

FEMALE GENITAL MUTILATION

REPORT OF A RESEARCH METHODOLOGICAL WORKSHOP ON ESTIMATING THE PREVALENCE OF FGM IN ENGLAND AND WALES

10 DEAN FARRAR STREET, LONDON SW1H 0NY
London, March 22-23, 2012



CITY UNIVERSITY
LONDON



UCL Elizabeth Garrett Anderson
Institute for Women's Health

FORWARD
Safeguarding rights & dignity

Funded by the Home Office

AGKNOWLEDGEMENTS

Equality Now wishes to thank Alison Macfarlane, Professor of Perinatal Health, City University London; Professor Peter Brocklehurst, the Director of UCL Elizabeth Garrett Anderson Institute for Women's Health; Ms Sarah Creighton, Consultant Gynaecologist, Honorary Clinical Reader, UCL Elizabeth Garrett Anderson Institute for Women's Health and Dr Lih Mei Lao, Consultant Clinical Psychologist, Honorary Reader, also of the UCL Elizabeth Garrett Anderson Institute for Women's Health; and Naana Otoo-Oyortey MBE, Executive Director of FORWARD, for their collaboration and valuable contribution.

Acknowledgement also goes to the following:

Efua Dorkenoo OBE, Advocacy Director FGM Programme, Equality Now, Honorary Senior Research Fellow, City University London, for developing the concept for the workshop, organising and finalising the report; to Shanta Bhavnani (Equality Now) for her role as Rapporteur for the meeting and for compilation of the initial workshop report; Claire Dupuy (Equality Now) and Charmaine Elliot (UCL) for their valuable assistance.

We wish to acknowledge the valuable inputs made by all the presenters and participants at the workshop. A full list of the presenters and the participants is given at the end of the document.

We also gratefully acknowledge the financial contribution of the Home Office for the workshop, and the Violence Against Women Team at the Mayor's Office for Policing and Crime (MOPAC) for providing the workshop with a free venue.

CONTENTS

AGKNOWLEDGEMENTS	1
EXECUTIVE SUMMARY	3
1 BACKGROUND AND JUSTIFICATION	6
2 OBJECTIVES	8
3 SUMMARY OF METHODOLOGICAL CHALLENGES AND CONSTRAINTS ON FGM	8
3.1 STUDIES IN EUROPEAN SETTINGS.....	8
3.2 PREVIOUS WORK ON ESTIMATION OF FGM PREVALENCE IN EUROPEAN COUNTRIES	8
3.3 CLINICAL AUDITS AND ONLINE SURVEYS	9
3.4 COMMUNITY STUDIES	12
4 DISCUSSIONS ON PLANNING A PROPOSAL FOR A PREVALENCE STUDY ON FGM IN ENGLAND AND WALES	14
5 PLANNING THE WAY FORWARD: CONCLUSIONS AND RECOMMENDATIONS	18
FGM Research Methodological Workshop	21
ANNEX - PRESENTATIONS	22
1. UNITED KINGDOM: Estimating the prevalence of FGM in England and Wales. Paper presented by Professor Alison Macfarlane, Department of Midwifery, City University, London.	22
2 BELGIUM: Estimating the numbers of women with FGM in Belgium.....	26
3 NETHERLANDS – Lessons learned on methodologies from a workshop on doing situation analysis on FGM in Netherlands. Paper presented by Marja Exterkate, FGM Programme Officer, PHAROS (Centre of expertise on Health for Migrants and Refugees), Utrecht, The Netherlands	28
4 CLINICAL AUDITS - Management of Female Genital Mutilation in Pregnancy at Barts	31
Paper presented by Denise McEaney, currently Consultant Midwife for Public Health, Royal London Hospital, Tower Hamlets	31
5 ONLINE SURVEYS : UK Youth online survey	32
Dr Eiman Hussein, Independent Consultant and Researcher, FORWARD/University of East London	32
6 COMUNITY STUDIES.....	34
6.1 COMMUNITY STUDIES : Peer Research on FGM, Key Findings to date	34
Paper presented by Ellie Brown, Head of UK Programmes, Options UK.....	34
6.2 COMMUNITY STUDIES: Researching Female Genital Mutilation (FGM) Intervention Programmes Linked to African Communities in the EU (REPLACE).	35
6.3 COMMUNITY STUDIES: Listening to African Voices, Female Genital Mutilation /Cutting among Immigrants in Hamburg: Knowledge Attitudes and Practice	36

EXECUTIVE SUMMARY

Background

There are no complete or reliable data on the prevalence of female genital mutilation (FGM) - the partial or total removal of the external female genitalia or other injury to the female genital organs for cultural or other non-therapeutic reasons - in the UK.

Previous estimates

A FORWARD study estimated that 66,000 women resident in England and Wales in 2001 had undergone female genital mutilation and 23,000 girls under the age of 15 were either at risk of FGM or might have undergone FGM.¹ The study, published in 2007, estimated the prevalence of FGM in the population of women of childbearing age in England and Wales, the numbers of girls aged under 15 with or at risk of FGM and the prevalence of FGM among women giving birth in England and Wales from 2001 to 2004.

Data from the 2001 census were used to derive numbers of women aged 15-49 and numbers of girls aged under 15 who were born in FGM-practising countries and resident in England and Wales in 2001. Data from birth registration were used to derive numbers of girls aged under 15 born in England and Wales to women born in FGM practising countries and numbers of women born in FGM practising countries giving birth in England and Wales each year. Migration statistics were used to attempt to estimate numbers of women migrating from FGM-practising countries to England and Wales each year. Country specific FGM prevalence rates derived from surveys in countries of origin were applied to data about women in England and Wales.

Although the study was the first systematic attempt to make estimates for England and Wales, there were some limitations in using secondary data to estimate the prevalence of FGM in England and Wales. The method underestimates the numbers affected as the Census does not identify second generation women who were born in non-practising countries but who may have been subjected to this practice. The estimated FGM prevalence was also based on the probability of women having FGM in their country of birth. Basing the probability of having FGM purely on the country of birth does not take into account the ways in which the practice might change with migration. An additional problem of basing the probability of having FGM on country of birth is that in many countries it is particular regions or specific ethnic groups who practice FGM. These groups may be more or less likely than others to have migrated to the UK.

Interim estimates and recent trends

The numbers of girls and women affected by FGM are likely to have increased since 2001, as reflected in the increase in the estimated percentages of all maternities which were to women with FGM from 1.06 per cent in 2001 to 1.43 per cent in 2004.² More recent interim estimates, which did not take account of mothers' ages, suggest a rise from 1.04 per cent in 2001 to 1.67 per cent in

¹ Efua Dorkenoo, Linda Morison and Alison Macfarlane. *A Statistical Study to Estimate the Prevalence of Female Genital Mutilation in England and Wales*, 2007, FORWARD

² Data compiled by Alison Macfarlane City Department of Midwifery and Child Health, City University.

2008, reflecting the rising numbers of births to women from FGM-practising countries. This underlines the need to update and improve current estimates of the prevalence of female genital mutilation in England and Wales

The workshop

To explore the methodological options for the collection of robust prevalence data on Female Genital Mutilation (FGM) in England and Wales, Equality Now, collaborated with the Department of Midwifery, City University London; the Elizabeth Garrett Anderson Institute for Women's Health, University College London, and the Foundation for Women's Health Research and Development (FORWARD), to organise a research methodological workshop on 22-23 March 2012 in London with funding support from the Home Office.

The workshop was attended by epidemiologists, demographers, statisticians and social scientists from England and Wales, as well as from Belgium, the Netherlands and Germany. Practitioners in public health, midwifery, gynaecology, clinical psychology, and education, as well as representatives from key NGOs working on FGM also participated in the workshop.

Having critically examined the methodological challenges in estimating the prevalence of FGM in the contexts of migration to and between European countries, there was consensus that a population-based survey to gather data on the prevalence of FGM in England and Wales was not a feasible option due to the potential high cost and the inherent complexity of sampling.

A clinical audit would produce actual prevalence rates among women giving birth in England and Wales but there are currently major barriers to overcome. However, maternity units are currently not prepared for the recording of data on FGM. There are no UK-wide standardised obstetric notes. In addition, there is no government directive to report on FGM. Addressing the barriers to data collection in maternity units on FGM would require a strong and sustained commitment from government and other concerned parties. In addition, as women with FGM may selectively use maternity units with specialist services, unit based data would be likely to be subject to biases.

