SMT Stigma

SMT Stigma Project Report

KNCV Tuberculosis Foundation

July 2024

KNCV
TB | PLUS

Project contributors

Agnes Gebhard - KNCV Global Office

Amanzhan Abubarikov – Kazakhstan's National Tuberculosis Program

Bianca Tasca – KNCV Global Office

Danara Izmukhanova – KNCV Global Office

Elizabeth Chamwalira– KNCV Malawi

Emmy van der Grinten – KNCV Global Office

Ineke Huitema – KNCV Global Office

Inez de Kruijf – Carter – KNCV Global Office

Janine Manuel – KNCV Global Office

Jense van der Wal – KNCV Global Office

Juan Mora Barrios – KNCV Global Office

Kathy Fiekert – KNCV Global Office

Lilian Polderman – KNCV Global Office

Mario Willemsem – KNCV Global Office

Natalia Andreeva – KNCV Global Office

Niesje Jansen – Aaldring – KNCV Global Office

Sara Keller – KNCV Global Office

Svetlana Pak – KNCV Kazakhstan

Final reporting: Agnes Gebhard, Bianca Tasca, Ineke Huitema, Inez de Kruijf – Carter, Juan Mora Barrios, Svetlana Pak

TABLE OF CONTENTS

BACKGROUND

Stigma in healthcare institutions, patients and communities is among the most identified barriers to overcoming the tuberculosis (TB) epidemic. The situation is exacerbated by COVID-19, stretching the resources and resilience of the workforce, and, due to the similarity in some of the symptoms, being fever and cough, adding the stigma of COVID-19 to the existing stigma of TB. Reducing stigma impacts many facets of TB eradication, including timely care seeking, commencing, and completing treatment, contact screening and provision of preventive treatment. However, stigma prevention and reduction interventions are generally underfunded in both countries' National Strategic Plans as well as Global Fund applications and domestic budgets; one reason is the lack of guidelines and documented best practices on how to reduce stigma.

STRATEGIC RELEVANCE

WHO guideline development is greatly dependent on systematic evaluation of impact of interventions, requiring rigorous monitoring and evaluation of interventions. While strong guidance on stigma interventions is much needed to ensure inclusion in National Strategic plans and funding allocations, to date there is insufficient evidence to allow strong WHO recommendations on specific stigma reduction approaches. To ensure in the near future stronger recommendations can be made, KNCV is aiming at generating the needed evidence on the area.

The KNCV experiences include stigma measurement as well as the implementation of three intervention tools, addressing stigma of TB in health care facilities and among health care providers (the Allies Approach), stigma experienced by patients, including self-stigma (From the Inside Out), and stigma in communities (Photo Voices).

The development of these stigma tools was informed by the experience with tools developed earlier by KNCV and technical partners, like the Quote Light tool, as well as by KNCV development of a stigma measurement guidance (1), and existing methodologies and materials from work on stigma in the fields of TB, HIV and leprosy. It must be noted though, that not many intervention tools have documented the effectiveness of the intervention, although there are various tools available to measure stigma prevalence within settings.

To implement the KNCV Strategic Plan 2020-2025, KNCV defined innovation pathways, one of which concerns reducing stigma of TB and related health problems:

KNCV Innovation pathway 5: Reducing stigma of TB and related health problems
Expected landscape by 2025: the application of evidence-based stigma reduction tools is mainstreamed in National Strategic Plans and major donor funded programs
a. Advocating and policy development for mainstreaming of stigma reduction in NSPs and grant applications
b. Making tools available for stigma measurement
c. Further development of tools to raise awareness about stigma and stigma prevention & intervention packages
d. Capacity building and evidence generation on the use of stigma reduction tools in key countries
e. Collaborating on use of TB stigma reduction tools for application in other diseases like COVID.

To contribute to stronger global guidance and demand country and donor commitment to finally address stigma effectively, KNCV aims at making three intervention tools available for scale-up, which reduce stigma among

health care workers, patients, and communities respectively, while measuring impact, contributing to the body of evidence on their use.

Key steps to contribute to this ambition are as follows:

- Adjusting the TB stigma reduction tools for application in various contexts and for various health conditions, including those that go hand-in-hand with TB (HIV) or have similar symptoms to TB (COVID-19).
- Building capacity in key countries for implementation.
- Measuring effect, generating evidence to strengthen the WHO recommendations on the topic.

With this project we focused on addressing stigma in health care facilities, the first and most feasible step to ensure safe, accessible, patient-centred, quality services. The intention for this project was that the evidence generated would directly impact the strength of the recommendations in the stigma section of the WHO social protection guidelines.

OBJECTIVES

The main objective of this project was to produce evidence on stigma interventions to inform the WHO guidelines on stigma reduction in health care workers and health care facilities in different settings.

Subobjectives included:
1.) Adapting the KNCV Allies approach for implementation in Malawi, Kazakhstan, and Nigeria;
2.) Building capacity in key countries for implementation;
3.) Measuring the effect of the Allies Approach in all settings - generating evidence to strengthen the WHO recommendations on the topic.

IMPLEMENTATION PLAN AND APPROACH

The overarching implementation plan and approach for this project was to build on tools, experiences, and data generated during the initial limited piloting of the KNCV "Allies Approach – Stigma reduction toolkit for health care institutions" (AA) implemented between September 2018 and January 2019.

To provide strong global guidance, the WHO needs evidence from different areas of the world, representing a variety of populations, health care systems and settings. The choice of countries was in Africa and Central and Southeast Asia and, of course, guided by the KNCV presence in the countries. In Africa two countries were chosen: Nigeria given earlier work in stigma was identified as a barrier to DR TB care; and Malawi, where TB is significantly associated with HIV. In Asia, Kazakhstan and Indonesia were selected because of their high (DR) TB burdens and high commitment to reducing stigma of TB/COVID-19.

Our initial plan for roll-out of this intervention in Nigeria was to do so through the Obafemi Awolowo University Teaching Hospitals (OAUTH), where KNCV collaborated on a joint TB training program. A scoping discussion with the university, showed their priority was more on national stigma measurement than on training of healthcare workers, which was beyond the scope of this project. To be able to roll-out the training we developed an adapted approach – the Hybrid Allies Approach, combining on-line with face-to-face sessions in a distance learning program.

In Malawi we joined efforts with the NTP and the USAID funded LON project implemented by Development Aid for People by People (DAPP), implementing the Allies Approach, while the SMT funded project implemented base- and endline studies to assess the interventions' effect. In Kazakhstan KNCV directly partnered with the NTP and the Kazakh National Medical University. Indonesia was removed from the plan as already different stigma reduction interventions are happening by patient support groups and more time and investment would be needed to identify the right approach there. In the following sections a more detailed report on implementation in Kazakhstan, Malawi, and the Hybrid implementation of the Allies Approach is given.

One of the activities of this project was assessing the effect of the interventions through a before-and-after assessment tool. The baseline and endline assessments were specifically developed for the Allies Approach intervention to measure potential changes in constructs such as healthcare workers' (HCWs) attitudes and feelings, enacted stigma, and perceived organizational support. The scales selected have been validated for use in various settings and contexts and employed as recommended in previous research (1–4).

In all settings, participants completed the assessment just before the training began and again on the last day, after the final session. For the Hybrid version of the Allies Approach, a similar setup was implemented: participants had one week before the beginning of the first module to complete the baseline assessment, and for approximately fifteen days after the last module ended, the endline survey was available to be filled in the RedCap online survey tool through a link sent to them. Additionally, participants completed a course evaluation alongside the endline assessment.

A copy of the full version of the assessment tool and results can be found in Annex 1.

KAZAKHSTAN

In Kazakhstan, the Allies Approach objectives were 1) to engage up to 30 health care facilities providing TB care in Astana by introduction of the Allies Approach' concept and train 1-2 representatives of each facility as Key Opinion Leaders (KoLs)[1] to guide their colleagues through the implementation of the Allies Approach, and 2) to pilot the Allies Approach toolkit with a group of medical students to explore the possibility of future inclusion of stigma reduction training into the preservice training standard curriculum.

IMPLEMENTATION OF ALLIES APPROACH INTERVENTIONS IN PRIMARY HEALTHCARE FACILITIES FACILITIES

In Kazakhstan, the Allies Approach was implemented in primary healthcare facilities (PHC) both public and private that provide TB care. In total, 31 healthcare facilities were engaged (Figure 1). Among these, we selected fourteen private clinics that provide ambulatory care including TB care in the framework of the state' Guaranteed Volume of Free Medical Care (GVFMC).

