

TB Stigma Assessment

Background and Key Findings

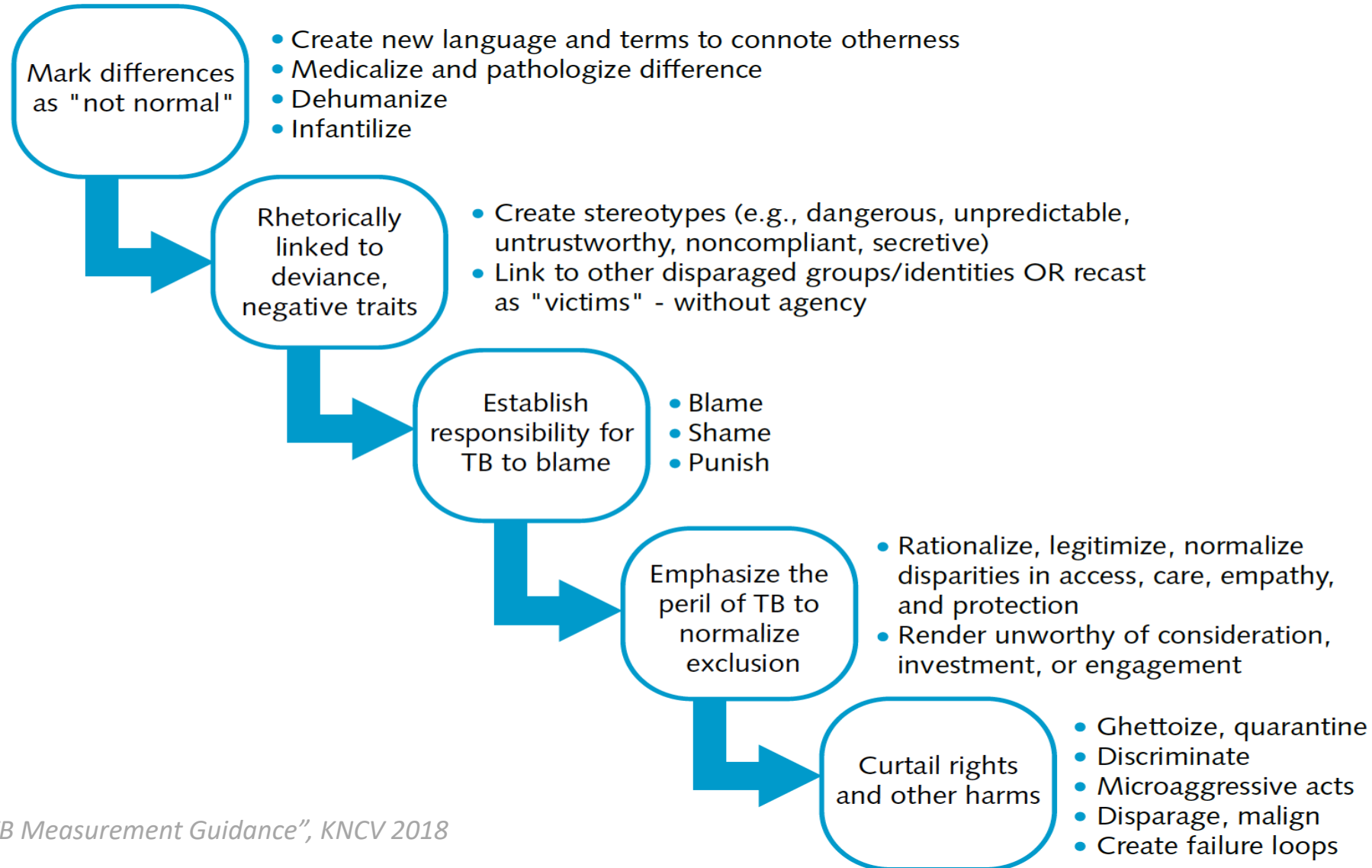
Pre Reading

Stop TB Partnership

What is stigma?

- Stigma originates from the ancient practice of branding or marking someone who is thought to be “morally flawed” or to have behaved badly based on certain characteristics.
- The person therefore ought to be avoided by other members of society.
- It is often described as a process of devaluation, whereby a person is discredited, seen as a disgrace, or perceived to have less value or worth in the eyes of others.

