

**Optimizing Tuberculosis Contact Investigation  
and Linkage to Care in Nairobi, Kenya**  
*TB KWISHA*

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W80/97809/2015

**A thesis submitted in part fulfillment of the requirements of the  
University of Nairobi award of the degree of Doctor of  
Philosophy in Tropical and Infectious Diseases**

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## DECLARATION

This thesis is my original work and has not been presented for the award of a degree in any other university.

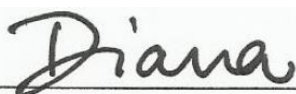
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## DEDICATION

This work is dedicated to my beloved family – Julius Brown Mburugu, Florence Marangu, Brenda Marangu and Vincent Marangu. Thank you for your endless support.

*'I can do all things through Christ who strengthens me'*

*Philippians 4:13*

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## APPROVAL BY SUPERVISORS

This thesis has been presented with our full approval as supervisors.


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## List of Abbreviations

AMREF – African Medical and Research Foundation

ARC – Accelerated and Care

ART – Anti Retroviral Therapy

CDC – Centre for Disease Control

CHEW - Community Health Extension Worker

CHS – Centre for Health Solutions

CHW - Community Health Worker

CI – Contact Investigation

CO – Clinical Officer

CXR – Chest Radiography

DOTS – Directly Observed Treatment

DOTS-A – Directly Observed Treatment with Active contact tracing

FGD - Focus Group Discussion

HIV – Human Immune-deficiency Virus

HW – Health Worker

IPT - Isoniazid Preventive Therapy

ITECH – International Training and Education Centre for Health

KAPTLD – Kenya Association of Prevention of Tuberculosis and Lung Diseases

KII - Key Informant Interview

KNH – Kenyatta National Hospital

LMIC - Low and Middle Income Countries

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MDH – Mbagathi District Hospital

MDR – Multi-Drug Resistant

NASCOP – National AIDS and STI Control Program

Neuro-QoL – Quality of Life in Neurological Disorders

NTLDP – National TB, Leprosy, Lung Diseases Program

PI – Principal Investigator

PLHIV – People Living with HIV

PSTC – Prisons Staff Training College

RIDU – Respiratory Infectious Disease Unit

SDG - Sustainable Development Goal

SNA – Social Network Analysis

SSCI – Stigma Scale for Chronic Illness

TB – Tuberculosis

WHO – World Health Organization

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**ABSTRACT**

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**Background:** The World Health Organization End Tuberculosis (TB) Strategy is geared towards zero deaths, disease and suffering due to TB, including TB-related stigma, worldwide. Optimal TB contact investigation (CI) impacts TB prevention, timely case finding and linkage to care. However, data on routine TB-CI implementation in high TB burden contexts in low and middle income countries (LMICs) are limited. Furthermore, validated tools to measure stigma in TB patients, in order to examine stigma's role in TB-CI are scarce. Specific operational guidelines and a framework to optimize TB-CI including an instrument that comprehensively measures TB-related stigma among patients in Kenya, a high-burden TB/HIV/multidrug resistant TB and LMIC African context, are envisioned in the national strategic plan but do not currently exist.

**Objectives:** To identify and describe patient and health worker perspectives regarding barriers and facilitators to TB CI and utilize these to inform the design of TB-CI specific operational guidelines as well as a framework for optimization of TB-CI and linkage to care in Nairobi County, a high TB/HIV burden urban setting. Secondly, to evaluate understanding, acceptability and relevance of the 26-item Stigma Scale for Chronic Illness (SSCI) tool (by Rao et al.) among Kenyan TB patients and utilize findings to adapt the scale for use in our local context.

**Methods:** Between April 2015 and July 2016, I led a multi-method qualitative study based on individual interviews with pulmonary TB patients, facility observations and focus group discussions with health workers (HWs) in 13 health facilities in Nairobi County, and key informant interviews with governmental and non-governmental experts in Kenya. Facilitators, barriers and opportunities to optimize TB-CI were identified through triangulation of data and methodology, synthesized themes, and study findings informed the design of TB-CI specific operational guidelines and implementation framework. Findings were analysed based on a conceptual

framework developed apriori of themes at 3 levels: the index TB patient, health worker (HW) and health system. Additionally, qualitative research to adapt the Stigma Scale for Chronic Illness (SSCI) tool by Rao et al. was performed to assess internalized and enacted TB-related stigma in Nairobi, Kenya. Feedback on the English- and Swahili-translated SSCI tools was elicited through individual cognitive interviews with 20 pulmonary TB patients in eleven health facilities in Nairobi County. Difficulties in translation, differences in meaning, TB contextual relevance, patients' acceptability to the questions, and issues in tool structure were assessed. The interviews were audio recorded, transcribed, and translated.

For methodological robustness, I invited two multilingual research assistants to participate in this work: (i) an anthropology expert who transcribed all interviews, translated the 20 cognitive interviews, and independently coded and analysed themes, and (ii) a Swahili/English translator and communicator, who served as a tie breaker when we did not reach consensus in our independent data analysis, and also ensured results presented truly reflected participants' perspectives. Each of us independently translated the original SSCI (by Rao et al.) into Swahili and back into English and harmonized the tool for HW administration.

**Results:** Invitation of TB patients to bring close contacts by HWs was key for all patient decisions that led to contact screening. Additional facilitators included the patients' understanding of TB transmission and desire to avoid contacts suffering from TB; and pro-active measures by HWs including home-visits and sputum container provision for unavailable contacts. Barriers reported included long wait-times, non-conducive clinic hours for contacts who were working or in school, poor community awareness and TB stigma. Missed opportunities included sub-optimal enquiry and lack of HW invitation of close contacts presenting at the facility, and these stemmed from lack of TB-CI specific operational guidelines, documentation tools and HW training. Stakeholders proposed provision of fast tracked and holistic health packages to add value for contacts seeking

TB screening, and synergistic facility and community health strategies customized to diverse contexts. Interoperable, efficient and user-friendly computerized health information systems, sustainable government led funding for infrastructure and an adequate well-trained health workforce for optimized TB-CI delivery were also proposed.

From the cognitive interviews, most questions in the Rao-SSCI tool were understood in both English and Swahili, deemed relevant in the context of TB, and acceptable to TB patients. Key areas of adaptation of the SSCI included adding questions that address fear of infecting others and death, HIV stigma, and intimate, family, and workplace relationship contexts; and beginning with an open question to capture all patients' concerns. Questions were revised for non-redundancy, specificity, and optimized sequence.

**Conclusion:** The key barriers to CI in our setting are failure by HWs to educate and invite TB patients to bring close contacts for TB screening, sub-optimal processes and flow of TB patients, HW and community TB-related stigma, and general health system challenges. With regard to adaptation of the SSCI by Rao et al for TB-related stigma, the main items that needed adaptation to make the tool locally acceptable and relevant included beginning with an open question to capture all patients' concerns; adding questions that address fear of infecting others and death, HIV stigma, and intimate, family, and workplace relationship contexts; and eliminating redundancy. Patient and HW perspectives gained from this study were useful for the development of a novel context appropriate TB-CI specific operational guideline and framework for optimized TB-CI.

**Implications and Recommendations:** The novel operational guideline and framework developed is proposed for pilot implementation and possible scale up to optimize TB-CI in the local setting. Secondly, the adapted 8-item SSCI developed appears to be a useful tool that may

be administered by HWs in English or Swahili to quantify TB-related stigma among TB patients in Kenya. The implementation tools developed from this study shall be disseminated to the National TB and Lung Disease Program, and other relevant stakeholders involved in TB services for consideration for implementation and further evaluation.

## CHAPTER 1

### INTRODUCTION

In 2015, it was estimated that there were 10.4 million new cases of active tuberculosis (TB) worldwide, 11% of whom were HIV-positive (2). Great regional disparities exist in TB epidemiology. The World Health Organization (WHO) African region has the second highest TB incidence worldwide with approximately 275 new TB cases per 100,000 population (2). Kenya's TB incidence is estimated at 233 cases per 100,000 population, currently ranking among the top 30 high TB burden countries globally. It is also considered a high multi-drug resistant TB burden country with an estimated 2,000 new cases in 2015, and a high HIV burden country with an estimated national prevalence of 5.9% (2, 3). TB-HIV co-infected individuals have about a 30-fold increased risk of TB disease compared to HIV uninfected individuals (4, 5). Although approximately 94% of TB cases in Kenya are aware of their HIV status, with 84% of them on anti-retroviral treatment (ART), the 100% HIV testing and ART provision target for TB-HIV co-infected patients has not been reached (6-8). Notably, TB-HIV co-infection in Kenya has decreased from 38% in 2013 to 17% in 2016, suggesting that interventions to control TB among people living with HIV (PLHIV) have been successful and the greater burden of TB currently exists among people living without HIV (9). Almost 70% of TB cases occurs in Kenyans aged below 44 years, which suggests ongoing transmission in the community. Data on children under the age of 15 years was not collected in the recent national TB prevalence survey (9). Though often neglected, children are another important population at high risk of TB (10). During the past five years, children have accounted for 10-12% of TB cases diagnosed in Kenya and it is estimated that children may contribute up to 40% of the total TB cases in developing countries with high TB incidence (6, 10, 11). TB prevalence in Kenya is higher in urban areas (760 per 100,000 population) than in rural areas (453 per 100,000 population) (9).

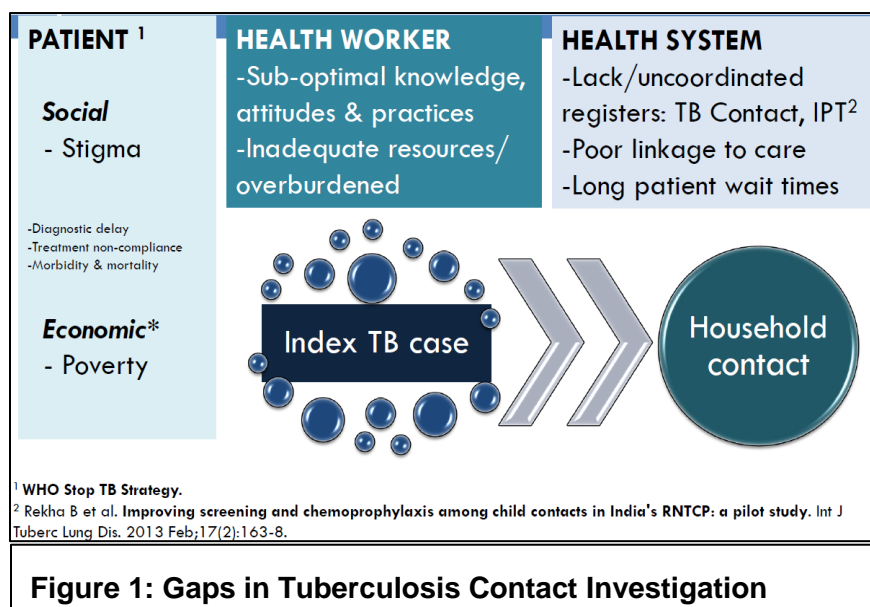


Although TB is curable and preventable, only 82,000 adults in Kenya were diagnosed with TB in 2015 while it is estimated that 138,105 adults in Kenya fall sick with TB annually, meaning that 40% of adult TB cases went undetected and untreated (9). This significant number may be fueling further disease transmission considering that one undiagnosed and untreated person with TB disease can infect 10 - 15 other people through close contact over the course of one year (12). In a meta-analysis of 71 studies including 878,724 participants in low and middle income countries (LMICs), pooled prevalence of TB disease among persons who were exposed to TB was 3.1%, and pooled prevalence of latent TB infection was 51.5% among 60,557 contacts screened in 76 studies (13). TB CI (CI) is a fundamental tool that enables early identification of active TB and HIV with appropriate linkage to care. Investigation of TB contacts also identifies asymptomatic individuals who are at high risk for TB disease (4, 14). These include children under 5 years old and HIV infected individuals who are eligible for isoniazid preventive therapy (IPT), an effective measure to prevent active TB (4, 6, 7, 14-16). Thus, TB-CI is both the gateway to the IPT delivery cascade and an important part of diagnosis and linkage to TB-HIV testing and care.

## CHAPTER 2

### STUDY JUSTIFICATION

Disparities in the burden of TB disease reflect the fundamental role social determinants play on health. TB patients and their contacts face barriers at the community or health system level (Figure 1). These include the complexities of stigma (17), costs in transportation, tests, medication

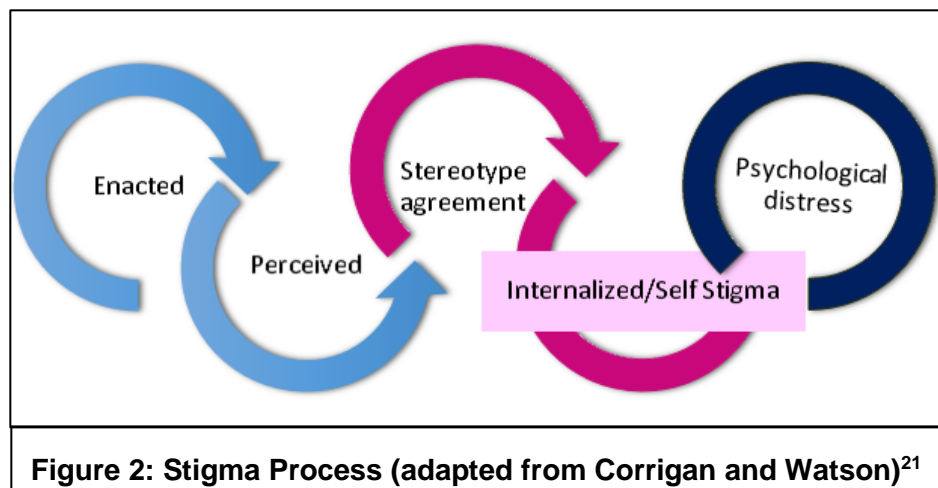


and loss of income incurred individually from work absences or from caring for TB patients. (18, 19) Barriers at the health worker level may include lack of correct knowledge on TB management and poor attitudes and

practices, which are detrimental to the care of TB patients and their contacts. The health system may lack infrastructure, human resources and efficient reporting tools (20).

Weiss and Ramakrishna define health-related stigma as “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem” (21). TB-related stigma is a barrier to health service utilization that is potentially modifiable. Drivers of stigma in TB include the fact that it is an infectious condition spread in the air and its association with HIV (17, 22, 23). The stigma process proposed by Corrigan and Watson suggests that negative stereotype awareness, agreement and application result in reduced self-esteem and self-efficacy (24). In the case of TB CI, the index TB

case may experience discrimination (enacted stigma), become aware of the negative stereotype around TB (perceived stigma) then concur that the negative stereotype applies and internalize the stigma (self-stigma) (Figure 2). Internalized stigma potentially results in the index TB case not



**Figure 2: Stigma Process (adapted from Corrigan and Watson)<sup>21</sup>**

fully seeking TB care and avoiding cooperation in having their close contacts investigated for TB. In this way, TB-related stigma is not only detrimental to TB

patients' health at an individual level but may also promote further spread and drug resistance (17, 22, 25, 26).

Understanding facilitators and barriers to TB-CI in the context of high TB and HIV burden with a focus on the culturally diverse Nairobi County can inform design of acceptable and sustainable solutions to improve TB CI and linkage to care locally (17, 19, 22, 27, 28). Current methods for TB-CI include facility-based, community-based or integrated approaches and novel strategies such as social network analysis (4, 14, 29-33). Data on the impact of TB-related stigma on these TB-CI approaches is limited (1, 17, 34). Validated tools to quantitatively measure stigma in TB patients are scarce (35, 36) and challenges in TB-related stigma tool development include the inability to capture all the feelings of TB patients (34); and the varying cultural and TB/HIV epidemiological contexts in which they are utilized (17, 34, 37).

## CHAPTER 3

### STUDY OBJECTIVES

The overall objective of this study was to evaluate tuberculosis CI (TB-CI) and linkage to care utilization in Nairobi, Kenya and develop an operational framework for its optimization including the adaptation of the stigma scale for chronic illness tool (SSCI) developed by Rao et al. to measure TB-related stigma in this setting.

The specific objectives of this study were as follows:

**Specific Objective 1:** To identify and describe facilitators, barriers and potential solutions to TB CI in Nairobi, Kenya that inform the design of an operational framework for optimization of TB-CI and linkage to care implementation in a high TB/HIV burden setting.

**Specific Objective 2:** To develop an operational framework for optimization of TB-CI and linkage to care including specific standard operating procedures and documentation tool, and optimization of processes and patient flow at the health facility and community levels.

**Specific Objective 3:** To evaluate the understanding, acceptability, and relevance of the 26-item SSCI tool (by Rao et al) among Kenyan TB patients, and utilize findings to adapt the scale for use in our local context.

## **CHAPTER 4**

### **LITERATURE REVIEW**

Despite the strides that have been made in TB care, TB prevention remains a high public health priority. In 1993 the WHO declared TB a global emergency (38). Recommended strategies were put in place, including Directly Observed Treatment (DOTS), DOTS Plus (a more comprehensive initiative addressing MDR-TB and HIV), and the STOP TB strategy launched in 2006. Between 1990 and 2012, TB death rates dropped by 45% and WHO estimated that 22 million lives were saved as a result of these strategies (27, 39). Notwithstanding this tremendous success, TB remains a significant public health concern (39) and is currently one of the top 10 causes of death worldwide (12). The current WHO's End TB Strategy in the post 2015 era of the sustainable development goals (SDGs) is geared towards ending the global TB epidemic and envisions a world free of TB with zero deaths, disease and suffering due to TB. It targets 90% incidence and 95% death rate reduction by 2035, and zero TB-affected families facing catastrophic costs due to TB by 2035 (40).

TB has unique social determinants, high costs to families, and is associated with considerable stigma. Scholars in social medicine have identified social determinants of TB including social injustice and inequity (19, 26, 28, 41, 42). Recommendations that address socio-economic and health system determinants of TB have been captured in the past STOP TB strategy and the current End TB strategy, but these concerns persist and pose challenges to TB care (43). In a systematic review and meta-analysis from China, the main factors that contributed to patient and diagnostic delays in TB care at the individual level related to socio-economic dynamics, health seeking behaviors, poor knowledge of TB and stigma (28). These included poverty, rural residence, low education level, lack of health insurance, inability to afford time away from work, and first visiting a traditional healer. Key factors at the health facility level included lack of

resources (such as x-rays and smear microscopy), poor health worker knowledge of TB management, shortage of qualified health workers, and poor access to facilities providing TB care (28). Similar challenges have been identified in other high TB burden countries. Three national TB programs: Ghana, Dominican Republic and Vietnam used a tool to assess direct and indirect TB costs incurred by patients in their respective countries. The results underscored the fact that free TB diagnosis and treatment is not enough because patients incurred costs that went beyond these, potentially ensnaring them in a poverty rut. Major costs included health service charges, transport, nutrition and accommodation costs as well as lost time, income and productivity (19). Mauch et al reported similar results when they employed the same TB cost tool in Mutomo and Kitui districts in Eastern Kenya (18). In Western Kenya, the factors contributing to TB diagnostic delays and poor adherence to treatment are analogous to those described in China particularly inadequate knowledge on TB in both patients and health workers (44). Additionally, the private sector seemed to have missed TB diagnoses, which were later detected in public health facilities (44).

“Consumption” and “the White Plague” are terms that have been used to refer to tuberculosis (TB) in the past that connote the deadly nature of this disease (22). TB takes different names in different communities in Kenya, such as “Chebuonit”, “Kahera”, “Olwera”, “Murimu/TB”, “Itirian” and “Kifua Kikuu” denoting a disease in the chest that keeps one coughing (45). Studies conducted in different countries including Kenya, Zambia and South Africa show that family members discriminate TB patients by not sharing food, kitchen utensils and beds with them (45-47). In Illala district hospital in Tanzania, almost 50% of TB patients did not disclose their TB status, the main reason being fear of stigmatization. One third of the TB patients revealed that their friends or relatives discriminated against them (48).

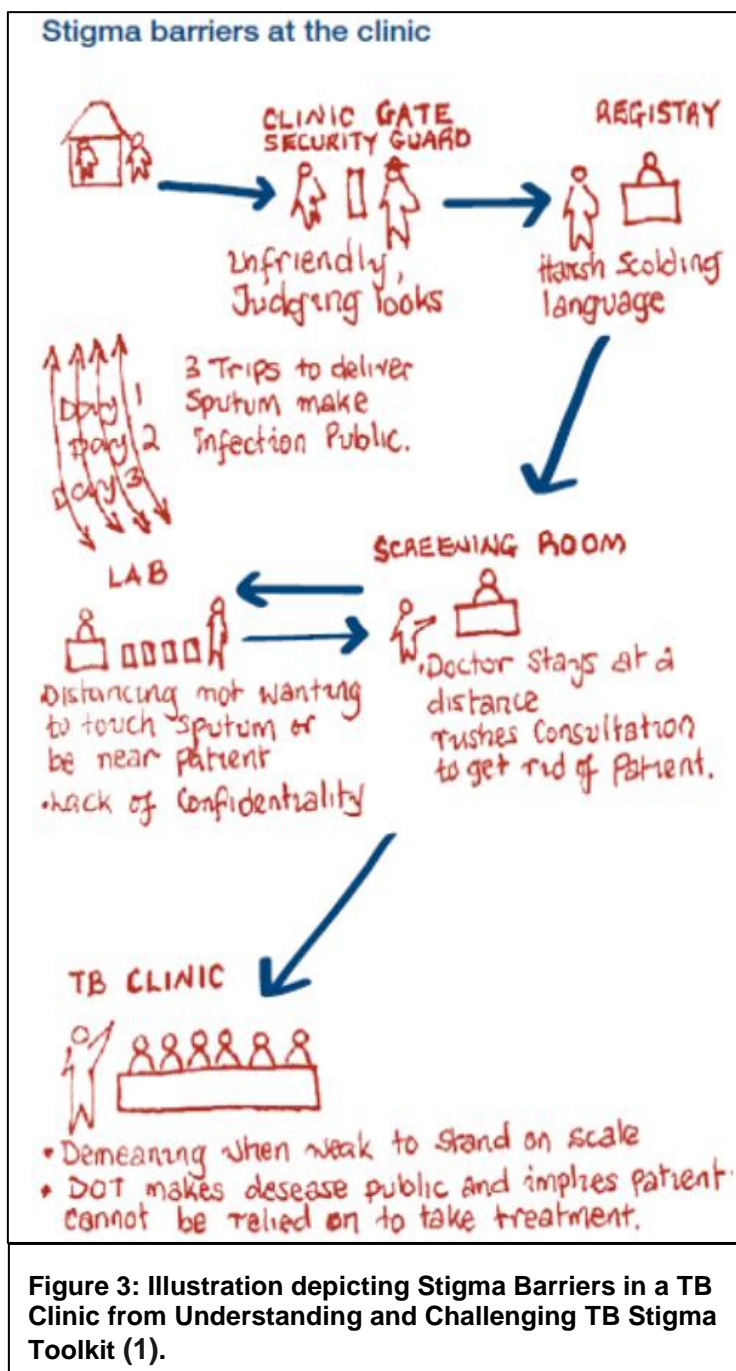
The infectious nature of TB is one of the main pathways through which stigma is propagated (17). In Kenya's Uasin Gishu's District Hospital in 1997, TB was viewed to be 'sensitive', 'dangerous' and 'difficult' as the community felt it was a condition that was highly contagious, difficult to treat by both modern and traditional medicine resulting in death and that it interrupted a patient's social life leading to isolation and stigmatization of both the individual and their family (45). Fear of infection similarly emerged as the main theme identified as the cause of TB stigma in a qualitative study conducted in an urban setting in Ghana. Community members and HWs expressed this fear, describing TB to be dangerous and highly infectious and explaining that it was for this reason that TB patients were expected to "sit quietly, not dance among crowds, shout or talk like others, and should carry their own cup or buy bottled water" among other expected behaviors because TB was an airborne disease and they would infect others (49).

The association of TB with HIV is another main pathway through which stigma is propagated (17). In a Kenyan study in 2011, half of the participants felt there was an association between TB and HIV resulting in anticipated stigma. Enacted and self TB-related stigma perceived to be associated with HIV was less within families and more from individuals outside the family (44). Surprisingly in a 2014 study by Wynne et al from Uganda, stigma in HIV was noted to be declining, while stigma associated with TB was high (50). Conversely in a 2016 study from South Africa, another high TB/HIV burden country, TB stigma connected to HIV has continued to be documented, stemming from an apparent higher stigma of HIV than TB because HIV is not curable, and high levels of co-infection (51). Even in low TB/HIV burden settings such as Ghana, the association of HIV with TB has been identified as a cause of TB stigma, and a moderating element that enhances the fear of infection, which in turn enhances the association with HIV (49).

In addition to the fear of TB infection, and its association with HIV causing TB stigma, eight other causes cited in the Ghanaian urban-based study by Dodor et al included: 1) physical frailty, 2)

perceived causes and spread of TB, 3) outdated societal beliefs and practices about TB, 4) public health practice and discourse, 5) health staff's own fear of TB, 6) self-stigmatisation by TB patients, 7) judgement, blaming and shaming TB patients, and 8) past experiences with TB. These causes were also identified as moderators of fear of TB infection, and the fear of TB infection was similarly reported to enhance these moderating elements (49). Similar causes of TB stigma have been reported from other settings (46). Additional pathways through which TB stigma is propagated as noted by Courtwright include poverty and low social class (17).





As illustrated in Figure 1, TB stigma is also enacted by workers at various points of health care delivery in TB clinics, beginning with the security guards at the health facility entrance, to clerks at the registry, and HWs at other areas of health care provision as documented (1). Community members and patients with TB have reported health professionals as stigmatisers of TB (52). Patients with TB may also be subjected to societal stigma facilitated by the health institution set-up and process flows, as members of the public may judge patients seen going to and from the laboratory or TB clinic (1). TB stigma enacted by workers in health facilities among colleagues has also been cited as a barrier to the use of occupational health units for TB services (53).

Although an effective cure for TB is available, patients are subjected to social exclusion (54) which leads to strained family and social relations (55). Other effects of stigma include shame and embarrassment, fear of or actual job loss, and fear of infection (56, 57). Stigma has been described to be closely related to contextual aspects including gender-roles, socio-economic

status and level of education which seem to be mediated through denial and concealment of a TB diagnosis (55). Josaphat et al in a paper from Portugal reported that TB patients tend to identify family and household contacts for TB screening and CI however occupational contacts were an independent factor for not being identified (58). This could be explained by stigmatizing views that may still persist in our society, more so outside the social support system of a family. TB stigma may hinder the willingness of TB patients to disclose their diagnosis to contacts and consequently the quality and completeness of CI among other TB control strategies. A global call has recently been put out for researchers to provide insights on how to measure and reduce TB stigma (59).

There is need for innovations in TB contact screening. The WHO considers CI an efficient approach to intensified TB case finding and it is one of 10 indicators of the End TB Strategy, with a recommended target level of  $\geq 90\%$  by 2025 (2, 60). TB-CI is considered to be of value in high HIV/multidrug resistant (MDR) TB contexts as these are known to reduce TB treatment success rates (61, 62).

Although CI has been shown to be feasible in some LMICs (63), data on routine TB-CI implementation in high TB burden contexts is scarce. TB-CI approaches have been traditionally classified broadly as passive or active based on the initiative of the health worker, however a number of configurations have been described in the literature. See Table 1.

Facility-based CI relies on inviting index TB cases to bring their household contacts to the facility for TB screening. In a study from Malawi undertaken in 44 hospitals by Claessens et al, only 12% of index adult patients had their child contacts brought in for screening and 9% of the child contacts under the age of 5 years were screened for TB (64). Nyirenda et al, also in a Malawian study reported a 7.7% rate of compliance by index adults with active TB to bring their contacts (41). Work on the operational challenges of IPT in high TB-HIV burden settings in South Africa

displays the realities on the ground with regard to the IPT cascade: of 522 sputum TB-positive adult cases or 158 sputum TB culture-positive adult cases, only 1 child was documented to have started on IPT (65). TB contact screening may be even worse in other settings in Sub-Saharan Africa.

**Table 1: Summary of Interventions Relevant to TB Contact Investigation**

	<b>Intervention</b>	<b>Description</b>
1	Facility based approach (41, 64, 66)	Index TB case is invited to bring contacts for screening. Basic minimum.
2	Active approach (29, 31, 67)	Involves community health workers (CHWs). Linked to a facility with TB testing capabilities. Reaches more people and generally preferred approach.
3	Integrated approaches (68, 69)	Can utilize M-health, cash, transport/food incentives for CHWs and/or patients.
4	Social network analysis (33, 70-72)	Close contacts in social networks beyond the household are investigated.
5	Health education (73)	May promote adherence to latent TB treatment.
6	Incentives and contracts (74)	Cash incentives may be more effective than non-cash incentives, which may be as effective as structured education. Limited research on contracts.
7	Stigma reduction (1, 17, 34, 75, 76)	TB clinics and home visits reduce internalized stigma. Peer-led activities at TB clinics, the ZAMBART stigma toolkit and Photo voice may reduce stigma.

Another strategy for TB CI involves community health workers actively seeking out TB contacts in the community. A 10% decrease in TB incidence was documented in active contact tracing

(DOTS-A) communities when compared to those in which DOTS alone was employed in a cluster randomized trial conducted in Brazil between 2000 and 2004. Although 73% of contacts evaluated in the active intervention had some screening, standardized contact data in the passive group was not collected and therefore a comparison cannot be made (29). In Southern Ethiopia, Yassin et al reported doubling in TB case notification by using health workers on motorbikes to reach members in the community, taking sputum samples to the laboratory in the facility and bringing back results (31). In India only 16% of individuals traced were screened with 0.44 contacts screened per index case (31). A limitation of household CI is that children <6 years old cannot expectorate and give a viable sputum sample. In most community approaches, although the patient may be screened at home, if they are asymptomatic and IPT-eligible, IPT is provided only at the facility. Symptomatic patients require further evaluation including obtaining a microbiological sample and a chest x-ray (14). The community strategy is an excellent initial approach but is limited by the need for facility-based diagnostic testing (77). Integrated approaches that provide incentives and m-Health strategies have also been utilized to optimize TB contact screening. An integrated strategy involving food and transport incentives and text reminder used in Pakistan resulted in an 84% consent rate and 6.3 contacts screened per index case (32). An ongoing cluster randomized trial is comparing a traditional passive versus active TB CI approach in Vietnam (30).

Social network analysis (SNA) is a novel strategy that has been employed for CI in some low TB prevalence countries (33, 70, 72, 78, 79). Cook et al describes a social network as a set of nodes (persons and place) and connections among them, thus SNA, also known as transmission network analysis measures the nature of these connections (e.g. work or school associated activity) and the effect on this activity within the network. The unit of analysis is the connection linking 2 nodes i.e. person-person and person-place dyads. This can help explore the relevance of social structure to transmission of disease with wide application. Furthermore, ongoing

transmission can be detected earlier by monitoring interconnected cases, contacts and places through SNA and help in prioritizing contacts and places for CI. Hence SNA can be utilized as a decision making tool for outreach workers planning CIs and TB control program managers for allocation of resources (33). Despite the United States of America Centre for Disease Control and Prevention (CDC) acknowledging the benefits of this approach, it notes that this strategy may requires additional labour and recommends further operational research (80). SNA has not been explored as a supplement to traditional CI in high burden TB regions.

Although socio-economic and health systems factors are acknowledged as fundamental barriers to TB contact tracing, the ideas proposed to translate these into action are few (42). Recent Cochrane systematic reviews and meta-analyses included evaluation of patient education and counseling, material enablers and incentives, and contracts to enhance TB care (73). In this series M'Imunya et al evaluated patient education and counseling to promote adherence to TB treatment. Only 3 trials were identified which evaluated effects of educational and counseling interventions on adherence for latent TB with no trials for active TB. Generally, these revealed that there may be a beneficial effect of education and counseling however the extent of the benefit differed depending on the intervention and the location (73). In the meta-analyses on the use of material enablers and incentive use in TB care, cash incentives were more effective than non-cash incentives in improving return for test results and adherence to IPT, with higher amounts of cash being more effective. In the same analyses, material incentives were shown to be more effective than motivational education in improving return for Mantoux test results but just as effective as either peer counseling or structured education in improving completion of IPT. The reviews noted the generally low quality of evidence and the need for high quality studies (74). It is worth noting that none of these interventions were tailored to TB CI.

Interventions targeting stigma in TB include the use of TB clubs and home visits (17, 34). These were studied in a cluster-randomized trial in Nicaragua and were shown to reduce internalized TB stigma. However no treatment outcome benefits were realized (34). A toolkit to address TB stigma especially in high TB-HIV burden areas was developed by the International HIV/AIDS Alliance regional training program in collaboration with the Zambia AIDS Related Tuberculosis (ZAMBART) Project. This intervention includes participatory pictures, exercises and games that can be helpful in tackling stigma with the potential to be adapted in similar contexts (1). Another innovation to address TB stigma is Photovoice which has been employed in TB advocacy in Karachi, Pakistan. It recognizes that TB patients can play a more active role in research by sharing their experiences through photos and voice, essentially being co-researchers. The photovoice methodology was used in the 'Tasweer-e-Zindagi', or 'Picture of Life' study to understand what TB patients experience and promote a supportive atmosphere culminating in a 3-day gallery event open to participants, key policy makers, community leaders, NGO representatives, media and the public (75). Another example of an innovative strategy to address TB stigma is friend-led clinics in Uganda, where TB peers lead activities in the TB waiting rooms to provide motivation and encouragement (76).

### ***Need for innovations to align with global and national TB goals***

The WHO Post 2015 End TB Strategy calls for innovative TB care, bold policies and support systems, and intensified research and innovation, specifically research to optimize implementation and impact, and promote innovations (81). The National Tuberculosis, Leprosy and Lung Diseases Program (NTLDP) in Kenya has similarly called for a multi-sector approach encompassing all players including academia and industry (6). This study was performed to support these calls for action and provide a contextual situation analysis by exploring the barriers and facilitators of TB CI as well as their potential solutions. We therefore titled our study, '*TB Kwisha*', Swahili slang for 'End TB', a catchy phrase that resonates with most Kenyans,

particularly those living in Nairobi. This is in line with the End TB strategy goal towards zero deaths, zero cases and zero suffering from TB with CI as one of its 10 indicators, with a target of  $\geq 90\%$  by 2025 (40). Gaps in specific policy, guidelines, tools and financial resources for CI scale-up have been recognized, however the implementation of routine CI has not been formally assessed (82). Additionally, an instrument that comprehensively measures stigma among TB patients in Kenya, a high burden TB/multi-drug resistance (MDR) TB and HIV country (2), is envisioned in the national strategic plan (82), but does not currently exist. Adaptation of an existing validated stigma tool to assess TB-related stigma in this context would be a first step. Findings from this study will be used to develop contextually appropriate and relevant interventions that are responsive to the current cultural and socio-economic dynamics at play in TB control in Nairobi, Kenya.

## **CHAPTER 5**

### **METHODOLOGY**

This study was conducted between April 2015 and July 2016. The study took place at 13 study sites in Nairobi namely; Kenyatta National Hospital (KNH), Mbagathi District Hospital, Mama Lucy Kibaki Hospital, Mathari Hospital, Waithaka Health Centre, Mukuru Health Centre, Eastleigh Health Centre, Prison Staff Training College Health Centre, Langata Health Centre, Makadara Health Centre, Ngara Health Centre, Kangemi Health Centre and Dandora I Health Centre.

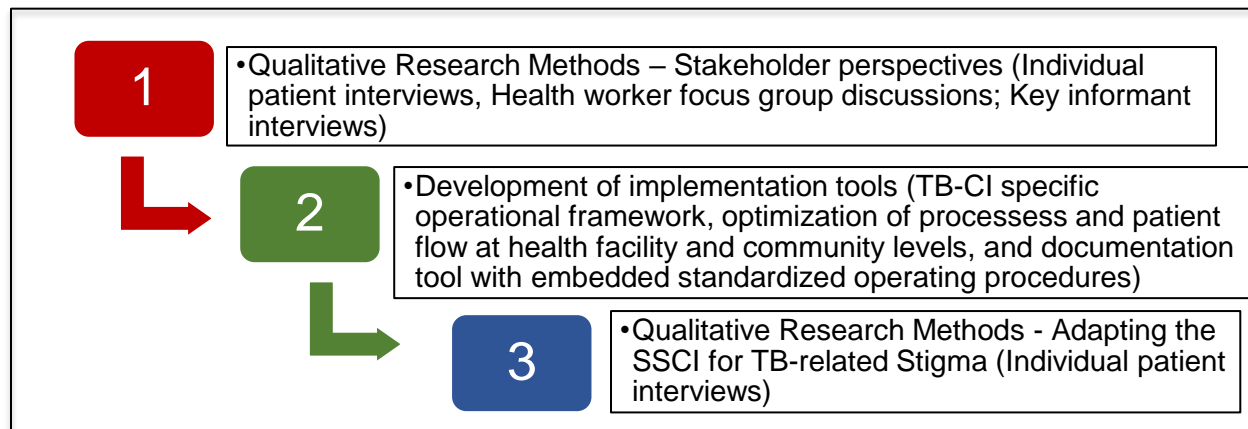
Institutions involved in diverse areas related to TB-CI represented in this study included Ministry of Health, Kenya: NTLDP, National AIDS and STI Control Program (NAS COP), Child and Adolescent Health Program, Division of Disease Surveillance and Response (DDSR) and Division of Health Informatics; WHO-Kenya, Kenya Association for the Prevention of Tuberculosis and Lung Diseases (KAPTLD), TB Accelerated Response and Care - Centre for Health Solutions (TBArc - CHS), African Medical and Research Foundation (AMREF) Global Fund TB Project, KNH Respiratory Infectious Disease Unit (RIDU), Departments of Paediatrics and Child Health, and Internal Medicine - University of Nairobi, Division of Paediatric Pulmonology - Aga Khan University Hospital Nairobi, iLab Africa - Strathmore University, Savannah Informatics, and International Training and Education Centre for Health (I-TECH), Kenya.

#### **STUDY DESIGN**

We conducted a multi-method qualitative study to identify and describe facilitators, barriers and potential solutions to TB CI and linkage to care (Figure 4). Stakeholders, specifically TB patients, health workers and experts in TB care nationally were engaged to gain their perspectives through individual interviews, focus group discussions and key informant interviews respectively which informed the formulation of an operational framework for optimization of TB CI and linkage to care



implementation in Nairobi County, Kenya. In addition, qualitative methodology was used in the adaptation of the SSCI tool to assess internalized and enacted TB-related stigma in Nairobi, Kenya.



**Figure 4: Study Design - Multi-Method**

### Research Team and Reflexivity

As a Kenyan paediatrician with formal training and experience in qualitative research I made facility observations and conducted individual patient interviews, key informant interviews (KIIs) and focus group discussions (FGDs), as well as the cognitive interviews without establishing a relationship with participants prior to study commencement. For methodological robustness and to ensure transparency of findings, H.M, a Kenyan anthropologist with extensive training and experience in qualitative research transcribed all the interviews and translated the cognitive interview audio recordings. Data were analyzed independently and differences resolved by consensus. A Swahili/English Translator and Communicator experienced in translation and localization, S.N served as the tie breaker where consensus was not reached, and independently reviewed TB patient interviews to ensure recommendations proposed accurately reflected patient needs. The original SSCI was independently translated into Swahili and back into English by the three of us, harmonized and thereafter adapted for health worker (HW) administration.