In the absence of primary data about the prevalence of FGM among women from FGM-practising countries who migrated to other countries, secondary analysis of data from surveys in FGM practising countries in conjunction with census and routine birth data from receiving countries is the most systematic way of estimating the prevalence of FGM amongst a minority immigrant population. It is also the least complex and costly method of deriving some rough estimates of numbers of women and girls likely to be affected by FGM in minority populations in Western country settings. The workshop made the following recommendations to improve data on FGM:

Recommendation 1:

There should be a staged approach to deriving and improving estimates of the prevalence of FGM:

- a) In the short term, updated estimates of the prevalence of FGM in England and Wales should be derived, using routine data about numbers of women in England and Wales reported in

the 2011 census, age-specific birth data, available migration statistics and new country-specific FGM prevalence rates derived from surveys in countries of origin.

- b) These revised estimates should be complemented with an updated literature review on FGM, to look for more recent research on ethnic groups from FGM-practising countries who have settled in England and Wales. This would highlight known social norms surrounding the practice of FGM in the relevant groups. This review will address the immediate needs for data and information on FGM for policy makers, local authorities and NHS commissioners, advocates and campaigners against FGM. It should help all concerned to take advantage of the current impetus to address FGM.
- c) The next priority should be a longer term study, using primary data (clinical audit) to determine the prevalence of FGM among women giving birth in England and Wales. This should overcome the main constraints identified with the use of secondary data to estimate the prevalence of FGM in England and Wales, such as potential underestimation of undocumented immigrants, asylum seekers, or refugees who may be reluctant to participate in the census.

Recommendation 2:

The workshop participants agreed that the focus of research on FGM should not just be on numbers but on attitudes. There are good qualitative studies on Somali and Sudanese communities settled in England.^{3,4} It is important to widen studies to other under-studied communities who have settled in England and Wales and are from countries where the prevalence of FGM is high – for example, Egypt (95.8%), Sierra Leone (94%), the Gambia (78.3%), Eritrea (88.7%), and Ethiopia (74.3%).

There should be qualitative studies amongst high risk groups who have migrated and are settled in England and Wales. The outcome of community based studies is crucial to the development of targeted interventions tailored to each group.

Recommendation 3:

Guidelines on FGM exist, but they are not being followed. At best the implementation of FGM policy is patchy and ad hoc and varies between Local Authority and NHS organisations in England and Wales. Research is needed to understand the obstacles to the implementation of FGM policy and guidelines amongst professionals in health, social care, education and the justice system. This should be linked to a training strategy for professionals.

³ Kate Norman, Joanne Hemmings, Eiman Hussein, Naana Otoo-Oyortey (July 2009) *FGM is always with us, Experiences, Perceptions and Beliefs of Women Affected by Female Genital Mutilation in London Results from a PEER Study*, <http://www.forwarduk.org.uk/news/news/563>;

⁴ Alexis Palfreyman, Eleanor Brown, Sara Nam (April 2011) *Understanding Female Genital Mutilation in Birmingham, Findings from a PEER Study* <http://www.bswaid.org/wp-content/uploads/2012/01/Final-report.-PEER-FGM-in-Birmingham.-06.05.2011.pdf>

1 BACKGROUND AND JUSTIFICATION

Female genital mutilation (FGM) is the collective term used to describe a range of procedures that include the partial or almost total removal of the external female genital organs for cultural or other non-therapeutic reasons. It is mostly carried out on girls between the ages of 0 and 15 years, although occasionally adult and married women are also subjected to the procedure. FGM “reflects a deep-rooted inequality between the sexes, and constitutes an extreme form of discrimination against women”.⁵ There are adverse obstetric, gynaecological, psychosexual and psychosocial consequences associated with FGM.⁶

The WHO estimates that between 100 and 140 million girls and women worldwide have been subjected to one of the first three types of female genital mutilation shown below.⁷ An estimated 3 million girls in Africa are at risk of undergoing female genital mutilation every year.

WHO Classification of FGM Types

Type	Description
------	-------------

- | | |
|------|---|
| I: | Partial or total removal of the clitoris and/or the prepuce (clitoridectomy). |
| II: | Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision). |
| III: | Narrowing of the vaginal orifice with creation of a covering seal by cutting and repositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation). |
| IV: | All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization. |

Types I, II and III FGM have been documented in 28 countries in Africa and in a few countries in Asia and the Middle East. Some forms of FGM have also been reported from other countries, including among specific ethnic groups in Central and South America. Mainly as a consequence of migration, women who have experienced FGM are increasingly found in the United Kingdom. FGM is illegal in the UK⁸ but to date there has been no prosecution on the issue. FGM is considered a form of child abuse in the UK.⁹

Despite recognition that FGM affects some girls and women in the UK, there are still no complete and reliable data on the prevalence of female genital mutilation. A FORWARD study estimated that

⁵World Health Organisation (2008). *Eliminating Female Genital Mutilation. An inter-Agency Statement*, OHCHR, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNICEF, UNIFEM, WHO. Geneva.

⁶ Ibid

⁷ Ibid

⁸ In England, Wales and Northern Ireland the practice is illegal under the Female Genital Mutilation Act 2003 (this offence captures mutilation of a female’s labia majora, labia minora or clitoris), and in Scotland it is illegal under the Prohibition of Female Genital Mutilation (Scotland) Act 2005.

⁹ HM Government (2011) Multi-Agency Practice Guidelines: Female Genital Mutilation.

66,000 mainly African women resident in England and Wales in 2001 had undergone female genital mutilation and 23,000 girls largely from African communities here under the age of 15 were at risk of FGM or may well have undergone FGM.¹⁰ More recent estimates, which did not take account of mothers' ages, suggest a rise from 1.04 per cent in 2001 to 1.67 per cent in 2008, reflecting the rising numbers of births to women from FGM practicing countries.¹¹

Reliable data on FGM are needed for planning and commissioning of services,¹² to inform maternity, gynaecological and psycho-sexual care provision as well as other support services that are needed for girls and women with complications of FGM, for targeted advocacy with affected communities; and to monitor progress (trends) towards ending FGM in the UK.

To explore the methodological options for the collection of more robust prevalence data on Female Genital Mutilation (FGM) in England and Wales, Equality Now, collaborated with the Department of Midwifery, City University London, the Elizabeth Garrett Anderson Institute for Women's Health, University College London, and with the Foundation for Women's Health Research and Development (FORWARD) to organise a research workshop on 22-23 March 2012 in London. The workshop was funded by the Home Office.

The workshop was attended by epidemiologists, demographers, statisticians and social scientists from England and Wales, as well as from Belgium, the Netherlands and Germany. Practitioners in public health, midwifery, gynaecology, clinical psychology, and education, as well as representatives from key NGOs working on FGM also participated in the workshop.

Equality Now's London Office Director, Jacqui Hunt, welcomed the participants to the workshop. Jane Ellison, MP for Battersea and co-chair of the All Party Parliamentary Group on FGM (APPG on FGM), gave short remarks highlighting the APPG's interest in the collection of data on the prevalence of FGM in the UK. The APPG on FGM was established last year to promote greater awareness of the issue in parliament and to raise awareness of the problems caused by FGM in the UK and across the world, in such a way as to make elimination of FGM more likely.

¹⁰ Efua Dorkenoo, Linda Morison and Alison Macfarlane. *A Statistical Study to Estimate the Prevalence of Female Genital Mutilation in England and Wales*, 2007, FORWARD.

¹¹ Data compiled by Alison Macfarlane City Department of Midwifery and Child Health, City University.

¹² Department of Health (2007) *Guidance on Joint Strategic Needs Assessments*. See www.dh.gov.uk/publications Data on FGM is needed to inform on Local Authority Joint Strategic Needs Assessments (JSNA) which are now written into the Health and Social Care bill. The Health and Wellbeing Boards and Clinical Commissioning Groups are required to use data from the JSNA to prioritise on local needs and to inform commissioning.

2 OBJECTIVES

The objective of the workshop was to thoroughly investigate how to determine the prevalence of FGM in England and Wales by:

- (a) discussing the methodological challenges and agreeing on how to overcome them;
- (b) discussing and agreeing on the research questions;
- (c) discussing how the research will be used, particularly by answering the local policy makers' and commissioners' questions about FGM;
- (d) estimating how much it would cost; and
- (e) establishing how it would fit with other research initiatives on FGM.

The planned outcome was a report of the meeting which would be used to develop a full proposal including research to estimate the prevalence of FGM in England and Wales (as a tool to aid the prevention and elimination of FGM), with a consensus on methodology, questions, costing and a dissemination strategy.

3 SUMMARY OF METHODOLOGICAL CHALLENGES AND CONSTRAINTS ON FGM

3.1 STUDIES IN EUROPEAN SETTINGS

There were presentations on previous prevalence studies, clinical audits, online surveys and community studies conducted with hard-to-reach groups in England and Wales, Belgium, the Netherlands and Germany. Details of the methodological challenges and constraints highlighted in the studies are summarised below.

