’t start with the academic concept but with the data that is available. And that’s very little […] Data is only available for the African and some Arabic countries. When it comes to FGM in Asia and within Asian communities in Germany we are completely in the dark.” Katharina Kunze

“Collecting data on the prevalence of FGM within EU Member States is a difficult and highly sensitive task as it concerns a practice which is unlawful, taboo, and affects mostly migrant women.” Elise Petitpas

“Caution should be exerted in presenting data given the current populist and anti-migrant discourse in political spheres. Data could be (mis)used to stigmatise entire communities or to justify cutting resources put towards the prevention programmes, protection measures or service provision for women and girls having undergone FGM.” Elise Petitpas

However, it was emphasised that these issues were difficulties to be overcome and managed, rather than being impediments to measurement and providing data. This is important in a context where evidence based data is needed to stimulate and inform effective action on FGM.

“Just because something is hard to measure, is illegal or is associated with particular sections of society does not mean we cannot attempt to measure it. We do this all the time with sensitive issues such as substance misuse, drug use, HIV prevalence, child assault etc. But we must be careful how the data is presented and used and what change it can influence.” Siobán O’Brien Green
Proposals

Future developments in promoting a shared definition of the prevalence of FGM and a commitment to measuring this prevalence should be driven by international obligations that Member States have in relation to combating FGM.

"EU Member States have to be reminded that they have signed up to Treaties placing positive obligations on them towards ending the practice. These include an obligation to provide data on the phenomenon of FGM and on their action to meet their international obligations. This was reiterated in the UNGA Resolution on intensifying global efforts for the elimination of FGM." Elise Petitpas

More in-depth research is required to establish a shared and workable definition of the prevalence of FGM and methodology for establishing the prevalence. This research could be multi-disciplinary. This definition and methodology could also benefit from experience in other fields, including the field of other forms of violence against women.

"The adoption of a common definition and methodology that can generate comparable and reliable data for all EU Member States, should be subject of a thorough study. We need input from statisticians, demographers, FGM experts etc. to be able to come up with such a definition, indicators and methodologies." Prof. Dr. Els Leye

"Can I suggest GIS (geographic information systems) experts as this is being used more and more in terms of health data collection and analysis." Siobán O’Brien Green

"Given the specificity of the question, an in-depth and technical discussion is necessary to develop a solid European approach and an innovative methodology." Elise Petitpas

Finally, a distinction was suggested between what was needed and possible at EU level and what was needed and possible at Member State level. A broader and more general approach at EU level could be combined with a diversity of approaches at Member State level that could take advantage of particular data sources available in different jurisdictions.

"I like the idea of an overall broader definition which can be used. Then there can be ‘enhanced prevalence definitions’ where specific data sets are used to gather FGM figures. These would be dependant on what data is available in each country. Guidelines could be available for how these enhanced definitions could be applied and these could verify other statistical extrapolations or prevalence studies." Siobán O’Brien Green

"The EU could adopt a common and broad definition of prevalence of FGM and stipulate basic indicators that would allow estimating of the phenomenon EU-wide. It is important to know which data is available in all Member States so that the prevalence of FGM can be estimated." Catarina Arnaut

Session 2: Developing common indicators and methodologies to determine the prevalence of female genital mutilation and the number of women and girls at risk

Data sources

The health services were identified as a key data source in the discussion. Support services in the field of violence against women were also seen as further possible sources.

"There are routes to gather accurate prevalence data through health related sources: cervical screening, maternal health care records, maternal death inquiries etc." Siobán O’Brien Green

"Support services, such as counseling, and sexual violence services could also collect data on clients they are working with where FGM is an issue. Irish sexual assault guidelines for professionals, including the police, include a section on FGM." Siobán O’Brien Green

It was emphasised that data collection from such sources required support and, in particular, training for the people involved in gathering the data, if it was to be sensitive and accurate.

"However without training and supports for staff in relation to this data gathering, it is hard to ensure that data is collected and collated with respect to confidentiality and accuracy." Siobán O’Brien Green

"Registering cases by health professionals is feasible provided they have a code they can use, they know what to register and they receive proper training." Prof. Dr. Els Leye
Female Genital Mutilation. Report from online discussion.

An EU wide data source with some potential to contribute to this field of measuring prevalence of FGM was also identified.

“To add to the discussion on sources for data collection on prevalence that would allow for comparability, experts have suggested to consider the EUROPERISTAT project which monitors and evaluates maternal and child health in the perinatal period – pregnancy, childbirth and the postpartum – in Europe using valid and reliable indicators.” Elise Petitpas

A particular data gap was also identified in relation to children and FGM.

“Data in relation to child protection interventions and reported cases of FGM also needs to be collated as there is a big gap in terms of information on children and FGM in the EU!” Siobán O’Brien Green

In Belgium and Portugal, systems of data collection on FGM were provided within the health services to support staff to gather necessary data.