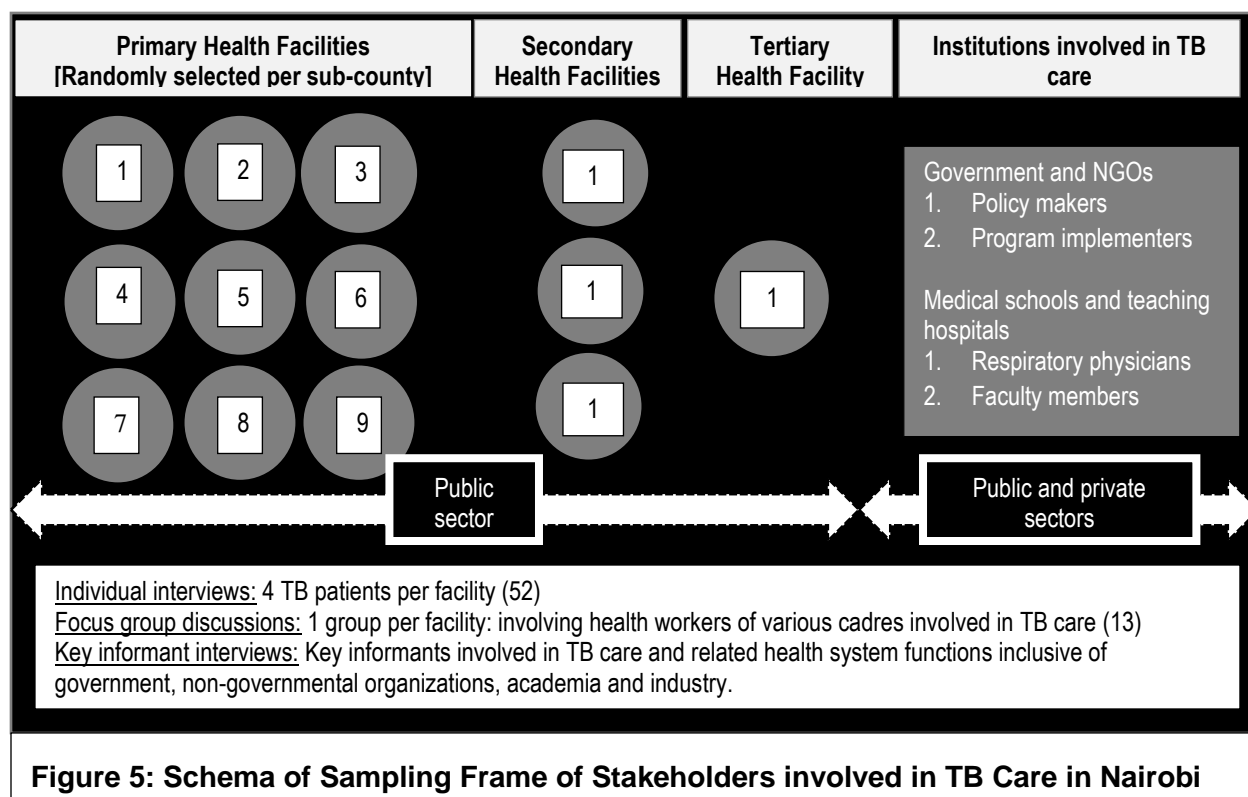
### **Ethical considerations**

Ethical approval to conduct this study was obtained from the Kenyatta National Hospital-University of Nairobi Ethics and Research Committee (P549/09/2014) and the University of Washington Institutional Review Board (#47618). Written informed consent was obtained from each of the study participants before collecting any data from them. All information obtained from study participants was kept confidential. In this regard, participant names during interviews were not audio recorded. Furthermore, data was stored in password protected files with access restricted to researchers, and destroyed audio-recorded files six months after transcription.

### **SPECIFIC OBJECTIVES 1 AND 2 - RESEARCH PROCEDURES AND DATA ANALYSIS**

#### **Participant Selection**

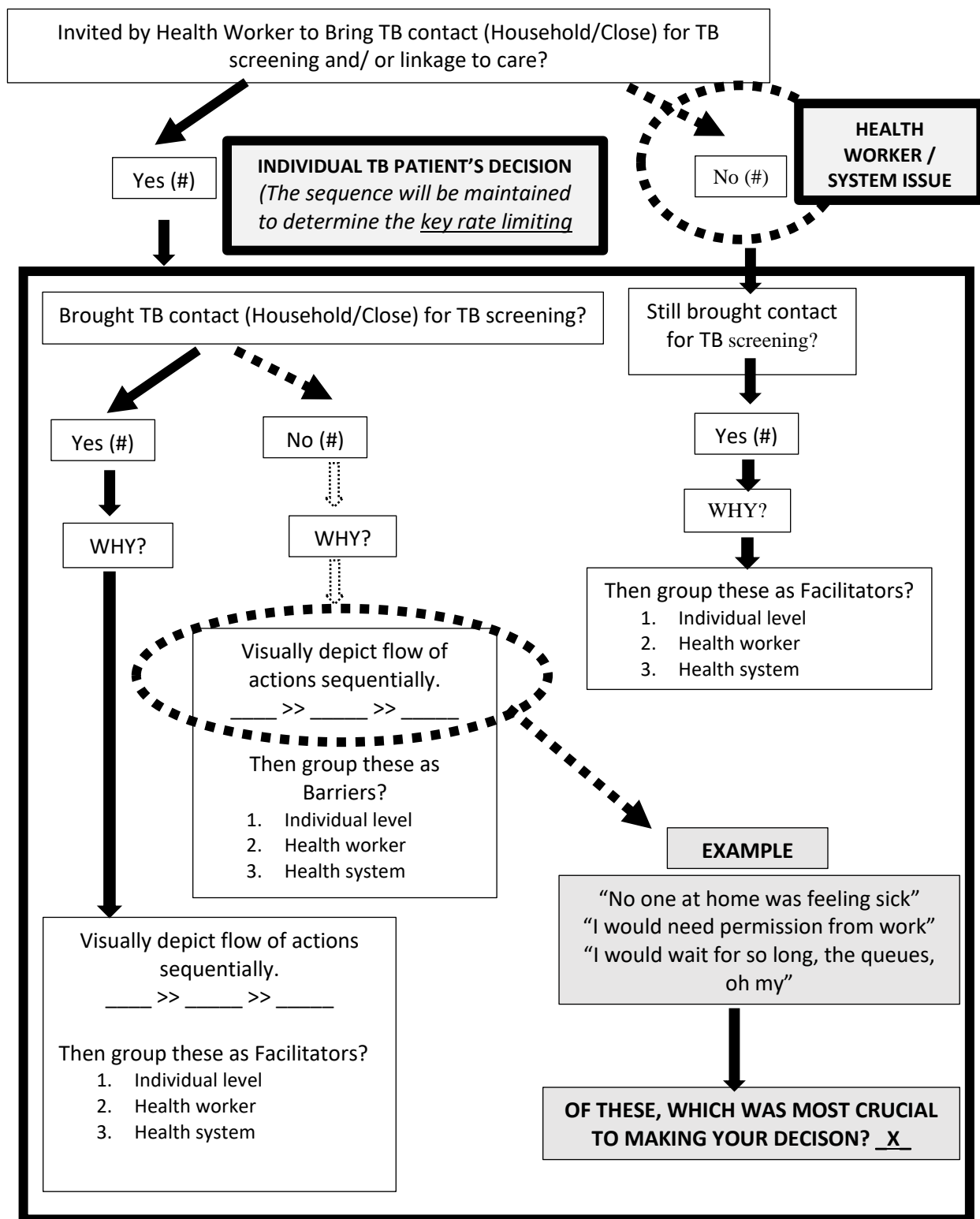
Through a multi-stage sampling approach restricted to public health facilities in Nairobi, Kenya, study participants were selected from 13 TB clinics stratified by the level of health care provided as shown in Figure 5. These included all tertiary and secondary public referral facilities in Nairobi County offering TB services. In addition, one facility from each of the nine sub-counties were randomly sampled among 27 public primary health facilities listed in the 2014 master-list of health facilities (83). First, index TB patients were selected consecutively to gain individual perspectives in decision making for TB screening, and were eligible to participate in the study if they had clinician-diagnosed pulmonary TB, were aged  $\geq 18$  years and attended the selected TB clinics. On two separate visits at each selected TB clinic, the researcher consecutively selected the first male and female patients from the TB patient register at the time of the visit. Where gender balance was not possible at the visit, a second participant of the same gender was conveniently selected. Therefore four patients from each of the 13 health facilities were selected with the goal of having a balanced sex distribution where possible.



Second, health worker provider teams responsible for TB-CI at each of these selected clinics were selected to gain their 'on the ground' perspective. These teams comprised of various cadres involved in TB care including nurses, clinical officers (COs), community health workers (CHWs), HIV counselors, social workers and laboratory technicians. FGDs comprised of HWs from various disciplines in each TB clinic leveraged on the existing group dynamic and provided a safe environment to generate and gain valuable insights.

Third, key informants who were stakeholders involved in diverse aspects of TB-CI including policy makers, program implementers, academia, and industry, were purposefully selected to gain an in depth and holistic understanding of the health system in relation to TB-CI. TB patients, TB clinic leaders and their teams, and key informants were invited to participate in the study. Informed consent was sought and obtained from each participant prior to conducting face-to-face interviews and FGDs. These interviews and discussions were conducted during hours of facility or institution

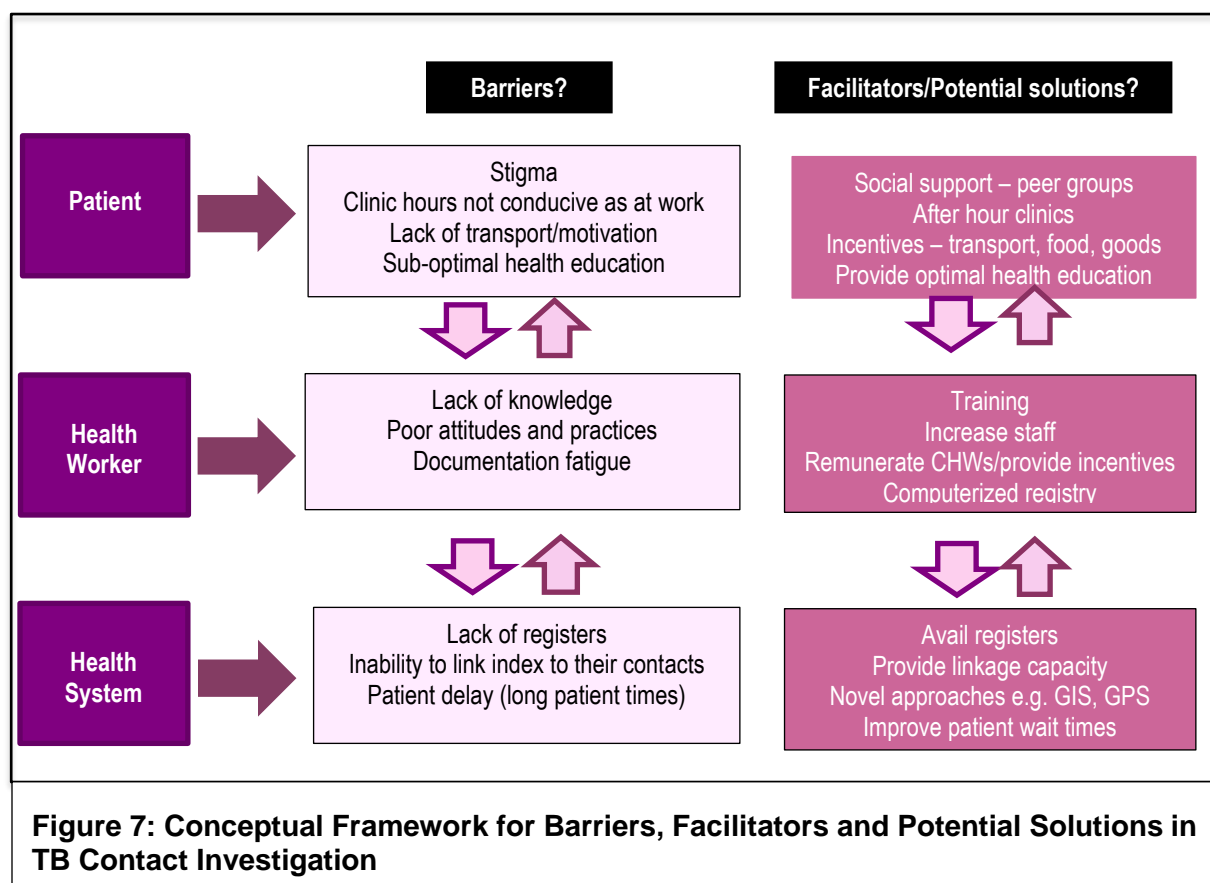
operation.



**Figure 6: Hypothetical Decision Model - Index TB Patients' Decisions on Contact Investigation**

## Data Collection Process

Prior to study commencement, a hypothetical TB-CI decision model for index TB patients was created, with plausible decision arms based on past literature and prior experience in caring for TB patients. See Figure 6. This model was used as the framework to guide the open ended interviews with individual TB patients and build a patient-oriented, pragmatic model. After obtaining informed consent, rapport was first established with the study participants prior to enquiring about pertinent sociodemographic characteristics such as: a) age, b) education level, c) occupation, d) duration since TB diagnosis, e) living dynamics with regard to household and close contacts including young children, f) where TB patients spent most of their time including travel, g) processes that took place at the health facility, h) the health education/advice given by the HW including that pertaining to household and i) close contacts and the general TB care provided for each individual TB patient.



Thereafter, an enquiry was made about facilitators, barriers and opportunities for TB contact screening optimization at each decision node an apriori developed conceptual framework (Figure 7).



**Figure 8: Overarching WHO's Six Health System Building Blocks Framework showing its Dynamic Nature and Interconnectedness**

To guide FGDs, documentation of facility observations including mapping flow of TB-CI related activities and KIIs, the WHO's six building blocks framework was used (Figure 8). These building blocks include: 1) health service delivery, 2) health workforce, 3) health information systems, 4) access to essential medical products, vaccines and technologies, 5) health systems financing and 6) leadership and governance. Since health systems are highly context-specific, this framework enables a health system to be analyzed in its totality, utilizing a unified approach that allows for identification of strengths and gaps (84). In addition to the insights gained from HWs during the FGDs regarding general and TB-CI care at their facilities, we also provided scenarios to gauge the spectrum of TB-CI actions specific to contacts who were children or who were HIV-infected. CI in this respect was not restricted to conventional approaches involving only household contacts. Potential facilitators and barriers to novel methodologies that would involve close contacts within social networks or require the use of geographical information system and global positioning systems were also explored. Interviews were audio recorded. In addition, field notes were taken and when data were saturated this was recorded. Interviews were transcribed verbatim.

### **SYSTEMS THINKING FOR OPTIMIZING TB-CI IN NAIROBI, KENYA**

A system is “a set of elements connected together which form a whole thereby possessing qualities of the whole rather than of its component parts” (85). Utilizing WHO's health system building blocks overarching framework, we employed systems thinking, an approach to problem solving that has been recommended globally for health systems strengthening (86). Scholars have advocated for this paradigm shift as it is a highly versatile approach. It is especially useful for complex problems involving multiple interacting agents in context (87). We adopted systems thinking to understand the dynamic and interconnected nature of the health system specific to TB-CI and its stakeholders in the context of Nairobi County, Kenya.

According to Peter, systems thinking “deploys explicit models with assumptions laid out that can be calibrated to data and repeated by others”, a quality of good research. Numerous theories, methods and tools have been described in the area of systems thinking (87). Despite all models being wrong, we concur with Box et al that some models are useful (88). For this work we chose to use our hypothetical model for TB-CI (Figure 6), based on ethnographic decision modelling to understand how TB patients make the decision to bring their contacts for TB screening. Ethnographic decision models, borrowed from the works of theorists Lancaster in 1966 and Tversky in 1972 and elaborately described by Christian Gladwin in 1989, are qualitative causal analyses (89). Modelling human decisions can enrich our understanding of the behavioural choices that people make when faced with alternatives and improve our understanding of the underlying cognitive processes (90), and can also be used to predict behaviour (89). Secondly, we employed process mapping, a flexible set of system thinking tools that provides a pictorial representation of a sequence of actions and responses and has been extensively described by Damelio et al (91). Process mapping is increasingly being used in diverse fields of health care to empower HWs audit their current service delivery practices (92). We chose to use process mapping to identify barriers and facilitators of TB-CI implementation at each of the selected 13 health facilities and subsequently produce a composite map for use by health facility teams involved in TB care across Nairobi County and similar settings. We envisaged that teams could use the composite map to identify and prioritize bottlenecks they wished to act on for optimization of TB-CI and continually audit their performance. Thirdly, we used our conceptual framework (Figure 7) listing barriers and facilitators/opportunities to TB-CI and linkage to care for each of the stakeholder groups as a placeholder for perspectives gained from this research that would in turn serve as an operational framework for optimizing TB-CI and linkage to care in Nairobi County, Kenya.



Besides prediction Epstein et al, explained that there are at least 16 other reasons to build models (93). At the design stage of this study, I used systems thinking with four of these reasons in mind: 1) to explain how TB-CI occurred in Nairobi from the perspectives of key stakeholders, 2) to guide data collection during facility observations, interviews with TB patients, HW FGDs, and KIIs, 3) to elucidate key dynamics of TB-CI in context, and 4) to keep a scientific mind, remaining cognizant that the conceptual framework of TB-CI barriers and facilitators developed apriori (Figure 7) would be contingent to the scientific evidence generated in the context of Nairobi County.

### **Analyses**

I chose a hybrid approach to thematic analysis incorporating both a deductive approach (94) and an inductive approach (95, 96). Apriori, I developed a codebook of general themes based on the conceptual framework illustrated in Figure 7 that was informed by the literature and clinical experience. It comprised three levels: the (1) patient, (2) health worker and (3) health system. Both myself and H.M deductively coded from this codebook. We manually coded the transcripts independently and also used Atlas.ti GmbH, Berlin version 7.5.10 (Student License) (97), qualitative research software to manage the data. Employing various qualitative methodologies, we triangulated data from different sources. At the patient level, the TB-CI decision model was assessed based on two decision levels: (1) Was the TB patient invited by a HW to bring his/her close contacts for TB screening? (2) Were any of the close contacts screened for TB? At each decision node, facilitators, barriers and opportunities for TB-CI optimization were identified and themes analyzed based on these categories. We also analyzed data from facility observations, HW FGDs and stakeholder KIIs based on these categories. As themes emerged from the data, we inductively created new codes which we arranged within WHO's six building blocks for health systems overarching framework of analysis employing systems thinking. Throughout this iterative qualitative analysis process, both H.M and I discussed study findings, refined code definitions, and settled analytic discrepancies by consensus. Independent review of patient interviews was

undertaken by S.N to ensure proposed recommendations accurately reflected patient needs. This robust methodological approach to data analysis served to ensure data accuracy and increase validity.

Through triangulation of methodology and complimentary findings from stakeholder perspectives, specifically TB patients, health workers and experts in TB care nationally engaged through individual interviews, focus group discussions and key informant interviews respectively, we developed an operational framework for optimization of TB CI and linkage to care implementation in Nairobi County, Kenya. This included a documentation tool with embedded standard operating procedures and also a framework of specified areas of optimization of processes and patient flow at both the health facility and community levels.

### **SPECIFIC OBJECTIVE 3 - RESEARCH PROCEDURES AND DATA ANALYSIS**

#### **Participant Selection**

Study participants were selected through a multi-stage sampling approach restricted to public health facilities in Nairobi County, a densely populated urban metropolis and the capital of Kenya similar to that described above. Ethical approval to interview 20 participants was obtained, a sample size suggested in the literature to be sufficient to reach qualitative data saturation in a study such as mine with a narrow scope, specific sample and established theoretical framework (98), among other factors that contribute to adequate information power (99). Participants were eligible if they were aged  $\geq 18$  years, had clinician diagnosed TB and were attending the selected TB clinics. The participants were approached individually and their informed consent sought, after which face-to-face interviews were interviewed at each selected TB clinic during hours of operation. The goal was to achieve a representative sample with regard to the level of health facility (primary, secondary and tertiary) and sub-county distribution in Nairobi County.

### **The Stigma Scale for Chronic Illness (SSCI)**

The original 26-item SSCI by Rao et al is made up of 13 items that measure internalized stigma, 11 items that measure enacted stigma and two items that address disclosure concerns as a result of disease-related manifestations. It is also referred to as the Neuro-Qol (Quality of Life in Neurological Disorders) Stigma Scale and is available in Spanish, Simplified Chinese and Korean translations of the English version (100). The SSCI has been used across neurological conditions including epilepsy, multiple sclerosis, Parkinson's disease, stroke and amyotrophic lateral sclerosis (101). It has also been used to assess stigma among African Americans living with HIV (102). Myself, H.M and S.N independently translated the SSCI from English to Swahili and back to English.

### **Data Collection Process**

No one else was present during data collection besides the participants and me. A cognitive interview guide was used, and the tool was continually revised through an iterative process to incorporate TB patients' suggestions (103). See Table 10. The interviews were audio recorded, field notes taken and data saturation noted. The interviews were translated into English and transcribed verbatim. The interviews were not repeated nor were transcripts returned to participants for comments or correction. To maintain confidentiality, participant names during interviews were not audio recorded. Data was stored in password protected files with access restricted to researchers, and destroyed audio-recorded files six months after transcription as per our protocol.

### **Analyses**

Themes related to SSCI tool adaptation were identified in advance. These included difficulties in translation, differences in meaning, TB contextual relevance, acceptability of the questions to

patients, and issues in tool structure. Similar to our aforementioned analyses, a hybrid analytic approach was employed. I developed a codebook with these five themes apriori, and H.M and I deductively coded from this codebook. We manually coded the transcripts independently and also used Atlas.ti GmbH, Berlin version 7.5.10 (Student License) (97) to manage the data. We inductively created new codes from sub-themes related to stigma in the context of TB in English/Swahili speaking patients in Nairobi derived from the data which we categorized as: (1) factors promoting TB stigma, (2) factors reducing stigma and (3) time. When analytical discrepancies arose, S.N served as the tie breaker. After analysis, feedback on the tool was received from HWs and incorporated. Our robust approach to data analysis served to ensure data accuracy and increase validity.

## CHAPTER 6

### RESULTS

#### **FACILITATORS, BARRIERS AND POTENTIAL SOLUTIONS TO TB CONTACT INVESTIGATION IN A HIGH TB/HIV BURDEN SETTING**

##### **Participant Characteristics**

*TB Patients:* This study included 52 adult TB patients attending one of the 13 selected health facilities in Nairobi County, Kenya. As shown in Table 2, 27 (52%) were male, the median age was 33 years (IQR 26-40, range 21-50) and 36 (69%) were from primary health facilities. Approximately two thirds of patients lived with either members of their nuclear family, or with extended family members including grandparents, grandchildren, cousins or in-laws. One in five patients traveled out of Nairobi frequently to visit family members.

*Health Workers:* A FGD was conducted among HWs in each of the 13 selected facilities. The median number of participants for each FGD was 7 HWs (IQR 6-8). Most focus groups included nurses, COs, HIV counselors, CHWs, nutritionists and lab technicians. (Table 3)

*Key Informants:* Key informants involved in TB-CI related activities comprised 5 policy makers/program implementers in government, 4 policy makers/program implementers in non-governmental organizations, 5 respiratory health experts in pediatric and adult medicine including academic faculty in public and private sectors, and 3 health information system consultants. (Figure 9)

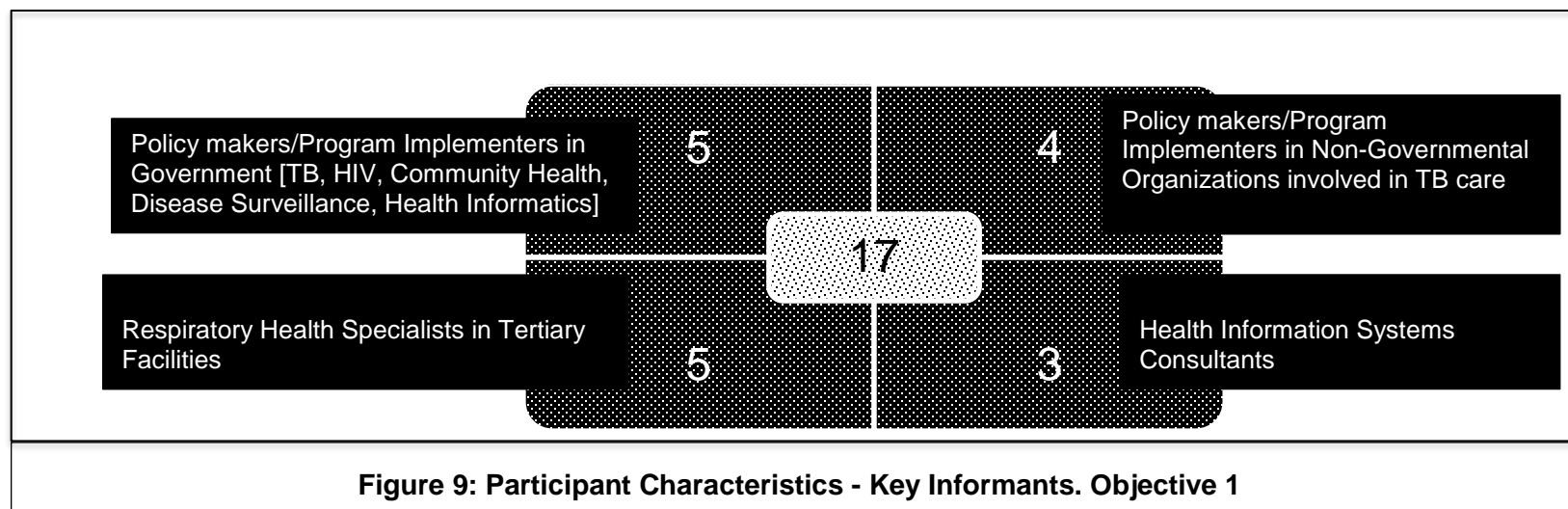
**Table 2: Participant Characteristics (Patients) – Objective 1**

<b>Patient Characteristics (N = 52)</b>	<b>Freq (%) or Median (IQR) [Range]</b>
Median age (IQR) [Range]	33 (26-40) [21,50]
Male (%)	27 (52)
Smear positive PTB (%)	44 (85)
Median duration in months since PTB diagnosis (IQR) [Range]	2.0 (1-3) [0.04,8]
Previously treated for TB and cured (%) <ul style="list-style-type: none"> <li>• Second time TB diagnosis</li> <li>• Fourth time TB diagnosis</li> </ul>	10 (19) 8 (15) 2 (4)
MDR TB	1 (2)
Level of education (%) <ul style="list-style-type: none"> <li>• No formal education</li> <li>• Incomplete primary education</li> <li>• Complete primary education</li> <li>• Complete secondary education</li> <li>• Complete tertiary education (polytechnic/college/university)</li> </ul>	3 (6) 12 (23) 17 (33) 15 (29) 5 (10)
Occupation (%) <ul style="list-style-type: none"> <li>• Employed – upper tier [white collar] (manager, marketer, administrator, hotelier, messenger)</li> <li>• Employed – lower tier [blue collar] (hair stylist, tailor, shop assistant, mechanics, public vehicle drivers, public vehicle conductors, barmaids, cleaner, casual laborers )</li> <li>• Self-employed (businessmen/women: khat, charcoal, cooked food, tailor, art, unspecified)</li> <li>• Students (college/university)</li> <li>• Unemployed (housewives, no jobs/looking for jobs, refugee)</li> </ul>	5 (10) 20 (38) 10 (19) 3 (6) 14 (27)

Patient Characteristics (N = 52)	Freq (%) or Median (IQR) [Range]
Primary health facility (%)	36 (69)
Sub-county (Health Facility Code) <ol style="list-style-type: none"> <li>1. Dagoretti (I, II, V)</li> <li>2. Embakasi (IX, XIII)</li> <li>3. Kamukunji (X)</li> <li>4. Kasarani (XII)</li> <li>5. Langata (III)</li> <li>6. Makadara (VIII)</li> <li>7. Njiru (VII)</li> <li>8. Starehe (IV, XI)</li> <li>9. Westlands (VI)</li> </ol>	12 (4, 4, 4) 8 (4, 4) 4 (4) 4 (4) 4 (4) 4 (4) 4 (4) 8 (4, 4) 4 (4)
Index TB patient-contact living dynamics (%) <ol style="list-style-type: none"> <li>1. Live with their nuclear family in Nairobi               <ol style="list-style-type: none"> <li>a. Husband/wife and children</li> <li>b. Siblings</li> </ol> </li> <li>2. Live with their extended family in Nairobi</li> <li>3. Live alone (single), has close contacts in Nairobi               <ol style="list-style-type: none"> <li>a. Girlfriends/boyfriends</li> <li>b. Neighbors</li> <li>c. Workmates</li> <li>d. College mates/friends</li> <li>e. Relatives</li> </ol> </li> <li>4. Live alone (married), has family outside Nairobi</li> <li>5. Travel out of Nairobi (frequently)               <ol style="list-style-type: none"> <li>a. To visit husband/wife and children</li> <li>b. To visit parents</li> </ol> </li> <li>6. Travel to Nairobi – to seek medical care</li> </ol>	21 (40) 17 (33) 4 (8) 13 (25) 10 (19) 1 (2) 3 (9) 3 (9) 4 (8) 4 (8) 5 (10) 11 (21) 5 (10) 5 (10) 1 (2)

**Table 3: Participant Characteristics (Health Workers) – Objective 1**

<b>Health Worker Focus Group Characteristics</b>	<b>Total (N = 13 FGDs)</b>													
Median Number of Participants (IQR) [Range]	7 (6-8) [4-10]													
Distribution of HWs per FGD	Total	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII
Nurses	26	1	2	0	4	1	3	2	2	3	3	2	3	0
Clinical officers	15	1	1	0	1	1	1	1	0	2	1	2	1	3
HIV and psychosocial support counselors	15	3	1	0	1	1	0	4	1	2	1	0	1	0
Community health workers	11	0	0	1	0	1	1	1	2	2	1	0	1	1
Nutritionists	7	0	1	1	0	1	1	0	1	0	1	0	0	1
Lab technicians	6	0	0	1	1	1	0	1	0	0	1	1	0	0
Pharmacy technicians	2	0	0	1	0	0	0	1	0	0	0	0	0	0
Medical superintendent	1	0	0	0	0	0	0	0	0	0	0	0	0	1
Community health extension worker	1	0	0	0	0	0	0	0	0	0	0	1	0	0
Social worker	1	0	0	0	1	0	0	0	0	0	0	0	0	0
Total	85	5	5	4	8	6	6	10	6	9	8	6	6	6

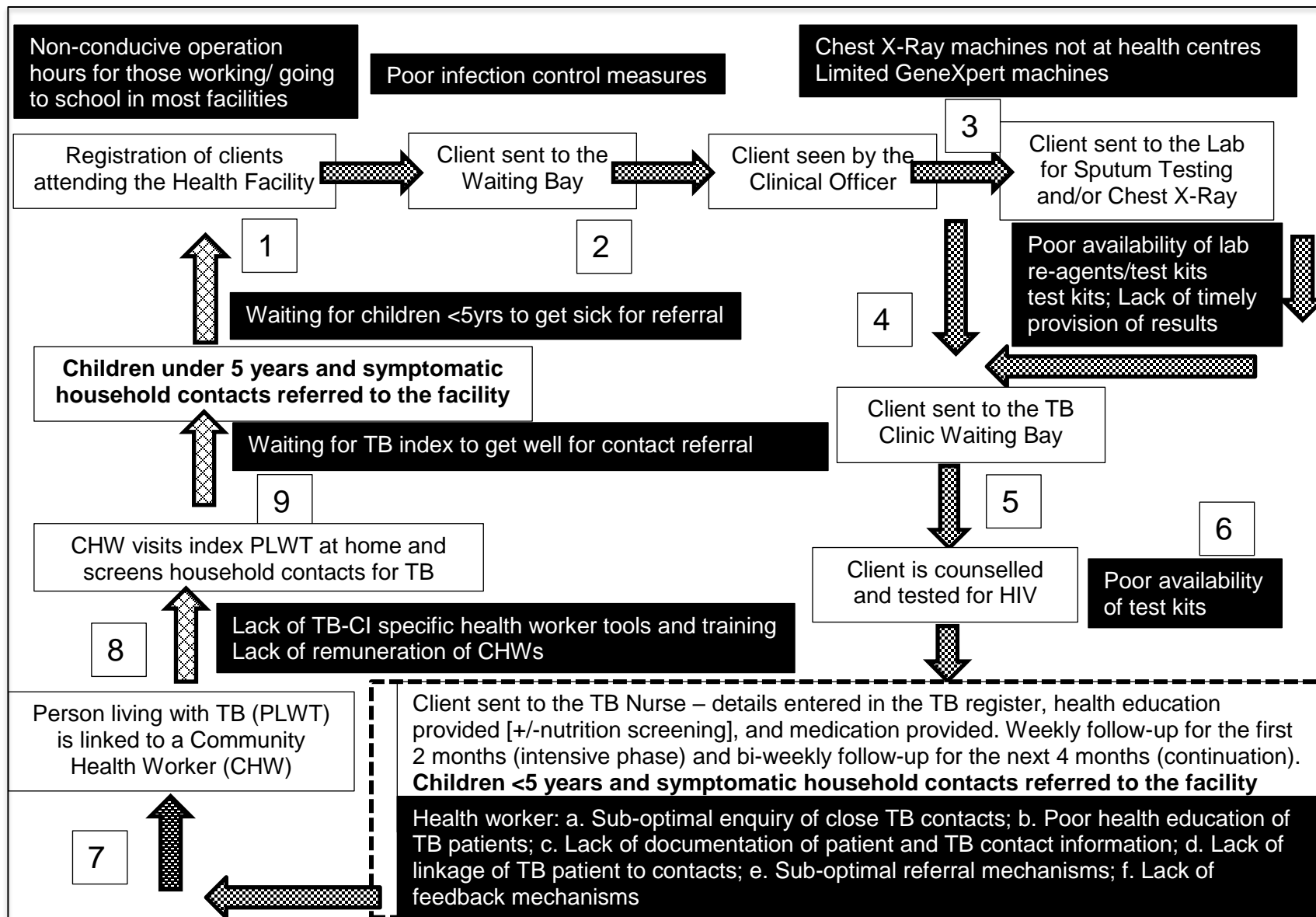
**Figure 9: Participant Characteristics - Key Informants. Objective 1**



## **Flow of Tuberculosis Contact Investigation Related Activities at the Health Facility**

### *Index TB patients*

As shown in Figure 8, it was observed that patients seeking care in these facilities would begin at the registration desk where socio-demographic characteristics including age, sex, residential address and contact phone number were recorded in a file/booklet. A patient would then wait to be seen by a CO in the waiting bay comprised of patients of various ages and illnesses, and in most facilities was indoors with poor ventilation and lighting (12/13). Following history and a clinical exam by the CO usually in a private well-ventilated room, patients suspected to have PTB would then be sent to the laboratory for sputum testing. Patients would expectorate sputum samples outside the lab, which in many facilities would be outdoors. Most facilities (11/13) had laboratories that could perform sputum microscopy and few (2/13) had gene Xpert/RIF™ machines on site. Chest radiography (CXR) was only performed in secondary and tertiary referral facilities (3/4). Therefore, in most facilities TB suspects who were sputum-negative on microscopy would be sent to secondary/tertiary facilities for CXR and bring the plain radiographs to the health facility. Once a TB diagnosis was confirmed either on sputum testing and/or in combination with CXR, patients in all facilities were referred to a counsellor for HIV testing in a private room, and the results would be entered into each patient's TB card and the HIV register. Thereafter, a patient would be sent to the nurse in the TB clinic who would enter his/her details in the TB register including treatment buddy contact details, provide health education and dispense medication. Most TB clinics had their waiting bays outdoors (8/13). Only one out of five facilities that had indoor waiting bays for TB patients, was well-lit and ventilated. Patients in tertiary or secondary facilities would be referred to facilities near where they lived/worked.



**Figure 10: Observation of Health Facility Activities related to TB Contact Investigation Highlighting Common Barriers**

### *TB Contacts*

Apart from the tertiary facility which employed a facility-only based approach to TB-CI, all other facilities had CHWs whose function was to link the community to the facility. Most CHWs were supported by development partners or a Global Fund TB-CI initiative ongoing during the period of this study. In some facilities, CHWs mainly focused on defaulter tracing. The active approach provided by CHWs involved screening members of households for TB using the 4 questions recommended by the WHO (104). This information would be entered in triplicate: one copy remained with the CHW, another with the community health extension worker (CHEW) to facilitate compensation of the CHWs if active case finding in that facility was supported by a partner or Global Fund, and the third copy remained in the facility. All children under 5 years, and symptomatic older children and adults were referred to the health facility. Documentation of TB-CI activities linking individual patients and their contacts, and follow-up of contacts was lacking in both facility and active approaches. The composite map of TB-CI related activities in the health facilities is summarized in Figure 10.

