

**Technical Brief** 

# CONSIDERATIONS ON THE USE AND INTERPRETATION OF SURVEY DATA ON FGM/C

NOVEMBER 2016





This technical brief "Considerations on the use and interpretation of survey data on FGM/C," has been written by Bettina Shell-Duncan as an addendum to the trends presented in the "State of-Art-Synthesis of Female Genital Mutilation/Cutting: What Do We Know Now?" published in October 2016.

*Evidence to End FGM/C: Research to Help Girls and Women Thrive* generates evidence to inform and influence investments, policies, and programs for ending female genital mutilation/cutting in different contexts. Evidence to End FGM/C is led by the Population Council, Nairobi in partnership with the Africa Coordinating Centre for the Abandonment of Female Genital Mutilation/Cutting (ACCAF), Kenya; Gender and Reproductive Health & Rights Resource Center (GRACe), Sudan; Global Research and Advocacy Group (GRAG), Senegal; Population Council, Nigeria; Population Council, Egypt; Population Council, Ethiopia; MannionDaniels, Ltd. (MD); Population Reference Bureau (PRB); University of California, San Diego (Prof. Bettina Shell-Duncan); and University of Washington (Dr. Gerry Mackie).



The Population Council confronts critical health and development issues, from stopping the spread of HIV to improving reproductive health and ensuring that young people lead full and productive lives. Through biomedical, social science, and public health research in 50 countries, we work with our partners to deliver solutions that lead to more effective policies, programs, and technologies that improve lives around the world. Established in 1952 and headquartered in New York, the Council is a nongovernmental, nonprofit organization governed by an international board of trustees. **popcouncil.org** 



The University of Washington is one of the world's preeminent public universities. Our impact on individuals, our region, and the world is profound— whether we are launching young people into a boundless future or confronting the grand challenges of our time through undaunted research and scholarship. We turn ideas into impact and transform lives and our world. washington.edu

**Suggested citation:** Shell-Duncan, Bettina. "Considerations on the Use and Interpretation of Survey Data on FGM/C. Addendum to the SOTA. November 2016," *Evidence to End FGM/C: Research to Help Women Thrive.* New York: Population Council.

More information about the *Evidence to End FGM/C: Research to Help Women Thrive* work is available on our website: <u>http://www.popcouncil.org/EvidencetoEndFGM-C</u>.

Dr. Jacinta Muteshi, Project Director, jmuteshi@popcouncil.org

© 2016 The Population Council, Inc

Funded by:



This document is an output from a project funded by UK aid by the UK Government for the benefit of developing countries. However, the views expressed and information contained in it are not necessarily those of, or endorsed by the UK Government, which can accept no responsibility for such views or information or for any reliance placed on them.

# Considerations on the Use and Interpretation of Survey Data on FGM/C

# Household surveys with nationally representative data on FGM/C

Scholars and reformers have long sought reliable figures on the prevalence and geographic distribution of FGM/C, as they are useful in a number of respects. They provide information on the distribution of FGM/C practices, suggesting where resources and programming efforts may best be directed. They allow for estimates of the number of girls and women at risk of being cut each year, and provide information on changes in the practice of FGM/C over time. Additionally, when combined with immigration records, they can be used to estimate prevalence in the African diaspora, and to provide estimates of the global prevalence of FGM/C.

For many years there was insufficient data to track changes in the prevalence and distribution of FGM/C. Fran Hosken, in the 1979 and subsequent editions of The Hosken Report (most recently 1994), was a pioneer in generating estimates of the prevalence of FGM/C on a country by country basis. However, in the absence of large scale, nationally representative data, she was forced to rely on anecdotal accounts. Since that time, important sources of reliable data have been generated, providing more accurate information on FGM/C practices and attitudes. The majority of these data are derived from cross-sectional survey research, and the strengths and limitations of this research approach should be born in mind when using and interpreting these data.

### **Data Sources**

Nationally representative data on FGM/C are available from a number of population-based surveys:

- Demographic and Health Surveys (DHS)
- Multiple Indicator Cluster Surveys (MICS)
- Sudan Health and Household Survey (SHHS)
- Risetkesehatan Dasar, Basic Health Research Survey (RISKESDAS)
- Zambia Sexual Behavior Survey (ZSBS)

Table 1 summarizes the survey data available as of August, 2016. ZSBS collected information on FGM/C in 2005 and 2009, but are not listed in this table here because questions on FGM/C status are not comparable to those in the DHS or MICS surveys, and FGM/C appears to be found only in immigrant communities. All other survey data are from countries where FGM/C is found in at least 1% of the population. RISKESDAS, a recent survey conducted in Indonesia by the National Institute of Health Research and Development of the Ministry of Health reports data on girls ages 0-11 only, whereas the DHS, MICS and SHHS collect data from women ages 15-49 (and in some instances also data on daughters, and some surveys from men).