Engaged healthcare facilities (N=31)

- public PHCs
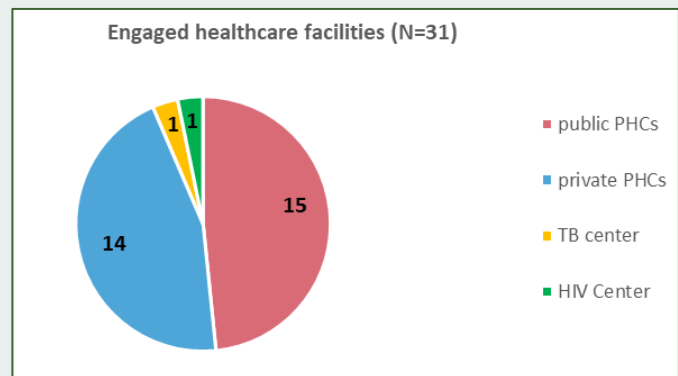- private PHCs
- TB center
- HIV Center

FIGURE 1 – HEALTHCARE FACILITIES ENGAGED IN THE ALLIES APPROACH

---

[1] A Key Opinion Leader is defined as a "service provider who is respected, trustworthy, and influential among co-workers and peers. They are expected to demonstrate concern for their medical community and be willing to make efforts to improve the quality of services provided".

Three Trainings of Trainers (ToTs) were conducted for 46 key opinion leaders (30 KoLs from public PHCs, 14 KoLs from private PHCs, 1 from each HIV/AIDS and TB centers). By gender all participants were distributed as follows - 43 females and 3 males. Among them there were 35 general practitioners (GPs), 4 psychologists, 3 epidemiologists and 4 nurses.

First two ToTs were conducted for representatives of public primary healthcare facilities from 3rd till 5th October and from 7th till 9th November in 2022. ToT for the KoLs from private clinics was conducted from 13th till 15th February 2023. The first ToT in October 2022 was facilitated by Niesje Jansen from the KNCV Global Office with support of Amanzhan Abubakirov (representative of the national TB program who was involved in piloting of Allies Approach toolkit in 2018 – 2019 in Almaty) and Svetlana Pak (KNCV consultant based in Kazakhstan). The other two ToTs in November 2022 and February 2023 were facilitated by Amanzhan Abubakirov and Svetlana Pak.

Selection of KoLs was based on their interest in stigma associated with diseases, their availability and dedication to apply new competences on their job. As an additional selection criterion, KoLs had to be well respected by their colleagues and well communicate with others. City TB Centre in Astana provided support in identification of PHCs and selection of KoLs.

Before the start of trainings, KoLs signed the *Informed Consent Form* on voluntary participation, gave permission on using workshop' photos for advocacy purposes and filled in the Stigma Baseline Measurement Questionnaire which was translated to Russian*.

During the first two days of training the exercises from all the five modules of Allies Approach toolkit (Values, Heart, Hands, Face and Head) were facilitated*. Interactive methodology was used for training. Thus, participants were learning by doing. Each exercise was followed by the group' discussion and evaluation. Specific focus was on self-assessment, self-reflection, and peer review to acknowledge one's needs for recognition and acknowledgements, identification of health work environment, negotiating and supporting change.

On the third day of training the focus was on the implementation phase of Allies Approach interventions at the PHC' facilities. As a result of 3rd day, participants worked out Allies Approach facility implementation plan that included the list of exercises selected from five modules, preparation and schedule.

After KoLs returned to their workplaces they initiated meetings with PHC' facility management to brief them about ToT, AA interventions and next step to get their support for implementation of AA exercises at the facility. Implementation of interventions took about five months as it was not easy to get the same participants for all exercises. All participants signed the Informed Consent Form. In all facilities implementation started from the introductory session explaining the meaning of stigma, its drivers and facilitators, and presentation of Allies Approach toolkit to build the basis for implementation of exercises. All participants gave positive feedback on the interventions and methodology as it was their first experience. Support to KoLs was provided by assigned trained specialist of city TB Center and Svetlana Pak through regular mentoring visits to PHC facilities, peer support sessions (face-to-face or online) throughout the implementation period. Participants filled in the Stigma Measurement Questionnaire (baseline and endline assessment) before and after exercises.

PILOT THE ALLIES APPROACH TOOLKIT WITH A GROUP OF MEDICAL STUDENTS

The Allies Approach toolkit was piloted with the group of final year students of Kazakh National Medical University during their course on physiology. According to the local regulations free hours are granted to each

faculty to include the topics which are not on the training agenda. Thus, such free hours were used for piloting the Allies Approach interventions. We could pilot the AA interventions with the group of 15 medical students who were educated in Russian language. Unfortunately, it was not possible to pilot it with the group of students educated in Kazakh language as we didn't have materials in Kazakh language. During preparation we selected one exercise from each of all five modules that are most relevant for medical students and adjusted the baseline and endline measurement tool. The selected exercises were the following – "*Cross the Line*", "*Comfort Continuum*", "*Four Corners*", "*My imperfection, Your imperfection*" and "*Labeling*". In total, implementation of five exercises took 15 academic hours. According to the students' feedback these exercises should be included in the training agenda of medical university as they are important for professional development and better understanding of stigma associated with the diseases.

KEY IMPLEMENTATION CHALLENGES

Implementation of Allies Approach interventions in PHC facilities took seven instead of four months as initially planned because:
- the authorization of facilities' managers was needed to get participants for exercises,
- it was not easy to get participants as many of facility' staff members refused because they do not consider stigma as a problem relevant for the health facilities,
- only one or two exercises could be conducted in a week as it was difficult to get the same group of participants as they had different working schedules, and additionally high stuff turnover particularly at PHC level.

Initially we planned to pilot Allies Approach with the students of Medical Academy in Astana city, but approval process took long time. So, we decided to pilot it with the students at the National Medical University in Almaty city. There was no problem with getting permission, but the group of students who could participate was small, only 15 people, because of the language issue. All the materials were translated into Russian language and the trainer could not facilitate exercises in Kazakh language.

BASELINE & ENDLINE ASSESSMENTS RESULTS

In Kazakhstan, 145 people participated in the Allies Approach training (including KoLs and other health facility staff) . Of these, 92% were women, with a median age of 33 years. The majority of participants were physicians (50%) and nurse professionals (36%). Regarding their involvement in TB care, 43% of participants worked within the area of TB/HIV, 22% with DR-TB, 16% with DS-TB solely, and a small fraction with HIV alone. In terms of training, 58% had not received formal training on stigma, and 62% had not received training on discrimination. However, 17% had received stigma training in the past three years, and 14% had received discrimination training in the same period. A minor percentage of participants were unsure or could not recall their training status.

TABLE 1 – BASELINE CHARACTERITICS OF PARTICIPANTS – KAZAKHSTAN (N=145)

Characteristic	Baseline Assessment (N = 145)[1]
Gender	
Man	12 (8.2%)
Woman	134 (92%)
Age	33 (27 - 50)
Unknown	4 (2.7%)
Occupation	
Nurse associates (e.g., Nurse aid, Community health worker)	3 (2.1%)
Nurse Professional	53 (36%)
Other	5 (3.4%)
Other Health Staff (e.g., Pharmacist, Psychologist)	11 (7.5%)
Other Support Staff (e.g. Cleaning, janitor, secretaries)	1 (0.7%)
Physician	73 (50%)
Are you involved in the treatment and care of people with	
DS-TB	24 (16%)
DR-TB	32 (22%)
HIV	7 (4.8%)
TB/HIV	63 (43%)
Missing	20 (14%)
Have you received any formal training on the topics of stigma?	
I don't know what stigma is	3 (2.1%)
I do not remember	13 (8.9%)
No	85 (58%)
Yes, in the past 3 years	25 (17%)
Yes, more than 3 years ago	19 (13%)
Missing	1 (0.7%)
Have you received any formal training on the topic of discrimination?	
I don't know what discrimination is	2 (1.4%)
I do not remember	10 (6.8%)
No	90 (62%)
Yes, in the past 3 years	20 (14%)
Yes, more than 3 years ago	21 (14%)
N/A	2 (1.4%)
Missing	1 (0.7%)

1 n (%); Median (IQR)

The baseline and endline assessments were filled by all participants (N=145). The table under provides the difference estimates for all assessed scales in the country: Neff's self-compassion scale, Pommier's compassion scale, perceived organizational support scale, Corrigan attribution questionnaire short form, other co-workers' external TB stigma, fear-based scale, modifiers of stigma scale, and drivers of stigma scale (Table 2). Detailed results per each of the scales components can be found in the supplementary material.

Results from the before/after analysis show minimal difference between the two assessments. The scales intercepts range from 2.65 to 5.47, indicating the baseline levels which were all around the median value of each scale. The survey effects show varying degrees of change, with none reaching statistical significance.