### ***TB Patient Decision Model***

From the individual patient interviews, all TB patients whose contact underwent screening had received a HW invitation either of the index TB patients or direct invitation of the TB contact. Most (70%) patients seeking TB care at the facilities were invited by a HW to have their contacts screened and almost half (40%) had at least one contact screened for TB. Of 16 TB patients invited by a HW but did not have their contacts screened, 4 reported they would bring at least one close contact on a specific date in the future, 7 would have their close contacts screened if they were symptomatic, and the remainder reported that: they were not feeling well enough or did not have finances to bring close contacts to the facility; that the HW had not inquired about other close contacts including children under the age of 5 years who were not part of the nuclear family; or that their close contacts were out of town. (Table 4)

**Table 4: Patient Identified Facilitators and Barriers to Having Contacts Screened**

Reason	Number of participants	Selected representative quotes [participant code]
<b>Facilitators</b>		
<u>Patient</u>		
1. Understand TB.	4	<i>"For me, no (there are no barriers) because you know for infectious diseases, they are very dangerous. If you fail to take precautions, now the whole family will be destroyed. Me I don't find any problem with that (my family being tested) because I love them and I need them. I want them to survive."</i> [P08]
2. Health benefits of contacts	4	<i>"I live with my mother and this small child. Yes, here in Facility X, I was told to bring my mother and child to be checked for TB. I brought them for the benefit of their health."</i> [P32]
3. Contacts not to suffer	2	<i>"I do not want my contacts to suffer like me."</i> [P051]
<u>Community/Contacts</u>		
1. Contact cares/support	1	<i>"My brother came because he decided to, but also because he loves me and it's also good that he came to learn more."</i> [P05]
2. Seen improved health	1	<i>"Perhaps my mother saw the changes that happened to my health, and so she saw it was good she came. Like three weeks (of taking medicine is when she saw the changes)"</i> [P32]
3. Treatment supporter	1	<i>"Yes, there is a doctor who asked him (my brother) to be checked for TB, and he came. He came because I could have infected him, just in case. He is the one who brought me to hospital. So the doctor also told him to get tested."</i> [P19]
<u>Health System Service Delivery</u>		
1. HW invitation	22	<i>"I asked them (my family living in Mombasa) to go for testing for both HIV and TB. Yes, they (the doctors at the TB clinic) told me, in fact several times (to tell my family to get tested)." [P08]</i>
2. Good service and kind	9	<i>"They (health workers) handle me in a good way when I come here. They welcome me in a very nice way."</i> [P33]
3. Reverse contact investigation	2	<i>"Yes, they found my TB when she (my daughter) came to the ward. So they (the doctors) sent me for the X-ray, it came out positive. I am a mother of three... Tomorrow before we get discharged the others have to come and get X-rays or tested if actually we have given it to them, and even if not, they is something they call anti-TB drugs which you have to take to prevent it."</i> [P30]

Reason	Number of participants	Selected representative quotes [participant code]
4. CHW home visits	1	<i>"Yes, I was told to bring my brother for testing. The Community Health Worker explained to me. Sometimes they call us on phone, or they visit us at home. He explained to me that it is good they know where I live, they took our phone numbers so that in case they came and missed me, he would call me just to know how I'm fairing, and to visit us to know how the place we live in is like, and how the person we live with is like, many things about the home and living."</i> [P05]
5. Sputum container provision	1	<i>"When I came, I was given a container for my husband to collect his sputum, and also for the children (in school, 10yrs and 8yrs). His (my husband's) he removed (sputum) I returned it (to the facility) and he was found to be negative."</i> [P06]
6. IPT provision	3	<i>"I only have these two children. I don't have a husband. Yes, the doctor told me to bring them so that they are tested if they have TB. This one is 9 years and this other one is two. They were tested in this facility. None of them has TB. The younger one was given medicine to prevent TB."</i> [P24]
<b>Barriers</b>		
<u>Patients</u>		
1. Busy at work*	1	<i>"I will bring them when I get an off from work."</i> [P09]
2. Lack of money*	2	<i>"I will bring them when I get money."</i> [P37]
3. Feeling unwell*	2	<i>"I will bring them when I get better."</i> [P12]
4. Lack of transport*	2	<i>"I don't have transport."</i> [P16]
<u>Community/Contacts</u>		
1. Contact not agreeable	6	<i>"For my husband, if he agrees, then he'll come for a check-up."</i> [P41]; <i>"The children I can take them. You know a woman is not a kid. If you like it, you can go, and if you don't, you cannot force her."</i> [P23]
2. TB/HIV stigma	4	<i>"You know sometimes some things you do secretly because people think that because you have TB you have HIV. Therefore, if you tell them, they will think you are positive so you try to be private."</i> [P04]
3. Busy contacts	2	<i>"I don't know when my husband will come for screening, because of work."</i> [P41 ]
4. Contact out of town	1	<i>"My contacts are out of town."</i> [P43 ]
<u>Health System Service Delivery</u>		
1. Lack of HW invitation	15	<i>"No one has ever asked me (to bring my close contacts for screening)"</i> [P03]

Reason	Number of participants	Selected representative quotes [participant code]
2. Sub-optimal education	10	<i>"No, I wasn't explained about how TB is transmitted. No, I wasn't given any health advice on TB. They just tested me for HIV. No, they didn't tell me anything else."</i> [P10]
3. Sub-optimal enquiry	2	<i>"No one has asked me if I have a family or not. If I was sent (to bring my close contacts for TB screening), because I understand that this (TB) is airborne, I would go and tell them that: 'I have TB and it's good that even you when you come you are tested because I don't know if I could have given it to someone.' I would explain it to them and they come. But the doctor hasn't told me so I wouldn't know."</i> [P03]
4. TB/HIV stigma	4	<i>"They (the HWs) would tell you to sit outside. You know, they have a tent but you don't sit inside the tent, you sit outside. You don't expect someone to sit outside even if sunlight helps to kill the bacteria. You cannot keep me in the sun for four or five hours to kill that bacteria. And you know someone feels so bad! And they shout at you: 'Go and sit there, go and sit there!' It is not what you tell someone, it is how you tell them."</i> [P26]
5. Long wait-times	3	<i>"There are long queues; the HWs are busy."</i> [P03]
6. Non-conducive clinic hours	2	<i>"I'm not able to pick drugs over the weekend."</i> [P20]
7. Distant health facility*	1	<i>"This clinic is too far (my family is upcountry)."</i> [P01]
8. No CHW home visit	1	<i>"They (CHWs) never came (home). I think it was like last month [7<sup>th</sup> month of MDR treatment] he was still telling me, 'Now we will be coming with that lady.' So I was like, 'You started telling me in October...November, December.' So I told him, 'I don't think I'm really so important. You have taken so much time. [P26]</i>

## ***Patients' Perspective of the Community, Health Workers and the Health System***

### ***Facilitators to TB Contact Investigation***

Patients reported that good rapport established by HWs because of their flexibility, consideration, well-spoken nature and generally handling patients well were facilitators for TB-CI. Other facilitators included provision of services and patients seeing improvement in their health; not having to wait long at the facility; conducive clinic hours for contacts; and facilities being nearby. Invitation of TB patients by HWs to bring close contacts was key to successful TB-CI. Additional facilitators included CHW home-visits and HW provision of sputum containers for unavailable contacts to overcome barriers such as contacts being at work or in school, and talking to family members, particularly husbands who were reported to be difficult to convince to come to the facility for TB-CI. Furthermore, patients reported that HWs utilized TB-CI for provision of IPT for eligible contacts including children under the age of five years. Screening of close contacts was also facilitated by the identification of TB in children (reverse CI). (Table 4)

Patients' desire to avoid contacts suffering from TB, their concern for each other's health, as well as the positive health changes that were seen once on treatment also promoted TB-CI activities. Patient characteristics including wanting to understand their illness, and past TB experience were other facilitators for TB-CI. Some male heads of households felt that there would be no barriers contact screening as they were in authority. (Table 4)

### ***Barriers to TB Contact Investigation***

Lack of HW invitation was the main barrier to TB-CI. Approximately half of the TB patients who did not have their contacts screened were not invited by a HW but expressed willingness to come if invited. Sub-optimal HW enquiry of contacts, particularly for those who stated that they lived alone, led to lack of HW invitation. Despite HW invitation, some TB patients felt that contact screening depended on the agreeability of their close contacts. This was mostly reported by TB

patients regarding their spouses. Some husbands felt that they could not force their wives to undergo TB screening. Similarly, some wives felt that it depended on their husband's decision. (Table 4)

Other barriers cited by TB patients who did not have their contacts screened despite HW invitation and willingness included distance, long wait-times and non-conducive clinic hours for contacts at work/school. Patients experienced numerous delays from patient diagnosis to treatment. Indeed it was observed that patients waited long to receive care in a number of TB clinics. It was also observed that most clinics opened late and closed early. However, one TB clinic opened as early as 6:30 AM once a week. (Table 4)

TB-related stigma either internalized or perceived by patients, or enacted by the community/HWs, was reported to be a barrier to TB-CI. It was apparent that patients generally had poor knowledge on the cause of TB, how it was transmitted and its seriousness. Misconceptions regarding TB transmission were common, including through sex, sharing utensils and genetics. Nonetheless, HWs played an important role in correcting these misconceptions and empowering patients with information on TB transmission and prevention. Additionally, patients got information about TB through posters in the facilities. (Table 4)

#### *Opportunities and Proposed Solutions*

Missed opportunities for care that we identified from patient interviews included sub-optimal enquiry by HWs about contacts, uncooperative contacts, and patients' assumption that they had to physically bring their contacts to the facility. Gaps in IPT provision including IPT unavailability at facilities and poor HW knowledge, attitude or practice were also identified. HWs advised TB patients to bring contacts when they were symptomatic, which was not optimal particularly for children under 5 years and those who were HIV positive as this would be too late and they would



not benefit from IPT. Other barriers to TB-CI despite HW invitation included HWs not giving information on TB transmission. In some instances HWs did not help the TB patients identify whom their close contacts were, particularly if they lived alone. Additionally, the timing of HW invitation of TB patients to have their close contacts screened was not standard and in some cases sub-optimal, for example in the final month of the patient's TB treatment. Patients proposed solutions to TB-CI which centered on timely screening of close contacts, preventing TB stigma and improving community awareness of TB, particularly on etiology, transmission and prevention. Some patients felt that home visits by HWs were useful in reinforcing invitations done at the facility so that all family members understand the importance of screening of close contacts, particularly in the context of spousal power-dynamics. Moreover, patients felt that it was the government's responsibility to be aggressive on TB campaigns, to prevent patients from suffering. (Table 4)

## ***Health Workers' Perspective of the Patients, Community and the Health System***

### ***Barriers to TB Contact Investigation***

TB-related stigma among TB patients emerged as a major barrier to TB-CI and linkage to care in all the HW FGDs (13/13). Lack of proper knowledge and the presumption that all patients with TB had HIV were the main reasons for the stigma. CHWs cited experiencing near-violent encounters when visiting patients' homes due to patients' fear of their TB status being known by others, and others found that patients provide wrong home addresses and/or phone numbers to avoid CHWs visiting their homes – possibly fearing inadvertent disclosure. TB-related stigma was also reported to be enacted by HWs, largely driven by HWs fear of infection. Although evident, staff members were hesitant to admit that HW stigma was present. Conversely, HWs put themselves at risk for TB transmission by not putting on masks as they did not want to be seen to perpetuating stigma. Health-workers in most facilities (12/13) emphasized the challenges of poverty faced by the patients. (Table 5)

Poverty was described in the context of overcrowding and poorly ventilated housing (10/13), which HWs described to promote TB transmission. Additionally, patients' poor socioeconomic status was reported by HWs with regard to lack of adequate food and money/transport (11/13). On some occasions this was noted to negatively influence nutrition supplementation programs as well as incentives provided at the facility for selected patients in that patients either considered it as acts of HW favoritism or stigmatization. Alcoholism and other forms of drug abuse (3/13) were also identified by HWs to negatively affect TB patients and their communities including in self-neglect, drug non-compliance, and interpersonal disharmony resulting including violence to CHWs visiting their homes. (Table 5)

Table 5: Health Worker Perspectives on Patient Barriers and Solutions to Implementation of TB-CI

HEALTH FACILITY	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII
<b>Barriers to Patients</b>													
Stigma (TB/HIV) – requiring community education (§including stigma from HWs/staff)	+++	+++	+++	+++	+++	+++ §	+++	+++	+++	+++	+++	+++	+++
Poverty - difficulties accessing food, transport etc.	+++	+++	+++	+++	+++	+++	+++	-	+++	+++	+++	+	+++
Poor patient housing mainly slums with poor ventilation & lighting and overcrowding – requiring improvement	-	+++	+++	+++	+++	+++	+++	-	+++	+++	+++	-	+++
Drug addiction (including alcoholism) identified as an issue for TB patients	-	-	-	+++	-	+++	-	-	-	-	+++	-	-
<b>Solutions</b>													
Media for community education on TB-CI/reduce stigma	-	-	+++	+++	+++	-	+++	-	+++	+++	-	-	-
Proposed sustainable measures e.g. seed money for self-help groups/investment groups	-	-	-	+++	-	-	-	-	-	-	-	-	-
Unsustainable incentives were an issue <sup>†</sup> ; promote stigma <sup>§</sup> ; other patients find it unfair*	+++ †	-	+++ §	-	-	-	-	-	+++ †	+++ §	-	-	+++ <sup>*</sup>

Key:



Major barrier to TB-CI implementation



Partial barrier to TB-CI implementation



Optimal for TB-CI implementation

Clear operational guidelines on TB-CI were reported by HWs to be lacking in all 13 health facilities, despite TB national guidelines being available in most of the health facilities. On asking HWs whether TB patients brought their contacts/had their close contacts screened for TB, the response was either “*few*” or “*some*” in all the 13 FGDs. The TB register present in all TB clinics had a column for TB patients identified due to CI, however this was rarely checked. It became apparent from the HW FGDs that there was no standardized tool for ascertaining that HWs had invited TB patients to have their contacts screened and neither was there a tool that linked TB patients to their contacts, particularly at the facility. These findings were consistent with TB patient interviews and our facility observations. (Tables 4 and 6, Figure 9)

During this study period, there were active TB-CI activities conducted in selected facilities in Nairobi County in the context of programs funded by non-governmental organizations (NGOs) and 10 of the 13 facilities were participating. Training specific to TB-CI was only described in one FGD in 10 of these participating facilities, however CHWs did have tools to suggest they may have received some training. The key gap observed in this active TB-CI initiative was that despite contacts in the community being referred to the facility for screening, they did not receive any documentation that would identify them to the facility as being referred for contact investigation, making it difficult to measure the efficacy of this active TB-CI activity. In addition, a mechanism to link contacts to a particular TB patients was lacking, making it difficult to establish if all close contacts had been screened and estimate effectiveness of this strategy. (Table 6)

**Table 6: WHO-HS Matrix depicting Facility Observations, Health Worker and Key Informant Perspectives  
on Implementation of TB-CI**

HEALTH FACILITY	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII
<b>1. Leadership and governance related</b>													
1a. Clear direction [TB Program; HIV Program; CH Program]	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*
1b. Support from experts	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
1c. Support from health facility leaders	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>2. Service delivery related</b>													
2a. Availability of operational guidelines for TB-CI	No	No	No	No	No	No	No	No	No	No	No	No	No
2b. TB patients agreeing to bring/inform contacts	Few	Few	Few	Some	Few	Some	Few	Few	Some	Few	Few	Some	Few
2c. Turnaround time optimal	No	No	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
2d. Integration of services [i. HIV; ii. Nutrition; iii. Other]	i*	i, ii	i, ii	i, ii, iii	i, ii	i, ii, iii	i, ii	i, ii	i, ii, iii	i, ii	i, ii	i, ii, iii	i, ii
2e. Focus on ALL PTB patients (NOT only smear positive TB)	No	No	Yes	No	No	No	Yes	Yes	No	No	No	Yes	Yes
2f. Good ventilation & lighting in TB* waiting bays	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No	No
<b>3. Supplies and products related</b>													
3a. Sputum containers [*no lab]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No*	No*	Yes	Yes	Yes	Yes
3b. Microscopy/Gene Xpert reagents [*no lab; *stock-outs]	Yes*	Yes*	Yes	Yes	Yes	Yes	Yes	No*	No*	Yes	Yes	Yes	Yes
3c. HIV test kits [*occasional stock-outs]	Yes	Yes	Yes	Yes	Yes*	Yes	Yes	Yes*	Yes*	Yes*	Yes*	Yes	Yes
3d. Chest radiography	Yes	Yes	No	No	No	No	No	No	Yes	No	No	No	No
3e. TB drugs available [*but occasional stock-outs]	Yes	Yes	Yes*	Yes*	Yes*	Yes	Yes*	Yes*	Yes*	Yes*	Yes*	Yes	Yes
3f. Isoniazid prophylaxis [i. Infants; ii. Children; iii. HIV]	i*	i*	ii, iii	ii, iii	ii, iii	iii*	iii*	ii, iii	ii, iii	iii*	ii, iii	ii, iii	ii, iii
3g. Supplementary feeds [*occasional stock-outs]	No	Yes	Yes	Yes	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes*	Yes	Yes*
<b>4. Health system financing related</b>													
4a. Presence of central budget support for TB-CI	No	No	No	No	No	No	No	No	No	No	No	No	No
4b. Partner support for TB-CI activities	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
<b>5. Health information system related</b>													
5a. Monitoring and supervision by NLTDP and NASCOP	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5b. Standard report forms/registers for TB-CI by NLTDP	No	No	No	No	No	No	No	No	No	No	No	No	No
5c. TB contact investigation forms provided by an NGO	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes*	Yes*	Yes*	No	Yes*

HEALTH FACILITY	I	II	III	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII
<b>6. Health workforce related</b>													
6a. Staff to monitor and evaluate TB-CI at national level	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6b. Training of HCWs leading to confidence in TB-CI	No	No	Yes*	No	No	No	No	No	No	No	No	No	No
6c. Sufficient workload for HCWs	No	No	No	No	No	No	Yes	No	Yes	Yes	No	No	No
6d. Adequate CHW remuneration [*agency assistance]	N/A	No	No*	No*	No*	No*	No*	No*	No*	No*	No*	No	No
6e. Staff cohesion/team work & Passion for work done	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Key:



Major barrier to TB-CI implementation



Partial barrier to TB-CI implementation



Optimal for TB-CI implementation

Lack of sustainable funding for TB-CI activities was reported. An inner will to serve was the driving force for most CHWs who were essentially volunteers. Supervision of TB activities was done in all the facilities. Although TB-CI specific trainings were not conducted, some HWs reported attending general TB trainings including updates on paediatric TB, and IPT training. HW confidence regarding TB-CI was only reported in one FGD. Some HWs complained they did not receive feedback from their colleagues and sometimes this lack of knowledge in current practice was used to avoid working in the TB clinic. National roll-out of IPT also occurred during this study period. In most of the TB clinics (8/13), HWs reported that they provided IPT to asymptomatic contacts under the age of 5 years and HIV positive individuals. In three of the 13 facilities, IPT was only provided in HIV clinics and not TB clinics. This was largely due to limited drug stocks. In two of 13 facilities, IPT was only provided to infants of TB sputum positive mothers who were breastfeeding. There were gaps in HW knowledge such as either not providing IPT to other children under 5 years or requiring children to have chest radiographs to make the decision on IPT resulted in sub-optimal practice. (Table 4 and 6)

Other health system barriers reported by HWs included large workloads (10/13), poor integration of HIV, nutritional, psychosocial and other medical services (9/13), focus on only smear positive TB (8/13), general TB drug stock-outs (8/13), HIV kit stock-outs (5/13), long turn-around times for TB results leading to diagnostic delays (5/13), poor ventilation and lighting (5/13), and unavailability of sputum microscopy (2/13). Once weekly TB clinics and lack of chest radiography was brought up in few FGDs, but we observed that this occurred in most primary health facilities. In addition to serving the wider community, these TB clinics were also housed in health facilities serving unique populations of patients including prisoners, refugees, drug addicts, patients with psychiatric comorbidities highlighting the importance of multi-disciplinary team approaches when designing TB-CI programs. (Table 4 and 5, Figure 9)

### *Facilitators and Proposed Solutions*

The main strength reported in all 13 FGDs was HW team work and passion for their work. Moreover, HWs ability to keep matters confidential and not disclosing to others was also noted to be one of the main facilitators. Maternity TB screening and TB clinic opening hours as early as 6:30 AM was reported in one primary facility.

Key solutions health workers proposed to improve TB-CI included capacity building specific to TB-CI. In-house continuous medical education was proposed to provide feedback to HWs rather than out of station trainings with limited slots. HWs also proposed sustainable funding initiatives for TB-CI activities particularly remuneration and transport allowances for CHWs who were volunteers, provision of airtime for mobile phone communication, and the availability of commodities in the facility. Government-led health activities previously managed at the national level were reported to be better in comparison to the current decentralized system. Community education on TB transmission and TB-CI through the media, engaging leaders and community as used in recent successful polio vaccination campaigns were suggested. Additionally, HWs came up with solutions to improve infection prevention and control (IPC), some of which they could implement themselves despite structural barriers. (Table 6)



## ***Key Informants' Perspective of the Patients, Community and the Health System***

### ***Barriers to TB Contact Investigation***

All key informants acknowledged that there was a national TB register which had a section for referral of the newly diagnosed TB patient to the clinic. However, the key barrier to TB-CI described by key informants was a lack of clear operational guidelines specific to TB-CI, a result similar to findings that emerged from HW FGDs. There were no standard tools for documentation and linkage of index TB patients to their contacts, and the referral system was poor and lacked a feedback loop. It was noted that not only did the patients suffer, but also HWs were under a lot of stress at the workplace. Although lack of funding was described by HWs as a barrier to TB-CI, some experts felt that the actual barrier was in fund allocation. The issue regarding lack of CHW remuneration also emerged in expert interviews. All key informants reported that community health was integral in TB-CI. Patients' living dynamics and mobility were also appreciated by key informants to be important considerations in TB-CI activities. Similar to all HW FGDs as well as in some patient interviews, all experts identified that TB stigma was a barrier to TB-CI. (Table 4 and 5)

### ***Facilitators and Proposed Solutions***

Despite these barriers, experts acknowledged strengths in the health system, which included strong multi-sectoral government leadership, supportive structures for service delivery and supervision in the TB, HIV and Community Health programs, as well as a resilient health workforce. Key solutions proposed by stakeholders included a robust health information system to support TB-CI that is user-friendly, efficient and interoperable. Experts felt that it was imperative that health management information systems (HMIS) made it easy for patients, HWs and the health services. According to the key informants, it was important for data to be useful in decision making as well as provision of feedback to those collecting the primary data. Experts recognized the national TB program's innovative electronic surveillance and management system, TIBU, and

suggested the use of telephone reminders for contacts to encourage them to come for TB screening. Other innovative technology suggested for TB-CI included data visualization and geographic information systems. Experts explained that a national unique patient identifier (NUPI) was essential to avoid duplication of records and allow for linkage of data. It was acknowledged that the government was taking the lead in this process.

Additional suggestions on how value could be created for TB patients as well as contacts in the context of TB-CI were provided by key informants. Provision of holistic packages for contacts was proposed by most key informants. Beyond seizing the opportunity of contacts presenting at the TB clinic, experts also identified inpatient, outpatient, general clinics, antenatal, mother and child health clinics and wider health services as opportunities for TB contact screening. Fast-tracked care for TB patients and contacts was also put forward. Provision of alternatives was already demonstrated in some facilities when patients reported that they were given sputum containers for those contacts who could not come to the facility. In addition, experts proposed fast-tracked care for contacts undergoing screening as well as infection control measure instituted in health facilities to avoid TB infection.

Key informants proposed synergistic facility and community health strategies in TB-CI that were customized to diverse contexts and backed by sustainable funding. In addition, widespread community awareness that did not propagate TB stigma was described. Sustainable government-led funding for infrastructure and an adequate health workforce that is trained to deliver optimized TB-CI services was deemed imperative. Poverty was recognized to be an underlying barrier to care and policymakers described the importance of social protection schemes to avert catastrophic costs. All key informants expressed the importance of TB-CI and emphasized its role in the elimination of TB.

## **SELECTED QUALITATIVE RESEARCH QUOTES**

In this section selected quotes highlighting themes and sub-themes synthesized from patient, health worker and key informant perspectives are presented. These capture the actual voices of stakeholders involved in TB care in Nairobi County and provide the authentic basis of findings from this study.

### ***Patient Perspectives***

Facilitators identified in these selected quotes include: a) health worker invitation, knowledge, kindness/positive attitude, b) availability of commodities e.g. medication for treatment and prevention, c) availability of services e.g. testing and imaging, d) patient education, e) close proximity to health facility, f) phone calls, g) home visits, h) family support, i) self-efficacy, j) screening of close contacts at health facilities near to them despite changing living dynamics with index TB patients and k) posters on TB treatment. Emerging barriers captured from the selected quotes include: a) working contacts not able to get opportunities away from work when not 'sick'; b) delays in bringing contacts e.g. waiting for them to become symptomatic, or index TB patients waiting to get better so as to bring their contacts for screening, c) poor health worker knowledge/action – lack of patient invitation, lack of provision of IPT to eligible patients, no home visits as indicated, d) TB-related stigma and e) sub-optimal community awareness. Opportunities identified include: a) sputum containers to take home for working contacts; b) testing close contacts conveniently present at the health facility, and contacts of hospitalized patients; c) better health worker probing techniques for close contacts and d) TB media campaigns. Sub-themes that emerged were around family dynamics, occupational risks and nutrition.

**[Index 21]:** *“I live with my brother. He is 23 years old. No, there is no one else who lives in our house. I don’t have a family. I don’t have a wife. I used to be married, and they went up country. No, I don’t visit them. Yes, there is a doctor who asked him (my brother) to be checked for TB,*

*and he came. He came because I could have infected him, just in case. He is the one who brought me to hospital. So the doctor also told him to get tested. I don't think he could have refused to be tested. If you are sick, it's a must you are checked. You can't be afraid, it's a disease or something. It'll be you who suffers. I also told him to get tested. In fact, he (my brother) himself made the decision to be tested. It (TB) is advertised in the posters that if you've been coughing for 3 weeks, see the doctor. No (he wasn't coughing), just doubting himself. He is a driver. He asked for permission from work and came to hospital."*

**[Index 24]:** *"I only have these two children. I don't have a husband. Yes, the doctor told me to bring them so that they are tested if they have TB. This one is 9 years and this other one is two. They were tested in this facility. None of them has TB. The younger one was given medicine to prevent TB. I brought my children to be tested for TB because we live in the same house and I sleep with them, and now I could have transmitted the TB to them. So I brought them to be tested, and if they were found to have TB they could take medicine. I like this clinic because it's close to where I live. I don't see any barriers for not having my children tested for TB."*

**[Index 5]:** *"For now, I live with my brother. My children are upcountry. Yes, here in Facility X, I was told to bring my brother for testing. Yes, the Community Health Worker explained to me. Sometimes they call us on phone, or they visit us at home. He explained to me that it is good they know where I live, they took our phone numbers so that in case they came and missed me, he would call me just to know how I'm fairing, and to visit us to know how the place we live in is like, and how the person we live with is like, many things about the home and living. He asked me if my brother can come for testing, because he may perhaps also have TB or not. He gave me health advice about good hygiene and living. My brother came. They even have his phone number. You know perhaps I could have infected him with TB in another way, you can't know. Even by his coming to the facility, he got good health advice on how to cook for me, you know*

*there is that balanced diet, not just cooking, if it is utensils, you clean well, I think you understand. The health advice the community health worker gave me helped. For me, I see it is good he (the CHW) came home because some things need you to be clean if you are taking care of someone who is sick, then the cooking, it is not a must that someone eats a lot of food I don't know what, eat even if it is little but balanced because those drugs you take are strong, so if you eat something balanced it helps but it is not a must let's say for example you put a big piece of 'ugali' and only two pieces of vegetables. My brother came because he decided to, but also because he loves me and it's also good that he came to learn more... They found that he (my brother) was ok. Yes, but he did not get tired of taking care of me. But as of now, I can do everything for myself."*

**[Index 6]:** *"Yes, I have (a family, a husband and children). Three (children) – 10 years, 8 years and 3 years. Yes, the doctors here invited me to have my people tested for TB. My husband didn't come. I brought this child, the youngest one. Yes, this one who is three years. When I came, I was given a container for my husband to collect his sputum, and also for the children. His (my husband's) he removed (sputum) I returned it (to the facility) and he was found to be negative. Even these two children have never coughed so they did not remove sputum. And this little one (3 year old) I was given medicine and told it is for preventing him (from getting TB). I was told he will take until the same time I will finish, for six months. I brought the children because I stay with them, I sleep with them, I breastfeed him, so I was told there was a possibility they could have gotten (TB) so it was good I bring him. I did not find it difficult to bring him, because the treatment comes from the doctor, therefore I could not stay with him and I have been told to bring him. I could not stay at home without knowing his status. I even found it very good when they told me to bring him therefore I did not hesitate to bring him. For my husband, his reason for not coming was because he works, so getting that chance is difficult. So I came and explained to the doctor and he told me that there was no problem, as long as he brings his sputum. So what made him not come (to the facility) was work. When I told my husband, he did not hesitate, he didn't have*

*any problem, in fact he was happy because in the beginning we don't know why I was coughing despite being given medicine, but when I found out what the problem was, and I was explained what to do and to bring them (my family), I did not find it difficult. Even him (my husband), he did not find it difficult. He was happy. The only barrier for him was work, if he was free, he would have come. For the 10 year old and the 8 year old, I was only told to bring their sputum, and because they did not produce any sputum, now I saw even if I bring them and I was not told to bring them, perhaps the sputum would still not come out even when we reached the hospital. If the doctor had told me to bring them even if they were not coughing, I would not have hesitated to bring them. Even this one who is 3 years old, I didn't take him to school that day, I brought him because I was told to bring him. I stopped him from going to school that day because I explained to them (the teachers) that the doctor had asked for him. Let's just say, the doctor is of higher priority, or health is more important than education."*

**[Index 30]:** *"(I started taking my TB drugs) about four days ago. The reason being my daughter got admitted (in hospital) with the same thing. So I didn't know if I gave it to her. In January, she started coughing. I took her again to a chemist, got some drugs but what alarmed me is the weight loss. She was 28 (kilos) and all of a sudden went to 18 and then to 16. By the time we were bringing her to hospital she was really bad so they admitted her and treated her for 15 days. She has been on drugs which she is actually doing very well and responding well. So currently we are taking the anti-TBs. Yes, they found my TB when she came to the ward. They (the doctors) told me: 'You also have to do an X-ray' and I said: 'It is okay'. So they sent me for the X-ray, it came out positive. I am a mother of three. I have a fourteen year old, I have a nine and I have a six. I live with them in the same house so currently I think tomorrow before we get discharged the others have to come and get X-rays or tested if actually we have given it to them and even if not they is something they call anti-TB drugs which you have to take to prevent it from generating in them because the bacteria grow slowly without you knowing and with time it just hits you."*

**[Index 41]:** *“I live with my husband and two children. They (children) are five, and two and half (years old). The only thing the doctor told me then was to take my drugs well for six months. I was not explained anything regarding my family. Shortly thereafter, my youngest child was infected. He just started coughing coughing, no fever, let’s say about a month ago. He was started on medication yesterday after he was found to have TB on the chest X-ray. The child was coughing... That’s when I started thinking, perhaps I could have infected him... I knew for myself that it (TB) is infectious, but I wasn’t taught. If my child was not coughing, I would not have thought of bringing my family. This week is when the doctors asked me if there is any family member of mine who is coughing and they asked me to bring him (my youngest). I was told to have him give a sputum sample but he was unable. That’s when the chest X-ray was taken. I haven’t brought my other child who is five years yet. Today, I didn’t bring him because I didn’t want the young one to be left alone when I came to the clinic. He has closed school, so I wanted him to keep the young one busy, they play play. We live close by. I plan to bring him when I come to be tested for my second sputum. I’m about to complete 2 months on TB treatment. Then I’ll have a check up to assess my treatment. So on Monday when I come, I’ll come with him (the five year old).”*

**[Index 8]:** *“I asked them (my family living in Mombasa) to go for testing for both HIV and TB. Yes, they (the doctors at the TB clinic) told me, in fact several times (to tell my family to get tested). I talked to Dr Elizabeth. She talks to us, she advises us and the last time I came here, last month, I was asked to give the names and the hospital they went for testing including the telephone number of my wife. After two weeks again I was called by another doctor here. They asked me to confirm if the children were tested and their current status. Yes, testing for TB, but I told them they were tested. The doctor advised me that it is better for the family to be tested because it (TB) is an infectious disease, so I told them to go for testing. All of them went for testing but all turned to be negative. In fact that is why I am avoiding that place. I don’t want to cause more harm. For*

*me, no (there are no barriers) because you know for infectious diseases, they are very dangerous. It (TB) can spread quickly and at long last you can have the whole family infected which will be a burden now, instead of having one or two being infected or undergoing treatment. If you fail to take precautions, now the whole family will be destroyed. Me I don't find any problem with that (my family being tested) because I love them and I need them. I want them to survive."*

**[Index 32]:** *"I have four children, (first born) is 13 years, (second born) is 11 years, (third born) is nine years (and the fourth born) is three and a half months. (No) I don't live with my husband. We are separated. I live with my mother and this small child. Yes, here in Facility X, I was told to bring my mother and child to be checked for TB. I brought them for the benefit of their health. They were tested and found to be fine. But for this small child I was given medicine for prevention. I was told he will continue to use it (the medicine) for six months. No (there was no barrier for me). I wanted them to come and see if they are sick and be treated. Here the doctors are good. I can say, perhaps my mother saw the changes that happened to my health and so she saw it was good she came. Like three weeks (of taking medicine is when she saw the changes) When she came, her sputum was tested. She was also tested for the virus (HIV). Yes, they (the doctors) took her weight."*

**[Index 30]** *"When I get sick and I am getting medication, I like asking questions; Why? Where does it come from? What do these drugs do? So next time something like that happens, I already know what are you supposed to do and what are you supposed to take. In 2007 (when I got TB for the first time).... I really learnt a lot. If I get an infection I learn totally about it so next time I know how to deal with it. I ask the doctor and the nurse. I befriend the doctor very much, and find out why... My sisters because they all always come and see us. They also have to come and get tested and apparently my nephew about four months ago also contracted TB from somewhere else and was brought here, so I am thinking it is wide spread thing."*



**[Index 18]:** *"I have had good service. They are really kind and nice. They give me my medicines. Sometimes I propose they give me two weeks medication because of exams and they agree. It has been quite good. They thought it is easier and better for me if I picked them from the school (clinic) but I think I prefer going there (Facility X) since I am home on Wednesday."*

**[Index 19]:** *"When you come here you get your services, you are treated well."*

**[Index 22]:** *"From the time I started receiving my care at this facility, I have never come across a bad person (HW). They talk to me like they are coaxing me."*

**[Index 33]:** *"They handle me in a good way when I come here. They welcome me in a very nice way."*

**[Index 51]:** *"The staff have been good."*

**[Index 52]:** *"The treatment is good."*

**[Index 40]:** *"You see, like the day I found out I have TB, I had been treated by many many people, but when the doctor here gave me the TB medication, on the third day my body had changed because if you take something and it's not working, it means you are taking something that's not helping you. I only took (the medication) and on the third day I felt at least there was a change. The services are good."*

**[Index 39]:** *"Here (in this clinic) there are no problems because I have been helped a lot. I get flour and vitamins. Here there are no problems. You just come and find the doctor. You don't*

*queue. I'm given my medicine, I take there and then I'm given others for four days, the fifth day I come take other drugs. Here there are no problems."*

**[Index 40]:** *"I love the way you (HWs) talk. You are free and you don't have that thing we call 'stigma'. You are fine, and also it's nice when one visits. It's very nice. Don't add anything and also don't take anything down. Also it's (the clinic) is 24 hours. Yeah! When one comes it's open. There's not time you'll come and just stand there. It's very nice."*

**[Index 24]:** *"I love this clinic because it very close to where I live."*

**[Index 52]:** *"I was told that if I hear anyone (my close contacts) coughing, if I see anyone getting sick sick like the way I was sick, I bring them (to the facility). I have already brought two people now: my sister and thereafter another young man we used to live in the same plot and used to hang out together in the stage... we used to drink alcohol together and he got sick. Yes, I brought them. One started the TB medication, took them for 2 months and stopped. I wanted to bring my daughter who has a small child, but she refuses refuses. She says there's no place that's hurting her. We live in the same house. [When probed to understand what other barriers were present] You know, that time I could not walk so I could not bring them, but because now I'm recovering and getting better, I can now bring them. You know they are big people. It's refusing that they are refusing. [When probed whether HWs had visited her at home] No, none of the HWs have come home, except those for polio."*

**[Index 18]:** *"I told my aunt and she has small kids. There is one who is three or four and one is two years. I told her to you know, go to hospital. The little one, the two year old one was a bit sick that one was checked... Yeah. Then there was nothing...No, the little one was not put on any medicine for prevention."*

**Index 10]:** *“No, I wasn’t explained about how TB is transmitted. No, I wasn’t given any health advice on TB. They just tested me for HIV. No, they didn’t tell me anything else.”*

**[Index 26]:** *“They (CHWs) never came (home). I think it was like last month [7<sup>th</sup> month of MDR treatment] he was still telling me, ‘Now we will be coming with that lady.’ So I was like, ‘You started telling me in October...November, December.’ So I told him, ‘I don’t think I’m really so important. You have taken so much time.’ I think the moment you have brought those people, I think that is the point they need to do the test instead of postponing it, because I don’t think it is a long process. I think that is the point they should do it. Like now my friends are not even available, so for you to tell them to take an off from work or to miss their lessons and they were there (at the clinic with me). And like my mum she is now on retirement, she went on retirement in March, so any time soon she will not be here around in Nairobi, so you don’t expect her to come like from ‘ushago’ (upcountry) to come and do a test! Anyway we are not sick. It has been a long time and we have not fallen sick. Even that psyche that they had because they can see you in that position, they have the fear so they would anything. But for now people have been a little bit relaxed.”*

**[Index 3]:** *“I live alone. I spend most of my time at work. I am mechanic in the garage. No one has ever asked me (to bring my close contacts for screening), and no one has asked me if I have a family or not. If I was sent (to bring my close contacts for TB screening), because I understand that this (TB) is airborne, I would go and tell them that: ‘I have TB and it’s good that even you when you come you are tested because I don’t know if I could have given it to someone.’ I would explain it to them and they come. But the doctor hasn’t told me so I wouldn’t know.”*

**[Index 42]:** *“Yes, in the hospital they asked me whom I live with. I think they asked me this question so that the other person comes to be tested if they have TB. I live alone. <When probed if he has a romantic friend> Yes, I have a partner. No, the doctor did not ask me to bring her. But*

*we've stayed long without meeting. Now, there's no need for her to be tested because since I was diagnosed to have TB, we have not met often. <When probed about visiting relatives and friends with children> Yes, I visit my relatives who have children. They are about 4 years old. Sometimes we spend the whole day together, sometimes a few hours, but it's not daily, because I try to prevent them from getting TB. I cover my mouth with a handkerchief when I cough."*

**[Index 23]:** *"You know women. [Laughs] Sometimes they have a problem. Obstacles. 'I don't want. You go.' And when I go, I will be by myself, something like that. The children I can take them. You know a woman is not a kid. If you like it, you can go, and if you don't, you cannot force her."*

**[Index 41]:** *The doctor also told me to bring my husband and my other child to be tested. For my husband, if he agrees, then he'll come for a check-up."*

**[Index 5]:** *"There is no barrier to TB screening for my family. An illness is an illness. Even if they are diagnosed with it (TB) they'll be treated. No, they cannot refuse to be screened. Who has the authority? It's me, and when I say something it has to be obeyed."*

**[Index 3]:** *"I went to the chemist, I explained to him how I was feeling. I did not know it was TB. I had coughed for three weeks so that's why I went to the chemist. I told him I was coughing a lot. They told me it's a common cold, gave me syrups and tablets. I took them for two week but didn't get better. I stayed one more week. The thing that made me come to this hospital is that when I returned to that chemist and explained that I was coughing blood, now that's when I was told to come to this facility because they deal with the chest. I came and explained to the doctor. He told me to take an x-ray. I took it to him. He told me to give a sputum sample, which I gave. I was told to take my results after two days. Yesterday is when I was told that I have TB, but I missed the*

doctor. I was told to come back today. They have assessed me and I have been shown how to get my drugs.”

**[Index 3]:** “You know at the garage, I was coughing until my workmates tell me: ‘Is it that you have HIV? Have you’ve walked badly or what? (Meaning: Have you slept with someone with HIV?)’ Until I was perplexed, is it that someone with HIV is the one who coughs or how does it go? You know, when someone coughs a lot it becomes a problem. Almost 3 workmates have asked me this question because I have coughed for almost one month. You ask yourself: ‘Is it true that I’m dying?’”

**[Index 7]:** “You know sometimes we are in denial. ‘That such a disease (TB) cannot get me.’ And I myself, I thought so. At first I had an argument with the doctor. ‘No it is a cough, it is a just a cough or it is pneumonia and it cannot get me. No! No! No!’ And people associate TB with many diseases, so it becomes a weird or bad disease.”

**[Index 4]:** <If I explained that it was important for you to bring your close contacts for testing what would you do, what would you say?>. “You know sometimes some things you do secretly because people think that because you have TB you have HIV. Therefore, if you tell them, they will think you are positive so you try to be private. Perhaps I would tell my sisters. I would bring my people because they are close to me and TB is said to be an air borne disease, therefore the moment you cough or spit, people will look at you a lot. I would hide a bit from my workmates. The people at work, the reason I would not bring them is because I have not told them that I have TB, because of that link (TB/HIV).

**[Index 26]:** “At Facility III, they (the HWs) would tell you to sit outside. You know, they have a tent but you don’t sit inside the tent, you sit outside. So I was thinking, why can’t they put us in their tent somewhere? So that even you, you get the shade. You don’t expect someone to sit

*outside even if sunlight helps to kill the bacteria. You cannot keep me in the sun for four or five hours to kill that bacteria. And you know someone feels so bad! And they shout at you: 'Go and sit there, go and sit there!' It is not what you tell someone, it is how you tell them. But here (Facility XIII) they talk to you well. Even if they put on the mask, and you don't understand what is going on. I have never seen anywhere masks are worn. They are like: 'Stay there!' And they make you sit in the sun. Yes, I was made to understand, but there is a way to tell somebody something."*

**[Index 36]:** *"I have a question. Let's say like now I'm taking medicine. And then I meet a guy and he loves me. I stay with him, I don't understand how it goes... and I'm taking the medicines or something. Yes (TB medicines) and it becomes hard to explain to him and it reaches a point, can I sleep with him? Yes, I was checked for HIV. That one I have been tested many times and it was negative."*

**[Index 39]:** *"This TB is transmitted if you drink something in the same cup as someone who has TB. You see alcohol, the glass in which someone with TB, if the person leaves for you that alcohol and you drink, and food if someone has TB or long nails like mine and they are dirty, and you eat something like meat that has soup, this way you get TB right there."*

**[Index 42]:** *"I have some questions. Is TB only caused in the air or can it be caused through genetics also? No, I was not explained by the doctor how TB is transmitted, but I know it's airborne. But I have never known if it can also be ...?"*

**[Index 18]:** *"I told her (my roommate) but everyone I have told (to get tested for TB), everyone I had had close contact with including my relatives at home, all of them kind of ignored. They felt like it wasn't any serious."*

**[Index 42]:** *No, the doctor did not tell me that I should bring my close contacts with signs of TB. No, that one I was not told. Signs, I think I read them there. On the poster there, before I was tested, I saw those signs. Even me, because the poster was there, I know the signs. So anytime I hear someone coughing and they feel like that, I tell them to go be tested because I know those signs.”*

**[Index 46]:** *“(The doctors here) told me how to take my drugs and then they told me that when I’m in my house, I should at least open my window so that the air can get out. And now, when I’m with my child, when I cough, I cover my mouth. And then I asked them, ‘You know I live with my sister and child.’ I asked them ‘We use the same utensils, is there a problem? The doctor told me that there is no problem because I’m taking my TB medicine. The problem is if I don’t take my medicine.”*

**[Index 34]:** *“I am a ‘matatu’ (minibus) driver. Yes, she (the nurse) told that if the vehicle has passengers, I should open the windows because of the TB. Yes. Because there needs to be good ventilation (to prevent transmission).*

**[Index 26]:** *“The moment you know one has TB that is the moment every one they are in contact with should be... because if they did the same... I think when I was in college the moment they got the lady in the cube I used to visit, at least most of us who used to be in that cube could have been screened when it was still very early. Yes people knew, her cube mates knew. So I heard she had TB and everything, and all the rumours about her having HIV and she was pregnant at the same time. For me it was like they were treating her badly, maybe because of the fear that she has HIV. So they told her don’t use our utensils, don’t use this, don’t lie on my bed. I thought it was just them being cruel. So me when I entered the cube I was very comfortable. I didn’t know much about TB. In high school if someone would cough around the corridor, we would shout, ‘TB*

*ina Tiba!* You know just for the sake of it. Not really because you know what that means, because you only hear them advertising it. So we were just making fun of it... So for me I was comfortable, I would go sit around the cube. So I think the others were more aware, that is why they kept off, but me I didn't see anything wrong."

**[Index 41]:** "I don't know when my husband will come for screening, because of work. Because you can't ask him 'When will you go?' or push a man to be tested. (He'll respond) 'Why are you pushing me to go?' Now if he decides it is. Because a man, if you push him to do something, he'll tell you: 'No! All the time you tell me to go be checked. Who has told you I'm sick?' You know men have some questions that will make you get annoyed at each other and you don't want to get annoyed at each other. So let him take himself. You know work is for a short time, your life is yours. Your life is in danger. If he decides one morning when he wakes up to come get checked, it is good for him. Sometimes it's good for HWs to visit families. When you visit a family as a whole and you talk, the head of the house will express his sentiments so that he sees what can be done for him, because he can tell you work, and you tell him something else. That's where I see you both will get a solution. There are others you can visit at least you save their lives. There are others who will say, like the way I was told to take my child to the clinic for chest xray, and initially I said 'Aah, that is something small', but that time, my child continued to suffer."

