

What to measure and why? Experience developing monitoring indicators for an emerging maternal health issue: the case of obstetric fistula

Carrie NGONGO ^{a,1}, Evelyn LANDRY ^a, Karen LEVIN ^a, Simon NDIZEYE ^b, Iretoluwa SUTTON ^c, and Vandana TRIPATHI ^a

^aEngenderHealth, 440 9th Ave. Fl 13, New York, NY, 10001 USA

^bEngenderHealth/Uganda, 143 Kira Road, Kamwokya, Kampala, 34016, Uganda

^cEngenderHealth/Nigeria, 7B Ona Crescent, Maitama, Abuja, Nigeria

Abstract. The field of obstetric fistula has historically lacked common definitions for measuring needs and outcomes. This paper recounts the process of developing, refining, and using standardized monitoring indicators as part of a fistula prevention and repair project in fourteen countries—Bangladesh, Benin, Democratic Republic of the Congo, Ethiopia, Ghana, Guinea, Liberia, Mali, Niger, Nigeria, Rwanda, Sierra Leone, Togo, and Uganda. The process included collaborative indicator development, introducing standardized data collection at health facilities, and promoting the integration of fistula indicators into national health management information systems (HMIS) to enable continued measurement and support for fistula treatment services. As monitoring of obstetric fistula continues to become more standardized and routine, the multi-country scope of the project has enabled a wide-ranging effort through which indicators for an emerging maternal health content were introduced and applied.

Keywords. Indicators; monitoring; Health Management Information System; maternal health; fistula

1. Introduction

High levels of maternal mortality and morbidity in low-resource settings reflect gender inequality and the weaknesses of health systems. One of the most severe maternal morbidities, obstetric fistula, results from tissue necrosis between the vagina and bladder and/or rectum during prolonged, obstructed labor without timely medical intervention such as cesarean section. Immediate catheterization may close a small proportion of fistulas [1], but the majority require surgery by surgeons with specialized skills. These services are typically available only in a limited number of facilities.

Though devastating for individual patients, obstetric fistula is a rare event at the population level, making prevalence and incidence difficult to measure. Demographic and Health Surveys (DHS) in some countries have attempted to assess lifetime prevalence; estimated prevalence based on women's self-reports ranges from less than

¹ Corresponding Author: cngongo@gmail.com

1% in Burkina Faso (0.1%) [2], Nigeria (0.4%) [3], and Tanzania (0.5%) [4] to 2.0% in Uganda [5]. Global estimates suggest that between one and two million women suffer from fistula [6-7].

There is considerable variation in the etiology and distribution of obstetric fistula, which affects women of all age groups and can occur among women with low or high parities [8-10]. The severity of fistula can vary depending on factors such as how long a woman experienced obstructed labor without treatment. Additionally, some fistulas are caused by trauma, including sexual violence [11]; others are iatrogenic, resulting from operative delivery, hysterectomy, and other surgeries [12]. Clinically, the prognosis for closure of a fistula may be related to preoperative bladder size, number of previous repair surgeries, vaginal scarring, and urethral involvement [13].

Given this heterogeneity and the rapid expansion of programs addressing fistula prevention and treatment, there has been wide variation in fistula indicators. For instance, standard diagnostic and classification systems for obstetric fistula are needed, but there is no consensus about which would be most effective [14]. Data on treatment and social outcomes have not been routinely published, though the body of literature is growing [8-10, 15-16]. Historically, individual fistula surgeons kept data on the repairs they performed, but there were no uniform monitoring or reporting indicators at national or regional levels. The field also lacks consensus about the definition of a repair's "success" [15]. From a surgeon's perspective, success might mean the closure of the hole. A woman would probably not consider herself to be cured, however, if her fistula is closed but she is still leaking [17].

While practitioners and decision-makers working on obstetric fistula services recognize the need for standardizing indicators, there are no consensus global indicators. The United States Agency for International Development (USAID) and the United Nations Population Fund (UNFPA) have provided funding to the U.S. Centers for Disease Control (CDC) to lead the development of a compendium of indicators for fistula prevention, treatment, and reintegration in collaboration with the International Obstetric Fistula Working Group (IOFWG). The compendium is still under development; in the interim, drawing from the work of the WHO [7] and the International Obstetric Fistula Working Group, MEASURE Evaluation has included 13 suggested indicators for obstetric fistula programs in their compendium of reproductive health indicators [18].

