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. Iatrogenic 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.

At a Glance: FC+ Uganda
• 1,431 surgical fistula repairs completed; 99% closed at discharge
• 4 fistula surgeons and 1,661 other healthcare workers trained in fistula prevention and treatment
• 124,209 family planning counseling sessions and 159,912 couple-years of protection delivered at project-supported health facilities
• 822,569 individuals reached through in-person community outreach

Fistula Care Plus (FC+) is a global project initiated in 2013 by the United States 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. EngenderHealth's USAID-supported fistula prevention and repair efforts in Uganda began in July 2005 and continued under the Fistula Care and FC+ projects, until May 2019.

Fistula is a devastating morbidity, with profound social consequences for those affected. In Uganda, FC+ emphasized building capacity for providing safe surgery including routine fistula repair, community awareness, integrating voluntary family planning (FP) services within fistula and maternal healthcare, and piloting efforts to meet the reintegration needs of clients who have undergone fistula repair. The project partnered with six health facilities for fistula treatment and prevention services and 15 facilities providing prevention services; this included public and faith-based health facilities across seven districts in central, east-central, and western Uganda.

ENABLING ENVIRONMENT
FC+ and its partners strengthened the enabling environment in Uganda to institutionalize fistula prevention, treatment, and reintegration in the public and private sectors.

Dates of support: May 2014 to May 2019
Supported fistula treatment facilities: Hoima Regional Referral Hospital, Jinja Regional Referral Hospital, Kagadi General Hospital, Kamuli Mission Hospital, Kisii Mission Hospital, Kitovu Mission Hospital
Population: 45,741,000
Lifetime prevalence of fistula: 19.2 per 1,000
Estimated number of current fistula cases: 74,200
Maternal mortality ratio: 375/100,000 live births
Contraceptive prevalence rate (all methods, married women ages 15 to 49): 42%
private sectors by improving national and facility policies, guidelines, and resources, including addressing the needs of women with incurable fistula.

**National Policy and Government Partnerships**

FC+ staff and partners worked with the Ugandan Parliament to ensure dedicated funding for reproductive health (RH) services, successfully securing line items for fistula prevention, detection, and treatment in the national budget. To strengthen national coordination of fistula prevention and treatment efforts, FC+ co-facilitated the national Fistula Technical Working Group (FTWG) with the United Nations Population Fund (UNFPA). FC+ assisted the FTFW in convening quarterly stakeholder coordination meetings and reviewing progress and challenges in fistula prevention, repair, and reintegration services under the authority of the Ministry of Health (MOH).

With an emphasis on partnerships, the FTFW collaborated with an expert surgical consultant to develop and launch Uganda’s first national fistula strategy, as well as a follow-on strategy on fistula prevention, detection, treatment, and reintegration, and outlined plans to ensure sustainable funding.

**Safe Surgery**

FC+ conducted quality improvement assessments at supported treatment facilities and, based on findings, conducted targeted trainings on identified topics (e.g., infection prevention and FP integration) and established supportive supervision mechanisms. The project also supported facility infection prevention and control committees to review national guidelines and formulate action plans to address identified gaps.

To address identified gaps in clinical records, challenges in understanding clinical data trends, and clinical staff requests at project-supported facilities, FC+ developed and introduced the Surgical Safety Toolkit (SST). Designed to support and enhance quality surgical care and routine monitoring for fistula and pelvic organ prolapse services, the toolkit includes clinical trackers and quality assurance checklists to promote a minimum acceptable standard, as outlined by global actors such as the World Health Organization (WHO) and the Lancet Commission on Global Surgery. FC+ harmonized SST tools with existing facility and MOH quality assurance tools before introducing it into five project-supported fistula repair sites as part of routine clinical monitoring. Project staff provided ongoing mentoring and clinical support to facility implementation teams, which included surgeons, nurses, and program administrators. These teams are now regularly reviewing SST data to inform in clinical decision-making and improve care.

When project data demonstrated an increase in reports of iatrogenic fistula cases, FC+ supported targeted capacity building for medical officers who regularly perform caesarean sections in Hoima and Masaka districts. Obstetrician gynecologists (ob-gyns) from regional hospitals provided mentoring and comprehensive coaching to medical officers at the selected facilities and an MOH trainer provided follow-up to reinforce competencies. Similarly, when assessments revealed that some facilities lacked standard instruments for providing safe cesarean section, the project procured and distributed the needed supplies.