**[Index 30]:** "I am thinking there is no much campaign being done about tuberculosis or educating people. I am saying the government should do something because I am thinking tuberculosis is a...., kids of three months in the wards have tuberculosis, Why? Why is it spreading so much? Aren't people getting educated about it? What are the precautions? What do we do about it? How is this virus spread? Yes in the vehicles when someone coughs or something but I think they should come up, like in HIV there is so much campaign about it, about sex, about what, and you



*can see it is now reducing. Why can't we do something about TB because of course TB is not about sexual...it is an airborne disease."*

### ***Health Worker Perspectives***

Facilitators for TB-CI in Nairobi that emerged from HW perspectives included: a) health worker invitation and provision of health education to patients, b) close proximity to health facility, and c) team work. Among the barriers cited: a) propagation of TB and HIV stigma by the community, b) TB patients providing incorrect contact information including phone numbers and home addresses, c) lack of remuneration particularly CHWs who are volunteers, d) lack of motivation for TB-CI for HWs – no tools, no resources for phone calls and CHW transport, e) poor TB prevention control practices and infrastructure in the facilities, f) CHWs at risk of violence in the community, g) poor communities, h) lack of TB-CI specific training, i) sub-optimal HW probing techniques and knowledge on IPT, and j) 'Contacts are not sick' thus making it difficult to come to hospital. Opportunities identified by HWs included: a) creating community awareness, b) optimizing TB-CI specific HW training, c) provision of linked TB-CI tools, d) in-facility training, and e) sustainable resources led by the Ministry of Health. In addition to family dynamics, occupational risks and nutrition similar to patient perspectives, HWs also brought up the conversation of TB prevention and control, patient/community poverty and religion playing a role in stigma.

**[FGD I, Counselor]:** *"One (of the barriers) is that people don't know what causes TB so that is one key thing; people don't know the cause of TB very well. They hear of TB they have their own..., because once they come to our clinic and ask them do you know how TB is spread, they don't know so they will not expect themselves to be victims of the same so that is one of the challenges because they don't know that TB is everywhere and everybody can get it, so that is challenge number one; people are not well informed of the cause. Some will and some will not*

*(bring their contacts when we invite them to do so) because there is still that TB stigma. TB has a lot of stigma, even amongst ourselves, so majority will wait till that time that your body is weak and you just bring yourself, otherwise just a very few number will agree to bring the other relatives for investigations, very few. Stigma is still very key. (When it comes to linkages to care) linkages especially for patients with TB and HIV, they seem to stigmatise themselves because HIV has....is a condition with stigma, they feel so and so is watching me, so and so might know, but as it is, we assure them that everything is confidential. Am also going to agree, not all want to be linked to our CCC, some want to be linked outside, but you see every patient has a choice to make and we honour that.” HIV stigma was noted to be present in the community and also related to culture and religion.*

**[FGD X] <Why don't some TB patients give you the correct phone number?>**

**[Pharmacist/Psychologist]:** *“That is stigma.”* **[TB Nurse]:** *“Stigma.”* **[All]:** *“Stigma.”*

**[Pharmacist/Psychologist]:** *“Shame, fear and all that. So it leads to all those issues. Yes there is stigma because when it comes to a co-infected person with HIV/TB especially the Somali communities, they usually believe that HIV is not for the Somalis or it is not meant for Muslims. They say it is meant for Non-Muslims. So you find that when this patient is tested and turns out to be HIV positive and yet he has TB, they run out of the service because they don't believe that Somalis can be HIV positive. So that one can also make them default from the TB programme. So that is the problem that we have. But we are trying to give them health talks, we are trying to pass the information so at least a number of them nowadays are accepting.”*

**[TB Nurse]:** *“They actually become outcasts. That is what they would say is if you are found to be HIV infected...TB is a bit accepted but HIV makes you an outcast, so there is a lot of*

stigma.” **[HIV Nurse]:** “They usually attach HIV to promiscuity, so they usually say this disease is a punishment for going out of the matrimonial bed.” **[Nutritionist]:** “Some say it is a curse.”

**[FGD 7, Clinical Officer]:** “The N95 masks are supposed to be given but then, don’t you think it will show that we are proud? Because now I am talking to you, then I am wearing a mask, are you getting the idea? It is not something which is practiced and patients here will not understand. This is a slum area. The moment you present like you want to be so special, the patient will also show you that they can do without you. So in other words we need to be humble like the patients. But the room should be well ventilated, that is the flow of air...like the way this room is. The door and the window of this room is good. It is well arranged. But other rooms, the window and the door it is like they are clashing, the air is moving the other way so the air is not good.”

**[FGD XIII, CHW-1]:** “The community; we are in a slum. This is XXX, a slum and this is the only public facility which offers free services, I would say free... in quotes. Yes, for most of the people, health is not their priority. Their priority is.... **[CHW-2]:** “What will I gain? The basics. How is the housing? Do I have a house to live in? Do I have food to eat? It doesn’t matter the quality of food, for them as long as they’ve eaten and they are satisfied. So when they come and there are these lentils, flour, and oil for a specific group of people, they don’t want to understand that this is targeting the health status of a particular group. What is in their mind is: ‘These doctors have been bribed so that they give these people. They give ‘XXX’ and not ‘YYY’, they give ‘AAA’ and not ‘BBB’. So then they don’t see it as a treatment, they look at it that you have been paid something. **[Nurse-2]:** “If you are given something...”. **[Nurse-1]:** “Like the other day we had some 20 jerricans here and the hospital was almost been brought down because

of... , these jerricans for fetching water, we got them as a result of cholera outbreak and all that....so we were giving the patients with cholera, but this hospital was almost burnt down. **[TB Coordinator]:** “Who was being given?” **[Nurse-1]:** “The households that have had direct contact with cholera cases. Now the community could not understand, we are giving those people who were affected by cholera. Then they were wondering, ‘Why do you give this one a container but you don’t give me?’ And that is just a container, not food. Can you imagine if it was food? Here, we’ll be beaten! Actually we had to call the security. This hospital was being broken, even this....just the other day.” **[CHW-1]:** “They entered the gate, even some glasses of the doors got broken. Nurse-1: So you can imagine food. That is just a container!” **[Nurse-1]:** “of water, so what about food? Yes we keep the containers in the CCC now.” **[Nutritionist]:** “You find....like today I had a patient who I gave some two bags of flour. So the next patient who came in asked, ‘How come me I’m not being given?’ Because he knows the problem of that person is the same as his, how come he’s not being given? He doesn’t want to know about the BMI.” **[CHW-2]:** “So education level is so down, the economic status of this community is so low. All these major problems, socioeconomic status is down so when the patient comes, they don’t see that that one has TB and that the reason, even if you explain, they look at you with an eye of ‘No. They are not satisfied (with that explanation).’ So those are the challenges.”

**[FGD II, Clinical Officer]:** *“We give them health education and then we tell them how the TB is transmitted, so when they know how it is transmitted, and then we inform them that even those people you are staying with in the house they should also be tested for TB. So they bring them after the health education and then they have sense on how TB is transmitted. For the contacts, no often we don’t indicate it anywhere. Because this is verbal, where you talk to the patient and just explain to them the risk of transmission to the people they live with. So we don’t*

*really indicate it anywhere that we have asked them to bring in their patient or rather to bring in their relatives or persons they stay with.”*

**[FGD VII, Clinical Officer]:** *“So you are to advise TB patients to tell their close contacts to come for screening. Those who are able to remove the sputum, they are screened. Those who are not able, we send them for other investigations in ‘a secondary health facility’. In the TB register, there is no provision for that (indicating that the TB patient came with their particular contacts) and I tend to think that is a good recommendation if at all you will recommend to the government. The tool that we have is the treatment supporter, but do we have any other that is written the contacts? We don’t have. That is our own initiative to look for the contacts. It is not like a tool that is there that you will have to fill that there is this contact.”* **[TB Nurse]:** *“What I see is there is a guideline, but the tool for that is the one that is not there for contacts.”* **[HIV Counselor]:** *“We don’t have a place where we register that you have seen this contact and you have done one two three. We don’t have that.”* **[Clinical Officer]:** *“But still the place where that one can now fit is in the isoniazid register. The register has somewhere you tick whether it is a contact, may be the person could be having HIV or... Those are the things in the register. But it is a new tool. A register which was provided that we are now using. But otherwise in the TB clinic in the TB card there is no where it is written contacts whether they have been traced or whether they have been tested.”*

**[FGD 7, HIV Counselor]:** *“Actually I must say at our facility we are blessed because we have ‘an NGO’. ‘The NGO’ is our partner and it does a lot of that (assists with administration costs at the facility). We really appreciate what they are doing. When things are thick, they can also provide money for credit (airtime) because the way the government works it is not easy to ... When it comes to money wise, there has never been a problem. The HWs here have phones*

*and they communicate so well with the 'NGO' people and whoever you want to talk to. Even the TB Clinic, anyone can use the phone to follow up on patients."*

**[FGD VII, Nurse in Charge]:** *"Initially CHWs were given something like a token to motivate them because they are giving themselves and they do a lot of work. Up to last year, the partners were very active. But since early this year, most of the partners have withdrawn, others have terminated. But purely they (CHWs) are doing good positive work as much as there is nobody paying them, but out of the concept of 'they have volunteered to work'. They are still going on and though they have met a lot of challenge, I give them a chance to come to my office and listen to them. So I listen, we share and I guide, because they are doing volunteer work purely. The only few who are being supported by one or two partners are very few. It is actually cutting across the country. So 90% of them are doing volunteer work, only 10% are being supported by being given a token of may be 20,000. So that's sacrificing." [TB Coordinator]:* *"Like in TB, now when they do contact tracing, for all the smear positive, for each patient she visits, she gets 800/= and also for defaulters or those who have missed coming for treatments, so they trace patients. There are some forms they fill and then there is a partner who takes care of that. Now with the sputum transport or also culture, they get 400/= for transport." <Apart from money, what makes you get up every morning and do this job?> [CHW]:* *"I had an agreement with my God. I woke up and decided that I will serve his people, and I started that way."* It was recognized that there were staff shortages and funds to communicate with patients was largely donor driven.

**[FGD VIII, Nurse in Charge]:** *"Sometimes there are challenges. You can find that sometimes we normally have shortages of staff so you have to make effort to look for them and people with this knowledge are very rare so sometimes when our clinician is not there or our senior*

nurse is not around we have a problem so we have few people who are trained on or who have thorough knowledge on HIV and TB so we still need to train more people on that area. The number is not enough and also sometimes we also have problems with the linkage but that one we have managed because we have meetings with them or the group and try to make them understand to cooperate so that the patients are linked well and they get the care they need. Basically those are some of the challenges. With the communication as we have said whether it is left to the office we assign, but because now we have a partner it is easier but I don't think the partner will be there for long time so we should also look for our ways to solve our problems. With the HCCF which the government provides, we have tried to... We are making a plan to set aside some money for this kind of exercise; communication and for the credit (airtime) and also to facilitate for these community health workers at times, as we have said somebody could be in 'another area' and maybe the community health worker would like to follow or to trace the defaulters. At times it is hard, but we have some little cash to facilitate that. The plans are that we will set some money aside for that if the government is going to improve on the amount."

**[FGD XIII, TB Coordinator]:** "Sometimes we train somebody like 'the TB Nurse-1' and she doesn't come and give the feedback or doesn't come and tell the others about this, this and this meaning. If 'the TB Nurse-1' is not in today, 'TB Nurse-2' can't work. So, that is one of the challenges that we have. The other challenge, is 'TB Nurse-1' has been trained, 'Nurse-3' is not trained, so if 'Nurse-3' is requested to work in the TB room, she will say: 'That's for 'the TB-Nurse-1/2. There I'll get TB'." <Has this happened here?> **[All]:** "Yes it has." **[Nutritionist]:** "I don't want to go there, I'll..." **[TB Coordinator]:** "I have not 'eaten chicken'?" **[Nutritionist]:** "They have not gone to 'China.'" **[TB Coordinator]:** "They have not gone for training, because the training comes with chicken" **[TB Nurse-1]:** "She is saying that because she didn't go to Clarion Hotel." **[TB-Nurse-2]:** "That one I didn't know." **[TB Coordinator]:** "Then it is also

*attitude.” [TB Nurse-1]: “But it is individuals.” [TB Nurse-2]: “But you know you cannot get TB because you work in a TB clinic, especially if you practice IPC. Not everybody (has this attitude), just some, so probably that is also one of the challenges that affects us.” [CHW-1]: “And you can find that the person who is telling you like that, they have been invited to a training, and they have declined to go. So it all boils down to the attitude that you will have.” [TB Coordinator]: “And actually that is one of the challenges that we also have. As the sub county coordinators, we invite you for a training. Probably you have been told you will get 25 slots, you miss out, you don’t tell us you are not coming, so the slot is blank and getting some of these slots also becomes a challenge. You know sometimes, we call you over and over again so that you tell us if are you coming or you are not coming so that we give that chance to someone else or another facility.”*

**[FGD II, TB Clinical Officer]:** *“I would be more concerned with a mother may be who is lactating for example and she is diagnosed with smear positive TB, then I would want to bring in their child to investigate them and find out whether they are infected and if they are not infected I would want them to be put on isoniazid prophylaxis so as to prevent them from getting the infection. At least they are the major ones that I would really want to bring. For the rest of the relatives you know now this will depend on the individual when you talk to the patient and you have counselled them and you have given them the health education so depending on how they view whether this is important then they will advise their relatives to come along. We have seen a few bring their relatives along actually because they have understood the whole concept but not many, I would say that majority of them don’t do that, it is a very small number that would respond to that aspect.”*



**[FGD V, CHW]:** *“One challenge especially for the kids is that the community cannot afford so you send them for that x ray, they disappear and once you send them for the chest x ray you will not start them on IPT until they bring the chest x ray so it is a challenge because if they are treated free, maybe if the x ray is free at Facility II (a secondary referral facility) they could go, but if are to pay some charges they don’t go.”*

**[FGD X, TB Nurse]:** *“I think we should work closely with community leaders like the sheikh and also the radio (local FM channel) and....”* **[CCC Nurse]:** *“Even the television (local TV channel) because that is what they watch. [TB Nurse]:* *So what we do, is when we have the health talks, we produce information in Somali and Kiswahili, and the same is going to be aired on TV and radios, because it doesn’t take much time to air the same using these media. Like in TV, the issue of crowding and ventilation, it can be taken as an important factor by the people.”* **[HIV Counselor]:** *“We also have a phone (from our partner). So we tell the TB patients: ‘In case of any challenges, anything you are facing, if you cannot come to us just call. Yea, we are able to give the solution on the phone, if you feel you are not able to come.’”* **[CCC Nurse]:** *“That is what I am basically saying, the TB sector must borrow this from their colleagues and do the campaigns on health and maybe use the same people (as they did for the recent polio campaign we participated in) so that awareness can be done. And they go household to household, so they are very organized. And they can reach out the information to the grass root so that is what we used to enlarge...”* **[Nutritionist]:** *“Like the way we do medical camps. We can just say that this time round, we will be screening for TB.”* **[CCC Nurse]:** *“Either we can use the leaders or go to households. We have sheikhs, opinion leaders, TVs, the campaigns; use a way that we can reach the community.”*

**[FGD V, CHW]:** *“First it is the policy of the ministry of health. I think that one can be sustainable, instead of waiting for the donors to provide. Like the way they (MOH) do in immunization. Yes it (immunization) is ours and they know it must be there. But if it is from donors, it goes with the budget, priorities.... I think previously (before devolution) it was better but you see nowadays even the NGOs they are not ready to come in. And the NGOs are not sustainable.”* Despite incentives being recognized to be effective, HWs felt they needed to be sustainable.

**[FGD II]:** *<What are your thoughts on providing monetary or non-monetary (airtime, voucher to the kiosk to buy milk or bread, transport) incentives to patients so that they bring their contacts for screening?>* **[FGD I, HIV Counsellor]:** *“Is it sustainable? But I think it is not...for patients.... Sustainability becomes an issue. You will give for one month or two months, and then may be for third month it is not there, what will you answer?”* **[TB Nurse]:** *“Humanly speaking that is the best motivation ever in this life whether it is monetary or whatever it is but the challenge is sustainability, for how long are we going to do this and shall we sustain it so that is why now it can actually not work.”* **[HIV Counsellor]:** *“It is not practical because we have had studies like X and Y which involved counselling for discordant couples. They were being given reimbursement and they used to get very many couples. They come from all over, they come from upcountry, and they are given fare back and all that. And the study did really well. But then it comes to a point it is finished, so where do they go? They don’t come of course. The time there was money things were doing well. People were coming and there was good care.”*

**[FGD VI, Nurse-in-charge]:** *“When people are not sick, you don’t expect them to come to the hospital. But remember at the time they have one of them of their own getting sick, they are very anxious and they participate very positively. At that time when we get contact to them, we teach about the signs and symptoms of TB. Even though they may not come back, but they will*

*watch out for signs and symptoms of TB. And that is why there are those that will come back. And indeed you will find them having TB because they will say: 'We came here, by then we didn't have any signs of TB, but with time we have started seeing signs and symptoms which may be TB or not.' So we do investigation, we do screening and some of them don't have TB. That makes us know that they are watching. But sometimes they have come back and we have found that they have TB. So I find that education session even though they may not come back...others may completely never come back, but the fact that we have had people come back and say: 'We are connected to so and so and we want to be tested again.' or 'We want to be screened again.' that means they are also having an impact. "*

**[Clinical Officer]:** *"What I would like to say, for us to deal with TB, we need to do what we can to preventive infection amongst ourselves. Like now, you see the ventilation in our place. The place is covered... The waiting room, patients are stocked there. If you have ever come there, patients are many and it is covered. There is no open area. You see, that is a very good place where the patients infect each other. You see the way it is dark. We were wishing there is an idea of changing the TB clinic. In the TB clinic the patients to be waiting on this side rather than sitting here and infecting each other. Are you getting the idea? So that one in other words...you are going to lower the rate of TB transmission itself. Rather than a patient coming with a flu, and getting TB out of the hospital. **[Lab technologist]:** "We normally use the 95 mask. We have a hood and also some small papers to test the flow of air." **[Nurse in Charge]:** "If it was possible, we would have an incinerator because those things (the sputum slides and other wastes) are being packed here and burnt." **[Lab]:** "Even have the safety cabinets." **[Clinical Officer]:** "But you know, changing the government structure is a process. This hospital was constructed by the engineer, so we cannot even fix a window. You cannot. This is a government property, so what you can do is change the direction of flow of patients. Any patient with cough*

*is supposed to be triaged first and fast tracked so that they can be seen, so that they get out of the crowd instead of transmitting the disease. And the patient who is going to the lab to be tested for suspected TB, I think they are supposed to wait outside. Away from children, from the other side (outside) rather than sitting here and waiting while they are coughing. And the TB clinic starts from the end so that they cannot come and queue there. So I tend to think that will at least reduce the risk of transmission, but the structure we have no control.”*

**[TB Coordinator]:** *Because going forward open training will not be the main thing and CMEs will be much easier in the facilities. Because you realise when you came here you watched a very big number of people who were trained rather than invite one to a hotel.*

**[Nurse in Charge]:** *“So the CME approach is better.”* **[TB Nurse-1]:** *However the one who is invited, that person should come and give a feedback, so that anybody who is in contact with that forum or whichever service you have been trained on, then provide. And anybody who has been updated on that, it is also important to do that.”*

### **Key Informant Perspectives**

Facilitators for TB-CI in Nairobi that emerged from key informant interviews included: a) availability of a national TB register, b) policy guideline stipulating health worker invitation, c) general TB training for health workers and d) structures for supervision. Barriers cited included: a) lack of standard operating procedures specific to TB-CI, b) tools not linked and inefficient, c) working contacts not able to get opportunities away from work when not ‘sick’; d) delays in bringing contacts e.g. waiting for them to become symptomatic so as to bring their contacts for screening, e) poor health worker knowledge/action – lack of patient invitation, f) lack of provision of IPT to eligible patients, g) no home visits as indicated; and h) sub-optimal TB-CI specific training for medical students in the preservice stage. Key informants identified various opportunities

including: a) provision of alternatives for TB contacts regarding screening including providing index TB patients with sputum containers to take home for contacts/testing close contacts conveniently present at the health facility/ contacts of hospitalized patients; b) integrated and efficient health information systems that HWs find useful and incentivize their work, and c) social protection. Similar to HWs, emerging subthemes included family dynamics, poverty and occupational risks.

**[Interview 3, Policymaker]:** *“In our register, there is a column that indicates ‘referred by.’ So you have the option of saying you are a self-referral or probably you were unwell and you came for evaluation, you were referred probably from HIV care clinic or referred from any of the outpatient clinic for evaluation of TB, or a close contact has told you about the disease. So we are able to generate that kind of information.”*

**[Interview 1, Program Implementer]:** *“Currently there is.... What I can say? It seems there is, in a way but it is not rolled out everywhere and you find that it is not really a register. What I have seen mostly is that there is a programme being implemented by ‘NGO A’. We actually get fund from ‘NGO B’ to implement increased case finding. So one of things they have is a leaflet that is I think in duplicate that identifies a smear positive and list the contacts. And that slip is given to the community health worker to go and trace the contacts and hopefully bring them or ask those questions at home, and hopefully they come back. With that facilitation there is a bit of motivation there. But from my going round the facilities, it seems it is only in given areas but not standard. So what has happened is that, in some areas they ask the patient: ‘Do you have a child under five years? or ‘Do you have somebody who is coughing?’ They say: ‘Yes.’ You tell them: ‘Just bring them.’ But it is documented nowhere. So the next time it is not easy if there is a different person in the clinic or they just find the same person but the person forgets to*

*prompt, then you find it will fall through the cracks. I have seen this. You find may be three months or four down the line, they bring a child who has TB. It is like a missed opportunity there. So in terms of documentation, I would say that 'NGO-B' tool and some mixture of tools in the field by different people who try to capture it. Sometimes you find at the back of TB register they actually write the contacts in some cases. But I think that is one of the gaps. Fine, you ask: 'But how do you document and more so, how do you link the patient to the contacts behind there because you find the list of contacts, but then depending on how it is written, it is not written which patient this contact belongs to. And I think there is not a lot of follow up. As a health care worker you have done your part, you have told them, and you have told them it is good to bring because of this and that. So in terms of documentation, that is one of the gaps.'*

*[Interview 7, Respiratory Health Specialist]: "But there is no collaboration with other facilities. I would put it, systems of referral and feedback, they are not there."*

**[Interview 10, Program Implementer]:** *"Sometimes I feel like our systems don't make the health care worker's work easy. A lot of the stuff is dependent on you remembering things. The guidelines says that you should do these things. There is not time you seat with it (guidelines). It is not always in front of you when you are seeing the patient. So unless you have a system that requires you to document those 'twelve' things every time, a system which prompts you to remember or have something that creates for you an alert system to remind you of things that you ought to do, you would have to take many years to remember all those things all the time."*

**[Interview 7, Respiratory Health Specialist]:** *"The University where you are working, I don't know if it has participated adequately in contact tracing? How much has it contributed to contact tracing? I know you train the staff, once you have trained like you were, I was also trained there on even the capacity to go out there and make diagnosis, but how much emphasis or input in terms of contact tracing do you do there at the university which is the pillar of knowledge in this*

*country and specifically for us? We are concerned about TB and of course even HIV, how much do you do about that? And what makes you think that you cannot contribute to the strengthening that area? What makes you think you cannot? How much do you contribute to let me say TB contact tracing in terms of may be providing that education? Even in aiding in establishing a system which can be a reference point to which your students can actually say: 'Look, we have a contact tracing system which operates like this and it has these components and so if you want to do proper contact tracing for TB, this is the way it should work, because it has this person here, it has this and it is manned this way.' Do you have this system there where we can come and learn as Facility XXX or which your students can learn from, and they say this is the way things are done? Because personally, what am telling you about, is something I have acquired over time as a worker in TB, but I don't remember anybody in Facility XXX talking about contact tracing ever."*

**[Interview 2, Policymaker]:** *"One of the problems we have in this country and in many African countries, is the number of TB patients is still high, and for us to be able to reduce the numbers, as much as we do the treatment programme, we should do the prevention programme. The prevention programme is making sure the IPT issue is expanded, contact tracing and investigation is expanded, health education is expanded to prevent TB, and diagnosis is made simple so everybody who suspects they have TB, they don't have to go to the hospital, they can just go to a clinic and get their sputum tested and even gene Xpert investigation to make it more friendly, have programmes for people knowing their status and even prevention which we could also put funds in. Actually sustaining is not difficult. Our problem is policy makers, because we don't allocate funding and people to do it properly in a more honest system. We just say they will be done but we don't say who, when, how and the sustainability. I don't see*

*how we can have money for other things, drugs, vehicles and whatever, yet this is the least, you only need little money, lunch for a volunteer. So I don't think it is an honest explanation."*

**[Interview 9, Academia]:** *"I don't think that volunteerism works, no it doesn't work, and I don't think it does. Relying on volunteers to deliver health is being very whimsical. I don't think it is possible. Volunteerism to deliver an essential service I think is a misnomer. Yes it doesn't work. You know you have volunteers with other things but to deliver an essential service, No! I don't think it works. At least that is from my experience, because we used the so called community health volunteers but we pay them, and they are always asking for more..."*

**[Interview 17, Policymaker]:** *"I believe that our health indicators can only improve or be maintained high if the community and individual households are empowered with health knowledge. Health starts with the household. It is generated and it develops in the household. It is only repaired in the facility. If we really need to get to universal health coverage, then it is the community we should focus on."*

**[Interview 6, Program Implementer]:** *"In Nairobi it is quite unique in terms of the contact investigation. It is dependent on this person who has been registered and the CHV being able to trace them at the household level. But one challenge we are finding is that you hardly find some of the people given the mobility that is there. Much of the TB in Nairobi is within the slums and the people in slums, their movement patterns....one time they are here probably registered in a clinic in XXX, the next time they have moved to YYY or they have moved to another place. So you get the name is registered in the physical location, you get that this person is not there. There are also TB patients who are mobile in the sense that during holiday, for example, I have come to live with my brother, then I am diagnosed with TB, then the period has ended and I*



*have gone back. So I am on the TB register but when you want to trace me, you find I have already gone to ZZZ. Probably, I have been referred, so I am continuing with treatment there, but you will not trace my contacts. And then also the work that the people do, most of the people they kind of do casual jobs which means that if I registered and am already on my medication there are less chances that you find me at home. So we need to rethink this, because some of the reviews we are having in TB programme probably in Nairobi is to really say how do we extend this contact investigation to work places and not just the household?"*

**[Interview 11, Health Information Systems Specialist]** *"You see, processes are created because someone up there wants this kind of data. So he imposes certain procedures for his own benefit. But ideally this should not be there, it should be mutually beneficial. You want to make life for the person on the ground to be the best as possible. The source document person's life has to be easy and this is because he is your source of data. If his life is nice and is working well, we can see his results because he is incentivized, he is happy. To me work incentive is much better, always much better than the rewarding incentive. If people are satisfied by their work, if people are satisfied by the input of their work, even if it is as much work as possible, then there is a higher chance of them not leaving."*

**[Interview 15, Policymaker]:** *"We do this by showing the importance of what we want to introduce and going along with them (the users) to see the advantage. Then once that starts, feedback. If we have a feedback on the information they are giving and it starts from higher...you start from there going up, then start from high up coming down. I am happy that today I was in a launch where the President himself launched a data visualization tool. He is going to have his screening in his office every month, watching the indicators, how they are changing in health, and then if he finds something not going well, he will call the minister and*

*the minister will run down to DMS, DMS to us and goes down till where it was collected. That will make something change people will feel: 'Okay, so these things are very serious. What I am doing here, people are seeing it from that far.' And they will be taking keen interest, they will look for how they can aid that collection and by the time we do this, I am sure it will not be even waiting for a month, but it will be changing daily or weekly you see a change so that is the way to go."*

**[Interview 11, Health Information Systems Specialist]:** *"We must break down the silo effect by saying a patient has a unique ID only. Whichever programme he goes to, we track him with that. If we did a malaria test, we know it is patient one, 'XXX', did a malaria test, in this hospital, on this date then 'XXX' came for a viral load test in this hospital, and then 'XXX' came to this hospital for this test. We don't need to recreate 'XXX' again if she is in the malaria programme or in the CCC programme.... Yes (you can integrate any system) so long as this system is open or these people agree to open it up. HL7 standard is the standard which we people who build the health information system must comply to. This standard, which means that a certain set of data, a record must consist of, for it to be complete, for it to be described as complete record of patient 'XXX', it has to have all these set of data sets and some of this can be interchanged with another system. Obviously because of commercial interest most of the people don't build systems which are open because it is much easier to build it that way and that is why we are forcing most of the people who have the EMRs (electronic medical records) to do this and this is the advice at national level they can do. National level can create standards and advice county governments even private hospitals that you need to comply with these standards."*

**[Interview 13, Health Information Systems Specialist]:** *"Yes, the person who sets the rules and ensures all the children are playing nice is Ministry of Health (MOH). And actually MOH*

*are not sitting back and doing nothing. There is something they are doing, which is development of something people like to call enterprise architecture. You will hear that term a lot. Basically enterprise architecture is just a framework. It defines how systems, processes, and all that should relate with each other, and so it goes beyond technology. Enterprise architecture is designed in a way that it optimizes achievement of the vision, but then more technologically it defines very clearly rules of engagement, roles and responsibility and what my system has to do to coexist with yours. In case of conflict, what is the resolution mechanism, who is resolves it. Its development is something they should have done years ago, before even most of us were working. This will help a lot in terms of defining the rules of engagement and basically defining the field, so this is the field, and this is how we all engage. That will help a lot in terms of just making sure people do the right thing. So that is currently underway. Hopefully they will have it ready soon. The biggest challenge is implementing it. Because it is not heavy and essentially all that we do, if you think about the banking system, it will really work the same way. So that you have your KCB, you have your Barclays, you have your whatever. At the end of the day you can go with your ATM and draw money from wherever so you end up paying a little bit more if you go to another bank but your card works. Like in Kenya, government of Kenya will not stop Dubai bank from setting up. Government of Kenya will not stop whoever like Chase or whoever. They will tell them: 'Yea, come and set up.' But as soon as those guys land here or even before they land, they are told: 'These are the rules. You set up your information system, you come with your ATMs and all, they have to comply with these rules of exchanging money and all that, making sure that if I come to your ATM and I have a visa that is recognised globally, because there are rules that define the visa card and all that. If I put it in your ATM, I can have the money out.' So at the end of the day, it is the user who matters. 'I am the patient. I am the card holder. It is my information and whoever else who provides me services...' So it is the same with the health sector. I always say that many times, we don't want to kill innovations. We*

*don't want to tell somebody we cannot strengthen the information systems in Kenya, but what are the rules? How do you make sure that you don't disrupt everything and you don't create your own island that you are the only one who knows what you are doing and you don't share all the good things with everyone else? So same thing. So I think that is where it is heading in my opinion, and the only person who can do that just like CBK does it, is the MOH. They need to say: 'Here are the rules.' and then let people just come. It doesn't matter, as long as we all comply to the rules, then it does not really matter so....and if they have done it in the bank sector I mean even globally, it doesn't matter where you are in the world, just pop in your card in the bank and get money, why can't we do it in the health sector?"*

**[Interview 12, Health Information Specialist]:** *"Create value or incentive...It could help if you told the patient that: 'I need your number so that I can SMS you the side effects of your medication. You may not remember, so can we SMS you? Could we text you and you respond whether you have any complication or not? Whether you have any challenges? Could we call you to find out whether you are okay?' Once the patient sees there is value in them giving us the certain unit, in this, the phone number, it helps. 'Could we give you our number so that if you change location and you travel somewhere and you don't have your medication, we can organise for you to collect it in another CCC?' So create value and then people will tell you the truth."*

**[Interview 9, Academia]:** *"You know the best way to look at it, is to look at it as a health maintenance strategy in a holistic manner. So may be that is the context you should look at, it not in the context of TB. What you are trying to deliver is health maintenance or prevention or what we may call preventive medicine. So when people show up for their annual check-up, then we know what exactly needs to be done to makes a difference in terms of preventing disease. So if they have shown up because their reason for coming is because they were*

*contacts of a person with TB, and let us say it is a thirty five old woman, you are not just testing TB, but you will also check her breasts, her cervix, blood pressure and blood sugar. So it is really looking at or delivering the package with the...what is the word, being holistic, not being, you know tunnel-visioned, but you are actually looking at people holistically. So if it is a male of 50, they show up because indeed they have been a contact with a person with TB, but you also want to use that opportunity to check their prostate, do their blood sugar, take their blood pressure, do their urinalysis to check their kidneys and all those. So it is not TB per say, but delivering a comprehensive package of health maintenance or preventive medicines. If it is a child, you are having their ears checked for hearing loss or assessing their vision, you are checking their milestones and those kinds of things.”*

**[Interview 8, Respiratory Health Specialist]:** *“Ideally the patient should be given options. For example: ‘You have TB, other people in your house might have TB. There are two ways in which we can do this.’ You are already giving me an option. ‘One, we can send somebody to come and talk with your household contacts and do this and this. Alternatively, you can chose to bring them over.’ That is not dogmatic, that is allowing that person and empowering that person to make choices. In a lot of our public health programmes, patients are not given those choices. It is: ‘We are coming home to screen your people.’ And if I don’t want, I say: ‘I don’t want. Period. If I have refused, I am put down as declined. But I declined because I don’t want to be bothered. If you told me there is an option of coming, I might have been able to do that. So it is that interaction. I am going to emphasise the interaction between the patient and health care provider and the choices that patients are given. If patients are given choices, I would wonder how many of those would say: ‘Don’t worry, you don’t need to come home, I will bring them over.’ or ‘It is convenient for you to come home and may be come on Sunday morning,*

*when we are all at home, and I will have my uncle, my brothers, so that you come screen all of us.' That choice is what is often not given to patients."*

**[Interview 14, Academia]:** *"Developing systems that are specifically tailored to handling these contacts when they come in so they can be fast tracked. They don't have to queue with all the other sick patients. So having a system where you say, okay on this particular days, or if a contact comes, if you come back with your relative, this is the room you will be handled, you won't queue. And have very clear registers where I know that this contact on their card they took note of, for example: 'they have a three year old, a one year old and they have a HIV infected spouse'. So having clear records so that when they come, you have a system that again quickly helps the health worker, to quickly use a checklist to screen, and then very easily enables them to either give treatment and to make decisions on the spot."*

**[Interview 8, Respiratory Health Specialist]:** *"I think it would be critical to engage community health care workers and get down to the communities in a sustainable way. I would design a remuneration package for them. I would ensure they are not doing full time community health work. They need to do other things or they devote an hour or two in a day to do their health care work. The rest of the time they are doing other activities. I compensate them for that time and ensure that the system is all linked from health centre to health extension workers to community health worker. Everything is very well linked, everything is recordable and reportable. I would ensure that people go to people's homes not just for TB but go for health screening. Combine it may be with communication messages. Create community awareness. We must remember that TB is a stigmatising disease and if you do your community work and your contact investigation badly you can increase stigma and discrimination so you must make*

*sure you build a mechanism to reduce stigma and discrimination as you go out in to your community.”*

**[Interview 6, Program Implementer]:** *“I think we need to have systems in place that will make the devolved government take responsibilities for these community activities in their budget.”*

**[Interview 4, NGO]:** *“I think for me I would just mainstream it (TB contact investigation) in the mainstream services for TB. That is the only way to ensure that it is sustainable. So every time you are planning for TB services, plan for contact investigation among all the other interventions that you will do. We should not do it as a stand-alone activity because as you see, as I have told you, it is resource intensive and the yield is relatively low. And yet it is also a very essential service, because at the household level, it means a lot if someone has TB and transmit to the relatives or neighbours. It can be quiet catastrophic in terms of the cost to the household. So it is an essential service and yet it is costly, it is labour intensive and the yield is low but it is essential, so it is very critical that it is mainstreamed into the health system in the counties.”*

**[Interview 3, Policymaker]:** *“What we have done in our strategic plan is to come up with something on social protection recognising the fact that TB mostly affects the poor. So, how are we able to protect these people from what WHO calls catastrophic costs? We are aware there are schemes available under the Ministry of Labour. So, how do we expand these schemes to cover poor TB patients? We have initiated those discussions and we are getting some support to operationalize social protection for TB patients. It is not an easy thing, so to speak.”*

**[Interview 14, Academia]:** *“I think that it is not difficult to put all these measures in place. It saves a lot of money to prevent that one case of active TB in a child than it costs to treat that*

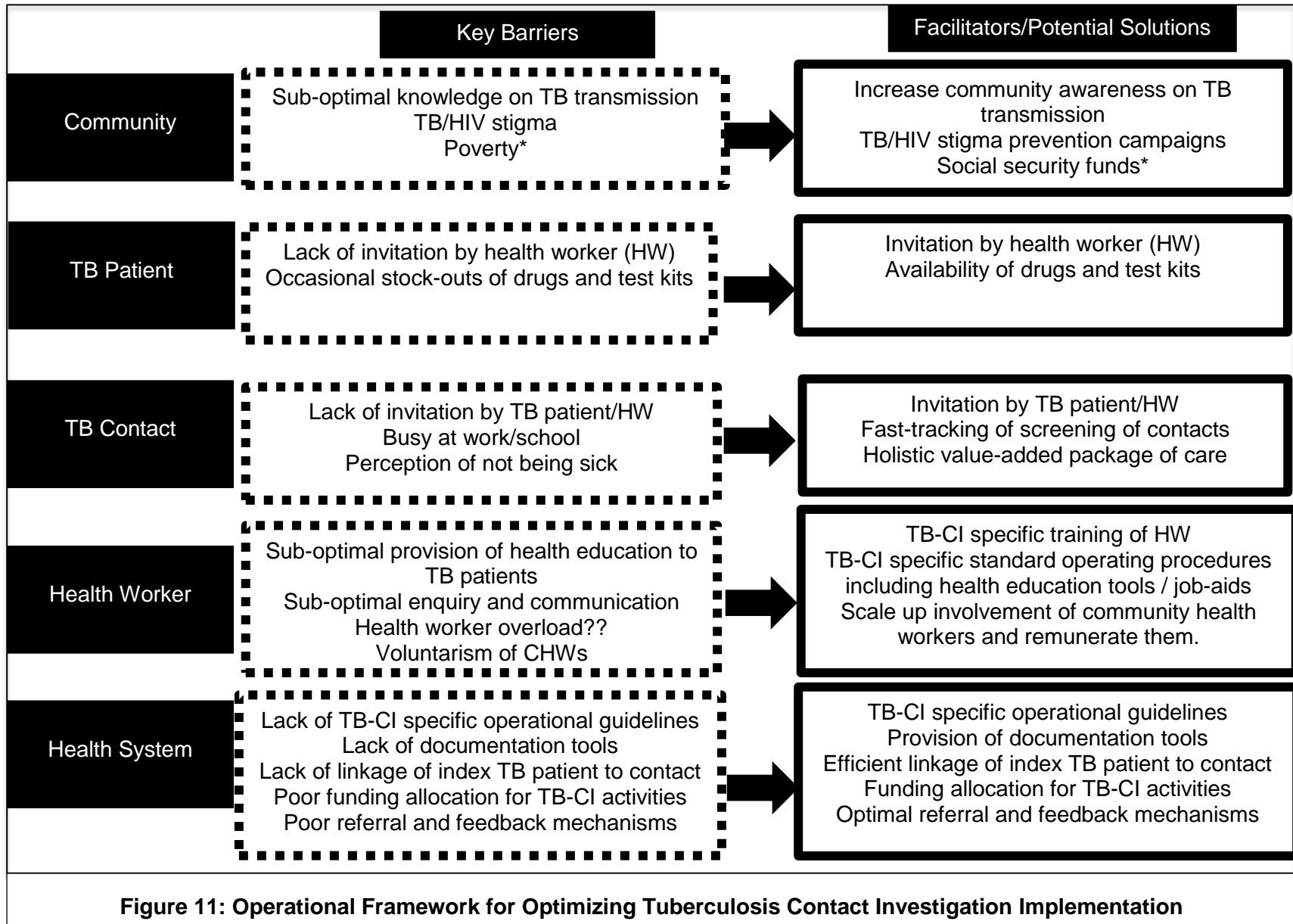
*child. And so I feel that if we get our health economics right, and we put our resources and training and our commodities and everything in place to make sure whenever we have an adult who has TB, anybody who is their close contacts whom we can protect, we make sure we protect, in the long run we will prevent unnecessary diseases and deaths. By the time we are seeing a child with TB, it is a reflection of ongoing transmission. By the time we have allowed a child to get TB, those are the children who become the TB carriers, who will continue to propagate these decades to come. If we want to win the war against TB, we need to get this right, because that child who is infected today will be 20 or 30 years later the one who develops active disease, and the cycle continues.”*

