Female Genital Mutilation


**Starts at:** 29/10/2013, 10:00 CET (+01:00)
**Ends at:** 10/11/2013, 10:00 CET (+01:00)

The number of girls and women around the world who have suffered genital mutilations ranges between 100 and 140 million (WHO 2012). FGM is mostly carried out on young girls between infancy and the age of 15. At a European level, FGM is recognised as a violation of the rights of girls and women, and is a 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.

There is no reliable and comparable data on the prevalence of FGM at EU level. In all EU MS, legal provisions dealing with body injury, mutilation and removal of organs or body tissue, are applicable to the practice of FGM and may be used for criminal prosecution. In addition, in some countries, a principle of extra-territoriality renders it possible to prosecute the practice even when it is committed outside of the country’s borders.

In 2013 EIGE published the report “Female Genital Mutilation in the European Union and Croatia”. The report identified a lack of a common definition of “prevalence of FGM”, lack of comparable data which is caused by different methodologies, definitions and approaches used, as well as a wide variation in the use of information sources to collect data and to estimate the extent of FGM at national or regional level.

The online discussion on Female genital mutilation aims at gathering policy makers, academics and activists to debate and share knowledge. The objective is to obtain views on developing a common EU-wide definition on prevalence of Female Genital Mutilation, and obtain suggestions for the definition and how to develop this, as well as to develop common indicators and methodologies to determine this prevalence.

The online discussion will start at 10 am CET on Tuesday, 29 October. There will be 2 moderated sessions on Tuesday. The discussion space will remain open till 10 November. Till this date you will be able to post your reflections that will be later included in the report from this online event.

**Facilitators:** Katarzyna Pabijanek, barbara leda kenny

1. **barbara leda kenny** | 29/10/2013, 11:01 EET (+02:00)
   
   Welcome to the Female genital mutilation(FGM) discussion.

   My name is Barbara Leda Kenny and I am very honoured to moderate this debate. I hope today represents an opportunity to contribute to the progress in the fight against FGM in the European Union!
Our discussion is organized in two sessions. The now opened session, ‘Discussing a need for a common definition of prevalence of Female genital mutilation’, will last until 12.30pm. The second session will deal with ‘Developing common indicators and methodologies to determine the Female genital mutilation prevalence and the number of women and girls at risk’ and will last from 14.30pm until 17.00pm.

Please feel free to join whenever you can and want, even during the break. You can contribute to the debate in many different forms: reading, writing a post, posing questions, sharing a document or a video, recommending a website and so on.

Please introduce yourself when you join, and let us know your specific interest in the topic, if appropriate. I hope that you have been able to register and log in to the platform successfully, but if you encounter any problems, please don’t hesitate to contact the EuroGender Administrator at Katarzyna.pabijanek@eige.europa.eu

2. **barbara leda kenny** | 29/10/2013, 11:04 EET (+02:00)

"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 contrast FGM at a European level, we need prevention policies. In order to advocate for policies we need to know the size 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 is to share knowledge among experts, and to have a fruitful discussion to work towards the achievement of a common definition of prevalence of FGM. You are kindly invited to share the definition you believe to be the most reliable. It will be extremely interesting to know your concerns on the pros and cons that can arise from the use of a particular definition. The floor is open!

3. **Jurgita Peciuriene** | 29/10/2013, 11:04 EET (+02:00)

Good morning from sunny Vilnius!

I am gender expert at EIGE. I was the project manager for the study on FGM, which started end 2011. The report, country fact-sheets and publication on good practices, as well as databases, are available at [http://eige.europa.eu/content/female-genital-mutilation](http://eige.europa.eu/content/female-genital-mutilation)

I would like to welcome you all to the online discussion and hope we will have a fruitful debate!
4. *barbara leda kenny* | 29/10/2013, 11:15 EET (+02:00)

Here is our first question for the debate.

There are different definitions of prevalence of FGM. We would like to know which one you use and why you consider it the most reliable.

Feel free to share your view on this!

5. *Megin Reijnders* | 29/10/2013, 11:18 EET (+02:00)

Good morning everyone,

I am Megin and I will be joining today’s discussion from EIGE’s side, as a trainee for the gender-based violence team.

**Comments:**

- *barbara leda kenny* | 29/10/2013, 11:19 EET (+02:00)
  
  Welcome Megin! We look forward to your input.

6. *Jurgita Peciuriene* | 29/10/2013, 11:23 EET (+02:00)

As for the starting point of the discussion we propose the following definitions applied for Health statistics[1]:

**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.[2]

**Incidence** is the number of new cases of a given phenomenon arising in a given period in a specified population.[3]

Any comments regarding pros and cons are more than welcome.


Comments:

- barbara leda kenny  | 29/10/2013, 11:27 EET (+02:00)  
  Thank you Jurgita. These are helpful definitions to start contextualising the discussion.

7. Zulema  | 29/10/2013, 11:31 EET (+02:00)

Good morning from Vilnius!