In collaboration with the American College of Obstetricians and Gynecologists, Makerere University Kampala, and Mbarara University of Science and Technology, FC+ strengthened surgical maternal health services by supporting monitoring and evaluation in the delivery of the Essential Training in Operative Obstetrics curriculum. This curriculum

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covered management, technical, and surgical skills needed to perform critical obstetric operations, including caesarean section. Implemented across the country, 128 individuals completed this training.

To strengthen maternal, newborn, and child health systems, FC+ supported fistula surgeons to attend regional meetings of the College of Surgeons of East, Central, and Southern Africa. The project also supported the establishment of the East, Central, and Southern Africa College of Obstetrics and Gynecology to standardize and strengthen state-of-the-art training, capacity building, and professional development for obstetricians in the region. When the East, Central, and Southern Africa College of Obstetrics and Gynecology launched in Kigali in 2017, the project supported 16 obstetricians to attend—all of whom are now actively participating in the college.

**Women with Incurable Fistula**

In collaboration with the FTWG and a local nongovernmental organization (NGO), TERREWODE, FC+ sought to delineate the social and medical dimensions of incurable fistula and to develop strategies and rights-based guidelines for responding to the needs of women with incurable fistula. This process highlighted the need for social reintegration efforts to respond to the persistent, and often lifelong, social exclusion challenges facing women with incurable fistula.

FC+ and TERREWODE jointly researched the effectiveness of interventions aiming to improve quality of life of women with incurable fistula. Through the study, clients identified as potentially having incurable fistula received referrals to expert surgeons at Mulago National Referral Hospital and Soroti Regional Referral Hospital to assess and confirm their status. Following a confirmation of their status as incurable, the women participated in a structured intake process to assess well-being and quality of life. Participants then received an individualized package of services based on the TERREWODE reintegration and support model. This includes interventions such as vocational and legal rights training, comprehensive health education, ongoing psychosocial counseling, and pairing with a “sister-friend” in their community. At the conclusion of the social reintegration program, participants completed an end line assessment, which documented requested and received services and tracked perceived effects and value. Participants reported significant improvements in well-being and quality of life and findings showed that while many practical effects of incurable fistula cannot be eliminated, individualized and multifaceted interventions can significantly mitigate the impact of this condition on quality of life.

**Improving Quality and Availability of Routine Fistula Data**

The Ugandan MOH, with support from WHO, developed a Sexual and Reproductive Health/Family Planning Monitoring and Evaluation Framework in 2015 to guide program implementation. FC+ and the FTWG reviewed the framework to incorporate new updates and align it to new program indicators included in the revised national health management information system (HMIS). FC+ also proposed new fistula indicators for inclusion, before submitting the revised framework for final review and approval by the WHO and MOH.

At the request of the FTWG, FC+ designed a simplified fistula reporting form that fistula treatment sites nationally are now using to update the MOH. The project then provided training and mentoring to build the capacity of district biostatisticians and supported facilities to ensure accurate and consistent reporting of the revised fistula, FP, and maternal and child health indicators into the national HMIS and DHIS2 systems. FC+ also participated in the Health Information System/Data Management Technical Working Group, a platform through which health-related implementing partners meet and share information and receive updates from the Health Information System division of the MOH.

Project-supported facilities conducted routine data quality assessments, which provided opportunities for clinical mentoring and identification of challenges related to service delivery and data management. FC+ introduced and supported quarterly data for decision-making meetings with facility staff and administration.

**COMMUNITY OUTREACH AND ADVOCACY**

Community plays an essential role in fistula prevention, treatment, and reintegration. In Uganda, FC+ worked to enhance community understanding and practices to prevent fistula, identify potential fistula cases, improve access to treatment, reduce stigma, and support reintegration—including of those with incurable fistula and those whose fistula is the result of sexual violence.
Aflateen PLUS

Uganda has one of world’s youngest populations, with 50% estimated to be less than 15 years old.10 The project employed positive youth development approaches to empower young people to engage in behaviors that increase their ability to make responsible financial, social, and health decisions. Underpinning this strategy was the principle that when young people can manage their reproductive lives, they are more likely to stay in school, develop skills, and establish strong social connections.

