Fistula Care Plus

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End of Project Report December 11, 2013 to March 31, 2021

Managing Partner: EngenderHealth; Associate Partners: The Population Council, Dimagi, Direct Relief, Fistula Foundation, Maternal Health Task Force, TERREWODE

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EXECUTIVE SUMMARY

USAID support to EngenderHealth for fistula services began in FY04/05 under the ACQUIRE and AWARE projects, primarily focused on training surgeons and strengthening the capacity of sites to provide quality fistula surgery. The Fistula Care project was awarded to EngenderHealth in September 2007 and ended on December 31, 2013. USAID/Washington awarded the Fistula Care *Plus* (FC+) project on December 11, 2013, to EngenderHealth in partnership with the Population Council, Dimagi, Direct Relief International, Fistula Foundation, Maternal Health Task Force, and TERREWODE. Following two no-cost extensions granted by USAID, the project ended on March 31, 2021.

Building on the previous ACQUIRE and Fistula Care (FC) projects, FC+'s vision was to advance knowledge and care to make female genital fistula an extremely rare event for future generations of African and Asian women by developing strategic partnerships with public and private sectors to maximize and leverage resources towards a fistula-free generation.

Operating in seven countries—Bangladesh (2013-2020), the Democratic Republic of Congo (DRC: 2014 -2021), Mozambique (2017-2021), Niger (2013-2021), Nigeria (2014-2018), Togo (2014), and Uganda (2014-2019)—FC+ focused on five objectives:

- 1. Strengthening the enabling environment to institutionalize fistula services in the public and private sectors.
- 2. Enhancing community understanding and practices to prevent fistula, improve access to treatment, reduce stigma and support reintegration.
- 3. Reducing transportation, communications, and financial barriers to care.
- Strengthening provider and health facility capacity to provide and sustain quality services.
- 5. Strengthening the evidence base to improve fistula care and scale up application of standard M&E indicators for prevention and treatment.

Key Accomplishments

- 15,230 surgical and 1,127 nonsurgical fistula repairs completed at facilities in 6 countries in Africa and Asia
- 3,775 ancillary procedures for fistula clients completed
- 54 treatment and prevention facilities, and
 1,117 prevention-only facilities supported
- **34** supported sites provided pelvic organ prolapse treatment to **4,880** women
- 123 surgeons trained in surgical fistula repair
- 10,531 health personnel trained in nonsurgical services
- >1.5 million counseling sessions at supported facilities
- >1 million couple years protection provided
- 3,387 community volunteers and educators trained
- >66,000 in-person community outreach and education events reaching >2.2 million people
- Mass media outreach to >57 million people
- 37 peer-reviewed journal publications
- 42 research reports and technical briefs
- 11 webinars, 84 blog posts, and more than 175 presentations at conferences

A selection of quantitative accomplishments of the project are highlighted in the side box; however, numbers tell only part of the story. FC+ collaborated with partners to challenge and change the environment, work toward a holistic continuum of care, and engage with communities, governments, and other actors to address the health inequities that lead to genital fistula and limit access to care. Selected highlights from this work are described below.

Improving Access to Safe, Quality Surgical and Non-Surgical Services

Eliminating fistula by 2030, the global target set by the United Nations Campaign to End Obstetric Fistula, requires treating existing cases and preventing new ones. FC+ partnered with international, regional, national, and local institutions to work towards this end.

latrogenic fistula and cesarean section (CS) safety and quality: The volume of CS in low-and middle-income countries (LMIC) has increased steadily in recent years¹ arousing concern in the fistula community about the number of iatrogenic fistulas that may be caused by unsafe CS. While prolonged/obstructed labor (P/OL) remains the reported cause of most diagnosed fistula, project data on fistula etiology demonstrated this growing problem. Where etiology data were available (60% of cases), P/OL was cited as the cause of fistula in 75.4% of cases, and 20% were deemed iatrogenic. There was variation across countries in the iatrogenic rate from 4% in Niger to 45% in Bangladesh. Through data assessments, technical consultations, presentations, publications and webinars, FC+ and partners increased awareness of and action on unsafe CS provision and iatrogenic fistula trends among obstetric, midwifery, and safe motherhood communities of practice at the national and global levels and advocated for regular investigation and standardized classification of iatrogenic fistula, as well as consideration of iatrogenic fistula as a reportable sentinel indicator of health systems failure.