Stigmatisation Process



Source: "TB Measurement Guidance", KNCV 2018

What is Discrimination?

- Treating someone in a different, unjust, unfair or prejudicial manner, often on the basis of stigmas attached to his/her belonging – or perceived belonging – to a particular group.
- Acting or Not Acting towards those individuals based on stigmas directed at them.
- Treating someone differently to his/her disadvantage because the person is known to have or have had TB or be closely associated with people with TB, such as their spouse or other members of their household.

Discrimination is often viewed as the end result of the process of stigmatisation - when stigma is acted upon.

Types of Stigma Facing People with TB (PWTTB) and their Family

- **Internalised (PWTTB)**

- *PWTTB self-stigmatising attitudes*

- **Anticipated (PWTTB)**

- *PWTTB fear after observing others being stigmatised*

- **Enacted stigma or discrimination (PWTTB)**

- *PWTTB actually experienced*

- **Secondary (PWTTB family)**

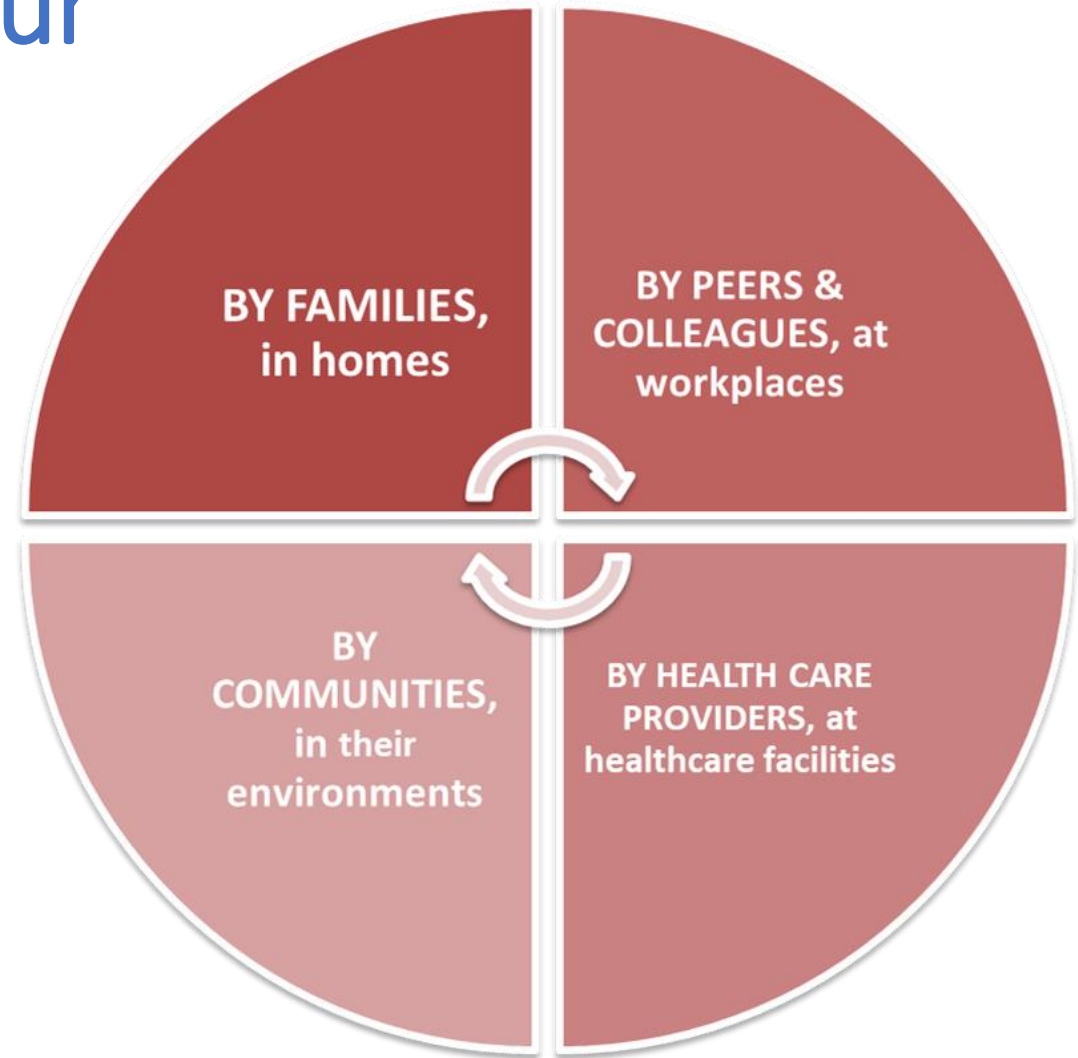
- *Stigma or discrimination PWTTB family or care takers actually experienced*
- *Stigmatising attitudes towards PWTTB family members they are looking after*