FC+ partnered with two global NGOs, Aflatoun International and the Private Education and Development Network, to adapt their evidence-based Aflateen curriculum.11 This curriculum targets young people (boys and girls) ages 14 to 19 and emphasizes social and financial education using a learner-centered, activity-based approach. FC+ staff developed a supplemental module addressing voluntary FP, RH, and fistula prevention for integration with the existing Aflateen curriculum. Known as Aflateen PLUS, this curriculum served as a core element of FC+’s youth engagement strategy in Uganda.

FC+ implemented the Aflateen PLUS curriculum with clubs for in- and out-of-school youth in Uganda in partnership with teachers, health workers, and community members. Between October 2018 and September 2019, 359 Aflateen PLUS members participated in club meetings; 1,154 individuals benefited from club outreach activities; 356 club members received education on RH; 523 individuals received referrals to health facilities; 315 club members participated in community activities; and 223 club members implemented financial enterprises.

Community Education

FC+ increased awareness about the causes of fistula, prevention approaches, and availability of treatment, including using radio to reach populations in remote areas. Staff created content for national and community radio, including recorded programs and live interviews with representatives from government agencies and treatment facilities on maternal and RH issues, including the availability of fistula and pelvic organ prolapse services. The project timed broadcasts to mobilize potential fistula clients to seek treatment during concentrated repair efforts at supported hospitals. In total, FC+ organized 668 mass media activities delivering maternal and RH information to more than 42.2 million Ugandans.

Describing the outcomes of her work with out-of-school youth, an Aflateen Plus peer educator noted, “They are discussing about STIs [sexually transmitted infections] and counseling their peers to open up in case they have any disease. Sometimes the [facility] in-charge calls me to let me know how one of my group members managed to take a colleague to access treatment from the health center, so I see that as tremendous change among the youth.”

A Muslim leader serving as both a religious leader and a teacher integrated fistula prevention messages in the teaching program. ©Frank Baguma

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FC+ leveraged the trusted positions of leaders from the three largest religious groups in the country to promote acceptance of and support for maternal health and FP service uptake. The project engaged 143 religious leaders from Hoima and Masaka districts to participate in trainings in which they explored the core beliefs of their respective religions to better understand the root causes of poor maternal health in the communities they serve. These project-supported religious leaders reached 1,137,910 congregants (69% female, 31% male) through more than 11,000 information sessions, covering topics such as male involvement, birth spacing, birth preparedness, and the importance of accessing antenatal care and skilled maternity services. Religious leaders engaged in this initiative enthusiastically to promote maternal health, FP, and RH service uptake and, at project close, came together to discuss achievements and challenges in mobilizing obstetric fistula clients and to make commitments for the future. This effort demonstrated how religious leaders can be a valuable resource for community engagement and awareness.

Family support is crucial to recovery and reintegration after fistula repair, including the ability to use voluntary FP and maternal health services that can prevent fistula recurrence. FC+ encouraged spouses to accompany clients to treatment sites. Spouses attending concentrated fistula repair activities were able to join meetings to learn about the causes of fistula and other issues that increase risks associated with maternal morbidities, as well as related factors such as poverty, gender-based violence, and alcohol and substance abuse. Participants also discussed topics such as voluntary FP, healthy pregnancy, and the impact of delays in seeking care on women's health—with a focus on the importance of respectful communication. These sessions concluded by encouraging participants to commit to ensuring their spouses were financially supported, helping with domestic work and abstaining from sex during their spouses’ recovery period, and to serving as community role models to share information regarding fistula prevention. These meetings also provided opportunities to discuss barriers to increasing male engagement in healthcare.

FC+ trained 136 community volunteers, largely from village health teams, which are a core element of Uganda's national community health strategy. Through these trainings, volunteers learned to provide information about a range of maternal health topics, including voluntary FP, fistula causes and symptoms, reintegration following fistula repair, and stigma reduction. Community educators also referred individuals to health facilities to access quality health services. When volunteers in Hoima indicated that they were unable to reach clients in some villages because of distance, the project provided 154 bicycles to the district. Together with partner facilities and organizations, FC+ supported 42,804 in-person community outreach activities through community volunteers, reaching more than 822,560 people.

**Barriers Research**

FC+ and Population Council conducted a research-to-action study to identify and respond to barriers to fistula treatment uptake. Formative research conducted in Hoima and Masaka explored barriers and enabling factors for fistula repair and care delivery and access. In-depth interviews and focus group discussions captured a range of perspectives from women living with fistula, clinicians, and community members. Lack of awareness, financial constraints, and transport issues consistently emerged as challenges.