The Corrigan Attribution questionnaire short form showed the largest survey effect (-0.25, p = 0.076). This scale includes statements describing the attitudes and feelings of healthcare providers toward TB patients. In Kazakhstan, the statement "I think it would be best for TB patients to be isolated in the intensive phase", had a significant increase from 5.04 (SD = 3.70) to 5.61 (SD = 3.72) with a p-value of 0.032, suggesting a growing preference for isolation during treatment.

In the Perceived Organizational Support scale, it was possible to note a significant decrease in the mean score of the statement "Help is available from my organization when I have a problem" from 5.33 at baseline to 5.06 at endline (p = 0.014). This could suggest a reduction in the perceived availability of organizational support. The detailed results by scale statements can be found in the annexed material.

TABLE 2 – RESULTS FROM GENERALIZED LINEAR MIXED MODELS (GLMM) ANALYSIS BETWEEN BASELINE AND ENDLINE ASSESSMENTS IN KAZAKHSTAN

		Estimate	p- value
Neff's self-compassion scale	**Fixed Effects**		
	Intercept	3.07	
	Survey	-0.07	0.13
	Random Effects		
	Group Variance	0.13	
	Residual Variance	0.14	
Pommier's compassion scale	**Fixed Effects**		
	Intercept	3.09	
	Survey	-0.03	0.4
	Random Effects		
	Group Variance	0.04	
	Residual Variance	0.13	
Perceived organizational support scale	**Fixed Effects**		
	Intercept	4.3	
	Survey	0.06	0.44
	Random Effects		
	Group Variance	0.57	
	Residual Variance	0.55	
Corrigan attribution questionnaire short form	**Fixed Effects**		
	Intercept	5.47	
	Survey	-0.25	0.07
	Random Effects		
	Group Variance	1.28	
	Residual Variance	1.38	

		Estimate	p- value
Other co-workers' external tb stigma	**Fixed Effects**		
	Intercept	2.65	
	Survey	0.09	0.46
	Random Effects		
	Group Variance	0.75	
	Residual Variance	1.19	
Fear based scale	**Fixed Effects**		
	Intercept	2.8	
	Survey	0.06	0.95
	Random Effects		
	Group Variance	0.52	
	Residual Variance	0.85	
Modifiers of stigma scale	**Fixed Effects**		
	Intercept	4.1	
	Survey	-0.01	0.9
	Random Effects		
	Group Variance	0.75	
	Residual Variance	0.66	
Drivers of stigma scale	**Fixed Effects**		
	Intercept	3.68	
	Survey	0.04	0.63
	Random Effects		
	Group Variance	0.42	
	Residual Variance	0.44	

MALAWI

The short-term technical assistance (STTA) mission had an objective to strengthen competencies (knowledge, skills, and attitudes) of selected key opinion leaders/ change agents from all health care facilities (N=21) in 3 districts in Malawi (Mulanje, Machinga, Mangochi) to implement the "KNCV Allies Approach: Tuberculosis Stigma Reduction for Health Care Institutions" interventions.

A workshop was organized in the country to address staff competency gaps, with the following objectives:
1. Plan and execute stigma reduction activities according to the specific facilities' needs.
2. Define needs for further planning and decision making;
3. Monitor roll-out process;
4. Evaluate intended and actual results.

The duration of the workshop was in total three days. It took place from Tuesday 26 till Thursday 28 April 2022. Immediate roll-out of stigma reduction interventions in the three districts would be implemented according to the schedule made in the workshop.

The KNCV Global Office consultants (Ineke Huitema and Niesje Jansen) worked with 17 key opinion leaders/ change agents, nine females and eight males. Among them were representatives from the National TB Program,

National Stigma Coordinator, District Community Coordinators and District Technical Coordinators. An important selection criterion was their interest, dedication, and time available to apply new competences on their job and cover all 21 facilities. In addition, all participants' were persons well respected in their communities, being early adopters of new procedures and communicating well with others. They all have good technical knowledge of TB and are familiar with the role of facilitator. The selection was done through KNCV, Development Aid for People by People (DAPP) and in close collaboration with the National TB program.

The participants were guided through the process of planning, execution, and evaluation of stigma reduction interventions. Adult learning principles were applied. Plenary discussions and individual/group work were the main methodologies employed. During the workshop, specific focus was on self- assessment, self- reflection, and peer review to acknowledge one's needs for recognition, identification of health work environment; negotiating and supporting change using training materials developed for key opinion leaders/ change agents.

On the last day of the training the three teams for each District made a plan for roll-out of the Allies Approach in their own District.

The Training of Trainers (ToT) was part of the Lon Malawi project. For the SMT stigma project we looked at the baseline and endline assessments to include the results in this project.

KEY IMPLEMENTATION CHALLENGES

The implementation of the Allies Approach after the ToT was planned to be done in the three Districts Mulanje, Machinga and Mangochi - this roll-out was funded by the LON project. Each district had their own teams for further roll-out activities within healthcare facilities. However, the overarching coordination for these roll-out activities was limited due to restricted funding available for central coordination; monitoring; and follow up support to trainers of the intervention. This lack of funding and therefore central coordination led to each district planning their own manner of roll-out, dependant on their capacities and available time for investment. The initial guidance provided during the roll out planning with the recently trained trainers was that exercises should be selected from each chapter (values, health, head and face), to ensure that participants received a holistic training of themes related to stigma within the healthcare profession. Additionally, each facility should have several training sessions to ensure the full integration of knowledge, skills and experience over multiple points in time by revisiting themes and topics. However, this guidance was only applied in one of the three districts, namely the Mangochi district.

In the Mangochi district no major challenges were noted – they were able to conduct the training over a 4 month period, meeting multiple times over this time period to ensure that all thematic areas of the Allies Approach course were sufficiently covered.

In the Mulanje district over 100 participants were invited for the training, where the need to come to a central training location, led to reduced training hours as people had trouble arriving at the training facility in time. In the Machinga district, the training took place at respective healthcare facilities (in total 7 facilities were trained on the methodology). The challenge noted with this approach was that only one day could be dedicated for the training per facility, as for financial reasons only 1 day training was reserved per facility, sufficient to complete only two exercises ("who else if not me" and the "breathing exercise"). Therefore, not all topics were covered and healthcare providers did not receive a comprehensive and holistic understanding of factors that influence stigma. The entire training package was provided to healthcare providers to review at their own pace individually – however, the training guide is not fit for purpose for healthcare providers to work through themselves, as it is structured as a facilitators guide, used during training of trainers.

BASELINE & ENDLINE ASSESSMENT RESULTS

In Malawi, 288 participants completed the baseline assessment (N=80 in Machinga, N=100 in Mangochi and N=108 in Mulanje), with gender distribution of 33% of females in Machinga, 45% in Mangochi, and 39% in Mulanje. The median age across districts ranged from 39 to 40 years. Occupational distribution varied, with the highest percentage of nurse professionals in Mangochi (30%), and other health staff being relatively evenly distributed across districts. Screening and prevention involvement in TB/HIV was highest in Mulanje (88%) and lowest in Mangochi (82%). Similarly, treatment and care involvement for TB/HIV was high in all districts, ranging from 86% to 90%. Training on stigma and discrimination showed that the majority of participants had not received formal training, with Mangochi having the highest percentage of untrained participants (85% for stigma, 85% for discrimination training) (Table 3).

FIGURE 2- ALLIES APPROACH PEER-LEARNING INTERVENTION PACKAGE MODULES

TABLE 3 – BASELINE CHARACTERISTICS OF PARTICIPANTS PER DISTRICT–MALAWI (N=288)