Country	Data source
Benin	DHS 2001, DHS 2006, MICS 2014
Burkina Faso	DHS 1998-99, DHS 2003, MICS 2006, DHS/MICS 2010
Cameroon	DHS 2004
Central African Republic	DHS 1994-95, MICS 2000, MICS 2006, MICS 2010
Chad	MICS 2000, DHS 2004, MICS 2010
Côte d'Ivoire	DHS 1994, DHS 1998-99, MICS 2006, DHS 2010
Djibouti	MICS 2006
Egypt	DHS 1995, DHS 2000, DHS 2003, DHS 2005, DHS 2008, DHS 2014
Eritrea	DHS 1995, DHS 2002
Ethiopia	DHS 2000, DHS 2005
Gambia	MICS 2005-06, MICS 2010, DHS 2013
Ghana	DHS 2003, MICS 2006, MICS 2011
Guinea	DHS 1999, DHS 2005, DHS 2012
Guinea-Bissau	MICS 2006, MICS/Reproductive Health Survey (RHS) 2010, MICS 2014
Indonesia (girls under age 12)	RISKESDAS 2013
Iraq	MICS 2011
Kenya	DHS 1998, DHS 2003, DHS 2008-9, DHS 2014
Liberia	DHS 2007, DHS 2013
Mali	DHS 1995-96, DHS 2001, DHS 2006, MICS 2010, MICS 2015
Mauritania	DHS 2000-01, MICS 2007, MICS 2011
Niger	DHS 1998, DHS/MICS 2006, DHS 2012
Nigeria	DHS 1999, DHS 2003, MICS 2007, DHS 2008, MICS 2011, DHS 2013
Senegal	DHS 2005, DHS 2014 (continuous)
Sierra Leone	MICS 2005, DHS 2008, MICS 2010, DHS 2013
Somalia	MICS 2006, MICS 2011 (for Somaliland and for Northeast Zone)
Sudan (Northern)	DHS 1989-90, MICS 2000, SHHS 2006, SHHS 2010, MICS 2014
Tanzania	DHS 1996, DHS 2004-05, DHS 2010
Тодо	MICS 2006, MICS 2010, DHS/MICS 2013-14
Uganda	DHS 2006, DHS 2011
Yemen	DHS 1997, DHS 2013

#### Table 1. Population-Based Surveys with FGM/C Modules/Questions as of August, 2016

Since its initiation in 1984, DHS have been carried out in over 90 countries, and in most cases are repeated at 5 year intervals. DHS provide relatively comparable data on fertility, family planning, child health, morbidity, and mortality. A module on FGM/C was developed for the 1989-90 survey conducted in the northern part of what was then known as Sudan. Subsequently, the survey was offered as an optional module for countries where the prevalence of FGMC is thought to be greater than 1%. The decision as to whether to include the FGM/C module is made by the individual countries concerned, and customized questions are often tailored to meet the data needs of Ministry of Health and other interested parties. The Multiple Indicator Cluster Survey program was developed by UNICEF in 1995, and beginning in 2000 a module on FGM/C was added. Data are currently available for 27 African countries, plus Yemen and Iraq, and data on girls under age 12 are available from Indonesia.

# **Development of a Standardized FGM/C Survey Module**

The module developed by DHS and MICS prior to 2010 commonly included questions about four topics:

- The circumcision status of the respondent herself (targeting women between ages 15 and 49);
- 2) Information about the event for those respondents who were circumcised;
- Information about the status of one daughter (sometimes the eldest and sometimes the most recently cut daughter) and details about the event in cases where a daughter had undergone FGC; and
- 4) Women's (and sometimes men's) opinion of the practice.

The form in which questions were asked has varied significantly across different survey questionnaires; UNICEF has compiled a list of more than 200 different questions that have been used in surveys (see UNICEF 2013: appendix). This creates challenges in comparing data from consecutive surveys in a single country or in surveys across countries. After a series of meeting to discuss possible revisions to the module on FGM/C, DHS and UNICEF agreed to coordinate module revisions, and in 2010 they adopted a standardized module. This module differs from the one used in DHS surveys between 2001 and 2009 in several respects:

- 1) Questions on the benefits or effects of FGC for daughters were dropped because they did not produce reliable data that was easy to interpret;
- 2) The question on intention to circumcise a daughter was dropped due to concerns about reliability;
- 3) The module asks each respondent with at least one living daughter about the current FGC status *all daughters* under the age of 15 (not just the eldest or most recently cut); and
- 4) The number of questions about opinions about FGC are reduced.

The decision to collect data on circumcision data on all daughters under age 15 was driven by an interest in calculating prevalence of FGC in girls 0-14 where the effects of the most recent intervention efforts are most likely to be visible. In most West African surveys, an FGM/C module was also developed for men. In 2010 this module was also revised and standardized to include only 3 questions:

- 1) Have you ever heard of female circumcision;
- 2) Do you think the practice of FGC is required by your religion; and
- 3) Should the practice of FGC continue or be stopped?

Questions that were dropped from the modules for both men and women were done to save space and time, and because answers to the questions were difficult to interpret. With the revision and standardization of the FGC modules, repeat data collection allows for comparison of trends across 5 year intervals, comparison of data across countries, and analysis of rates and correlates of change in the nature and practice of FGM/C.

# **Survey Sampling Considerations**

The population-based surveys are not census data, but instead are sample surveys, and therefore there are sampling errors around the point estimates. However, the sample sizes are large enough that the confidence intervals are within acceptable ranges and the estimates are robust. The sampling strategy for DHS and MICS survey are designed to be nationally representative, and ideally provide information for each region.

