Five Years of Fistula Care Plus: Looking Back at Key Achievements and the Way Forward to End Fistula

WHAT IS FISTULA?

A genital fistula is an abnormal opening in the upper or lower female genital tract that causes uncontrollable, constant leakage of urine and/or feces. Obstetric fistula is usually caused by several days of obstructed labor without timely medical intervention. latrogenic fistula is caused by surgical error, most often during cesarean section. Traumatic fistula is caused by injury for instance, through sexual violence, female genital mutilation, or accidents.

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BACKGROUND

Fistula Care *Plus* (FC+) is a global project initiated in 2013 by the US Agency for International Development (USAID) and implemented by EngenderHealth. FC+ builds on and enhances the work undertaken by USAID's previous Fistula Care project (2007–2013), also led by EngenderHealth. FC+ has supported activities in 843 facilities (45 fistula treatment sites and prevention and 798 prevention-only sites) in Bangladesh, Democratic Republic of Congo (DRC), Mozambique, Niger, Nigeria, Togo, and Uganda.

Between one and two million women currently need fistula repair services and thousands of new cases occur each year. Obstetric fistula is a devastating consequence of childbirth without skilled birth attendance or adequate emergency obstetric care. Women with fistula have usually survived prolonged/obstructed labor, often lost their child to stillbirth or early neonatal mortality, and frequently faced profound social consequences due to their condition. With appropriate resources, awareness, and strong health systems for prevention, treatment, and reintegration, fistula can be eliminated for future generations.

FC+ has five objectives:

- Strengthen the environment for fistula prevention and treatment services in the public and private sectors through partnerships that enhance programmatic, institutional, and financial sustainability
- Enhance community understanding and practices to prevent fistula, improve access to treatment, reduce stigma, and support reintegration of women and girls with fistula—including those whose fistula is deemed incurable, and those whose fistula is the result of sexual violence
- Reduce transportation, communication and financial barriers to accessing preventive care, detection, treatment, and reintegration support
- Strengthen provider, health facility, and system capacity to provide and sustain quality services
- Strengthen the evidence base to improve fistula care and scale up application of standard monitoring and evaluation and indicators for prevention and treatment

Achievements from the first five years of project implementation (December 2013–December 2018) in Bangladesh, DRC, Mozambique, Niger, Nigeria, Togo, and Uganda are summarized in this brief.







World Health Organization (WHO). 2018. 10 Facts on Obstetric Fistula. http://www.who.int/features/factfiles/obstetric fistula/en/.

FC+ Project Highlights: December 2013-December 2018

- 13,840 surgical fistula repairs and 1,092 nonsurgical repairs supported in six countries
- 76 fistula surgeons and 5,698 other healthcare workers trained in fistula prevention and treatment
- 1.4 million voluntary family planning counseling sessions and 935,607 couple years of protection (CYP) delivered at project-supported health facilities
- 12 research studies conducted by FC+ and its partners to improve the knowledge base for fistula programming
- 25 peer-reviewed journal articles documenting program learning and evidence published

EXPANDING ACCESS TO FISTULA REPAIR

Between December 2013 and December 2018, FC+ supported the provision of 13,840 surgical fistula repairs in six countries: Bangladesh, DRC, Mozambique, Niger, Nigeria, and Uganda (see Figure 1). In 86% of these repairs, the fistula was successfully closed (see Figure 2). FC+ has supported the training of 76 fistula surgeons and 5,698 other health workers in the skills required to prevent and treat fistula.

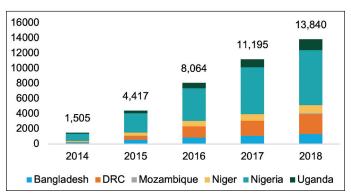


Figure 1: FC+ Cumulative Surgical Fistula Repairs



Figure 2: Outcomes of FC+ Surgical Fistula Repairs

FC+ has also worked to increase awareness of and support for nonsurgical fistula treatment. Such treatment is appropriate for a proportion of fistulas, particularly recent fistulas and those that are relatively small. FC+ supported 1,092 nonsurgical fistula repairs via bladder catheterization, mostly in Nigeria. In 76% of these repairs, the fistula was successfully closed. The prior Fistula Care project developed a set of recommendations for use of catheterization for prevention of fistula after prolonged/obstructed labor and for fistula treatment. FC+ supported Nigeria's Ministry of Health in adapting these recommendations and developing the first national guidelines on catheterization for fistula prevention and treatment. FC+ has also supported the translation and dissemination of these guidelines in other countries.