This is Zulema, Seconded National Expert in EIGE, working in the Gender Based Violence team. I will also join this debate from EIGE's side, hoping we will have a very interesting and fruitful debate on FGM today.

Comments:

- barbara leda kenny  | 29/10/2013, 11:33 EET (+02:00)  
  Welcome Zulema! Thank you for taking part in the online discussion.

8. barbara leda kenny  | 29/10/2013, 11:35 EET (+02:00)

Everyone is welcome to contribute with their opinions and thoughts on the issue.

If you are online, please feel free to introduce yourself and tell us why you are interested in this topic.

9. National Institute of Health and Welfare  | 29/10/2013, 11:53 EET (+02:00)

barbara leda kenny wrote:

Everyone is welcome to contribute with their opinions and thoughts on the issue.

If you are online, please feel free to introduce yourself and tell us why you are interested in this topic.
Good morning from Helsinki!

My name is Seija and I work as a Specialist connected with the prevention of female circumcision in National Institute of Health and Welfare in Finland.

Our first national Action Plan for the Prevention of Circumcision of Girls and Women was published in August 2012. The purpose of the Action Plan is to create permanent structures to prevent FGM in Finland, and to improve the welfare and quality of life of circumcised girls and women.

I'm looking forward to an interesting discussion.

Comments:

- barbara leda kenny | 29/10/2013, 11:56 EET (+02:00)
  Welcome to the discussion Seija! Would you like to tell us more about the Action Plan that you worked on? Did you do an estimation of the prevalence of FGM in Finland? What kind of methodology did you use?

10. Catarina Arnaut (Yellow Window) | 29/10/2013, 11:54 EET (+02:00)

Good morning from sunny Portugal!

I am Catarina Arnaut and I was part of the core team of EIGE’s study on FGM.

According to what we have learnt from this study, measuring the prevalence of FGM poses many challenges. In addition, 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.

Based on the discussions of an expert meeting organised within the framework of this study, we proposed to define prevalence as follows:

“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” (EIGE’s report on FGM).

What are your views?

Comments:

- barbara leda kenny | 29/10/2013, 12:00 EET (+02:00)
  Thank you for joining the discussion Catarina and for proposing this definition of prevalence. We look forward to receiving more comments on this definition.
11. **Siobán O'Brien Green** | 29/10/2013, 12:06 EET (+02:00)

Hello from sunny Dublin,

I’m Sioban and I was involved in the 3 FGM prevalence statistical extrapolation estimates undertaken in Ireland since 2008. I was also part of the EIGE FGM study researching Ireland and later as the core team.

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.

The latest Irish FGM data is published here;


However the lack of a common definition is problematic in Europe.

**Comments:**

- **barbara leda kenny** | 29/10/2013, 12:09 EET (+02:00)
  
  Thank you for your contribution Sioban. Could you give us more details on the definition of prevalence that you used in your studies in Ireland? We are glad to hear that you were able to use the data for legislation and prevention policies.

12. **Prof. Dr. Els Leye** | 29/10/2013, 12:07 EET (+02:00)

Hi, I'm Els Leye and I was one of the coordinators of EIGE's study on FGM. As Catarina said, we suggested the definition she mentions in her comment. However, I believe 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 methodology.

**Comments:**

- **barbara leda kenny** | 29/10/2013, 12:12 EET (+02:00)

  Thank you for your input, Els. You make an interesting point - do you know of any instances of a common definition and methodology that were devised through the joint work of statisticians, demographers and other experts?
Welcome Seija, Catarina, Sioban and Els! Great to see you here

Dear Sioban,

What would you suggest to include into the definition of prevalence? What do you think about the definition developed within the framework of the study?

http://eige.europa.eu/content/female-genital-mutilation

At this address, you can find all resources from EIGE on female genital mutilation.

In June 2012, the European Parliament adopted the Resolution on ending female genital mutilation. EIGE launched a “Study to map the current situation and trends of female genital mutilation in 27 EU Member States (MS) and Croatia” on the request of EU Commissioner Viviane Reding. The results of the project are the report, collections of resources, methods and tools and good practices and country fact sheets. It supports policy makers in their efforts to follow the law obligation in this area.

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What are your views?

The National Institute for Health and Welfare (THL) produces information on the health and wellbeing of the Finnish population through comprehensive population studies. There is however little knowledge available on the health, wellbeing and use and need of health services of migrants in Finland.

Therefore Migrant Health and Wellbeing Study (Maamu study) was carried out in 2010-2012 to produce comprehensive information on the current health status of migrants in Finland and the factors influencing it. The target groups of the study were Russian, Somali and Kurdish origin adults in Finland.

The study included questions of female circumcision as well. According to the study 70% of the Somali women and 32% of the Kurdish women, who answered the questions, had been circumcised.

Here is the link to the Maamu study:


17. barbara leda kenny | 29/10/2013, 12:27 EET (+02:00)

In this session of the online discussion, we have received contributions from Finland, Portugal and Ireland.