3.2 PREVIOUS WORK ON ESTIMATION OF FGM PREVALENCE IN EUROPEAN COUNTRIES

The method used for the calculation of prevalence of FGM in two studies – the FORWARD commissioned study on the prevalence of FGM in England and Wales which was undertaken with researchers from the London School of Hygiene and Tropical Medicine and City University London¹³; as well as a study on the prevalence of FGM in Belgium conducted under the Institute of Tropical Medicine.¹⁴ The methods used in these were adapted from those used by the Centers for Disease Control and Prevention for estimating the prevalence of FGM in the United States.¹⁵ These involved

¹³ See Annex for details of presentation by Professor Alison Macfarlane, Department of Midwifery, City University, London, FGM Research methodological workshop, Equality Now, London, and 22 March, 2012.

¹⁴ Dubourg D et al (2011). *Estimating the number of women with female genital mutilation in Belgium*. The European Journal of Contraception and Reproductive Health Care, 2011; Early Online, 1–10. Institute of Tropical Medicine, Antwerp.

¹⁵ W.K Jones, J Smith, B Kieke, Jr and L.Wilcox. *Female genital mutilation. Female Genital Circumcision. Who is at risks in the U.S.* Public Health Rep. 1997 Sep-Oct; 112(5): 368–377.

collecting data on the prevalence of FGM in women's countries of birth from several surveys, including the Demographic and Health Surveys (DHS) implemented by Macro International for USAID, Multiple Cluster Indicator Surveys (MCIS) undertaken by governments with help from UNICEF and other ad hoc national surveys on FGM. The census data on the numbers of women aged 15-49 resident or born in FGM practising countries, by five-year age groups were obtained from each of the countries' national statistics office. To estimate numbers of women with FGM, the estimated age-specific FGM prevalence rates in the mothers' country of birth were multiplied by numbers of women in the same age group born in that country.

Summary of Methodological Constraints Identified:

- Unable to obtain data on undocumented migrants, refugees and asylum seekers from census data
- Unable to obtain data on second generation women from census data
- Unable to obtain data on ethnicity
- No information on the type of excision
- No information on age at excision: 1st weeks of life, puberty, adulthood, at marriage or childbirth
- No information on influence of migration on FGM such as
 - Age at arrival in Europe
 - Length of stay
 - Place of socialisation
 - Links with country of origin
- No information on husband, family and immigrant community

An ongoing prevalence study on FGM in the Netherlands, being implemented by PHAROS and Erasmus University Medical Center, decided against implementing a household survey to determine the situation of FGM in the Netherlands due to the complexities of doing such a study on a "sensitive" subject (migration) and the potential high cost of a household survey.¹⁶ PHAROS therefore plans to complement the analysis of secondary data on women and girls affected by FGM with a series of planned targeted qualitative research studies among high risk groups who have migrated to the Netherlands.¹⁷

3.3 CLINICAL AUDITS AND ONLINE SURVEYS

Clinical Audit: Management of FGM in pregnancy

Bart's Hospital, London maternity unit had comprehensive guidelines as follows:

¹⁶ PHAROS. Outcome of the meeting. Expert Meeting FGM/C Situation Analysis in the Netherlands, 12 and 13 September 2011, ministry of Health, Welfare and Sport, The Hague, The Netherlands.

¹⁷ See Annex for details of presentation by Marja Exerkate on FGM Situation Analysis in the Netherlands, Pharos, FGM Research methodological workshop, Equality Now, London, 22 March, 2012.

Antenatally

- Take history, review medical notes and assess complications of FGM
- Refer within 2-4 weeks to an obstetric consultant for assessment and onwards referral to FGM specialist for de-infibulations
- Advise about the choices available prior to onset of labour

In Labour

- Inform Specialist Registrar (SpR), of admission to labour ward of any woman with FGM
- If there is no management plan, assess the external genitalia at early stage and discuss with consultant regarding management plan
- Specify against the law to re-infibulate

A clinical audit on FGM sought to assess the adherence by staff to the above hospital guidelines on FGM.¹⁸

The audit aimed to quantify:

- FGM assessment during antenatal history-taking
- Antenatal diagnosis allowing discussion of management options prior to onset of labour
- Number of patients with FGM referred to consultants within 2-4 weeks for management plan
- Those referred for specialist input
- Cases of FGM notified to Specialist Registrar during labour
- Cases of FGM without management plans notified to consultants during labour

Problems identified during the clinical audit:

- Retrieving records was difficult, and therefore the sample was small. There may be questions about the accuracy of the audit results.
- There were discrepancies in the recording of FGM. Sometimes it was recorded in the birth register and sometimes in the maternity notes. Some sets of notes recorded FGM as present in one place whilst in other places it was stated that the vagina was normal.
- Because of the discrepancies in record-keeping, the auditors were unable to say with certainty whether no record of FGM meant that FGM was not present.
- The vast majority of records did not document the type of FGM.

¹⁸ See Annex for details of presentation by Denise McEaney, currently Consultant Midwife for Public Health, Royal London Hospital, Tower Hamlets, FGM Research methodological workshop, Equality Now, London, 22 March, 2012.

Online Surveys: FORWARD National Youth Survey on FGM

The UK FORWARD National Youth Survey on FGM started in February 2012 and will run for six months with the aim of getting 2000 responses.¹⁹ The survey objectives are:

- To ascertain young people's knowledge of and attitudes to FGM
- To assess the scope of FGM in the UK by collecting data on young people's experiences
- To develop a better understanding of young people's experiences of accessing services relating to FGM

There is a separate survey for males and females to ascertain their respective knowledge of FGM.

An online survey was chosen because of the high level of internet use amongst young people. The survey was also considered cheap for quick and high volume data collection.

Difficulties Encountered and Other Challenges Experienced:

- It took 11 months to get ethical clearance.
- If the researchers receive information that girls are at risk, because the surveys are anonymous, there is very little they can do to help. They tried to address this by giving as much information as possible on the website about agencies that will be able to help.
- There can be technical problems with the survey if the internet is not working or if Survey Galaxy (the website hosting the survey) is down.
- Advertising the survey has taken a lot of effort, using all the organisation's contacts. Because of the sensitivity of the issue, many institutions (such as universities) have not wanted to publicise it.
- They have received responses from people not from FGM-affected communities who want to give their views on the issue. This was not the intended research group.
- The respondents are reporting their own ages and they may not be honest about this.

The key methodological issue on the youth survey raised by the workshop was that it would be very difficult to interpret the results because of the potential for sample bias. Even if there were 2000 responses, there would be no way of knowing to what extent the experiences and attitudes uncovered were representative of the total population.

¹⁹ See Annex for details of presentation by Dr Eiman Hussein, Independent Consultant and Researcher, FORWARD/University of East London.

3.4 COMMUNITY STUDIES

The workshop discussed the various methods used in community-based studies on FGM in England and Wales, Netherlands and Germany to reach out to hard-to-research groups in affected communities.

(a) Peer Research on FGM, Key Findings to Date²⁰

Options UK have carried out three studies on FGM using participatory ethnographic evaluation and research (PEER).^{21,22,23}

PEER is a methodology that seeks to gain insight into the attitudes of hard-to-research groups by training members of those groups to carry out in-depth conversational interviews with trusted individuals they select from their own social networks. By using established relationships of trust between peer researchers and their friends, PEER provides insight into how people view their world, conceptualise their behaviour and experiences, and make decisions.

Limitations of Method

- PEER cannot tell us about prevalence.
- PEER studies tell us what people say about FGM. What people actually do may be different and PEER cannot tell us this.

(b) Participatory Action Research (PAR): Researching Female Genital Mutilation (FGM) Intervention Programmes Linked to African Communities in the EU (REPLACE).²⁴

Participatory Action Research (PAR) is an approach that uses the research process to bring about long-term change in the research group. It engages the community being researched in the research process which means that interpretations of data are debated with the researched community and the research process is empowering to those taking part.

²⁰ See Annex for details of paper presented by Ellie Brown, Head of UK Programmes, Options UK.

²¹ Kate Norman, Joanne Hemmings, Eiman Hussein, Naana Otoo-Oyortey (July 2009) *FGM is always with us, Experiences, Perceptions and Beliefs of Women Affected by Female Genital Mutilation in London Results from a PEER Study*, <http://www.forwarduk.org.uk/news/news/563>;

²² Alexis Palfreyman, Eleanor Brown, Sara Nam (April 2011) *Understanding Female Genital Mutilation in Birmingham, Findings from a PEER Study* <http://www.bswaid.org/wp-content/uploads/2012/01/Final-report.-PEER-FGM-in-Birmingham.-06.05.2011.pdf>

²³ Joanne Hemmings (October 2011) *The FGM Initiative Interim Report* <http://www.trustforlondon.org.uk/FGM%20Interim%20Report.pdf>

²⁴ See Annex for paper presented by Dr David Beecham, Faculty of Business, Environment and Society, Coventry University and Hussein Hussein, Researcher.

