FISTULA CARE *PLUS*:

Report of Technical Consultation on Fistula Measurement and Estimation

July 10-11, 2014

USAID FROM THE AMERICAN PEOPLE

Fistula Care *Plus*

EngenderHealth for a better life

Maternal Health Task Force

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Acknowledgements

The EngenderHealth Fistula Care *Plus* and Maternal Health Task Force teams would like to thank meeting participants (please see Appendix A) for sharing their ideas, insights, and experiences.

We would also like to thank the United States Agency for International Development, especially Mary Ellen Stanton and Erin Mielke, for their support of these meetings and for their commitment to fistula prevention and treatment in low-resource settings around the world.

This report was authored by Vandana Tripathi, with contributing material from Karen Beattie, Bethany Cole, and Kacie Dragan.

I. Overview of Report

The Fistula Care *Plus* (FC+) project and the Maternal Health Task Force co-convened a technical consultation in July 2014 to examine the measurement and estimation of fistula incidence, prevalence, and treatment backlog. This brief report describes meeting activities, presents the recommendations and research priorities identified through the meeting, and summarizes and an FC+ action plan developed in consultation with USAID.

Appendices provide the meeting participants, agenda, and technical presentations.

II. Meeting Processes

On July 10-11, FC+ staff; several members of the FC+ International Research Advisory Group (IRAG); and epidemiologists, demographers, fistula surgeons, midwives, and other researchers from around the world met at the Harvard School of Public Health. Appendix A provides the list of participants and Appendix B provides the meeting agenda.

This group's goal was to build a consensus regarding FC+ priorities related to the measurement and estimation of the prevalence and incidence of obstetric fistula. Presenters summarized available approaches to measurement and estimation, such as household surveys, Health Management Information Systems (HMIS), and estimation models. These technical presentations are summarized in Table 1 and provided separately in Appendix C. Participants discussed the merits and challenges of each approach in small groups, discussing questions summarized in Text Box 1. Through these discussions, participants identified implementation and research priorities. As broad agreement on priorities emerged in plenary discussions, specific research questions and potential study designs were also identified when possible. Finally, participants provided a set of recommendations to guide future measurement and estimation activities.

The technical consultation was directly preceded by a meeting of the FC+ IRAG, at which research priorities related to fistula epidemiology were also discussed. IRAG priorities were shared with participants in the measurement consultation.

Table 1: Presentations on Measurement and Estimation Methods

Title (*topic*)	Presenter
Fistula Measurement through the DHS Program	Kimberly Peven, The DHS Program
Household Surveys on Fistula Prevalence	Vandana Tripathi, FC+
Obstetric Fistula Rapid Assessment (*Key Informant Surveys*)	Alma Adler, London School of Hygiene and Tropical Medicine (LSHTM)
Community-based Screening for Obstetric Fistula in Nigeria (*Mixed-Methods Surveys*)	Özge Tunçalp, World Health Organization
Estimating the Prevalence of Obstetric Fistula – A Meta-Analysis and Systematic Review	Alma Adler, LSHTM
Challenges of Measuring the Burden of Obstetric Fistula (*Estimation Models*)	Saifuddin Ahmed, Johns Hopkins School of Public Health
Tracking Fistula through HMIS and Surveillance Systems	Vandana Tripathi, FC+
Estimating maternal morbidities in the community: a prospective cohort study in the Brong-Ahafo region of Ghana (*Findings from preliminary analysis*)	Caitlin Shannon, EngenderHealth

Text Box 1: Discussion Questions for Consultation Participants

1. Given current evidence and experience, what methods would you prioritize for gathering information to help policymakers and health system stakeholders plan for (including geographic location), organize and measure fistula treatment services?

2. Given current evidence and experience, what methods would you prioritize for gathering information to help policymakers and health system stakeholders plan for (including geographic location), organize and measure programs targeting fistula prevention?

3. What measurement or estimation methods are promising but require additional development (testing, refinement) to improve their ability to provide information to policymakers and health system stakeholders?

4. Are there any priority research questions related to fistula prevalence and incidence measurement or estimation that you recommend for investigation by the FC+ project?

5. Are there approaches to gathering data on fistula prevalence or incidence that should **not** be used by governments or other fistula program implementers?

6. Are there special considerations you recommend in gathering data about fistula incidence, including via HMIS?

II. Meeting Outcomes: Research Priorities

Through the presentations and discussions described above, consultation participations identified the following research and implementation activities that could strengthen the tools available to quantify the burden of fistula. Activities that emerged as recommended priorities for FC+ are noted first.