It was mentioned that a common European definition of prevalence of FGM is needed: what are the fundamental issues that should be taken into account to provide it? How can we foster the development of this common definition of prevalence?

18. Siobán O’Brien Green | 29/10/2013, 12:32 EET (+02:00)

Hi Jurgita,

I think that this definition is a very good starting point and can be utilised in many countries, as I’ve mentioned previously I like the idea of an overall broader definition
(such as this) which can be used then there can be “enhanced prevalence definitions” where specific data sets are used to gather FGM figures but 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.

I hope that makes sense.

19. Christina Andersson | 29/10/2013, 12:33 EET (+02:00)

Good morning from Belgium

Comments:

   o barbara leda kenny | 29/10/2013, 12:34 EET (+02:00)
     Good morning Christina and welcome to the discussion. Would you like to tell us more about your interest in this topic?

20. Siobán O’Brien Green | 29/10/2013, 12:37 EET (+02:00)

Hi Barbara,

In Ireland we used a very simple model developed in the UK by FORWARD and we applied it to Irish census data. The definition we used in our tables was:

"Total number of women from FGM practicing countries aged 15-44 and resident in Ireland (who completed the census)". However, this statistical extrapolation of African data method is not prefect and has many limitations. But we were able to access the census data on a country by country level and with the age ranges we needed.

Comments:

   o barbara leda kenny | 29/10/2013, 12:40 EET (+02:00)
     Thank your for your reply. Can you describe the limitations of this approach in more detail? How do you think it could be improved?

21. Catarina Arnaut (Yellow Window) | 29/10/2013, 12:40 EET (+02:00)

I agree with what was said by Els and Sioban. The EC could adopt a common and broad definition of prevalence of FGM and stipulate basic indicators that would allow
estimating the phenomenon EU-wide. It is important to know which basic data is available in all MS so that the prevalence of FGM can be estimated. Having access to this info will allow designing better and targeted policies to combat FGM according to the particularities of each country.

22. Elise Petitpas | 29/10/2013, 12:40 EET (+02:00)

Hi

I'm Elise and work for the END FGM European Campaign of Amnesty International (www.endfgm.eu).

I would like to thank the EIGE for organising this online discussion and hope it will provide the agency with ideas on developing further action on the collection of data on prevalence of FGM in Europe.

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. However, EU member states have to be reminded that they have signed up to treaties placing positive obligations on them to work 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 call was reiterated in the UNGA Resolution on intensifying global efforts for the elimination of FGM (para 13 & 23).

As mentioned by Els, our campaign believes that any discussions on FGM prevalence in Europe should be conducted with the involvement of experts in demography, statistics and FGM. It would be useful for EIGE to organize a workshop with national statistics agencies and relevant professionals and EU and UN agencies which have developed expertise on the issue. Given the specificity of the question, we believe an in-depth and technical discussion is necessary to develop a solid European approach and an innovative methodology.

Comments:

- barbara leda kenny | 29/10/2013, 12:48 EET (+02:00)
  Thank you Elise for joining the discussion and for making very interesting points. Do you have any comments on the definition of prevalence you want to share?

23. Christina Andersson | 29/10/2013, 12:41 EET (+02:00)

Thank you Barbara leda kenny
I just want to follow this discussion because this is a very very important topic
24. Zulema | 29/10/2013, 12:43 EET (+02:00)

Hi,

And in the study from the National Institute for Health and Welfare (THL). What is the definition of FGM prevalence that you have used?

25. Prof. Dr. Els Leye | 29/10/2013, 12:45 EET (+02:00)

Hi,

I have no knowledge at hand of a prevalence definition and method that was developed through multidisciplinary work, but there might be examples to be found in the area of violence against women.

26. Elise Petitpas | 29/10/2013, 12:48 EET (+02:00)

Some experts working with the END FGM Campaign have identified 3 elements key to the development of a European-wide research on FGM prevalence:

1) We need to know about the **risk of being mutilated and the prevalence rate in countries of origin**. This information is available for Africa and some countries in the middle-east through the MICS (UNICEF) and DHS studies. But prevalence studies for countries in Asia such as Indonesia or India or for countries in Latin America such as Peru or Colombia are still lacking (see Statement by the UN Inter-agency Statement on FGM referring to anecdotal evidence).

2) We need to know the **number affected migrant women** living in Europe and who they are (e.g. geographical location, ethnicity). However, we acknowledge that this would entail for EU MS to develop a comparable data registration system as data registration systems differ from one country to another. In some EU MS women are registered according to the country of birth, in some others according to their nationality of origin. Data related to female asylum seekers and refugees should also be included.

3) We need information on **second and third-generation women and girls**, who were born in Europe from parents originating from countries with high prevalence.

27. Siobán O’Brien Green | 29/10/2013, 12:50 EET (+02:00)
The shortcomings of the extrapolation method using census data are many but mainly not everyone 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 or flows (this depend how often a census occurs) and these extrapolations need to be repeated at regular intervals (as we have done in Ireland) to keep track of changes. But I feel the risks of not having FGM data as a starting point for national work and policy and service development are greater than the methodological considerations outlined.

