Innovative Solutions to Reduce Barriers to Fistula Care

Linking Community Health Systems, Digital Health Solutions, and Specialized Surgical Care

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Speakers

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Addressing Barriers to Fistula Treatment: A Research to Action Partnership

Dr. Vandana Tripathi, Fistula Care *Plus*
Project Director

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Female Genital Fistula

- An abnormal opening in the upper or lower female genital tract that causes uncontrollable urinary and/or fecal incontinence
- Up to a million women live with fistula; 6,000–50,000 new cases per year
- Causes
  - Obstetric
    - Inadequate management of prolonged/obstructed labor
  - Iatrogenic
    - Often from cesarean section or hysterectomy
  - Traumatic injury
  - Cancer/radiation therapy
  - Infection
  - Congenital defect

EngenderHealth and Fistula

- Through USAID funding, EngenderHealth has supported **>43,200** surgical/non-surgical fistula repairs, trained **365** fistula surgeons, and trained **>30,945** other health care workers in countries affected by fistula in Africa and Asia.

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Fistula Care *Plus* (FC+) Overview

- **Term**: December 2013 to March 2021
- **Countries of current/past activity:** Bangladesh, Democratic Republic of Congo, Mozambique, Niger, Nigeria, Togo, Uganda

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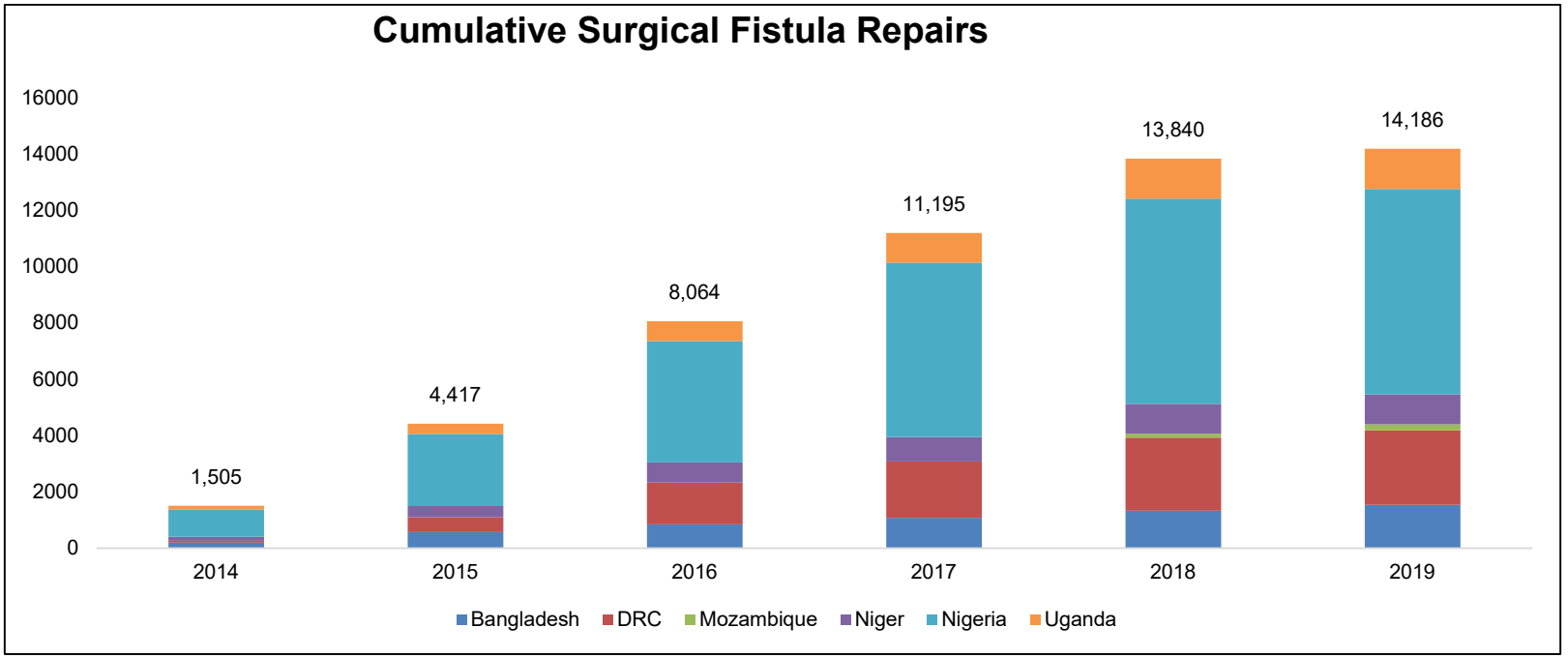
FC+ achievements:
Surgical Fistula Repairs



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Challenge

- We believe there are women with fistula who have not reached fistula services and are not well-served by existing outreach and service delivery models
  - Comparing estimates of fistula burden (e.g., modeling, surveys) with number of women served at fistula treatment sites
- Questions:
  - Who and where are these unserved women?
  - What barriers do they face in seeking, reaching, and receiving fistula care?
  - What enablers, and/or supports could address these barriers?
  - Many assumptions, theories, beliefs – little evidence

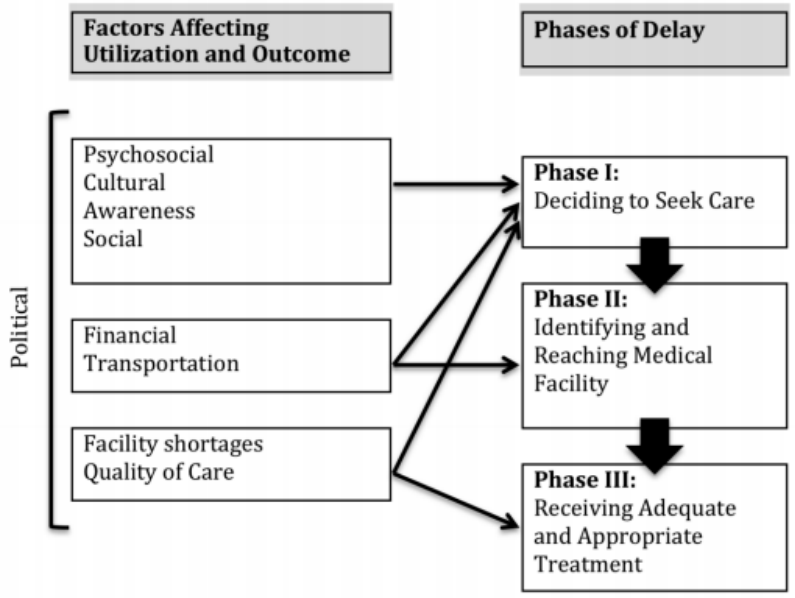
Research-to-Action Partnership

- 2014-2015: **Literature review** and **formative research** on barriers and enablers affecting women's access to genital fistula treatment in low-income countries – Population Council (PC)
- 2016: Design of an **information, screening, and referral intervention** targeting identified barriers to fistula treatment in Nigeria and Uganda (EngenderHealth/Viamo)
- 2017-2018: **Intervention implementation** in two sites in Nigeria and one site in Uganda (EngenderHealth/Viamo)
- 2017-2019: **Implementation research and documentation** of intervention effects (PC/EngenderHealth)