A two stage sampling process is typically employed. In the first stage clusters are selected from a list of enumeration areas with probability proportional to size. In the second stage, a complete household listing is completed in each selected cluster, followed by the random selection of a set number households per cluster. In each household, all women age 15-49 are typically interviewed.

At times there are variations in sampling frames that need to be taken into account when comparing data from two or more consecutive surveys. Such changes may include adding new regions to the survey, changing the eligibility criteria, or altering the sample fraction in particular regions. In such instances, the data may need to be adjusted to assure comparability. Examples from Kenya and Egypt illustrate two important cases in point.

#### Case 1: Sampling Changes in Kenya

In the Kenya DHS 1998, the North Eastern Province was not included. It was added in the 2003, 2008-09 and 2014 DHS. This change in sampling frame makes direct comparability of the 1998 national prevalence rates to those from later surveys inappropriate. We can compare the overall prevalence figures from 1998, 2003 and 2008-09 surveys by excluding data from the North Eastern Province from the calculation of FGM/C prevalence from the latter two surveys.

#### Case 2: Sampling Changes in Egypt

In Egypt there is a different change in the sampling frame across repeat surveys that results from a change in the eligibility criteria. The DHS surveys conducted between 1995 and 2000 sampled ever-married women between the ages of 15 and 49. In the 2008 and 2014 DHS, a change was made: both ever-married and never-married women between the ages of 15 and 49 were eligible. The apparent decline in the prevalence from 96% in 2005 to 91% in 2008 is largely due to the fact that the prevalence of FGM/C is lower among never-married women. Cross-survey comparisons need to adjust for these differences in sampling frame.

#### **Determination FGM/C Status**

The population-based surveys analyzed in this report provide data for calculating two types of prevalence indicators: the prevalence among women, and the prevalence among daughters. The first is calculated from self-reported circumcision status, in most surveys from the response to the question, "Are you circumcised?" or variants that seem to capture similar meaning: "Have you been circumcised?", "Have you ever been circumcised", "Have you yourself ever had your genitals cut?", and "Did you have your external genitals cut?" Exceptions are found in surveys from Sierra Leone (MICS 2005, DHS 2008) and Liberia (DHS 2007), where the questions were adjusted to eliminate the direct reference to FGM/C because of sensitivity of the topic. Respondents were

instead asked whether they had been initiated into a women's secret society, such as the Bondo or Sande in Sierra Leone and the Sande in Liberia, and who initiated her. This provides indirect information on FGM/C since it is performed during initiation.

#### Reliability of Self-Reported FGM/C Status

Self-reported data on FGM/C needs to be treated with caution as inaccuracies may arise for a number of reasons. Because of the sensitivity of the topic or illegal status, women may be unwilling to disclose having undergone FGM/C (Askew, 2005). Additionally, particularly when FGM/C is performed at an early age, women may be unaware of whether they have been cut or the extent of the cutting. Recall bias is also a possibility: a 45 year old woman reporting about being cut at age 5 is reporting about an event that occurred 40 years in the past. The translation of survey questions also opens possibilities for ambiguity; term "female circumcision" must be translated into a local term, and the choice of wording may influence which types of cutting are understood to be FGM/C.

A number of studies have attempted to determine the reliability of self-reports of FGC status by verifying them through clinical examinations. This body of research has assessed two aspects of self-reported data: 1) the reliability of women's self-reports about having been cut or not, and 2) the reliability of self-reports of the type of FGM/C performed. Studies that have compared women's self-report of being cut or not to clinically observed signs of FGM/C have reported variable rates of concordance. While one study in Sudan reported complete agreement between clinical examination and women's reports of having undergone some form of FGM/C or not (Elmusharaf et al., 2006), others report variable degrees of discrepancy.

Morison and colleagues found 3% disagreement in The Gambia, whereas studies in Tanzania and Nigeria reported disagreements in more than 20% of women (Adinma, 1997; Msuya et al., 2002; Klouman et al., 2005; Snow et al., 2002). Nicking would not be expected to produce any clinically observable alteration of the external genitalia, and may account for some degree is difference between self-reports and clinical observations. However, inaccuracies of self-reported data on FGM/C must be considered. A longitudinal study in Ghana afforded a unique opportunity to assess the consistency of women's self-reports of FGM/C status over repeat surveys (Jackson et al., 2003). The data showed that a substantial number of adolescent girls who initially reported having undergone FGM/C later denied being cut. The authors concluded that denials of having undergone FGM/C.

In a detailed overview of methodological considerations for measuring change in FGM/C, Askew (2005: 472-73) emphasizes the need to consider the context in which questions of FGM/C status are being asked: "If FGC is widespread, socially acceptable and there is no well-publicized interventions causing people to question its acceptability and legality..., then self-reporting is likely to be valid. If there are reasons why it would not be attractive for respondents to declare that they are cut..., then self-reported measures should be questioned and ways sought to validate the results." Nonetheless, there appears to be consensus among professionals working with DHS and MICS that "there is sufficiently strong confirmation of FGC status from women's reports to warrant the use of survey data to calculate the prevalence of FGC" (Yoder et al., 2004: 10).