28. Megin Reijnders | 29/10/2013, 12:51 EET (+02:00)

Elise Petitpas wrote:

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3) We need information on **second and third-generation women and girls**, who were born in Europe from parents originating from countries with high prevalence.

Thank you for this Elise. When using methods such as these, how should the effect of migration and/or the reason for migration be accounted for (e.g. lower risk)?

29. Prof. Dr. Els Leye | 29/10/2013, 12:51 EET (+02:00)

For your information, I have set up a small team of experts (demographers, statisticians and FGM experts) from 3 countries to look into this FGM definition and methodology discussion, with whom I designed a study protocol to come up with a "common
methodology and definition" to produce comparable data. We are trying to find funds to implement the study.

30. Jurgita Peciuriene | 29/10/2013, 12:56 EET (+02:00)

Hello Elise and welcome! I was trying to reply to your post but my answer disappeared twice. I will better post as a separate message not as a reply:) To organise a workshop of experts is a very good idea, but not sure if EIGE could be organising such.

EIGE implements its Annual Work Programmes and unfortunately does not have resources for additional events. That is one of the reasons why Eurogender organisers quite a lot online discussions, because it is easy assessable for many experts and we can discuss many different issues. The discussion will remain open so that the experts and demographers who showed their interest but could not attend today could still provide inputs.

31. Terre des Femmes - Human rights for women | 29/10/2013, 12:56 EET (+02:00)

Hello Everyone,

My name is Katharina Kunze, I'm the section manager FGM at TERRE DES FEMMES in Germany.

Probably the question how to define "prevelance of FGM" is difficult because we usually don't start with the academic concept but with the data that is available. And thats very little.

In our case: We can access statistics about how many women from foreign countrys live in germany at the moment ("illegal" residents and those with a newly gained german citizenship are excluded). We take those numbers and calculate by the percentage of FGM prevalence in the different countries. So if there are 200 women from country X and every second woman in X is cut, we publish "100 women in Germany from X are at risk or survivors of FGM".

Furthermore we differentiate between "Survivors" and "girls at risk" by age. For this we need the average age of being cut in each country mentioned. The data is often contradictive.

And, of course, 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.
So all we can do is to publish very inaccurate number just to satisfy the media and to give an impression on the importance of our topic.

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?

etc - but it's hard to impossible to gain data for this.

So, in my opinion, the question isn't how we define "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?

Comments:

- **barbara leda kenny** | 29/10/2013, 13:12 EET (+02:00)
  Hi Katharina, thank you for your contribution to the discussion. The points you make are very interesting and practical, especially when you note that giving a definition of "prevalence" which is based on incomplete data might be misleading. However, other participants have pointed out that there is also a need for a common European approach in order to have a complete picture of the phenomenon, for which a common definition is needed.

32. **Jurgita Peciuriene** | 29/10/2013, 12:59 EET (+02:00)

* Megin Reijnders wrote:

* Elise Petitpas wrote:

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3) We need information on **second and third-generation women and girls**, who were born in Europe from parents originating from countries with high prevalence.

Thank you for this Elise.
When using methods such as these, how should the effect of migration and/or the reason for migration be accounted for (e.g. lower risk)?

Regarding the point 2) we are aware that Eurostat is not collecting information on ethnicity and does not intend to do it in coming years.

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33. **Jurgita Peciuriene** | 29/10/2013, 13:00 EET (+02:00)

Hello Katharina, welcome to the discussion

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34. **Siobán O’Brien Green** | 29/10/2013, 13:01 EET (+02:00)

Hi Els,

This seems like the best way to move forward we need to have input from statistician and demographers and can I suggest GIS (geographic information systems) experts as this is begin used more and more in terms of health data collation and analysis globally. I also feel we can learn from domestic violence data collection too
Terre des Femmes - Human rights for women wrote:

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etc - but it's hard to impossible to gain data for this.
So, in my opinion, the question isn't how we define "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?

"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 an continuation?"

These are very good questions I believe to ask in the field.

36. Jurgita Peciuriene | 29/10/2013, 13:13 EET (+02:00)

Terre des Femmes - Human rights for women wrote:

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So, in my opinion, the question isn't how we define "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?

Dear Kataharina, you raised very important questions about the interpretation of data and how we call available data. What others think about the issues raised by you?

37. barbara leda kenny | 29/10/2013, 13:21 EET (+02:00)

The morning session of the online discussion is coming to an end.

This is a summary of some of the key points that have emerged in this session.

- the use of a "two-level" approach, consisting of a broad European definition and a national one based on the specific data available for each country.
- a multidisciplinary approach that includes contributions from statisticians, demographers, and experts in FGM.
- the use of GIS (geographic information systems) was also suggested as a way to obtain a more complete picture of the phenomenon.
- more generally, it was proposed to adopt a wider approach that takes into account also the cultural and social context of FGM and is not limited to data collection.
Please feel free to integrate further comments to this summary.

