USAID TULONGE AFYA

Tuberculosis (TB) Audience Insights | Summary Report

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Tuberculosis (TB) Insights Activity Overview

Social and behavior change (SBC) campaigns often start with listening to the hearts and minds of their target audiences. Without knowing what audiences feel, think, and believe, it is a challenge to create impactful SBC messages, activities, or strategies. However, asking straightforward questions often leads to straightforward lies. The "lies" audiences may tell in traditional focus group settings may be a deliberate attempt to role play for the moderator or group, with the intent to look better or smarter, or may be to protect their most intimate fears. Research suggests that 95% of decisions are based on subconscious or unconscious motivators and not logic and facts, so respondents may also simply be unaware of how they really feel about an issue.

Projective techniques

For years, researchers have relied on straightforward questions to gather data. Creating messages and activities on data that didn't represent respondents' truth rarely led to desired social and behavior changes or effective campaigns.

Projective techniques are questions that have no obvious answer. No one knows the correct answer to questions like "if behavior change were a car, what kind would it be." Because respondents don't know the "correct" answer, they project from their truth. This results in rare insights into the deepest desire of the heart, rather than superficial and often untrue data. This also provides program and message developers fresh and unique insights to inform message and campaign strategies.

Audience Insights Objectives

The goal of the TB audience insight gathering was to determine the emotional drivers of audiences related to priority TB behaviors along with barriers and facilitators to uptake of priority behaviors. Broad desired SBC (to be later prioritized) for each target group are listed below.

General Population Adults, including primary caregivers of children under 5 years of age

- **Seek accurate information on TB symptoms and take preventive steps to reduce risk**
    - Cover your mouth when you cough, laugh or sneeze. Use a tissue. Put your tissue in a bag, seal it and throw it away.
    - Wash your hands with soap and water after sneezing, coughing or holding your hands near your mouth or nose, especially before preparing or eating food.
    - Ventilate rooms. Open the window or put a fan in the window to blow indoor air out. Enjoy time outdoors instead of in cramped rooms.
- **Go for TB screening and testing services if symptomatic**
    - Go to a health facility for TB testing if you have ***even one*** of these symptoms: a cough that lasts two or more weeks, coughing up blood, chest pain with breathing or coughing, drenching night sweats, unexplained weight loss, fatigue, fever, chills, or loss of appetite.
    - Encourage family and friends to go for TB testing if they have any of these symptoms: a cough that lasts two or more weeks, coughing up blood, chest pain with breathing or coughing, drenching night sweats, unexplained weight loss, fatigue, fever, chills, or loss of appetite.

Adults currently undergoing treatment for TB, including men and women and those who are HIV positive and those who are HIV negative or of unknown HIV status

- **Adhere to the full course of TB treatment, and follow your health provider's instructions**
    - Stay home and wear a mask during the first three weeks of TB treatment.
    - Don't sleep in a room with other people during the first three weeks of TB treatment.
    - Return to the health clinic if your symptoms do not go away, or they get worse, even after you take the TB medicine.
    - Take your medications at the same time each day.
    - Take the TB medications exactly as prescribed, even if you begin to feel better. Stopping medications early gives TB bacteria the opportunity to develop resistance to the drugs.
    - Ask a friend or family member to remind you when to take your TB medications, watch you take them and record each dose.
    - Don't take all your medications at one time.
    - Take your TB medications with a full glass of water. Don't drink alcohol while taking TB medications.
    - Plan ahead so you don't run out of TB medications. Carry an extra dose with you when you leave your home.
    - Call your health provider if you experience any of the following while on TB medications: nausea or vomiting, loss of appetite, dark urine or a fever lasting three or more days
    - Encourage family and friends to seek TB testing if they develop symptoms similar to yours like a cough that lasts three or more weeks, coughing up blood, chest pain with breathing or coughing, drenching night sweats, unexplained weight loss, fatigue, fever, chills, or loss of appetite.
    - Be hopeful. TB is a curable disease when you follow your health provider's advice

Health workers who interact with TB patients

- Ask all patients (including mothers at child visits) if they have experienced TB symptoms such as a cough that lasts three or more weeks, coughing up blood, chest pain with breathing or coughing, drenching night sweats, unexplained weight loss, fatigue, fever, chills, or loss of appetite
- Ask and probe for TB symptoms when treating HIV+ patients as they are especially vulnerable to TB
- Test for TB if patient presents any symptoms (rather than treat without testing)
- Talk to patients who have a confirmed TB diagnosis about actions to take including medication compliance
- Ask patients who have TB to encourage family and friends to be tested for TB
- Identify "what's in it for them" to be (more) diligent in case detection and treating TB

Approach

Design and Planning

USAID Tulonge Afya developed discussion guides for each target audience segment based on TB audience insights objective, background on the tuberculosis context in Tanzania, and priority behaviors the project aims to address. The discussion guides were then reviewed and revised before being submitted to FHI 360's Office of International Research Ethics (OIRE) for review and non-research determination, which was approved.

