

# REDUCING BARRIERS TO ACCESSING FISTULA REPAIR: ESTABLISHING A BASELINE IN UGANDA

## BACKGROUND

Obstetric fistula (OF) is preventable and surgically treatable, but women who lack access to quality maternal healthcare often live with OF for many years. In Uganda, about 2% of women aged 15–49 years report having experienced OF-like symptoms, with the highest prevalence occurring in the western region. Despite the presence of fistula camps in tertiary hospitals in Uganda, many women remain unrepaired.

As a partner on the EngenderHealth-managed Fistula Care Plus (FC+) project, the Population Council is conducting implementation research that tests solutions to treatment barriers. Formative research in Uganda confirmed that a lack of knowledge among lower level providers and women and families of how the condition occurs, where treatment is available, and the signs and symptoms of OF, as well as transportation costs, affect women's access to screening and repair.

## IMPLEMENTATION RESEARCH

The research aim is to understand whether a comprehensive information, screening, and referral intervention can reduce transportation, communications, and financial barriers to accessing preventive care, detection, and treatment of fistula in Uganda.

The intervention model follows a “3-1-1” pattern:

- **Three** channels for fistula messages and screening so women can learn about their fistula status:
  - Mass media and interactive voice response (mobile phones)
  - Community outreach agents
  - Primary health care workers
- **One** screening algorithm for detecting fistula condition
- **One** enabler: transport voucher for suspected fistula cases to the fistula repair center.



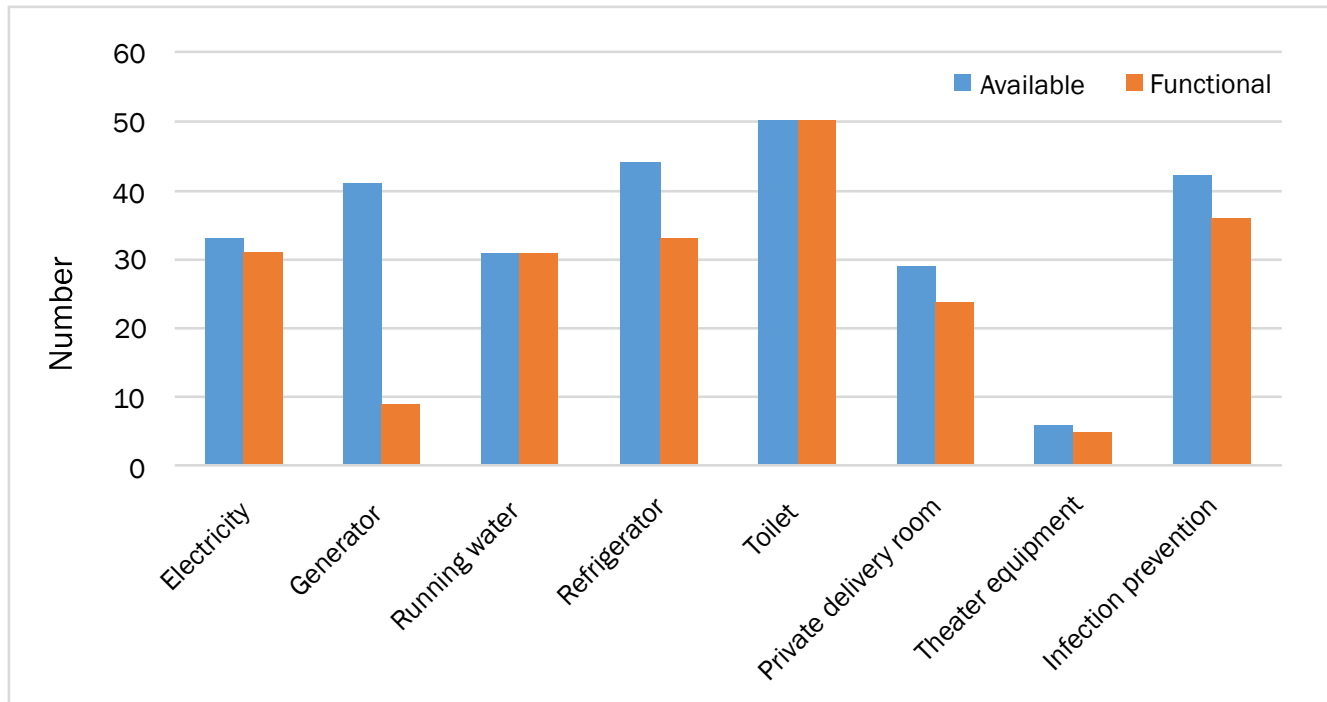
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**FIGURE 1. Capacity of PHC Facilities (n=50)**



## BASELINE DATA COLLECTION

In Uganda, Population Council collected baseline data from both intervention and comparison districts. Researchers conducted 50 facility assessments of primary health centers (PHCs) to assess health systems capacity; 144 PHC provider surveys that assessed knowledge, attitudes, and perceptions of barriers, and operational challenges that influence how women access care for fistula; and 142 surveys with women who had received fistula repair about the barriers and enablers they experienced. A subset of 27 post-repair women interviews and six focus group discussions - held separately with men and women residing in selected communities - also further explored barriers and enablers to accessing care. Guides covered transport and referral barriers, as well as psycho-social, cultural, facility shortages, awareness of service options, quality of care, social, political, and financial barriers to accessing care.