“In Belgium, admissions to hospitals and day hospitalizations must be registered. The data that doctors are filling in a patient’s file are coded according to the ID-9-CM classification system. The coding for FGM includes: 629.2x, which has subdivisions for the four types of FGM: 629.21, 629.22, 629.23, and 629.29, and a specific code for FGM as a risk factor during delivery: 648.9.” Prof. Dr. Els Leye

“The Portuguese General-Directorate of Health was organizing a registration system for FGM in hospitals and primary care units.” Catarina Arnaut

Indicators

It was suggested that significant multi-disciplinary work and thought was required if adequate indicators on FGM were to be designed and effectively applied.

“Any questions related to indicators to calculate the prevalence of FGM can only be answered after an in-depth discussion with experts in demography and statistics and professionals who have experience in working on internationally comparable data collection […] and relevant EU and UN agencies.” Elise Petitpas

The specificity and importance of at-risk FGM indicators was raised. These indicators require particular attention.

“The obvious indicators are asking the woman or girl has undergone FGM, usually in a medical context, and possibly documenting this through medical examination […] the at-risk indicators are harder to outline. The Youth Health Care in the Netherlands (JGZ) has a very good list of risk indicators for girls. This is outlined in the Pharos 2013 FGM prevalence study.” Siobán O’Brien Green

The need for a diversity of indicators in relation to FGM was suggested as a means of verifying accuracy.

“We need a variety of indicators that can be used depending on what is available at a national level so that this data could “boost” or corroborate the statistical extrapolation figures. It could act as a cross-checking function for national FGM figure estimates or extrapolations.” Siobán O’Brien Green
Conclusions

The focus for this online discussion was the issues of definition and measurement of prevalence of female genital mutilation (FGM).

A number of general and specific definitions of prevalence were reported to be in use. However, it was made clear that further work is required to develop an adequate definition of prevalence. In particular, it can be concluded from the discussions that:

- A multi-disciplinary expertise could usefully be brought to bear on this issue of defining the prevalence.
- The definition of prevalence could be developed and applied that encompass both the occurrence of FGM as well as the risk of FGM.
- A perspective on the prevalence could be developed so that it can identify second and third generation women and girls whose parents originated from countries where FGM is practiced and establish their experience.
- Any definition must be fit for purpose and should ensure that it enables the actual significance and seriousness of the issue to be captured and stimulates appropriate and adequate action on the issue.

Measurement of prevalence is still lacking in many Member States. This limits the potential for effective and adequate action on the issue. Where prevalence is measured there are still issues to ensure comparability between Member States. This diminishes the possibilities for peer exchange and learning and effective action at the EU level. It can be concluded from the discussions that:

- An in-depth multi-disciplinary initiative could usefully be taken to develop adequate indicators to measure the prevalence of FGM. This could include statisticians, demographers, experts in geographic information systems and expert on FGM.
- A variety of indicators could usefully be developed to allow for cross-checking and corroboration of FGM estimates or extrapolation figures.
- A broad and shared approach could be developed across the EU in measuring FGM and this could be combined with more detailed and specific measurements within particular Member States to avail of particular data sources available in each jurisdiction.
- Data gaps on FGM and on migrant communities need to be addressed. Data gaps in relation to girls require particular attention.
- Health services and services in relation to violence against women could usefully be mobilised to provide necessary data in relation to the prevalence of FGM.
- Training, guidelines and data systems need to be made available within health services and other services to support data collection on FGM.
- The sensitivity, both for individuals affected or at risk and for communities within which FGM is an issue, in relation to data collection on this issue needs to be taken into consideration and appropriate steps taken in terms of collecting and communicating the data.
Annex I - Resources on Female Genital Mutilation

List of resources made available on the EuroGender platform during the discussion

Written Materials


Additional references provided by the participants

3. The new Irish Maternity Healthcare Record that includes a section on FGM is available at: http://www.hse.ie/portal/eng/about/Who/qualityandpatientsafety/safepatientcare/healthrecordsmgmt/
Annex II - Transcript of the online discussion on Female Genital Mutilation

Link to the online discussion transcript:

## Annex III - List of participants

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About EIGE

The European Institute for Gender Equality (EIGE) acts as a knowledge centre on gender equality with the aim supporting the EU and its Member States in their efforts to promote gender equality, to fight discrimination based on sex and to raise awareness about gender equality issues.

The European Network on Gender Equality (EuroGender) was established following on from EIGE’s mission to become the European knowledge centre on gender equality issues by making key data, knowledge and expertise available to relevant stakeholders and partners.

The vision for EuroGender is to be a secure environment for specialists from a variety of gender equality areas, enabling them to share knowledge, best practices and resources. It has been developed for the discussion and publication of documents, but also to enable authorised users to work online together thanks to a series of collaborative tools.

Acknowledgements

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