USAID began supporting activities for fistula treatment in 2005 [19]. The EngenderHealth-managed Fistula Care project was funded by USAID from 2007 to 2013; Between 2007 and 2013 Fistula Care worked to establish and strengthen fistula prevention, repair, and reintegration programs at 92 sites across 14 countries in Sub-Saharan Africa and South Asia: Bangladesh, Benin, Democratic Republic of the Congo, Ethiopia, Ghana, Guinea, Liberia, Mali, Niger, Nigeria, Rwanda, Sierra Leone, Togo, and Uganda. Over 27,000 fistula repair surgeries were reported between January 2005 and December 2013 by facilities supported by EngenderHealth with USAID funding. EngenderHealth fistula activities continue through the *Fistula Care Plus* project (launched in late 2013).

From its inception, the Fistula Care project needed monitoring data to report and assess service needs, capacity, quality, and outcomes. This paper describes the project's experience in designing monitoring indicators for an emerging maternal health issue as well as progress to date in the adoption of fistula indicators into health management information systems (HMIS).

2. Methodology

2.1 Development and refinement of fistula indicators

The development and use of monitoring indicators for fistula treatment services was a collaborative and iterative process completed over an eight-year period with fistula surgeons and other key stakeholders in the countries listed above. In 2005, before the launch of Fistula Care, a set of four monitoring indicators for quarterly reporting were identified, based on a 2002 needs assessment [20] and the personal experience of fistula surgeons: number of women seeking fistula repair, number of women receiving fistula repair surgery, number of women who received surgery who are successfully repaired (dry), and number of women who received surgery who experience complications (anesthesia-related, post-operative, other). Between 2007 and 2008, four additional indicators were added: two to describe the clinical profile of women seeking services (number of previous repairs, and type of fistula (urinary, rectal or both)); one about demand for services (number of women requiring surgery); and one about service capacity (number patients discharged). Between 2007 and 2009, Fistula Care expanded and refined these indicators based on recommendations from implementing partners [21], programmatic experience, and a recognition of the need for additional data which could help facilities, surgeons, and project staff to assess trends and identify potential problems.

Fistula Care's partner treatment sites provided quarterly reports on eight indicators. These indicators were grouped into four categories to measure and monitor demand for services, site capacity, clinical patient profiles, and fistula surgery outcomes at time of discharge (Table 1). Refinements in indicators over time were not significant enough to affect the ability to gather data about trends. However, some indicators were introduced later than others; thus, earlier data were not available for analysis. The rationale for these indicators and examples of how data were used to monitor trends are described below.

Table 1. Fistula Care Quarterly Monitoring Indicators for Fistula Treatment

Category	Indicator	Years of data collection
Demand for services	Number of women arriving at facility seeking fistula repair surgery	2005-2013
	Number of women requiring fistula repair surgery	2007-2013
Service capacity	Number of women receiving fistula repair surgery ²	2005-2013
	Total number discharged/ number remaining in facility	2007-2013
Clinical profile of patients	Number of previous repairs (first attempt, second attempt, >2 nd attempt)	2007-2013
	Number of repairs by type (urinary-vaginal, rectovaginal fistula, combination)	2008-2013
Fistula surgery outcomes at time of discharge	Outcome by type of fistula repair: -Number of discharged patients who are closed and dry -Number of discharged patients remaining with incontinence -Number of discharged patients not closed	2005-2013. Modified in 2007 to include number with remaining incontinence and not closed.
	Number of complications by type (major surgical, anesthesia related, post-operative complications related to perceived success of surgery). Death, a rare event, was also reported. ³	2005-2013. Modified in 2009 to clarify categories of complications

²On a quarterly basis the number of women served is accurate. However aggregation of the data for reporting annual reporting requires that we refer to the number of repairs to avoid double counting of women who undergo repeat fistula repair surgery.