#### Reliability of Self-Reports on Type of FGM/C

Studies of the correspondence between self-reported type of FGM/C and clinically observed type also report variable levels of disagreement, with more frequent under-reporting than over-reporting of the extent of cutting (Morison, et al., 2001; Elmusharaf et al., 2006). It may be difficult to make a clear correspondence between the local vernacular describing type and descriptions used in survey questions. Additionally, women may be unaware of the details of their own genital modification. Information on the FGM/C status of daughters, the type, and the circumstances surrounding the practice is generally regarded as more reliable than women's self-reports since daughter's FGM/C occurred more recently, and mothers are assumed to have been involved in the event (Yoder et al., 2004).

### Prevalence of and Support for FGM/C before and after Passage of a Law: Considerations Regarding Reliability of Survey Data

Legislative measures that prohibit the practice of FGM/C have been put in place in many countries, including some where survey data have been collected both before and after enacting criminal bans. How does criminalization of FGM/C influence reliability of survey data collection? Analysts have looked, in particular, at potential impacts on two outcome measures: stated support for the continuation of FGM/C and self-reported FGM/C status. Deterrence theory suggests that where there is widespread knowledge of a law and belief in its enforceability, fear of prosecution should reduce support for FGM/C and contribute to a decline in the practice. However, when legal norms run counter to social norms, moral values or religious beliefs, legislative reform may have a limited effect on change in attitudes and practices, and it may drive the practice underground and influence truthfulness in survey responses regarding FGM/C. This could lead to inaccurate reporting on both support for FGM/C and a woman or daughters' cutting status. The degree to which survey respondents are influenced to change in FGM/C practices and attitudes resulting from fear of prosecution or, alternatively, influenced to be unwilling to honestly disclose their FGM/C status or views due to fear of prosecution or courtesy bias is, however, unclear and requires further research.

# Use and Interpretation of Data on FGM/C Status of Daughters

#### Different Ways that Data on Daughter's FGM/C has been Collected

Information of the girls' FGM/C status has been collected in a variety of ways across different surveys, some of which do not allow for the calculation of prevalence of FGM/C among daughters. In surveys up to 1999, female respondents who had at least one living daughter were asked about their eldest daughter: whether she was cut, age at which FGM/C was performed, type of FGM/C and the person who performed FGM/C. When the eldest daughter was reportedly not cut, respondents were asked whether they intended to have their daughter cut.

Beginning in 1999, rather than asking about the eldest daughter, DHS surveys began asking respondents whether any of their daughters had undergone FGM/C. Those who answered negatively were asked whether they intended to cut any daughters. Those who answered positively were next asked how many of their daughters were cut. This was followed by questions on details about the FGM/C procedure (age, type of FGM/C and type of practitioner) for the daughter most recently cut.

Data on the cutting status of one daughter (either eldest or most recently cut) can be used to calculate the percent of women with at least one living daughter who is cut. It cannot, however, be used to estimate the prevalence of FGM/C among girls under the age of 15 because it does not provide the needed denominator. This is unfortunate since this age group is the one that has most recently been at risk of being cut, and where the impact of recent efforts to end FGM/C will be seen. To address this limitation, the Egypt DHS and Sudan SHHS modules on FGM/C began to collect information on FGM/C status on all respondent's living daughters.

Complete data on age at FGM/C amongst all daughters therefore has two benefits:

- 1) it allows for the estimation of prevalence of FGM/C at the youngest ages where effects of recent changes will be detected, and
- 2) it allows for the analysis of trends in age at FGM/C across generations.

Because of the value of this additional information, the MICS and DHS modules on FGM/C have been standardized to include question on all daughters as of 2010.

# Considerations for Analysis of Complete Daughter Data: Understanding the Difference between Current and Final FGM/C Status

One reason for asking about FGM/C status of all daughters of respondents is to obtain data that can allow for comparison of rates of FGM/C to those in older generations, providing clues about recent progress toward abandonment of FGM/C. The analysis and interpretation of data on all daughters age 0-14 are not as straight forward as it might seem since not all girls have reached their final cutting status. Girls under the age of 15 include three groups:

- 1) girls who are currently cut;
- 2) girls who are currently uncut, but will be cut in the future; and
- 3) girls who are currently uncut, and never will be cut.

Hence, not all daughters have attained their final cutting status. Statistical analysis of these type of data require specialized approaches.

Cases in which a girl may still be at risk of being cut in the future are described as statistically "censored" observations. As age at cutting varies in different settings, the amount of censoring will vary. Stated another way, we must carefully distinguish between current FGM/C status and final FGM/C status. Mother's reports of daughter's FGM/C status only tells us about current status. As data on prevalence of FGM/C in early age cohorts are compared, this must be kept in mind. It also influences whether prevalence data from the 5-9 and 10-14 age cohorts can be used to detect recent changes. Where most cutting is performed by age 5, as is the case in Senegal, the prevalence in 5-9 and 10-14 cohorts will reflect recent changes in the prevalence of FGM/C. By contrast, in countries such as Egypt and Kenya where many girls are cut after the age of 10, the data in the youngest cohorts are highly censored, and do not provide a clear picture on recent change.