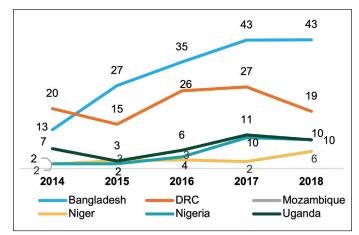


Figure 3: Percent of Diagnosed Fistula with latrogenic Etiology

A review of FC+ clinical data showed wide variation in the reported etiology of diagnosed fistula cases across time and location. Prolonged and/or obstructed labor is the reported cause of the majority of diagnosed fistula. However, the percentage of cases classified as iatrogenic (i.e., caused by error during a medical procedure) has become concerning, with the highest proportion occurring in Bangladesh (nearly 43%) (see Figure 3). In most FC+ supported countries, iatrogenic fistula is primarily associated with cesarean section; however, in Bangladesh it frequently follows hysterectomy. These trends indicate a need to address the increasing volume of cesarean deliveries in low-resource settings and to ensure safety and quality across obstetric and gynecological surgical procedures.

IMPROVING SURGICAL SAFETY AND QUALITY

FC+ has undertaken activities at the global, regional, and national levels to strengthen surgical safety and quality, particularly related to cesarean section and fistula repair. FC+ has raised awareness about the problem of iatrogenic fistula, leveraging the project's large body of clinical service data and







its partnerships with eminent fistula surgeons to document current trends and identify actions that partners can take to address the problem.² FC+ convened a technical consultation with the Maternal Health Task Force to examine health systems challenges contributing to unsafe cesarean sections and to develop a responsive action agenda.³ FC+ also provided monitoring and evaluation support to the American College of Obstetrics and Gynecology's Essential Training in Operative Obstetrics program in Uganda, which is working to improve cesarean delivery skills among clinical trainees.

FC+ developed and introduced the Surgical Safety Toolkit, a novel, integrated package of clinical trackers and quality assurance checklists.4 This toolkit includes: (1) a client tracker for recording clinical outcomes of surgical and nonsurgical care for fistula, pelvic organ prolapse (POP), and incontinence; (2) a surgical skills tracker to document the results of clinician trainings for fistula, prolapse, and incontinence; and (3) a sentinel event tracker to identify trends of near-miss morbidity events in order to help target quality improvement support for facilities. The toolkit also guides and supports teamwork with surgical safety checklists on topics including candidacy for surgery, daily postoperative care, and discharge followup planning. FC+ and Medical Aids Films produced an orientation video introducing the toolkit, contextualizing it within the global surgery movement, and demonstrating its potential impact.5

Globally, FC+ has promoted and supported the United Nations' 2016 call to action to "end fistula within a generation" through surgical systems strengthening. Specifically, FC+ has advocated for the integration of obstetrics/maternal, newborn, and child health within National Surgery Obstetrics Anesthesia Plans; collaborated with the World Health Organization (WHO) Global Initiative for Essential and Emergency Surgical Care, and participated in the G4 Alliance and World Health Assembly. FC+ also provides financial and technical support to regional and national networks involved in regional surgical safety efforts, particularly the College of Surgeons of East, Southern, and Central Africa; the East, Central, and Southern Africa College of Obstetrics and Gynecology; the West African College of Surgeons; and the South Asian Group on Fistula and Related Morbidities.

SUPPORTING VOLUNTARY FAMILY PLANNING COUNSELING AND SERVICES

Voluntary family planning services are an essential element of fistula prevention. Between December 2013 and September 2018, FC+ supported facilities delivered more than 1.4 million family planning counseling sessions and 935,607 couple years of protection (CYP) in Bangladesh, DRC, Niger, Nigeria, and Uganda (see Figures 4 and 5).⁶ FC+ also supported the training of 1,280 healthcare personnel in skills related to family planning service provision.