3. Results

3.1 Demand for services

An analysis of the indicator “number of women requiring surgery”, along with “number of women receiving fistula repair surgery” (from the capacity category) provided insight into the estimated backlog of women needing surgery (i.e., if more women arrived at the site requiring surgery than received surgery during a given time period). Project and site staff worked together to determine the causes of identified backlogs and how to address these (e.g., by referral to other sites or by conducting special repair sessions for complicated cases). The data on “number of women seeking services” and the “number requiring surgery” could also signal the need for clarification of messages about obstetric fistula. For example, if significantly more women sought services than actually needed fistula repair in a given period, outreach efforts may require revision to ensure clear messaging on the symptoms of fistula. Women seeking but not requiring fistula surgery could suffer from other urogynecological morbidities requiring clinical attention (e.g., uterine prolapse).

3.2 Service capacity

The indicator “number of women receiving fistula repair surgery” required careful interpretation. While this indicator accurately reflected services provided for a quarterly period, it was not aggregated across reporting periods. Many women who have fistula require more than one surgery in order to either close the hole or stop the incontinence; in addition, a few women who are discharged with a diagnosis of “closed and dry” may experience a breakdown in the surgical repair which requires another surgery. Women were unlikely to have more than one repair in the same reporting period. Thus they were unlikely to be counted twice in a single reporting period, but would be counted again if returning for additional surgery at a later time. Because some women require multiple surgeries, Fistula Care reported on the repairs performed, rather than the number of women who had been treated.

Because women are hospitalized for 3-4 weeks after surgery, the indicator “number of women discharged” provided insight about the number of women remaining at a facility, which could result in possible backlogs due to limited bedspace.

3.3 Clinical profile of women undergoing fistula surgery

These two indicators provide insight into the complexity of a woman’s fistula and are crucial because there are no standard algorithms for classifying a fistula as simple or complex; guidelines vary from surgeon to surgeon. From a program perspective, it is important to ensure that facilities have surgeons with the skills to provide appropriate care or provide referral options for women with clinical needs that cannot be handled on-site.

³ Facilities reported to Fistula Care whenever a death occurred. In this rare event, Fistula Care and the facility jointly conducted a thorough investigation.

3.4 Surgical outcomes of discharged patients

Outcome of surgery at time of discharge was expanded in 2007 to clarify whether the woman’s fistula was closed, if there was remaining incontinence, or if the fistula was not closed at time of discharge. If a site consistently reported low “closed and dry” rates (70% or less), Fistula Care clinical staff worked with facility surgeons to identify systemic causes and possible solutions. The categories for surgical complications were expanded and clarified in 2009 with a detailed guide to describe the type of complication to report (major surgical complications, anesthesia complications, and post-operative complications related to perceived success of surgery).

3.5 Integrating fistula indicators into national health management information systems

While high-quality program monitoring is essential, routine national monitoring of fistula indicators is required for sustainable measurement of the fistula burden and its consideration when governments allocate resources. Fistula Care partners in six countries—Bangladesh, Guinea, Mali, Niger, Nigeria and Uganda—worked with technical working groups and Ministries of Health (MOH) to advocate for the integration of fistula indicators into their national HMIS. These countries identified three to 10 obstetric fistula indicators for inclusion in HMIS.

All six countries identified indicators of demand, capacity, and outcomes, but specifics vary (Table 2). For instance, Mali selected two indicators about available human resources (i.e., staff capable of fistula repair surgery and diagnosis), while Niger chose an indicator about social reintegration.

Table 2. Variations on how fistula indicators are expressed in national health management information systems

Question to be answered	Expression of indicator
Demand: How big is the problem?	“Number of women presenting with incontinence” (Mali, Nigeria) “Number of women referred with incontinence” (Mali) “Number of women diagnosed with fistula” (Mali, Uganda) “Number of women registered with fistula” (Guinea) “Number of women needing repair” (Niger) “Number of women who reported leaking urine or feces” (Nigeria)
Technical capacity: What is the staffing capacity of the site?	“Number of staff capable of clinically diagnosing fistula” (Mali) “Number of staff capable of fistula surgery” (Mali)
Site capacity: How many have we treated?	“Number of fistula repair surgeries” (Guinea, Mali) “Number of women receiving fistula repair” (Bangladesh, Niger, Nigeria, Uganda) “Number of fistulas repaired” (Niger) “Number of women treated by catheter [for fistula]” (Niger)
Clinical characteristics of women receiving services	“Number of women with previous repair attempts” (Mali and Niger) “Number of new cases of fistula” (=first repair attempts) (Niger) “Number of cases repaired by type” (vesico-vaginal, recto-vaginal) (Niger) “Number of women receiving a first repair”/“Number of women receiving a second repair” (Nigeria)