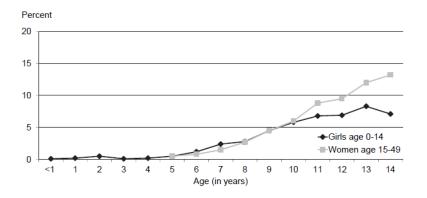
#### Considerations for Making Mother-Daughter Comparisons

There is great interest in determining whether recent efforts to end the practice are having an impact, and one way to begin to examine progress on abandonment of FGM/C is to compare rates among younger and older generations of girls and women. It is important to note that the data on prevalence do not isolate the effect of any one strategy. For instance, girls and women residing in any one region may have participated in multiple intervention programs or workshops aimed at discouraging FGM/C, they may have knowledge that the practice has become banned, and ongoing social change, such as increases in women's education, that drive changes in the practice. Nonetheless, data on daughter's age 0-14 provide insights on the effects of combined factors potentially discouraging the continuation of FGM/C in recent years.

Given that some daughters who are currently uncut may be still cut in the future, it is inappropriate to directly compare prevalence of FGM/C among girls ages 0-14 to that of women ages 15-49 without taking into account censoring. Doing so, however, is not a straight forward task. One simple method that has greater validity, though is still not perfect, is to compare the age-specific cutting rates of women and girls of different ages. In other words, one can compare the proportion of girls cut by their current age X to the proportion of women who reported having been cut by age X. Data from the 2014 Kenya DHS illustrate this (Figure 1). It is important to note a key difference between the data on girls and women: women age 15-49 are presumed to be at the final cutting status, while girls age 0-14 reflect current cutting status. A portion of these girls may still be cut in the future. This portion, however, decreases as age does up. Hence we have clues that rates of cutting appear to be declining in the younger generation of Kenyan women.

#### Figure 1. Age-specific rates of FGM/C among Kenyan women age 15-49 and girls age 0-14

(source: Kenya Demographic and Health Survey 2014 Report)



Also of interest is a comparison of the way FGM/C is performed across generations, including a comparison of average age of cutting between mothers and daughters. A direct comparison of the mean age at FGM/C between mothers and daughters is inappropriate because a portion of the currently uncut girls will be cut in the future. Consequently, girls who are cut at later ages are systematically underrepresented, resulting in an underestimation of the mean age at FGM/C. These censored cases provide valuable information because we know that girls did not undergo FGM/C at least until the date of the interview.

An analytical technique known as survival analysis can handle censored data, allowing for analysis of factors associated with rates of FGM/C in girls, as well as comparison of age at cutting in two or more groups, such as mothers and daughters. Data analysis of the 2008 Egypt data illustrate this.

Overall, the mean age at FGM/C for mothers was 9.4 years, and the mean age at FGM/C for daughters was 8.5 years. A direct comparison of the mean age at FGM/C, uncorrected for censoring, would suggest that the age at FGM/C is declining across generations. However, a survival analysis that statistically adjusts for censoring provides a different result. The survivor functions, show in Figure 2 reveal that the age at FGM/C is higher among daughters than among mothers. This suggests that the trend toward increased age at FGM/C detected across cohorts of adult women is continuing in the next generation.

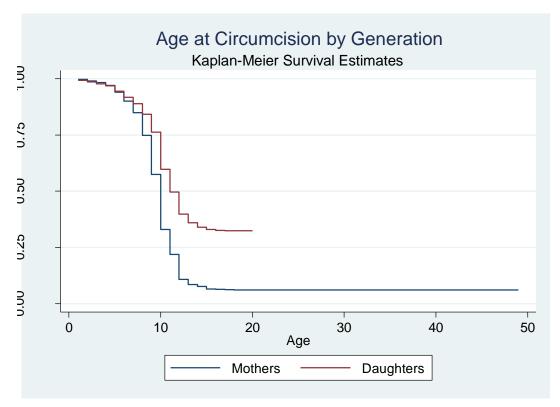


Figure 2 Survivor functions of Age at Circumcision among Egyptian Mothers and Daughters

# Estimating the Total Number of Girls and Women Affected by FGM/C

Once prevalence data on FGM/C have been generated for a particular country, a question that commonly follow is: How many girls and women are affected by FGM/C? Interest in this figure is two-fold: first, information on the number of girls and women who have undergone FGM/C provides information on the size of the population with specialized healthcare needs to address potential complications of FGM/C. This group is referred to a women "affected by" FGM/C. Second, girls who are currently not cut but may be cut in the future are described as an "at risk" population. It is this group that is in need of protection and efforts to prevent FGM/C. The short-hand term "at risk" is sometimes used to describe both groups of women. This is unfortunate, as it conflates two groups that have very different needs.

#### Estimating the Total Number of Women "Affected by" FGM/C

For girls and women age 15-49, generating the total number cut is a straight forward calculation: population size estimates from the US Census Bureau's International database census data provide estimates of the number of women aged 15-49, and this number is multiplied by the estimated prevalence of FGM/C for this same age group derived from nationally-representative survey data. To estimate the number of women over age 49 who have been cut, extrapolation methods are used. This involves using the estimated prevalence among women age 45-49, and applying this to the population estimates of women age 50+. Using this method, we can calculate the total number of women cut from the 29 countries for which we have data. This results in an estimated total number of women cut at 96,151,412. This is an update of earlier estimates produced by Yoder and colleagues (2013).