Literature Review Findings

- Nine key barriers – organized in conceptual framework based on Three Delays Model
- Limited assessment of interventions – 'low-grade' evidence

Figure 1: Three Delays Model to Fistula Treatment



Box 1: Studies mentioning barrier category

Barrier Category	Frequency[2]
Financial	71
Facility Shortages	65
Social	65
Transportation	62
Quality of Care	58
Awareness	57
Cultural	42
Psychosocial	30
Political	12

Baker et al., 2017.
https://onlinelibrary.wiley.com/doi/full/10.1111/tmi.12893

Formative Research Findings

- Widespread lack of awareness about fistula causes and treatment among women with fistula, family members, and general public
- Stigma may prevent women from participating in community awareness events or discussing symptoms with those who attend
  - Media (e.g., radio) strategies may directly reach women not served by community-based, in-person approaches
- Care-seeking decisions are not made exclusively or even primarily by women with fistula – gatekeepers abound

Formative Research Findings

"I had not heard [*about fistula*] before and later, except the woman I told you about. I hid my experience, I didn't tell anybody." (Ebonyi, Nigeria)

"It has secluded me and I always keep to myself. It has derailed me in business, I don't go to my shop, I don't go to market…I heard that people started gossiping that it is because I lost my child that am behaving strangely." (Ebonyi, Nigeria)

Formative Research Findings *(Nigeria and Uganda)*

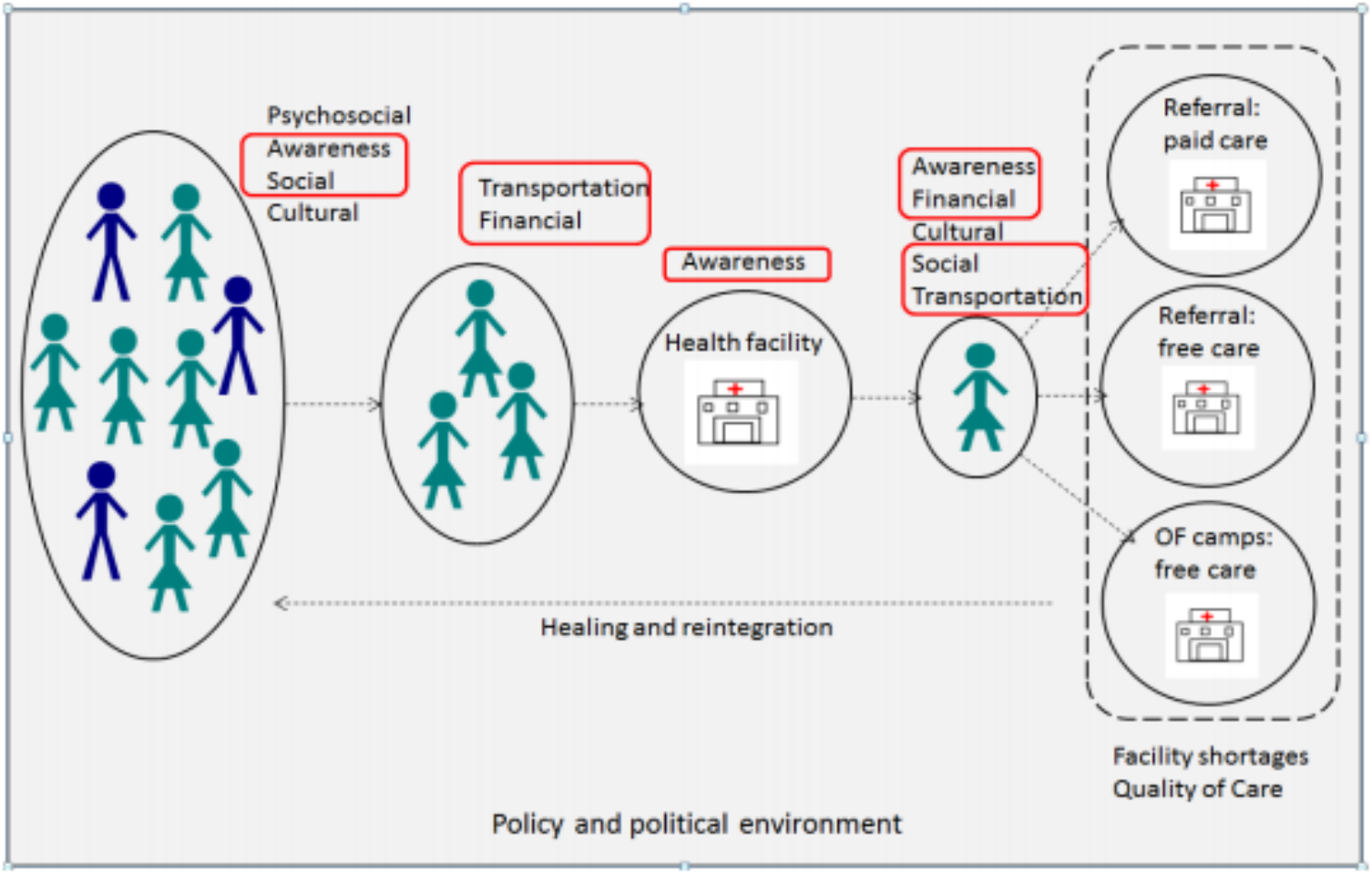
- Knowledge and behavior barriers **within** health system as well
  - Primary health care (PHC) providers not well informed about fistula or existence of fistula treatment centers; unable to provide correct referrals (“passive” barrier)
  - PHC providers attempt to treat at lower-level facilities without adequate training, knowledge, etc. (“active” barrier)
- Transportation cost was a barrier to reaching fistula care; research did not uncover instances of women being banned or discouraged from using transport due to fistula symptoms
  - Drivers were sympathetic to fistula clients’ situation

Formative Research Findings

"It was just the lack of money that hindered me from seeking care for eight years. We were looking for traditional treatment because of lack of money to come here…yes no money to come here. My husband hadn't, and his father hadn't, my father had to sell some things for us to come here." (Kano, Nigeria)

"Health care workers should be trained that once a woman has this kind of problem, she should be referred for expert management instead of trying and causing more harm to the woman…." (Kano, Nigeria)

Barriers Along the Care Pathway



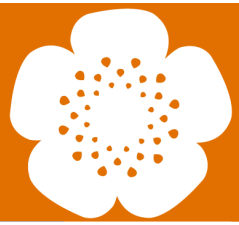
Responding to Barriers: *An intervention package*

- Target barriers:

Population	Low awareness	High cost	High stigma
Health system	Low awareness	Provider gate-keeping	

- Planned intervention:
  - **Three** pathways for fistula messages and screening
    1. *Mass media + interactive voice response (IVR) hotline*
    2. *Community outreach agents*
    3. *PHC providers*
  - **One** screening algorithm: *4-5 question screening tool*
  - **One** enabler: *Transport voucher for suspected cases → straight to accredited fistula treatment center*

Intervention Framework



Primary health facility

Women with incontinence seek care & primary health workers screen for fistula using job aid

Positively screened women referred to fistula facility & health worker facilitates free transport for patient & companion

Community level

Women reached about fistula hotline through mass media (*radio, flyers, word of mouth*)