- **Structural (society at large)**

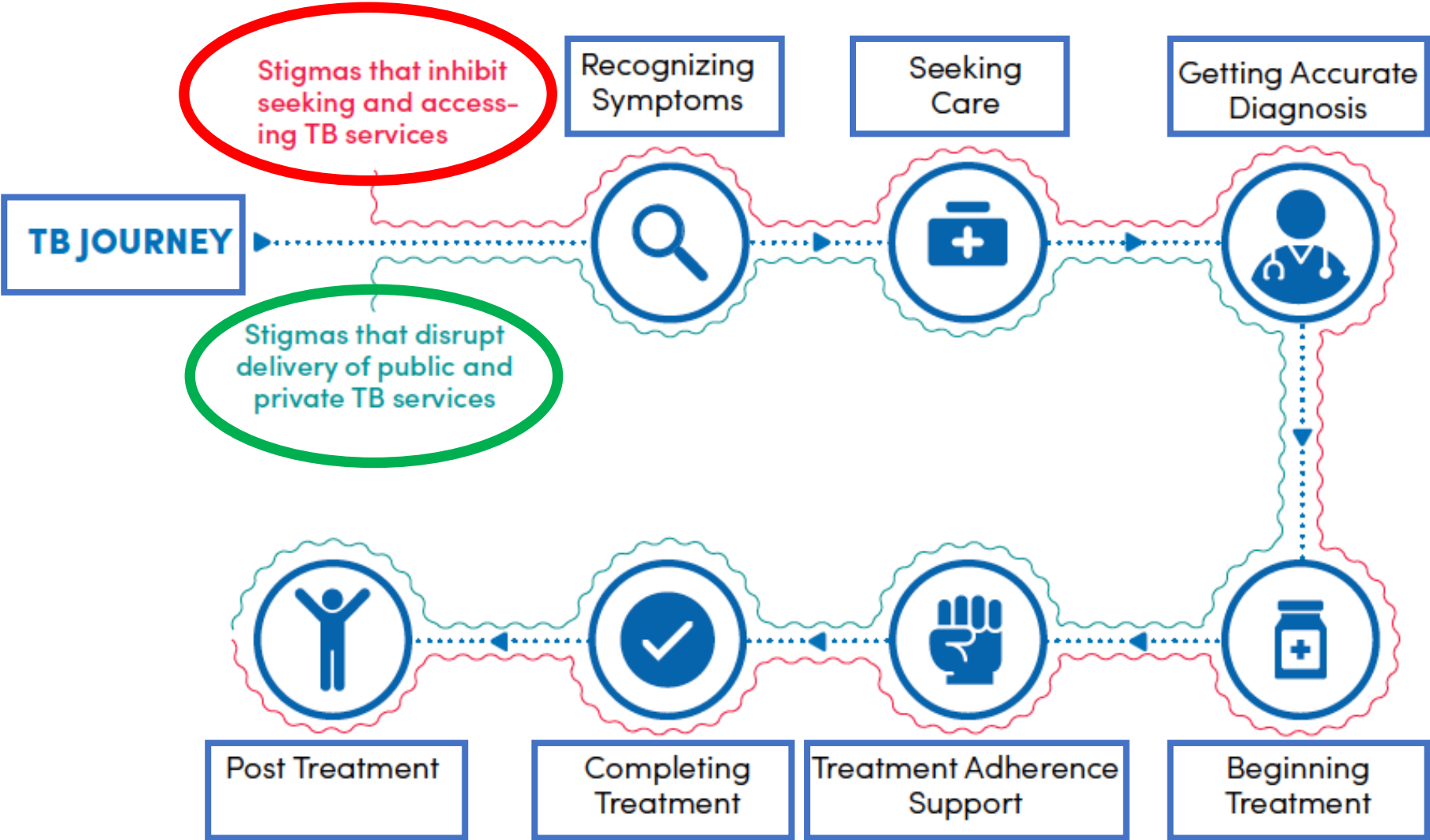
- *Laws and policies existence, enforcement and media coverage*