Bladder catheterization for prevention and treatment: Catheterization of small, fresh fistula offers an early intervention for some women that does not require surgery and can be provided at many more facilities, thereby reducing the potential surgical caseload. In 2013, the prior project, Fistula Care, convened a technical consultation with eminent international surgeons to discuss guidelines for catheterization in fistula prevention and repair. FC+ continued this work and guidelines were published by the Nigerian Federal Ministry of Health in 2016² with FC+ support. FC+ worked with partners in other countries to further adapt these guidelines and introduce them to the international community for broader consideration and use.

Bladder catheterization also plays an important role in post-operative care after surgical fistula repair. Longer periods of catheterization increase the burden of fistula care for women and can be a limiting factor in the volume of repairs facilities can provided. Following a randomized controlled trial conducted under FC and FC+, the World Health Organization (WHO) issued a

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¹ Betrán A.P., J. Ye, A.B. Moller, J. Zhang, A. Metin Gülmezoglu, and M.R. Torloni. 2016. "The Increasing Trend in Caesarean Section Rates: Global, Regional and National Estimates: 1990-2014." *PLoS One* 11 no. 2 (February): e0148343. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0148343

² Nigeria Federal Ministry of Health. 2016. *Guidelines on Urethral Catheterization for Prevention and Management of Obstetric Fistula*. Abuja: FMOH. https://fistulacare.org/wp-content/uploads/2017/02/Nigeria-FMOH-Guideline-CATHETER-TREATMENT.pdf

recommendation for shorter-duration bladder catheterization following surgical repair of a simple obstetric urinary fistula.³

Advancing the safe surgery ecosystem: FC+ acknowledged the emerging international conversation⁴ about the lack of surgical care available to millions of people around the world as well as concerns about the feasibility of ending fistula by 2030 due to the lack of human and financial resources. With international, regional, and national partners, FC+ advocated for and supported increased access to surgical care, specifically care relating to childbirth or childbirth injury. Actions to address the safe surgery ecosystem included training surgical staff and supporting surgical care, introducing the Surgical Safety Toolkit (SST)⁵ in 2016, and providing technical input to a nascent *G4 Alliance* beginning in 2015. FC+ also strengthened professional associations and surgical colleges in Africa and Asia to advance a global safe surgery community of practice.

Integrating Services to Enhance Care

Family planning (FP): Voluntary FP is essential to enable clients to delay early births, space desired births, and limit family size—and it can also help women with a repaired fistula achieve successful pregnancies, if they desire, and prevent fistula recurrence by delaying future pregnancies until they are fully healed. In addition to creating awareness about fistula and increasing access to high-quality fistula care, FC+ emphasized the importance of FP and introduced or strengthened the concepts of choice and voluntarism for women and men in FP use across project-supported sites. More than 1.5 million FP counseling sessions were provided at FC+ prevention and treatment sites in five countries⁶ (Bangladesh, DRC, Niger, Nigeria, and Uganda), and FP services resulted in more than 1 million couple-years of protection (CYP). The overall method mix contributing to this total CYP included implants (52%), injectables (14%), IUD (11%), tubal ligation (10%), fertility awareness methods (5%), oral pills (4%), condoms (3%), and vasectomy (<1%).

Pelvic organ prolapse (POP) service integration: FC+ considered the feasibility of integrating POP services with fistula services, recognizing that many more women worldwide are affected by POP than by fistula, and fistula care sites may be cost-effective platforms for integrated POP care. FC+ supported training for POP treatment and procurement of commodities for nonsurgical POP treatment. An FC+ survey of fistula treatment centers indicated wide variation in

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³ WHO. 2018. WHO Recommendation on Duration of Bladder Catheterization after Surgical Repair of Simple Obstetric Urinary Fistula. Geneva: WHO. http://www.who.int/reproductivehealth/publications/simple-obstetric-urinary-fistula/en/.