Characteristic	N	Machinga, N = 80[1]	Mangochi, N = 100[1]	Mulanje, N = 108[1]
Gender	285			
Female		26 (33%)	44 (45%)	42 (39%)
Male		54 (68%)	54 (55%)	65 (61%)
Missing Value		0	2	1
Age	278	40 (31, 47)	39 (30, 45)	40 (33, 44)
Missing Value		2	5	3
Occupation	269			
Nurse associates (e.g., Nurse aid, Community health worker)		7 (9.6%)	8 (8.7%)	7 (6.7%)
Nurse Professional		13 (18%)	28 (30%)	20 (19%)
Other Health Staff (e.g., Pharmacist, Psychologist,		22 (30%)	24 (26%)	30 (29%)
Other Support Staff (e.g. Cleaning, janitor, secretaries)		8 (11%)	13 (14%)	9 (8.7%)
Others		14 (19%)	4 (4.3%)	24 (23%)
Physicians		9 (12%)	15 (16%)	14 (13%)
Unknown		7	8	4
Are you involved in screening and prevention of people with	273			
DR-TB		6 (7.9%)	12 (13%)	5 (4.8%)
DS-TB		5 (6.6%)	3 (3.2%)	6 (5.8%)
HIV		2 (2.6%)	2 (2.2%)	2 (1.9%)
TB/HIV		63 (83%)	76 (82%)	91 (88%)
Missing Value		4	7	4
Are you involved treatment and care of people with	273			
DR-TB		6 (8.1%)	4 (4.3%)	6 (5.7%)
DS-TB		2 (2.7%)	2 (2.1%)	3 (2.9%)
HIV		1 (1.4%)	3 (3.2%)	6 (5.7%)
TB/HIV		65 (88%)	85 (90%)	90 (86%)
Missing Value		6	6	3
Have you received any formal training on stigma?	273			
I do not know what stigma is		2 (2.7%)	3 (3.2%)	7 (6.7%)
I do not remember		6 (8.0%)	4 (4.3%)	4 (3.8%)
None		42 (56%)	80 (86%)	76 (72%)
Not applicable		2 (2.7%)	0 (0%)	2 (1.9%)
Yes, in the past 3 years		12 (16%)	4 (4.3%)	9 (8.6%)
Yes, more than 3 years ago		11 (15%)	2 (2.2%)	7 (6.7%)
Missing Value		5	7	3
Have you received any formal training on discrimination?	272			
I do not know what discrimination is		2 (2.7%)	2 (2.2%)	2 (1.9%)
I do not remember		5 (6.8%)	5 (5.4%)	4 (3.8%)
None		42 (57%)	79 (85%)	81 (77%)
Not applicable		2 (2.7%)	1 (1.1%)	2 (1.9%)
Yes, in the past 3 years		12 (16%)	4 (4.3%)	10 (9.5%)
Yes, more than 3 years ago		11 (15%)	2 (2.2%)	6 (5.7%)
Missing Value		6	7	3

[1] N (%); Median (IQR)

The results from the before/after analysis are divided between the three districts because of the differences in the AA implementation in each of the settings. In Malawi the scales measured in the assessments were: Neff's self-compassion scale, Pommier's compassion scale, Perceived organizational support scale, Corrigan attribution questionnaire short form and Other co-workers' external tb stigma.

From the results under (TABLE 4), it is not possible to see any difference on the Neff's Self-Compassion scale in any of the districts, with the survey estimates ranging from -0.01 to 0.08. The Pommier's Compassion scale also showed non-significant differences across all districts, with the highest change in Mulanje (survey difference: -0.11, p = 0.17). The Corrigan Attribution questionnaire short form showed a slight positive change in Mulanje (0.31, p = 0.4), but this was not significant.

Finally, the Other Co-workers' External TB Stigma scale indicated a significant positive change in Machinga (0.62, p = 0.01), while changes in Mangochi and Mulanje were non-significant. This scale comprises of five items and measures how respondents perceive the general attitudes of their co-workers towards co-workers with TB. This scale is composed of statements such as " I have witnessed HCWs who are suspected of having tuberculosis being stigmatized in my work environment". A positive change in this scale means that participants were more likely to agree with the statements on endline assessment and can indicate that they have become more aware of stigmatizing behaviors perpetuated by colleagues in their work environment.

TABLE 4 – RESULTS FROM GENERALIZED LINEAR MIXED MODELS (GLMM) ANALYSIS BETWEEN BASELINE AND ENDLINE ASSESSMENTS IN THE THREE DISTRICTS OF MALAWI

		Machinga		Mangochi		Mulanje	
		Estimate	**p- value**	**Estimate**	**p- value**	**Estimate**	**p- value**
Neff's self-compassion scale	**Fixed Effects**						
	Intercept	3.42		3.56		3.31	
	Survey	0.01	0.9	0.03	0.7	0.08	0.43
	Random Effects						
	Group Variance	0.04		0.029		0.05	
	Residual Variance	0.22		0.17		0.22	
Pommier's compassion scale	**Fixed Effects**						
	Intercept	3.26		3.24		3.29	
	Survey	-0.01	0.82	-0.01	0.75	-0.11	0.17
	Random Effects						
	Group Variance	0.02		0.03		0.06	
	Residual Variance	0.18		0.09		0.13	
Perceived organizational support scale	**Fixed Effects**						
	Intercept	5.11		5.13		5.07	
	Survey	-0.13	0.29	-0.12	0.25	-0.1	0.49
	Random Effects						
	Group Variance	0.3		0.33		0.16	
	Residual Variance	0.55		0.33		0.66	
Corrigan attribution questionnaire short form	**Fixed Effects**						
	Intercept	5.41		5.04		4.52	
	Survey	-0.05	0.84	0.07	0.76	0.31	0.4
	Random Effects						
	Group Variance	0.1		0.73		0.6	
	Residual Variance	0.2		0.16		3.19	

		Machinga		Mangochi		Mulanje	
		Estimate	**p- value**	**Estimate**	**p- value**	**Estimate**	**p- value**
Other co-workers' external tb stigma	**Fixed Effects**						
	Intercept	2.69		3.92		3.6	
	Survey	0.62	**0.01**	-0.42	0.1	-0.05	0.86
	Random Effects						
	Group Variance	0.71		1.52		1.12	
	Residual Variance	2.12		1.95		2.47	

HYBRID ALLIES APPROACH

For the Hybrid AA, we build on tools, experiences, and data generated during the initial piloting of the KNCV "Allies Approach – Stigma reduction toolkit for health care institutions" between September 2018 and January 2019. Due to the restrictions associated with COVID-19, we adapted the course in a format that was able to accommodate for meeting restrictions, thereby limiting the need for an expert trainer conducting the sessions, and rather that it became a self-led learning process alongside additional small peer group discussions. To this end, the Allies Approach was adapted to its hybrid version, which entailed a self-led e-learning module (module one) and a peer-led discussions module (module two).

The e-learning module (module one) provides theory about TB stigma, raising awareness of TB stigma and providing essential knowledge for stigma reduction. This module is hosted on the Eloomi platform and is typically completed in three hours. It saves an individual's progress so they can return to it and continue the course until it's completion.

The peer-led discussions module (module two) creates opportunity for participants together to explore, question, clarify, and affirm their values and beliefs about TB stigma, and to embed the theory learnt in module one in practical terms through discussion and exploration with peers. The peer-led discussion guide could be downloaded by participants upon completion of the e-learning course (module one).

We planned to have a touch point online via a Teams meeting with participants during the course, to ensure sustained engagement from participants, enthusiasm, and ultimate completion of the course. Once participants finished the course we planned to send an endline assessment to fill, as well as a certificate of completion.

While originally aiming for implementation in Nigeria, in principle there were no limitations to the country of origin of the participants, as long as English was an effective way to communicate. To familiarize more people with the Allies Approach methodology, participants were invited from across the KNCV network to enrol for the course.

The benefits we expected to see from inviting people from across the KNCV network was to be able to assess the intervention within different contexts, including different country and cultural contexts; people already working

in the healthcare profession and those still in training; people working in healthcare facilities, and in civil society organizations.

IMPLEMENTATION FOR HYBRID ALLIES APPROACH

The Hybrid Allies Approach was carried out from September 26 to December,2023. We started the recruitment process by sending invitations to the KNCV network e-mailing list. Concurrently, we created posts across Twitter, Facebook, and LinkedIn KNCV's accounts, extending invitations for participation in an introductory live webinar scheduled for September 14, 2023. The webinar was held to explain the course objectives, timeline, methodology and ways of registering, and what was expected from the participants if they would register in this pilot intervention. A dedicated email channel (stigmareduction@kncvtbc.org) was established for effective communication with prospective participants.

A total of 319 individuals registered to the webinar, with an active participation count of 76 during the live session. Enrollment for the course summed 178 participants. The course methodology was designed to be preferably carried out in peers, however if they were not able to formulate a peer group, they were advised to go through the course on their own, using module two as a self-reflective guide, so as to ensure all interested people were able to participate and glean benefit from the intervention. Peer groups had a maximum suggested amount of 6 people per group. A total of 17 peer groups registered in the course. All participants were enrolled in the "Eloomi" platform – KNCV current online tool for online trainings.

Among the registered participants, 91 (51%) were from Nigeria, followed by 37 (21%) from Uganda and 9 (5%) from Mozambique. Other participants came from Indonesia, Botswana, Ethiopia, Egypt, Namibia, South Africa and The Philippines.

319	76	178
People registered for the webinar	People attended the webinar	Participants registered and enrolled in the Allies Approach course

Throughout the eight weeks of the course, we maintained regular communication with enrolled participants through scheduled emails, aiming to assess their progress and address any doubts. On the 26th of October we hosted a follow-up meeting to assess participants' progress and give out best practices on how to go through Modules 1 and 2. In total, 53 people attended this live webinar.