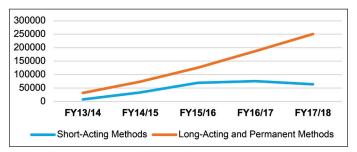


Figure 4: Cumulative CYP at Project-Supported Facilities

MEASURING THE BURDEN OF FISTULA

A case of fistula, whether obstetric or iatrogenic, is an indicator of the failure of health systems to deliver accessible, timely, and appropriate obstetric care. Incidence and prevalence estimates of the fistula burden are needed to inform effective healthcare planning and resource mobilization. *FC+ convened a technical consultation with the Maternal Health Task Force to examine the measurement and estimation of fistula incidence, prevalence, and treatment backlog.* FC+ collaborated with WHO to review

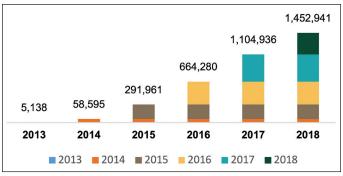


Figure 5: Cumulative Voluntary Family Planning Counseling Sessions at Project-Supported Facilities







https://fistulacare.org/wp-fcp/wp-content/uploads/2015/10/latrogenic-fistulatechnical-brief_2016-1.pdf.

https://fistulacare.org/resources/program-reports/cesarean-section-technical-consultation/.

⁴ https://fistulacare.org/resources/fistula-services/.

⁵ https://fistulacare.org/resources/fistula-services/.

⁶ This includes nearly 700,000 counseling sessions and 330,805 CYP delivered at former USAID/Targeted States High Impact Project (TSHIP) sites in Nigeria, where FC+ monitored family planning services.

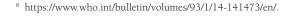
https://fistulacare.org/wp-fcp/wp-content/uploads/pdf/resources/ MeetingReport_FC+MeasurementConsultation_9.141.pdf.

methods and tools used to identify fistula cases in research studies and surveys. FC+ advocated for the inclusion of fistula and POP in the development of the Bangladesh Maternal Mortality and Morbidity Survey and provided technical assistance for a clinical validation study to evaluate the sensitivity and specificity of a questionnaire to screen for fistula and POP cases.

In Bangladesh, FC+ worked with BRAC to convert a simple fistula screening checklist into a job aid (the 4Q Checklist) that can be used by community health workers to conduct household screenings to identify fistula and complete perineal tear cases. Women suspected to have these conditions receive referrals to community-based fistula diagnosis events and, if needed, to follow-up medical services. The 4Q Checklist is sensitive to the economic, physical, and sociocultural barriers that many women face when seeking healthcare. This approach brings fistula information and referrals to women in their own homes, identifies previously isolated women with fistula symptoms, and provides linkages to care. The Ministry of Health is currently examining how to integrate the 4Q Checklist into the 14,000 community clinics that deliver healthcare across the country.

PUBLIC-PRIVATE PARTNERSHIPS FOR FISTULA INFORMATION AND SERVICES

Partnerships between the public and private sectors can expand access to quality fistula services. FC+ has developed collaborations with manufacturers to strengthen facilities' capacities to provide fistula services. For example, FC+ collaborated with LABORIE to introduce pelvic floor therapy treatment and urodynamics for women with persistent incontinence post-repair and with Gradian Health Systems to improve anesthesia quality of care through training, supply provision, and ongoing technical support. FC+ has also worked through project partner Direct Relief International to secure sustainable donations of Fistula Repair Modules—standardized packs of quality medicines and disposable surgical and anesthesia supplies necessary for fistula repair surgeries. These modules are available to qualified health facilities at no cost and FC+ has facilitated delivery of these modules to 11 project-supported sites in four countries. FC+ has also established in-country partnerships with media outlets that donate airtime to publicize specific fistula outreach and treatment efforts as well as to directly deliver information on fistula prevention and treatment to the community.





International Day to End Obstetric Fistula activities at LAMB Hospital, Bangladesh Photo: ©Isharab Hossain

STRENGTHENING FISTULA POLICY AND NETWORKS

To ensure country-led sustainability of fistula service provision, FC+ has actively supported national fistula working groups and national fistula strategy development in Bangladesh, DRC, Mozambique, Niger, Nigeria, and Uganda. FC+ has facilitated national stakeholder meetings in Nigeria and Uganda to address the needs of women with incurable fistula through fistula policy, strategy, and programming. FC+ provides substantial technical and financial support to the International Society of Fistula Surgeons and the International Obstetric Fistula Working Group for their ongoing global efforts to promote the highest standards of obstetric fistula care for women in a safe, effective, and ethical manner.