Participants

Participants were selected from primary and secondary target audiences: general population adults, including parents and primary caregivers of children under 5 years of age; adults currently undergoing treatment for TB; and health workers who interact with TB patients.

Recruitment

Prior to recruitment of participants, the USAID Tulonge Afya team introduced the insight gathering activities to Government of Tanzania partners, and secured an approval letter that was used with Regional, District, and community leaders. Recruitment of participants took place in coordination with the Regional Health Management Team (RHMT) and Community Health Management Team (CHMT), USAID Tulonge Afya zonal staff, and community health workers. Recruiters asked potential participants for verbal agreement to participate in the activity but collected no demographic information in order to maintain confidentiality.

Insight Gathering Process

For general population audience groups, small group discussions were conducted (4-6 participants), while individual interviews were utilized for adults undergoing treatment for TB and health workers. Thirty-four audience consultations were held with a total of 89 respondents in Ilemela Municipal Council (MC) and Buchosa District Council (DC) in Mwanza Region, and Morogoro MC and Mvomero DC in Morogoro Region (sites selected in collaboration with the National Tuberculosis & Leprosy Control Programme). In all cases, conversations were directed by a trained facilitator in Kiswahili using audience-specific projective discussion guides. All interviews and discussions were audio recorded for later reference. After the interviews, moderators participated in an in-depth de-brief with experienced team leaders to tease out key information and insights. Moderators also completed a written de-brief form to document their impressions of the session, and key findings that arose during the activities.

Analysis

The traditional approach to analysis is logic based. Social and behavior change analysis is emotion based. To start the analysis in an emotion-based arena, the following springboard questions were used to gather information from the facilitators about each interview or discussion:

- What surprised you about this group conversation?
- What was upsetting to you about the group conversation?
- What about this group conversation made you happy or gave you hope?

- What did someone in the group say that you will never forget?
- Was there an emotional reaction to any of the conversation topics? Tears? Anger? Surprise? Disbelief? (Positive or negative)
- What are three key findings that were uncovered in this group?
- What was the most powerful emotional "heart buttons" for this group? Help me understand that choice.
- What other emotional "heart buttons" were important? Help me understand those choices.
- Please share other important thoughts or comments that would help me understand this group conversation.

While these questions helped to target emotional responses, the team leads followed up these questions with targeted probes and logic-based questions as needed. The team leads then compiled and summarized the information from the debriefs into an insight report that will be used to draft creative briefs for each target audience.

Findings

When presented with a behavior change opportunity, people ask themselves these three questions when considering the change:

- What's in it for me to change?
- Why should I believe you?
- How will taking action solve a problem in my life?

This activity provided insights into these questions so SBC messages and strategies can provide answers to these questions in subtle yet effective ways.

What's in it for me to change?

The TB campaign and its integration into other health areas will target a wide range of social and behavioral objectives. Although the specific behaviors are different, the emotional drivers of related behaviors within targeted groups are likely to be the same.

General Population Adults

Table 1: Key emotional drivers for general population adults by sex and age. Primary drivers indicated in bold font.

	Young Adults	Older Adults	Caregivers
Male	• **Status** • Power • Recognition • Achievement	• **Achievement** • Recognition • Status • Belonging	• **Status** • Power • Achievement • Recognition
Female	• **Independence/Control** • Achievement	• **Recognition** • Power	• **Family values** • Independence/control

	• Recognition • Belonging	• Family values • Status	• Status • Nurturing

Young Women (18-35 years)

As young women transition into being independent from their parent's households, we saw their emotional drivers focus on the need to be self-reliant and included anxieties over who they can trust in life. When it comes to their hopes and dreams for the future, these young women feel they need to make it "on their own". They don't want to be dependent on their parents forever, but have also seen that men cannot always be trusted. They hope to be a financial success both to make their parents and community proud, but also to gain a happy marriage with a partner who will not be violent and controlling. These young women describe negative perceptions and anxiety over the thought of a "**strange" or "not normal" illness such as tuberculosis**, and **feared being considered as a "sick" person** (Box 1), because this could **derail their plans for business success and a happy marriage**. They also brought up worries that TB treatment is "strong" and might **affect their future fertility**, which is integral to establishing a **happy marriage and achieving the "good life".**