Out of the 178 registered individuals, 94 (52%) of them assessed the Eloomi platform at least once. Sixty-two individuals (34%) completed module 1. We were technically not able to assess how many people participated or completed module two. Further background on this will be provided under implementation challenges.

A fundamental activity of this project is to assess participants' knowledge of stigma and observe the impact of the Allies Approach course on their levels of self-compassion and enacted stigma. To achieve this, we developed an online version of the Allies Approach baseline and endline assessment using the RedCap survey tool.

KEY IMPLEMENTATION CHALLENGES

For the Hybrid Allies Approach people were expected to enrol for the course as a group by identifying peers from their place of work or study to formulate a discussion group for module two. Although we had 178 people enrol for this course from various countries, we noted that many people did not register as a group, but instead as individuals, requesting to be placed in a group. We, as project team at the KNCV Global Office, had not planned to place people into groups ourselves, particularly as the group meetings were designed to take place in person, as some activities can only be conducted in such setting. When receiving feedback on the course during the follow up survey, as well as during the qualitative interviews, it was stated as a challenge by participants to form their own groups. This led to numerous participants using the discussion guide to reflect on their own experiences and behavior, without a peer group. Although this is effective to an extent, our ambition was for people to discuss and learn from one another's experience, and 'learn by doing' as a way of fully integrating the content and themes into their values, behavior, etc. as people providing healthcare.

The following challenges were directly related to people's participation, progress and follow up during the course. Once people had registered for the course, they were granted access to module one on the e-learning platform (Eloomi). Within this platform we were able to keep track of people's progress of the course: How many people started the course; how far each person was in the course; and who completed the course. Following completion of module one on the e-learning platform, people were able to download the discussion guide directly from the e-learning platform.

Through our e-learning system we noticed that active participation was lower than the enrolment rate despite follow up reminders to all participants to stimulate engagement. The total number of people that completed the course on Eloomi was 62 compared to the 178 that had enrolled.

Secondly, once people had downloaded module two (the discussion guide), it was no longer possible to keep track of their engagement in the same way we had done through the Eloomi platform, as the discussion guide was in PDF format. Although we had a mid-term follow up meeting which all registered participants were invited to, where we gained insight into people's progress through the second module, we were not able to have an in depth understanding about whether they completed the entire guide; if they stopped part of the way through; which activities they focused on; etc. Module two was designed as a peer-led module, where each participant took ownership for their participation and preparation, and used the discussion guide as a 'facilitator'. This clearly was not fitting the needs of the majority of participants.

Lastly, there were challenges associated with receiving endline assessments from participants who had completed the entire course – especially for module two. For the baseline assessment people were guided directly to the assessment before beginning module one in the Eloomi platform. However, this was not possible following the module two as people were not naturally guided to the endline assessment in module two. Therefore it required manual follow up by the project team to ensure the endline assessment was completed.

BASELINE & ENDLINE ASSESSMENT RESULTS

The baseline assessment, open for completion before the course commencement, had 143 responses. Following the removal of duplicated entries (N=18) and incomplete surveys (N=20), a final sample size of 105 participants was obtained. For the endline assessment, we initially received 76 responses in the RedCap software. After eliminating duplicate entries (N=14) and incomplete surveys (N=9), the final dataset consisted of 53 individuals. From these, 46 participants responded to both the baseline and endline surveys, allowing for an analysis of their answers prior and after the course.

From the baseline survey we have that 57% of participants identified as woman, and the majority of participants were between 25-34 years of age (39%), and 35% of them had between 35-44 years of age on the baseline assessment. The majority of participants, 55%, came from Nigeria, followed by Uganda, with 15%. Concerning participants' occupation, the majority were health staff (pharmacist, psychologist) with 22%. Among other professions described we have Monitoring and evaluation officer; public health practitioner; student; volunteer; medical laboratory officer; and scientist.

When asked whether they were involved in the treatment of TB and other diseases, 63% of participants said they had experience working with people with DS-TB, 48% had experience working with people with HIV and 23% with other diseases such as Leprosy, Malaria, Sexual Health and Silicosis. This question allowed for more than one answer. When asked whether they've received formal training on the topics of stigma and discrimination, 54% of participants stated never receiving formal training and 24% had received some sort of training in the past 3 years (Table 5). 44% of participants said they've felt stigmatized because their work involves interacting with people that have or had TB.

FIGURE 3 – HYBRID ALLIES APPROACH E-LEARNING MODULE ON ELOOMI PLATFORM

TABLE 5 – HYBRID ALLIES APPROACH PARTICIPANTS CHARACTERISTICS – BASELINE ASSESSMENT (N=105)

Characteristic	Baseline Assessment (N = 105)
Gender	
Man	43 (41%)
Woman	60 (57%)
I prefer not to disclose	2 (1.9%)
Age	
18-24 years	2 (1.9%)
25-34 years	41 (39%)
35-44 years	37 (35%)
45-54 years	12 (11%)
55-64 years	13 (12%)
Occupation	
Nurse associates (e.g., Nurse aid, Community health worker)	13 (12%)
Nurse Professional	9 (8.6%)
Other	35 (33%)
Other Health Staff (e.g., Pharmacist, Psychologist)	23 (22%)
Other Support Staff (e.g. Cleaning, janitor, secretaries)	4 (3.8%)
Physician	21 (20%)
Are you involved in the treatment of people with TB (DS and/or DR-TB)	
Yes	71 (67.6%)
No	34 (32%)
Are you involved in the treatment and care of people with	
Drug Sensitive Tuberculosis	66 (63%)
DR-TB	51 (48.5%)
HIV	50 (48%)
Other*	24 (23%)
N/A	11 (10%)
Have you received any formal training on the topics of stigma and/or discrimination?	
I do not remember	7 (6.7%)
No	57 (54%)
Yes, in the past 3 years	25 (24%)
Yes, more than 3 years ago	16 (15%)
Have you ever felt you were stigmatized because your work involves interacting with people with or who have had Tuberculosis?	
No	53 (50%)
Yes	46 (44%)
Not applicable	6 (5.7%)
1 n (%)	

**Other answers included: Leprosy, Malaria, Sexual Health, Silicosis

In the Hybrid version of the Allies Approach the baseline and endline assessment was composed of three scales: The Neff's self-compassion, Health care worker stigma scale and Other co-workers external TB stigma.

The results from Neff's self-compassion scale indicated a statistically significant increase in two self-compassion components in the intention to treat (ITT) population, specifically in the statements: "I try to be understanding and patient towards those aspects of my personality I don't like" (p = 0.05) and "I try to see my failings as part of the human condition"(p = 0.04). Additionally, there was a noticeable, though not statistically significant, decrease in self-judgmental attitudes, as shown by the statement "I'm disapproving and judgmental about my own flaws and inadequacies" (p = 0.068). However, in the per protocol population (PP), the total self-compassion score slightly decreased, indicating minimal change in self-compassion levels. Linear mixed model analysis showed no significant change in self-compassion scores over time in both ITT (p = 0.46) and PP (p = 0.34) populations, with minor individual variability.

The Health Care Worker Stigma Scale (AQ-9) results showed slight increases in the mean scores for the statements "Some health care workers are nervous about treating TB patients" and "Some health care workers feel TB patients are dangerous". The total mean stigma score increased slightly from 3.45 to 3.53 in the ITT population, but these changes were not statistically significant. Similarly, in the PP analysis, changes in mean scores were minor and not statistically significant. Linear mixed model analysis confirmed no significant change over time in both ITT (p = 0.56) and PP (p = 0.77) populations.

The Other Co-workers' External TB Stigma scale showed minimal changes, with no significant differences in scores over time in both ITT and PP analyses, indicating stable perceptions of TB-related stigma among healthcare workers post-intervention. On the table below results from the ITT and PP populations are summarized for the three scales utilized. Detailed results for each of the scales components can be found in the annexe material.

TABLE 6 – INTENTION TO TREAT AND PER PROTOCOL GENERALIZED MIXED MODEL RESULTS FROM THE HYBRID ALLIES APPROACH.