FC+ has worked within the global fistula surgical community to address identified gaps in terminology definitions, from etiology to evaluation and management to surgery and reintegration. FC+'s contributions to the International Continence Society Standardization Committee's scoping document regarding the need for standardized terminology for female pelvic floor fistula led to the creation of the fistula terminology working group, which FC+ leadership currently vice-chairs. FC+ also contributed to the International Urogynecological Association/International Continence Society Joint Report on the Terminology for Female Pelvic Floor Dysfunction.⁹







⁹ https://www.ics.org/committees/standardisation#currenticsreports.

INCREASING COMMUNITY ENGAGEMENT

FC+ enhances community understanding and practices to prevent fistula, improve access to treatment, reduce stigma, and support reintegration of women and girls with fistula. To strengthen linkages between health facilities and the communities they serve, FC+ has implemented site walk-throughs in Uganda and Niger. Site walk-throughs consist of a guided tour of the health facility for community members and local officials to learn about the services provided and to support the development of action plans to improve service quality, mobilize clients, and grow resources for the facility. Site walk-throughs foster community ownership of health services while engaging community representatives in addressing health priorities at the community level.



A religious leader in Sokoto, Nigeria, working with the family of a fistula patient. $\mbox{Photo: } \mbox{$\tt OFC+/Nigeria}$

Recognizing that lifelong habits are often formed during the early years of life, adolescents are a key target group for fistula prevention efforts. FC+ has worked with adolescents in Bangladesh through the School Girls for a Fistula-Free Bangladesh initiative and in Uganda through partnerships with Aflatoun International and the Private Education Development Network. In Bangladesh, FC+ has mobilized and supported teachers and female students throughout the country to develop road maps for fistula prevention within their families and communities and that link them with local community clinics and local institutions for social action. Students are recognized by their schools and communities for their accomplishments, including learning about fistula, pledging to delay marriage, referring their peers for antenatal care and hospital delivery, and identifying and referring girls and women with fistula for treatment. In Uganda, FC+ adapted the evidence-based Aflateen curriculum, integrating new reproductive health/family planning and gender equity modules with existing social and financial education for youth. FC+ implemented this



School girls' orientation at Nalta Girls High School in Kaligonj, Bangladesh. Photo: ©PK Poddar

curriculum as part of a strategy for reaching in- and out-of-school adolescents and empowering them to make positive decisions about their education, financial, health, and social well-being.

FC+ also works closely with local traditional and religious leaders who influence health behaviors in communities by providing accurate information on health services while discouraging harmful traditional and religious practices and beliefs that can lead to maternal morbidities and mortalities. In DRC, Nigeria, and Uganda, FC+ has trained these leaders to conduct ongoing community outreach efforts.

Family support is crucial to recovery and reintegration after fistula repair, including the ability to use voluntary family planning and maternal health services that can prevent fistula recurrence. The FC+ project addresses gender inequities and mitigates their effect on fistula prevention and care. In Nigeria, FC+ strengthened Men as Partners® (MAP) groups by supporting community-based organizations providing training and implementing peer education sessions to encourage male involvement in maternal health and shared decision-making power between spouses. In Uganda, partner facilities have worked to increase male involvement in caretaking by mobilizing and supporting husbands accompanying wives seeking fistula services. Both men and women receive meals and transport assistance. Men also participate in sensitization meetings to discuss gender issues that increase women's vulnerability to fistula and other maternal morbidities as well as poverty, genderbased violence, and alcohol and substance abuse. Participants also discuss voluntary family planning, healthy pregnancy, and the impact of delays in care-seeking behaviors on women's health. These conversations focus on generating awareness about the importance of respectful communication within couples and encouraging men to serve as community role models and to share information regarding fistula prevention.







IDENTIFYING AND ADDRESSING BARRIERS TO FISTULA TREATMENT

In Nigeria and Uganda, formative research conducted by FC+ and the Population Council identified long journeys to health facilities and limited decision-making ability among women as barriers to fistula care. ¹⁰ Low literacy of female community volunteers and women affected by fistula additionally limit the utility of traditional communication materials and job aids for patient screening and mobilization. Limited knowledge about and capacity for addressing fistula among primary healthcare workers further delay appropriate screening, referral, and treatment. Finally, stigma about fistula makes it difficult for women with symptoms to attend community events that disseminate information about fistula services.

FC+ developed a comprehensive intervention to address these identified barriers. This intervention pairs the provision of consistent fistula information and screening through multiple channels—community agents, health facilities, and an interactive voice response (IVR) hotline—with transportation vouchers for positively-screened women and a companion for travel to an accredited, quality fistula treatment center. The Population Council is evaluating the effectiveness of this intervention in three sites in Nigeria and Uganda.