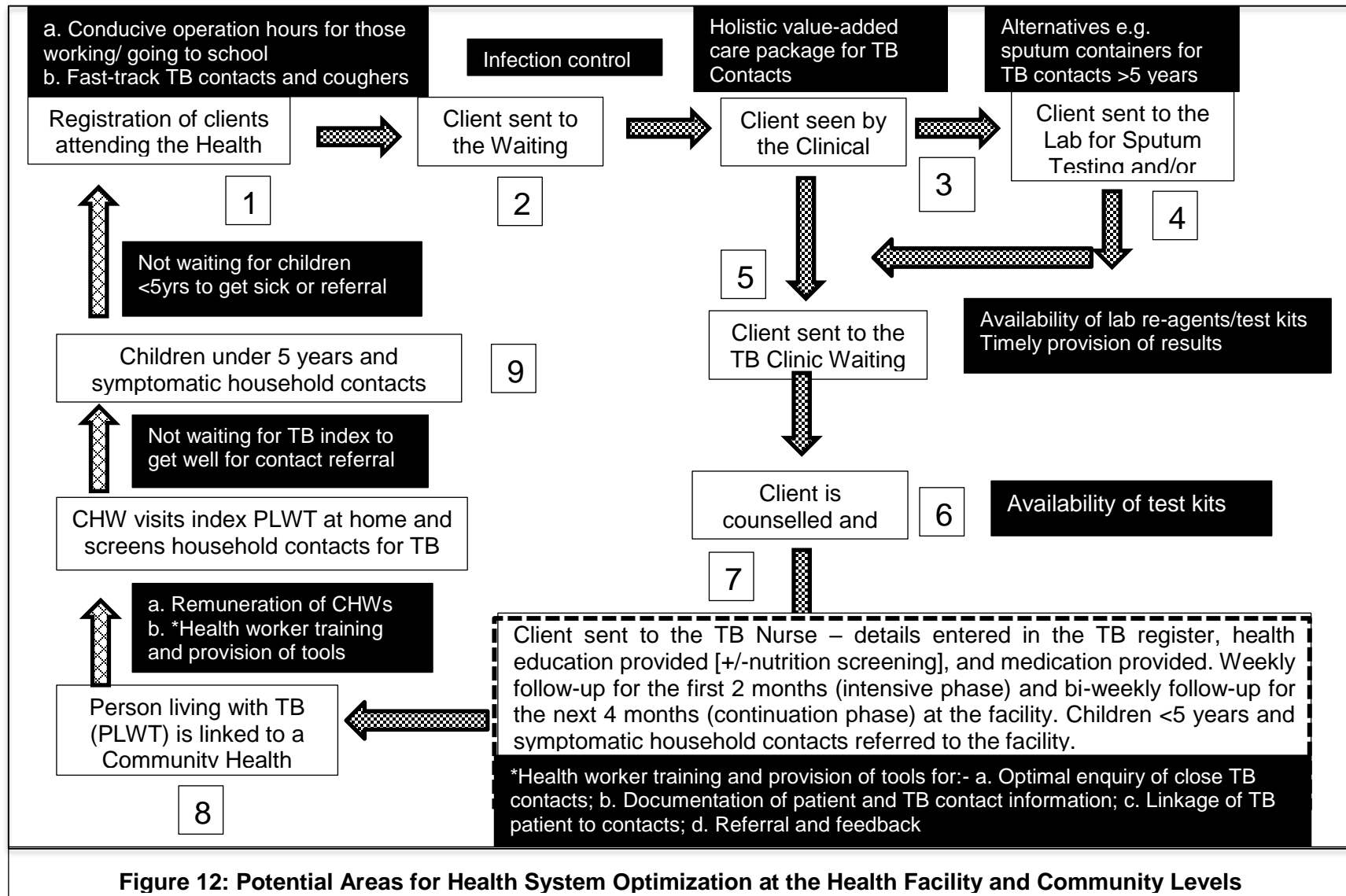


## **PROPOSED IMPLEMENTATION TOOLS: OPERATIONAL FRAMEWORK FOR TB CONTACT INVESTIGATION OPTIMIZATION**

We designed an innovative operational framework and specific tools to optimize TB-CI in Nairobi County based on perspectives gained from TB patient interviews, HW FGDs and KIIs. The WHO's building blocks framework for health systems were incorporated into this framework, with HWs identified as key actors in the health system. TB patients, their contacts and the broader community were also incorporated as key players in TB control. At each of these levels, we distilled common barriers and facilitators for TB-CI activities into this summary framework for action at policy or program implementation level. (Figure 11)

Furthermore, we designed a composite TB-CI process flow map to identify common gaps and solutions at the health facility and community levels; and standardized operating procedures (SOPs) for TB-CI for use by HWs at both these levels. (Figure 12 and Table 7)





**Table 7: Suggested Standard Operating Procedures for TB Patient Contacts Identification and Invitation**

COMPONENT	DESCRIPTION
HW Attitude	<Respectful and kind to the patient and their caregiver(s)>
Introduction and establishing rapport	Hello, My name is _____ (Health Worker). What's your name? [address patient by name/respectfully as appropriate] Which language do you prefer for us to talk in? [Probe: English, Swahili, Other (specify)] How do you feel today? [Probe: Are you coughing, coughing blood, fevers, night sweats, feeling tired, lost weight?]
Diagnosis of Smear Positive Pulmonary TB meets Government of Kenya Protocol	*Coughing? <input type="checkbox"/> Yes AND Either <u>ONE</u> of the following:- (Verify Data from the Patient's File or TB Card) a. <input type="checkbox"/> Any sputum smear positive for TB on microscopy b. <input type="checkbox"/> Any sputum smear positive for TB on gene Xpert c. <input type="checkbox"/> Sputum culture & sensitivity positive for <i>M.tuberculosis</i> d. <input type="checkbox"/> Children with negative/no sputum results: signs, symptoms, mantoux or chest x-ray that is suggestive for TB
Socio-demographic characteristics (I)	*When were you born? [Probe: Date of birth] How old are you? What is the highest level of education you have attained? What do you do for a living? [Probe: What work do you do? Do you go to school?] Are you married or in an intimate relationship? Do you have children? Where do you live? [Probe: What's the nearest landmark and major road? What's the nearest public health facility to you?] How long did it take to get to the hospital today? What means of transport did you use to get to the hospital today? How much money did you use for transport to get to the hospital today?
Socio-demographic characteristics (II) – Household	In the house you live in: What is the floor made of? What are the walls made of? What is the roof made of? What do you use for cooking, most of the time? Where do you get your water, most of the time? What type of toilet do you use, most of the time? Do you share this toilet facility with other households? Does your household have a:- radio, TV, fridge, microwave, motorbike, bicycle, car? How many rooms in your house have at least one opening [window/door] on two opposite walls? Are the windows or doors in your house opened daily? If No, Why? If Yes, for about how many hours in a day? How many rooms are there in which people sleep in?

COMPONENT	DESCRIPTION
Current living dynamics	<p>How many people live in your house currently? Who do you live with? [Probe]:-</p> <p>Does your spouse/boyfriend/girlfriend live with you?</p> <p>Are there any children who live with you? Who takes care of them? Do you have a Nanny/House-help?</p> <p>Do you live with your relatives? Do you travel to visit your family members? [Specify: Nuclear family? Other relatives?]</p> <p>How often do you travel to visit your family members in a month? How long do you spend with them in a month?</p>
Assessing other current close contacts beyond the household	<p>Where do you spend most of your time?</p> <p>[Probe: At home? With friends? With neighbours? At work? At school? In prison? Other, specify?]</p> <p>What social activities do you engage in? [Probe: Sports? Parties? Bar? Do you drink alcohol/take drugs?]</p> <p>[Probe: How many times in a month? How many hours a day do you spend there?]</p> <p>What religion do you profess? Do you go to church/mosque/other place of worship? [Probe: How many hours a day do you spend there?]</p>
Establishing time-frames of household and close contacts in the past 1 year	<p>When did you find out that you had TB? (Which date?)</p> <p><u>In the last one year:</u></p> <p>Are there other people you have lived with (apart from those mentioned above)?</p> <p>Are there other people you have been in close contact with (apart from those mentioned above)?</p> <p>Are there any children who you were in close contact with (apart from those mentioned above)?</p>
Household and Close Contact Characteristics	<p>For each contact listed: What is your relationship? How old is he/she? Does he/she currently live in Nairobi? What work does she/he do? Is he/she sick? [Cough, fever/ night sweats, weight loss, lethargy/reduced play]; Known contact with HIV?</p> <p>Number of contacts who are symptomatic _____ [For TB testing/treatment]</p> <p>Number of under 5's or HIV positive who are asymptomatic _____</p>
TB status disclosure and Stigma	<p>Is there anyone you have told about your TB diagnosis? [Whom?]</p> <p>What thoughts have you had so far? [Patient gives examples of TB-related stigma]</p> <p><input type="checkbox"/> Internalized TB stigma? <input type="checkbox"/> Perceived TB stigma? <input type="checkbox"/> Enacted TB stigma?</p>
Baseline TB knowledge; Health education and TB contact invitation	<p>Do you know someone with TB? [Who?]</p> <p>Tell me, what do you know about TB? [How does TB SPREAD from one person to another? Can TB be PREVENTED from spreading to another person? Can TB be CURED? Is there anything else you know about TB? specify]</p> <p>[PROVIDE HEALTH EDUCATION, CORRECT MISCONCEPTIONS, INVITE TB PATIENT TO INFORM ALL HOUSE HOLD AND CLOSE CONTACTS IN THE PAST 1 YEAR FOR TB SCREENING AT NEAREST FACILITY]</p> <p>Care to be provided: <input type="checkbox"/> IPT <input type="checkbox"/> TB testing <input type="checkbox"/> TB treatment <input type="checkbox"/> Wellness package (based on age and sex)</p>

COMPONENT	DESCRIPTION
Identify TB Patient Co-morbidities	<input type="checkbox"/> Severe acute malnutrition (W/H <u>&gt;-3SD</u> in <5years; BMI for age <u>&gt;-3SD</u> in 5-19 years; BMI <u>&lt;18.5</u> in those >19 years) <input type="checkbox"/> Known diabetes or symptomatic [ <input type="checkbox"/> passing lots of urine OR <input type="checkbox"/> drinking lots of water OR <input type="checkbox"/> increased appetite] <input type="checkbox"/> Medical conditions requiring steroids/chemotherapy (e.g. cancer, transplant, joint disorders, skin disorders etc.) <input type="checkbox"/> Previously known HIV + <input type="checkbox"/> Newly diagnosed HIV + <input type="checkbox"/> Other, specify _____ <input type="checkbox"/> None
Ensure TB Patient linkage to care	<input type="checkbox"/> TB treatment <input type="checkbox"/> Nutritional support <input type="checkbox"/> HIV testing <input type="checkbox"/> HIV clinic <input type="checkbox"/> Medical Clinic <input type="checkbox"/> Other, specify _____

**ADAPTING SSCI DEVELOPED BY RAO ET AL. TO MEASURE TB-RELATED STIGMA AMONG ENGLISH/ SWAHILI SPEAKING PATIENTS IN A HIGH TB/HIV BURDEN SETTING**

**Patient Characteristics**

Twenty adult TB patients attending study TB clinics sampled from 11 of the 13 selected health facilities in Nairobi County, Kenya underwent cognitive interviewing using the SSCI by Rao et al to adapt the tool for TB-related stigma in context between May and September 2015. Of the 20 adults, most (14) were male with a majority having completed primary education. (Table 8)

**Table 8: Characteristics of 20 patients interviewed about TB Stigma using the SSCI – Objective 3**

<b>Participant Characteristics (N=20)</b>	<b>Frequency (%) or Median (IQR)</b>
Median Age (IQR) [Range]	32.5 (29-37.5) [23,47]
Male (%)	14 (70)
Completed Primary School Education (%)	17 (85)
Median Duration since TB diagnosis (IQR) [Range]	2 (1-3.5) [0.07,8]
TB re-treatment (%)	2 (10)
Voluntarily disclosed HIV+ status to the interviewer (%)	3 (15)
Multi-drug resistant TB (%)	1 (5)
Responses in mixed English and Swahili (%)	10 (50)
Responses in Swahili (%)	7 (35)
Primary health facility (%)	14 (70)
Sub-county (Health Facility)	
Dagoretti (Kenyatta National Hospital, Mbagathi District Hospital, Waithaka Health Centre)	5 (2,1,2)
Embakasi (Mama Lucy Kibaki Hospital, Mukuru Health Centre)	4 (2,2)
Kamukunji (Eastleigh Health Centre)	2 (2)
Kasarani (Prison Staff Training College Health Centre)	2 (2)
Langata (Langata Health Centre)	1 (1)
Makadara (Makadara Health Centre)	0
Starehe (Ngara Health Centre, Mathari Hospital)	1 (0,1)
Westlands (Kangemi Health Centre)	3 (3)
Njiru (Dandora I Health Centre)	2 (2)
<b>Non-Participant Characteristics (N=3)</b>	<b>Frequency (%)</b>
Male	2 (67)
Primary health facility	3 (100)
Reasons for non-participation:-	
1. Busy schedule	2 (67)
2. Not comfortable being involved in research	1 (33)

Half of the participants responded in mixed Swahili and English whereas few responded in Swahili or in English. Most participants had disclosed their TB status to at least one person, and attended primary health facilities. The median age was 32.5 years (IQR 29.0-37.5), with youngest and oldest interviewees being 23 and 47 years, respectively. Median time since TB diagnosis was 2 months (IQR 1.0-3.5), and median interview duration was 32.5 minutes (IQR 21.5-47.5). Three TB patients refused to participate, two due to a busy schedule and one due to feeling uncomfortable being involved in research. (Table 8)

### **Translation and Meaning of the Questions**

Generally, no difficulties in the translation of individual words from English to Swahili, were noted except in one interview in which two errors were made in Question 20 and 21 (Table 9-11) which influenced the meaning of the question [Interview 2].

TB patients understood most questions adequately but in a few interviews we noted differences in meaning between the patient and the researcher. Patients initially interpreted '*looking at you*' in Question 8: "*Do you think that because you have TB, people avoided looking at you?*" in Swahili to mean '*looking after you*' [Interview 6, 10, 14, 16, 18 and 20]. The word '*kuangalia*' in Swahili has two meanings, to look at and to look after. We provided further clarity to enable the patient to understand the question during the interview process. We also adjusted the question in the final harmonized Swahili SSCI to '*kukuangalia usoni/machoni*' – '*to look at you in the face/eye*' to make this distinction. Another Swahili word with two meanings is '*rafiki*', which in this context could mean a general friend or a romantic friend, was used in Question 22: "*Do you think that because you have TB, you avoided making new friends?*" and some TB patients explicitly requested a distinction [Interview 16 and 18]. From other interviews, it became apparent that the context of relationships was an important aspect in TB stigma, and distinguishing the various levels of



relationships was necessary, particularly general and romantic relationships. Patients occasionally misinterpreted '*physical limitation*' in Question 17: "*Do you think that because you have TB, you felt embarrassed because of your physical limitations?*" for '*weight loss*' [Interviews 5, 12 and 14]. In the final harmonized SSCI tool, the question was revised to provide situations in which one would be limited physically – at home/school/work. Participants initially misinterpreted, '*felt left out of things*' in Question 4: "*Do you think that because you have TB, you felt left out of things?*" in Swahili to mean '*felt left behind*' [Interview 1 and 13]. For clarity we added an option in Swahili back translated into English as "*you have felt excluded from things*". The initial meaning of Question 10: "*Do you think that because you have TB, you worried about other people's attitudes towards you?*" was noted to be difficult to understand [Interview 1].

**Table 9: Patient responses regarding the SSCI Tool for TB-related stigma (N=20)**

	<b>Characteristic</b>	<b>Q1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>	<b>13</b>	<b>14</b>	<b>15</b>	<b>16</b>	<b>17</b>	<b>18</b>	<b>19</b>	<b>20</b>	<b>21</b>	<b>22</b>	<b>23</b>	<b>24</b>	<b>25</b>	<b>26</b>	
1	Difficulties in translation	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	01	01	0	0	0	0	0
2	Differences in meaning between the interviewer and patient	0	0	0	02	0	0	0	06	0	01	0	0	0	0	0	0	03	0	0	01	01	02	0	0	0	0	0
3	Relevance in the TB context	20	20	20	20	20	20	20	20	14	20	20	20	20	16	20	20	20	18	20	20	20	20	20	20	20	20	20
4	Patients' acceptability to the questions	0	0	0	0	0	04	0	0	0	0	0	0	0	0	0	0	0	0	0	01	0	01	0	0	0	0	0
5	Issues in the tool structure	<p><b>Redundancy and sub-optimal flow - 05/20</b> [ID: 9,10,12,17,19]  <b>Incorrect intonation - 01/20</b></p> <p><b>5A. Format</b>  <u>Suggestions:-</u>  1. To arrange questions according to similar constructs for optimal flow while conducting the health worker administered interview [01/20]  2. To include open questions to get a wider variation of patient responses e.g. "What do patients with TB think?" [01/20]</p> <p>To "put a question mark at the end of each question" so that each question sounds like a question and not a statement. [01/20]</p>																										
	<b>5B. Content</b>	<p><u>Suggestions:-</u>  1. To include questions related to relationships – "How do TB patients relate with family members, friends, co-workers and employers?" [04/20]</p> <p>To include questions regarding TB treatment and outcomes. [02/20]</p>																										
	<b>5C. Ranking [5,3, E, N]</b>	<p><u>Preference:-</u>  5 point scale (2/8) – gives more options  3 point scale (4/8) – brevity (people are busy – they go to work, simpler than the 5 point scale)  Either scale (1/8)  No scale (1/8) – restricts responses</p>																										

Q4 meaning (left out of things) – interview 1&13 in Swahili; Q6 sensitivity (make fun of) – interview 5,6,7&9 in English & Swahili; Q8 meaning (kuangalia has 2 meanings to look at and to look after requires clarity) interview 6,10,14,16,18,20 in Swahili; Q10 meaning interview 1 in Swahili; Q17 meaning (physical limitations) in interview 5,12,14 in English and Swahili; Q20 & 21 translation – interviewer asked the questions incorrectly in interview 2 in Swahili [initial set of interviews]; Q20 & 22 sensitivity – interview 7 in Swahili; Q22 meaning (rafiki has 2 meanings - friend in general/ romantic friend) interview 16&18 in Swahili. †Diverse cases.

## Relevance of the Stigma Scale for Chronic Illness Questions in the Context of Tuberculosis

Most of the patients deemed all 26 questions in the SSCI tool to be relevant in the context of TB. Although responses to each question varied from patient to patient, TB patients provided rich and diverse perspectives which clearly depicted that the questions were applicable to TB stigma.

Question 18: *“Do you think that because you have TB, you felt embarrassed about your speech?”* was one such question. While patients could hardly see a relationship between TB and speech, others viewed the question in the context of their appearance. Some TB patients cited personal experiences where they felt embarrassed about how they appeared when they talked, particularly when coughing uncontrollably, coughing blood or panting due to breathlessness. Other patients felt embarrassed because people would judge the content of their speech and ignore their points because they suffered from TB. We noted that this question was not very specific and omitted it in the final adapted SSCI for TB stigma, but retained the question on appearance, which was the context in which most TB patients responded to this question.

Another question with differing responses was Question 13: *“Do you think that because you have TB, it was hard to stay neat and clean?”* Although possible, some TB patients felt that being dirty and disorganized was just an excuse when one had TB, whereas others could consider situations when this could apply, and even relate to situations where they were too sick from TB to bathe or stay clean. Nonetheless, most TB patients responded that for them it was not hard to stay neat and clean. We noted that TB severity and substance abuse may influence the ability of TB patients to perform tasks which require support from caregivers, and thus considered them important patient variables to collect. Similar to question 18, we omitted this question but added a question

on support from family, friends, co-workers/ school-mates or employers, as this was connected and emerged as a major theme.

Question 9: *“Do you think that because you have TB, strangers tended to stare at you?”* also elicited differing responses. Some TB patients brought out an important aspect of disclosure: strangers did not know they had TB, so why would they stare? Patients, especially those with physically apparent symptoms agreed that strangers tended to stare at them, whereas TB patients who did not have distinctive signs of illness could not understand this question since there had no tell-tale signs. We also omitted this question but recognized the importance of collecting data on disclosure/TB signs and retaining the question on appearance.

Emerging major themes related to TB stigma in this context were classified under three intertwined categories: factors promoting TB stigma, factors reducing stigma, and time which formed the basis of the 8-item adapted SSCI for TB stigma. (Figure 12 and 13, Table 10 and 11)

#### **A. Factors Promoting TB Stigma**

One of the main factors promoting TB stigma was fear of infecting others or experiencing exclusion by others in the community for fear of getting infected. TB Patients reported that they would stay away from others including their intimate partners for fear of infecting them. [Interview 5]: *“I may transmit (my TB) infection, so I keep off.”* [Interview 17]: *“I have been concerned that I will transmit TB to my husband if we sleep together, so I told him that the doctor disallowed us to sleep together for the period I am on TB treatment.”* Enacted stigma due to community members’ fear of getting infected with TB was most apparent when a patient had manifest signs such as a persistent cough or haemoptysis. [Interview 18]: *“The reason they were running from me is (because) there is a day I coughed blood. I was at home, at my mother’s place. Now on coughing*

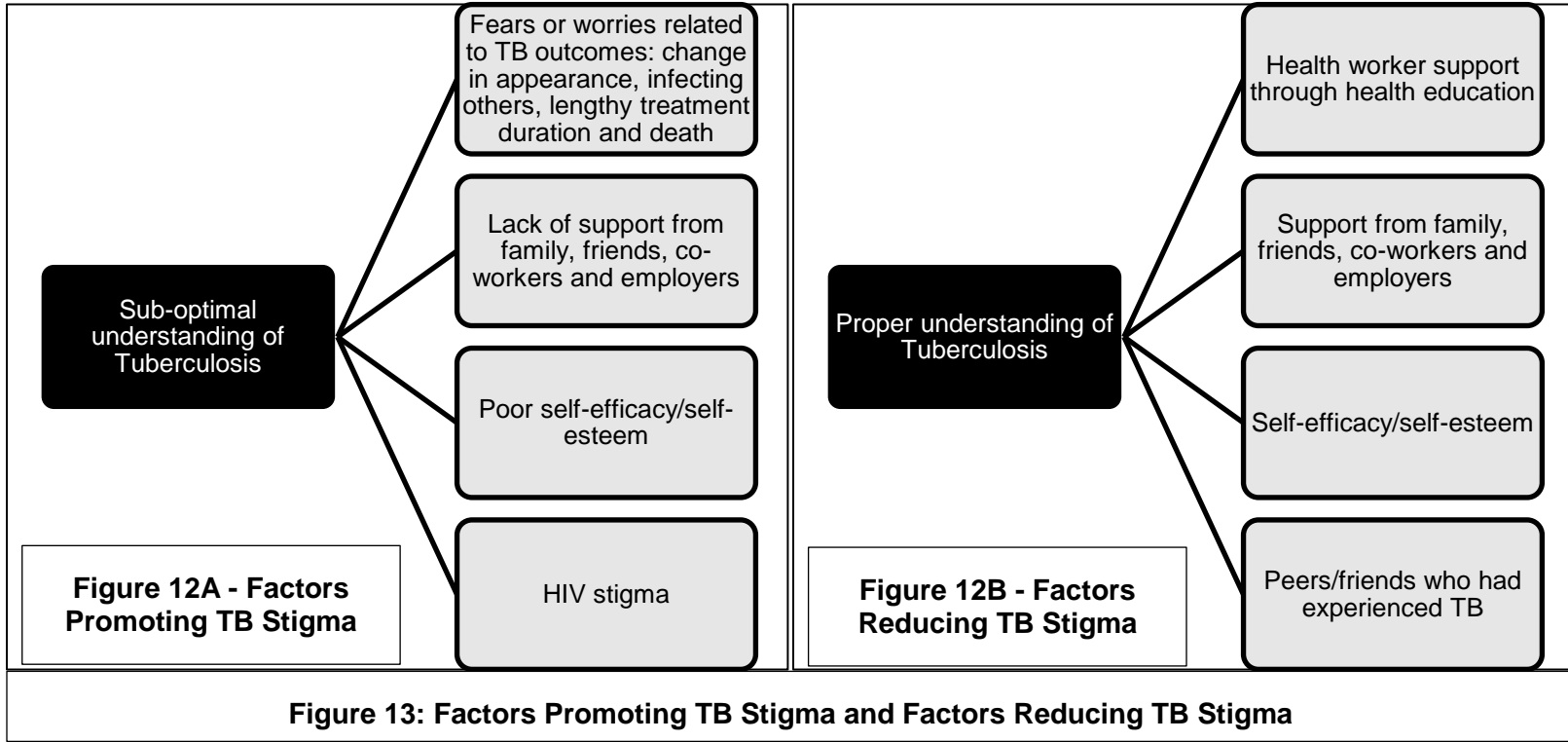
*blood, my brother saw. He gave an order that even food, when I go there, I be given with my plate and it is put aside. When I come, I am given (food) with it (that plate)... The cup itself that they put tea for me, is thrown in the toilet.”*

TB patients also reported the lack of support from members of the community including family, friends, co-workers and/ or employers as a factor promoting stigma. Patients expressed that it was more painful when they experienced stigma from relationships that they regarded to be close such as intimate and family relationships. [Interview 3]: *“So I wonder: What is the reason that is keeping her (my sister) away from me? Is it the fear that maybe she has helped me and now she is tired or is she scared that she will get infected?”* [Interview 12]: *“(Some people can seem uncomfortable with me). Yes it can happen with close people. And they can take you as an outcast or something like a taboo and say that TB is a bad disease, that you have brought shame. It depends on the understanding. So close people, that can be family members, it can be a relationship partner and sometimes family members, make it more painful. Their attachment is too close, they are the ones you rely on for confidence, for courage. So if it becomes negative to them, and they treat you in some other way, it will stress you.”* Other factors promoting TB stigma identified were fears or worries related to TB outcomes including changes in appearance, lengthy treatment duration, drug side effects and death.

Disclosure of TB status was mainly influenced by HIV stigma; and the nature of the friendship between the patient and the person to whom they would disclose. TB patients reported that it was difficult to disclose their TB status as community members immediately assumed that they were HIV co-infected. TB patients' disclosure of their TB status was easier if they considered the nature of the relationship to be close. [Interview 9]: *“Even telling people right now, somebody who is not a close friend or maybe can be a friend, that I have TB is not easy, because I feel embarrassed. I feel bad. It is a bad disease. It is like HIV.”* However, patients reported that they found it difficult

to disclose their TB status to their intimate partners, despite this being considered a close relationship. [Interview 11]: *“I told my girlfriend that I was being treated for pneumonia. If you tell them TB, some ladies will turn off quickly. She’ll not be getting your attention and maybe she’ll go away. So you have to cover it a little.”* [Interview 14]: *“I have not yet told people I have it (TB) but I think they (others) can avoid somebody. You know some people think TB is associated with other things. Like the way you get AIDs people are.....you know people fear, they stigmatise others, not really nowadays but somehow in a small way. It has still not ended. They can think that this person is sick with some other things, especially friends, maybe boyfriend. He (the boyfriend) can think maybe you are sick with things like HIV/AIDs.”* Additionally, disclosure of a patient’s TB status was perceived to promote enacted stigma. [Interview 10]: *“I have never told anyone that I have TB. They know I have ‘Allergy’. If they knew (I have TB) they would change.”*

TB patients and their communities exhibited misconceptions on TB transmission such as sharing utensils, sharing common cigarettes, sexual contact and acts of the devil; and that children/old people would not get TB; and a poor understanding of strategies to prevent TB and the reason for HIV testing. A lack of a proper understanding of TB was the underlying factor promoting TB stigma. This may have been perpetuated by lack of health education provision to individual patients and the community. [Interview 11]: *“I ask myself, where did I get this TB? Some people are patients and they don’t understand. Nobody educated me. Still, no one has educated me.”* [Interview 9]: *“So my embarrassment is the way I used to take others (with TB). So it (TB) has come to me. The way I used to think about others, is the same way they are now thinking about me. That bad thought I had about people who have TB, it’s not that they are having it, but personally I see as if somebody can think of me in that way.”* (Figure 13A)



Sub-optimal understanding of Tuberculosis

Fears or worries related to TB outcomes: change in appearance, infecting others, lengthy treatment duration and death

Lack of support from family, friends, co-workers and employers

Poor self-efficacy/self-esteem

HIV stigma

**Figure 12A - Factors Promoting TB Stigma**

Proper understanding of Tuberculosis

Health worker support through health education

Support from family, friends, co-workers and employers

Self-efficacy/self-esteem

Peers/friends who had experienced TB

**Figure 12B - Factors Reducing TB Stigma**

**Figure 13: Factors Promoting TB Stigma and Factors Reducing TB Stigma**

### **B. Factors Reducing TB Stigma**

Health worker support through health education was identified as one of the main factors decreasing TB stigma. In addition, TB patients also reported that belief in God influenced their self-efficacy. [Interview 17]: *“(When I learnt that I have TB), I thought I will either die or recover because I have never gotten it (TB). I went and asked the doctor. The doctor told me: ‘Have faith and you will be well’. (The doctor told me that) If I use those medicines correctly, I would recover... So from that point I had faith. So I don’t have bad thoughts. I have thoughts of telling God to heal me. I am totally free.”*

Relationship support from family, friends (including peers/friends who had experienced TB), co-workers and employers which could be physical, financial, emotional or spiritual, and non-disclosure of TB status decreased TB stigma. [Interview 12]: *“No (I didn’t feel embarrassed about my situation). As for me no, because I knew people who..... I had a very good idea about TB. Believing at first is what I had a denial, but when it came to my mind that I have it (TB), I now concentrated on healing myself. (I learnt about TB) through people who experienced it, through some awareness programmes and through some advertisements, but mostly through people; people with experience. Yes (some of the people who have experienced TB are my friends), because I live in a place where there are many people. I live in the other part of town. So you get people here with this disease. So many people with the disease. So, many are friends with TB. I have had of one who died but it was not from TB, but the others are cured.”*

Individual patient outlook also decreased TB stigma and positively influenced TB patients’ self-esteem/self-efficacy. Interview 10]: *“You know for TB, most people say it is a bad disease, but when you understand what it is.... (TB) is like an accident. I must accept that accident, because I am not the one who looked for that accident... If I think about what they (others) are thinking about*



*me, I will not be able to deal with my treatment (and) my life well... What is left for me is to leave what they are thinking about me, and continue with my life normally.”*

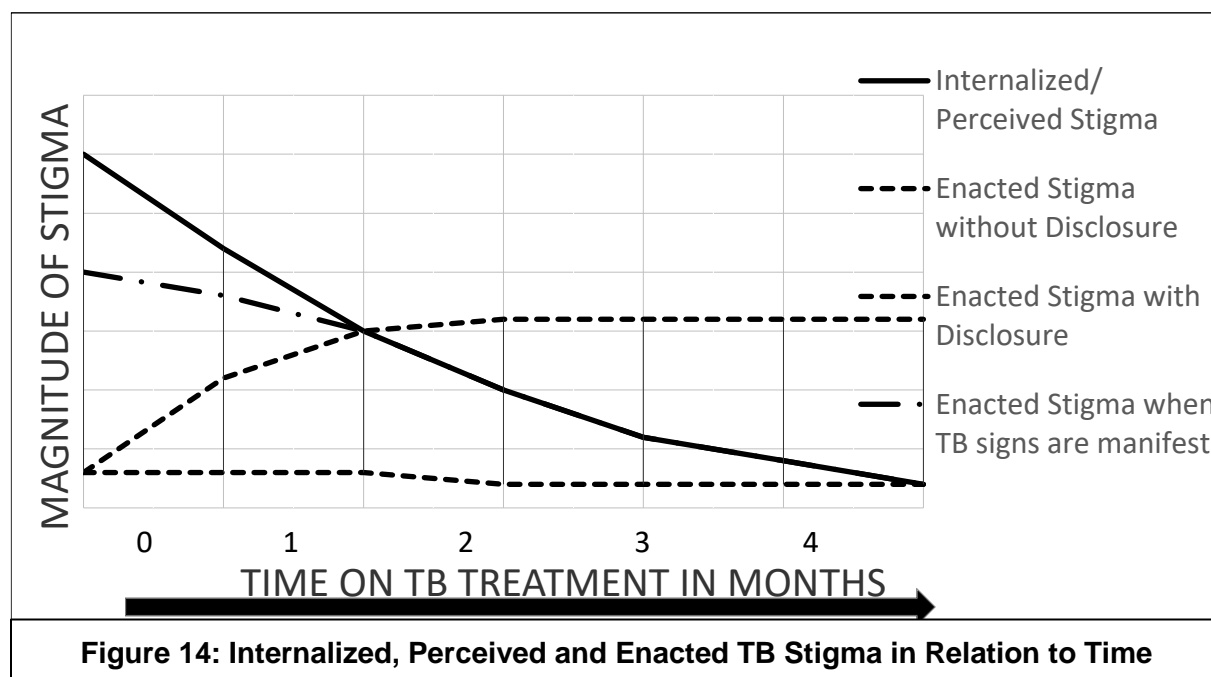
The overall underlying factor reducing TB stigma was a proper understanding of TB by individual TB patients as well as their community members. [Interview 4]: *“I understand the disease (TB). I will recover because people recover.”* [Interview 12]: *So they (close people, that can be family members, it can be a relationship partner and sometimes family members) have to be happy with you and they also have to understand the disease. They make it lighter for you and say ‘Yes, that is a small thing. That is not a big thing.’ TB nowadays is another small thing, not like the other days. So you have to get people who are....a strong foundation and people who are close to you.”*

(Figure 13B)

### **C. Internalized, Perceived and Enacted TB Stigma in Relation to Time**

TB stigma appeared to change based on time between diagnosis and treatment. Initially patients reported both internalized and perceived TB stigma especially prior to health education/treatment. Patients who had commenced treatment and noted clinical improvement tended to be more positive, with reduction in internalized/perceived stigma with time on TB treatment. [Interview 12]: *“It was a series of thoughts (that came to my mind in the last two months with TB). There were first thoughts, and they were too many thoughts. And they kept on reducing. And right now there are some thoughts also. At first, there were some thoughts that were negative: That I can lose my health at any time; TB is a disease that is so severe; and TB is a disease that you have to be treated for a very long time, and if you don’t take care of yourself very carefully, the treatment can backfire. So it made me get some phobia myself, but I controlled some thoughts after some help from the nurses here, and I got some awareness. And through taking the treatment, it happened for itself. It is not that I was given the awareness, it happened for itself. The drugs were working*

*in the body and then right now, those thoughts are not there. Now they are transformed to be positive.”*



Conversely, patients who reported persistent symptoms despite treatment tended to be negative. [Interview 10]: *“I am not far from people. Apart from now I have told you this disease, it is like, I think as if am doing zero work of using medication. Sometimes I feel pain because my children are small, so it is bad if there is no work that these medicines are doing. Because let us say I can leave my children, that is the only thing that is making me feel different. I continue using these medication and am not getting well. That is the only thing that makes me feel distant from people. It is increasing, so I think I might die, yet am using medication. But if this disease can be treated and I continue getting well and I improve, I cannot feel distant from people. I feel distant from people because of only that; am using medicines and am not getting well. Now it is like am doing nothing. But let us say, if I use the medicines and I get well, I cannot feel distant from people.”*

Participants tended to be more likely to disclose their TB status more over time, and if they shared their diagnoses with negative individuals, they experienced more enacted stigma. Similarly, less/no disclosure resulted in less/no enacted stigma. TB patients with manifest signs e.g. persistent cough, hemoptysis or weight loss, experienced enacted stigma much earlier even without disclosure of their TB status, and the enacted stigma decreased with time on TB treatment as the patient improved. (Figure 14)

### **Issues in Tool Structure**

From TB patients' responses during the cognitive interviews, redundancy and sub-optimal flow in the questions were noted. Although this study had a very narrow scope i.e. the 26-item SSCI, one of the patients suggested that we might gain richer responses if we simply asked about the thoughts of TB patients. Other participants reiterated that TB patients wanted to be listened to [Interview 10, 12, 16]. After introducing this open question first and re-ordering the questions for optimal flow, the interviews enabled us to glean a deeper understanding of TB stigma while still focusing on the 26-item of the SSCI. The duration of responses to this open question ranged from one to 13 minutes.

With regard to content, one TB patient pointed out explicitly that there was no specific question on the various levels of relationships including family, friends, co-workers and employers and suggested this addition [Interview 4]. This TB patient's observation further solidified our decision to include this dimension as it was found that support from various relationships was an important sub-theme of TB stigma that emerged from our data.

Another TB patient suggested that we include a question on TB treatment and outcomes. From the data, components that were brought up included treatment adherence, drug side effects, cure/recovery, non-cure/non-recovery and death. The most common aspects that were discussed

by the patients with regard to TB stigma were worry of not recovering and other people assuming they would die. We incorporated these latter two in the 8-item adapted SSCI, and included an 'other, specify' section for additional thoughts, worries or fears of TB patients.

Response option preferences in eight interviews were explored, asking TB patients to choose between a 5-point and a 3-point Likert scale of frequency of experiences ranging from never to always. Four of 8 patients preferred the 3-point Likert scale for its simplicity and brevity, especially because *"people had other things to do, like go to work"*. Two out of 8 patients preferred the 5-point Likert scale because it provided more options. One patient was ambivalent and another felt that this scale restricted her responses. Although most of these TB patients understood both Swahili and English, some felt the rating in English was simpler. All eight TB patients interviewed found it easy to point on a chart compared to having the options committed to memory or the health worker repeating the options after each question.

### **Patients' Acceptability to the Questions**

Most TB patients liked these questions and made it clear that they wanted to be listened to. They found the questions acceptable, relevant and helpful because they reduced the fear and provided a sense of relief and hope through unburdening. We questioned the influence of positionality of the interviewer being a health-worker when some patients stated that all the questions were good and *"you are a doctor"*. Despite this concern, we were encouraged that some TB patients were confident in stating which questions they found 'sensitive'.

Four TB patients did not find Question 6 acceptable, *"Do you think that because you have TB, people made fun of you?"* These patients were alarmed at how someone would make fun of one who was sick. *"They cannot make fun of me because it is a disease which is not your fault."* [Interview 15]. Some patients could relate to the superficial and deeper meanings of making fun

of TB patients. For example, there were TB patients who were told by their co-workers/friends “*Unadedi/Unaenda*”, Swahili slang to jokingly mean ‘you are dying’ [Interview 9, 20]. For others, the jokes were around wasting/weight loss. Although this question was omitted, questions relating to fear of death and appearance were retained.

One TB patient found Question 20, “*Do you think that because you have TB, you will blame yourself?*” and Question 21, “*Do you think that because you have TB, you will not make friends?*” to be sensitive [Interview 15]. These two questions were omitted, but related questions were retained: TB patients worrying about being a burden to others, and lack of support from friends leading to possible rejection/loss of friends.