38. Jurgita Peciuriene | 29/10/2013, 13:25 EET (+02:00)

Prof. Dr. Els Leye wrote:

For your information, I have set up a small team of experts (demographers, statisticians and FGM experts) from 3 countries to look into this FGM definition and methodology discussion, with whom I designed a study protocol to come up with a "common methodology and definition" to produce comparable data. We are trying to find funds to implement the study.

This is great, Els. The funding is always an issue.

39. Siobán O’Brien Green | 29/10/2013, 13:26 EET (+02:00)

Thanks Katharina,

For some good questions and ideas. If the limitations of any form of data collection and extrapolations or estimates are clear and outlined in any publications or press releases I believe that there is no misleading of the public or media. Just because something is hard to measure, is illegal or is associated with a 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, used and what change it can influence.

40. National Institute of Health and Welfare | 29/10/2013, 13:26 EET (+02:00)

Zulema wrote:

Hi,

And in the study from the National Institute for Health and Welfare (THL). What is the definition of FGM prevalence that you have used?

Hello Zulema,

It's the number of the circumcised Somali or Kurdish women aged 18-64 per all studied Somali and Kurdish women aged 18-64.
Half of the Somali women aged 18-29 years old reported to have been circumcised.

Detailed analysis of the data will be done later. Now we have only the basic results.

41. Prof. Dr. Els Leye | 29/10/2013, 13:27 EET (+02:00)
   o I'm not sure if I understand what is meant with "more generally, it was proposed to adopt a wider approach that takes into account also the cultural and social context of FGM and is not limited to data collection". what methodology will be used to take "cultural and social context" into account, and more importantly, what is meant with this?

Comments:
   o barbara leda kenny | 29/10/2013, 13:38 EET (+02:00)
     That point referred to the comments made by Katharina from Terre des Femmes.

42. Elise Petitpas | 29/10/2013, 13:27 EET (+02:00)

Megin Reijnders wrote:

Elise Petitpas wrote:

Some experts working with the END FGM Campaign have identified 3 elements key to the development of a European-wide research on FGM prevalence:

1) We need to know about the risk of being mutilated and the prevalence rate in countries of origin. This information is available for Africa and some countries in the middle-east through the MICS (UNICEF) and DHS studies. But prevalence studies for countries in Asia such as Indonesia or India or for countries in Latin America such as Peru or Colombia are still lacking (see Statement by the UN Inter-agency Statement on FGM referring to anecdotal evidence).

2) We need to know the number affected migrant women living in Europe and who they are (e.g. geographical location, ethnicity). However, we acknowledge that this would entail for EU MS to develop a comparable data registration system as data registration systems differ from one country to another. In some EU MS women are registered according to the country of birth, in some others according to their nationality of origin. Data related to female asylum seekers and refugees should also be included.
3) We need information on second and third-generation women and girls, who were born in Europe from parents originating from countries with high prevalence.

Thank you for this Elise. When using methods such as these, how should the effect of migration and/or the reason for migration be accounted for (e.g. lower risk)?

Dear Megin,

Thanks for your comment. I would say it would be for experts on the collection of qualitative data to answer.

43. *barbara leda kenny* | 29/10/2013, 13:28 EET (+02:00)

Thank you everyone for participating and contributing to the discussion.

Participants can still contribute to the discussion with their comments during the break.

Moderated discussion will resume with the afternoon session, which will begin at 14.30 CET and is titled "Developing common indicators and methodologies to determine the Female genital mutilation prevalence and the number of women and girls at risk".

Thanks again for your participation. We look forward to your contributions in the afternoon session.

44. *Elise Petitpas* | 29/10/2013, 13:33 EET (+02:00)

I would like to make further comments on issues to take into account for any work on prevalence studies at European level.

When disseminating information on FGM prevalence, we believe there is a need to be clear that existing figures can only be estimates.

Also, we would recommend using EU estimate number on FGM prevalence linked to geographical location rather than percentages of the overall population (as used in DHS survey for instance).

The publication of percentages of estimated prevalence of FGM with regard 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.

With the economic crisis and the lack of funds, states are reducing expenses in particular in the field of health and they might invoke this small percentage to justify withdrawing funds for specialized clinics (several clinics have had to close down in the UK) or for the NGOs—which are the main actors when it comes to prevention measures.

Therefore, caution should be exerted in presenting data given the current populist and anti-migrant discourse in political spheres. Data could be (mis)used either to stigmatize entire communities or to justify cutting resources put towards the prevention programs, protection measures or service provision for women and girls having undergone FGM. Guidelines making reference to states’ international obligations should accompany the release of data related to the prevalence of FGM in the EU.

Finally, let's recall that prevalence studies should be accompanied with incidence study. In particular, there is a need to evaluate the risk of FGM for second and third-generation women and girls originating from countries with high prevalence.

Comments:

- Barbara leda kenny | 29/10/2013, 13:42 EET (+02:00)
  Thank you Elise, you raise some very interesting points on how data collection methods should be conceived with future advocacy in mind.