FC+ partnered with Viamo (formerly VOTO Mobile), a leader in voice-based mHealth solutions, to develop and test the innovative fistula screening and referral IVR hotline. The IVR hotline links women identified as suspected fistula cases with community agents who can provide referrals to quality treatment facilities and transportation vouchers. This innovation extends beyond common fistula case-finding approaches and uses context-appropriate methods to address the realities of women's lives—particularly barriers related to stigma, isolation, limited mobility, and low literacy. This approach also allows women to bypass many cultural and health system gatekeepers, directly receive health information, and link with community agents for vouchers that mitigate transport and financial barriers.

BUILDING AND SHARING KNOWLEDGE AND EVIDENCE

FC+ has strengthened the evidence base for improved fistula programming and care by implementing a research agenda developed through consultation with its International Research Advisory Group. 11 The FC+/Population Council



A transportation voucher helps restore women's dignity Photo: ©FC+/Nigeria

In 2017, FC+ launched an intervention to improve access to fistula treatment in Nigeria and Uganda, as part of a research-to-action partnership with the Population Council. Peace Ogah from the Ikwo Local Government Area in Nigeria's Ebonyi State was among the women whose used the transportation voucher provided through this intervention. After two failed attempts at seeking treatment for her fistula, Peace could no longer afford the cost of transportation from her community to a treatment facility and continued to live unhappily with her condition.

"One day, a community agent came to our compound and informed us about the free transportation to NOFIC Abakaliki, but it was hard to believe it."

On the scheduled date and time, the driver, a member of the National Union of Road Transport Workers, arrived at Peace's compound.

"I was waiting anxiously, then I heard the sound of a car. I was treated like a queen.... it was a wonderful and unbelievable experience. I will tell other women hiding, so they can come out and enjoy the good things!"

Peace received successful surgical treatment for her fistula and plans to become a fistula advocate.

partnership to examine and address barriers to fistula treatment has been a key research initiative of the project. Other highlights of research conducted through FC+ and its partners include:

- A survey of project-supported fistula repair sites to document demand for and capacity to provide POP services as well as perceptions about integrating POP and fistula repair services¹²
- A global survey of skilled birth attendants to understand knowledge, attitudes, and practices related to intrapartum







¹⁰ https://www.popcouncil.org/research/fistula-care-plus.

https://fistulacare.org/wp-fcp/wp-content/uploads/pdf/resources/ MeetingReport_FC+IRAG_9.141.pdf.

¹² https://www.ncbi.nlm.nih.gov/pubmed/29411073.

- and postpartum bladder care, including catheterization to prevent fistula after prolonged/obstructed labor¹³
- A study in Uganda with a local organization (TERREWODE) to understand the effects of psychosocial support interventions on the lives of women with incurable fistula
- Country-level studies that address topics of local partner interest, for example: the characteristics and prevalence of non-obstetric fistula in DRC and needs and channels for community-based education and mobilization for fistula prevention and care in Nigeria
- An analysis of Demographic and Health Survey and Service Provision Assessment data from 44 countries by the London School for Hygiene and Tropical Medicine to assess cesarean section trends in low-resource settings, with in-depth case studies of Bangladesh and Tanzania^{14,15,16}
- A secondary analysis by the Demographic and Health Survey Program of all surveys that incorporated the fistula module¹⁷



Supportive supervision visit with nurses and midwives.

Photo: ©FC+/Nigeria

- An in-depth sub-analysis examining associations between self-reported fistula symptoms and gender-based violence¹⁸
- An exploratory, mixed-methods study conducted by the University of California-San Francisco with Makerere University in Uganda to understand the long-term trajectories of women's physical and mental well-being after fistula repair and to develop and validate an instrument to measure these issues¹⁹
- https://fistulacare.org/wp-fcp/wp-content/uploads/2015/10/LSHTM-report_ Nov-8_final_for-web.pdf.
- https://fistulacare.org/wp-fcp/wp-content/uploads/2015/10/LSHTM-report_ Nov-8_final_for-web.pdf.
- https://fistulacare.org/wp-fcp/wp-content/uploads/2018/12/Tanzania_ CSPolicyBrief_2018-3.pdf.
- https://bmjopen.bmj.com/content/8/9/e024216.info.
- 17 https://dhsprogram.com/pubs/pdf/OD67/OD67.pdf.
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Meeting of community volunteers, Niger. Photo: ©FC+/WAN

A randomized controlled study²⁰ conducted by the Fistula Care project determined that seven days of catheterization is non-inferior to longer catheterization after simple fistula repair. Following advocacy and support by FC+ and USAID, in 2018 WHO released a recommendation for seven-day inpatient bladder catheterization following surgical repair of a simple obstetric urinary fistula.²¹ This recommendation has the potential to dramatically shorten required hospital stays for fistula repair patients, thereby reducing patient burden and increasing the number of patients who treatment centers can serve.