Women reached in-person & community agents screen for fistula using hotline (IVR technology)

Women call hotline & screen for fistula using IVR technology

Community agents follow up with all positively screened women and facilitate free transport to fistula facility

Positively screened women & companion travel to fistula treatment facility with driver from local transportation partner using transport voucher mechanism

Fistula treatment facility

Positively screened women greeted by facility staff & receive clinical diagnostic examination

Confirmed fistula clients receive free treatment

Patients diagnosed with POP, urinary/colorectal incontinence receive free treatment at facility

Patients diagnosed with other conditions referred to relevant facility

Women & companion travel home with driver from local transportation partner using transport voucher mechanism

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Partnerships on the Ground

Catchment Area		Fistula Treatment Facility
Nigeria	Ikwo LGA, Ebonyi State	National Obstetric Fistula Center (NOFIC), Abakaliki
	Katsina LGA, Katsina State	NOFIC, Babbar Ruga
Uganda	Kalungu District	Fistula Clinic at Kitovu Mission Hospital, Masaka

Partner type	Ebonyi, Nigeria	Katsina, Nigeria	Kalungu, Uganda
PHC facilities	19 facilities across Ikwo LGA	22 facilities across Katsina LGA	21 facilities across Kalungu District
Community agents	DOVENET CBO	FOMWAN CBO	Village Health Teams (VHTs)
Transportation provider	National Union of Road Transport Workers (NURTW)	Aba Jamil Car Hire Services	Lukaya Taxi Operator Cooperative Society Limited (LUTOCs)
Fistula treatment facility	NOFIC, Abakaliki	NOFIC, Babbar Ruga	Fistula Clinic at Kitovu Mission Hospital

Innovation: IVR Fistula Screening Hotline

- FC+ partnered with Viamo to develop a free hotline to screen women for fistula
  - IVR technology via mobile phones
  - IVR algorithm screens caller for fistula and provides recorded messages in chosen language about how and where to get treatment
  - For women who answer “yes” to the screening question, data collected on demographics, self-reported fistula etiology, and experienced barriers to treatment
- Women who screen positively within intervention catchment areas hear recorded message about follow-up process
- **IVR is not limited by low literacy**

Advertising the IVR Hotline

- Community outreach, mass media announcements, and flyers distributed at community sites and health facilities

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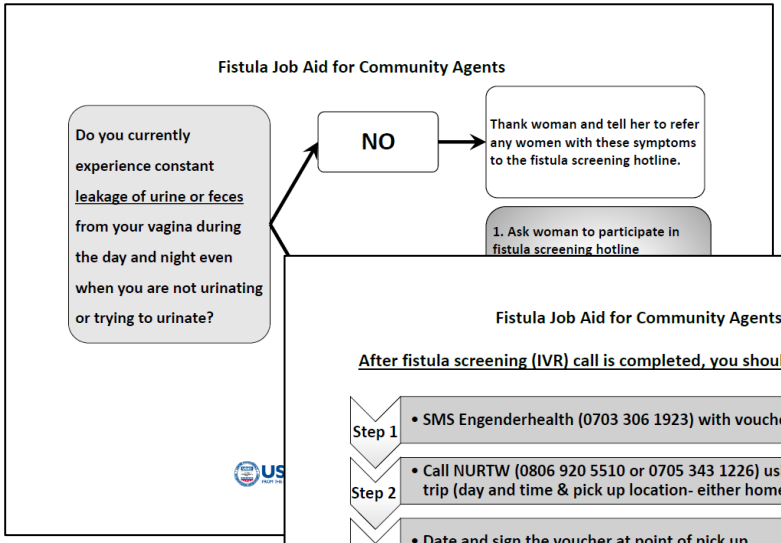
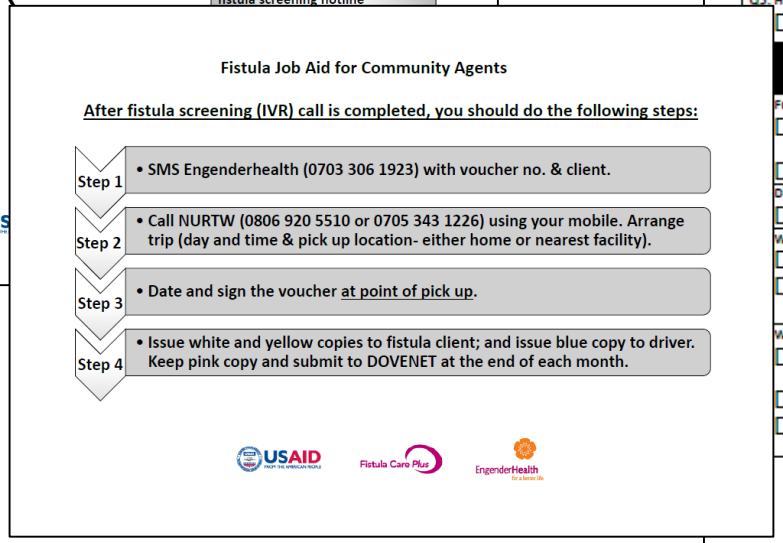
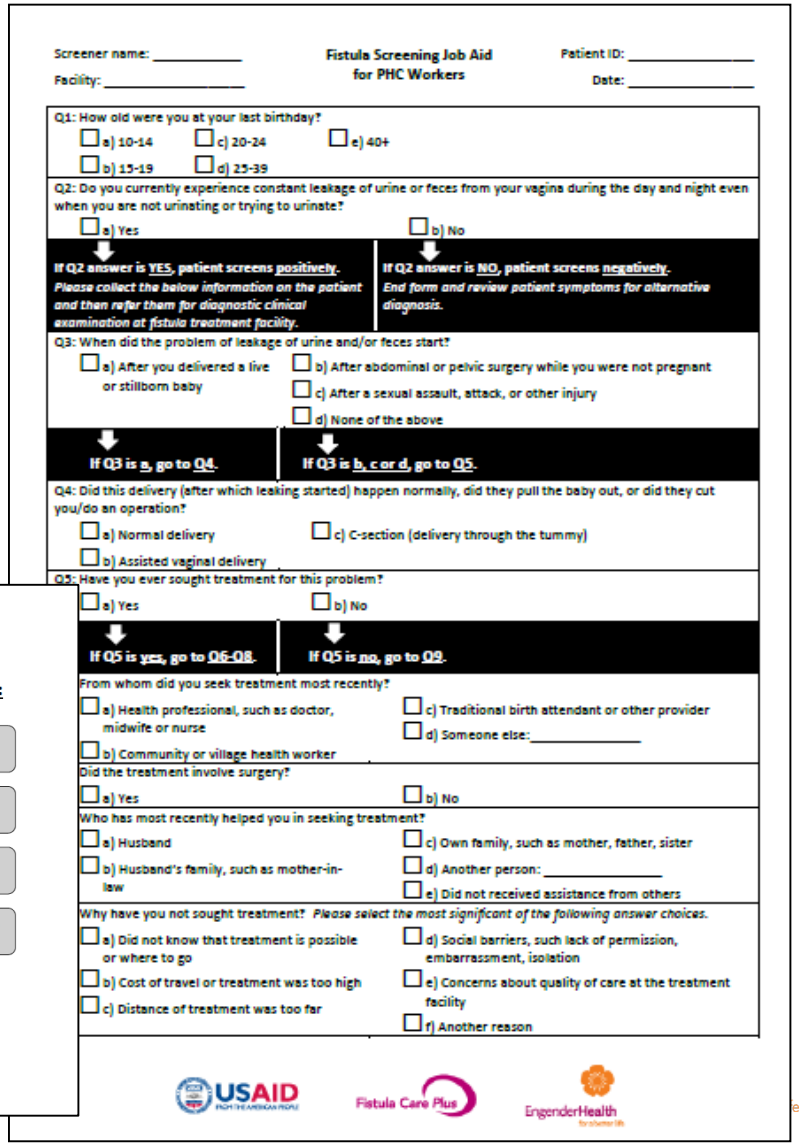
Building PHC Provider and Community Agent Capacity