Settings where Stigma Occur

- Self-stigma
- Stigma by family members
- Stigma by communities/neighbours
- Stigma in the workplace
- Stigma by healthcare providers



Stigma Inhibit Both Accessing and Delivering TB Services Throughout the Entire TB Journey



Assessment Design

- **Assessment key principles**
 - Multi-stakeholder
 - *community-led, NTP-guided, PWTB-involved, women-involved*
 - Participatory
 - *analysis, recommendations, action planning*
 - Analysis and recommendations to support action planning
 - *action plans costed (or at least costing-ready) and alignment with related action plans (NSP, CRG)*
- **Assessing what**
 - Stigma that inhibited PWTB accessing TB services
 - *in 5 settings – self, health care, community, family, work (first 3 are Global Fund indicators)*
 - Stigma experienced and observed, stigmatising attitudes against PWTB, family, HCWs
 - *along TB Journey – (1) Recognizing symptoms, (2) Seeking Care, (3) Getting Accurate Diagnosis, (4) Beginning Treatment, (5) Getting Treatment Adherence Support, (6) Completing Treatment, (7) Getting Post-treatment Follow Up Services*
 - *in 5 settings – self, health care, community, family, work*
 - Law and policy environment
 - *7 specific rights – (1) Freedom from Discrimination (enacted stigma), (2) Access Information, (3) Access Services, (4) Privacy, (5) Informed Consent, (6) Freedom from Arbitrary Arrest/Detention and Involuntary Isolation, (7) Safe Workplace*
 - *Status - existence, enforcement, media coverage*

Country Assessment Status



Assessments Reviewed

(completed in 2021-2024)

- **10 countries (national level)**

- Azerbaijan, Bangladesh, DRC, Ghana, Indonesia, Moldova, Mongolia, Nigeria, Pakistan*, Ukraine
- 3.1m or 29% of 10.8m estimated global TB incidence in 2023