FC+ is committed to disseminating knowledge from programs and research at the national, regional, and global levels. The project has presented program learning and evidence at many forums, including global conferences convened by institutions and networks such as the Global Health Workforce Network, Health Systems Global, the International Confederation of Midwives, the International Federation of Gynecology and Obstetrics, the Institute for Healthcare Improvement, the International Society of Fistula Surgeons, and the International Obstetric Fistula Working Group. In addition, FC+ has published 25 peer-reviewed journal articles as well as multiple technical briefs and research reports.²² FC+ initiated and now manages a fistula community of practice for facilitating knowledge sharing and coordination related to fistula care. Through the fistula community of practice, FC+ convenes webinars on topics related to fistula prevention and treatment.²³ The FC+ twitter account and blog are also sources of information and advocacy for the fistula community.

- ²² https://fistulacare.org/resources/publications/journal-articles/.
- ²³ https://fistulacare.org/resources/webinars/.







²⁰ http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)62337-0/abstract.

http://www.who.int/reproductivehealth/publications/simple-obstetricurinary-fistula/en/.



Surgeons participating in surgical training in Nigeria. ${\tt Photo: @FC+/Nigeria}$

TOWARD A FISTULA-FREE GENERATION

Key learnings from the FC+ experience thus far can help inform a global road map for future action. In addition to sustained support from national governments and development partners for the provision of fistula repair, priority areas for the future 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 the national level; 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. To create synergy with the Sustainable Development Goals and the United Nations' 2016 call to action to end obstetric fistula by 2030, advocate for obstetric fistula to be a reportable, sentinel indicator of maternal health systems gaps.
- Fistula prevention. Increase the focus on and funding for fistula prevention measures including voluntary family planning, community education, safe motherhood, health systems strengthening of midwifery services, safe surgery, and universal health coverage.

- Fistula screening and referral. Expand access to screening and referral services through innovative, evidence-based approaches that involve the community and address documented barriers.
- Nonsurgical fistula repair and prevention. Expand awareness of and access to bladder catheterization as both prevention and treatment approaches 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 of fistula, POP, and non-fistula incontinence care. Integrate genital fistula, incontinence, and POP services to enhance the financial sustainability of fistula services; engage the academic sector; and provide



Nigerien First Lady Dr. Lalla Malika Issoufou greets fistula clients during IDEOF celebrations.

Photo: ©FC+/WAN

care for women with serious health needs who are turned away from condition-specific sites.

• Fistula and the safe surgery ecosystem. Continue to advocate for fistula care representation within the safe surgery community and to promote the importance of fistula prevention and treatment as part of the safe surgery ecosystem.

Acknowledgements

This brief was written by Karen Levin and Vandana Tripathi. The authors thank Erin Mielke, Lauri Romanzi, and Mary Ellen Stanton for their review. The brief was edited by Amy Agarwal and designed by Robert Vizzini. This publication was made possible by the generous support of the American people through the US Agency for International Development (USAID) under cooperative agreement AID-OAA-A14-00013. The information provided here does not necessarily represent the views or positions of USAID or of the US government.

Suggested citation: Fistula Care Plus. 2019. International Day to End Obstetric Fistula (IDEOF) 2019: Looking Back at Five Years of Fistula Care Plus. Washington, DC: Fistula Care Plus/EngenderHealth.

The USAID-funded, EngenderHealth-led Fistula Care *Plus* project works to prevent fistula from occurring, treats and cares for women with fistula, and assists in the rehabilitation and reintegration of women with fistula. Fistula Care *Plus* partners with ministries of health, faith and community-based organizations, nongovernmental organizations, United Nations agencies and other stakeholders, including facilities providing surgical and nonsurgical fistula repair in South Asia and Sub-Saharan Africa.

For more information about fistula and the Fistula Care Plus project, visit www.fistulacare.org.

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