Question to be answered	Expression of indicator
Outcomes: What is the outcome of surgery at time of discharge?	“Number of women discharged “dry and continent”/“not dry” (=either not closed or closed with stress incontinence)” (Uganda) “Proportion/Number of fistula cases/women who are closed and dry [at discharge]” (Bangladesh, Guinea, Mali, Niger) “Number receiving repair who were discharged not closed” (Bangladesh) “Number of women receiving repair who remained with incontinence at discharge” (Bangladesh, Niger) “Number of women discharged after fistula surgery”/“Number of women who had a closed and dry fistula at discharge” (Nigeria)
Postoperative services	“Number of women benefitting from a social reintegration program” (Niger)

Country approaches to introducing these indicators into the HMIS varied. Some countries established technical working groups to discuss definitional nuances and disseminate information. Methods for transmitting data from the facility level to the national HMIS also differed, ranging from paper reports to electronic documentation tools.

3.6 Program challenges and solutions

While all 45 fistula repair facilities supported by Fistula Care routinely monitored and reported on clinical aspects of fistula treatment using indicators developed by the project and its partners, there were challenges to monitoring, reporting, and quality assurance. Partners and staff were able to identify solutions for some of these problems, while others required additional investigation and resources to address.

3.7 Data collection and reporting challenges

Though reporting forms contained clear definitions for all indicators, many sites experienced high turnover among staff responsible for data collection and reporting, requiring ongoing training and supportive supervision.

One indicator that proved particularly challenging to collect was “complications from surgery.” Complications are expected to occur occasionally with any type of surgery. Some sites were forthcoming in reporting complications. Other sites consistently reported no complications despite high caseloads, which seemed unlikely. Fistula Care conducted a facility-level complications audit in 2013 at selected sites to learn more about the challenges of reporting this indicator. The audit found that although the complication rates were indeed low (less than 20%), they were nevertheless under-reported at several sites. Systemic challenges included a lack of diagnostic resources, non-meticulous perioperative follow-up, and a need for better record-keeping [22].

3.8 Building consensus for HMIS indicators

Incorporating indicators into an HMIS is a logical step for national programs that want to make informed decisions [23]. National HMIS are invariably complicated and often lack cohesion, having been developed piecemeal under diverse pressures [24-25]. In Uganda, the MOH was reluctant to incorporate the indicators recommended by the fistula technical working group, given the complexity and detail already required by the

HMIS. The inclusion of fistula indicators resulted from careful negotiation, creative merging of variables, and strong advocacy for the importance and future utility of the indicators. Challenges remain in capturing fistula indicators through the HMIS; the countries that chose the indicator “number of women receiving fistula repair/surgery” instead of “number of fistula repair surgeries” will need to carefully interpret these data due to possible double-counting, as discussed above.

4. Discussion

Fistula indicator standardization has faced many of the same issues as other health initiatives measuring the regional or national provision of services in resource poor settings. Many programs are interested in developing, standardizing, and applying indicators to evaluate service availability and quality in a consistent manner across settings. For example, the United Nations process indicators enable the gathering of information about emergency obstetric care (EmOC) as a signal of health system function and have now been applied in many countries as a common framework for EmOC assessment [26].

Increasing utilization of maternal health services has prompted particular interest measuring service quality [27]. In the case of obstetric fistula, the selected quality indicators focused on clinical outcomes: Is the fistula closed? Does the patient experience remaining incontinence? Less directly, indicators regarding patient clinical profiles can also point to the quality of delivery care women received leading up to the development of a fistula. Variations in women’s clinical profiles and fistula treatment outcomes are important to monitor for quality assurance and improvement.

Indicators that describe the size of the problem and the capacity to address it convey the “met need.” Measuring the met need for fistula repair services among identified cases at facilities is only partially informative; a coverage measure would convey how many women are being repaired among all of the women in need of repair. However, reliable population-based prevalence figures are required to estimate coverage. Such numbers are currently unavailable in most settings believed to have a high fistula burden [28]. This exemplifies a common tension, between what is important and what can actually be measured cost-effectively: a challenge faced across numerous health issues [29-30]. In the absence of precise prevalence numbers, the “number of repairs” relative to the “number women requiring repair” can express the reach of a fistula treatment program. Similarly, there is a tension between the desire for comprehensive information and the need to limit the number of indicators [28]. This was a challenge at the outset of the Fistula Care project and later, as MOHs negotiated which indicators would to include in national HMIS.