In 2017, formative research findings informed the design of a comprehensive information, screening, and referral implementation research study. FC+ implemented multipronged interventions in Kalungu district, with Masaka district as a control, to address awareness, financial, and transportation barriers. The intervention employed a “3-1-1” model, which involved disseminating consistent messages.
through three communication channels, using a single screening algorithm, and distributing a transport voucher to each positively screened woman and their companion to visit a fistula center for diagnosis and repair.\textsuperscript{14} FC+ also supported training and capacity building activities to strengthen community-based screenings and referrals.

As part of the intervention, FC+ collaborated with Viamo, a digital health social enterprise, to design a free interactive voice response fistula screening hotline, advertised through flyers disseminated by community agents and primary healthcare workers.\textsuperscript{15} Community agents followed up with hotline callers to facilitate transport to the fistula treatment facility using the transportation voucher. Community agents also used the fistula hotline to screen women during community mobilization activities (home visits, community forums, etc.).

Project interventions contributed to increases in admissions and surgeries at the fistula treatment center. Monitoring data suggest the hotline generated a large volume of callers, many of who sought fistula care. Voucher data also suggest that the project increased access for clients by removing barriers associated with transportation. Through this experience, as well as discussions with policy makers, FC+ and Population Council identified key recommendations for future policies and programs aiming to reduce fistula treatment barriers.\textsuperscript{16}

**Site Walk-Throughs**

To strengthen linkages between communities and health facilities,\textsuperscript{17} FC+ implemented the site walk-through (SWT) approach in Hoima, Jinja, Kamuli, Kasese, and Masaka districts. During the SWT, healthcare workers guide community and district representatives on a tour of a health facility, explain the services provided, and answer questions—encouraging positive dialogues between community members and facility staff. The SWT culminates in action planning to address barriers to service uptake and support community representatives to champion behavior change. The approach establishes accountability of the community to address demand-side challenges and of the healthcare institution to address supply-side challenges for maternal and FP services.

Following SWTs, the project supported quarterly meetings to review progress on action plans. A review of routine health facility service statistics showed significant improvement in the use of voluntary FP and maternal health services following the SWT. To help meet increased demand and ensure a high quality of care, the SWT action plan and FC+ follow-up support included building the capacity of district officials to strengthen the contraceptive commodity supply chain as well as conducting training on a variety of contraceptive methods, infection prevention and control, and use of the partograph for labor monitoring. In addition to increased service utilization, qualitative feedback showed that the SWTs enhanced local leaders’ sense of ownership; local leaders reported that they had begun developing plans to extend the SWT approach to other health facilities within their districts.

**HEALTH PROVIDER, FACILITY, AND SYSTEM CAPACITY BUILDING**

FC+ strengthened health provider, facility, and system capacities to deliver sustainable, high-quality services in Uganda by directly supporting surgical fistula repairs; training health facility staff (including fistula surgeons); and developing and implementing tools and approaches to improve clinical quality, surgical safety, and facility preparedness. Project partners provided 1,431 surgical fistula repairs and 86 nonsurgical repairs (using catheterization) at six health facilities across the country. Nearly all (99%) these repairs were closed at the time of client discharge. The vast majority, 86%, of fistula clients were undergoing their first fistula repair attempt, with 10% receiving their second repair, and 4% their third or more. Where fistula etiology was available (80% of diagnosed cases), nearly all fistula were obstetric (90%) or iatrogenic (9.5%), with a small number caused by trauma, cancer, or congenital abnormality (0.5%). The project also supported 418 complete perineal tear repairs, as the symptoms of this maternal injury are identical to fistula.

FC+ clinical staff worked closely with staff at all supported facilities, providing mentoring and feedback, discussing data trends, and supporting safer surgery. Historically, fistula repair surgeries in Uganda were available through concentrated repair efforts—often known as a “camp” model. Introducing routine


fistula care enables health systems to plan and deliver fistula treatment locally to clients in a timely manner, rather than relying on sporadic visits from external clinicians. With the goal of providing safe and routine access to fistula repair services, FC+ supported training and mentoring to improve the skills and competencies of surgical teams and facilitated the availability of necessary instruments and supplies. The project also worked with facilities to schedule designated fistula clinic and theatre days and with the MOH to allocate adequate human resources. As of 2019, five project-supported hospitals reported successful provision of routine surgical repairs, and the percentage of supported repairs provided through routine services rose from 5% to 22%.