- **1 sub-national territory**

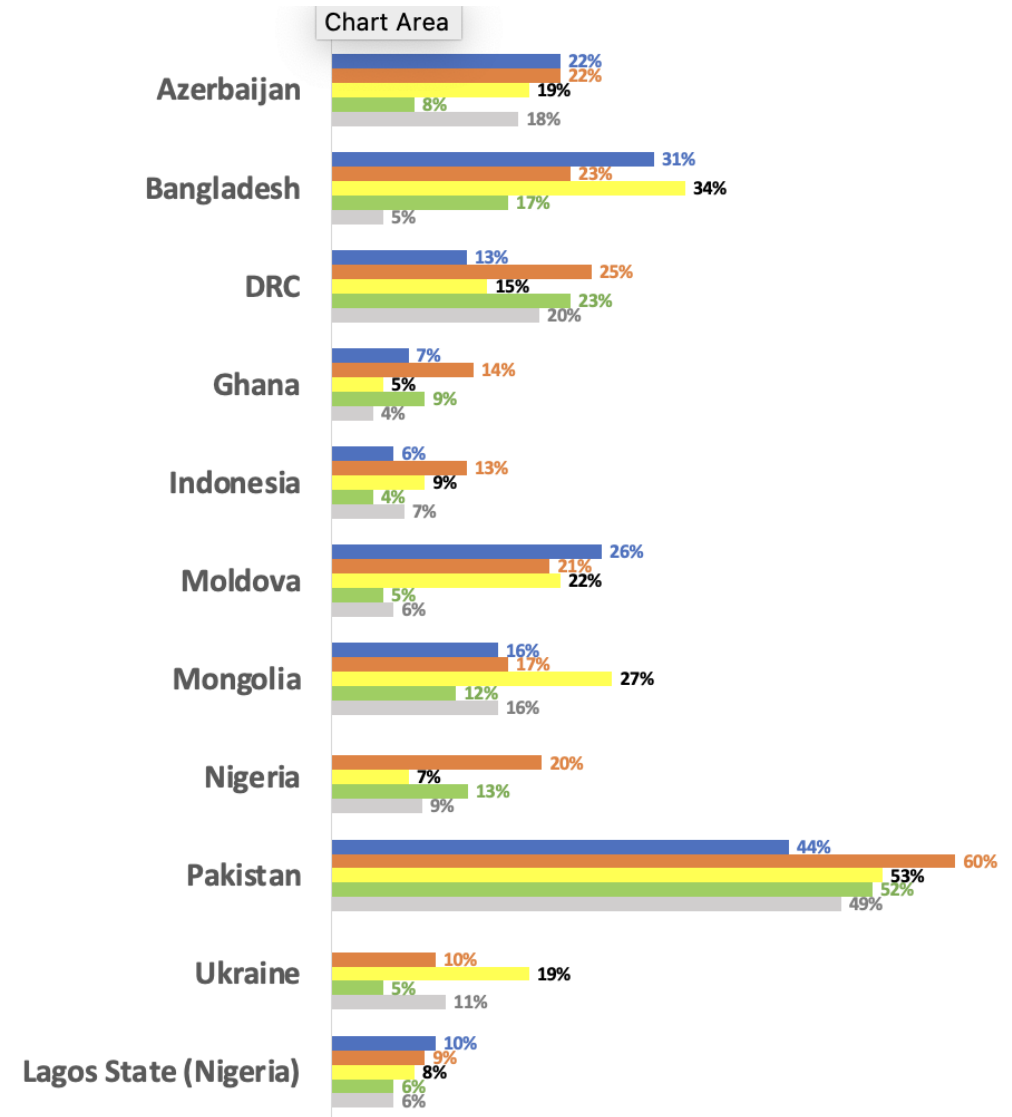
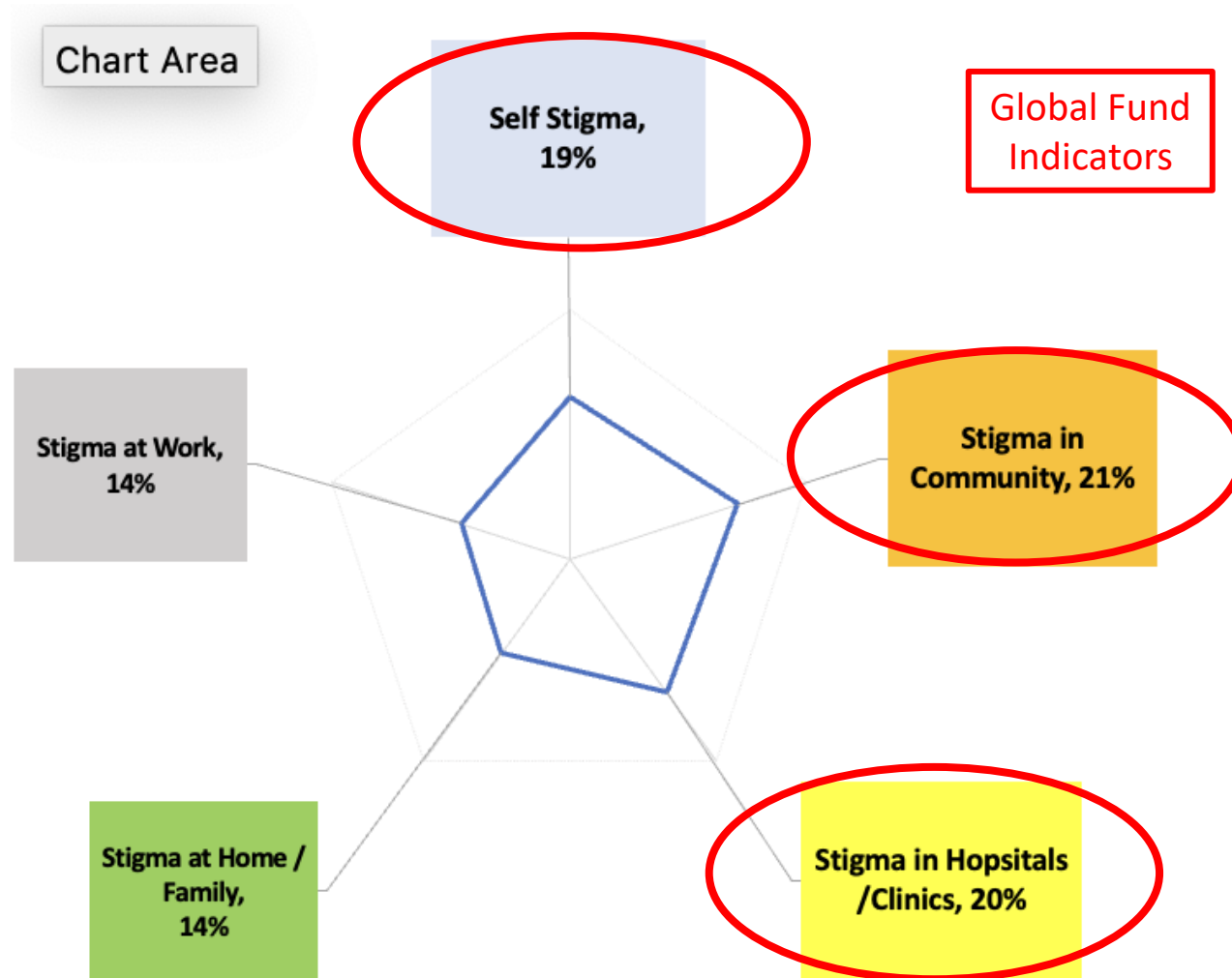
- Lagos State, Nigeria
- 53k estimated TB incidence in 2022