⁴ Meara, J.G., A.J.M. Leather, M.S.L. Hagander, B.C. Alkire, N. Alonso, E.A. Ameh, S.W. Bickler, L. Conteh, A.J. Dare,

J. Davies, E.D. Mérisier, S. El-Halabi, P.E. Farmer, A. Gawande, R. Gillies, S.L.M. Greenberg, C.E. Grimes, R.L. Gruen, E.A. Ismail, T.B. Kamara, C. Lavy, G. Lundeg, N.C. Mkandawire, N.P. Raykar, J.N. Riesel, E. Rodas, J. Rose, N. Roy, M.G. Shrime, R. Sullivan, S. Verguet, D. Watters, T.G. Weiser, I.H. Wilson, G. Yamey, and W. Yip. 2015. Global Surgery 2030: evidence and solutions for achieving health, welfare, and economic development. *The Lancet* Vol 386:993. https://doi.org/10.1016/S0140-6736(15)60160-X

⁵ The Safe Surgery Toolkit is an integrated package of tools to monitor and improve the quality of surgical treatment, based on internationally accepted standards and guidelines for pre-, intra-, and post-operative care.

⁶ FP service provision was not directly supported in Mozambique.

⁷ A total of 699,225 of these counseling sessions and 330,805 of this CYP were reported from 500 former USAID Targeted States High Impact Project (TSHIP) facilities in Nigeria where the FMOH requested FC+ monitor FP services during an interim period between projects.

assessment, evaluation, and surgical skills to treat POP, but high demand for POP services and significant interest in POP integration among providers.⁸

Physical therapy: Physical therapy, while not routinely or reliably available in many LMIC, has been shown to reduce the severity of symptoms, improve quality of life, decrease hospital stays, and reduce the need for expensive medical procedures. In collaboration with the *Panzi Foundation* and *Mama, LLC*, FC+ introduced physical therapy services for women who are awaiting or have had a fistula repair. The FC+ project also contributed to the development and publication in 2020⁹ of a new physiotherapy training manual, supported provider training, and conducted a webinar to advocate for physical therapy as a key element of women's healthcare.

Embracing Public-Private Partnerships

FC+ collaborated with (1) *LABORIE* to introduce pelvic floor therapy treatment and provide a urodynamics unit to one supported health facility to improve diagnostics and case management; (2) *Gradian Health Systems* to improve anesthesia care through training, supplies, ongoing technical support, and provide a Universal Anesthesia Machine (UAM) to one supported facility; (3) *Direct Relief International* to secure donations of Fistula Repair Modules; (4) *mass media* for donated airtime, articles, and interviews to increase public awareness; and (5) *Viamo*, a social enterprise, to develop and test an interactive voice response (IVR) hotline to support direct communication with potential fistula clients.

Increasing Community Engagement

FC+ enhanced community understanding and practices to prevent fistula, improve access to treatment, reduce stigma, and support reintegration of women and girls with fistula. The project trained community health educators and volunteers, including traditional and religious leaders, ¹⁰ to provide information to promote community and family support for prevention, treatment, and reintegration, including through uptake of FP and maternity services. Site Walk-Throughs, through which FC+ invited community members to visit facilities and learn about available services, strengthened linkages between facilities and communities and fostered local action planning, ownership, and accountability to support quality and sustainability. ¹¹

FC+ engaged adolescents in fistula prevention and taking responsibility for their own sexual and reproductive health. In Bangladesh, FC+ linked schoolgirls with local community clinics and institutions for social action. In Uganda, collaboration with *Aflatoun* and *PEDN International* resulted in the development of an expanded curriculum incorporating SRH and gender equity

⁸ Tripathi, V., S. Elneil, and L. Romanzi. 2018. Demand and Capacity to Integrate Pelvic Organ Prolapse and Genital Fistula Services in Low-Resource Settings. *International Urogynecology Journal* 29 no. 10 (October): 1509–1515. doi: 10.1007/s00192-018-3561-2. https://www.ncbi.nlm.nih.gov/pubmed/29411073.

⁹ Mama, LLC, Fistula Care *Plus*, and USAID. 2019. *Implementing Physical Rehabilitation Services into Comprehensive Fistula and Maternity Care: A Training Guide for Health Care Workers*. Boston: Mama, LLC. https://www.themamas.world/training-guide.

¹⁰ FC+. 2017. Engaging Religious Leaders in Support of Maternal Health in Uganda. New York: EngenderHealth. https://fistulacare.org/wp-content/uploads/2019/05/FCPlus-ReligiousLeaders_v3-1-1.pdf.

¹¹ FC+. 2019. Communities and Health Workers Improving Maternal Health Together in Jinja District, Uganda. Washington DC: EngenderHealth. https://fistulacare.org/wp-content/uploads/2019/05/FCPlus-Health-Workers_v2.pdf.

modules to empower youth to make positive decisions for their futures, and the successful implementation of this curriculum to mobilize in- and out-of-school youth. ¹² In all countries, FC+ focused attention on family support, and in particular male involvement, supporting community-based organizations to provide training and peer education sessions for men to address gender issues that increase women's vulnerability to fistula and other maternal morbidities and to discuss the benefits of FP, healthy pregnancy, the impact of delays in careseeking on women's health, and value of shared decision-making.