- Trainings for PHC providers and community agents: information about fistula, screening, and referral processes
- Job aids to guide screening and referral







Transportation Voucher

- Community agents and PHC providers follow up with positively screened women and facilitate free transport to the fistula treatment facility using a transportation voucher
- Positively screened women and companion entitled to free round-trip to and from fistula facility for diagnosis and treatment

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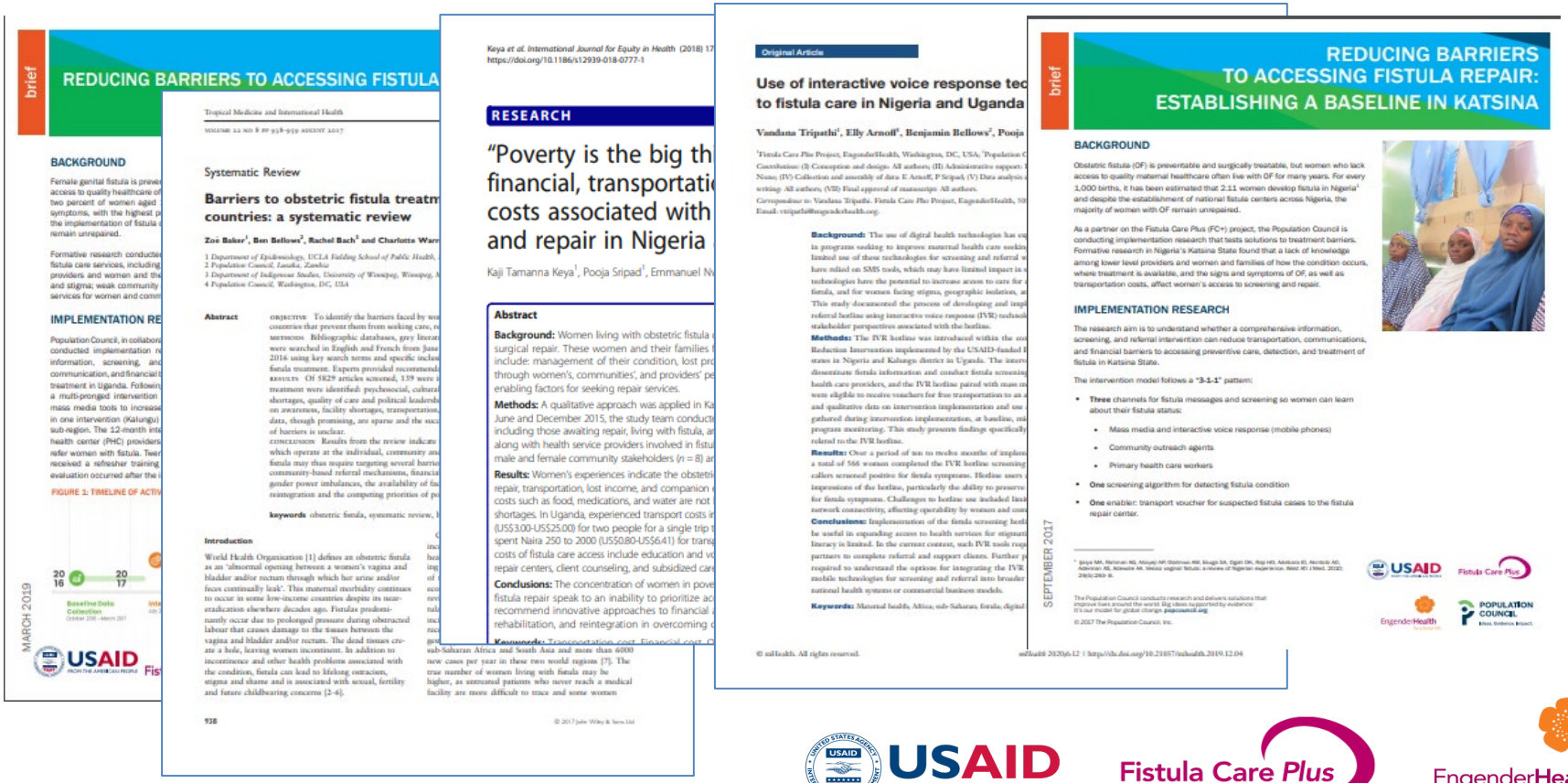
Resources

- https://fistulacare.org/resources/program-reports/barriers-partnership/
- https://www.popcouncil.org/research/fistula-care-plus
- https://viamo.io/



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Thank you!

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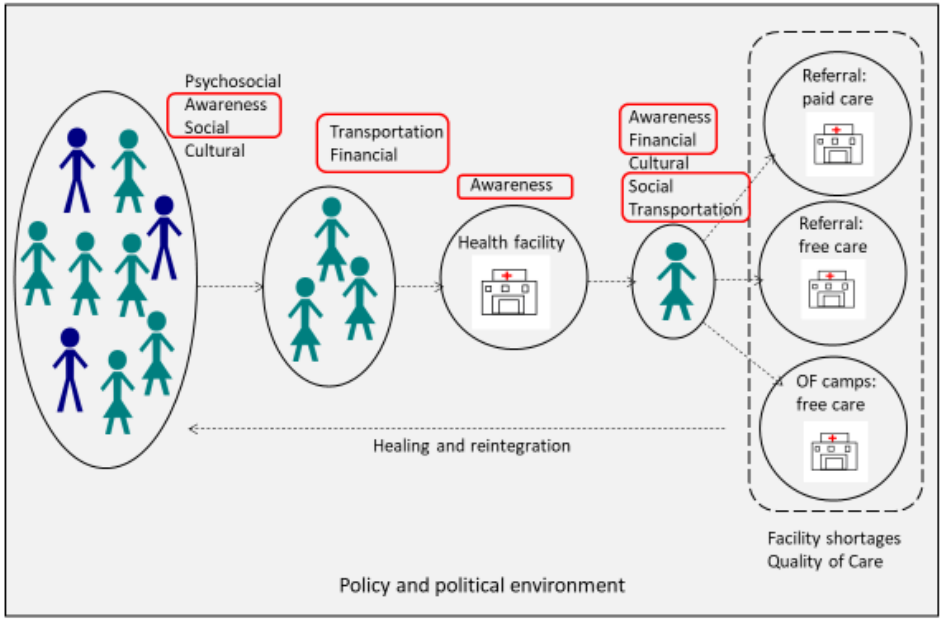
REDUCING BARRIERS TO ACCESSING FISTULA REPAIR IN NIGERIA AND UGANDA: IMPLEMENTATION RESEARCH STUDY

Dr. Pooja Sripad, Population Council

Associate, Reproductive Health Program

Introduction

- Final phase of a research-to-action agenda in collaboration with FC+/EngenderHealth
- Intervention targets: subset of comprehensive set of barriers presumed to have wide effects



Evaluation study goal

Assess whether a comprehensive information, screening and referral intervention reduces the awareness, financial and transportation barriers that impede women's access to fistula treatment.