45. Barbara leda kenny | 29/10/2013, 15:27 EET (+02:00)

Welcome back to today's online discussion. The afternoon session begins now and focuses on "Developing common indicators and methodologies to determine the FGM prevalence and the number of women and girls at risk".

After discussing the importance of finding a reliable definition of prevalence of FGM, we will now try to answer the following questions: what are the indicators that allow calculating the prevalence of FGM? What sources for data collection could allow comparability among Member States?

Comments:

- Barbara leda kenny | 29/10/2013, 15:32 EET (+02:00)
  If you are online, please feel free to contribute to this topic. Also, briefly introduce yourself if you haven't already!
National Institute of Health and Welfare wrote:

[quote=barbara leda kenny]

Everyone is welcome to contribute with their opinions and thoughts on the issue.

If you are online, please feel free to introduce yourself and tell us why you are interested in this topic.

Good morning from Helsinki!

My name is Seija and I work as a Specialist connected with the prevention of female circumcision in National Institute of Health and Welfare in Finland.

Our first national Action Plan for the Prevention of Circumcision of Girls and Women was published in August 2012. The purpose of the Action Plan is to create permanent structures to prevent FGM in Finland, and to improve the welfare and quality of life of circumcised girls and women.

I'm looking forward to an interesting discussion.

Hello Barbara,

Here are answers to your questions.

The Action Plan has been prepared for the years 2012 to 2016, during which the prevention of female circumcision should become established practice in Finland. The aim is to preserve the existing expertise and the long-term development of the preventive work. The key measures include e.g. the securing of training (of professionals of different fields), influencing attitudes, production of material, promotion of research and distribution of information. The key target groups of the Action Plan are the decision-makers and professionals who meet in their work girls and women who have been circumcised or who are at risk of being circumcised.

There has been no actual study of the prevalence of FGM in Finland before the Maamu Study (Migrant Health and Wellbeing Study) that I mentioned earlier in the discussion here. The Maamu study is a survey. It consisted of an interview and a health examination, which were both conducted by bilingual field staff. We’ll collect new data from wider target group, and the data should be available in the end of 2014. This survey will also include questions of female circumcision. Before the Maamu Study, the estimates of the prevalence of FGM in Finland were based on the figures of prevalence of FGM in the countries of origin of immigrants.

Comments:
Hi Seija, thanks again for contributing to the discussion. What would you say are the main strengths and weaknesses of the methodology that was used for the Maamu study you described?

Hello again,

I think data sources are where we need to be flexible and work on what is available at a country level. I suggest that there are routes to gather accurate prevalence data through health related sources: cervical screening programmes, maternal health care records, maternal death inquiries etc. However, without training and supports for staff in relation to this data gathering it is hard to ensure the data is collected and collated with respect to confidentiality and accuracy.

Thank you Siobán, looks like health services are fundamental for data collection in every country. Then training the staff and establishing common guidelines for data collection could be a relevant step forward. What do you think?

Hello all,

This morning Els mentioned the need for the indicators. What kind of indicators you would find are necessary? On prevalence, services, policies, ...? What would be the priorities?

I agree with Sioban. Registering FGM cases by health professionals is feasible, provided they have a code they can use, they know what to register, and they receive proper training. We are currently evaluating the Belgian registration of FGM in hospitals, and it shows that if unless health professionals are urged to register it and are informed and followed up, registration is poorly done. It also does not take into account day to day consultations. In Belgium, admissions to hospitals and day hospitalisations 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 risk factor during delivery: 648.9.

Please note, there are no codes for ambulant care, only hospitalisations.

50. Megin Reijnders | 29/10/2013, 16:16 EET (+02:00)

Health services can provide very relevant data on FGM. What are other sources that you have come across where data on FGM can come from? And were these through direct indicators or through a combination of indicators (e.g. age, nationality etc.)?

51. Siobán O’Brien Green | 29/10/2013, 16:23 EET (+02:00)

Yes I think for indicators we need to using data that can be feasibly collected and collated. We already collect data for patient health care records and for Eurostat on health issues but 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.

Comments:

  o barbara leda kenny | 29/10/2013, 16:28 EET (+02:00)
    Do you have any suggestions of what these indicators could be? Which ones would you say could be more widely used for the estimation of FGM prevalence?

52. barbara leda kenny | 29/10/2013, 16:32 EET (+02:00)

Thank you for coming back to the discussion and welcome to those who are joining in now.

In this afternoon session, we are talking about indicators and methodology to estimate the prevalence of FGM. In particular, we have discussed how to collect data from health services and how this can be integrated with other methods of data collection.

53. Siobán O’Brien Green | 29/10/2013, 16:38 EET (+02:00)
Support services (such as counselling) and sexual violence services could also collate data on clients they are working with where FGM is an issue. Our Sexual Assault guidelines for professionals including the police in Ireland include a section on FGM.

Data in relation to child protection interventions and reported cases of FGM also needs to be collated as there is a big data gap in terms of information on children and FGM in the EU.