Box 1: Being "sick" is a noun, not just a verb

Across participant types, people conceptualized the idea of having an illness such as TB or HIV that requires long term treatment or going to the health facility regularly as a factor that sets one apart from the general community. This theme appeared to be an underlying factor behind reservations about visiting health facilities. Our participants described that people with these types of illnesses are considered "sick people", regardless of whether they are experiencing active symptoms. Men in particular spoke of the need to have children as part of proving that they are "whole" and strong enough to work and provide. Once you have a chronic or long-term illness like TB, people fear the community will not recognize them as whole and they will not be able to achieve their goals for their life.

Young Men (18-35 years)

Emotional drivers for unmarried young men focused on establishing their status as a real man to their friends and community. They focus on the need to have financial success in their lives so they can give their future family the good life. Unexpected illness such as TB was viewed as **a threat to their ability to give the good life and to their status** amongst friends, and **could also affect their sex life**. They described a desire for positive recognition from their peers and community, and also a desire to give back to the community so people will see them as an important person. They describe having money as a route to having power and respect. They described that TB prevention steps are something for people unlike themselves, such as those who are wealthy or those who have HIV, and do not necessarily see themselves as at risk for TB.

Mothers and female caregivers of children under five (18+)

For female caregivers, their emotional drivers are deeply tied to how they identify as a mother and wife. Their hopes and dreams focus on proving to their family, friends, and community that they have the **perfect family and can provide their children with a wonderful environment** in which to grow up. They feel it is up to them to be the **peace keeper in the home and avoid conflicts** with their husband and keep him happy. They want to avoid violence and arguments for their sake, for the children, and for the family's image. They describe their ability to make decisions about caretaking for their young children—including in situations such as coughing or other TB symptoms—as limited by their **husband's control over decision-making and encouragement from in-laws, grandparents, and other community members to seek services from pharmacies or traditional providers**. Deep down, they **worry about the stability of the family** and **hope to have their own business activities** in case of abandonment, but say they **have to keep their husband from leaving at all costs**, in the meantime.

Fathers and male caregivers of children under five (18+)

The need to gain and preserve the **status of a real man** is a key emotional driver for married men and fathers, including having children, being the head of the family, and being a financial provider. While they want to be a good role model for their children and be seen in the community as someone who has the good life, they **worry about their lack of financial opportunities and how this undermines all their hard work**. Although they say they are "**too busy" to be bothered with going to the health facilities**, they **want to be consulted about all decisions** in the household, including deciding if and when mothers and children can go to the health facility. They are **comfortable using violence or threats** of divorce or abandonment—which we have seen is wives' biggest fear—to enforce this dominance. Across health topics, behind the excuse of being busy, fathers link resistance to go to health facilities to **worries about HIV testing or finding that he is "sick", or others assuming he is sick, all of which would set him apart as not a true, capable man**.

Older women (45-60)

Overall, older women showed concern for being seen as good mothers who have raised good families, and they are **looking for positive recognition**. They want to be looked at as **sources of wisdom** and want their adult children to look to them for advice. They want the community to recognize that they have a nice home and successful children.

Older Men (45-60)

Older men continue to want to **preserve their image of being a man, but with a stronger focus on being financially independent and having the ability to give back to their community and family**. Some expressed that they didn't want to have to rely on the government or their children, but also discussed the need for **reciprocity among neighbors**, such that you are known as someone who helps others in the community, and you also trust that your neighbors would be willing to help you. Just as with younger men, these men **feared the threat of becoming sick** with something like TB and how it **could threaten their chances to achieve their goals and could cause them to lose support** from their family and

community.

Patients living with TB

Women

- Primary emotional driver: Belonging
- Secondary drivers: Nurturing, achievement

As may be expected, now that they have found themselves in the category of "sick people", this has threatened their sense of belonging within their family and their community. For women, these were particularly emotional interviews where they expressed **deep feelings of hopelessness tied by being separated from their children and families**. While they spoke of the hardships of adhering to their treatment and being isolated, the d**rive to protect their children and families from sickness and the hope of being healthy again and able to care for their family motivated them to be adherent to their treatment**. They have learned much about TB during their illness and wish that they could use this knowledge to help others in the community.