**Table 10: Adapting the 26-Item SSCI into an 8-Item SSCI for English/Swahili Speaking TB Patients**

NO.	26-ITEM SSCI	ADAPTED 8-ITEM SSCI FOR TB-RELATED STIGMA	RATIONALE/JUSTIFICATION
1	<p>†You felt embarrassed in social situations [Q7] (8/20)</p> <p>†You worried about other people's attitudes towards you [Q10] (3/20)</p> <p><b>*You were unhappy about how your situation affected your appearance [Q12] (20/20: 10 unhappy; 10 fine)</b></p> <p>†You felt embarrassed about your situation [Q16] (5/20)</p> <p>†You felt embarrassed about your speech [Q18] (6/20)</p> <p>†You felt different from others [Q19] (1/20)</p>	<p><b>You were unhappy about how TB affected your appearance?</b></p> <p>*Reference to how TB affects appearance [20/20 interviews]</p> <ul style="list-style-type: none"> <li>• †Unhappy about appearance (10/20);</li> <li>• Fine with appearance (10/20)</li> </ul>	<p>We noted redundancy in questions 7, 10, 12, 16, 18 and 19 of the original SSCI from the patients' responses. Question 12 best captured aspects of embarrassment, unhappiness and the feeling of being different with regard to how TB affected the appearance of patients and was thus retained. Examples of unhappiness due to how TB affected patients' appearance included coughing (coughing continuously in social gatherings, coughing when speaking, and coughing blood); weight loss (looking very thin); and skin changes such as altered pigmentation/itchy skin that were adverse reactions of TB treatment.</p>
2	<p>Some people have seemed uncomfortable with you [Q1] (3/20)</p> <p>You felt distant from other people [Q3] (4/20)</p> <p>You felt left out of things [Q4] (3/20)</p> <p>You felt embarrassed in social situations [Q7] (1/20)</p> <p>You worried about other people's attitudes towards you [Q10] (1/20)</p> <p>You avoided making new friends [Q22] (1/20)</p>	<p><b>You avoided others for fear of infecting them with TB?</b></p> <p>Reference to avoiding others specific to fear of infecting them with TB [11/20 interviews]</p>	<p>Patients' responses from questions 3, 4, 10 and 22 on the feeling of being distant/left out/avoiding making new friends centered on avoiding others for fear of infecting them with TB, a major factor identified to be associated with TB stigma promotion. We thus modified these four related questions and included the phrase on 'fear of infecting them with TB' to be specific.</p>
3	<p>†You felt distant from other people [Q3] (1/20)</p> <p>†Some people have seemed uncomfortable with you [Q1] (1/20)</p> <p>People made fun of you [Q6] (2/20)</p> <p>†You felt embarrassed in social situations [Q7] (1/20)</p> <p>†Strangers tended to stare at you [Q9] (1/20)</p> <p>†You worried about other people's attitudes towards you [Q10] (3/20)</p> <p>†You were treated unfairly by others [Q11] (1/20)</p> <p>†You felt embarrassed about your situation [Q16] (2/20)</p>	<p><b>You worried that you will not recover from TB/ may die?</b></p> <p>Reference to TB treatment outcome of cure/non-recovery/death [20/20 interviews]</p> <ul style="list-style-type: none"> <li>• †Worried will die/not recover: [13/20]</li> <li>• Not worried i.e. positive about a TB cure [7/20]</li> </ul>	<p>A major emergent theme was fear of death or non-recovery apparent from unlikely questions such as 6, 9 and 10 and general conversation triggered by open questions. TB patients also recommended that a question on TB outcomes/treatment be included. We therefore included a new question specific to worry about death or non-recovery as there was no question on this in the original SSCI.</p>

NO.	26-ITEM SSCI	ADAPTED 8-ITEM SSCI FOR TB-RELATED STIGMA	RATIONALE/JUSTIFICATION
3	†You felt embarrassed because of your physical limitations [Q17] (2/20) †You avoided making new friends [Q22] (1/20) †You worried that people will tell others about your situation [Q24] (1/20) † Responses to open questions (2/20)		
4	†It was hard for you to stay neat and clean [Q13] (4/20) <b>*You worried that you were a burden to others [Q15]</b> (20/20: 12 burden; 8 not a burden) †You felt embarrassed about your situation [Q16] (3/20) †You felt embarrassed because of your physical limitations [Q17] (6/20) †You tended to blame yourself for your problems [Q20] (2/20)	<b>You worried that you were a burden (physically/ financially/ emotionally) to others?</b>  *Reference to burden[20/20 interviews] <ul style="list-style-type: none"> <li>• †Burden [12/20]               <ul style="list-style-type: none"> <li>○ Physical [8/20]</li> <li>○ Financial [7/20]</li> <li>○ Emotional [1/20]</li> <li>○ Not specified [2/20]</li> </ul> </li> <li>• Not a burden [8/20]</li> </ul>	Questions 16, 17 and 13 were redundant with patients' response centered on worry of being a physical burden. Patients distinguished that the context of being a burden went beyond the physical domain to include emotional and financial aspects, which patients distinguished. This worry of being a burden tended to result in patients blaming themselves for their problems. We therefore retained question 15 which captured the patients' responses best and modified it to include a category for patients to explicitly clarify the type of burden they were experiencing as this was not captured explicitly in the original SSCI.
5	<b>You were careful who you told about your situation [Q23]</b> (20/20) You worried that people will tell others about your situation [Q24] (20/20) Responses to open questions (1/20)	<b>You were careful who you told you have TB?</b> Reference to being careful on TB status disclosure or worry that people will tell others: [20/20 interviews] <ul style="list-style-type: none"> <li>• Disclosure of TB status [17/20]</li> <li>• Careful about disclosure [17/20]</li> <li>• Worried that people will tell others [16/20]</li> </ul>	Enacted stigma was influenced by disclosure. Disclosure of TB status was mainly influenced by the closeness of the friendship and HIV stigma. Question 23 and 24 were redundant and therefore question 23 was retained qualitatively and quantitatively.
6	Some people have seemed uncomfortable with you [Q1] (8/20) <b>Some people have avoided you [Q2]</b> (6/20) People were unkind to you [Q5] (3/20) People avoided looking at you [Q8] (3/20) You were treated unfairly by others [Q11] (4/20) You were careful who you told about your situation [Q23] (1/20)	<b>Some people avoided you, for fear of infecting them?</b>  Reference to some people avoiding TB patients specific to fear of infecting others with TB [16/20 interviews]	Fear of infection went both ways. TB patients experienced being avoided by others stemming from the community's fear of TB patients infecting them. Responses to this question also came up when questions 1, 5, 8, 11, and 26 came up implying redundancy. Avoidance occurred especially when patients had disclosed their TB status as from responses to questions 23 and 24. Question 2 of the original SSCI was retained and modified to include the phrase on 'fear of infecting them with TB

NO.	26-ITEM SSCI	ADAPTED 8-ITEM SSCI FOR TB-RELATED STIGMA	RATIONALE/JUSTIFICATION
6	<p>People in your situation lost their jobs when their employers found out about it [Q25] (1/20)</p> <p>You lost friends when you told them about your situation [Q26] (1/20)</p> <p>Responses to open questions (4/20)</p>		to be specific as done in question 2 of the adapted 8-item SSCI.
7	<p>Some people have avoided you [Q2] (1/20)</p> <p>You felt embarrassed in social situations [Q7] (2/20)</p> <p>Strangers tended to stare at you [Q9] (2/20)</p> <p>You worried about other people's attitudes towards you [Q10] (4/20)</p> <p>You were treated unfairly by others [Q11] (1/20)</p> <p>People tended to ignore your good points [Q14] (2/20)</p> <p>You felt embarrassed about your situation [Q16] (2/20)</p> <p>You felt embarrassed because of your physical limitations [Q17] (1/20)</p> <p>You felt different from others [Q19] (1/20)</p> <p>You tended to blame yourself for your problems [Q20] (2/20)</p> <p>You avoided making new friends [Q22] (1/20)</p> <p>You were careful who you told about your situation [Q23] (2/20)</p> <p>You worried that people will tell others about your situation [Q24] (2/20)</p> <p>Responses to open questions (3/20)</p>	<p><b>You worried that some people assumed you have HIV because you have TB?</b></p> <p>Reference to some people assuming you have HIV because you have TB [12/20 interviews]</p>	HIV stigma was a major factor that influenced TB stigma and disclosure of TB status. This emerged from patients' responses to questions 2, 7, 9, 10, 14, 16, 17, 19, 20, 22, 23 and 24, as well as responses to open questions. We therefore added a new question specific to the assumption of having HIV as there was no question on this in the original SSCI.
8	<p>People were unkind to you [Q5] (17/20)</p> <p>You were treated unfairly by others [Q11] (17/20)</p> <p>People tended to ignore your good points [Q14] (16/20)</p> <p>Some people acted as though it was your fault [Q21] (14/20)</p> <p>*You were careful who you told about your situation [Q23] (17/20)</p> <p>*You worried that people will tell others about your situation [Q24] (16/20)</p>	<p><b>Some people did not support you (physically/ emotionally/ financially) because you have TB?</b></p> <p>Reference to lack of support of any kind because of having TB: [20/20 interviews]</p> <p><input type="checkbox"/> Husband/Wife/ Boyfriend/Girlfriend (3/20)</p> <p>    He/she rejected/left me.(1/20)</p> <p><input type="checkbox"/> [Other] Family Members (4/20)</p>	<p>Similar to the question on worry about being a burden, patients distinguished that lack of support was manifested in various forms: physical, financial and emotional. Although there was no question specific to lack of support in the original SSCI, patients responses to questions 5, 11, 14, 21, 25 and 26 addressed this major factor identified to promote TB stigma.</p> <p>*Disclosure of TB status to others increased this form of enacted stigma as evident from responses to questions 23 and 24.</p>



NO.	26-ITEM SSCI	ADAPTED 8-ITEM SSCI FOR TB-RELATED STIGMA	RATIONALE/JUSTIFICATION
8	<p>You lost friends when you told them about your situation [Q26] (2/20)</p> <p>People in your situation lost their jobs when their employers found out about it [Q25] (20/20)</p>	<p>Some rejected/left me. (3/20)</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Friends (17/20) Some rejected/left me. (2/20)</li> <li><input type="checkbox"/> Co-workers/Schoolmates (3/20) Some rejected/left me. (1/20)</li> <li><input type="checkbox"/> Employer/Teacher/Warden* (3/20) I was fired from work/ chased from school.(0/20)</li> </ul>	<p>According to the TB patients, the closer the relationship, the more it hurt if there was lack of support. Similar to distinguishing the various forms of support, TB patients also distinguished the various types of relationships which fell into five general categories focusing on intimate, family and workplace relationships. The most extreme form of lack of support in a relationship was rejection/abandonment; or being fired from work.</p> <p>Although all TB patients felt that other TB patients may lose their jobs when their employers find out about their TB status, none of the TB patients had been fired from work because of TB.</p>

**Table 11: Adapted 8-Item SSCI for English/Swahili Speaking Patients with Tuberculosis**

<p><b>Q. A and B are to elicit UNPROMPTED RESPONSES-ALLOW TIME and Tick Boxes to the Left appropriately. If present ASK “HOW OFTEN DID IT OCCUR?” “ILITOEKA MARA NGAPI?”</b></p> <p><b>RANKING:</b> 0-Never (Haikuwahi Tokea); 1-Rarely (Mara Chache); 2 – Sometimes (Wakati Mwingine); 3 – Often (Mara Mingi); 4 – Always (Kila Wakati). You can show the patient a CHART.</p> <p>Probe questions are in parenthesis with an asterisk [*]. Only ask the probe questions <u>after the patient has completed answering Questions A and B freely. Ensure proper question intonation.</u></p>					
<p><b>[*This last 1 month. (Je, katika mwezi huu mmoja ambao umepita):-]</b></p>					
<p><b>A. WHAT worries/fears/thoughts did you have, because you have TB? Ulikuwa na wasiwasi/hofu/fikira GANI, kwa sababu una TB?</b></p>					
<p><b>B. IS THERE ANYONE whom you were careful telling you have TB? KUNA YEYOTE ambaye ulikuwa mwangalifu kumwambia una TB?</b></p>					
<p><b>1. WHO (NANI)?</b> .....</p>					
<p><b>2. WHY (KWA NINI)?</b> .....</p>					
<p><b>3. HOW OFTEN DID IT OCCUR? (ILITOEKA MARA NGAPI?) [† Rank Q5]</b></p>					
0	1	2	3	4	
1	<input type="checkbox"/>	<p><b>I was unhappy about how TB affected my appearance. Sikufurahia jinsi TB ilivyoathiri ninavyoonekana.</b> [*Were you unhappy about how TB affected your appearance? (Ulihi hauna furaha kwa sababu ya jinsi TB ilivyoathiri ulivyoonekana?)]</p> <p><input type="checkbox"/> <b>HW Action:</b> THE SITUATION IS TEMPORARY WITH PROPER TREATMENT (HALI HII NI YA MUDA MFUPI UKITUMIA DAWA VIZURI)</p>			
2	<input type="checkbox"/>	<p><b>I avoided others/kept my distance from others for fear that I will infect them with TB. Niliwaepuka watu wengine/nilikaa mbali na watu wengine kwa hofu kwamba nitawaambukiza TB.</b> [*Did you avoid others for fear that you will infect them with TB? (Ulihepa wengine kwa hofu kwamba utawaambukiza na TB?)]</p> <p><input type="checkbox"/> <b>HW Action:</b> I WILL TEACH YOU HOW TO AVOID SPREADING YOUR TB TO OTHERS (NITAKUFUNZA JINSI YA KUZUIA KUAMBUKIZA TB YAKO)</p>			
3	<input type="checkbox"/>	<p><b>I was afraid that I will not recover from TB/ that I may die. Niliikuwa na hofu kwamba sitapona TB/ ninaweza kufa kutoka TB.</b> [*Were you afraid that you will not recover from TB/ that you will die? (Ulikuwa na hofu kwamba hutapona TB/ unaweza kufa kutoka TB?)]</p> <p><input type="checkbox"/> <b>HW Action:</b> WE WILL GIVE YOU MEDICINE THAT WILL CURE YOU, IF YOU TAKE THEM CORRECTLY. (TUTAKUPA DAWA ZITAKAZO KUPONYA, UKITUMIA VIZURI)</p>			
4	<input type="checkbox"/>	<p><b>I worried that I was a burden to others. Niliikuwa na wasiwasi kwamba nilikuwa mzigo kwa wengine.</b> [*Did you worry that you were a burden to others? (Ulikuwa na wasiwasi kwamba ulikuwa mzigo kwa wengine?)]</p> <p><input type="checkbox"/> <b>HW Action:</b> BY THE SECOND WEEK OF THIS MEDICATION, YOU WILL BE FEELING BETTER AND GET STRONGER (KWA WIKI YA PILI YA KUTUMIA HIZI DAWA, UTAJISKIA VIZURI ZAIDI NA KUPATA NGUVU.)</p>			
5	<input type="checkbox"/>	<p><b>I was careful who I told I have TB. Niliikuwa mwangalifu kuhusu niliyemwambia kwamba nina TB.</b></p>			

[*This last 1 month, (Je, katika mwezi huu mmoja ambao umepita):-]		0	1	2	3	4
<p>C. <b>WHAT worries/fears/thoughts did you have</b>, because you have TB? <b>Ulikuwa na wasiwasi/hofu/fikira GANI</b>, kwa sababu una TB?</p> <p>D. <b>IS THERE ANYONE</b> whom you were careful telling you have TB? <b>KUNA YEYOTE</b> ambaye ulikuwa mwangalifu kumwambia una TB?</p> <p>1. <b>WHO (NANI)?</b> .....</p> <p>2. <b>WHY (KWA NINI)?</b> .....</p> <p><b>HOW OFTEN DID IT OCCUR? (LITOKEA MARA NGAPI?)</b> [± Rank Q5]</p>						
6	<input type="checkbox"/> I worried that some people assumed I have HIV because I have TB. <b>Nilikuwa na wasiwasi</b> kwamba watu wengine walifikiri nina HIV kwa sababu nina TB. [*Did you worry that some people assumed you have HIV because you have TB? (Ulikuwa na wasiwasi kwamba watu wengine walifikiri uko na HIV kwa sababu uko na TB?)] <input type="checkbox"/> <b>HW Action:</b> <i>Based on the patient's HIV test results:</i> <b>HIV POSITIVE:</b> WE ARE GOING TO WALK WITH YOU THROUGH THIS AND MANAGE HIV SO THAT YOU LIVE A NORMAL LIFE (TUTATEMBEA NA WEWE KWA HAYA NA KUKUPA MATIBABU YA HIV ILI UISHI MAISHA YA KAWAIDA) <b>HIV NEGATIVE:</b> NOT EVERYONE WITH TB HAS HIV, REMAIN HIV NEGATIVE (SI KILA MTU ALIYE NA TB ANA HIV, BAKI HIV NEGATIVE)					
7	<input type="checkbox"/> <b>Some people avoided me/kept their distance</b> from me, for fear of infecting them with TB. <b>Watu wengine walinihepa/walikaa mbali</b> na mimi, <b>wakihofu kwamba nitawaambukiza TB</b> . [*Did some people avoid/keep their distance from you, for fear of infecting them with TB? (Kuna watu wengine walikuhepa/walikaa mbali na wewe, wakihofu kwamba utawaambukiza TB?)] <input type="checkbox"/> <b>HW Action:</b> I WILL TEACH YOU HOW TO AVOID SPREADING YOUR TB TO OTHERS (NITAKUFUNZA JINSI YA KUZUIA KUAMBUKIZA TB YAKO)					
8	<input type="checkbox"/> <b>Some people did not support me.</b> ( <input type="checkbox"/> physically [P] / <input type="checkbox"/> emotionally [E] / <input type="checkbox"/> financially [F] ) because I have TB. <b>Watu wengine hawakunipatia msaada</b> (kunisaidia na kazi/ kihisia/ kifedha) kwa sababu nina TB. [*circle P, E or F as appropriate if prompted] [*Did some people not support you (physically/emotionally/financially) because you have TB? [ <i>Probe</i> ] <b>Who? Did they reject/leave you?</b> (Kuna watu wengine hawakukupatia msaada (kukusaidia na kazi/kihisia/kifedha) kwa sababu una TB?)] [ <i>Probe</i> ] <b>Nani? Je walikuacha/walikukataa?</b> <input type="checkbox"/> <b>HW Action:</b> THE SITUATION IS TEMPORARY WITH PROPER TREATMENT (HALI HII NI YA MUDA MFUPI UKITUMIA DAWA VIZURI)					
8a	<input type="checkbox"/> <b>Spouse/Boyfriend/Girlfriend (Bwana/Bibi/Rafiki wa kimapenzi).</b> <input type="checkbox"/> He/she rejected/left me. (Alinikataa/aliniacha.) [* Y N ]					
8b	<input type="checkbox"/> <b>[Other] Family Members (Wanafamilia [wengine]).</b> <input type="checkbox"/> Some rejected me. (Watu wengine walinikataa.) [* Y N ]					
8c	<input type="checkbox"/> <b>Friends (Marafiki).</b> <input type="checkbox"/> Some rejected/left me. (Watu wengine walinikataa/waliniacha.) [* Y N ]					
8d	<input type="checkbox"/> <b>Co-workers/Schoolmates (Unaofanya kazi nao/unaoenda shule nao).</b> <input type="checkbox"/> Some rejected me. (Watu wengine walinikataa.) [* Y N ]					
8e	<input type="checkbox"/> <b>Employer/Teacher/ Warden (Mwajiri/ Mwalimu/ Msimamizi Gerezani).</b> <input type="checkbox"/> I was fired from work/ chased from school. (Nilifutwa kazi/ nilifukuzwa kutoka shule) [* Y N ]					
	<input type="checkbox"/> <b>Other, specify</b> (Nyingine, fafanua):					

**Table 12: Major Themes Emerging from Data Analysis of Cognitive Interviews in the Adaptation of the 26-Item Scale for Chronic Illness (SSCI) into an 8-Item SSCI for English/Swahili Speaking TB Patients**

QUESTION	EXCERPTS
<b>Translation and Meaning</b>	
<p>Question 8: “Do you think that because you have TB, people avoided looking at you?” translated into Swahili as “Je, unafikiri kwa sababu uko na TB, watu waliacha kukuangalia”</p>	<p>Interpreted to mean: “Do you think that because you have TB, people avoided visiting you?” [Interview 6, 10, 14, 16, 18 and 20] Revised to: “Je, unafikiri kwa sababu uko na TB, watu waliacha kukuangalia usoni/machoni”</p>
<p>Question 22: “Do you think that because you have TB, you avoided making new friends?” translated to “Je, unafikiri kwa sababu uko na TB, umeepuka kufanya marafiki wapya?”</p>	<p>Interpreted to mean: “Do you think that because you have TB, you avoided making new general friends/romantic friends?” [Interview 16 and 18]</p>
<p>Question 17, “Do you think that because you have TB, you felt embarrassed because of your physical limitations?” translated into Swahili as “You felt embarrassed because of your physical limitations”</p>	<p>Interpreted to mean: “Do you think that because you have TB, you felt embarrassed because of your ‘weight loss’?” [Interviews 5, 12 and 14] Revised to: “Do you think that because you have TB, you have felt embarrassed because you were unable to do the activities/things you used to do (at home, school or work)?” and “Je, unafikiri kwa sababu uko na TB, umeona aibu kwa sababu umeshindwa kufanya kazi au mambo uliyokuwa ukifanya (nyumbani, shuleni au kazini)?” in Swahili.</p>
<p>Question 4: “Do you think that because you have TB, you felt left out of things?” translated into Swahili as “Je, unafikiri kwa sababu uko na TB, umehisi umeachwa nje ya mambo?”</p>	<p>Interpreted to mean: ‘felt left behind’ Revised to: “Je, unafikiri kwa sababu uko na TB, umehisi umeachwa nje ya mambo/ umehisi kuwa unatengwa katika mambo?”</p>

QUESTION	EXCERPTS
<p>Question 10: “Do you think that because you have TB, you worried about other people’s attitudes towards you?” translated into Swahili as “Je, unafikiri kwa sababu uko na TB, umekuwa na wasiwasi kuhusu mitazamo ya watu wengine juu yako?”</p>	<p>Initially difficult to understand in Interview 1. This question was further optimized to “Je, unafikiri kwa sababu uko na TB, umekuwa na wasiwasi juu ya mtazamo wa watu kukuhusu/umekuwa na wasiwasi kuhusu jinsi watu wanavyokufikiria?” back translated into English as, “Do you think that because you have TB, you have worried about how people perceive you/think of you?”</p>
<b>Relevance in the context of TB</b>	
<p>Question 18: “Do you think that because you have TB, you felt embarrassed about your speech?”</p>	<p>[Interview 3]: “In terms of sickness, I don’t really get it. People will not understand, Speech! Really? I think because for the rest of the questions I have never experienced them but still I could imagine for somebody who has TB, [but for this question] I cannot relate.”</p> <p>[Interview 9]: “I think speech and appearance is the same thing. If my appearance is without talking, it is not meaningful. My appearance is seen when I talk but speech alone, I don’t see.”</p> <p>[Interview 12]: “The tone of my speech, the content of my speech or what? Yes because you can talk, you can decide to express yourself in front of your friends, when you try make a statement and in seconds you start coughing, they don’t understand, then you try to finish the statement and you cough again. So it will be difficult to express yourself so it will tamper with your social...you know. (Also) The voice tends to hoarse and sometimes goes because of the congestion of...you know, the so many things going on in the chest. So it will affect the throat so when you talk like that it irritates some people.”</p> <p>[Interview 10]: “If people know that you have TB, it is a must you feel embarrassed, because people will not be keen on what you are telling them even if you are making a point as you speak, they see as if there is nothing you are saying.”</p>
<p>Question 13: “Do you think that because you have TB, it was hard to stay neat and clean?”</p>	<p>[Interview 9]: “According to me there is a possibility but I try so that I won’t be somebody who is not clean because you find that sometimes after taking these drugs your strength goes, you feel tired so there is something that I am supposed to do so that I be neat but I feel tired. I start being lazy. I feel fatigue, but I have personally refused. I must be neat, so there is possibility, but me I refuse.”</p> <p>[Interview 12]: “There is no way TB can make you, you know...unless you are very careless and you don’t have attention but not if you can walk to a distance between the bed and the bathroom. Alcoholics are people who can go to an extent of losing their hygienic practices but someone who is more conscious and strong can you know...and even cleanliness can help in body temperature, when you go and take a bath you feel good and if you don’t take a bath you know you get the fever, the side effects of the drugs and the body temperature, you can get a fever.”</p>

QUESTION	EXCERPTS
<b>Relevance in the context of TB</b>	
	<p>[Interview 13]: <i>"It happened a few times. My TB had affected my legs so I was not able to stand and it is a must you bathe. You are put for water, so when you go to bathe, you sit, pour water for yourself and come out. Sometimes you have pain in the chest you cannot bend, you wipe yourself and come out."</i></p>
<p>Question 9: <i>"Do you think that because you have TB, strangers tended to stare at you?"</i></p>	<p>[Interview 12]: <i>"Strangers are people you don't know and people you don't know are people who don't know anything about you. People who don't know anything about you, when they look at you in a bad way, you don't think it is TB first. You think in another way. Maybe this person is a policeman, or maybe this person is a security guard, maybe this person is a mugger. So you will think it is abnormal, but you will not take the perspective that it is related with the disease. So that question I cannot answer it. In my view, I was just saying how I got the question. It doesn't apply."</i></p> <p>[Interview 18]: <i>"When I didn't have strength they used to look at me so much, and whenever I passed them, they'd stand to talk asking: 'Which disease is this? The hair itself has finished.' Some say some things like: 'This is AIDS!' They would tell me not to catch their things with my hands. They used to fear me. Even now is when they are talking to me because they see I am recovering."</i></p> <p>[Interview 4]: <i>"When you are somewhere and then you cough a lot, people look at you and say 'Eeh! Is this one dying or what?'"</i></p> <p>[Interview 14]: <i>"I don't think so. You know it does not show in the face that you are sick. Right now, do I look sick? You cannot tell."</i></p>
<p>Question 13: <i>"Do you think that because you have TB, people tended to ignore your good points?"</i></p>	<p>[Interview 3]: <i>"It does not apply to anyone who is sick..... I cannot relate."</i></p> <p>[Interview 4]: <i>"For example, when you are in a place talking or contributing something, people tell you: 'Aah! That one has TB, there is nothing he/she is saying.'"</i></p> <p>[Interview 5]: <i>"Yes, they can ignore because they can see this one, it is like he/she is going (dying)."</i></p>

QUESTION	EXCERPTS
<p><b>A. Factors Promoting Stigma in TB patients</b></p>	
<p>Worries about change in appearance</p>	<p>[Interview 20]: <i>"Let us say you were 70kg and then you become 50kg. Your body weight will have reduced so much that those that know me will definitely see that change. What will they think about you? They think even you, now you are dying."</i></p> <p>[Interview 16]: <i>"The day before yesterday there is another madam I met and she asked me why I have started being dark. She told me I am no longer brown the way I used to be before. I had started being dark. She just asked me like that. I told her: 'Maybe there are those medicines I am taking for TB, maybe they are the ones making my colour change, I cannot explain what it is.' That one I felt it (worry) somehow, until I asked myself if people have started seeing me as being dark or what is going on."</i></p> <p>[Interview 18]: <i>"I felt embarrassed (about my situation) because now my hair had fallen out. My eyes were sunken, I didn't have strength. I was not able to go up the stairs. I was being blown by the wind, I'd fall down."</i></p>
<p>Fear of infecting others and others fearing being infected by patients with TB</p>	<p>[Interview 17]: <i>"You know I don't want to infect my husband (with TB), so I told him that the doctor refused us to share the same bed until I complete my treatment."</i></p> <p>[Interview 9]: <i>"Your husband or wife can start to exclude you or stay far from you. He/she may change the bed...Yes, sleeps in a different bed because he/she thinks that you will infect him/her...I have seen one case like this one, where the husband is the one who changed the blanket. That brings about a lot of stigma if my husband doesn't want to share the same blanket with me (because I have TB)."</i></p> <p>[Interview 4]: <i>"There are times they (others) can exclude me and say: 'This one, I cannot stay with him the whole day. Perhaps (I can stay with him) while watching TV. TB is airborne so I can get it.' Sometimes they can exclude but not every time."</i></p> <p>[Interview 10]: <i>"They don't want you to unite with them, so that you don't infect them. So you are like something that is excluded already. They are trying to avoid you a lot because they fear you will infect them."</i></p>
<p>Fear of death or not recovering</p>	<p>[Interview 9]: <i>"This disease, which is taking months to be treated, is not like malaria which is treated within a day or two days, it is a disease that takes some months to treat... The way it was in my mind is that TB is a disease that kills somebody; if you get TB you die."</i></p> <p>[Interview 10]: <i>"If you have no guarantee of recovering, why make new friends? You are going (dying). This disease is killing people. According to me, I don't see if there will be a day that TB will come to end because like now I have taken medicine for three or four months and there is no improvement. So I don't see if there is any help I get by taking these medicines, because I believe there is no day that will come and I will feel well. So even if we make friends....but if I recover then I can make (friends) but for now I have not made friends, maybe you... This (TB) is something even if you are told that right now it will cost ten million or even five, you will know how you will get it. At least you get that five so that you get well because it is not something to praise. It (TB) is bad. Even when somebody has TB, they don't want their colleagues to know they have TB."</i></p>

	<p>[Interview 13]: <i>"Mine (my embarrassment) is just because I have never had TB and I am coughing, and in my family nobody else ever got TB. Now I am thinking I will die and leave them."</i></p>
<p>HIV Stigma</p>	<p>[Interview 16]: <i>"Long ago, when I heard that somebody was sick from TB, I used to 'hear' that that person is leaving us (dying). I heard my mother one day saying when we were just at home, that nowadays if you hear somebody has TB, that is HIV/AIDS."</i></p> <p>[Interview 13]: <i>"(My embarrassment is) with that AIDS. Because every time I went to the hospital I was told to get tested for HIV. I didn't know TB. I used to know HIV before TB appeared... I went to three hospitals before I knew I have TB. Yes (every hospital tested me for HIV) till I was surprised. When you look at me like this, do you think I have AIDS?"</i></p> <p>[Interview 10]: <i>"That name (TB) is bad, just pronouncing it alone. That person who has malaria - malaria is better off; or somebody who has allergy, that is better. But when it comes to HIV or TB, that one is bad! Right now if you want to disagree with somebody don't bother telling him/her a lot of things. Try and talk with him/her a little bit and tell him/her you have TB, he/she will avoid you right at that moment. Even when you want to avoid somebody when you don't have TB, just tell him/her that you have TB or you have HIV, they will avoid you from that moment."</i></p>
<p>Lack of support from family, friends, co-workers, employers and/or health workers</p>	<p>[Interview 3]: <i>"I know my sister never came back (home) when I was sick. For the sake of her kids she avoided coming home. Maybe she didn't understand when she heard in [Facility Z] that it is airborne, so she really kept the distance. Maybe she could be communicating and maybe talking to me and not making me feel that I am a burden. So I wonder: What is the reason that is keeping her away from me? Is it the fear that maybe she has helped me and now she is tired or is she scared that she will get infected?"</i></p> <p>[Interview 5]: <i>"Yes, (because I have TB, I am worried) I will be a burden (to others) because I might have stopped working and now I might stress them. I might a burden to them because maybe I'm not working, because I'm so sick so they will look after me by giving me money for food, money for transport, so they will see me as a burden to them."</i></p> <p>[Interview 10]: <i>"Yes there is discrimination (because I have TB, I have been treated unfairly by others). Like in our plot, I cannot spit my saliva in the toilet. Even my sputum, I cannot spit. It cannot even be seen by anybody, because now (they know) I'm the one who coughs every day. If somebody else comes to the toilet and spits the sputum, people will say it is me who spits the sputum. So it is a must for people to discriminate you. That you did that. Even if you try to do good, people must discriminate you. I don't know if you get me"</i></p> <p>[Interview 18]: <i>"My colleagues who previously used to look for casual jobs for me (before my illness) would deny me work. They'd say: 'This one cannot lift metal. This one is sick.' I used to feel bad. Even now I feel bad. There is a place (where they usually are) that I don't pass. If I pass (that place) they look at me like this (facial expression displaying surprise) and say (in my mother tongue): 'God, he got well. He will not die!'"</i></p> <p>[Interview 10]: <i>"Even the doctors themselves, in their minds they don't remember that this disease was brought to you. They think you are the one who brought it upon yourself."</i></p>



QUESTION	EXCERPTS
<p><b>A. Factors Promoting Stigma in TB patients</b></p>	
<p>Disclosure of TB Status</p>	<p>[Interview 15]: <i>"You know you cannot tell everybody (that you have TB) because some are not friends. There are friends who give you advice, and those that you stay with, those you eat with (those are the ones) you can tell properly what you have (TB)."</i></p> <p>[Interview 9]: <i>"So my embarrassment is the way I used to take others. So it (TB) has come to me. The way I used to think about others (with TB) is the same way they are now thinking about me. ...Even telling people right now, somebody who is not a close friend or maybe can be a friend, that I have TB is not easy, because I feel embarrassed. I feel bad. You feel like...it is a bad disease. It is like HIV according to me. Those are my thoughts. According to me I see as if it is HIV."</i></p>
<p>Lack of a proper understanding of TB</p>	<p>[Interview 18]: <i>"The reason they were running from me is (because) there is a day I coughed blood. I was at home, at my mother's place. Now on coughing blood, my brother saw. He gave an order that even food, when I go there, I be given with my plate and it is put aside. When I come, I am given (food) with it (that plate)... The cup itself that they put tea for me, is thrown in the toilet."</i></p> <p>[Interview 4]: <i>"My friends told me that: 'You personally wanted to get it (TB) because you were smoking cigarettes, and we warned you. It is your mistake! If you would have not done this (smoked cigarettes) you would not have this disease (TB)."</i></p> <p>[Interview 1]: <i>"They (people) don't want to come near me because they have heard I have TB. People don't lack such kind of behaviours but I usually tell God that this disease infected my brother when I was very young and we used to eat from the same plate. So if he (my brother) was the one infecting me, he would have done that a long time ago. But I have gotten this disease when I am old. I don't know what happened because sometimes you wonder when things happened, but you don't get the answer. I have gotten this disease (TB) when my grandchildren are old and my last born is in form two, yet I would have been infected earlier on. But because the devil had his own plans, I became infected when I was too old... It is said that this disease is spread by air but I tell God that is a lie because the child who is now 13 years old, I started to take care of her when she was very small...I have never thought that she can be infected. So the person who thinks like that, that is his/her own problem."</i></p>

QUESTION	EXCERPTS
<p><b>B. Factors Reducing Stigma in TB patients</b></p>	<p>Support from family, friends, co-workers, employers and belief in God</p> <p>[Interview 18]: <i>“Yes (it was hard for me to stay neat and clean) because when I was very sick I never used to bathe, because If I wash my body I’d feel cold and cough. But now I am bathing very well and I’m able to apply oil on myself. (Before) I even used to defecate in the house. I’d defecate in the basin. I used to make my children do hard work of pouring the faeces. (But things) changed when my sister brought me here (to this health facility). When I started taking the medicines, the medicines started working in my body and I started to touch water. I was bathed for like one month, then I started bathing myself and I stopped defecating in the house.”</i></p> <p>[Interview 12]: <i>“No, as for me no (I did not feel embarrassed about my situation) because I knew people who (had TB).....I had a very good idea about TB. At first I was in denial, it was hard to believe I had TB, but when it came to my mind that I have it (TB), I now concentrated on getting healed. (I learnt about TB) through people who experienced it, through some awareness programmes and through some advertisements but mostly through people; people with experience. Yes (some of them were my friends) because I live in a place where there are many people. I live in the other part of town. So you get people here with this disease, so many people with the disease. So, many are friends with TB.”</i></p> <p>[Interview 1]: <i>“I have one friend of mine an army woman, even the husband is an officer. She tells me that: I should not care; I can even go and eat and drink at her place; and all this I am going through is about God. They are saved and they love me. They told me to leave people to say what they want to say. They are close to me. She even comes to my place and we eat and drink.”</i></p> <p>[Interview 19]: <i>“Even when I fell sick I told my employer. My employer and co-workers just saw me coughing blood. They were shocked. I told them not to worry, ‘it is TB’.... But I think my employer considered it to be abnormal. ‘I am taking you to the hospital’. My employer took me to the hospital because he saw it was not normal, but I knew it was TB.”</i></p>
<p>Support from Health Workers</p>	<p>[Interview 1]: <i>“Right now am okay. There was a time I was bad until my face was black, but I still used to go (to social functions) and if anyone asked a question (regarding the change in colour in my face), I would tell them with great pleasure that it (my face) was just the way they were seeing. I didn’t put that in the mind because I knew TB is a disease like other diseases. It is just like the flu which you recover. The doctor who started to give me medication told me to put cotton wool in my ears because I will hear a lot from people. ‘But if you are a free person you will not think about it.’ He even showed me his friend who was fat and living well because he did not think about it.”</i></p> <p>[Interview 17]: <i>“(When I learnt that I have TB), I thought I will either die or recover because I have never gotten it (TB). I went and asked the doctor. The doctor told me: ‘Have faith and you will be well’. (The doctor told me that) If I use those medicines correctly, I would recover... So from that point I had faith. So I don’t have bad thoughts. I have thoughts of telling God to heal me. I don’t have any bad thoughts. I am totally free. I don’t have any bad thoughts, I only think good thoughts.”</i></p>

QUESTION	EXCERPTS
<p><b>B. Factors Reducing Stigma in TB patients</b></p>	<p>Self-Efficacy and Self-Esteem (Inner Strength/ Inner Courage)</p> <p>[Interview 4]: <i>"I understand the disease (TB). I will recover because people recover..... I cannot be a burden to others because I depend on myself."</i></p> <p>[Interview 16]: <i>"I came to understand that you can have TB but you don't have HIV. I came to know it is a disease that can be treated if you follow the instructions, and you recover."</i></p> <p>[Interview 6]: <i>"I cannot feel embarrassed. It (TB) is a disease like any other and I am not the first to get it."</i></p> <p>[Interview 19]: <i>"The first thing you can tell somebody is 'I have TB, and if you see me going on this side, don't follow me. Maybe I am going to cough and if you come where I am, maybe I will infect you.' Now friendship is a must. Make friends with people, but take care you don't infect people."</i></p> <p>[Interview 10]: <i>You feel embarrassed (in social situations) but you are not to admit that embarrassment. If you admit the embarrassment, you will not be able to continue with your life."</i></p> <p>[Interview 9]: <i>"There are people who will look at you and they don't accept you, even if you have good points. But because you have TB, they just refuse. For example, there is what we call self-esteem. When I see myself to be inferior, I can start doing things in a way that I see myself inferior. So when I make myself inferior, this other person can also view me as useless, I am not somebody who can do something in a way it should. Then there is, I have been found with a disease, as I had said, let me repeat, some take it as if I can be infected if I sit near that person. So you want to exclude yourself and stay far a bit. So that (good quality/point) which can be of help or of value to somebody else, he/she starts ignoring it. He/she starts looking for it from somebody else because if they see me sitting near them, they think they will be infected with such a disease."</i></p>

QUESTION	EXCERPTS
<p><b>C. Time</b></p>	<p>[Interview 15]: <i>“(Because I have TB, I will feel distant from people) for a short period of time. For a period of like 14 days. If you take the medicines, when you come near these other people, they cannot be infected with this disease because you are taking medicines...If I use them (TB medication) the way I am being told, I will recover.”</i></p> <p>[Interview 12]: <i>“I have had TB for the last two months...At first there were some thoughts that were negative. (I thought) that I can lose my health any time. TB is a disease that is so severe and TB is a disease that you have to be treated for a very long time. And if you don’t take care of yourself very carefully, the treatment can backfire. So it made me get some phobia myself, but I controlled some thoughts after some help from the nurses here, and I got some awareness. And through taking the treatment it happened for itself... The drugs were working in the body and then right now, those thoughts are not there. Now they are transformed to be positive.”</i></p> <p>[Interview 10]: <i>“The only thing that is making me feel different is that I continue using these medication and am not getting well. That is the only thing that makes me feel distant from people. It is increasing, so I think I might die yet am using medication. But if this disease can be treated and I continue getting well and I improve, I cannot feel distant from people.....You know I usually help people a lot. Nobody has ever known that I have TB, because even if I have TB I have never told anybody. So there is nothing that can have reduced (my relationship) between me and people because I have never told anybody. They know it is (an) allergy but nobody knows it is TB.”</i></p>
<b>Patients’ Acceptability to the Questions</b>	
<p>Most questions were acceptable to TB patients.</p>	<p>[Interview 16]: <i>“All these questions are according to the health of your body, when you were not sick and now when you are sick. Now when I am sick let us say me, all these questions you have asked me, I think they are fit because every question you have asked me even if I don’t have it, I think there are many people who are thinking a lot of things in their minds.”</i></p> <p>[Interview 3]: <i>“I would have loved to be asked these questions because it helps you to make other people understand more about what you are going through and how maybe you would want to be treated. And what maybe hurts you because you are also sick. If you are sick what makes you better is when people understand you and what you are going through, because sometimes people might do things and they don’t know they are hurting you.”</i></p> <p>[Interview 5]: <i>“If a Doctor/Nurse requested, me I would answer (these questions).”</i></p>

QUESTION	EXCERPTS
<b>Patients' Acceptability to the Questions</b>	
<p>Question 6: "Do you think that because you have TB, people made fun of you?" translated in to Swahili as "Je, unafikiri kwa sababu uko na TB, watu wengine walikuchekelea?"</p>	<p>"They cannot make fun of me because it is a disease which is not your fault." [Interview 15] The responses were similar to the questions we earlier documented with divergent responses.</p> <p>Other patients could relate to the superficial and deeper meanings of making fun of TB patients. For example, there were patients who were told by their co-workers/friends "Unadedi" or "Unaenda", Swahili slang to mean 'you are dying', or "You remove your disease from here!" because they had TB [Interview 9, 20; 18].</p> <p>For others, the jokes were around wasting/weight loss and TB patients would be told things such as: "Are you on hunger strike?" [Interview 13].</p>
<p>Question 20: "Do you think that because you have TB, you will blame yourself?" translated in to Swahili as "Je, unafikiri kwa sababu uko na TB, utajilaumu kwa ugonjwa wako?"</p>	<p>The patient felt that this question makes the person feel bad, and suggested the inclusion of the word 'may' translated to "unaweza" in Swahili.</p>
<p>Question 21: "Do you think that because you have TB, you will not make friends?" translated in to Swahili as "Je, unafikiri kwa sababu uko na TB, hautatengeneza marafiki?"</p>	<p>A suggestion to include the word 'perhaps' translating to "pengine" in Swahili was made.</p>

## **CHAPTER 8**

### **DISCUSSION**

In this multi-method qualitative study, it is evident that TB contact screening occurs in Nairobi County, Kenya, however gaps exist, specifically a lack of TB-CI specific SOPs, and sub-optimal documentation and linkage of TB-CI activities. I have utilized findings from stakeholder perspectives and facility observations to design (i) an innovative operational framework for TB-CI optimization at the program level, (ii) a process mapping tool to systematically assess TB-CI activities at the health facility/community level, and (iii) a practical script embedded in SOPs for HWs to improve health information captured when interacting with individual TB patients and contacts and enable provision of patient-centered TB-CI actions. Finally, I learnt that TB-related stigma is a key barrier to TB care in our context and is mainly driven by a poor understanding of TB. The research team successfully adapted the 26-item SSCI to an 8-item tool to measure TB-related stigma in English/Swahili speaking patients. The utility of the operational TB-CI framework, specific TB-CI tools, and the adapted stigma tool developed from this work will be tested in a larger prospective study, as the next phase of this project.