Difficulties Experienced with the Methodology:

- It was very difficult to get ethical clearance because of the illegality of FGM. The ethics committee was concerned about what would happen if a research participant disclosed that they had or were planning to carry out FGM.
- The research may not be fully participatory as it is unlikely to capture the voices in the community of those who are strongly in favour of the practice.
- All of the researchers were highly educated and therefore may not have been representative of the communities they were researching.
- Participants were suspicious of the researchers and it took a long time to convince people to be involved.
- Men in particular were not keen to talk about the issue as they saw it as women's business.
- Some researchers lost the trust of their communities by being involved and suffered from criticism and name-calling.

(c) Female Genital Mutilation Knowledge Attitudes and Practice Survey amongst Africans in Hamburg.²⁵

The main purpose of the survey on Female Genital Mutilation Knowledge, Attitudes and Practice Survey among Africans in Hamburg was to develop an effective approach to promoting the prevention of FGM among immigrant groups in Hamburg. The specific objectives were:

- To assess the proportion of immigrants with roots in practising families in Hamburg.
- To explore the attitudes, perceptions and opinions among immigrants from Sub-Saharan Africa toward FGM/C; notably the perceived advantages, the position of their religion on FGM/C and the proportion of supporters and opponents of the practice.
- To provide an estimation of the proportion of girls and women concerned from different countries of origin.
- To assess the ratio and profile of girls at risk.
- To investigate whether families subject their daughter(s) living in Hamburg to the practice and if so, how they do so.
- To establish profiles of low- and high-risk communities (by country and region).
- To explore the level of awareness of the medical risks and other disadvantages resulting from FGM/C among immigrants from Sub-Saharan Africa in Hamburg.
- To collect ideas from men and women immigrants on how FGM/C can be addressed and effectively prevented among practising communities in Hamburg.
- To identify opponents of FGM/C within communities of practising origin who are interested and motivated to lead and participate in activities against FGM/C.

Methods: Both qualitative and quantitative community based surveys.

²⁵ See Annex for details of paper presented by Dr Anja Stuckert, Project Coordinator of Plan Germany.

Difficulties with Methodology

- Participants in the quantitative survey were not randomly sampled. Because interviewers used their social networks as a source of participants, community members not involved in those networks were less likely to be interviewed.
- The results cannot be extrapolated beyond Hamburg. As a result of chain migration, there are very high concentrations of specific minority ethnic groups in the city. Other locations are likely to have high concentrations of different ethnic groups.
- The interviewers needed psychological back up: some were treated as traitors to their communities; others were shocked and upset at what they learned about the practice of FGM.
- It was very difficult to do interviews with people who did not have residence permits. Even though they were assured the interviews were anonymous, they worried that the information would be handed over to the authorities.
- It was almost impossible to find asylum seekers who were willing to be interviewed.
- The report focused exclusively on sub-Saharan Africa. Furthermore, the interviewers were not able to identify participants from some sub-Saharan countries.
- Data was collected using oral testimonies. Therefore there is a risk that participants responded in ways they regarded as being more socially desirable.

4 DISCUSSIONS ON PLANNING A PROPOSAL FOR A PREVALENCE STUDY ON FGM IN ENGLAND AND WALES

Having considered the different methodological challenges and constraints on collecting data on FGM in a European immigration setting, the workshop participants focused on the design of a proposal for a prevalence study on FGM in England and Wales.

(a) Literature Review

The European Institute for Gender Equality is currently mapping the situation of FGM in the European Union and Croatia.²⁶ The mapping exercise which is due at the end of 2012 includes carrying out an extensive literature review on FGM. The ongoing baseline study on FGM in the Netherlands also includes a literature review on FGM. Workshop participants therefore agreed there was no need to undertake a further literature review.

²⁶ See European Institute for Gender Equality study of mapping current situation and trends of female genital mutilation (FGM). Details can be accessed on <http://eige.europa.eu/content/eige-2011-oper-18>

However, aside from countries where the practice of FGM is near universal (for example, Somalia, Northern Sudan, Eritrea, Ethiopia, Mali, Guinea), FGM is practised only by specific ethnic groups in other countries. Because FGM is linked to ethnicity, it might be useful to consider a literature review both to collect information on prevalence of FGM in countries of origin and also to identify the specific ethnic groups from FGM practising communities that have migrated to Britain. It would also be useful for targeted advocacy and for documenting what we know about the social norms relating to FGM in the ethnic group concerned. This information would enhance a study on the prevalence of FGM in England and Wales. It would fill the gaps in information on FGM required by practitioners working with families and communities.

(b) Updating and improving current estimates of the prevalence of female genital mutilation in England and Wales

There was a new census in 2011. Therefore, there is potential for updating and improving current estimates of the prevalence of female genital mutilation in England and Wales. In the absence of primary data about the prevalence of FGM among women from FGM-practising countries who migrated to Western countries, the analysis of secondary data provides the most systematic estimates of the prevalence of FGM amongst a minority immigrant population.

(c) Collection of primary data on FGM

A population-based national survey with a representative sample to determine the prevalence of FGM in England and Wales would be complex to design given that FGM concerns a minority population. It would also be very expensive to conduct. While there may be potential for the inclusion of FGM questions in a number of national population studies, for example, the Health Survey for England, the British Birth Cohort study which is due to start in 2014, the British Crime Survey and the National Survey of Sexual Attitudes and Lifestyles, due to the illegality of the practice and the emotions surrounding it, such questions would be unlikely to produce reliable information.

The workshop considered the option of gathering data through cervical screening programmes, family planning, and abortion, urology, and gynaecology clinics. Cervical screening programmes, urology, and gynaecology clinics are not widely accessed by women from immigrant communities. Family planning and abortion services were thought to be too controversial to use as an avenue to combine with the collection of data on FGM – another 'sensitive' issue.

A system of annual genital examinations of girls by school nurses was ruled out as many schools no longer have school nurses. Aside from the difficulty of gaining parental consent for physical examination, many workshop participants felt this would be considered too intrusive for girls and alien in the British context.

The workshop agreed that the period of caring for women during pregnancy and childbirth offers an opportunity to collect primary data to estimate the prevalence of FGM in England and Wales.

The advantages are:

- All women access health care during pregnancy
- Pregnancy may be the only occasion on which a woman comes into contact with health care professionals
- National prevalence data could be reported annually to identify national and local trends
- Effective triaging for sensitive and safe antenatal care and safeguarding
- Leaves the more complex qualitative data about FGM to be collected at local or at community level.

The workshop acknowledged that collecting data at birth would not capture women who have had FGM but who do not have children; and those women giving birth may therefore not be representative of women with FGM. However, collecting such data would give a comprehensive enough picture to enable effective planning and targeting of resources. There are currently a number of barriers to data collection on FGM in maternity units, including:

- No UK-wide standardised obstetric notes - some paper, some electronic, many different systems
- No national or statutory requirement to report FGM
- FGM may not be included in antenatal notes. If included, it may not be a compulsory question. If not answered, it may not mean no.
- Staff unaware of FGM or unsure of how or who to ask
- Some units do not have clear protocols of what to do if FGM found
- Agency staff, locum doctors may lack the awareness of FGM or fail to comply with protocols on FGM if not supervised
- Some women present late (in labour)

These barriers would have to be addressed before recording of FGM could start.

(d) Community studies

The workshop participants agreed that community studies are important for understanding the reasons why FGM continues when people migrate and are also crucial to the development of targeted interventions tailored to different groups. There is a need to go beyond just numbers on FGM to understand the attitudes surrounding the FGM practice amongst groups who have migrated. Existing community-based studies in England and Wales have focused on Somalis and Sudanese communities. It would be important to widen studies to other FGM-practising communities (e.g. Egyptians, Sierra Leoneans and Gambians) who are currently under studied.

(e) Adherence to FGM policy and guidelines

The workshop agreed that other than estimating the prevalence of FGM in England and Wales, another priority area for research is a study to understand obstacles to the implementation of FGM guidelines by professionals. Whilst comprehensive guidelines on FGM exist, they are not being followed. The workshop participants agreed that we need to understand why this is in order to be able to promote training, to guarantee consistent behaviour amongst professionals and to ensure that FGM is comprehensively addressed.