54. Siobán O’Brien Green | 29/10/2013, 16:48 EET (+02:00)

Really we are trying to ascertain if a woman or girl has undergone FGM or is at risk of FGM so the obvious indicators are asking her if she has undergone FGM (usually in a medical context) and possibly documenting this through medical examination (where appropriate and relevant to patient care for example in an ante-natal appointment or cervical smear taking setting).

I think that the “at risk” indicators are harder to outline but that the Youth Health Care in the Netherlands (JGZ) have a very good list of risk indicators for girls. This is outlined in the Pharos 2013 FGM prevalence study.

Comments:

- barbara leda kenny | 29/10/2013, 17:04 EET (+02:00)
  This is the study carried out by Pharos on FGM prevalence in the Netherlands mentioned by Siobán:

55. barbara leda kenny | 29/10/2013, 16:59 EET (+02:00)

Can you think of any good examples and good practices of data collection that you have encountered in your work or research?

Please rembember that in your posts you can include links to documents, articles, videos or other materials to further contribute to the discussion.

56. Siobán O’Brien Green | 29/10/2013, 17:04 EET (+02:00)

Here is the link to the new Irish National Maternity Healthcare Record. It was introduced in all maternity care settings in 2012 and one of its aims is; “ It will also assist in the
collection of standardised data in maternity hospitals/units and facilitate future research into maternal and fetal health.”

There is a section in the ante-natal section on FGM under risk factors.

It is too early to collate data from the forms yet but hopefully by next year we can look at FGM figures from it in Ireland.

http://www.hse.ie/portal/eng/about/Who/qualityandpatientsafety/safepatientcare/healthrecordsmgt/

57. Siobán O’Brien Green | 29/10/2013, 17:12 EET (+02:00)

Apologies I have to leave the discussion now, best of luck for more information sharing through this medium.

Sioban

Comments:

 o  barbara leda kenny | 29/10/2013, 17:13 EET (+02:00)
   Thank you for your participation and your helpful contributions!

58. Catarina Arnaut (Yellow Window) | 29/10/2013, 17:14 EET (+02:00)

I know that the Portuguese General-Directorate of Health was organising a registration system for FGM in hospitals and primary care units. It would be worth to enquire if there is already any assessment about the implementation of this registration system, so that other countries could learn from the experience from Belgium and Portugal in this respect.

Comments:

 o  barbara leda kenny | 29/10/2013, 17:16 EET (+02:00)
   Yes indeed! Do you know if there is any further documentation on how the registration system works?

59. Catarina Arnaut (Yellow Window) | 29/10/2013, 17:19 EET (+02:00)

@Barbara: No, but I can ask. To whom should I send the info?
Comments:

- **barbara leda kenny** | 29/10/2013, 17:23 EET (+02:00)
  I am sure it will enrich EIGEs team work on FGM. The discussion will be open until November the 10th and you could post it here, so that we can integrate it in the report, or you could also use Eurogender to link it or upload it.

60. **Jurgita Peciuriene** | 29/10/2013, 17:23 EET (+02:00)

  *Catarina Arnaut (Yellow Window) wrote:*

  @Barbara: No, but I can ask. To whom should I send the info?

  Please send it to [jurgita.peciuriene@eige.europa.eu](mailto:jurgita.peciuriene@eige.europa.eu)

61. **Catarina Arnaut (Yellow Window)** | 29/10/2013, 17:27 EET (+02:00)

  Page 29 and 30 of EIGE's report on FGM provide recommendations of the type of data that could be collated for a baseline prevalence estimate, and for an enhanced estimation. The enhanced estimation will depend on the information/data available in each country. These recommendations were the result of the expert meeting focussing on measuring FGM and also other inputs from the desk and in-depth researches of this study. In fact, as corroborated by several participants, it would be very relevant to put together different experts (including FGM, statistics and demography expertise) to define common indicators in the MS to produce data on the prevalence of this phenomenon. It would be relevant to have experts from different countries in order to assess which could be the common indicators. This could, indeed, take place in one of these online consultations.

62. **Elise Petitpas** | 29/10/2013, 17:27 EET (+02:00)

  *Prof. Dr. Els Leye wrote:*

  I agree with Sioban. Registering FGM cases by health professionals is feasible, provided they have a code they can use, they know what to register, and they receive proper training. We are currently evaluating the Belgian registration of FGM in hospitals, and it shows that if unless health professionals are urged to register it and are informed and followed up, registration is poorly done. It also does not take into account daily day to day consultations. In Belgium, admissions to hospitals and day hospitalisations 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 risk factor during delivery: 648.9.

Please note, there are no codes for ambulant care, only hospitalisations.

Adding on Els' contribution, it seems that FGM is part of ICD10 according to icd10data.com.

63. barbara leda kenny | 29/10/2013, 17:30 EET (+02:00)

For those of you are joining the online discussion now, we are are talking about good practices in data collection and collation on FGM prevalence.

Feel free to share your thoughts or further materials you might have on this issue with us.