		Intention to treat			Per protocol		
	Parameter	Estimate	SE	p- value	Estimate	SE	p-value
Neff's self-compassion	Fixed Effects						
	Intercept	3.48	0.08		3.57	0.11	
	Survey	-0.04	0.05	0.46	-0.05	0.06	0.34
	Random Effects						
	Individual Variance	0.12	-	-	0.11	-	-
	Residual Variance	0.09	-	-	0.08	-	-
Health Care Worker Stigma Scale	Fixed Effects						
	Intercept	3.40	0.13		3.46	0.17	
	Survey	0.05	0.0	0.56	0.02	0.10	0.77
	Random Effects						
	Group Variance	0.27	-	-	0.21	-	-
	Residual Variance	0.24	-	-	0.23	-	-
Other Co-workers' External TB Stigma	Fixed Effects						
	Intercept	4.48	0.32		4.45	0.41	
	Survey	0.08	0.23	0.7	0.2	0.25	0.43
	Random Effects						
	Group Variance	0.72	-	-	0.50	-	
	Residual Variance	1.63	-	-	1.47	-	

Apart from the validated stigma scales, the endline assessment for the Hybrid version of the AA also included course evaluation questions, summarized in the table below. These results indicate a positive effect on participants' understanding and attitudes towards stigma associated with TB. The vast majority of respondents (91%) agreed (19%) or strongly agreed (72%) that their understanding of stigma increased after completing the course, and 93% felt that the course helped them develop more empathy towards people affected by TB. Additionally, 94% of participants (strongly) agreed that they felt more prepared to interact with people affected by TB and 92% felt better equipped to address stigmatizing behavior. Overall satisfaction with the course was high, with 94% participants agreeing (30%) or strongly agreeing (64%) they were satisfied, and 96% saying they would recommend the Allies Approach to their colleagues.

TABLE 7 – HYBRID ALLIES APPROACH EVALUATION QUESTIONNAIRE (N=53)

Evaluation statements	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**	**Total Respondents**
1. I believe my understanding of stigma has increased after completing the course	2 (4%)	0 (0%)	3 (6%)	10 (19%)	38 (72%)	53
2. I feel the course has helped me develop more empathy towards people affected by tuberculosis	1 (2%)	1 (2%)	2 (4%)	13 (25%)	36 (68%)	53
3. I feel more prepared to interact with people affected by tuberculosis after completing the course	1 (2%)	0 (0%)	2 (4%)	16 (30%)	34 (64%)	53
4. I feel better equipped to address stigmatizing behavior after completing the course	1 (2%)	0 (0%)	3 (6%)	15 (28%)	34 (64%)	53
5. I am overall satisfied with the course	1 (2%)	0 (0%)	2 (4%)	16 (30%)	34 (64%)	53
6. I would recommend the Allies Approach course to colleagues	1 (2%)	0 (0%)	1 (2%)	11 (21%)	40 (75%)	53
Mean (%)						

BASELINE & ENDLINE ASSESSMENT RESULTS SUMMARY & DISCUSSION

Results from the baseline and endline assessments across all the implementation settings revealed minimal changes on the various stigma-related measures. Overall, the analysis indicated no significant changes in self-compassion, perceived organizational support, and healthcare worker stigma total scores from baseline to endline. For instance, Neff's self-compassion scale in Malawi and Kazakhstan showed stability around the mean scores, with no significant improvement in self-kindness or reduction in self-judgmental attitudes.

The results from the Hybrid Allies Approach Neff's Self-Compassion Scale showed a statistically significant increase in two self-compassion components, indicating improved self-kindness among participants. Important to note that these results were not significant in the per protocol population. Other studies designed specifically to enhance self-compassion have reported changes in the scale responses after interventions which were related to an increase in participants optimism, happiness, life satisfaction, self-efficacy, and body appreciation (4,5).

The Corrigan Attribution Questionnaire, assessing healthcare workers' attitudes towards TB patients, showed no changes in any of the settings. In a stigma reduction intervention in Taiwan, designed for first-line TB caregivers,

it was found that there was a general reduction in stigmatization scores, among public health workers with lower education levels and volunteers (6). The sociodemographic characteristics of the AA participants (mostly highly educated with many years of work experience) could partly explain the lack of observed effect.

The Health Care Worker Stigma Scale results indicated no significant changes in attitudes towards TB patients in any of the settings, with mean scores for most statements showing only minor variations from baseline to endline. Similarly, the Other Co-workers' External TB Stigma scale also exhibited minimal changes. These findings might suggest that shifts in stigma-related attitudes among healthcare workers were less pronounced. Similar findings were reported in a cluster randomized trial carried out with HCWs in South Africa where similar results on the Other Co-workers' External TB Stigma scale were reported and there was no significant difference between baseline and endline values and between the intervention and control arms (7).

On the other hand, the AA course evaluation questionnaire performed in the Hybrid approach indicate a positive experience among participants. Most respondents reported an increased understanding of stigma, greater empathy towards TB-affected individuals, and better preparedness to recognize and address stigmatizing behaviors after completing the course. This feedback suggests that participants valued the training and perceived it as beneficial in enhancing their attitudes and approaches towards TB stigma.

The discrepancy between the findings of the assessment tool and the anecdotal evidence gathered from participants, as well as the Hybrid AA evaluation, underscores the complexity of measuring changes in stigma. Throughout the analysis of the assessments, we've started considering two hypotheses: either the AA had no effect on participants' knowledge and behavior related to TB stigma; or the assessment tool failed to demonstrate an existing effect.

Several factors could explain why the baseline/endline assessment might have failed to capture the effect of the intervention. Firstly, stigma is a complex and multifaceted issue that is not easily grasped by quantitative measurements. It has a cross-cutting nature that varies in its particularities across countries and cultures, reflecting the multi-dimensional nature of the construct and the different perspectives from which it can be measured (8–10). Apart from that, the lack of methodological and tool consistency in the stigma measurement field makes it difficult to compare results across interventions (11).

Also, changes in attitudes and behaviors can take time to manifest and may not be immediately apparent in survey responses conducted shortly after the intervention (12) - which was the case in our setting where participants answered the endline survey on the day of their last encounter or shortly after. Results from a patient-centered stigma reduction intervention in rural Nicaragua show that an assessment performed 15 days after the intervention implementation revealed no significant differences in measured internalized stigma between the intervention and control groups. However, two months later, a follow-up assessment indicated a decrease in internalized stigma in the intervention group, which had benefited from TB clubs and home visits, while the control group showed no change (13). These findings suggest that it would have been beneficial to conduct the endline assessment after a longer period following the course roll-out or to perform multiple assessments over time.

Additionally, the scales used in the assessment tool were not originally designed for pre- and post-intervention measurement and may not have been sensitive enough to detect subtle changes in attitudes and behaviors. This limitation is particularly relevant for the Allies Approach participants, many of whom had extensive experience with TB patients and might already have relatively low levels of stigma and/or high knowledge on the topic, resulting in a baseline ceiling effect (12).

The lack of observed differences in the assessment result between the three settings in Malawi, despite significant variations in implementation—particularly with Mulanje failing to conduct the training as expected—further suggests that the assessment tool, as utilized, failed to demonstrate any effect.

Apart from that, cultural differences and contextual factors might also have influenced how participants responded to stigma-related questions, adding another layer of complexity to the assessment. Even though the measurements used in the Allies Approach assessment tool were all validated in several languages and different contexts, we did not conduct any kind of validation study to the settings where we implemented the Allies Approach (2,14). Apart from that, social desirability bias (when participants provide answers they believe are socially acceptable rather than their true feelings), could also have further skewed the measurement results (15), adding to the baseline ceiling effect.

It is also important to note that the knowledge and need for infection control practices underwent significant changes with the COVID-19 outbreak, where measures such as wearing masks, once seen negatively and a reason for discrimination, are now praised as good public health measures. This shift can have influenced the relevance and interpretation of the infection prevention related scales such as the Fear Based scale (16,17).

Another hypothesis that could help explaining the results comes from the response shift theory (18). This theory posits that a participant's response, especially regarding subjective constructs, is influenced by their current perception of their reality at a given time. Essentially, the meaning of a construct can evolve over time as individuals gain new experiences and reinterpret their understanding of it.

Over the course of time, between the baseline and endline assessment, there may be a divergence between participants' intended construct (such as perceived organizational support for example) and its measurement. This divergence could result from changes in an individual's internal scales (recalibration), values (reprioritization), or a redefinition of the construct itself (reconceptualization) (18,19).

Given all the points discussed above, the research team considered that an in depth qualitative assessment could help further explore whether the assessment tool used is suited for assessing the AA effect. The methods and results of this additional exploration are presented on the section that follows.

ALLIES APPROACH: IN-DEPTH QUALITATIVE ASSESSMENT

During the months of May and June 2024, an in-depth qualitative assessment was conducted with participants from Kazakhstan as well with those who participated globally in the hybrid version of the Allies Approach. An initial sample size of five participants per intervention setting (Kazakhstan and hybrid version) was established. For practical reasons this research was not conducted in Malawi. This qualitative research aimed to assess participants' experiences throughout the course, identify key learnings, determine the impact of the intervention on their daily lives, and further explore which questions could grasp the intervention effect.