5 PLANNING THE WAY FORWARD: CONCLUSIONS AND RECOMMENDATIONS

Having critically examined the previous studies on FGM, and the methodological challenges on estimating the prevalence of FGM in the context of migration to Europe, the following were the conclusions and recommendations from the workshop:

1. Research Question:

(a) What is the prevalence of FGM among women aged 15 and over in England and Wales; and (b) what are the estimated numbers of girls aged below 15 at risk of FGM by type of FGM?

There was consensus that although population based research used to gather data on the prevalence of FGM in England and Wales would provide the most robust evidence on the prevalence of FGM in England and Wales, it is not a feasible option due to the high cost and the complexity inherent in a sampling design. Adding questions on FGM to existing national population studies such as the Health Survey for England, the British Birth Cohort study which is due to start in 2014, the British Crime Survey, and the National Survey of Sexual Attitudes and Lifestyles would reduce the cost but would require careful consideration because of the risk of capturing inadequate numbers of women in the sample.

Although a clinical audit for determining the prevalence of FGM amongst women giving birth would not capture all women in the community who have had FGM, collecting data on FGM from maternity units is an option for accessing primary data to determine the incidence of FGM. However, maternity units are currently not prepared for the recording of data on FGM. There is no government directive to report on FGM. Addressing the barriers to data collection in maternity units on FGM would require a strong and sustained commitment from government and other concerned parties. In addition, as women with FGM may selectively use maternity units with specialist services, unit based data would be likely to be subject to biases.

In the absence of primary data about the prevalence of FGM among women from FGM-practising countries who migrated to other countries including the UK, an analysis of secondary data from surveys in their country of birth provides the most systematic estimates of the prevalence of FGM among the minority immigrant population concerned. It is also the least complex and cheapest method of making some rough estimates of numbers of women and girls affected by FGM in minority populations in Western country settings. This method has been used to estimate the prevalence of FGM by the Centre for Disease Control (CDC) in the US; and by other countries in Europe including France, Switzerland and Belgium and with the ongoing study in the Netherlands.

Recommendations:

A staged approach with improved data on the prevalence of FGM in England and Wales was recommended. In the short term, an approach using routine data about women in England and Wales, drawing on data from the 2011 census, age-specific birth data and available migration statistics was recommended. This should be complemented with an enhanced literature review with fuller details on ethnic groups from FGM practising countries who have settled in England and Wales, highlighting the social norms surrounding the practice of FGM for the different groups. This would address the immediate needs for data and information about FGM for policy makers, local authorities and NHS commissioners, advocates and campaigners against FGM, and would help all to take advantage of the current impetus to address FGM.

The next priority should be to design and pilot a longer term study to collect primary data on the prevalence of FGM for England and Wales. This would overcome the main constraints identified with the use of secondary data to estimate the prevalence of FGM in England and Wales. The aim would be to include women such as undocumented immigrants and asylum seekers, or refugees who may be reluctant to participate in the census.

2. Research Question: What are the attitudes, perceptions and motivations of women and families from FGM-practising communities on FGM in the context of settled communities in England and Wales?

The workshop participants recommended that the focus on research on FGM should not just be on numbers but on attitudes. There are good qualitative studies on Somalis and Sudanese communities. It is important to widen studies to other under studied communities who have settled in England and Wales and are from countries where the prevalence of FGM is high – for example, Egypt (95.8%), Sierra Leone (94%) the Gambia (78.3%), Eritrea (88.7%), and Ethiopia (74.3%).

Recommendations:

There should be targeted qualitative studies of high risk groups who have migrated and are settled in England and Wales. The outcome of community based studies is crucial to the development of targeted interventions tailored to different groups.

3. Research Question: What are the barriers to FGM prevention by professionals in health, social care, education and the justice system?

Whilst numerous guidelines on FGM exist, they are not being followed. At best the implementation of FGM policy is patchy and ad hoc and varies between Local Authority and NHS organisations in England and Wales. Workshop participants agreed that training of professionals on FGM needs to be evidence-based.

Recommendations: There should be a study to understand the obstacles to the implementation of FGM policy and guidelines amongst professionals in health, social care, education and the justice system in order to ensure that a robust and joined-up system is put in place to address FGM. This should be linked to a training strategy for professionals.

FGM Research Methodological Workshop
March 22-23, 2012, 10 Dean Farrar Street, London SW1H 0NY

List of Participants

Dr Sade Adenekan, Consultant in Public Health, NHS Brent Public Health team, London
Nimco Ali, Director, Daughters of Eve, London
Dr David Beecham, Postdoctoral Research Assistant, Coventry University, REPLACE Project/UK FORWARD/IFSAN-Netherlands, Coventry
Professor Peter Brocklehurst, Director, UCL Elizabeth Garrett Anderson Institute for Women's Health (**Co- Chair**)
Eleanor Brown, Head of UK programmes, Options UK, London
Sarah Creighton, Consultant Gynaecologist, Honorary Clinical Reader, UCL Institute for Women's Health
Efua Dorkenoo OBE, Advocacy Director, FGM Programme, Equality Now and Honorary Senior Research Fellow, Department of Early Years, City University London (**Co- Chair**)
Dr Dominique Dubourg, Research Fellow, UON Network, Department of Public Health, Maternal and Reproductive Health Unit, Institute of Tropical Medicine, Antwerp, Belgium
Annabel Durling, Grants Manager, FGM Initiative, Esmée Fairbairn Foundation
Charmaine Elliot, PhD student, UCL
Jane Ellison MP, Member of Parliament for Battersea, London, Chair of the All-Party Parliamentary Group on Female Genital Mutilation
Marja Exterkate, FGM Programme Officer, Pharos (Centre of expertise on Health of Migrants and Refugees), Utrecht, Netherlands
Judy Fladmark, News Programme Planning, BBC, London
Jacqui Hunt, Director, Equality Now London Office
Dr Eiman Hussein, Independent Consultant and Researcher, FORWARD/University of East, London
Hussein Hussein, Researcher REPLACE Project, Bristol
Julie Jefferies, Head of Demographic Analysis Unit - fertility, families, ageing and mortality, Population and Demography Division, Office for National Statistics
Asma Khan, Research Associate, School of Social Sciences, Cardiff University, Cardiff
Dr Lih-Mei Liao, Consultant Clinical Psychologist, Honorary Reader, UCL Institute for Women's Health
Dr Hermione Lovel, Consultant in Public Health, NHS Surrey
Professor Alison Macfarlane, Statistician, Professor of Perinatal Health, Department of Midwifery, City University London (**Co- Chair**)
Denise McEaney, Consultant Midwife for Public Health, Royal London Hospital, Tower Hamlets, London
Zeinab Mohammed, Midwife/Development Officer, Manchester
Dr Comfort Momoh MBE, Public Health Specialist, Guy's and St Thomas Hospital Trust, London
Naana Otoo-Oyortey, Executive Director, Foundation for Women's Health Research and Development (FORWARD), London
Dr Anja Stuckert, Project Coordinator, Plan International, Hamburg, Germany
Anne-Marie Wilson, Director, 28 Too Many, London
Naimat Yousif, Anthropologist/teacher, London

ANNEX - PRESENTATIONS

1. UNITED KINGDOM: Estimating the prevalence of FGM in England and Wales.²⁷ Paper presented by Professor Alison Macfarlane, Department of Midwifery, City University, London.

Study Objectives:

To estimate for residents of England and Wales:

1. Prevalence of FGM among women aged 15 and over;
2. The estimated numbers of maternities which were to women who have undergone FGM; and
3. The numbers of girls aged under 15 with or at risk of FGM and the type of FGM.

Objective 1: Estimating the prevalence of FGM among women aged 15 and over in 2001.

The method used for the calculation of prevalence was adapted and refined from an FGM prevalence study in the United States conducted by the Centre for Disease Control and Prevention (CDC). Data on the prevalence of FGM in women's countries of birth was collected from several sources.

Sources of data on prevalence of FGM in country of birth

Source	Countries
Demographic and Health Surveys (DHS) implemented by Macro International for USAID.	Benin, Burkina Faso, Cameroon, Cote D'Ivoire, Egypt, Eritrea, Ethiopia, Ghana, Guinea, Kenya, Mali, Mauritania, Niger, Nigeria, Senegal, Tanzania, Yemen
Multiple Cluster Indicator Surveys (MCIS) undertaken by government with help from UNICEF or other UN agencies.	Central African Republic, Chad, Sudan (North)
Other ad hoc surveys and estimates	Democratic Republic of the Congo, Djibouti, Gambia, Djibouti, Guinea Bissau, Liberia, Sierra Leone, Somalia, Togo, Uganda

The census data on the numbers of women aged 15-49 resident in England and Wales and born in FGM-practising countries, from Table M1000, population by sex by five year age group were obtained from the Office for National Statistics (ONS).