Measuring the Burden of Fistula

The incidence of obstetric and iatrogenic fistula indicates the failure of health systems to deliver accessible, timely, and appropriate obstetric care. Lacking reliable fistula data, FC+ and the WHO reviewed existing measurement approaches. The project subsequently co-convened technical consultations to examine the measurement and estimation of fistula incidence, prevalence, and treatment backlog. FC+ successfully advocated for the inclusion of estimates of fistula and POP in the Bangladesh Maternal Morbidity and Mortality Survey and documented the effectiveness of fistula indicators adopted following FC advocacy in three countries: Guinea, Nigeria, and Uganda. FC+ also supported the expanded use of a simple screening tool for fistula and POP cases—the 4Q checklist. FC+ partners used the 4Q checklist to screen and refer positively-screened women to community fistula diagnosis events for diagnosis and care, as well as to establish a local estimate of the fistula burden.

Building and Sharing Knowledge and Evidence

FC+ advanced knowledge and evidence through multiple research initiatives, including:

- A research-to-action study identifying and addressing barriers to fistula treatment in Nigeria and Uganda¹⁶
- A global survey of skilled birth attendants on knowledge, attitudes, and practices on intrapartum and postpartum bladder care, including catheterization to prevent fistula after P/OL¹⁷

 ¹² FC+. 2019. Engaging Youth for Improved Life Skills and Reproductive Health: The Aflateen PLUS Pilot in Uganda. Washington, DC: EngenderHealth. https://fistulacare.org/wp-content/uploads/2019/05/FC_Plus_TechBrief-UgandanPilot-4.pdf.
 ¹³ Tunçalp, Ö., V. Tripathi, E. Landry, C. Stanton, and S. Ahmed. 2015. "Measuring the Incidence and Prevalence of Obstetric Fistula:

¹³ Tunçalp, O., V. Tripathi, E. Landry, C. Stanton, and S. Ahmed. 2015. "Measuring the Incidence and Prevalence of Obstetric Fistula: Approaches, Needs, and Recommendations." *Bulletin of the World Health Organization* 93 (December): 60–62. doi: 10.2471/BLT.14.141473. https://www.who.int/bulletin/volumes/93/1/14-141473/en/.

¹⁴ MEASURE Evaluation, icddr,b, the Maternal and Child Health Integrated Program, FC+, and Johns Hopkins University. 2018. *Prevalence of Obstetric Fistula and Pelvic Organ Prolapse in Bangladesh: Summary of the 2016 National Estimates*. https://www.measureevaluation.org/resources/publications/fs-18-290.

¹⁵ FC+. 2019. Development and Implementation of the 4Q Checklist for Fistula Screening and Referral in Bangladesh. Washington DC: EngenderHealth. https://fistulacare.org/wp-content/uploads/2019/11/FCPlus_4Q-checklist_v3.pdf.

¹⁶ Sripad, P., E. Arnoff, C. Ndwiga, G. Odwe, and E. Nwala. 2020. *Reducing Barriers to Accessing Fistula Repair in Nigeria and Uganda: An Implementation Research Study*. New York; Population Council. https://www.popcouncil.org/uploads/pdfs/2020RH_FistulaCareNigeriaUganda-IRreport.pdf

¹⁷FC+. 2018. Bladder Care and Management of Prolonged/Obstructed Labor: Global Survey of Intrapartum and Postpartum Clinical Practice. New York: EngenderHealth/Fistula Care Plus. https://fistulacare.org/wp-content/uploads/2018/07/Report_Survey-of-Intrapartum-and-Postpartum-Clinical-Practices_Final_7.18.pdf.