As the scope of data collection expands from program facilities to the health system as a whole, questions arise regarding data quality. While authorities in six countries have begun to incorporate fistula indicators into their HMIS, the quality and use of these data have not yet been systematically documented and examined. The variations in indicator definitions may limit the possibility of making comparisons between countries. Countries that count the number of women repaired, versus the number of repairs provided, may end up overestimating the actual number of women who have been treated. Close monitoring of the implementation of HMIS fistula indicators is needed to assess whether these issues are indeed posing problems for the validity of HMIS data and to identify sustainable solutions.

5. Conclusion

The Fistula Care experience illustrates how monitoring indicators can be developed to assess the introduction, implementation, and quality of new or expanded health services in developing country contexts in sub-Saharan Africa and South Asia. Effective data collection, analysis, and use require collaborative action from the local facility level to the national health systems level. This experience may provide lessons for the monitoring and evaluation of other emerging health issues in low-resource settings.

Acknowledgements

The authors thank the dedicated staff of supported health facilities for their patient care and data collection; EngenderHealth monitoring and evaluation colleagues around the world; and Karen Beattie, Joseph Ruminjo, Bethany Cole, Christopher Lindahl, and Pamela Harper for comments on earlier drafts of this article. EngenderHealth's fistula programs and the development of this manuscript were funded by the United States Agency for International Development (USAID) under associate cooperative agreements GHS-A-00-07-00021-00 and AID-OAA-A14-00013. The views expressed here do not necessarily reflect those of USAID.

References

- [1] Waaldijk K. The immediate management of fresh obstetric fistulas. *Am J Obstet Gynecol.* **191**(3) (2004), 795-9.
- [2] Institut National de la Statistique et de la Démographie (INSD) et ICF International. 2012. Enquête Démographique et de la Santé et à Indicateurs Multiples du Burkina Faso 2010. Calverton, Maryland, USA: INSD et ICF.
- [3] National Population Commission (NPC) and ICF Macro, 2009. Nigeria Demographic and Health Survey 2008. Abuja, Nigeria: NPC and ICF Macro.
- [4] National Bureau of Statistics (NBS) [Tanzania] and ICF Macro. 2011. Tanzania Demographic and Health Survey 2010. Dar Es Salam: NBS and ICF Macro.
- [5] Uganda Bureau of Statistics (UBOS) and ICF International, 2012. Uganda Demographic and Health Survey 2011. Kampala, Uganda, and Calverton, Maryland, US: UBOS and ICF International.
- [6] Adler AJ, Ronsmans C, Clavert C, Filippi V. Estimating the prevalence of obstetric fistula: a systematic review and meta-analysis. *BMC Pregnancy and Childbirth* **13** (2013), 246.
- [7] World Health Organization. Obstetric fistula: guiding principles for clinical management and programme development. Geneva: 2006.
- [8] Landry E, Frajzyngier V, Ruminjo J, Asimwe F, Barry TH, Bello A, et. al. Profiles and experiences of women undergoing genital fistula repair: findings from five countries. *Global Public Health* **8**(8) (2013), 926-42.
- [9] Roush K. Social implications of obstetric fistula: an integrative review. *J Midwifery Women's Health.* **54**(20) (2009), E21-33.
- [10] Zheng AX, Anderson FW. Obstetric fistula in low-income countries. *Int J Obstet Gynaecol.* **104**(2) (2009), 85-9.
- [11] Longombe AO, Claude KM, and Ruminjo J. Fistula and traumatic genital injury from sexual violence in a conflict setting in Eastern Congo: case studies. *Reprod Health Matters.* **16**(31) (2008), 132-41
- [12] Raassen TJ, Ngongo CJ, and Mahendeka MM. Iatrogenic genitourinary fistula: an 18-year retrospective review of 805 injuries. *Int Urogynecol J.* **25**(12) (2014), 1699-1706.