²⁷ Dorkenoo E, Morison L, Macfarlane A (2007). A Statistical Study to Estimate the Prevalence of Female Genital Mutilation in England and Wales, unpublished report, FORWARD, London.

To estimate numbers of women in England and Wales with FGM, the estimated age-specific FGM prevalence rates in country of birth were multiplied by numbers of women in the same age group born in that country.

Updating the 2001 estimates

The prevalence study was conducted in 2006 using 2001 census data. This meant that the estimates calculated using the methods described were five years out of date. Therefore migration data were requested from ONS with the aim of updating estimates of numbers of women from practising countries. Because of disclosure control these were requested for groups of countries rather than for all individual countries.

FGM Practising Country Group

1(i)	Almost universal FGM, over 30% FGM Type III	Sudan (north), Somalia, Eritrea, Djibouti.
1(ii)	High national prevalence of FGM WHO Type I and II	Egypt, Ethiopia, Mali, Burkina Faso, Gambia, Guinea, Sierra Leone
2	Moderate national prevalence of FGM WHO Type I and II	Central African Republic, Chad, Cote D'Ivoire, Guinea Bissau, Kenya, Liberia, Mauritania, Senegal, Togo
3	Low national prevalence of FGM WHO Type FGM I and II	Benin, Cameroon, Ghana, Niger, Nigeria, Democratic Republic of Congo, United Republic of Tanzania, Uganda, Yemen

ONS' Migration Statistics Unit provided data about inward and outward migration over the years 2001 to 2005 to update these estimates. It was unable to subdivide estimated numbers of migrants by age as these estimates are based first on the International Passenger Survey, which has a relatively small sample and does not record informants' ages.

In addition, asylum seeking statistics are not disaggregated by sex and therefore could not be used. The data provided implied a net inflow of women migrants from countries practising FGM. Although the largest numbers came from countries with low FGM prevalence, it was estimated that there was a net inflow of about 3,000 women from the high prevalence countries. Better data are needed and ONS has undertaken a review of migration statistics.

Taking the migration data into account, the results were as follows:

Women born in FGM-practising countries

<i>Number enumerated</i>	<i>174,528</i>
<i>Estimated number with FGM</i>	<i>65,790</i>

Barriers encountered

There were a number of limitations to the methodology set out above:

- There were 9,030 women born in Africa who did not state their country of birth and so could not be included
- Low response to the census in inner city areas meant possible under-enumeration of groups relevant to the study
- Women who migrated may not have been typical of women in the population as a whole
- Estimates do not include women who were born in non-practising countries but still underwent FGM
- Numbers are likely to have increased since 2001 because of further migration.

Objective 2: Estimating the numbers of maternities which were to women who have undergone FGM

The following method was used to estimate the numbers of maternities which were to women who have undergone FGM:

- Analysis of the numbers of registered maternities (defined as pregnancies leading to one or more registrable live or stillbirths) to residents of England and Wales by mother's country of birth and age.
- Estimated age-specific FGM prevalence rates in country of birth were multiplied by numbers of maternities to women in the same age group born in that country to estimate numbers with FGM.

Barriers encountered:

Maternity data could not be readily released to the study team due to the Population (Statistics) Act. It took eight months to get through ONS' Microdata Release Panel which led to major delays in the study. In order to satisfy disclosure control procedures, tabulations of numbers of maternities by age and mother's country of birth for mothers born in FGM-practising countries for each year from 2001 to 2004 were held within ONS and not released to the research team. The study team provided age-specific FGM prevalence for each of the countries to ONS. ONS calculated estimates of numbers of maternities to women with FGM in each local authority by multiplying the number of women delivering in each local authority area in each age-group and in each country where FGM is practised by the age-specific FGM prevalence estimate for that country. These numbers were then summed over all the countries where FGM is practised to estimate the total number of women with FGM overall in England and Wales and for each region.

Objective 3: Estimating numbers of girls aged under 15 with or at risk of FGM and the type of FGM.

As there is no data for girls under 15, we estimated numbers in FGM risk groups rather than attempting to estimate prevalences themselves.

Method:

1. Numbers of girls born in practising countries and under the age of 15 in 2001 derived from 2001 census.
2. Numbers born in England and Wales to mothers born in FGM-practising countries derived from birth registration 1993-2004.

Estimated numbers of girls aged under 15 with or at risk of FGM and the type of FGM.

	FGM group of country	Born in country	Born in England and Wales	Total
1(i)	High risk of FGM Type III	6,800	17,212	24,012
1(ii)	High risk FGM Type I or II	1,972	6,941	8,913
2	Medium risk FGM Type I or II	2,346	13,488	15,834
3	Low risk FGM Type I or II	7,622	41,995	49,617
	Total	18,740	79,636	98,376

Barriers encountered

Two main problems were encountered when estimating numbers of girls aged under 15 with or at risk of FGM and the type of FGM:

- Under-enumeration in census
- Attitudes to FGM may change with migration. At the time of the study the latter information was not available.

Conclusions

An estimated 66,000 women with FGM were living in England and Wales in 2001

This is likely to be an underestimate. Migration statistics suggest numbers have increased since 2001 but are inadequate for quantifying the increase. Estimated percentages of all maternities to women with FGM increased from 1.06 in 2001 to 1.43 per cent in 2004. This is likely to have reached 1.6 per cent by 2006. Over 24,000 girls under the age of 15 are at high risk of Type III FGM and nearly 9,000 are at risk of Type I or Type II. A survey is needed to obtain better estimates.

2 BELGIUM: Estimating the numbers of women with FGM in Belgium.²⁸

Paper presented by Dominique Dubourg, Research Fellow, Maternal and Reproductive Health Unit, Institute of Tropical Medicine, Antwerp, Belgium.

Study Objective:

The objective of the study was to estimate the number of women with FGM living in Belgium, the number of girls at risk, and the target population for medical and social services (MSSs).

Methods:

The overall approach was to identify the most recently published Demographic and Health Surveys (DHS) and the UNICEF Multiple Indicator Cluster Surveys (MICS) data about the prevalence of FGM by age group in countries in Africa and in Yemen from the Pan Arab Project for Family Health. The study did not include The Democratic Republic of Congo (DRC) as the data on DRC was thought to be anecdotal. Prevalence data were then applied to all migrant women from these countries living in Belgium and to their daughters born in Belgium since 1998.

Data on female migrant population (by age, current nationality, nationality of origin, and province of residence in Belgium) were provided by the Federal Directorate General for Statistics and

²⁸ Dubourg D et al (2011). *Estimating the number of women with female genital mutilation in Belgium*. The European Journal of Contraception and Reproductive Health Care, 2011; Early Online, 1–10. Institute of Tropical Medicine, Antwerp.

Economic Information (DGSIE). Data were obtained on the female population by the 1 January 2008.

Due to legal restrictions the research team was not able to access data from a “Waiting Register” on the numbers of female asylum seekers and refugees from DGSIE. The team obtained some data on female asylum seekers from each of the 28 African countries where FGM is practised from a study by Fedasil, the national organisation in charge of asylum seeker reception in Belgium.

Data on second generation girls were obtained from the national office of statistics and from birth registration data.

Results:

Amongst the 22,840 women and girls living in Belgium who are from an FGM-practising country, 6,260 have ‘most probably already undergone a FGM’ (women born in the country of origin), and 1,975 are ‘at risk’ (second generation born in Belgium). The target population of MSSs comprises 1,190 girls less than five years old attending well-baby clinics, 1,690 girls aged 5–19 years attending preventive school health centres, 4,905 women 20–49 years old and 450 women over 50 years of age attending reproductive health services. The population of women concerned is unequally dispersed in Belgium and reflects the distribution of migrant settlement in the different provinces.

Methodological constraints:

- Not able to get full data on refugees and asylum seekers
- Not able to get data on undocumented migrants
- Ethnicity data was also not available
- No information on the type of excision
- No information on age at excision: 1st weeks of life, puberty, adulthood, at marriage or childbirth
- No information on influence of migration on FGM such as
 - Age at arrival in Europe
 - Length of stay
 - Place of socialisation
 - Links with country of origin
- No information on influence of husband, family and immigrant community

Conclusion:

FGM in Belgium requires a more concerted approach in terms of prevention, and medical and social care. Accurate information about the distribution of women concerned should permit better planning of competent services.

3 NETHERLANDS – Lessons learned on methodologies from a workshop on doing situation analysis on FGM in Netherlands.²⁹ Paper presented by Marja Exterkate, FGM Programme Officer, PHAROS (Centre of expertise on Health for Migrants and Refugees), Utrecht, The Netherlands

The need:

The population possibly at risk of FGM are girls and women living in the Netherlands who, or whose parent(s) originate from one of the 29 countries in Africa where FGM is practised. National prevalence of FGM in those countries of origin for some of the groups is extremely high: Somalia (97.9%), Egypt (95.8%), Ethiopia (74.3%), Sudan-north (90%), and Sierra Leone (94%).