- Does implementation of this intervention increase fistula care-seeking, diagnosis, and repairs?
- Can digital health interventions and transportation vouchers reduce barriers to seeking/receiving fistula care?
- Did focused training and job aids increase PHC provider ability to diagnose and refer?
- How did community outreach agents and providers interact to promote an efficient community-based referral system?

Setting and context

- Katsina, Nigeria: Routine surgical repairs
- Ebonyi, Nigeria: Routine surgical repairs
- Central sub-region 1, Uganda: pooled/camp-based and some routine repairs

Each of the 3 sites had a comparison and intervention area

Pre-post mixed methods: data sources across sites

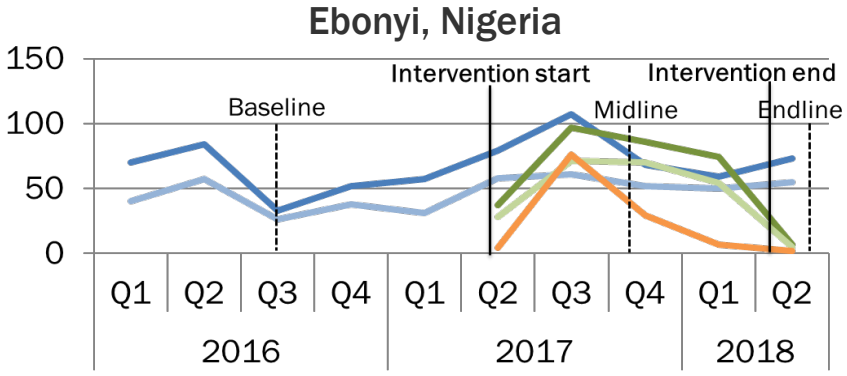
Method	Baseline			Midline			Endline		
	Nigeria		Uganda	Nigeria		Uganda	Nigeria		Uganda
	Ebonyi	Katsina	Central 1 sub-Region	Ebonyi	Katsina	Central 1 sub-Region	Ebonyi	Katsina	Central 1 sub-Region
Facility assessments of PHCs	39	37	50	N/A	N/A	N/A	38	31	43
Fistula center assessment	1	1	1	N/A	N/A	N/A	1	1	1
Surveys of PHC providers	117	88	119	N/A	N/A	N/A	100	93	100
Surveys of post-repair women	91	81	96	N/A	N/A	N/A	51	44	47
In-depth interviews (IDIs)	30*	30*	29*	19	18	18	11	19	18
FGDs with men and women residing in selected communities	0	4	6	N/A	N/A	N/A	8	8	8
Program monitoring data	N/A			Intervention period only			N/A		

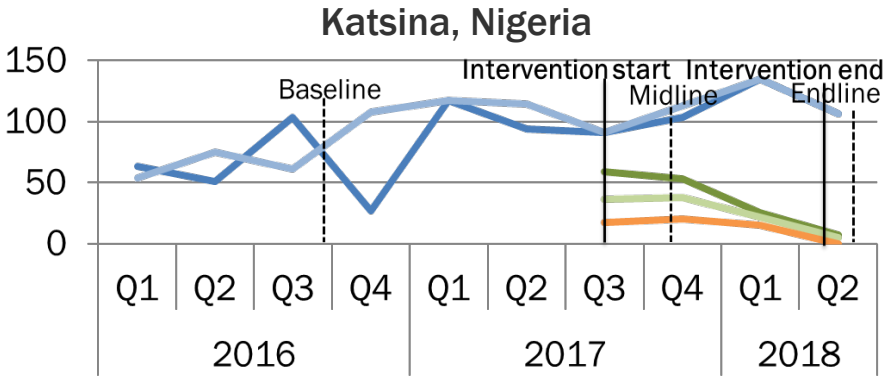
IDIs with:

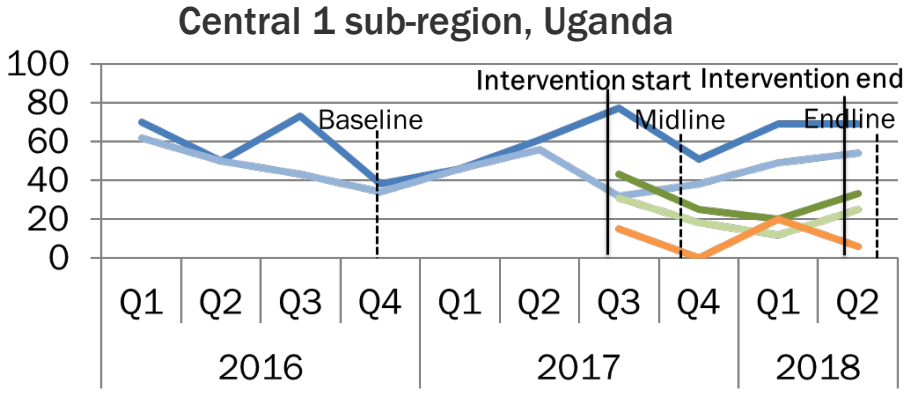
- Post-repair clients*
- Fistula center staff, District managers, FC+ staff
- PHC providers, Community supervisors, Community volunteers

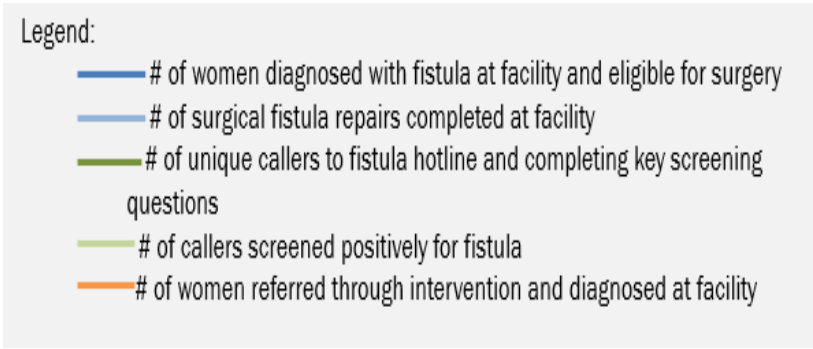
Key Results

Does this intervention increase care-seeking, diagnosis, and repairs?









Can a digital health intervention reduce barriers to reaching fistula care?

Indicator	Ebonyi	Katsina	Uganda
# of fistula hotline calls	301	144	121
# positively screened	228	101	86
% of calls, positively screened for fistula	76%	70%	71%
% referred through intervention and diagnosed with fistula	46%	53%	54%

~20% of calls in Nigeria and 63% in Uganda were from outside the intervention sites.

How does mobile screening influence women's awareness and access?