- [13] Barone MA, Frajzyngier V, Ruminjo J, Asimwe F, Barry TH, Bello A, et. al. Determinants of postoperative outcomes of female genital fistula repair surgery. *Obstet Gynecol.* **120(3)** (2012), 524-31.
- [14] Frajzyngier V, Guohua L, Larson E, Ruminjo J, and Barone M. Development and comparison of prognostic scoring systems for surgical closure of genitourinary fistula. *Am J Obstet Gynecol* **208** (2013), 112.e1-11
- [15] Arrowsmith SD, Barone MA, Ruminjo J. Outcomes in obstetric fistula care: a literature review. *Curr Opin Obstet Gynecol.* **25(5)** (2013), 399-403.
- [16] Frajzyngier V, Ruminjo J, and Barone M. Factors influencing fistula repair outcomes in developing country settings: a systematic review of the literature. *Am J Obstet Gynecol.* **207(4)** (2012), 248-58.
- [17] Wall LL. Obstetric vesicovaginal fistula as an international public-health problem. *Lancet.* **368** (2006), 1201-09.
- [18] MEASURE Evaluation PRH. Family Planning and Reproductive Health Indicators Database. Obstetric fistula. Accessed March 27, 2013. https://www.cpc.unc.edu/measure/prh/rh_indicators/specific/of/obstetric-fistula.html?searchterm=indicators
- [19] McDonald P, Stanton ME. USAID program for the prevention and treatment of vaginal fistula. *Int J Obstet Gynaecol.* **99** (2007), S112-S116.
- [20] UNFPA and EngenderHealth. Obstetric fistula: needs assessment report: findings from nine African countries. New York: UNFPA; 2003. Available at <http://www.unfpa.org/fistula/docs/fistula-needs-assessment.pdf>.
- [21] Fistula Care. Fistula partners' meeting, Accra, Ghana, April 15- 17. New York: EngenderHealth; 2008. Available at: <http://www.fistulacare.org/pages/pdf/accra-meeting/english/meeting-report-final.pdf>.
- [22] Fistula Care. Final Project Report, October 2007-December 2013. Part I: Global Accomplishments. New York: EngenderHealth/Fistula Care; 2014. Available at: <https://dec.usaid.gov/dec/content/Detail.aspx?q=KERvY3VtZW50cy5GaWxlOihGaXN0dWxhIENhcmUpKSBBTkQgKERvY3VtZW50cy5JbnN0aXR1dGlvbI9vcI9VU0FJRf9CdXJlYXVfQXV0aG9yOihFbmdlbmRlckhlYWx0aCkp&ctID=ODVhZjk4NWQtM2YyMi00YjRmLTkxNjktZTcxMjM2NDNmY2Uy&ph=VHJlZQ==&bckToL=VHJlZQ==&>
- [23] Bhattacharya, M, Shahrawat R, Joon V. Understanding Level of Maternal and Child Health Indicators used in Health Management Information System among Peripheral Level Health Functionaries in Two Districts of India. *Journal of Health Informatics in Developing Countries* **6** (2012), 385-395.
- [24] AbouZahr C, Boerma T. Health information systems: the foundations of public health. *Bull World Health Organ.* **83(8)** (2005), 578-83.
- [25] Nyella, E. Challenges in Health Information Systems Integration: Zanzibar Experience. *Journal of Health Informatics in Developing Countries* **5** (2011), 1-14.
- [26] Paxton A, Bailey P, Lobis S. The United Nations Process Indicators for emergency obstetric care: Reflections based on a decade of experience. *IJGO.* **95** (2006), 192-208
- [27] Mathai M. To ensure maternal mortality is reduced, quality of care needs to be monitored and improved alongside increasing skilled delivery coverage rates. *BJOG.* **118 Suppl 2** (2007), 12-4.
- [28] Stanton C, Holtz SA, Ahmed S. Challenges in measuring obstetric fistula. *Int J Gynaecol Obstet.* **99 Suppl 1** (2007), S4-9.
- [29] Requejo JH, Newby H, Bryce J. Measuring coverage in MNCH: Challenges and opportunities in the selection of coverage indicators for global monitoring. *PLoS Med.* **10(5)** (2013), e1001
- [30] Hodgins S. Achieving better maternal and newborn outcomes: coherent strategy and pragmatic, tailored implementation. *Glob Health Sci Pract* **1** (2013), 146-153.