Recently, population-based data on the prevalence of FGM/C have been released for Indonesia. Unlike the DHS and MICS surveys, data were not obtained on the FGM/C status of women age 15-49. Instead, data on prevalence was obtained only for girls aged 0-11 years. To add estimates of women from Indonesia to the total number of women cut, extrapolation is required: prevalence of FGM/C from girls ages 0-11 are applied to census estimates of the number of women age 15 and over. This produces a revised estimate of the total number of women age 15 and over who have been cut, this time from 30 countries, including Indonesia. This produces an estimated total number of women cut at 143,427,374. The validity of the extrapolation method used in Indonesia is unclear. Obtaining direct data on FGM/C in women ages 15-49 in Indonesia is an important gap that should be filled.

#### Estimating the Total Number of Girls "At Risk" of FGM/C

The total number of girls "at risk" of FGM/C is estimated by two methods. For the 29 countries with data on FGM/C from women ages 15-49, the prevalence estimates from girls in the 15-19 age cohort can be multiplied by the census estimates of the number of girls ages 0-14 from each country. This method that the rate of FGM/C in girls under age 0-14 are continuing at the same rate as girls age 15-19. If rates of FGM/C are, in fact, declining, this overestimates the true number of girls ages 0-14 who will be cut. Calculations using this method estimate that 52,725,544 girls age 0-14 are at risk of FGM/C. This includes a combination of girls who are already cut and girls who will be cut in the future.

Data from Indonesia provide estimates of the prevalence of FGM/C in girls ages 0-11. This number is multiplied by the population size of girls ages 0-14, and added to produce a total number of girls at risk of FGM/C from 30 countries, including Indonesia: 69,476,244.

#### Estimating FGM/C in Immigrant Communities

There has also been interest in estimating the prevalence of FGM/C in countries in Western Europe and the United States that have for some 20 to 30 years been recipients of migrants from countries where FGM/C is practiced. This interest is motivated by a growing awareness of the need to direct resources and training to provide appropriate medical care to women who have been cut, and social services to prevent FGM/C from being performed on immigrant girls. Nationally representative survey data on FGM/C are not available in these countries.

Estimates of the prevalence of FGM/C have, therefore, been generated by combining figures on the number of women who migrated from a country of origin where FGM/C is found, and the national prevalence in their country of origin. The number of girls who are at risk of being cut is calculated by applying the national prevalence of FGM/C to the number of daughters of immigrants

from these same countries. In some instances estimates are applied to girls born in a country of origin where FGM/C is found, and in other cases it is also applied to second generation girls (those born in the new host country, but with at least one parent born in a country of origin where FGM/C is found).

Two important sources of uncertainty have been identified in the indirect estimation methods. First, Ortensi and colleagues (2015) find support for the migration selection hypothesis, which posits that voluntary migrants are not, in many instances, representative of the population in their country of origin. Migrants are more likely to be from higher socioeconomic sectors, more highly educated, and more likely to have resided in an urban area in their country of origin prior to migration. These factors are also associated with a lower risk of FGM in the country of origin are likely to over-estimate the number of women affected by FGM/C and the number of girls at risk of undergoing FGM in the future, and represent a maximum estimate. However, if migrant communities are composed in large part by resettled refugees, it is not clear that the migration selection hypothesis applies.

Second, it is unclear how much the process of acculturation affects the practice of FGM among girls under 18. A series of qualitative studies have demonstrated that the practice of FGC quickly falls from favor in immigrant communities as parents become aware of laws prohibiting the practice, learn that the practice is counter-normative in their new host societies, become more aware of the harmful health effects, and come to learn that FGC does not secure the future wellbeing of their daughters in their new host society (e.g. Johnsdotter, 2007; Johnson, 2007; Johnsdotter et al., 2009; Behrendt, 2010; Vloeberghs, 2011). We do not have quantitative data on the effects of acculturation. So it is recommended that rather than calculating a single "at risk" number, an upper and lower estimate should be computed. The upper estimate is based on the assumption that FGC among girls continues at the same rate as in the country of origin. The lower estimates that the risk drops to zero for second generation girls.

Much could be learned by gaining an improved understanding how quickly the probability of having a daughter cut decreases following immigration, and factors influencing this decline. Additionally, scholars in the European Union are currently developing a common definition of FGM/C prevalence, a common methodology and minimum standards for prevalence estimates of FGM/C in the EU, and methods for creating direct estimates of the number of women affected by FGM/C and number of girls at risk of FGM/C.

#### Global Estimates of the Number of Girls and Women at Risk or Affected by FGM/C

As UNICEF (2015) clearly states, the exact number of girls and women who are at risk or have been affected by FGM/C worldwide is unknown. Data on the prevalence of FGM/C among Indonesian girls ages 0-11 can be used to indirectly estimate prevalence on girls and women ages 12 and over by extrapolation. When this is done, we have estimates on FGM/C based on population based data from 30 countries (the other 29 countries have data from women ages 15-49). Tallying estimates on the number of girls and women at risk or who have undergone FGM/C, UNICEF (2015) estimates that at least 200 million girls and women in 30 countries are affected by FGM/C. They further emphasize that there many countries where data on FGM/C do not exist, and more reliable information is needed to complete more accurate global estimates of FGM/C worldwide.