## BASELINE FINDINGS

**Facility Assessment.** Most of the sample’s facilities were publicly owned; 11 were private (for profit) facilities and five were private (not for profit). The majority of providers at these facilities are nurse/midwives, nursing officers, or nurse assistants; followed by community health team

members and other cadres. Few doctors (5.3%) practice at PHCs. Facility representatives report varied infrastructural capacity across our overall sample (Figure 1). Facility referral mechanisms for suspected fistula cases are limited. Only 32% facilities have ambulances or a facility vehicle, while 68% of transport arrangements are made by fistula patients and their family.

**PHC Providers.** PHC providers have limited knowledge of prevention and treatment of fistula – 58% spontaneously mentioned prolonged and obstructed labor as labor and delivery complications, 0.9% correctly identified leaking urine, and no providers correctly identified feces or foul-smelling discharge as postnatal danger signs. About 36% of the providers reported prolonged or obstructed labor among their clients. While 30 referrals for suspected cases of fistula were captured across all 50 PHC facility assessments, only 25% providers report referring women with fistula to repair centers. Of those, out of only 34.5% counselled the referred client. This counseling rate is less than the already low proportion of providers who know that OF clients should be counseled and referred (38.6%).

Providers understand some of the barriers women face when trying to access fistula repair. In Uganda, the three most frequently mentioned barriers by providers were 1) Shame of having OF (37.7%), 2) Depression and anxiety (33.3%), and 3) Feeling unclean (32.6%).

**TABLE 1. Fistula repair client survey in Uganda (n=142)**

| Fistula experience indicator                                   | Frequency (%)                     |
|----------------------------------------------------------------|-----------------------------------|
| Clients began leaking post-delivery (obstetric fistula)        | 115 (81.0)                        |
| OF cases following normal delivery                             | 35 (30.4)                         |
| Average amount of time clients live with fistula (of any sort) | Mean: 5.9 years; Range: 0.04 - 40 |
| Average number of attempts to seek fistula treatment           | Mean: 3 times; Range: 0-15        |
| Clients who have previously sought treatment for fistula       | 78 (54.9)                         |

**Fistula repair clients.** Of the 142 women surveyed, 42.3% were between 15 and 29 years of age, 39.4% were married, 86.6% were Christian and were 13.4% were Muslim. Only 83.1% had any formal public education and 48.6% ever worked for an income. Table 1 shows that on average, women live with fistula for six years and previously sought formal and traditional treatment for their fistula.

**Barriers.** The stigma and shame associated with uncontrollably leaking in public leads to psychological barriers to care-seeking among most women. Nearly 95.8% of women were embarrassed and 71.8% felt isolated because of their condition. They also reported social barriers, such as not having someone to support them in reaching/seeking repair sites (40.8%). This provides insight into family and intimate partner dynamics affecting care seeking. Women lack knowledge that fistula is a condition that can be treated (75.4%) and do not know where to go for fistula repair (78.9%).

Despite free fistula repair surgeries available at camps and in select hospitals in Uganda, transport and perceived costs constrain access to repair. Abandoned women, those living with spouses and families, and those unable to work because of their condition, experience financial strain because competing costs in resource-poor households often deter or delay access to transport to/from repair centers. Our sample shows that many women felt they not have money to pay for the needed medical care (88%) and felt the cost of transportation to repair sites and accommodation was too high (65.5%).

Other barriers included fear of pain/discomfort during travel to facilities (45.8%) and of harsh treatment by providers at the fistula center (50%). Some women had been told by providers that their fistula would heal itself (9.2%), while others had been told by providers in the past that their fistula was untreatable (8.5%).

**Enablers.** Enablers of accessing the fistula center are complex, but center around effective media advertising of fistula centers, timely referral by PHC providers, and social support women have from their families and friends living in their communities in increasing awareness around fistula and facilitating transport to the facility.

*“When I went to hospital the doctor told me I had fistula and directed me to this place, that there was a woman who had been referred here {fistula camp}.... he wrote a referral letter for me. So I went and told my parents and we started looking for transport and when we got it we came here. It was a Thursday morning when we came here and I gave in my referral letter from the doctor so they worked on me.”* (IDI, Post-repair client, Masaka)

Post-repair women served as key information channels to women considering where to go for care. This combined with the promise of free and respectful care at the fistula camps shaped women’s perceptions of fistula care and motivated care-seeking behaviors.

*“I got in touch with a lady from our village who had a successful repair from this place she told me that the repairs are free they even refund you your transport even when you just borrowed the transport from someone I got impressed and prepared to come.”* (IDI, post-repair client, Masaka)

## CONCLUSION

Baseline data reveal the necessity of a comprehensive intervention to address fistula treatment barriers in Uganda. Not only do PHC providers lack adequate knowledge of fistula, referral, and counseling, but women and community members report that access barriers to fistula centers bring persistent logistical, financial, awareness, and social challenges. These findings inform the intervention, which builds on existing enablers in Uganda, such as media communication and transport/social support, and aims to promote greater access to fistula repair in the country.