An interview guide was developed to provide structure while allowing for flexibility. Researchers were trained on the interview guide and encouraged to explore topics based on participants' inputs. The interview guide was divided into the following main themes: participants' professional background and motivations to participate on

the AA; overall experience with the AA; knowledge gains; impact on behavior related to enacted stigma; overall impressions of the assessment tool; and recommendations for a new AA measurement tool.

Participants who had participated on the training were invited via email, and interviews were conducted online using Microsoft Teams. Two researchers from the KNCV Global Office were trained on the objectives of this in depth qualitative evaluation. Interviews were conducted in English and Russian, with informed consent obtained from all participants.

Researchers provided summaries of the interviews, highlighting key quotes for representativeness. A thematic analysis was conducted to systematically identify, organize, and offer insights into patterns of meaning (themes) across the data. Although the methodologies differed between the two versions of the training (in Kaz and Hybrid version), the qualitative assessment results are presented together to allow comparisons.

IN-DEPTH QUALITATIVE ASSESSMENT RESULTS

Eleven healthcare professionals from Kazakhstan (N=6) and the Hybrid Allies Approach (N=5) were invited to participate in video call interviews to discuss their experiences and insights regarding the training. Results from the two versions of the intervention are presented together here to give an opportunity to compare the similarities and differences between approaches.

PARTICIPANTS' DESCRIPTION

The interviewed participants had extensive experience in various roles related to TB care. Most participants, from both settings, had many years of work experience, ranging from five to 30 years in TB care. Their roles included physicians, TB nurses, survivors, and community researchers. Participants from Kazakhstan were invited by their health unit managers to participate in the training, while participants from the hybrid approach received invitations from friends or saw advertisements online. Among their reasons for participating were a desire for continuous training and an understanding that stigma is an important topic. Participants from the Hybrid Allies Approach were from different countries, namely Ethiopia, Namibia, Kenya and Nigeria.

CRITICAL EXPERIENCES THROUGHOUT THE AA TRAINING

In Kazakhstan, participants reported overall positive experiences with the Allies Approach. These healthcare professionals found the course materials, including modules on "imperfection," "heart-centered approach," and "boundaries and safety," to be relevant and beneficial for their work.

Despite some challenges with self-monitoring and scheduling in the hybrid format, participants found the course content relevant and impactful. The modules on vulnerability, shame, and the concept of "dirty work" stood out to them. A participant from Namibia emphasized the importance of language and body language in reducing stigma, stating,

> *"How you talk to patients and to other healthcare workers matters. I now think twice before I speak." (Participant #2, Kazakhstan)*

KNOWLEDGE GAINS AND BEHAVIORAL CHANGES

According to participants interviews, the training improved participants' understanding of the multiple facets of TB-related stigma. For some participants, the training provided a new perspective on the impact of stigma on patient care, which they had not previously considered. One participant reflected:

> *"After the course, I realized we were working incorrectly with patients due to our unawareness, routine, and heavy workload. This training made me more aware of how we should truly care for our patients."(Participant #1, Kazakhstan)*

This newfound awareness led to awareness on the need to improve communication and interactions with patients. On the behavioral effect of the intervention, another participant noted:

> *"After the course, I noticed improvements in how we interact with TB patients. There's a more empathetic approach now, which has reduced stigma in our practice." (Participant #3, Kazakhstan)*

This sentiment was echoed by others who observed a noticeable reduction in enacted stigma among healthcare providers, with patients now being treated with greater respect and understanding. Other participants, who already had a strong understanding of stigma, found the course to be motivational and inspiring. They appreciated the deeper philosophical and emotional understanding the course provided, which was difficult to quantify but essential for enhancing their approach to patient care. One participant explained:

> *"The course did not introduce new information regarding TB stigma for me, but it significantly impacted my approach and reinforced important concepts." (Participant #4, Hybrid AA)*

Participants highlighted the training made them reflect on their own attitudes and behaviors within the healthcare setting. They appreciated the clear, understandable language of the modules, which helped them conduct relevant training and implement the knowledge gained. The course's interactive methods, such as role-playing and discussions, were particularly impactful in teaching empathy and improving patient care. One participant mentioned:

> *"What I liked the most was the idea of compassion for the patient, the respect for the individual's personality." (Participant #1, Kazakhstan)*

ALIGNMENT WITH LOCAL CONTEXT AND ONGOING NEEDS

Participants reported that the training was well-aligned with the local healthcare context (in Kazakhstan and other countries represented) and addressed specific challenges faced in treating TB patients. However, participants noted some difficulties in adapting certain exercises to real-life scenarios and suggested incorporating more localized examples and case studies. This was especially relevant for participants in rural areas of Kazakhstan that described specific contextual challenges that were not reflected in the Allies Approach content.

There was a consensus on the need for ongoing education and support to sustain and deepen understanding and develop patient centered practices. Continuous education and refresher sessions were recommended to keep the topic of stigma on the radar and ensure healthcare providers remain informed and empathetic in their patient care.

ALLIES APPROACH KNOWLEDGE CASCADING

Participants trained as trainers in Kazakhstan reported actively cascading the knowledge gained from the course to their colleagues. They conducted training sessions using interactive methods and emphasized the importance

of an empathetic approach and proper patient communication. These cascading sessions were well-received and seem to be particularly profitable among younger staff who had little prior understanding of stigma.

Also, a participant emphasized the importance of keeping in mind local individuals on the ground, particularly those at the grassroots level when cascading the AA information.

> *"You see, we have community champions who are already empowered. What about somebody who is at the grassroots, who doesn't have this information? How can we cascade this information to the grassroots, so that then everybody gets empowered?" (Participant #2, Hybrid AA)*

Allies Approach assessment recommendations

Participants provided suggestions for developing effective assessments to evaluate the effect of the Allies Approach intervention. One recommendation was to ask participants about specific activities they engaged in prior to the course that they no longer do, as well as new activities they have started implementing as a result of the training. According to them, this approach can help identify practical changes in behavior and practice. Additionally, participants suggested evaluating whether healthcare providers have ever put themselves in the place of their patients, which could provide valuable insights into their understanding of patients' experiences. Another assessment recommendation participants provided was to ask healthcare providers if the course was meaningful to them and whether it added value to their existing knowledge. As one participant noted,

> *"I can ask the healthcare provider, was the course meaningful to you? Did it add any value to what you already know? Because we also have healthcare providers who have information, but sometimes they tend to ignore issues around stigma or discrimination. So what I would ask them is, is this course important to you and are you able to share with other healthcare providers?" (Participant #2, Hybrid AA)*

Participants also suggested incorporating personal reflections into the assessments. For example, asking participants how personal reflections from the course made them feel and seeking their opinions on different areas of the course can provide qualitative data on the course's emotional and psychological impact.

Practical improvements and future recommendations for the Allies Approach

Participants from the Hybrid Allies Approach also highlighted the need for some practical improvements, such as ensuring materials are easy to print and providing more videos, interactive materials and personal stories. Participants from Kazakhstan expressed that even though the Russian translations were good it would be good to have some materials in Kazakhstan to accommodate all participants.

Participants also said that having more opportunities to share experiences with other individuals undergoing the training would be profitable to share their knowledge and experiences.

In-depth qualitative assessment results summary and discussion

Results from the interviews suggests that participants from various countries appreciated the course content, despite challenges related to the hybrid version being a self- and peer-led process. Apart from that, overall participants reported improvements in their interactions with TB patients, leading to a reduction in enacted stigma.

Some participants gained new perspectives on the impact of stigma on patient care, leading to improved communication and interactions with patients. Others, who already had a strong understanding of stigma, found the experience to be motivational and appreciated the deeper philosophical insights it provided. Similar results were reported in a trial conducted in South Africa, where even though no effect of the intervention was observed through quantitative measurements, it was observed an increase in HCWs awareness of the detrimental effects of stigma in the workplace through the qualitative assessment (7).

When it comes to the AA assessment tool, participants suggested focusing on specific changes in behavior, such as activities that stopped or started after the training and evaluating whether healthcare providers have developed greater empathy and understanding of patient experiences. Incorporating personal reflections and asking if the course was meaningful and added value to existing knowledge were also highlighted as important elements for future assessments. These recommendations are aligned with the assessment suggestions from the response shift literature. According to this theory, "then-now" type of questions, where participants are asked to re-rate their initial statements from their current perspective, can help identify changes in their internal standards (10).

These results suggest that, although the baseline/endline assessment tool did not show measurable effects of the training, the in-depth qualitative assessment provides evidence to the contrary. The overall positive feedback from the in-depth qualitative assessment, including improvements in interactions with TB patients and reductions in enacted stigma, suggests that the Allies Approach training had a positive effect on participants understandings of the detrimental effect of stigmatizing behaviors in healthcare setting. This enhanced understanding was also reflected in noticeable behavioral changes.