Integrated with complementary community and health systems referral strengthening mechanisms

- User-friendly particularly for stigmatized conditions and effective to reach large populations
- Alignment with community agent messaging and promotion
- Requires adequate publicity to relevant stakeholders (radio, mass-media, posters)
- Connectivity & phone ownership

"Because of stigma, the person thinks, it's just me [a woman with fistula] and the radio gives the number – [she] calls the number… it was a wonderful strategy and really helped."
(Program manager, endline, Ebonyi, Nigeria)

"What is complicated … you only talk with a computer and that is it… I was about to lose hope. I wondered why we cannot get to people and instead the computer voices…"
(Post-repair woman who called hotline, endline, Uganda)

"A VHT came and told me about flyers with some numbers which you call. I went, she gave me that number, and I called."
(Hotline caller, midline, Uganda)

Does a transportation voucher reduce barriers to reaching fistula care?

Uptake of the free transportation voucher mechanism was low across the intervention areas within the broad study sites

$n_{Ebonyi}=17$ $n_{Katsina}= 3$ $n_{Uganda} = 27$

"I was given a transport voucher which enabled a private car to come and carry me from a PHC to a fistula center. After the operation, the same car came and carried me home after I submitted the last voucher to the hospital."
(Post-repair client, endline, Ebonyi Nigeria)

"Patient was not taken right to her home …it happens in situations where the vehicle cannot access her home due to heavy rains"
(Transport Officer, Midline, Uganda)

Did focused training and job aids increase PHC provider ability to diagnose and refer?

PHC provider knowledge of and practices around prolonged / obstructed labor and genital fistula												
	Ebonyi, Nigeria				Katsina, Nigeria				Central 1, Uganda			
	Intervention LGA		Comparison LGA		Intervention LGA		Comparison LGA		Intervention District		Comparison District	
	BL	EL	BL	EL	BL	EL	BL	EL	BL	EL	BL	EL
	n=44	n=46	n=73	n=54	n=42	n=61	n=46	n=32	n=57	n=40	n=62	n=60
	%	%	%	%	%	%	%	%	%	%	%	%
Report leaking urine is as a danger sign	0	4	0	15	5	8	9	19	14	60	19	25
Report seeing prolonged/obstructed labor patients	36	41	32	37	43	44	30	41	47	48	29	30
Ever-seen patient(s) leaking urine/feces uncontrollably	27	52	41	43	7	44	17	63	33	60	27	25
Ever referred woman with fistula symptoms	27	39	37	37	14	30	20	28	32	38	23	25

How did community outreach agents and providers interact to promote an efficient community-based referral system?

*"At times even if it's not the number, they listen to the announcements over the radio and they come asking me about it that, 'We heard an announcement over the radio, is it true?' Then I tell them that is true, that is how it is, and tell them to go there." (*Community agent, Uganda)

"Prior to the intervention, it was difficult for staff to visit every village to identify those patients. But when the training was done it was helpful…because we needed these people… if the VHT identifies the patient the woman goes to the VHT, then she is taken to the facility and screened…" (Health manager, intervention site, endline, Uganda)

"It was during my health talk that a woman received information and later came back to me, so we did the hotline calls, arranged for transport, and she went for treatment at the fistula center. (PHC provider, endline, Ebonyi, Nigeria)

"More awareness should be raised so people know that [fistula repair] is happening. If somebody had not told me, I wouldn't have known that they are curing it here." (Post repair client, endline, Ebonyi Nigeria)

Was there awareness and attitude change in the community?

Increased knowledge of fistula and care options

- Reduced myths and misconceptions (promiscuity, witchcraft)
- Early marriage and prolonged labor as causes
- Iatrogenic and sexual causes
- Lingering misconceptions

Express sympathy for women with fistula and the desire to learn more about the condition and its prevention

Exposure to intervention varied

- Radio-promoted hotline existence
- Familiarity with and confidence in community agents or any provider that conducts household visits
- Lacked knowledge of transport reimbursement

"We feel for others with such problems – to connect with medical team to help her and encourage her to get help."
(Community women, Uganda

Most of the victims of this problems are suffering from extreme poverty and used to beg for money in the mosques; if they were wealthy their situation would have never been escalated.
(Community women, Katsina)

In-country disseminations – implications for sustainability

- Varied stakeholder commitment to sustain "awareness-building"
  - **Ebonyi & Katsina, Nigeria**: SPHCDA intention to integrate training materials to orient PHC/secondary facilities and health educators, aligned with PHC Under One Roof Policy.
  - **Ebonyi**: place desk officer at LGA level to link women to care and sustain NOFIC outreach.
  - **Katsina**: media houses express interest in publicizing (TV/radio) fistula care options
  - **Uganda**: Fistula TWG and MoH aim to include findings within the National Fistula Strategy in Uganda and learnings around VHTs relevant for the Community Health Strategy.

- Hotline— unsustainable without national support— reinforces the need to widely educate communities about fistula to shift care-seeking norms.

- While transport vouchers are unsustainable, interest in supporting access (e.g. social insurance, transport worker unions, eligibility for ambulance services)

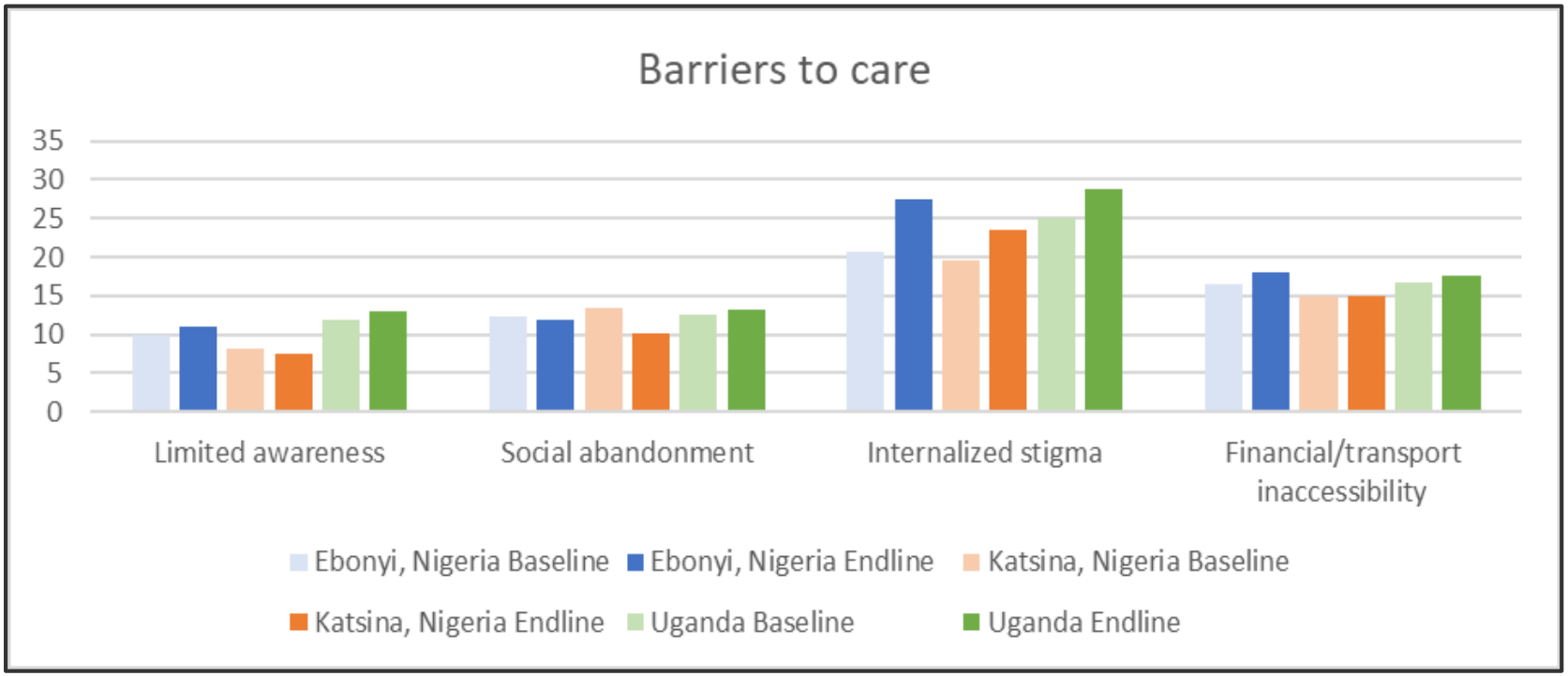
What worked and what didn't work?