#### Summary of Main Issues

The purpose of Table 2 is to provide a summary of the key findings reviewed in the State-of-the-Art Synthesis on Female Genital Mutilation/Cutting, and assess the degree of confidence we have in these findings based on the available data and methodological issues outlined in this addendum. To assess confidence in the findings, we rated each finding as adequate (with a score of 1) or inadequate (with a score of 0) according to four criteria:

- 1) Availability of comparable population-based data;
- 2) Consistency of results across populations or across consecutive surveys;
- 3) Degree to which data collection methods are influenced by potential bias or inaccuracy, leading to lower reliability;
- 4) Degree to which statistical inferences in the report are adequate to address the issue.

Ratings for each criterion were summed, creating an overall confidence score that ranged from 0-4. Confidence levels were defined the summed score as follows: High – 4; Moderately high – 3; Moderate – 2; Moderately low – 1; Low – 0.

Issue/Theme	Finding	Level of Confidence/ Data Considerations
Prevalence of f FGM/C a C r C	Nationally-representative data from women ages 15-49 area available for 29 countries Current prevalence estimates range from 1% (Uganda, Cameroon) to 98% (Somalia) Prevalence has been estimated	Level of confidence: Moderate Considerations: Data are from self-reports from women, which may be subject to bias; Sampling frames may not consistently include all women (e.g. unmarried women, women residing in districts not surveyed), but data from sequential surveys can be statistically adjusted to allow comparability. Level of confidence: Moderately low
	for other countries using extrapolation methods (data from country of origin in the case of migrant communities, or younger age groups in the case of Indonesia)	Considerations: Migrants may be select groups with prevalence rates different than women in the country of origin, and prevalence rates may alter after migration; Whether rates of cutting in Indonesian girls ages 0-11 applies to girls and women over age 12 in unclear.
FGM/C among Daughters	Data on FGM/C among daughters has been collected in different ways, including the cutting status of the eldest daughter, the most recently cut daughter or all daughters age 0-14; the latter is now the standardized method and can be used to estimate prevalence in girls age 0-14	Level of confidence: Moderate Considerations: Data obtained from mothers on the FGM/C status of their daughters may be less subject to recall bias; Interpretation of prevalence data on all girls 0-14 is complicated by the fact that it is a mixture of girls who have reached their final cutting status (cut or not cut) and those who may still be cut in the future
Age at which FGM/C was performed	In most countries women ages 15-49 report being cut before the age of 5;	Level of confidence: Moderate Trends in age at cutting come from self-report of women age 15-49, and may be subject to bias;

#### Table 2. Major Findings and Data Considerations

Issue/Theme	Finding	Level of Confidence/ Data Considerations
	Where cutting takes place at older ages, there is often, but not always, a trend toward younger age at cutting	Some countries collect age at cutting among daughters, which may be less subject to recall bias. However, not all daughters have reached their final cutting status, which needs to be factored into analysis of daughter data.
Type of FGM/C performed	Questions on type of FGM/C have not been collected uniformly across different surveys; it appears that most women 15-49 have been subjected to Type I and Type II FGM/C (categories combined); three countries with high rates of Type III are Eritrea, Somalia and Djibouti	Confidence: Moderate There may be inaccuracies in self-reported FGM/C status; Reports on type of FGM/C on daughters may be more accurate; Asks women to report information on anatomical detail that may be sensitive or difficult to describe.
Practitioners of FGM/C	Data on person who performed FGM/C has been collected in some surveys; the vast majority of girls are cut by traditional practitioners, rather than by health personnel; exceptions are Egypt and Sudan, where medical practitioners perform most FGM/C on daughters	Level of confidence: Moderate Women's self-reports may be less accurate than reports on daughters, particularly when women were cut at an early age; Data on both women and daughters may be subject to bias.
Subnational variation in FGM/C	In most countries the prevalence of FGM/C varies along lines of sub-region, urban vs. rural residence, ethnicity, household wealth, religion; this variation is often most pronounced in countries with a moderate or low prevalence of FGM/C, and can be useful to identify "hotspots" where FGM/C is practiced.	Level of confidence: Moderately high Analysis of sub-national variation in FGM/C among women ages 15-49 uses self-reported data on FGM/C status, which may be subject to bias; Accuracy of FGM/C data on daughters may be more accurate; Sampling frames may vary across repeat surveys, but data can be compared following statistical adjustment.
Trends in prevalence of FGM/C	Trends are easiest to see comparing prevalence of FGM/C across 5-year age cohorts among women ages 15-49. This methods reveals evidence of little or no change in prevalence of FGM/C 15 countries, 7 countries with apparent recent declines in the prevalence of FGM/C, and 7 countries with long-term, steady declines in FGM/C prevalence.	Level of confidence: Moderate Multivariate analyses that control for potentially confounding factors are needed to confirm these trends; Comparison of repeat consecutive survey data from a single country needs to examine changes in question wording and sampling methodology; Comparisons of prevalence across generations (mothers and daughters) need to control for the fact that daughters may not be at their final cutting status.
Support for the continuation of FGM/C	In many countries, the majority of women who have undergone FGM/C report wanting FGM/C to stop or are unsure whether it should continue; In many countries the majority of men also do not support the continuation of FGM/C.	Level of confidence: Moderately high Responses to questions on support for continuation for FGM/C may be subject to error from factors including courtesy bias or unwillingness to honestly disclose views.