Priority research and implementation activities:
- Inventory and validation of fistula screening/diagnostic questions, tools, and approaches
- Systematic review of community outreach methods and their effectiveness in case identification and care-seeking, noting context-specificity.
- Use and evaluation of multi-arm case finding (e.g., through different types of key informants) to estimate prevalence
- Testing and improving estimation models – comparing results from estimation models to those from DHS or other population-based fistula prevalence surveys
- Developing a fistula research toolkit, summarizing the advantages and disadvantages of different data collection approaches and tools

Other research and implementation activities of interest:
- Study of women's treatment pathways – surveying women at treatment sites to understand how long they had fistula, how they reached treatment facilities, and the costs incurred. This could include backlog assessment at same facilities.
- Using information about women coming to facilities, as well as relevant information about contraception, fertility, and facility delivery, to target community outreach/key informant case-finding
- Further analysis of sisterhood datasets to assess the usefulness of this method for fistula prevalence estimation (i.e., its valued-added relative to household surveys)
- Prospective data collection on timeliness of access to and receipt of care for obstructed labor as a proxy for fistula risk/incidence (e.g., at facilities able to provide comprehensive emergency obstetric and newborn care)
- Assessment and improvement of the Global Fistula Map (http://www.globalfistulamap.org/) – for instance, are listed sites currently providing treatment?
- Assessment of the feasibility of developing and maintaining fistula registries, both as measurement tools and as a list of people needing services.

Through small group and plenary discussion, participants also identified several recommendations to guide fistula measurement and estimation activities. Key consensus points are highlighted.

- **Household surveys looking only at fistula prevalence are not cost-effective nor are they an ethical use of resources.**
- **It is essential to link community and facility level data, including surveillance or reporting by existing community cadres (e.g., community health workers) and using mHealth tools.**

- **Data collection should reflect intended use; there are differences between measurement or estimation at a national level and the information needed to help plan services at a facility. In general, measurement must also be aimed at getting women into services.**
- Standard record-keeping forms are needed to improve surveillance of fistula cases and repairs.
- Data collection (whether at facilities or from households) should include questions about duration to help distinguish between incidence and prevalence.
- Incorporation of fistula questions into postpartum care should not occur immediately after birth. Six weeks post-delivery may be more appropriate due to physiological reversion to a normal/stable status.

The priorities identified by technical consultation participants overlapped considerably with those selected by the epidemiology sub-group of the FC+ IRAG at its earlier meeting. These priorities are summarized in Table 2.

Table 2: FC+ IRAG Priorities for Epidemiological Research

Topic	Description and recommendations
Priority 1: Improved measurement and estimation methodologies, starting with the development of a validated diagnostic interview/survey tool.	• Participants agreed that research on prevalence and incidence must link data from communities and the health system. • Potential study designs and resources for validating a diagnostic tool were identified (e.g., the DHS module questionnaires used in recent household surveys). • A literature review and inventory/content mapping of tools that have been used in past studies is needed. • Clinical exam follow-up of women identified as having fistula through DHS surveys might be an approach to tool validation, keeping in mind that validation may be sensitive to the settings and populations in which it is conducted. • Validation in multiple geographic regions is important given variation in prevalence, health systems, etc.
Topic 2: Association of fistula incidence and treatment outcomes with co-morbidities and socio-cultural factors	• Research on this topic could examine co-morbidities (e.g., HIV/AIDS) as well as socio-cultural issues that affect fistula prevention and treatment.

IV. FC+ Action Plan

FC+ has selected several topics and activities for near-term activities related to the measurement and estimation of the fistula burden. These have been selected based on:

- Priorities that emerged from the technical consultation on measurement and estimation and the FC+ IRAG meeting
- Internal assessment of feasibility, partnerships, and likelihood of impact
- Discussion with USAID

Planned activities in 2014-2015 include:

- Compiling an inventory of materials that have been used in surveys to measure fistula prevalence, including the DHS fistula module; survey interview guides; respondent questionnaires; and tools for respondent sampling, outreach, enrollment, and recruitment. FC+ will conduct a content mapping to identify common questions, language variation within similar topics, potential probes to ensure complete responses, and the reported sensitivity and specificity of these tools.
- Developing a research protocol for a multi-arm validation study to identify an optimal interview-based diagnostic tool for fistula. This validation will use a case-control model, sampling women with fistula, those with other uro-gynecological and/or reproductive health conditions, and those with no such symptoms. Validation will be conducted in at least two countries, possibly Nigeria and Bangladesh.
- Drafting a fistula research toolkit document, summarizing the known advantages and disadvantages of existing approaches to measurement and estimation of fistula prevalence. This toolkit will include summaries of existing studies, data collection tools when available, and recommendations regarding the utility of different approaches for the planning and organization of fistula prevention and treatment services.
- Collaborating with partners engaged in activities related to quantifying the fistula burden, including:
    - Providing technical inputs to future DHS Program comparative analyses of findings from surveys that have implemented the DHS fistula module.
    - Seeking opportunities to participate in further development, refinement, and implementation of estimation models such as those developed by Dr. Saifuddin Ahmed at JHSPH and applied through research supported by the UNFPA Campaign to End Fistula.
- Developing a process documentation template for use in countries where fistula indicators have been added to national Health Management Information Systems (HMIS) and/or a fistula surveillance/reporting protocol has been established. This documentation would gather information on the ongoing reporting and use of fistula data.