### **FACILITATORS, BARRIERS AND POTENTIAL SOLUTIONS TO TB CONTACT**

#### **INVESTIGATION IN NAIROBI COUNTY, KENYA**

Through the lens of TB patients attending public TB clinics, HWs in these facilities and key informants, I have evaluated and described how TB-CI is undertaken in the capital city of a high TB/HIV burden country. Although CI has traditionally not been part of TB control efforts in LMICs (13), most TB patients in this context brought or encouraged their contacts to undergo TB screening if they were invited by a HW in both passive/active approaches. Similar to a study in Vietnam, approximately one-third of TB patients did not know about the need of investigating

contacts (105). Most of the TB patients not invited by HWs expressed willingness to bring their contacts if they had been invited, underscoring the fundamental role HWs play and a potential area for TB-CI optimization.

Despite HW invitation being key for screening of TB contacts, clear operational guidelines and procedures for systematic enquiry by HWs, and documentation tools were lacking. The minimum requirements for TB-CI information collected and reported should include the number of CIs carried out, contacts eligible for CI, number, age, sex, and HIV status of contacts identified, contacts who complete clinical evaluation with the prescribed screening algorithm, contacts diagnosed with active TB, children aged <5 years commenced on IPT and persons living with HIV commenced on IPT (60). Standardizing protocols for TB-CI and training HWs to adhere to protocols has been shown to be useful in performing effective CIs and in conducting studies on the effectiveness of TB-CI (106, 107). Moreover, the systematic enquiry in TB-CI as has been described in the literature as both a science and an art, requiring effective interviewing skills (106). Based on findings from patient interviews we identified the following as important considerations during enquiry: HW kindness and confidentiality (108); HWs employing tactful probes to establish close contacts; patient sociodemographic characteristics including living dynamics; patient knowledge on TB etiology, transmission, treatment and prevention (105); and preventing TB-related stigma (109).

The findings from this study suggest specific areas of optimization regarding patient flow in health facilities geared at providing value added healthcare. For TB contacts, this includes firstly seizing the opportunity to screen contacts conveniently presenting at the facility as treatment buddies, caregivers or relatives/friends accompanying patients (110) and child contacts (111, 112). Secondly, fast tracking TB screening for those referred by index TB patients/self-refer. Thirdly, providing a holistic package of care for TB contacts that is appropriate for age and sex, for

example: immunization and growth monitoring for children, screening for hypertension and diabetes for adults, breast and cervical screening for women, prostate examination for men, among other checks suited for facility based or community based TB-CI activities. In addition, all patients attending these health facilities should benefit from infection control and prevention measures instituted to prevent acquiring new infections in the facility (113) and TB screening provided at all health service points including MCH, inpatient wards and outpatient clinics as is being done for HIV screening in health facilities in the country. Finally, strong leadership from the government in conjunction with partners was considered fundamental to enabling sustainable funding for TB-CI related activities including building capacity for policy development, provision of commodities, having an adequate workforce, delivering optimal health services to patients. In addition, widespread community health knowledge and promotion of TB etiology, transmission, treatment and prevention, social protection schemes, and proper housing and ventilation were identified to be essential to optimizing TB-CI activities.

Immediate benefits derived from this research included ability of HWs to learn from each other and identify barriers they could act upon, through reflecting on their responses and having discussions as a team during the FGDs. The leaders in the teams were keen to facilitate the creation of local solutions. In addition, patients got an opportunity to learn more about TB by being given correct information where gaps were identified after individual patient interviews. Findings from this study were utilized in the design of an operational framework for TB-CI in our context and may be useful to program implementers in similar contexts to design interventions addressing barriers to TB-CI.



## **INNOVATIVE OPERATIONAL FRAMEWORK TO IMPROVE TB CONTACT INVESTIGATION IN A HIGH TB/HIV BURDEN SETTING**

Considering program requirements and lessons learnt from TB patient interviews, HW FGDs and KIs, we have designed an innovative operational framework and specific tools to optimize TB-CI in Nairobi County, Kenya. The operational framework comprises five broad target areas for potential interventions, namely: the community, TB contacts, TB patients, HWs and the health system. It incorporates the WHO's building blocks framework for health systems. In addition it recognizes HWs as a distinct group of players in TB-CI for whom specific interventions may be required. Furthermore, individual patients, their contacts and larger communities are also included, thus being a more holistic approach with regard to stakeholders involved in TB-CI activities. Contextual barriers and facilitators for TB-CI activities are listed at each of these levels. It provides a bird's eye view of the current challenges and possible solutions, which may be utilized by policy makers and program implementers are likely to utilize this framework in developing suitable interventions for TB-CI in Kenya.

Additionally, we designed two specific tools for TB-CI optimization in context: 1) a composite TB-CI process flow map at the health facility and community levels identifying common gaps and solutions; and 2) standardized operating procedures (SOPs) for TB-CI for HWs at the facility. The composite process map may be individualized and utilized at the facility/community level by leaders/teams to help identify contextual barriers at baseline and serve as an operational research/audit tool for continuous improvement. In various fields in health, process map development has been utilized to optimize healthcare in numerous ways including increasing efficiency in healthcare delivery, designing solutions such as information systems, enhancing patient experience and improving quality of care (114-116).

The SOPs include a practical script that could be used by HWs in facility based and/or community based TB-CI strategies to capture baseline data, provide requisite health education to TB patients and their contacts, and follow-up all close contacts identified. We propose to pilot this tool on a health information system platform that allows for linkage of index TB patients to their contacts using unique patient identifiers in a pragmatic setting to assess its utility in TB-CI activities. Similar to the Vietnam National TB program, better health information and instructions by HWs may need to be given to contacts of TB patients to improve their health seeking behavior. In addition, TB-CI will need to be conducted more systematically including documenting TB contact information on management and follow-up (105). Although an active approach to TB-CI is favored compared to a passive one, the 'invitation model' can be efficient without significantly increasing costs (117).

### **INSIGHTS ON TB-RELATED STIGMA AND ADAPTATION OF THE STIGMA SCALE FOR CHRONIC ILLNESS**

To the best of our knowledge, this is the first study globally to adapt the SSCI for TB-related stigma, and also adapt a tool to measure stigma for English/Swahili speaking patients with TB particularly in an urban context in sub Saharan Africa. From the literature we identified three tools that quantitatively measure TB stigma: (i) the 10-item tool adapted by Macq et al. in Nicaragua, from the Internalized Stigma for Mental Illness (ISMI) scale by Ritsher et al (34, 35); (ii) the TB and AIDS Scale developed by Van Rie et al. in Thailand which has three scales: a 12-item experienced TB stigma scale, an 11-item perceived TB stigma scale and a 10-item perceived AIDS scale (36, 37); (iii) and a 5-item scale developed by Chowdhury et al in Bangladesh to measure enacted TB stigma (118). The 8-item SSCI for TB stigma adapted in this study for the assessment of TB stigma in Nairobi is consistent with the scales previously developed in three domains. It measures: perceived and enacted TB stigma as the Macq, Van Rie and Chowdhury

tools; internalized TB stigma as the tool by Macq et al.; and HIV perceived stigma in the context of TB disease as the Van Rie tool. The specific 8-items in this adapted scale center around fear of infecting others and death/non-recovery; feeling like a burden; lack of support from intimate/family/work-place relationships (119) and HIV stigma are consistent with the literature (17, 36, 50, 120).

In this analysis, time was a major emergent theme that influenced internalized, perceived and enacted stigma in different ways thus necessitating the measurement of TB stigma at baseline and at different time points, as ideal time points and references may not be known. In an interventional study in Nicaragua, Macq et al. assessed TB stigma at 15 days and at 2 months from the onset of TB treatment (34), but temporal changes in internalized, perceived and enacted stigma within TB patients were not reported. Other reference time points from commencement of TB treatment may include diagnosis, health education provision and disclosure. Additional covariates noted to potentially influence TB stigma in this context and were consistent with other studies and included: age, gender, level of education (17), and religion; education; income; TB knowledge on the cause, transmission, and cure; knowing a person with TB; HIV status; and TB symptoms (37).

The strength of this adapted tool lies in allowing for qualitative and quantitative assessment of TB stigma gleaned from TB patients in this context. Approaching TB stigma from an individual perspective and not just the public health one is imperative (26). Although it has been documented that no tool can be exhaustive with regard to measuring TB stigma (17), we think that beginning with an open question inquiring about the thoughts/worries/fears of TB the patient in the 8-item adapted SSCI for TB stigma may help capture aspects of TB stigma that are important to each TB patient. In the future, our 8-item adapted SSCI designed to measure TB stigma may be utilized

to test the effectiveness of TB stigma interventions, similar to the adapted ISMI by Macq et al. (34).

Additionally, this is the first study to elaborately translate the original 26- item SSCI in English into Swahili through a process of iteration by a multi-disciplinary team incorporating feedback from English/Swahili speaking patients. English and Swahili are the two dominant languages and are spoken by most Kenyans. While English is the language of instruction in all educational institutions, Swahili is the language of daily interactions with people of different ethnic backgrounds in Kenya and is widely spoken in Eastern and Central Africa (121). The translated SSCIs may be useful for researchers conducting stigma studies related to chronic illness in English/Swahili speaking populations in the future. (Appendix C)

TB awareness in Nairobi County is almost universal and approximately 90% of both the women and men who are aware of TB know that TB is spread in the air by coughing (122). It was therefore unsurprising to find that most participants knew that TB is spread in the air by coughing, however TB patients and their communities also harbored incorrect notions of TB transmission. The Kenya Demographic and Health Survey did not report on the proportion of those who also mentioned incorrect routes of TB transmission (122). Our team identified potential areas for TB patient empowerment that may be pertinent in averting TB stigma including knowledge on prevention despite infectiousness; cure despite deadliness; association with HIV in some but not all TB patients; anticipation of potential changes in appearance; and avoidance of negative feelings as the situation is temporary with proper treatment.

It is envisaged that HWs can utilize this one page tool to elicit rapid feedback from TB patients; identify individual gaps that may promote TB stigma at a glance; and facilitate a conversation that will enable TB patients gain a proper understanding of TB. HWs are not limited to clinicians and

nurses at the health facility, but also include social workers and community health workers who are very crucial cadres of HWs in TB care. This tool is envisioned to be simple to administer and findings will be easily interpreted by HWs. The embedded action points based on the potential areas for TB patient empowerment identified in this study could offer an opportunity for HWs to re-inforce health education, provided that it is specific to the gaps they will note. In addition, this tool may facilitate seamless follow-up among different HWs and potentially allow for audit of care provision related to TB stigma. Furthermore, this tool could be used for comparing TB-related stigma across various health facilities for monitoring and evaluation purposes.

Since cognitive issues are dynamic, it is proposed that this tool be used at diagnosis prior to treatment commencement as a baseline, at the end of the first month and thereafter monthly. This would assist HWs to consistently address stigma and reinforcing key messages tailored for each patient. These timings would align with routine TB follow-up visits, but may require to be individualized based on prior findings. Optimal timings for assessment could be piloted. The health workforce in many low and middle-income countries is constrained, and additional tools could be considered burdensome. The tool's utility and implementation challenges will be evaluated in a planned future study. To obtain a broader spectrum of responses, we propose to employ the 5-point Likert scale ranging from rarely to always.

This proposed tool has the potential for global adaptability. Translation to common languages is necessary for utilization in varied contexts. In addition, it is important to recognize unique drivers of TB epidemiology in context such as HIV prevalence.

## **LINKING STUDY FINDINGS TO HUMAN BEHAVIOR MODELS**

Behavior change is key in improving the implementation of evidence-based practice and public health (123). The patient decision making model designed in this work (Figure 6) takes into account all possible scenarios to assess the rate limiting factor that affects decision making for an individual patient to bring their contact for TB screening. Although our framework is very specific to TB CI, it is comprehensive and conceptually coherent, features that have been identified to be lacking in many other models according to a systematic review by Michie et al in 2011 (123). Scholars have recognized that “even when one or more (human behavior) models or theories are chosen to guide an intervention, they do not cover the full range of possible influences so exclude potentially important variables”, citing the commonly used Theory of Planned Behavior (124) and Health Belief Model (125) as examples that miss out on some important aspects of human behavior (123). Moreover, our model is consistent with the capability, opportunity, and motivation behavior (COM-B) system within the Behavior Change Wheel (BCW) which is currently considered to be a comprehensive health behavior model (123) and has been adopted in designing various interventions including health provider smoking cessation care for Australian indigenous pregnant women (126), promotion of physical activity and healthy nutrition in the workplace context in Finland (127), interventions to facilitate the transfer of information on medication changes on electronic discharge summaries in the United Kingdom (128) and TB contact investigation in Uganda (129).

The COM-B system borrows these three interactive components: 1) capability 2) opportunity and 3) motive from the United States Criminal Law, considered to be necessary and sufficient prerequisites to prove that someone is guilty of committing a volitional behavior. According to Michie et al, “Capability is defined as the individual's psychological and physical capacity to engage in the activity concerned. It includes having the necessary knowledge and skills. Motivation is

defined as all those brain processes that energize and direct behavior, not just goals and conscious decision-making. It includes habitual processes, emotional responding, as well as analytical decision-making. Opportunity is defined as all the factors that lie outside the individual that make the behavior possible or prompt it" (123).

From our study findings, examples cited by TB patients that demonstrate capability include patient's understanding of TB, appreciating the health benefits to their contacts and not wanting their contacts to suffer, whereas barriers to capability include being too busy at work, feeling too unwell to bring their contacts, lack of money/transport and internalized TB-related stigma. Regarding motivation, examples gleaned from this work included contacts coming for TB screening because they loved them and since they had seen the TB patients getting well, health worker kindness, and willingness to bring their TB contacts for screening had they been invited by a health worker; whereas barriers to motivation included perceived TB-related stigma from health workers, contacts and community members; and contacts busy at work/school/lack of value addition of contacts coming to hospital when they are not sick. With respect to opportunity, health worker invitation to TB patients to bring their close contacts, treatment supporters accompanying patients to the facility, reverse TB CI when children were diagnosed with TB, IPT provision, community health worker visits to the homes, sputum container provision for contacts at work or in school are among many such examples. These are summarized in Table 4 and complimentary findings regarding TB patients gained from health worker perspectives are provided in Table 5.

For health workers, I conducted focus group discussions to leverage their group dynamic. Their perspectives were framed based on the six WHO health system building blocks which includes a sub-section on issues pertaining to the health workforce. I facilitated good quality dialogue during the FGDs and gauged health worker practices through specific scenarios to gain an in-depth

understanding on facilitators, barriers and opportunities for TB-CI optimization in context. Similarly, our findings were consistent with the COM-B system. Examples cited by health workers that demonstrate capability include some health workers admitting they invited TB patients to bring their contacts for screening, IPT provision for children under the age of 5 years and HIV infected patients, however from most FGDs it was clear that the policy on this lacked clarity because HWs could not articulate what exactly was expected of them. Regarding motivation, examples gleaned from this work included health workers citing they were passionate about the work they do and the leadership was supportive; whereas barriers to motivation included health workers acknowledging that they were very busy in the clinic, some faced TB-related stigma from colleagues who did not want to assist in health care delivery when they were short-staffed for fear of infection, and community health workers reporting lack of remuneration and experiencing near violent experiences during home visits despite being passionate about their job. With respect to opportunity, although TB-CI is advocated from policy perspective, standard operating procedures, TB-CI specific health worker training, documentation tools and referral and feedback loops were lacking to facilitate implementation by health workers (Table 6).

Similarly, from perspectives gained from key informant interviews with experts purposefully selected from government programs involved in TB, HIV, community health, disease surveillance and health information systems; non-governmental organizations involved in TB-related care; academia and health information systems specialists involved in implementing national scale projects, our findings were consistent with the COM-B system. Examples of facilitators of capability from policy developers and program implementers include a written policy that includes health worker invitation of TB patients to bring their contacts for TB screening, whereas barriers include lack of a central budget specific for TB-CI activities, lack of specific health worker training, documentation tools and referral and feedback loops to facilitate implementation by health workers. With respect to motivation, facilitators included having the World Health Organization



advocating for a TB-CI goal of  $\geq 90\%$  and complimentary national program goals including TB, HIV and child mortality reduction. Regarding opportunity, a major facilitator was the TIBU computerized platform, seamless provision of government services through the computerized e-citizen portal which is a gateway that can be leveraged link patients through a national unique patient identifier; the barriers included vertical program approaches, lack of interoperability of information systems in health facilities with electronic medical records (EMRs) and lack of EMRs in most facilities.

My observations complimented majority of the perspectives gained from stakeholders. Specific observations of concern in the implementation of TB CI in the 13 health facilities in all nine sub-counties of Nairobi I visited included poor infection control measures for patients seeking health-care as well as general and TB-CI specific process flow challenges which can be classified as barriers to health system opportunities illustrated in Figure 9. Again, these observations were complimented by findings from TB patients, health workers and key informants (Table 6).

The COM-B system validates the use of a systems thinking approach in analysing interventions in complex health systems. Furthermore, although basing research on a health behaviour model is important, choosing the correct stakeholders or groups of stakeholders for optimization of an intervention may be even more fundamental to understand human behaviour. For example, despite the fact that Ayakaka et al employed the COM-B framework in understanding the barriers and facilitators to TB CI in Kampala, they did not involve perspectives from TB patients who are primarily involved in influencing decisions on having their close contacts screened which they stated in their limitations (129). Complementarity of our findings and triangulation of sources and methodologies to understand how TB-CI occurs in the context of Nairobi County in Kenya is a major strength of this thesis. Our holistic and pragmatic approach synthesized into a system thinking framework is consistent with COM-B system, a currently acceptable human behaviour

framework, and has enabled us to provide a synthesized operational framework for optimizing TB CI for uptake to policy makers and program implementors in Nairobi County, Kenya and other similar high burden settings. Moreover, the linkage of our study findings to the COM-B system and BCW provides researchers in similar high burden settings with a structured framework of viewing stakeholder behaviour and may inform future interventions targeting behaviour change at single or multiple levels. Most importantly, it is imperative that we appreciate the dynamism in the science of human behaviour. As the authors of the COM-B system state, “It must be recognized that there are a near infinite number of ways of classifying interventions and intervention functions. The one arrived at here (COM-B system/BCW) will no doubt be superseded.”

Finally, from a human behavioural perspective, the TB patient decision making model put forth in this thesis should be considered an additional innovation from this work. The findings presented in Table 4 provide the basis of a preliminary ethnographic decision model for TB CI in high burden settings. In the context of TB CI, this approach helps us better understand the role TB patients play in having their contacts screened for tuberculosis. Some examples of the application of EDMs from the literature include understanding how women in Taiwan make the decision whether or not to have a hysterectomy (130), recycling behaviour of Americans (90) and understanding the influence of urban- or rural-living on cardiac patients’ decisions about diet and physical activity (131). This TB patient decision model has the potential for further exploration in future research.

## **STUDY STRENGTHS AND LIMITATIONS**

TB contact decision data was not collected as this would be limited to contacts presenting at the facility. It was difficult to reach contacts outside the hospital setting, particularly those at work or in school. In addition, we did not explicitly ask patients about their HIV status to avoid introducing bias regarding HIV stigma, which was assumed to have been in the community. Positionality was a potential bias in this study likely reduced because the interviewer did not work in any of these TB clinics. We were not able to assess potential stigma promoted by HWs as the 8-item adapted SSCI is a HW administered tool. Although self-administered tools are superior in this respect, this approach may not be practical in the context of busy health facilities.

Despite these limitations, we believe that our study also has several strengths. Firstly, it provides a current contextual analysis of TB-CI activities from actual stakeholders involved in diverse areas in TB care. Therefore, the perspectives provided are holistic with regards to present challenges and opportunities for optimization of TB-CI in Nairobi, Kenya. Secondly, the multiple methodologies employed in gaining stakeholder perspectives, triangulating and verifying these data, validate our study findings. Thirdly, the operational framework, SOPs, composite TB-CI process flow map at the health facility and community levels, and adapted 8-item SSCI for TB-related stigma developed in this study seek to address gaps identified in context. These tools are designed to be pragmatic and their utility will be assessed in the next phase of this project. Finally, there is potential for translation of these study findings regarding optimization of TB-CI in a high burden setting to similar settings worldwide. This work is now published (132, 133).

## CHAPTER 9

### CONCLUSIONS, RECOMMENDATIONS AND DISSEMINATION

#### CONCLUSIONS

**Conclusion 1:** This study revealed significant barriers to TB contact screening in our setting, specifically failure by the HW to educate and invite TB patients to bring close contacts for TB screening; sub-optimal processes and flow of TB patients and close contacts at both facility and community levels; and HW and community TB-related stigma, in addition to general health system challenges. HW invitation of TB patients to bring their close contacts for TB screening, health education, and flexible and alternative approaches such as conducive hours of operation and provision of sputum containers for close contacts at work/school were perceived by patients and HWs as facilitators.

**Conclusion 2:** Stakeholder perspectives triangulated from this multi-method qualitative study were useful in our subsequent design of implementation tools and of an operational framework for optimized TB-CI in context. I successfully identified specific areas for optimization of processes and patient flow at the health facility and community levels inclusive of referral and feedback mechanisms, and developed a HW administered documentation tool with embedded standardized operational procedures for optimal enquiry.

**Conclusion 3:** The existing validated 26-item SSCI stigma assessment tool (by Rao et al) was successfully adapted into a shorter locally contextualized 8-item SSCI, which may be administered by HWs in English or Swahili to quantify stigma among TB patients in Kenya. The main items that needed adaptation to make the tool locally acceptable and relevant included

beginning with an open question to capture all patients' concerns; adding questions that address fear of infecting others and death, HIV stigma, and intimate, family, and workplace relationship contexts; and eliminating redundancy.

## **RECOMMENDATIONS**

The following recommendations arise from findings of this study, summarized in the proposed operational framework for optimizing TB-CI in Nairobi, Kenya illustrated in Figure 11. They are classified below as short-term, medium-term and long-term, with regard to considered ease of implementation.

### **Short Term Recommendations**

TB-related stigma emerged as the most cited social determinant influencing TB-CI at an individual TB patient, HW and community level. Stakeholder solutions primarily centered on health education by HWs for TB patients and the media for the broader community. Health education is embedded in the proposed HW administered tools provided in this study in Table 5 and Table 9. It is recommended that the Ministry of Health, Kenya consider the use of these tools as a starting point in the process of developing of tools to support health education in TB-CI activities.

Furthermore, assessment of the utility of the 8-item adapted SSCI for TB-related stigma in English/Swahili in a larger population is recommended to quantify TB stigma in our context and measure the impact of stigma reduction interventions. The insights gained in the cognitive interviews conducted in this study highlight the depth of TB-related stigma in our setting and complimented by findings from HW FGDs and interviews with key informants. The tool we have developed will measure stigma both quantitatively and qualitatively including specific areas such as fear of infecting others and death, HIV stigma, and intimate, family, and workplace relationship

contexts that were recognized to be significant to TB patients. The National TB and Lung Disease Program and researchers involved in the care of TB patients can utilize this tool for operational research at baseline and various points in time in the evaluation of innovations around stigma reduction.

This study provides a template of such a tool with HW guidelines encompassing a stepwise approach to TB-CI in our context shown in Table 7. This tool is informed by perspectives of the various stakeholders involved in this study. It is believed that this will be an ideal starting point, particularly for Nairobi County, and has the potential to be adapted to other counties in the country. The Ministry of Health, Kenya in conjunction with partners involved in TB-CI related activities need to further strengthen health systems related to TB-CI, specifically developing comprehensive operational guidelines and tools for TB-CI to be used nationally, and provision of training for HWs in their administration. Proper documentation of actions taken in the TB-CI process including referral and feedback loops are imperative in quantifying TB-CI in Nairobi County, regardless of the approach (i.e. facility, active, integrated or other) or platform (paper, computerized or combined) employed.

It is recommended that more immediate actions can be taken at the facility level by HWs with the support of the Ministry of Health and partners, involving the identification of individual facility barriers in the specific TB-CI processes as outlined in Figure 9. This figure provides a summary of processes that can be optimized based on observations in the 13 health facilities where we conducted this study such as patient flow that could prevent further TB transmission or outdoor but sheltered waiting areas for better ventilation among many examples. The strength of the NTLDP lies in an excellent supervisory structure with TB coordinators who can lead in this process at the facility level in conjunction with the facility leadership. Local budgets to support these activities will need to be provided but may be the most cost-effective.

### **Medium Term Recommendations**

Operational research to assess the effectiveness of TB-CI activities in this setting is needed and recommended. This study provides holistic insights for researchers, government and partners, that can inform the design of interventions to optimize TB-CI in this current context. Interventions suggested by stakeholders include media campaigns to reduce TB-related stigma in the community and optimized health education by HWs. Interestingly, although cash incentives and enablers have been proposed in the literature to improve uptake of care for TB patients, stakeholders pointed out that careful consideration of the approach and the sustainability of the intervention should be taken into account, as some of these interventions have been detrimental to patient care. The effectiveness of these and similar interventions will need to be assessed formally in randomized controlled trials.

### **Long Term Recommendations**

Finally, the Ministry of Health, Kenya in conjunction with partners involved in TB-CI related activities is recommended to further strengthen health systems related to TB-CI, particularly providing central and local government budgets for TB-CI related activities, robust infrastructure, and provision of an adequate and motivated workforce. It is also recommended that social protection measures be put in place by the government for TB patients and their families, as poverty was the second most cited social determinant influencing TB-CI. Adaptation of the SSCI for other chronic illnesses in sub Saharan Africa should also be considered.

## **DISSEMINATION**

As part of the dissemination strategy, publications from this work have been shared with all key informants who participated in this study.

A stakeholder engagement forum with team leaders from each of the 13 selected health facilities in which this study was conducted together with key informants is scheduled to discuss these study findings. Feedback on the frameworks and tools developed will also be elicited. Similarly, meetings with HW teams at each of the 13 health facilities will be scheduled to discuss general and facility specific study findings.



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## APPENDICES

### Appendix A – Ethical Approvals and Renewals



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Dr. Diana Marangu  
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School of Medicine  
University of Nairobi

Dear Dr. Marangu

**Research Proposal: Optimizing Tuberculosis contact investigation and Linkage to care in Nairobi, Kenya (TB Kwisha) (P549/09/2014)**

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 27<sup>th</sup> January 2015 to 26<sup>th</sup> January 2016.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website [www.erc.uonbi.ac.ke](http://www.erc.uonbi.ac.ke)

Yours sincerely

PROF. M. L. CHINDIA  
SECRETARY, KNH/UON-ERC

- c.c.
- The Principal, College of Health Sciences, UoN
  - The Deputy Director CS, KNH
  - The Assistant Director, Health Information, KNH
  - The Chairperson, KNH/UON-ERC
  - The Dean, School of Medicine, UoN
  - The Chairman, Dept of Paediatrics & Child Health, UoN
  - Supervisors: Prof. Grace John-Stewart, Prof. Walter Jaoko, Prof. Elizabeth Obimbo,  
Prof. Deepa Rao, Prof. Joseph B. Babigumira



KENYATTA NATIONAL HOSPITAL  
P.O. BOX 20723 Code 00202  
Tel: 726300-9  
Fax: 725272  
Telegrams: MEDSUP, Nairobi

27<sup>th</sup> January 2015



UNIVERSITY OF NAIROBI  
COLLEGE OF HEALTH SCIENCES  
P O BOX 19676 Code 00202  
Telegrams: varsity  
(254-020) 2726300 Ext 44355

**KNH-UoN ERC**  
Email: [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)  
Website: <http://www.erc.uonbi.ac.ke>  
Facebook: <https://www.facebook.com/uonknh.erc>  
Twitter: @UONKNH\_ERC [https://twitter.com/UONKNH\\_ERC](https://twitter.com/UONKNH_ERC)



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Telegrams: MEDSUP, Nairobi

Ref. No.KNH/ERC/R/10

28<sup>th</sup> January, 2016

Dr. Diana M. Marangu  
Dept. of Paediatrics and Child Health  
School of Medicine  
College of Health Sciences  
University of Washington

Dear Dr. Marangu,

**Re: Approval of annual renewal – Optimizing Tuberculosis Contact Investigation and Linkage to Care in Nairobi, Kenya 'TB Kwisha' (P549/09/2014)**

Your communication of 26<sup>th</sup> January, 2016 refers.

This is to acknowledge receipt of the study progress report and hereby grant you annual extension approval for ethical research protocol P549/09/2014.

The study renewal dates are from 27<sup>th</sup> January 2016 – 26<sup>th</sup> January 2017.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- c) Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (Attach a comprehensive progress report to support the renewal).
- f) Clearance for export of biological specimens must be obtained from KNH-UoN ERC for each batch of shipment.
- g) Submission of an executive summary report within 90 days upon completion of the study.  
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover

For more details consult the KNH-UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,

**PROF. M.L. CHINDIA**  
**SECRETARY, KNH-UoN ERC**

c.c. The Principal, College of Health Sciences, UoN  
The Deputy Director CS, KNH  
The Chair, KNH-UoN ERC





Date: February 25<sup>th</sup>, 2015

PI: Dr. Diana Marangu  
Global Health

CC: Dr. Grace John-Stewart  
Global Health

RE: Human Subjects Application #47618, "Optimizing TB contact investigation and linkage to care in Nairobi, Kenya (TB KWISHA)"

Dear Dr. Marangu,

Human Subjects application #47618, "Optimizing TB contact investigation and linkage to care in Nairobi, Kenya (TB KWISHA)" has been approved by the University of Washington IRB in Subcommittee EJ under Expedited Categories 5, 6 and 7. The Subcommittee has determined that this research meets all the requirements for approval outlined in 45 CFR 46.111. In addition, the following waivers and determinations apply:

- Please note that this approval is limited to the phase 1 study procedures and the adaptation of the SCCI scale procedures that will be conducted for phase 2. The research team must forward and receive IRB approval for modifications to add all other procedures prior to when those procedures are conducted (including recruitment procedures and procedures involving the collection of private identifiable information). The appropriate waivers and regulatory determinations for the RCT and for the rest of phase 2 will be considered when the modifications to add those procedures to the study are reviewed.
- The Subcommittee granted a waiver of consent for observations that will be conducted for phase 1 of the study in private settings where individuals have a reasonable expectation of privacy.
- The Subcommittee granted waivers of consent, assent, and parental permission for private identifiable information about 3<sup>rd</sup> parties that may be obtained during interviews and focus groups that will be conducted for phase 1 of the study.
- The Subcommittee has determined that the criteria for the inclusion of participants who are pregnant are satisfied.

The approval is valid from 2/26/2015 through 2/25/2016. If you have completed the study, including all data analysis, by 2/25/2016 you will need to close out the application. If you have not completed the project by that date, you will need to submit a Status Report requesting continuing approval six weeks before the expiration date. The Status Report to renew or close your study can be found on the HSD website.

The subcommittee has not approved a specific number of subjects for phase 1 of the study. However, you will still be asked to report on subject numbers during the annual status report.

The subcommittee approved 20 subjects for the SCCI scale procedures. Please note that subject number is part of your IRB-approved protocol. Over-enrollment is considered non-compliance with your IRB approval. Any revisions which need to be made to the IRB-approved protocol, including an increase to subject numbers, must be reviewed and approved by the IRB before they

are implemented. This review can be requested by submitting a Modification form, which can be found on the HSD website. Non adherence to the IRB-approved protocol may be considered non-compliance and must be reported to the IRB as soon as it is discovered.

If at anytime during your study an adverse event occurs, contact HSD immediately.

**Note that HSD policy requires that you use copies of the stamped approved consent materials with subjects.** If use of stamped copies is not applicable to your study because you have been approved to obtain oral or electronic consent, you must use the exact script that has been approved.

Please use the IRB application number listed above on any forms submitted which relate to this research, or on any correspondence with the HSD office.

If we can be of further assistance, please contact us at (206) 543-0098 or via email at [hsdinfo@uw.edu](mailto:hsdinfo@uw.edu). Thank you for your cooperation, and good luck in your research.

Sincerely,

**Blair Maman**  
Administrator for IRB J  
Human Subjects Division  
(206) 543-0919  
[uwvibro@uw.edu](mailto:uwvibro@uw.edu)

**APPLICATION: Continuing Review (Status Report), Renew or Close**  
Version 5.3

**W** UNIVERSITY of WASHINGTON  
Human Subjects Division  
Box 359470  
Seattle, WA 98195-9470  
Phone: 206-543-0098  
Fax: 206-543-9218

For instructions on how to complete this form, see the last page.

For HSD Office Use Only		Date Received:
<input type="checkbox"/> Master Copy	<input checked="" type="checkbox"/> Approved	RECEIVED Human Subjects Division
<input type="checkbox"/> IRB Working Copy	<input type="checkbox"/> Disapproved	JAN 12 2016
<input type="checkbox"/> Researcher Copy	<input type="checkbox"/> Withdrawn	UW
<input type="checkbox"/> Full IRB Review Required		
<input checked="" type="checkbox"/> Expedited Review		DORA CRR # 1
Approval period from: FEB 26 2016	To: FEB 25 2017	
Date of IRB action: FEB 04 2016	Printed name: Elizabeth Liss	
IRB Chair or Designee Signature: 		
Notes:		

Research Study Information			
Submission Reason	<input checked="" type="checkbox"/> RENEW IRB application	<input type="checkbox"/> CLOSE IRB application	
Expiration date of IRB approval	2/25/2016		
IRB Application #	47618	IRB Committee	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
IRB Application Title			
Lead Researcher Name	DIANA MARANGU	Contact Name	GRACE JOHN-STEWART
Position and/or academic appointment	STUDENT	Position and/or academic appointment	PROFESSOR
Department/Division		Department/Division	GLOBAL HEALTH
Phone #	+254-721-282815	Phone #	+1-206-543-4278
Fax #		Fax #	
Campus Box #		Campus Box #	
Street address, if applicable		Street address, if applicable	
Email	marangud@gmail.com	Email	gjohn@u.washington.edu
<input checked="" type="checkbox"/> Person completing this form is the same as the Lead Researcher		<input type="checkbox"/> Person completing this form is the same as the Contact	
Name of Person Completing This Form (If not Lead Researcher or Contact):		Email:	Phone:
Name and Mailing Address for all paper-based correspondence (If blank, correspondence will be directed to contact person, or lead researcher if no contact person)			
Name:	Campus Box#:	Other address if not at UW:	
PROF. GRACE JOHN-STEWART		BOX 359909 543-4278	

## Appendix B – Consents

TB KWISHA STUDY – APPENDIX 2

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FEB 25 2015

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### CONSENT TO PARTICIPATE IN RESEARCH

#### EXPLORING BARRIERS, FACILITATORS AND POTENTIAL SOLUTIONS TO TB CONTACT INVESTIGATION AND LINKAGE TO CARE IN NAIROBI, KENYA (TB KWISHA STUDY)

**Subject Population:** Health care workers of various cadres at selected primary, secondary and tertiary health facilities in Nairobi County.

**Introduction:** You are being asked to participate in a research study by Dr. Diana Marangu (PhD Student) from the University of Nairobi Institute of Tropical and Infectious Diseases (UNITID) in collaboration with the University of Washington. This study is being conducted as part of her PhD dissertation which is funded in part by the National Institute of Health (NIH). You were selected as a possible participant in this study because of your knowledge and / or experience in TB contact investigation in Nairobi, Kenya. This document explains what the study is about. Please read it carefully and ask any questions about the study before you agree to participate. You may also ask questions at any time after joining the study. This process is called 'Informed Consent'.

**Purpose of the study:** This study aims to explore what are the current obstacles and factors that promote the process of TB contact investigation and linkage of contacts to appropriate care. This study also aims to find out what factors currently promote this care and what would be optimal ways to improve TB contact investigation and linkage to care in the future.

**Procedures:** If you volunteer to participate in this study, we will ask you a series of questions within a group discussion. The discussion will be around TB contact investigation and linkage to care in Nairobi, Kenya and we will explore potential methods that could be used in the county. This will take approximately two hours. The group discussion will be audio-recorded and notes will be taken in the process. You may refuse to answer questions you do not want to answer.

**Anticipated Benefits:** You will participate in providing home-grown solutions to the barriers faced in TB contact investigation and linkage to care. Benefits of your participation will include informing the design of optimal TB contact investigation approaches relevant to Nairobi County.

AIM 1: CONSENT - HEALTH WORKER FGDs - ENGLISH  
25<sup>TH</sup> February 2015  
Version 1.4

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FEB 26 2015

UW Human Subjects  
Review Committee

## TB KWISHA STUDY – APPENDIX 2

**Risks of participation:** The risks from your participation are minimal. You may find some of the questions and responses during the discussion to be uncomfortable or tiresome. Disclosure (accidental or otherwise) of personal information may occur. To mitigate this risk, all research staff will be sworn to confidentiality prior to undertaking this study.

**Confidentiality:** We will respect your privacy. Audio-recordings will be destroyed 6 months after being transcribed. Data will be stored in locked cabinets in a room with restricted access. Results published or presented in public will occur without names or any other information that would allow people to identify you.

**Voluntariness:** Participation in this study is out of your own free will. You may choose not to participate or to leave the study at any time with no consequences whatsoever.

**Compensation:** Refreshments will be provided during the focus group discussion and transport amounting to Ksh. 500 will be re-imbursed.

**Who do I call if I have questions or problems?**

For any enquiries or further clarification about the study, or should you experience any harm by participating in this study, contact the Principal Investigator Dr. Diana Marangu: 0721-282815. For questions about your rights as a research participant, you should contact Professor A. Guantai, the Chair of the Kenyatta National Hospital Ethics and Research Committee, at 020-2726300.

I, the undersigned, have been informed about this study's purpose, procedures, possible benefits and risks. I have been given the opportunity to ask questions before I sign, and I have been told that I can ask other questions at any time. I voluntarily agree to participate in this study. I am free to stop this participation in the study at any time without the need to justify my decision. I have received a copy of this consent.

Print Name of Subject: \_\_\_\_\_

AIM 1: CONSENT - HEALTH WORKER FGDs - ENGLISH  
25<sup>TH</sup> February 2015  
Version 1.4



## TB KWISHA STUDY – APPENDIX 2

---

Name & Signature or Left Thumbprint of Study Participant

---

Date

---

Name & signature of Witness to Consent if Study Participant Unable to Read or Write

---

Date

*(Must be different than the person obtaining consent)*

**Signature of Investigator or Responsible Individual:**

I have explained and discussed the full contents of the study including all of the information contained in this consent form to the best of my ability. All questions of the study participants have been accurately answered.

---

Investigator/Person Obtaining Consent Name & Signature

---

Date

FEB 25 2015

UW

## CONSENT TO PARTICIPATE IN RESEARCH

**EXPLORING BARRIERS, FACILITATORS AND POTENTIAL SOLUTIONS TO TB CONTACT INVESTIGATION  
AND LINKAGE TO CARE IN NAIROBI, KENYA (TB KWISHA STUDY)**

**Subject Population:** Patients with tuberculosis (TB) and TB contacts at participating primary, secondary and tertiary health facilities in Nairobi County.

**Introduction:** You are being asked to participate in a research study by Dr. Diana Marangu (PhD Student) from the University of Nairobi Institute of Tropical and Infectious Diseases (UNITID) in collaboration with the University of Washington. This study is being conducted as part of her PhD dissertation which is funded in part by the National Institute of Health (NIH). You were selected as a possible participant in this study because of your knowledge and / or experience in TB contact investigation in Nairobi, Kenya. This document explains what the study is about. Please read it carefully and ask any questions about the study before you agree to participate. You may also ask questions at any time after joining the study. This process is called 'Informed Consent'.