# **References Cited**

- Adinma, J. (1997). Current status of female circumcision among Nigerian Igbos. West African Journal of Medicine, 16, 227-231.
- Askew, I. (2005). Methodological issues in measuring the impact of interventions against female genital cutting. *Culture, Health and Sexuality,* 7(5), 463-477.
- Behrendt, A. (2011). Listening to the African Voices. Female Genital Mutilation/Cutting among Immigrants in Hamburg: Knowledge, Attitudes and Practice.
- Elmusharaf, S., Elhadi, N., & Almroth, L. (2006). Reliability of self reported form of female genital mutilation and WHO classification: cross sectional study. *BMJ*, 333(7559), 124-128.
- Hosken, F. (1994). The Hosken Report: Genital and Sexual Mutilation of Females (5 ed.), Lexington, Massachusetts: Women's International Network News.
- Jackson, E. F., Akweongo, P., Sakeah, A., Hodgson, R., Asuru, R., & Phillips, J. E. (2003). Inconsistent reporting of female genital cutting status in Northern Ghana: Explanatory factors and analytical consequences. *Studies in Family Planning*, *34*(3), 200-210.
- Johnsdotter, S. (2007). Persistence of tradition or reassessment of cultural practices in exile? Discourses on female circumcision among and about Swedish Somalis. In Y. Hernlund & B. Shell-Duncan (Eds.), *Transcultural Bodies: Female Genital Cutting in Global Context*

(pp. 107-134). New Brunswick, New Jersey: Rutgers University Press.

- Johnson, M. (2007). Making Mandinga or making Muslims? Debating female circumcision, ethnicity, and Islam in Guinea-Bissau and Portugal. In Y. Hernlund & B. Shell-Duncan (Eds.), *Transcultural Bodies: Female Genital Cutting in Global Context* (pp. 202-223). Piscataway, NJ: Rutgers University Press.
- Kenya Demographic and Health Survey 2014 Report. https://dhsprogram.com/pubs/pdf/FR308/FR308pdf.
- Klouman, E., Manongi, R., & Klepp, K. I. (2005). Self-reported and observed female genital cutting in rural Tanzania: Associated demographic factors, HIV and sexually transmitted infections. *Tropical Medicine and International Health*, 10(1), 105-115.
- Morison, L. C., Scherf, C., Ekpo, G., Paine, K., West, B., Coleman, R., & Walraven, G. (2001). The longterm reproductive health consequences of female genital cutting in rural Gambia: A community-based survey. *Tropical Medicine and International Health*, 6(8), 643-653.
- Msuya, S. E., Mbizvo, E., Hussain, A., Sundby, J., Sam, N. E., & Stray-Pedersen, B. (2002). Female genital cutting in Kilimanjaro, Tanzania: Changing attitudes? *Tropical Medicine and International Health*, 7(2), 159-165.
- Ortensi, L. E., Farina, P., & Menonna, A. (2015). Improving estimates of the prevalence of female genital mutilation/cutting among migrants in Western countries. *Demographic Research*, 32(18), doi: 10.4054/DemRes.2015.4032.4018.
- Snow, R. C., Slanger, T. E., Okonofu, F. E., Oronsaye, F., & Wacker, J. (2002). Female genital cutting in southern urban and peri-urban Nigeria: Self-reported validity, social determinants and secular decline. *Tropical Medicine and International Health*, 7(1), 91-100.
- UNICEF (2013). Female Genital Mutilation/Cutting: A Statistical Overview and Exploration of the Dynamics of Change. NEW York: UNICEF.

- UNICEF 2015. Female Genital Mutilation/Cutting: A Global Concern. <u>http://www.unicef.org/media/files/FGMC\_2016\_brochure\_final\_UNICEF\_SPREAD.pdf</u>, accessed August, 2015.
- Vloeberghs, E., Knipscheer, J., van der Kwaak, A., Nalaie, Z., & van den Muijsenbergh, M. (2011). Veiled pain. A study in the Netherlands on the psychological, social and relational consequences of female genital mutilation.
- Yoder, P. S., Abderrahim, N., & Zhuzhani, A. (2004). *Female Genital Cutting in the Demographic and Health Surveys: A Critical Comparative Analysis*. Calverton, Maryland: Macro International.
- Yoder, P. S., & Wang, S. (2013). *Female Genital Cutting: The Interpretation of Recent DHS Data*. Retrieved from Calverton, Maryland:
- Yoder, P. S., Wang, S., & Johansen, E. (2013). Estimates of female genital mutilation/cutting in 27 African countries and Yemen. *Studies in Family Planning*, 44(2), 189-204.