Men

- Primary emotional driver: Belonging
- Secondary drivers: Independence, status, achievement

Men with TB also **struggled with losing their sense of belonging in the community**, as well as facing **physical isolation**. Some men spoke of the **embarrassment of being rejected** in the community, such as women refusing to have sex with a "sick" person and other men mocking them for not going to bars. Their **fear of being perceived HIV+ or testing for HIV delayed care seeking** for men who were not already HIV positive. When it comes to adherence, they are **motivated by the need to protect their families and to ensure they can regain their strength and return to working and being a provider**. Some insisted the isolation was necessary to protect others and said they did not want someone looking over their shoulder to make sure they take the medication.

Facility-based health workers

- Primary emotional driver: Recognition
- Secondary drivers: Status, nurturing, poverty of time

Recognition and the deep desire to be positively recognized, even celebrated, by those they serve represents a powerful **emotional driver for health workers**. Everyone likes to receive positive feedback on their work and have others recognize their service to others, and health workers are no exception. Some respondents enjoy positive recognition from patients, noting they feel loved and cherished when they walk through the community because they receive praise and thanks. Other health workers report awareness of negative community perceptions of health workers—likely themselves--noting that health workers are well aware of how the community perceives them as a health worker. Those who were less liked and valued know patients often refuse to see them and/or ask for a different provider.

Why should I believe you?

The audience consultations provided insights into the credibility of different audiences and SBCC channels.

General Population

Health Workers and Health Facilities

For adults with families, we c**onsistently heard that they believe that health workers have the most accurate information when it comes to TB**. This is the place to go when you have a "severe" problem or when symptoms worsen or do not go away after trying home care, pharmacists, traditional methods, or witchcraft. Despite this conviction, we also c**onsistently heard that the health facility is not the first choice for care seeking or information** and people would rather try more convenient options where they will not face costs associated with getting to the facility and **poor treatment from providers** who are rude, distracted, or judgmental. **Health facilities are also associated with people with serious or chronic illnesses** and they wonder **what others will think of them** for going to the health facility. Men in particular say they cannot visit facilities, but this puts the health knowledge in the hands of their wives, who do not have decision making power. Among general population audiences, **mothers generally had the highest levels of health knowledge about TB**, and it seems they have learned this information from ANC and child health visits.

Pharmacies and Shops

Parents described seeking medicines from the pharmacy for themselves and their children when they first notice signs of illness, such as fever and coughing. If the symptoms worsen or persist, then you can consider going to the health facility. People said they believe some problems, like the flu, are normal and don't need to be "complicated" by going to the health facility.

Traditional Healers and Witch Doctors

Participants described traditional healers and witch doctors as **widely available and convenient**. Although many of our participants were quick to clarify that they personally don't trust these methods, they say that others do—including their own family members. Similar to pharmacies, we heard that many people are willing to try traditional remedies as a first line of treatment when they notice problems like fever or coughing—for both themselves and for children. Some people expressed that TB is a **"strange" illness** that could be caused by a curse, so the witch doctor is the right person to treat it.

Family and Close Friends

While people said seeking health care for child illnesses is ultimately the father's decision, family elders are often consulted and usually suggest trying traditional healers before bothering with the health facility. Likewise, grandmothers and mothers also **advise against "complicating" things by going to the facility for every problem**. They say their children did not have these things and they grew up fine. Young mothers and fathers also look to other young parents as examples of what is normal when it

comes to childcare. They don't necessarily directly ask for advice, but they keep an eye open for what is going on around them.

Adults Facing Illness

Health Workers and Health Facilities

TB patients described themselves as in consistent contact with providers, and as with the other populations, they feel providers have the most accurate information. However, all spoke of **negative experiences at the facility**, including that the providers stigmatize them for having TB and do not protect their confidentiality. They consistently said the providers do not provide enough information or encouragement on how to take their medicines. For those who are not HIV+, most delayed going to the health facility when they first noticed symptoms because of the inconvenience and cost, the preference to try other types of providers first, and the anxiety over being perceived as HIV+ or fear that they had HIV.

Family and Close Friends

Families play a pivotal role in what happens next for someone who tests positive for TB, and are often the only people who know if someone has TB—particularly if they are not HIV+.

a) They can send the person away permanently or temporarily
b) They can allow the person to stay at home, but have them eat separately, sleep separately, minimize contact—regardless of whether the person is in the contagious period
c) They can play a supportive role in medication reminders, helping with food, housing, and childcare. As nearly everyone described that they are unable to work while on treatment, having or not having this support is important to treatment adherence and success

Each of these scenarios was described by individuals who participated in the insight sessions.