To strengthen clinical capacity and cultivate a safe surgery ecosystem, FC+ trained 1,661 healthcare providers—including nurses, midwives, doctors, and medical officers—on infection prevention and control, fistula counseling and treatment, FP counseling and services, treatment for pelvic organ prolapse, safe cesarean section, and advanced urogynecology and complex fistula-related reconstructive surgery. FC+ also facilitated surgical fistula repair training for surgeons using the Global Competency-Based Fistula Surgery Training Manual, developed by the International Federation of Gynecology and Obstetrics (FIGO) and partners, including EngenderHealth. FIGO-approved trainers from Mulago National Referral Hospital conducted training.

Informed, voluntary FP is crucial to fistula prevention. Project-supported facilities completed 124,209 FP counseling sessions and provided FP methods resulting in 159,912 couple-years of protection. FC+ trained clinicians to provide FP either as a stand-alone or integrated service, with an emphasis on clients’ rights to privacy, confidentiality, dignity, and safety. This included training on such topics as WHO medical eligibility criteria, EngenderHealth’s REDI (Rapport Building, Exploring, Decision Making, and Implementing the Decision): A Client-Centered Counseling Framework,18 HIV and FP integration, and insertion and removal of long-acting reversible contraceptives. FC+ also provided facilities with kits for insertion of intrauterine devices and implant insertion and removal, educational flip charts and posters, and other method demonstration materials to assist clients in making full, free, and informed choices.

**Strengthening Use of the Partograph**

The partograph is a key WHO-endorsed tool for monitoring labor and identifying signs of prolonged/obstructed labor—a leading cause of fistula. FC+ conducted partograph training for midwives at supported facilities and followed up with assessments to examine completeness, accuracy, and consistent use. Partograph trainers and identified “champions” filled gaps and provided technical assistance through on-the-job training. FC+ focused on strengthening partograph use at large referral hospitals and encouraged scale-up to lower-level health facilities through supportive supervision.

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Midwife practicing completing a partograph board during one of the trainings to become proficient with the tool. ©Lucy Asaba
FC+ reviewed data from 12 level-three health center facilities and two district hospitals (Kagando and Bwera) and surveyed 25 health providers from the facilities. Findings indicated an increase in utilization of the partograph to monitor labor and a decrease in adverse labor outcomes (fresh still births and macerated births). The majority (86.5%) of the partographs reviewed were complete and consistently plotted; facilities with fewer deliveries (less than 100 per month) and those with trained staff performed better than their counterparts.

To address the lack of available partographs at facilities, FC+ provided these tools as needed and worked with government officials to identify sustainable printing sources for partographs using government-allocated funds.

**EVIDENCE BASE**

FC+ completed a robust research agenda in Uganda. Together with Population Council, the project documented fistula treatment barriers,19 and evaluated its interactive voice response intervention.20 Partnership with TERREWODE enabled implementation of a mixed methods study to assess the effectiveness of interventions for women with incurable fistula.21 To understand the long-term outcomes of fistula repair, FC+ also supported Makerere University and the University of California, San Francisco to conduct a longitudinal study to measure reintegration success and document physical and mental health changes.22 Findings showed significant improvements in repair clients’ physical and mental health but documented challenges to recovery and reintegration. The study findings suggest that provision of targeted interventions including mental health counseling, health education, physical and occupational therapy, and economic assistance for women and their families may enhance recovery and facilitate reintegration. To address the high risk of adverse outcomes in subsequent pregnancies, fistula programs and/or clinicians should consider continuously following up post-surgery to minimize risk. Additionally, programs can strengthen integration of FP into fistula services to address unmet need among women post-repair.

FC+ shared research and programmatic findings from Uganda at global, regional, and national conferences and technical forums (including those organized by the International Society of Obstetric Fistula Surgeons, the International Confederation of Midwives, the International Conference on Family Planning, and FIGO) and through journal articles, technical briefs, and webinars.

**ELIMINATING FISTULA IN UGANDA**

The Government of Uganda continues its efforts to eliminate fistula by 2030, the global goal adopted by the Campaign to End Obstetric Fistula (http://www.endfistula.org). FC+ is proud to have worked with public and private partners across the country to advance this goal, and to support expanded, sustainable local capacity for fistula prevention, diagnosis, treatment, and comprehensive support for women who live with this condition.

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