It is important to note that implementation of these activities is subject to factors including resource availability and USAID Mission priorities.

Appendix A: Meeting Participants

Dr. Alma Adler, London School of Hygiene and Tropical Medicine
Dr. Saifuddin Ahmed, Johns Hopkins School of Public Health
Ms. Erin Anastasi, United Nations Population Fund
Dr. Steven Arrowsmith, Fistula Foundation
Dr. Mark Barone, EngenderHealth
Ms. Karen Beattie, Fistula Care *Plus* (FC+)
Dr. Ben Bellows, Population Council
Ms. Bethany Cole, FC+
Ms. Kacie Dragan, FC+
Dr. Veronica Frajzyngier, Pfizer
Dr. Ana Langer, Maternal Health Task Force (MHTF)
Ms. Erin Mielke, USAID
Ms. Kimberly Peven, The DHS Program
Dr. Joseph Ruminjo, FC+
Ms. Caitlin Shannon, EngenderHealth
Dr. Cynthia Stanton, Stanton-Hill Research/Johns Hopkins Bloomberg School of Public Health
Ms. Mary Ellen Stanton, USAID
Dr. Vandana Tripathi, FC+
Dr. Özge Tunçalp, World Health Organization
Ms. Mary Nell Wegner, MHTF

APPENDIX B: MEASUREMENT & ESTIMATION AGENDA

GOAL

To build a consensus regarding Fistula Care Plus (FC+) priorities related to the measurement and estimation of the prevalence and incidence of obstetric fistula.

OBJECTIVES

- To review existing and emerging approaches to measuring and estimating the prevalence and incidence of obstetric fistula.
- To prioritize approaches that require further testing/research
- To prioritize approaches that should be scaled up and/or applied in additional settings
- To identify specific opportunities for Fistula care *Plus* (FC+) activities related to measurement and estimation

THURSDAY, 10 JULY 2014

Time	Session	Speaker/Facilitator
8:30am	Breakfast	
9:00	Welcome: Introductions and review of agenda	Ms. Karen Beattie, FC+
9:30	Overview: FC+ project and the importance of improved data on incidence/prevalence Discussion of agenda and meeting aims	Ms. Mary Ellen Stanton, USAID Dr. Vandana Tripathi, FC+
10:15	Methods 1: Household surveys	Ms. Kimberly Peven, DHS Dr. Vandana Tripathi, FC+
11:15	Methods 2: Key informant/Mixed methods surveys	Dr. Alma Adler, LSHTM Dr. Özge Tunçalp, WHO
12:30pm	Lunch	
1:30	Methods 3: Meta-analysis/systematic review	Dr. Alma Adler, LSHTM
2:15	Methods 4: Estimation models	Dr. Saifuddin Ahmed, JHSPH
3:15	Break	
3:30	Methods 5: HMIS & surveillance systems	Dr. Vandana Tripathi, FC+ Ms. Caitlin Shannon, EH
4:00	Topic in focus: Incidence	Dr. Özge Tunçalp, WHO
4:30	Wrap-up, discuss Day 2 agenda (break at 5:00pm)	Dr. Vandana Tripathi, FC+

FRIDAY, 11 JULY 2014

Time	Session	Speaker
8:30am	Breakfast	
9:00	Review of Day 1 discussion and Day 2 agenda	Dr. Vandana Tripathi, FC+
9:15	Small group discussion of research and implementation priorities	
10:30	Break	
10:45	Report back on small group discussions	Small group rapporteurs
12:00pm	Lunch	
1:00	Generation of priority research activities for measurement and estimation	Ms. Mary Nell Wegner, MHTF Dr. Vandana Tripathi, FC+
2:00	Next steps and action plan	Ms. Karen Beattie, FC+
2:30	Thank you and wrap-up (break at 3:00pm)	Ms. Mary Nell Wegner, MHTF Ms. Mary Ellen Stanton, USAID Ms. Karen Beattie, FC+

APPENDIX C: MEETING PRESENTATIONS

[PROVIDED SEPARATELY]