Hi!

My name is Mary Nell and I work with the maternity team at EngenderHealth. We are delighted to have the opportunity to share some of our experiences with you today.

Thank you to conveners!

We have now conducted needs assessments on obstetric fistula in 12 countries, and are doing programming on fistula in another half dozen, as well as some research. What I will share with you today draws on experiences from our work in these countries in conjunction with a variety of partners: UNFPA, WDP, WHO, and local and national organizations.

I want to start by thanking my colleagues on the maternity team at EngenderHealth and with the ACQUIRE project, Joseph Ruminjo, Erika Sinclair, Lauren Pesso, and Manisha Mehta. Erika is here, as is one more colleague who has been enormously helpful, especially as we begin working on fistula in Sudan: Hadi el Tahir. I’ll ask them to chime in as I go.

We were asked to share our experience related to Improving Community Knowledge of Prevention and Treatment of fistula
In order to frame our experience, in the next 15 minutes or so, I am going to address these 5 questions:
First—and perhaps most obviously, the community is composed of potential fistula clients—and their social network: their friends, families, and partners.

We have learned that men are a particularly important part of this social network. In many situations, they are in the role of gatekeeper—a husband often determines if and when his wife may seek care for delivery, and also be in the role of facilitating her transportation and assisting with client fees, if they are called for.

In many of the needs assessments we conducted, not surprisingly we learned that much knowledge is shared word of mouth about what constitutes safe labor and delivery, what to look for, what fistula is, etc. For this reason, friends and relatives of women are a key entrypoint for communication.

Perhaps given the stigma around fistula, which in some locations appears to be especially pronounced, the role of social networks cannot be overestimated.
Key stakeholders and providers are also important community members.

These providers are people with whom we worked in Lira, Uganda, and they served a critical link to fistula clients. In fact, when we interviewed the medical superintendent (seen on the far right in this picture) about whether they made any announcements about fistula services being available when a visiting surgeon came, he said, “Oh no, we would be far too scared to do that. If we would make announcements, we would be overwhelmed. The last time a visiting fistula surgeon was going to come, we simply talked about it among the staff at the hospital, and overnight 200 women showed up for fistula repairs. Imagine what would have happened had we made a formal announcement.”

In Niger, our plans include working with key providers in communities, both TBAs and midwives, in order to increase the efficiency with which women are referred for care.
Policy makers are a very important group within communities.

Our work has included:

++ contributing to a congressional briefing here in the US
++ recognizing the important role that some of the first ladies play in countries in Africa where we are working on fistula, and garnering their support;
++ considering the broad role of Ministries—sometimes above and beyond the MOH—to include the Ministry of Transportation, for example
++ noting the role of those who influence policymakers, such as the famous singer---in Sudan, who came to the stakeholders meeting for policymakers that we held with the MOH and UNFPA and who has played an important role in raising awareness about fistula in that country
We have also learned from our colleagues in Asia how important it is to think of corporate partners as community members. In this case, the head of our office in Bangladesh called up the president of the Dutch-Bangla bank and noted that the clients we were helping to have repaired needed funds for transportation home, as well as basic necessities, such as food, for themselves and their attendants during treatment. As a result, the Dutch-Bangla bank has agreed to cover these costs for 100 women who would not be able to receive fistula repairs otherwise.
II. How can the community be reached?

In general ...

- radio
- village theater
- print media
- community education in markets, schools
How can the community be reached?

- word of mouth
- client networks
How can the community be reached?

For stakeholders, providers, policymakers...

1) find them
2) meet them on their turf
3) make fistula relevant
So—why does it matter that we think about community in these ways, define who they are, reach out to them in various ways?

Our community work focuses on the interaction between the community and the facility, for a number of reasons, not the least of which is because community perceptions frame expectations.

If a hospital is considered a place where people go to die, then it does not make much sense to waste precious resources to get there.
Given the resources, time, and energy that getting to a facility is going to require, even if they do recognize the urgency of obstructed labor, many families are put in the situation of having to make very difficult choices.
What we have also learned is that understanding the community and learning about what they think about the facility will enable us all to work together to improve the quality of care. The quality of care—whether good or bad—is always known.

An important component of that quality of care is how providers treat clients—which I mention as a sort of advertisement for EH’s upcoming training curriculum on counseling fistula clients.

An equally important part of this work is building capacity in labor monitoring and emergency obstetric care, so that fistulas are not forming in one part of the hospital while they are being repaired in another.
For this reason, one mechanism that EH uses to bridge the community and facility is community COPE, where members of the community such as the ones I just listed—spend time together articulating what they want and expect out of a facility and employing a variety of means to effect that change.

We have found the following:

1) Community members have opinions about the services and suggestions for how to improve them, but are rarely asked nor heard

2) Community members feel more ownership of health services when they are asked opinions about services “We now own the hospital” Offered to help raise funds

3) Community meetings provide an opportunity for health care workers to increase the community’s level of knowledge about a specific issue, such as fistula
“If men are not sought out as part of the solution, they may--knowingly or unknowingly--be part of the problem...”
Why does it matter?

If women are going to have safe deliveries and healthy babies, a group effort is needed...
IV. How do we know if community has become engaged?

• birth plans prepared
• transport schemes planned
• community insurance plans created to cover fees
How do we know if community has become engaged?

- births are attended,
- resources/skills are adequate (for labor and repair),
- outcomes are good
V. Outstanding Questions

In the community:
1) Who are we not reaching and how can we find them?

2) What will it take to tip the balance in favor of attended deliveries?

3) How can community members best be integrated into prevention of fistula and care for clients?
In the facility:

1) What can be done to address acute staffing shortages?

2) What are the best ways to motivate, train, and retain providers?

3) How can vertical programming be avoided?