64. Catarina Arnaut (Yellow Window) | 29/10/2013, 17:32 EET (+02:00)

One other thing: Portugal opened a call in April 2013 for conducting a prevalence study at national level. There were some problems in the assessment of the proposals and I'm not sure whether the study has already started. Maybe EIGE could contact the gender equality central structure to enquire which definition and indicators are being used for estimating the prevalence of the phenomenon in Portugal.

65. Christina Andersson | 29/10/2013, 17:33 EET (+02:00)

Thank you so much for letting me participate!

I must leave the discussion now but I will read your documents it was very interesting. Bye

Comments:

- barbara leda kenny | 29/10/2013, 17:35 EET (+02:00)
  Thank you Christina. Please keep in mind that the discussion space will stay open until the 10th of November.

66. Jurgita Peciuriene | 29/10/2013, 17:35 EET (+02:00)
Christina Andersson wrote:

Thank you so much for letting me participate!

I must leave the discussion now but I will read your documents it was very interesting. Bye

Thank you for your contribution!

67. Christina Andersson | 29/10/2013, 17:40 EET (+02:00)

Christina Andersson wrote:

Thank you so much for letting me participate!

I must leave the discussion now but I will read your documents it was very interesting. Bye

Thank you Barbara and Jurgita I will.

68. Jurgita Peciuriene | 29/10/2013, 17:43 EET (+02:00)

Catarina Arnaut (Yellow Window) wrote:

One other thing: Portugal opened a call in April 2013 for conducting a prevalence study at national level. There were some problems in the assessment of the proposals and I'm not sure whether the study has already started. Maybe EIGE could contact the gender equality central structure to enquire which definition and indicators are being used for estimating the prevalence of the phenomenon in Portugal.

Thank you Catarina, we will follow up on this.

69. Barbara Leda Kenny | 29/10/2013, 17:49 EET (+02:00)

We are into the last ten minutes of today's discussion. If you have any final remarks or comments, now is the time to share them!

70. Elise Petitpas | 29/10/2013, 17:50 EET (+02:00)
Again, we believe that 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 collections (such as experts involved in the ECHIM project for example) and relevant EU and UN agencies. It is hoped that the actions foreseen in the future European Commission communication on FGM will allow for such an in-depth discussion.

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.

71. Catarina Arnaut (Yellow Window) | 29/10/2013, 17:51 EET (+02:00)

Will the report of this online consultation be made available to the participants?

Thank you for inviting me and for the fruitful discussion!

Comments:

- barbara leda kenny | 29/10/2013, 17:56 EET (+02:00)
  The draft report will first be sent to participants for approval, then it will be published on the EIGE website. Thank you for taking part in the discussion!

72. barbara leda kenny | 29/10/2013, 17:55 EET (+02:00)

This is the end of today's online discussion. Thank you to everyone who participated and contributed. We hope you all found our conversation fruitful and stimulating.

Please remember that this discussion space will stay open until the 10th of November. You will still be able to post your comments or further reading material until then.

Thank you all again for your participation.

73. Jurgita Peciuriene | 29/10/2013, 17:57 EET (+02:00)

barbara leda kenny wrote:
This is the end of today's online discussion. Thank you to everyone who participated and contributed. We hope you all found our conversation fruitful and stimulating.

Please remember that this discussion space will stay open until the 10th of November. You will still be able to post your comments or further reading material until then.

Thank you all again for your participation.

Dear participants, dear Barbara,

Many thanks for your valuable contributions! The discussion stays open and the report will be available afterwards.

74. Jurgita Peciuriene | 29/10/2013, 18:05 EET (+02:00)

On behalf of EIGE, thank you very much for participating in this discussion. It is very valuable for EIGE to hear external experts' inputs. In order to make the most out of the discussion, the conversation will stay open until 10 November and you, and people who were not able to join today, will still be able to make remarks.

75. Prof. Dr. Els Leye | 29/10/2013, 18:28 EET (+02:00)

Thanks for the discussion, and apologies for not being more active this afternoon.

I look forward to the report!

have a nice evening,

Els

76. Siobhán O’Brien Green | 29/10/2013, 18:29 EET (+02:00)

Thanks Barbara and Jurgita,

I look forward to the report too and will try to read through the afternoon posts now,

Sioban
Here is the summary of this afternoon’s discussion on indicators and methodologies to determine the female genital mutilation prevalence.

Health services are a key source for data collection in every country. In order to make data collection effective, these tools should be used:

- training and awareness-raising for medical staff. It is fundamental that medical staff is aware of the importance of data collection.
- establishing common guidelines for data collection. In this regard it was underlined that the ID-9-CM classification system could be used, as it already foresees coding for FGM. 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 risk factor during delivery: 648.9.

As one of the problems in prevalence of FGM estimation is the comparability of country based data, one solution could be to identify 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.

Another proposal is to gather data from anti-violence services.

This summary represents the basis to continue the discussion. Feel free to keep on posting and sharing your thoughts and remarks.