There are no complete and overall data on the situation of FGM in the Netherlands. Two estimates on FGM incidence and prevalence are available:

1. 2005: An estimate from the Council for Public Health and Health Care (*Raad voor de Volksgezondheid en Zorg*) showed that at least 50 girls who are living in the Netherlands are being circumcised annually.
2. 2008: A retrospective survey of the prevalence of female circumcision in midwifery practice showed that 40% of pregnant women, originating from so-called 'at risk countries', who deliver in the Netherlands, are circumcised (TNO, 2009).

Baseline data on FGM were needed to:

- monitor effectiveness of (policy) measures and different interventions;
- anticipate possible future changes;
- know the greatest demand: prevention, medical & psychosocial health care, criminal investigation & prosecution;
- monitor progress towards ending FGM worldwide.

Questions for a situation analysis

²⁹ See PHAROS report (2011): Outcomes of the meeting. Expert Meeting FGM/C Situation analysis in the Netherlands, 12-13 September 2011, Ministry of Health, Welfare and Sport, The Hague, The Netherlands.

Pharos, the Dutch Centre of expertise on the health of migrants and refugees decided to do a situation analysis of FGM in the Netherlands with the following questions in mind:

- a) How many women living in the Netherlands have undergone FGM/C and are in need of care?
- b) Does circumcision take place among girls living in the Netherlands?
- c) What is the risk for a girl living in the Netherlands of being circumcised?
- d) What are the perceptions, attitudes and behaviour regarding FGM/C?
- e) FGM/C is a social norm. What are the determinants of this in the Dutch context?
- f) What is the influence of migration on perceptions, attitudes and behaviour?

What to consider

Prior to proceeding with a household survey, Pharos considered the following challenges to releasing the results of a survey of FGM in the Netherlands. These were:

For the community:

- Stigmatisation/aggression
- Possible re-emerging of bad memories
- Violation of confidentiality of data collected

For Pharos:

- Media sensation
- Complexity of research/quality interviewers
- How the results will be (mis)used?

PHAROS decided to first consult with other partners in Europe with expertise on FGM research, policy and programming through a preliminary two day expert meeting on FGM in September 2011.

Outcome of Expert Meeting

The meeting raised more questions than solutions. The main challenges identified in doing a survey on FGM were as follows:

1. How to obtain valid information about a controversial topic that is also liable to punishment?
2. How to select interviewers and what may (and may not) be expected of them?
3. How to be sure that the sample is representative?

The other challenge to contend with for researchers is the issue of whether information that could lead to punishment has to be provided to the government.

Conclusions

Based on the outcome of the Expert Meeting, a decision was taken by PHAROS not to do a household survey on FGM but to estimate the prevalence of FGM in the Netherlands through the analysis of secondary data. The original proposal has therefore been revised. PHAROS is partnering with *Erasmus University Medical Center, Department of Public Health, and Rotterdam* to implement the research in 2012. The results will be available in 2013.

4 CLINICAL AUDITS - Management of Female Genital Mutilation in Pregnancy at Barts **Paper presented by Denise McEaney, currently Consultant Midwife for Public Health, Royal London Hospital, Tower Hamlets**

Objective and Method

The audit sought to assess the adherence of Barts Hospital to its own guidelines on FGM. The hospital has comprehensive guidelines as follows:

Antenatally

- Take history, review medical notes and assess complications of FGM
- Refer for assessment within 2-4 weeks to an obstetric consultant for onwards referral to FGM specialist for deinfibulation
- Advise about the choices available prior to onset of labour

In Labour

- Specialist Registrar (SpR) to be informed of admission to labour ward of any woman with FGM
- If no management plan, an assessment of external genitalia at early stage and discussion with consultant regarding management plan
- Specifies against the law to reinfibulate

The audit aimed to quantify:

- FGM assessment during antenatal history-taking
- Antenatal diagnosis allowing discussion of management options prior to onset of labour
- Number of patients with FGM referred to consultants within 2-4 weeks for management plan
- Those referred for specialist input
- Cases of FGM notified to Specialist Registrar during labour
- Cases of FGM without management plans notified to consultants during labour

The audit reviewed the birth register for January-July 2010 and identified women of African, Indian and Pakistani ethnicity and also women who had undergone FGM. Of those, the maternity notes of all women who had delivered in January and February 2010, of African, Indian and Pakistani origin, were reviewed. Of that sample, 29 were Somali and 13 of those had documented FGM. There was no evidence of FGM in the other 34 women. Therefore, the audit was extended to Somali women only, for the period of January to July 2010. This gave 47 sets of maternity notes to be reviewed.

Results

According to the maternity notes, birth register and previous records, there were 32 cases of FGM, however only 19 of those cases had been recorded in the maternity notes; 8 of those

had been detected antenatally and 9 in labour; ³⁰ of the 8 that had been detected antenatally, 5 had a documented antenatal management plan. In 9 of the 19 cases the SpR was not aware the woman had had FGM and in 11 of the 19 cases the Consultant was not aware that the woman had had FGM.

The results of the audit raise concerns about detection of FGM and in particular the quality of history-taking. The number of cases detected early but with no management plan suggests a lack of awareness of the complications of FGM.

The audit made a number of recommendations for change including:

- reviewing the hospital's guidelines to make them more specific
- raising the awareness of the lead Consultant and Midwife of FGM
- development of teaching sessions to include detection and management of FGM
- community engagement to encourage women to disclose that they have FGM
- consideration of whether to offer external genital examinations antenatally to high risk groups.

Difficulties with the Method

- Retrieving records was difficult, and therefore the sample was small. The auditors requested 128 records but received only 74. Of those, 47 of the notes belonged to Somali women. There may therefore be a question about the accuracy of the audit results.
- There were discrepancies in the recording of FGM. Sometimes it was recorded in the birth register and sometimes in the maternity notes. Some sets of notes recorded FGM as present in one place whilst in other places the record stated that the vagina was normal.
- Because of the discrepancies in record-keeping, the auditors were unable to say with certainty whether no record of FGM meant that FGM was not present.
- The vast majority of records did not document the type of FGM.

5 ONLINE SURVEYS : UK Youth online survey

Dr Eiman Hussein, Independent Consultant and Researcher, FORWARD/University of East London

FORWARD National Youth Survey on FGM

Paper presented by Dr Eiman Hussein, independent consultant

Objective and method

FORWARD's aim in carrying out the youth survey is to develop a deeper understanding of the practice of FGM in the UK by exploring perceptions, attitudes and experiences of young people between the ages of 16 and 25. Its objectives are:

³⁰ One other was detected post-delivery and the antenatal notes of the remaining woman were missing.

- To ascertain young people's knowledge and attitudes to FGM
- To assess the scope of FGM in the UK by collecting data on young people's experiences
- To develop a better understanding of young people's experiences of accessing services relating to FGM

Quantitative data is currently being collected using an online survey. The survey was launched in February 2012 and will run for six months with the aim of getting 2000 responses. There is a separate survey for males and females. Both surveys cover knowledge of FGM, attitudes towards FGM, and FGM and the law. For female respondents there are questions about experiences of FGM and knowledge of FGM specialist services. FORWARD chose an online survey because of the high level of internet use amongst their target group of young people. It is also cheap and allows for quick and high volume data collection.

Results

By the date of the workshop FORWARD had received 105 responses and six of those respondents had experienced FGM. The number of responses from men so far is low. The results will be available by the end of the year.

Difficulties with the method

- It will be very difficult to interpret the results because of the sample bias. Even if there are 2000 responses there will be no way of knowing to what extent the experiences and attitudes uncovered are representative of the total population.
- It took 11 months to get ethical clearance.
- If the researchers receive information that girls are at risk, because the surveys are anonymous, there is very little they can do to help. They tried to address this by giving as much information as possible about agencies that will be able to help.
- There can be technical problems with the survey if the internet is not working or if Survey Galaxy (the website hosting the survey) is down.
- Advertising the survey has taken a lot of effort using all of FORWARD's contacts. Because of the sensitivity of the issue, many institutions such as universities have not wanted to publicise it.
- They have received responses from people not from FGM-affected communities who want to give their views on the issue. This was not the intended research group.
- The respondents are reporting their own ages and they may not be honest about this.