- Implementing an intervention to address barriers to fistula care is feasible and effective with strong local partnerships and resources
  - Applying models from prior research we estimate the intervention identified ~200 fistula cases, e.g., 15% of estimated fistula cases in Ebonyi state

- The digital health component increased women's ability to seek fistula care
  - Hundreds of women called the fistula screening hotline, three-quarters were positively screened with fistula symptoms, calls peaked in **first** quarter
  - Hotline also aided community agents with low literacy in screening
  - Digital health solutions require integration with with community health systems to be effective in connecting women to care "at the last mile"
- The intervention improved fistula recognition and referral knowledge and practices among PHC providers and community agents.
- The intervention was associated with positive changes in community awareness and attitudes toward women living with fistula.

- Transportation vouchers were helpful to some women, but had limited uptake.
- It is difficult to infer that the intervention led to increases in the volume of repairs.
- Measurement is challenging!

Lessons learned in understanding barriers to care: Challenges of measurement



Ideas. Evidence. Impact.

The Population Council conducts research and delivers solutions that improve lives around the world. Big ideas supported by evidence: It's our model for global change.

Reflections on Using IVR Hotlines for Fistula Screening and Referral

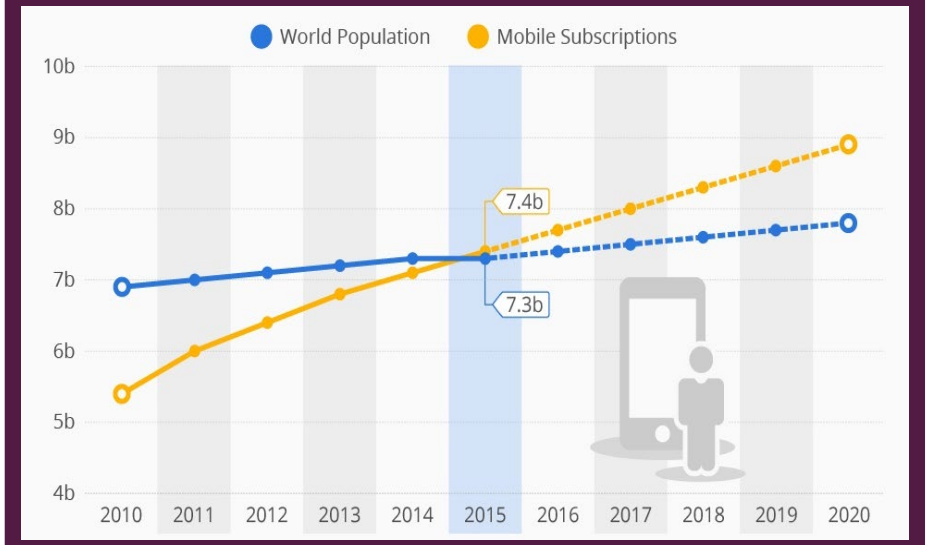
Emma Sakson, Viamo
Deputy Director of Partnerships

Viamo's Mission:

Connect individuals & organizations with digital technology to make better decisions

Why Mobile?

Mobile subscription have reached a critical mass...