- A realist review of the partograph to understand when and how it works for labor monitoring¹⁸
- A study on the effects of psychosocial support interventions on the lives of women with incurable fistula in Uganda¹⁹
- A survey of clinicians and epidemiological modeling to estimate the full burden of disease associated with P/OL²⁰
- Secondary analysis of all DHS surveys that included the fistula module to identify social, demographic, and other characteristics associated with self-reported fistula symptoms, including an in-depth analysis of the associations with gender-based violence²¹
- An exploratory, mixed methods study to understand the long-term trajectories of Ugandan women's physical and mental well-being after fistula repair and to develop and validate an instrument to measure these issues²²
- A Flexible Operations Research Training approach in the DRC to train local researchers to develop protocols and tools and to implement their research priorities²³

Key Learnings from FC+

Continued support from national governments and development partners is required for the sustained provision of fistula care. Additional priority areas for progress towards ending fistula emerging from project learning include:

- **Iatrogenic fistula:** Advocate for regular investigation and standardized classification of iatrogenic fistula; increase awareness about iatrogenic fistula trends among obstetric, midwifery, and safe motherhood communities of practice at national levels; and advocate for iatrogenic fistula to be a reportable, sentinel indicator of basic surgical systems gaps that undermine a minimum acceptable standard of care.
- **Obstetric fistula:** Advocate for obstetric fistula to be a reportable, sentinel indicator of maternal health systems gaps.

¹⁸ Bedwell, C., K. Levin, K., C. Pett, and D.T. Lavender. 2017. "A Realist Review of the Partograph: When and How Does It Work for Labour Monitoring?" *BMC Pregnancy Childbirth* 17 no.31 (January). doi: 10.1186/s12884-016-1213-4.

https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-016-1213-4#Abs1.

¹⁹ FC+. 2019. *Improving Quality of Life for Women with Incurable Fistula: A Fistula Care Plus and Terrewode Research Partnership in Uganda*. Washington DC: EngenderHealth. https://fistulacare.org/wp-content/uploads/2019/05/FCPlus-TerrewodeResearch_v4-1.pdf.

²⁰ Roa, L., L. Caddell, G. Ganyaglo, V. Tripathi, N. Huda, L. Romanzi, and B.C. Alkire. 2020. "Toward a Complete Estimate of Physical and Psychosocial Morbidity from Prolonged Obstructed Labour: A Modelling Study Based on Clinician Survey." *BMJ Global Health* 5: e002520. https://gh.bmj.com/content/5/7/e002520. https://gh.bmj.com/content/5/7/e002520.

²¹ Mallick, L. and V. Tripathi. 2017. "The Association between Female Genital Fistula Symptoms and Gender-Based Violence: A Multicountry Secondary Analysis of Household Survey Data." *Tropical Medicine & International Health* 23, no. 1 (November): 106–119. http://onlinelibrary.wiley.com/doi/10.1111/tmi.13008/full.

²² Él Ayadi, A., J. Barageine, A. Korn, O. Kakaire, J. Turan, S. Obore, J. Byamugisha, F. Lester, H. Nalubwama, H. Mwanje, V. Tripthi, and S. Miller. 2018. Trajectories of women's physical and psychological health following obstetric fistula repair in Uganda; A longitudinal study. *Tropical Medician & International Health* 24(1). https://doi.org/10.1111/tmi.13178.

²³ Delamou, A., V. Tripathi, S.C. Bienvenu, S.Sidikiba, M. Fassou, D. Grovogui, P. Kolie, M. Bouedouno, M. Mafu, D.F. Banze, and Z. Rony. Forthcoming. Flexible Operational Research Training (FORT) Approach: A Case Study in the Democratic Republic of Congo, 2017 to 2021.

- **Fistula prevention:** Increase the focus on and funding for fistula prevention measures including voluntary FP, community education, safe motherhood, health systems strengthening of midwifery services and safe surgery, and universal health coverage.
- **Fistula screening and referral:** Expand access to screening and referral services via innovative, evidence-based approaches that involve the community and address documented barriers.
- Nonsurgical fistula repair and prevention: Expand awareness of and access to catheterization as both prevention and treatment for fistula.
- **Holistic needs of fistula clients:** Embrace a holistic vision of fistula clients' needs, with particular focus on gender-based violence and physical and emotional well-being.
- **Service integration:** Integrate genital fistula, incontinence, and POP services to enhance the sustainability of fistula services; engage the academic sector; and ensure care is available for women with serious health needs who are often turned away from condition-specific sites.
- **Fistula and the safe surgery ecosystem:** Continue to advocate for fistula care representation within the safe surgery community, strengthen surgical capacity, and promote the importance of fistula prevention and treatment as part of the safe surgery ecosystem.

Additional information on the accomplishments of FC+ can be found on the project website: www.fistulacare.org.