**Purpose of the study:** This study aims to explore what are the current obstacles and factors that promote the process of TB contact investigation and linkage of contacts to appropriate care. This study also aims to find out what factors currently promote this care and what would be optimal ways to improve TB contact investigation and linkage to care in the future.

**Procedures:** If you volunteer to participate in this study, we will ask you a series of questions around TB contact investigation and linkage to care in Nairobi, Kenya and also explore potential methods that could be used in the county. This will take approximately one hour. Individual interviews will be audio-recorded and notes will be taken in the process. You may refuse to answer questions you do not want to answer.

**Anticipated Benefits:** You will participate in providing home-grown solutions to the barriers faced in TB contact investigation and linkage to care. Benefits of your participation will include informing design of optimal TB contact investigation approaches relevant to Nairobi County.

**Risks of participation:** The risks from your participation are minimal. You may find some of the questions and responses during the discussion to be uncomfortable or tiresome. Disclosure (accidental or otherwise)

AIM 1: CONSENT – INDIVIDUAL PATIENT INTERVIEW - ENGLISH  
25<sup>th</sup> FEBRUARY 2015  
Version 2.1

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## TB KWISHA STUDY – APPENDIX 4

of your TB diagnosis /TB contact status and care may occur. To mitigate this risk, all research staff and interpreters will be sworn to confidentiality prior to undertaking this study.

**Confidentiality:** We will respect your privacy. Audio-recordings will be destroyed after 6 months of being transcribed. Data will be stored in locked cabinets in a room with restricted access. Results published or presented in public will occur without names or any other information that would allow people to identify you.

**Voluntariness:** Participation in this study is out of your own free will. You may choose not to participate or to leave the study at any time with no consequences whatsoever.

**Compensation:** Study participants in the individual interviews will receive Ksh.500 for transport at enrolment.

**Who do I call if I have questions or problems?**

For any enquiries or further clarification about the study, or should you experience any harm by participating in this study, contact the Principal Investigator Dr. Diana Marangu: 0721-282815. For questions about your rights as a research participant, you should contact Professor A. Guantai, the Chair of the Kenyatta National Hospital Ethics and Research Committee, at 020-2726300.

I, the undersigned, have been informed about this study's purpose, procedures, possible benefits and risks. I have been given the opportunity to ask questions before I sign, and I have been told that I can ask other questions at any time. I voluntarily agree to participate in this study. I am free to stop this participation in the study at any time without the need to justify my decision. I have received a copy of this consent.

Print Name of Subject: \_\_\_\_\_

\_\_\_\_\_

Name & Signature or Left Thumbprint of Study Participant

\_\_\_\_\_

Date

AIM 1: CONSENT – INDIVIDUAL PATIENT INTERVIEW - ENGLISH  
25<sup>th</sup> FEBRUARY 2015  
Version 2.1

## TB KWISHA STUDY – APPENDIX 4

\_\_\_\_\_  
Name & signature of Witness to Consent if Study Participant Unable to Read or Write      Date  
*(Must be different than the person obtaining consent)*

**Signature of Investigator or Responsible Individual:**

I have explained and discussed the full contents of the study including all of the information contained in this consent form to the best of my ability. All questions of the study participants have been accurately answered.

\_\_\_\_\_  
Investigator/Person Obtaining Consent Name & Signature      Date



FEB 25 2015

UW

## CONSENT TO PARTICIPATE IN RESEARCH

**EXPLORING BARRIERS, FACILITATORS AND POTENTIAL SOLUTIONS TO TB CONTACT INVESTIGATION  
AND LINKAGE TO CARE IN NAIROBI, KENYA (TB KWISHA STUDY)**

**Subject Population:** Patients with tuberculosis (TB), their contacts and health care workers of various cadres at selected primary, secondary and tertiary health facilities in Nairobi County. Representatives from academia, research institutions, non-profit organizations, policymakers and program implementers involved in TB care in Nairobi.

**Introduction:** You are being asked to participate in a research study by Dr. Diana Marangu (PhD Student) from the University of Nairobi Institute of Tropical and Infectious Diseases (UNITID) in collaboration with the University of Washington. This study is being conducted as part of her PhD dissertation which is funded in part by the National Institute of Health (NIH). You were selected as a possible participant in this study because of your knowledge and / or experience in TB contact investigation in Nairobi, Kenya. This document explains what the study is about. Please read it carefully and ask any questions about the study before you agree to participate. You may also ask questions at any time after joining the study. This process is called 'Informed Consent'.

**Purpose of the study:** This study aims to explore what are the current obstacles and factors that promote the process of TB contact investigation and linkage of contacts to appropriate care. This study also aims to find out what factors currently promote this care and what would be optimal ways to improve TB contact investigation and linkage to care in the future.

**Procedures:** If you volunteer to participate in this study, we will ask you a series of questions around TB contact investigation and linkage to care in Nairobi, Kenya and explore potential methods that could be used in the county. This will take approximately one hour.

TB contact investigation will not be restricted to conventional approaches involving only household contacts but will also explore these factors in social network analysis and the use of geographical information and global positioning systems.

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FEB 26 2015

UW Human Subjects  
Review Committee

## TB KWISHA STUDY – APPENDIX 5

Key informant interviews will be audio-recorded and notes will be taken in the process. You may refuse to answer questions you do not want to answer.

**Risks of participation:** The risks from your participation are minimal. You may find some of the questions and responses during the discussion to be uncomfortable or tiresome. Disclosure (accidental or otherwise) of personal information may occur. To mitigate this risk, all research staff will be sworn to confidentiality prior to undertaking this study.

**Anticipated Benefits:** You will participate in providing home-grown solutions to the barriers faced in TB contact investigation and linkage to care. Benefits of your participation will include informing the design of optimal TB contact investigation approaches relevant to Nairobi County.

**Confidentiality:** We will respect your privacy.. Audio-recordings will be destroyed after being transcribed. Data will be stored in locked cabinets in a room with restricted access. Results published or presented in public will occur without names or any other information that would allow people to identify you.

**Voluntariness:** Participation in this study is out of your own free will. You may choose not to participate or to leave the study at any time with no consequences whatsoever.

**Compensation:** You will receive a card as a token of appreciation.

### **Who do I call if I have questions or problems?**

For any enquiries or further clarification about the study, or should you experience any harm by participating in this study, contact the Principal Investigator Dr. Diana Marangu: 0721-282815. For questions about your rights as a research participant, you should contact Professor A. Guantai, the Chair of the Kenyatta National Hospital Ethics and Research Committee, at 020-2726300.

I, the undersigned, have been informed about this study's purpose, procedures, possible benefits and risks. I have been given the opportunity to ask questions before I sign, and I have been told that I can ask other questions at any time. I voluntarily agree to participate in this study. I am free to stop this participation in the study at any time without the need to justify my decision. I have received a copy of

TB KWISHA STUDY – AIM 1: CONSENT – ENGLISH  
Version 1.3  
25<sup>th</sup> February 2015

TB KWISHA STUDY – APPENDIX 6

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## CONSENT TO PARTICIPATE IN RESEARCH

ADAPTING THE STIGMA SCALE FOR CHRONIC ILLNESS (SSCI) RAO ET AL. TO MEASURE INTERNALIZED  
STIGMA IN TUBERCULOSIS IN NAIROBI, KENYA (TB KWISHA STUDY)

**Subject Population:** Patients with tuberculosis (TB), their contacts at participating primary, secondary and tertiary health facilities in Nairobi County.

**Introduction:** You are being asked to participate in a research study by Dr. Diana Marangu (PhD Student) from the University of Nairobi Institute of Tropical and Infectious Diseases (UNITID) in collaboration with the University of Washington (UW). This study is being conducted as part of her PhD dissertation which is funded in part by the National Institute of Health (NIH). You were selected as a possible participant in this study because of your knowledge and / or experience in TB contact investigation in Nairobi, Kenya. This document explains what the study is about. Please read it carefully and ask any questions about the study before you agree to participate. You may also ask questions at any time after joining the study. This process is called 'Informed Consent'.

**Purpose of the study:** This study aims to adapt a stigma scale (SSCI) to measure internalized stigma in patients with TB in this context.

**Procedures:** If you volunteer to participate in this study, we will ask you a series of questions around stigma in TB. This will take approximately one hour.

**Anticipated Benefits:** You will participate in providing insights to the adaptation of this stigma scale (SSCI) to measure TB stigma in this setting. Results of this study may also inform research or work in other settings in the future.

**Risks of participation:** The risks from your participation are minimal. You may find some of the questions and responses during the discussion to be uncomfortable or tiresome. Disclosure (accidental or otherwise) of your TB diagnosis and care may occur. To mitigate this risk, all research staff and interpreters will be

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25<sup>TH</sup> FEBRUARY 2015  
Version 1.2

FEB 26 2015

UW Human Subjects  
Review Committee



## TB KWISHA STUDY – APPENDIX 6

sworn to confidentiality prior to undertaking this study.

**Confidentiality:** We will respect your privacy.. Audio-recordings will be destroyed after being transcribed. Data will be stored in locked cabinets in a room with restricted access. Results published or presented in public will occur without names or any other information that would allow people to identify you.

**Voluntariness:** Participation in this study is out of your own free will. You may choose not to participate or to leave the study at any time with no consequences whatsoever.

**Compensation:** Study participants in the cognitive interviews will receive Ksh.500 for transport at enrolment.

**Who do I call if I have questions or problems?**

For any enquiries or further clarification about the study, or should you experience any harm by participating in this study, contact the Principal Investigator Dr. Diana Marangu: 0721-282815. For questions about your rights as a research participant, you should contact Professor A. Guantai, the Chair of the Kenyatta National Hospital Ethics and Research Committee, at 020-2726300.

I, the undersigned, have been informed about this study's purpose, procedures, possible benefits and risks. I have been given the opportunity to ask questions before I sign, and I have been told that I can ask other questions at any time. I voluntarily agree to participate in this study. I am free to stop this participation in the study at any time without the need to justify my decision. I understand that my participation will have no consequences. I have received a copy of this consent.

Print Name of Subject: \_\_\_\_\_

\_\_\_\_\_

Name & Signature or Left Thumbprint of Study Participant

\_\_\_\_\_

Date

AIM 2: CONSENT – COGNITIVE INTERVIEW – ENGLISH  
25<sup>TH</sup> FEBRUARY 2015  
Version 1.2

TB KWISHA STUDY – APPENDIX 6

\_\_\_\_\_  
Name & signature of Witness to Consent if Study Participant Unable to Read or Write      Date  
*(Must be different than the person obtaining consent)*

**Signature of Investigator or Responsible Individual:**

I have explained and discussed the full contents of the study including all of the information contained in this consent form to the best of my ability. All questions of the study participants have been accurately answered.

\_\_\_\_\_  
Investigator/Person Obtaining Consent Name & Signature      Date

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25<sup>TH</sup> FEBRUARY 2015  
Version 1.2

## Appendix C – Guides

### TB KWISHA STUDY – APPENDIX 1

#### OBSERVATION & MAPPING GUIDE FOR TB CONTACT INVESTIGATION AND LINKAGE TO CARE

Date of form completion	
FACILITY: _____	
TIME PERIOD OBSERVED: _____	dd      mmm      yyyy
<b>TB CONTACT INVESTIGATION &amp; LINKAGE TO CARE PROCESSES AND FLOW MAP</b>	<p><b>1. What methods are used?</b></p> <p><input type="checkbox"/> Facility based</p> <p><input type="checkbox"/> Household based (CHWs)</p> <p><input type="checkbox"/> Social network analysis</p> <p><input type="checkbox"/> GPS/GIS</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> Other, specify _____</p> <p><b>2. Is there linkage to care?</b></p> <p><input type="checkbox"/> IPT</p> <p><input type="checkbox"/> further TB testing</p> <p><input type="checkbox"/> HIV testing</p> <p><input type="checkbox"/> Nutrition care</p> <p><input type="checkbox"/> Diabetes screening</p> <p><input type="checkbox"/> Other, specify _____</p> <p><b>3. Barriers?</b></p> <p><u>Patient</u>: stigma, clinic hours not conducive as at work, lack of transport/motivation, sub-optimal health education</p> <p><u>Health worker</u>: poor attitudes, knowledge and practices, documentation fatigue</p> <p><u>Health system</u>: lack of registers Inability to link index to their contacts, patient delay (long patient times)</p> <p><b>4. Facilitators?</b></p>  <p><b>5. Solution opportunities?</b></p>

AIM 1: OBSERVATION AND MAPPING GUIDE

17<sup>th</sup> April 2014

Version 1.1

## TB KWISHA STUDY – APPENDIX 1

**6. What makes this method(s) work?** Patient level

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 Health worker level

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 Health system level

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**7. Are there any barriers to this method?** Patient level

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AIM 1: OBSERVATION AND MAPPING GUIDE

17<sup>th</sup> April 2014

Version 1.1

## TB KWISHA STUDY – APPENDIX 1

<input type="checkbox"/> Health worker level <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<input type="checkbox"/> Health system level <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<p><b>8. Are there solution opportunities to these barriers? How would they work in this context at?</b></p> <p><b>Patient Level</b></p> <input type="checkbox"/> Household visits <input type="checkbox"/> M-health <input type="checkbox"/> Non-monetary incentives: transport, food baskets <input type="checkbox"/> Monetary incentives <input type="checkbox"/> Health education <input type="checkbox"/> Other <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

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## TB KWISHA STUDY – APPENDIX 1

Health worker level [specify cadre: _____ ]																				
<input type="checkbox"/> M-health <input type="checkbox"/> Non-monetary incentives: transport, food baskets <input type="checkbox"/> Monetary incentives <input type="checkbox"/> Better training on health education <input type="checkbox"/> Attitude change <input type="checkbox"/> Reduced number of registers <input type="checkbox"/> Reduced health worker risk <input type="checkbox"/> Other																				
<hr/> <hr/> <hr/> <hr/> <hr/>																				
Health system																				
<input type="checkbox"/> Reduced number of registers <input type="checkbox"/> Reduced health worker risk <input type="checkbox"/> Proper linkage of index patients/contacts to care – IPT, further TB testing, HIV testing, Nutrition & Diabetes screening <input type="checkbox"/> Proper linkage of data among health facilities <input type="checkbox"/> Shorter waiting times <input type="checkbox"/> Other																				
<hr/> <hr/> <hr/> <hr/> <hr/>																				
Filled in by _____ (Initials)	Date <table border="1"> <tr> <td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td> </tr> <tr> <td>dd</td><td>mmm</td><td colspan="7">yyyy</td> </tr> </table>											dd	mmm	yyyy						
dd	mmm	yyyy																		

## TB KWISHA STUDY – APPENDIX 1

**WHO Health System Building Blocks**

*Patient, health worker and health system components that will be observed and explored include:-*

*i. Patient*

- 1. Mapping TB patient and contact flow in the facility including linkage to care including IPT provision; further TB testing; HIV testing and care; nutrition screening and care; and diabetes screening and care.*
- 2. Clinic hours and time taken at each process time.*

*ii. Health worker*

- 1. Number of health workers involved in TB contact investigation and linkage to care.*
- 2. Role health workers play in TB contact investigation and linkage to care in public areas in the health facility (observations not in settings individuals would reasonably expect privacy e.g. private consultation or examination).*
- 3. General attitude of the health workers involved in TB contact investigation and linkage to care – confidence in care provision; propagation of stigma; work load.*
- 4. TB patient file documentation of invitation of contacts for TB screening.*
- 5. Filling of the TB contact register.*
- 6. Documentation of TB patient linkage to care.*

*iii. Health system*

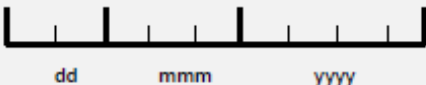
- 1. Leadership and governance: policy support (posters or visual documentation related to TB contact investigation and linkage to care displayed at the facility).*
- 2. Service delivery: availability of operational guidelines and details of TB contact investigation and linkage to care; availability of a TB contact register; ability of health worker to link the index TB patient to the contact [contact details e.g. phone number or physical address for both the index TB patient and the contact]; provision of IPT to eligible patients, further TB testing (chest radiography, mantoux test, sputum induction or gastric aspiration for children < 6 years/ patients who cannot produce a sputum sample), HIV testing, nutrition and diabetes screening.*
- 3. Supplies and products: availability of mobile phone airtime; transport for health workers involved in TB contact investigation; IPT in the pharmacy including formulations available; reagents for TB testing in the lab [microscopy, GeneXpert], working chest x-ray machine and film availability, mantoux reagents, facility for sputum induction/gastric aspiration; Mid Upper Arm Circumference (MUAC) tapes, stadiometer, weighing scales, Kenyan Integrated Management of Acute Malnutrition (IMAM) screening charts for children and adults; functional glucometer and glucose strips.*
- 4. Health system financing: Not able to observe this component.*
- 5. Health information system: availability of a health information system (paper based, computerized or combination); availability of a mobile phone based system, global positioning system (GPS), geographic information system (GIS) or other system for TB contact investigation and linkage to care.*
- 6. Health work force: (elaborated under health workers above); any visual documentation/posters on TB contact investigation and linkage to care trainings for health workers.*

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## FOCUS GROUP DISCUSSION / INTERVIEW GUIDE

<p style="text-align: right;">Date of form completion</p> <p>FACILITY/INSTITUTION: _____</p> <p style="text-align: center;">  </p> <p>PARTICIPANT CADRES: _____</p> <p> <input type="checkbox"/> TB patient   <input type="checkbox"/> TB contact   <input type="checkbox"/> Health worker (specify)   <input type="checkbox"/> Representative (specify) </p>	
<p><b>TB CONTACT INVESTIGATION &amp; LINKAGE TO CARE PROCESSES AND FLOW MAP</b></p> <p><u>Focus Group Discussion</u></p> <ul style="list-style-type: none"> <li>* Introduction and ground rules.</li> <li>* Ensure tape-recorder is on.</li> <li>* Provide scenarios for TB contact investigation.</li> <li>* Take questions, summarize discussion, thank participants and close.</li> <li>* Highlight key process barriers and potential solutions below.</li> </ul> <p><u>Interview</u></p> <ul style="list-style-type: none"> <li>*Introductory patient script and hypothetical model attached.</li> </ul> <p><u>Facility observations, Patient interviews, HW focus group discussions and Key informant interviews</u></p> <ul style="list-style-type: none"> <li>*WHO health system building blocks attached.</li> </ul>	<p style="text-align: center;"><b>SUMMARY</b></p> <p><b>What methods are currently used?</b></p> <p> <input type="checkbox"/> Facility based  <input type="checkbox"/> Household based (CHWs)  <input type="checkbox"/> Social network analysis  <input type="checkbox"/> GPS/GIS  <input type="checkbox"/> None  <input type="checkbox"/> Other, specify _____ </p> <p><b>Is there linkage to care?</b></p> <p> <input type="checkbox"/> IPT  <input type="checkbox"/> further TB testing  <input type="checkbox"/> HIV testing  <input type="checkbox"/> Nutrition care  <input type="checkbox"/> Diabetes screening  <input type="checkbox"/> None  <input type="checkbox"/> Other, specify _____ </p> <p><b>*If highlighted barriers are brought up explore deeper BARRIERS?</b></p> <p><b>Patient:</b> stigma, clinic hours not conducive as at work, lack of transport/motivation, sub-optimal health education</p> <p><b>Health worker:</b> irregular trainings/ guideline dissemination, documentation fatigue, poor attitude</p> <p><b>Health system:</b> lack of registers Inability to link index to their contacts, patient delay (long patient times)</p> <p><b>FACILITATORS/ SOLUTIONS?</b></p> <p><b>Patient:</b> household visits, incentives, m-health, peer support, local entrepreneurs</p> <p><b>Health worker:</b> incentives, m-health, increased staffing, regular staff training, timely guideline dissemination</p> <p><b>Health system:</b> linked registers, unnecessary processes eliminated, better linkage of care, GIS, GPS, social networks, data privacy</p>

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## TB KWISHA STUDY – APPENDIX 3

EXPLORING FACILITATORS, BARRIERS AND POTENTIAL SOLUTIONS TO TB CONTACT INVESTIGATION AND LINKAGE TO CARE IN NAIROBI, KENYA
<p><b>1. What type of TB contact investigation methods are used in your facility?</b></p> <p><input type="checkbox"/> Facility based   <input type="checkbox"/> Household based   <input type="checkbox"/> Social network analysis   <input type="checkbox"/> GPS/GIS   <input type="checkbox"/> None</p> <p><input type="checkbox"/> Other, specify _____</p>
<p><b>2. Is there linkage to care?</b></p> <p><input type="checkbox"/> IPT   <input type="checkbox"/> Further TB testing   <input type="checkbox"/> HIV testing   <input type="checkbox"/> Nutrition screening   <input type="checkbox"/> Diabetes screening   <input type="checkbox"/> None</p> <p><input type="checkbox"/> Other, specify _____</p>
<p><b>3. What makes this method(s) work?</b></p> <p><input type="checkbox"/> Patient level</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p><input type="checkbox"/> Health worker level</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p><input type="checkbox"/> Health system level</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>

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## TB KWISHA STUDY – APPENDIX 3

**4. Are there any barriers to this method?** Patient level

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 Health worker level

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 Health system level

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## TB KWISHA STUDY – APPENDIX 3

**5. Are there potential solutions to these barriers? How would they work in this context?****Patient Level**

- Household visits
- M-health
- Non-monetary incentives: transport, food baskets, other (specify) \_\_\_\_\_
- Monetary incentives
- Health education
- Other

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**Health worker level [specify cadre: \_\_\_\_\_ ]**

- M-health
- Non-monetary incentives: transport, other (specify) \_\_\_\_\_
- Monetary incentives
- Frequent re-fresher training on health education
- Timely guideline dissemination
- Attitude change
- Reduced number of registers/ Efficient or linked registers
- Reduced health worker risk
- Other

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**Health system**

- Reduced number of registers
- Reduced health worker risk
- Proper linkage of index patients/contacts to care – IPT, further TB testing, HIV testing, Nutrition & Diabetes screening
- Proper linkage of data among health facilities
- Computerized registers
- Shorter waiting times
- Other

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**6. Social Network Analysis [Explain what this means]**

ADVANTAGES	BARRIERS	POTENTIAL SOLUTIONS

**7. Global positioning systems and Geographical information systems [Explain what this means]**

ADVANTAGES	BARRIERS	POTENTIAL SOLUTIONS

**8. Would you like to share anything else regarding our discussion on TB contact investigation and linkage to care?**

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*Closure- thank the participant for their time*

Interview conducted by \_\_\_\_\_ (Initials)

Date

dd	mmm	yyyy							





[Type here]

### **WHO Health System Building Blocks**

*Patient, health worker and health system components that will be observed and explored include:-*

#### *i. Patient*

- 1. Mapping TB patient and contact flow in the facility including linkage to care including IPT provision; further TB testing; HIV testing and care; nutrition screening and care; and diabetes screening and care.*
- 2. Clinic hours and time taken at each process time.*

#### *ii. Health worker*

- 1. Number of health workers involved in TB contact investigation and linkage to care.*
- 2. Role health workers play in TB contact investigation and linkage to care in public areas in the health facility (observations not in settings individuals would reasonably expect privacy e.g. private consultation or examination).*
- 3. General attitude of the health workers involved in TB contact investigation and linkage to care – confidence in care provision; propagation of stigma; work load.*
- 4. TB patient file documentation of invitation of contacts for TB screening.*
- 5. Filling of the TB contact register.*
- 6. Documentation of TB patient linkage to care.*

#### *iii. Health system*

- 1. Leadership and governance: policy support (posters or visual documentation related to TB contact investigation and linkage to care displayed at the facility).*
- 2. Service delivery: availability of operational guidelines and details of TB contact investigation and linkage to care; availability of a TB contact register; ability of health worker to link the index TB patient to the contact [contact details e.g. phone number or physical address for both the index TB patient and the contact]; provision of IPT to eligible patients, further TB testing (chest radiography, mantoux test, sputum induction or gastric aspiration for children < 6 years/ patients who cannot produce a sputum sample), HIV testing, nutrition and diabetes screening.*
- 3. Supplies and products: availability of mobile phone airtime; transport for health workers involved in TB contact investigation; IPT in the pharmacy including formulations available; reagents for TB testing in the lab [microscopy, GeneXpert], working chest x-ray machine and film availability, mantoux reagents, facility for sputum induction/gastric aspiration; Mid Upper Arm Circumference (MUAC) tapes, stadiometer, weighing scales, Kenyan Integrated Management of Acute Malnutrition (IMAM) screening charts for children and adults; functional glucometer and glucose strips.*
- 4. Health system financing: Not able to observe this component.*
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- 6. Health work force: (elaborated under health workers above); any visual documentation/posters on TB contact investigation and linkage to care trainings for health workers.*

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## Appendix D – Stigma Scale for Chronic Illness

### English/Swahili Translation of the 26-Item SSCI by Rao et al.

**TO BE ADMINISTERED BY A HEALTH WORKER [within a 1 month time frame i.e. one month after TB diagnosis]**

**Translation from English to Swahili:** YA KUJAZWA NA MHUDUMU WA AFYA [inafaa kujazwa mwezi mmoja baada ya mgonjwa kupatikana na ugonjwa wa TB]

**Back Translation:** TO BE FILLED BY A HEALTH WORKER [it should be filled one month from when the patient was found to have TB]

**SSCI BY RAO ET AL. PILOT TOOL ADAPTED FOR TUBERCULOSIS (TB).** Rate each item within a 1 month time frame. Do you think that because you have TB:-

**Translation From English To Swahili:**

JARIBIO LA MASWALI YA SSCI (YALIYOBUNIWA NA RAO PAMOJA NA WENGINE) YAKIWA YAMEBADILISHWA KUTUMIKA KWA WAGONJWA WALIO NA TB. Tafadhali jibu maswali haya ukizingatia tu mwezi mmoja uliopita.

Je, unafikiri kwamba kwa sababu una TB:-

**Back Translation:**

TRIAL OF SSCI QUESTIONS (DEvised BY RAO TOGETHER WITH OTHERS) MODIFIED FOR USE AMONG PATIENTS WITH TB. Please answer these questions focusing on the last month only.

		Harmonized Translation	Back Translation
	Rate each item within a 1 month time frame	Tafadhali jibu maswali haya ukizingatia tu mwezi mmoja uliopita.	Please answer these questions focusing on the last month only
	The response options are:-	Kwa kila swali unaweza kujibu:-	For each question you can answer:-
	<b>NEVER</b>	<b>HAIJAWAHI KUTOKEA</b>	<b>IT HAS NEVER HAPPENED</b>
	<b>RARELY</b>	<b>IMETOKEA MARA CHACHE SANA</b>	<b>IT HAS HAPPENED A FEW TIMES</b>
	<b>SOMETIMES</b>	<b>IMETOKEA WAKATI MWINGINE</b>	<b>IT HAPPENED SOMETIMES</b>
	<b>OFTEN</b>	<b>IMETOKEA MARA NYINGI</b>	<b>IT HAS HAPPENED MANY TIMES</b>
	<b>ALWAYS</b>	<b>IMETOKEA KILA MARA/KILA WAKATI</b>	<b>IT HAS HAPPENED EVERY TIME</b>
1	Some people have seemed uncomfortable with you	Watu wengine wameonekana kuwa na wasiwasi na wewe	Some people have appeared anxious/worried when they are with you
2	Some people have avoided you	Watu wengine wamekuhepa/wamekutoroka	Some people have avoided you
3	You felt distant from other people	Umehisi uko mbali na watu	You have felt far/distant from other people
4	You felt left out of things	Umehisi kuwa unaachwa nje katika mambo/Umehisi kuwa unatengwa katika mambo	You have felt excluded from things
5	People were unkind to you	Watu wengine hawajakuwa wazuri kwako	Some people have not been good to you

		<b>Harmonized Translation</b>	<b>Back Translation</b>
6	People made fun of you	Watu wengine wamekucheka/wamekukejeli/wamekudhihaki	Some people have laughed at you
7	You felt embarrassed in social situations	Umeona aibu ukiwa na watu	You have felt embarrassed when with people
8	People avoided looking at you	Watu wengine wameepuka kukuangalia usoni/machoni	Some people have avoided looking at you in the eye
9	Strangers tended to stare at you	Watu usiwajua wamekuwa wakikuangalia sana/wakikuzubalia/wakikukodolea macho	People you don't know have stared at you
10	You worried about other people's attitudes towards you	Umekuwa na wasiwasi juu ya mtazamo wa watu kukuhusu/Umekuwa na wasiwasi kuhusu jinsi watu wanavyokufikiria	You have worried about how people perceive you/think of you
11	You were treated unfairly by others	Watu wengine hawajakutendea haki/Watu wengine hawajakufanyia haki	Some people have not treated you fairly
12	You were unhappy about how your situation affected your appearance	Haujafurahia jinsi hali yako imeathiri unavyoonekana	You have been unhappy about how your situation has affected how you appear
13	It was hard for you to stay neat and clean	Imekuwa vigumu kwako kukaa msafi na nadhifu (kupanga vitu vyako vizuri, kujiweka vizuri).	It has been hard for you to stay neat and clean
14	People tended to ignore your good points	Watu wengine wamepuuza uzuri wako	Some people have ignored your good aspects/the good things about you
15	You worried that you were a burden to others	Umekuwa na wasiwasi kwamba umekuwa mzigo kwa watu	You have worried that you have become a burden to other people
16	You felt embarrassed about your situation	Umeona aibu kuhusu hali yako	You have felt embarrassed about your situation
17	You felt embarrassed because of your physical limitations	Umeona aibu kwa sababu umeshindwa kufanya kazi au mambo uliyokuwa ukiyafanya (nyumbani, shuleni au kazini)	You have felt embarrassed because you were unable to do the activities/things you used to do (at home, school or work)
18	You felt embarrassed about your speech	Umeona aibu ukizungumza	You have felt embarrassed when you speak
19	You felt different from others	Umejihisi kuwa tofauti na watu wengine	You have felt (that you are) different from others
20	You tended to blame yourself for your problems	Umejilaumu kwa shida zako/matatizo yako	You have blamed yourself for your problems
21	Some people acted as though it was your fault	Watu wengine wamefanya mambo kana kwamba ni makosa yako	Some people have acted as though it is your mistake/fault
22	You avoided making new friends	Umeepuka kufanya urafiki na watu wapya/Umeepuka kufanya marafiki wapya	You have avoided making friends with new people

		<b>Harmonized Translation</b>	<b>Back Translation</b>
23	You were careful who you told about your situation	Umekuwa mwangalifu kuhusu unayemwambia juu ya hali yako	You have been careful about who you tell about my situation
24	You worried that people will tell others about your situation	Umekuwa na wasiwasi kwamba watu watawaambia wengine kuhusu hali yako	You have worried that people will tell others about your situation
25	People in your situation lost their jobs when their employers found out about it	Watu walio na TB wamepoteza kazi zao kwa sababu waajiri wao wamegundua kuhusu hali yao	People with TB have lost their jobs when their employers found out about their condition
26	You lost friends when you told them about your situation	Umepoteza marafiki tangu ulipowaambia kuhusu hali yako	You have lost friends since you told them about your situation

## Appendix E – Publication and Conference Abstracts



### RESEARCH ARTICLE

## Stakeholder perspectives for optimization of tuberculosis contact investigation in a high-burden setting

Diana Marangu<sup>1,2\*</sup>, Hannah Mwaniki<sup>3</sup>, Salome Nduku<sup>4</sup>, Elizabeth Maleche-Obimbo<sup>1</sup>, Walter Jaoko<sup>5</sup>, Joseph Babigumira<sup>6</sup>, Grace John-Stewart<sup>6,7,8,9</sup>, Deepa Rao<sup>6,10</sup>

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### OPEN ACCESS

**Citation:** Marangu D, Mwaniki H, Nduku S, Maleche-Obimbo E, Jaoko W, Babigumira J, et al. (2017) Stakeholder perspectives for optimization of tuberculosis contact investigation in a high-burden setting. *PLoS ONE* 12(9): e0183749. <https://doi.org/10.1371/journal.pone.0183749>

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**Data Availability Statement:** The data that support the findings of this study are included in this paper and its supplementary information files.

**Funding:** Diana Marangu is a recipient of the International AIDS Research Training Program (IARTP) MPH-PhD Implementation Science Scholarship funded by the Fogarty International Centre, National Institutes of Health (NIH) (1 D43 TW009580). Grace John-Stewart holds an NIH K24 Mentoring Award (K24 HD54314). Hannah Mwaniki and Salome Nduku received funding from the study budget as research assistants. The

## Abstract

### Introduction

Optimal tuberculosis contact investigation impacts TB prevention, timely case finding and linkage to care, however data on routine implementation in high burden contexts is limited.

### Materials and methods

In a multi-method qualitative study based on individual interviews with TB patients, facility observations and focus group discussions with health workers (HWs) in 13 public health facilities, and key informant interviews with governmental and non-governmental experts, we describe TB contact investigation in the context of an urban setting in Kenya and identify opportunities for optimization.

### Results

Invitation of TB patients to bring close contacts by HWs was key for all patient decisions that led to contact screening in addition to patients' understanding of TB transmission and desire to avoid contacts suffering from TB. Sub-optimal HW enquiry of TB patients and contacts presenting at the facility were missed opportunities which stemmed from lack of standardized operational procedures, documentation tools and HW training. Stakeholders proposed provision of fast tracked and holistic health packages for contacts seeking TB screening, and sustainable government led funding for the requisite infrastructure and workforce.

PLOS ONE | <https://doi.org/10.1371/journal.pone.0183749> September 8, 2017

1 / 15



Optimization of tuberculosis contact investigation

funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

**Competing Interests:** SM's affiliation to Semantics Africa Limited does not alter our adherence to PLOS ONE policies on sharing data and materials.

## Conclusion

TB contact invitation by HWs leading to contact screening occurs in this context. Stakeholder perspectives inform the design of an operational framework for optimized delivery.

## Adapting a Stigma Scale for Assessment of Tuberculosis-Related Stigma Among English/Swahili-Speaking Patients in an African Setting

Diana Marangu and Hannah Mwaniki  
University of Nairobi

Salome Nduku  
Semantics Africa Limited, Nairobi, Kenya

Elizabeth Maleche-Obimbo and  
Walter Jaoko  
University of Nairobi

Joseph Babigumira, Grace John-Stewart  
and Deepa Rao  
University of Washington

To adapt a validated instrument that quantitatively measures stigma among English/Swahili-speaking tuberculosis (TB) patients in Kenya, a high-burden TB country. Following ethical approval, we elicited feedback on the English- and Swahili-translated Stigma Scale for Chronic Illness (SSCI) tools through cognitive interviews. We assessed difficulties in translation, differences in meaning, TB contextual relevance, patients' acceptability to the questions, and issues in tool structure. The interviews were audiorecorded, transcribed, and translated. Open coding and thematic analysis of the data were conducted by 2 independent researchers. Between May and September 2015

we conducted a qualitative study among 20 adult TB patients attending 11 health facilities in Nairobi County, Kenya. Most questions were understood in both English and Swahili, deemed relevant in the context of TB, and acceptable to TB patients. Key areas of adaptation of the SSCI included adding questions addressing fear of infecting others and death, HIV stigma, and intimate, family, and workplace relationship contexts. Questions were revised for nonredundancy, specificity, and optimized sequence. The adapted 8-item SSCI appears to be a useful tool that may be administered by health workers in English or Swahili to quantify TB stigma among TB patients in Kenya.

*Keywords:* measuring stigma, TB, Nairobi, Kenya

*Supplemental materials:* <http://dx.doi.org/10.1037/sah0000056.supp>



**UNION CONFERENCE 2017 – ABSTRACT ACCEPTED**

Track: G- Global Plan to End TB 2016–2020 and End TB Strategy – country-level experiences on paradigm shift

**Title: Optimizing tuberculosis contact investigation in a high burden urban setting: a qualitative study**

Author(s): **D Marangu**<sup>1,2</sup>, H Mwaniki<sup>3</sup>, S Nduku<sup>4</sup>, E Maleche-Obimbo<sup>1</sup>, W Jaoko<sup>5</sup>, J Babigumira<sup>6</sup>, G John-Stewart<sup>6,7,8</sup>, D Rao<sup>6,9</sup>

*Institute(s):* <sup>1</sup>University of Nairobi, Department of Paediatrics and Child Health, Nairobi, Kenya, <sup>2</sup>University of Nairobi, Institute of Tropical and Infectious Diseases, Nairobi, Kenya, <sup>3</sup>University of Nairobi, Population Studies and Research Institute, Nairobi, Kenya, <sup>4</sup>Semantics Africa Limited, Nairobi, Kenya, <sup>5</sup>University of Nairobi, Department of Medical Microbiology, Nairobi, Kenya, <sup>6</sup>University of Washington, Department of Global Health, Seattle, WA, United States of America, <sup>7</sup>University of Washington, Department of Allergy and Infectious Disease, Seattle, WA, United States of America, <sup>8</sup>University of Washington, Department of Epidemiology, Seattle, WA, United States of America, <sup>9</sup>University of Washington, Department of Psychiatry and Behavioral Sciences, Seattle, WA, United States of America.  
e-mail: dmarangu@uonbi.ac.ke

Text: **Background:** Optimal tuberculosis (TB) contact investigation (CI) impacts TB prevention, timely case finding and linkage to care, however data on routine TB-CI implementation in high burden contexts is limited.

**Methods:** In a qualitative study based on individual interviews with pulmonary TB patients, facility observations and focus group discussions with health workers (HWs) in 13 health facilities, and key informant interviews with governmental and non-governmental stakeholders in Kenya, we identified facilitators, barriers and opportunities to optimize TB-CI through triangulation of data and methodology, synthesized themes, and inform the design of an operational framework.

**Results:** Invitation of TB patients to bring close contacts by HWs was key for all patient decisions that led to contact screening. Patients' understanding of TB transmission and desire to avoid contacts suffering from TB; and pro-active measures by HWs including home-visits and sputum container provision for unavailable contacts were additional facilitators. Barriers reported included long wait-times, non-conducive clinic hours for contacts who were working or in school, poor community awareness and TB stigma. Sub-optimal enquiry and lack of HW invitation of close contacts presenting at the facility were missed opportunities which stemmed from lack of TB-CI specific operational guidelines, documentation tools and HW training. Stakeholders proposed provision of fast tracked and holistic health packages to add value for contacts seeking TB screening, synergistic facility and community health strategies customized to diverse contexts, interoperable, efficient and user-friendly computerized health information systems, sustainable government led funding for infrastructure and an adequate well trained health workforce for optimized TB-CI delivery.

**Conclusions:** TB contact invitation by HWs leading to contact screening does occur in the public health sector however gaps exist. Patient and HW perspectives gained from this study inform the design of TB-CI specific operational guidelines and framework for optimized TB-CI in context.



**PAN AFRICAN THORACIC SOCIETY CONFERENCE 2016 – ABSTRACT ACCEPTED FOR POSTER DISCUSSION (PRESENTED)**

**ADAPTING THE STIGMA SCALE FOR CHRONIC ILLNESS FOR ENGLISH/SWAHILI SPEAKING PATIENTS WITH TUBERCULOSIS IN NAIROBI, KENYA.**

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Preferred presentation format: Oral presentation

**Background:** Tuberculosis (TB)-related stigma is a barrier to TB control with serious health and socioeconomic consequences. A validated instrument that quantitatively measures TB stigma in Kenya, a high burden TB country, is envisioned in the national strategic plan but does not currently exist.

**Methods:** The 26 item Stigma Scale for Chronic Illness (SSCI) is a tool for evaluating chronic illness stigma designed in English. Three independent multilingual researchers translated it into Swahili and back into English. Following ethical approval, we elicited feedback on the translated SSCI tools through cognitive interviews assessing semantic/conceptual difficulties in translation, differences in intended/referential meaning, TB contextual relevance, patients' acceptability to the questions, and issues in tool structure. The interviews were audio recorded, transcribed and translated. Open coding and thematic analysis of the data was conducted by two independent researchers. Findings were incorporated in the final English and Swahili health worker administered versions of the adapted SSCI tool for TB stigma assessment at diagnosis and follow-up.

**Results:** Between May and September 2015 we conducted a qualitative study among 20 adult TB patients attending 11 health facilities in Nairobi County, Kenya. The median time since TB diagnosis was 2 months (IQR 1-3.5) and 15 (75%) of the patients had disclosed their TB status. Most questions were understood in both English and Swahili, deemed relevant in the context of TB and acceptable to TB patients. The main identified factors promoting TB stigma were fear of infecting others, HIV stigma and poor relationship support all stemming from lack of proper understanding of TB. Key areas of adaptation of the SSCI included adding questions addressing fear of infecting others and death; HIV stigma; and intimate, family and workplace relationships. Questions were revised to be non-redundant, specific; and the sequence was re-ordered based on similar constructs to optimize flow.

**Conclusion:** The adapted 8 item SSCI appears to be a useful tool in quantifying TB stigma in a health worker administered format for English/Swahili speakers in Kenya in this pilot study. We will assess its utility in quantifying TB stigma in a larger population in the next phase of this study.