Other

Looking at other information sources, many said they initially sought services from a traditional healer or witch doctor, but now regretted that decision. There was one woman who mentioned hearing about TB symptoms on the radio and choosing to go for testing, but others did not mention radio, TV, newspapers or other mass media sources. Respondents were also positive about the potential of getting information from persons who had already undergone a successful course of TB treatment, and expressed their own interest in taking on this kind of role in the future.

How will taking action solve a problem in my life?

People only change when they feel the change will solve a problem in their lives. Based on the audience insight findings, these are potential ways in which targeted changes can solve a problem in the lives of target audiences.

General Population

Women who take steps to prevent TB and seek testing (for themselves or children) upon recognizing symptoms will:

- Be recognized by health workers and family and community as caring and responsible
- Will have peace of mind because they know they are being proactive and preventing costlier problems down the road; you will get the right diagnosis and services are free.
- Will be recognized by husbands and partners as smart and responsible (and a good wife and mother for those who are married)
- Know they are protecting their families' health and future

Men

Men who take steps to prevent TB, seek testing (for self or child) upon recognizing symptoms, and participate in discussions about health seeking will:

- Be recognized by health workers and family and community as caring and responsible
- Will have peace of mind because they know they are being proactive and preventing costlier problems down the road; you will get the right diagnosis and services are free.
- Be recognized as a role model in the community for protecting their family
- Be viewed as someone who takes their fitness and health seriously

Patients living with TB

Women

When women with TB adhere to treatment and enact preventive behaviors, they will:

- Be accepted and recognized in the community for seeking treatment for TB and protecting their family and children
- Be sought out for advice about TB
- Be able to continue to care for their children and be a good wife and mother

Men

When men with TB adhere to treatment and enact preventive behaviors, they will:

- Be accepted and recognized in the community for seeking treatment for TB and protecting their family and children
- Be seen as a good role model for children and an example in the community of someone who does everything in his power to give his family a good life
- Ensure they are strong enough to continue to be a leader in their household and the community

Facility-based health workers

When facility-based health workers take the desired actions, they will:

- Earn the respect and admiration of the people they serve
- They will feel recognized by community members for their caring actions
- Positive words and thanks will surround them as they walk through the community and people will seek them out for their attentive and gentle care, not just advice
- Other health workers will know they are esteemed when community members ask and accept them for appointment instead of refusing to see them

Barriers to change

There are always barriers to change. Knowing what barriers exist is important information for effective messages. This consultation identified many barriers for making tuberculosis-related behavior changes, which are detailed in the sections below.

General Population Adults

Barriers to testing

- Lack of accurate knowledge of causes, symptoms, testing and treatment
- Low perceived risk, especially among younger adults and male caregivers
- Stigma toward those with TB, including beliefs around need for complete isolation and association with HIV
- Normalized care seeking from witch doctors and traditional healers, promoted by elders
- Perceived challenges of accessing facilities, including distance, opportunity costs, negative perceptions of providers, lack of confidentiality
- Male dominance of care-seeking decision for child illness

Adults Facing Illness

Barriers to testing

- Lack of understanding of symptoms and causes and resulting low perceived risk
    - For those with HIV, failure to recognize TB symptoms as signs of an additional infection
- Seeking care from traditional healers and witch doctors before going to health facility
- Perceived costs of tests and treatment and opportunity costs of traveling to health facility
- Fear of HIV testing or being perceived as HIV+
- Perceived high costs of prevention methods (ventilate homes, fans, tissues) and low perceived need for these actions
- Perceived challenges of accessing facilities, including distance, opportunity costs, negative perceptions of providers, lack of confidentiality

Barriers to treatment adherence and prevention

- Social isolation and stigma
- Lack of social support
    - Reminders to take medicines
    - Financial assistance to purchase adequate food
    - Help with chores
- Side effects
- Lack of confidence in treatment
- Negative experiences with providers
    - Stigma and poor attitude
    - Lack of instructions and positive feedback

Providers

- The high number of patients is the primary barrier to following all SOPs and to respecting patients' feelings
- Some clients expect fast services and do not want to sit through lengthy standard procedures
- Providers less likely to follow SOPs with patients with potentially "complicated" situations
- Lack of confidence in knowledge and procedures

Next Steps

Based on these audience insights, the project will develop creative briefs to inform development of tuberculosis messages, SBCC tools, and materials for stand-alone and integrated SBCC activities.