LESSONS LEARNED & NEXT STEPS

THE ALLIES APPROACH: TWO OPTIONS REDUCING STIGMA IN HEALTHCARE PROVIDERS

When considering the two versions of the Allies Approach, the original version (training of trainers), and the e-learning version (being self-initiated and peer-led), it is important to emphasize that these are two separate approaches, and not completely comparable.

The original version is structured allowing much interaction between facilitators and participants, followed by a facilitated discussion after each activity.

The on-line version requires individual preparation by participants, in the form of reading articles; watching videos in module 1 and, module 2, which became a self-reflection exercise, preferably performed in small groups.

The in depth qualitative assessments conducted with participants from both approaches reflect that they both have value and can be applied as fitting the needs of setting: the original Allies Approach requires trainers to be trained to use the toolkit, and therefore a greater time and financial investment in this approach, which may be a hinderance to access. The Allies Approach e-learning requires limited training beforehand , much of the content

is fully explained in the course material and people can follow the course at a time and place convenient to them. While the text is standardized, with this method is more difficult to ensure peoples' understanding of the material during the learning process.

However, for both approaches a certain level of preparation is required to ensure that the tool is used in the way it is intended; to guide central coordinators in monitoring and evaluating the implementation and provide supportive supervision; and to ensure people facilitating the sessions are well equipped to stimulate and facilitate discussion during the trainings or peer group meetings. For nationwide implementation detailed planning and budgeting is required, as well as systematic follow-up of implementation of a national plan. Also, based on the in depth qualitative study it is important to develop additional locally relevant examples for inclusion in the course materials for each country or setting.

ADVOCACY FOR STIGMA REDUCTION THROUGH KNCV COURSES

Following the advertising of the Hybrid Allies Approach KNCV was offering, we noted a huge response and interest to the webinar we would be hosting on this stigma reduction course. This revealed that there is a large need and interest from various settings globally for interventions that target stigma. Clearly, many people, organizations and NTPs look to KNCV as an expert agency, in this case, for stigma reduction. KNCV is in a prime position to continue advocating for stigma reduction activities included in local budgets to eradicate TB; as well as advocating for the various approaches to address stigma.

E-LEARNING ON STIGMA AND WIDER LESSON FOR E-LEARNING AT KNCV

For the Hybrid Allies Approach we developed the module one (e-learning) to be a completely self-led modules, where participants gain an understanding of the theory surrounding stigma. In principle, this could be a stand-alone module if the intention is to ensure healthcare providers have a base level understanding of stigma. Should a TB programs intention be to raise the level of awareness about stigma, this would be a perfectly suited educational intervention. More in depth learning could be offered for people in leadership positions, supervisors and selected key personnel, through a combination with additional activities in the original Allies Approach.

Since the module one (e-learning) is currently hosted on the Eloomi platform, with associated monthly costs per enrolled participants, which is a barrier for implementation, it is imperative to consider a more sustainable solution to hosting this e-learning platform, with easy access by NTPs and implementing partners, as well as follow up access to the material after the course if completed for all participants.

PEER GROUPS AND THE HYBRID ALLIES APPROACH

As referenced in the experienced challenges of the Hybrid Allies Approach, people often ended up using the discussion guide as a reflection guide for themselves, rather than in discussion with peers. Also we noted that following the progress of individuals or groups during the use of the discussion guide was not possible. As a result we intend to 1) develop the discussion guide as a second e-module for individual learners, and 2) to develop the discussion guide into an e-module for groups where progress can be followed -up through the learning platform. In both options the evaluation questions will be automatically presented on finishing the second module, intended at improving the course evaluation and people's self-evaluation. If countries, organizations, or groups of people opt for the 2nd option, we will ensure there is a clear plan for forming of peer groups with an assigned

facilitator, to ensure they receive full value that discussion and group reflection offer. Adaptation of the discussion guide is needed to accommodate the role of the group facilitator.

IMPROVING THE ALLIES APPROACH TRAINING ASSESSMENT TOOL

As previously mentioned, stigma is a complex issue that is difficult to capture with a single measurement tool (10)(8). Based on the findings from the current assessment tool and the in-depth qualitative research results a new, simpler assessment tool will be developed.

BIBLIOGRAPHY

1. Mitchell EM, van den Hof S, Meershoek A, Zwerling A, Daftary A, Citro B, et al. TB Stigma Measurement Guidance. Jefry Acaba (APCASO). ANPUD; 2018. Available from: https://www.kncvtbc.org/en/2018/08/20/the-tb-stigma-measurement-guide-is-here/ [Accessed 07/08/2024].

2. Redwood L, Mitchell EMH, Nguyen TA, Viney K, Duong L, Phạm HT, et al. Adaptation and validation of the Van Rie tuberculosis stigma scale in Vietnam. International Journal of Infectious Diseases. 2022 Jan 1;114:97–104.

3. Pommier E, Neff KD, Pommier E. compassion scale: scoring. Available from: www.self-compassion.org. [Accessed 07/08/2024].

4. Neff KD. The Self-Compassion Scale is a Valid and Theoretically Coherent Measure of Self-Compassion. Mindfulness (N Y). 2016 Feb 1;7(1):264–74.

5. Albertson ER, Neff KD, Dill-Shackleford KE. Self-Compassion and Body Dissatisfaction in Women: A Randomized Controlled Trial of a Brief Meditation Intervention. Mindfulness (N Y). 2015 Jun 16;6(3):444–54.

6. Wu PS, Chou P, Chang NT, Sun WJ, Kuo HS. Assessment of changes in knowledge and stigmatization following tuberculosis training workshops in Taiwan. Journal of the Formosan Medical Association. 2009;108(5):377–85.

7. Sommerland N, Masquillier C, Rau A, Engelbrecht M, Kigozi G, Janse Van Rensburg A, et al. Reducing HIV- and TB-Stigma among healthcare co-workers in South Africa: Results of a cluster randomised trial. Soc Sci Med. 2020 Dec 26;6.

8. Van Brakel WH, Cataldo J, Grover S, Kohrt BA, Nyblade L, Stockton M, et al. Out of the silos: Identifying cross-cutting features of health-related stigma to advance measurement and intervention. BMC Med. 2019 Feb 15;17(1).

9. Morgan A, Reavley N. Measurement of stigma: Evidence review Executive summary Background. Centre for Mental Health Melbourne School of Population and Global Health. 2021 July.

10. Rao D, Elshafei A, Nguyen M, Hatzenbuehler ML, Frey S, Go VF. A systematic review of multi-level stigma interventions: State of the science and future directions. Vol. 17, BMC Medicine. BioMed Central Ltd.; 2019.

11. Foster I, Galloway M, Human W, Anthony M, Myburgh H, Vanqa N, et al. Analysing interventions designed to reduce tuberculosis-related stigma: A scoping review. PLOS Global Public Health. 2022 Oct 19;2(10).

12. Evans-Lacko S, Corker E, Williams P, Henderson C, Thornicroft G. Effect of the time to change anti-stigma campaign on trends in mental-illness-related public stigma among the english population in 2003-13: An analysis of survey data. Lancet Psychiatry. 2014 Jul 1;1(2):121–8.

13.   Macq J, Solis A, Martinez G, Martiny P. Tackling tuberculosis patients' internalized social stigma through patient centred care: An intervention study in rural Nicaragua. BMC Public Health. 2008;8.

14.   Hair JF, L.D.S. Gabriel M, da Silva D, Braga Junior S. Development and validation of attitudes measurement scales: fundamental and practical aspects. RAUSP Management Journal. 2019 Dec 9;54(4):490–507.

15.   Bispo Júnior JP. Social desirability bias in qualitative health research. Rev Saude Publica. 2022;56:101.

16.   Houben F, den Heijer CDJ, van Hensbergen M, Dukers-Muijrers NHTM, de Bont EGPM, Hoebe CJPA. Behavioural determinants shaping infection prevention and control behaviour among healthcare workers in Dutch general practices: a qualitative study reflecting on pre-, during and post-COVID-19 pandemic. BMC Primary Care. 2024 Dec 1;25(1).

17.   Carbon CC. About the Acceptance of Wearing Face Masks in Times of a Pandemic. Iperception. 2021;12(3).

18.   Schwartz CE, Rohde G, Biletch E, Stuart RBB, Huang IC, Lipscomb J, et al. If it's information, it's not "bias": a scoping review and proposed nomenclature for future response-shift research. Quality of Life Research. 2022 Aug 27;31(8):2247–57.

19.   Vanier A, Oort FJ, McClimans L, Ow N, Gulek BG, Böhnke JR, et al. Response shift in patient-reported outcomes: definition, theory, and a revised model. Quality of Life Research. 2021 Dec 1;30(12):3309–22.