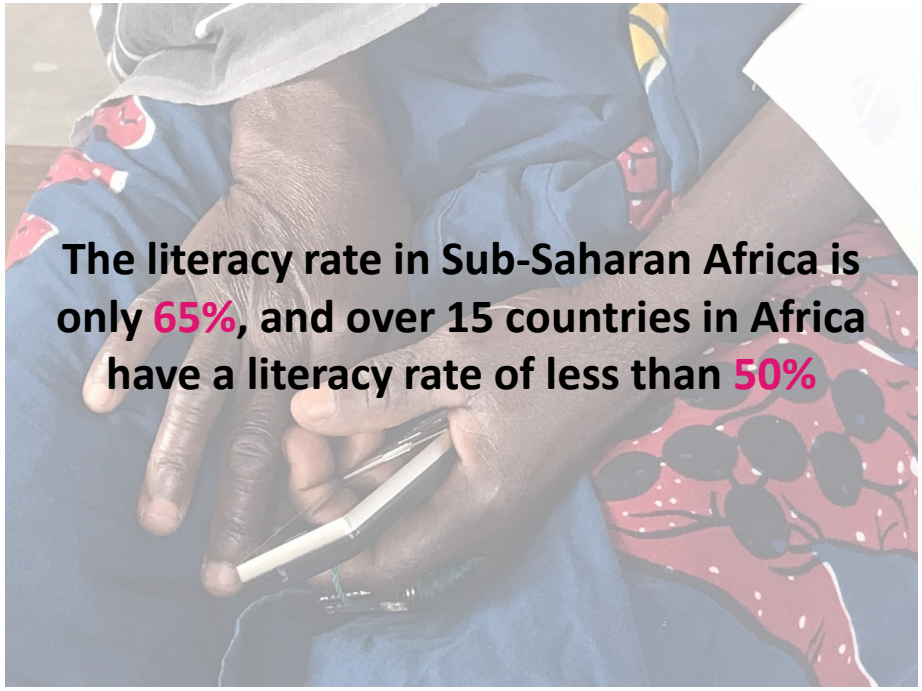


Interactive two-way communication

Unique experience for each user

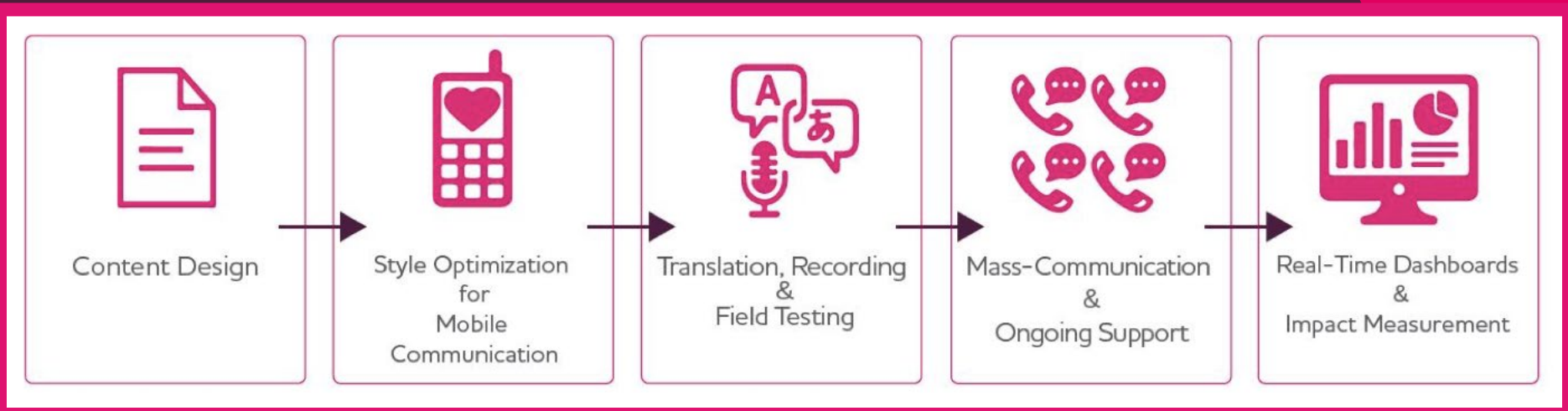
Measurable real-time impact

Why IVR?



- Low literacy rates
- Any phone, any network
- Accessible in local languages

Implementation Process



viamo

Fistula Care *Plus*

Nigeria and Uganda

Addressing barriers for women seeking fistula treatment

- Stigma
- Gatekeepers
- Distance
  - Social and geographic isolation
- Cost
  - Cost of care / services
  - Cost of transport
  - Opportunity cost
- Low literacy

Methodology

Inbound IVR hotline for fistula screening and referral paired with mass media messaging

- Pre-recorded messages by voice actors to take callers through a process of screening for fistula symptoms
- At the start of the call, women were able to select their preferred language
    - Nigeria: Igbo, Hausa and Nigerian Pidgin
    - Uganda: Luganda
- Collection of background information
- Provision of action messages depending on the screening result
- All positively-screened women were eligible to receive vouchers for free transportation to an accredited fistula treatment center

Welcome & Introduction Message

“Hello, welcome to the Fistula Treatment Hotline. This hotline is meant to help you know if you should seek medical care for something called fistula.

Fistula can cause constant leakage of urine and/or feces from your vagina during the day and night. This can be both uncomfortable and embarrassing, but you are not alone - many women like you experience this problem, usually after a difficult childbirth, but sometimes also after an assault or after a surgery or operation.

Thankfully, with proper medical care, fistula can be treated. We will ask you some personal questions about you and your health.

Please answer the questions using the keypad on your phone to select the option that is correct for you. Please answer honestly so that we can advise you well on the medical care that you should seek. This will take less than 5 minutes of your time – let's begin.”

Intake & Screening Questions

1. *How old were you at your last birthday?*

2. *Do you currently experience constant leakage of urine or feces from your vagina during the day and night even when you are not urinating or trying to urinate?*

3. *Do you live in xxx state/region?*

Referral Message

Example: Uganda

“Fistula is curable and you can receive free treatment at the Fistula Center at Kitovu Mission Hospital in Central Region.

A village health team volunteer will contact you within 2 days via the cell phone you used to make this call. They will provide you with more information on fistula as well as a voucher for a free trip for you and a companion of your choosing to and from the Fistula Center at Kitovu Mission Hospital, where you can get properly diagnosed.

After you have been diagnosed and return home, a village health team volunteer will be in contact with you to arrange another free trip for you and a companion to go to one of the upcoming Fistula camps at Kitovu Mission Hospital and receive treatment.”

Results

- Over a period 10-12 months of implementation, a total of 566 women completed the IVR hotline screening process
- Across the intervention areas, 415 (73%) hotline callers screened positive for fistula symptoms
  - Ebonyi: 228 (76%)
  - Katsina: 101 (70%)
  - Kalungu: 86 (71%)

You can learn more about the use of IVR hotlines in the Fistula Care Plus project here.

Implementation Challenges

- Gender issues
  - Limited mobile phone ownership
  - Frequent use of a single phone by many individuals
- Poor cellular network connectivity
- User skepticism about confidentiality
- Mass media messaging
  - Callers from outside the intervention zone
  - Limited awareness of the hotline

User Feedback

- Hotline users, community agents and other stakeholders reported positive impressions of the hotline
- Increased community awareness of fistula
- Ability to preserve anonymity
- Helped reduce stigma associated with disclosing fistula symptoms
- Provided mechanism for non-literate community agents to facilitate screening/referral

Case Study

Fistula Messages & Hotline in Tanzania

Project Details:

Country - Tanzania

Partner(s) - Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) and Vodacom Tanzania

Implementation Period - 3 months

Intervention:

Viamo developed messages about obstetric fistula on the country's 3-2-1 service in coordination with clinical experts at CCBRT. 3-2-1 callers who listened to the fistula messages were referred to the CCBRT Fistula Hotline if they wanted to learn more information or suspected they had fistula themselves.

Lessons Learned:

- Labelling fistula as a more accessible topic is important. On the 3-2-1 Service in Tanzania, the topic area that fistula is listed under is 'Complications After Birth,' which led to a high call volume
- Include men in the call for action; the 3-2-1 service receives a 50/50 gender split

Results of Hosting Fistula Messages on 3-2-1

300k

Calls to the service to learn about fistula

37%

Increase in knowledge among callers who listened to fistula on 3-2-1

1166

Referral calls as a result of 3-2-1 to the CCBRT Fistula Hotline

Lessons Learned

- The IVR-based screening approach can be effective:
  - In expanding access to health services for stigmatized conditions, especially with geographically dispersed populations
  - In settings where literacy is limited
  - When advertised extensively through a variety of partners and stakeholders (CHWs, radio, flyers and posters)

Recommendations

- Integration: IVR-based health solutions require pairing with complementary community and health system partners to complete referral and support clients
    - Face-to-face interactions are critical
    - IVR-based solutions are supplemental; there is no replacement for the role of healthcare workers
- Publicity: To be effective, hotlines must be promoted widely and frequently through radio, mobile network operators (MNO) promotion, peer or PHC promotion
- National support: Approval and endorsement by relevant ministries and stakeholders
- Financial commitment
- Sustainability
    - Referrals through CHWS and community ambassadors (ex: CCBRT)
    - Media and private sector actors can help sustain fistula awareness campaigns through television and radio
    - Local partners can be trained to manage the hotline and conduct consistent follow-up for positively-screened women

Implications for scale

- Mobile phone ownership
- Network connectivity
- Language comprehension
- Integration with health systems
- Sustainability mechanisms
- Government and stakeholder buy-in
- Necessity of in-person contacts for referral follow-up and transportation

Questions:

- Who is the intervention reaching?
- What dosage is the intended target population receiving?
- Where do “critical breaks” in the delivery of the intervention and follow-up services occur?

Thank you!

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viamo

Reflections on Lessons Learned and Implications for Future Programs

Mary Ellen Stanton, USAID Senior Maternal Health Advisor

USAID FROM THE AMERICAN PEOPLE

Fistula Care *Plus*

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Questions?

Thank you!

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