6 COMMUNITY STUDIES

6.1 COMMUNITY STUDIES : Peer Research on FGM, Key Findings to date Paper presented by Ellie Brown, Head of UK Programmes, Options UK

Objective and method

Options UK have carried out three studies³¹ on FGM using participatory ethnographic evaluation and research (PEER). PEER is a methodology that seeks to gain insight into the attitudes of hard-to-research groups by training members of those groups to carry out in-depth conversational interviews with trusted individuals they select from their own social networks. By using established relationships of trust between peer researchers and their friends, PEER provides insight into how people view their world, conceptualise their behaviour and experiences, and make decisions.

Results

- FGM is not openly discussed even within practising communities but many respondents reported that there is still strong pressure to circumcise daughters, and that at least some people still support and/or practice FGM.
- Girls may be circumcised against their parents' will, typically at the wish of their grandmothers. Stories were reported of girls being sent 'back home' to be circumcised, often following significant pressure from family and/or the wider community.
- The age at which young women were vulnerable to circumcision was not just in the pre-teen period, but also in the late teens or as high as 21 years.
- Attitudes to the law are changing. In the past it was thought that the Female Genital Mutilation Act was a deterrent but the lack of prosecutions makes it difficult for advocates to use the law as an argument.
- Type 4 FGM (which includes pricking, piercing or incision) is more widely accepted in the UK than other forms of FGM.
- Even if women are against FGM, it can be difficult for them to challenge the practice. Therefore, some respondents demanded that more needed to be done to stop FGM, through more rigorous enforcement of the law or greater efforts to educate people.

³¹ Kate Norman, Joanne Hemmings, Eiman Hussein, Naana Otoo-Oyortey (July 2009) *FGM is always with us, Experiences, Perceptions and Beliefs of Women Affected by Female Genital Mutilation in London Results from a PEER Study*, <http://www.forwarduk.org.uk/news/news/563>;

Alexis Palfreyman, Eleanor Brown, Sara Nam (April 2011) *Understanding Female Genital Mutilation in Birmingham, Findings from a PEER Study* <http://www.bswaid.org/wp-content/uploads/2012/01/Final-report.-PEER-FGM-in-Birmingham.-06.05.2011.pdf>;

Joanne Hemmings (October 2011) *The FGM Initiative Interim Report* <http://www.trustforlondon.org.uk/FGM%20Interim%20Report.pdf>;

- Men's perspectives on FGM are mixed. They are not as in favour of FGM as is often assumed. Because FGM is not discussed openly between men and women, there is a gap between the views of many men, and what women think men think.
- Migration may change attitudes, particularly if people have come through countries where advocacy on a rights basis is strong. For example, those who had come through the Netherlands were very opposed to the practice.
- There were stories about FGM being practised in the UK.
- Within the researched groups, arguments against FGM tend to be based on the negative health implications rather than women's rights and children's rights. This can make it difficult to formulate arguments against type 1 FGM and FGM carried out in a medical setting and using painkillers.

Difficulties with the method

- Peer studies cannot tell us about prevalence of FGM.
- The studies reveal that male attitudes are not uniformly and straightforwardly in favour of FGM and more work needs to be done to understand men's attitudes better.
- PEER studies tell us what people say about FGM. What people actually do may be different and PEER cannot tell us about this.

6.2 COMMUNITY STUDIES: Researching Female Genital Mutilation (FGM) Intervention Programmes Linked to African Communities in the EU (REPLACE).

Paper presented by Dr David Beecham, Faculty of Business, Environment and Society, Coventry University and Hussein Hussein, Researcher

Objectives and method

The study used Participatory Action Research (PAR), an approach that uses the research process to bring about long-term change in the research group. It engages the community being researched in the research process which means that interpretations of data are debated with the researched community and the research process is empowering to those taking part.

The objectives of the study were to:

- identify the key psychological, social and material barriers to ending FGM in the Somali and Sudanese communities.
- map these barriers onto behavioural change approaches and models.
- develop a behaviour change model that incorporates individual and community level change approaches.

Research was carried out with Sudanese and Somali groups in the Netherlands and the UK. Researchers were recruited who were representative of these groups. Each researcher carried out a focus group and in-depth interviews with people within their communities.

Results

- The researched communities regarded sunna and FGM as two different practices. They were more motivated to change behaviour concerning FGM Type III than other types of FGM.
- Religious leaders and prominent community leaders were seen as influential in setting the norms of the community, and therefore could be effectively used in anti FGM programmes.
- Whilst many women believed that men wanted to marry women who had been infibulated, men indicated this was not the case.
- Participants raised the issue of double standards in relation to male circumcision and also the legality of labiaplasty.
- There may have been a shift in the actual practice of FGM from Type III to FGM Types I and/or II, although it may be that this is only perceived to be the case. Without prevalence data it is hard to know.
- Focus on the health risks of FGM has meant that some communities appear to have adopted medicalisation procedures, including use of sterile equipment, antibiotics and anti-tetanus injections to prevent infection, and the procedure being performed in clinical settings and by medical professionals. Some community members are likely to view this as an appropriate compromise.

Difficulties with the method

- It was very difficult to get ethical clearance because of the illegality of FGM. The ethics committee was concerned about what would happen if a research participant disclosed that they had or were planning to carry out FGM.
- The research may not be fully participatory as it is unlikely to capture the voices in the community of those who are strongly in favour of the practice.
- All of the researchers were highly educated and therefore may not have been representative of the communities they were researching.
- Participants were suspicious of the researchers and it took a long time to convince people to be involved.
- Men in particular were not keen to talk about the issue as they saw it as women's business.
- Some researchers lost the trust of their communities by being involved and suffered from criticism and name-calling.

6.3 COMMUNITY STUDIES: Listening to African Voices, Female Genital Mutilation /Cutting among Immigrants in Hamburg: Knowledge Attitudes and Practice

Paper presented by Dr Anja Stuckert, Project Coordinator of Plan Germany

Objectives and method

The main purpose of the project was to develop an effective approach to promoting the abandonment of FGM among immigrant groups in Hamburg. The objectives were as follows:

- To assess the proportion of immigrants with roots in practising families in Hamburg.
- To explore the attitudes, perceptions and opinions among immigrants from Sub-Saharan Africa toward FGM/C, notably the perceived advantages, the position of their religion on FGM/C and the proportion of supporters and opponents of the practice.
- To provide an estimation of the proportion of girls and women concerned from different countries of origin.
- To assess the ratio and profile of girls at risk.
- To investigate whether families subject their daughter(s) living in Hamburg to the practice and if so, how they proceed.
- To establish profiles of low- and high-risk communities (by country and region).
- To explore the level of awareness about the medical risks and other disadvantages resulting from FGM/C among immigrants from Sub-Saharan Africa in Hamburg.
- To collect ideas from men and women immigrants on how FGM/C can be addressed and effectively prevented among practising communities in Hamburg.
- To identify opponents of FGM/C within communities of practising origin who are interested and motivated to lead and participate in activities against FGM/C.

The project recruited 21 interviewers from 14 African countries. They carried out 91 qualitative interviews and 1,767 quantitative interviews with African immigrants from 26 Sub-Saharan African countries.

Results

- FGM was not part of the tradition for 60% of respondents
- 40% of respondents belonged to practising families
- 81% of respondents rejected FGM
- There were strong supporters for FGM from Benin, Burkina Faso, Gambia, Guinea, Nigeria, and Togo
- Immigrants see other problems such as residency status, access to work permits and housing as more pressing than FGM
- About 30% of the women interviewed in Hamburg had been subjected to FGM
- Within the cohort of daughters of the interviewed immigrants, about 7% of the girls had been subjected to FGM in their countries of origin
- The laws in Germany are a strong deterrent and fear of discovery is high. They worried that if discovered they would lose their residency in Germany.

- All respondents were clear that FGM was not being carried out in Hamburg
- Prevalence rates in African countries cannot always be applied directly to immigrant communities.

Difficulties with the method

- Participants in the quantitative survey were not randomly sampled. Because interviewers used their social networks as a source of participants, community members not involved in those networks were less likely to be interviewed.
- The results cannot be extrapolated beyond Hamburg. As a result of chain migration, there are very high concentrations of certain ethnic groups in the city. Other locations are likely to have high concentrations of different ethnic groups.
- The interviewers needed psychological back up: some were treated as traitors to their communities; others were shocked and upset at what they learned about the practice of FGM.
- It was very difficult to do interviews with people who did not have residence permits. Even though they were assured the interviews were anonymous, they worried that the information would be handed over to the authorities.
- It was almost impossible to find asylum seekers who were willing to be interviewed.
- The report focused exclusively on sub-Saharan Africa. Furthermore, the interviewers were not able to identify participants from some sub-Saharan countries.
- Data was collected using oral testimonies. Therefore there is a risk that participants responded in ways they regarded as being more socially desirable.