- **1 prison system**

- Tajikistan
- 84 TB diagnosis in 2023 out of the country's total 14k prisoners/detainees

** Pakistan – quantitative findings only (action plan under development, assessment report, including recommendations, under revision per Stop TB Partnership's comments).*

Stigma Inhibited PWTB Accessing TB Services (self-reported by PWTB)



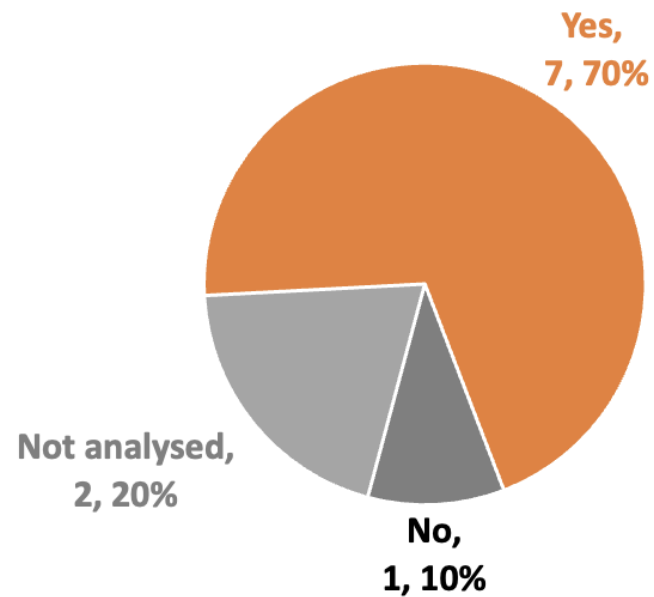
Assessments also Found Other Impacts of Stigma that Make Accessing and Staying with TB Services Even Harder

- Loss of employment
- Being isolated by fellow co-workers, even after completing treatment and cleared of TB
- Disowned by family, particularly women PWTB, often divorced
- Friends and family stopped visiting
- Being turned away by local market vendors
- Being turned away from local mosques
- Evicted from rental dwellings
- Treatment refusal by non-TB health providers
- Neighbours prohibited their children playing with PWTB or children of PWTB
- PWTB children not allowed to attend schools
- PWTB care-takers' income generation activities negatively impacted (e.g., less customers)
- Health care workers providing TB treatment being singled out by fellow health care workers as “Ms TB” or “Coughing Lady”

Women and KPs were found to more stigmatised*

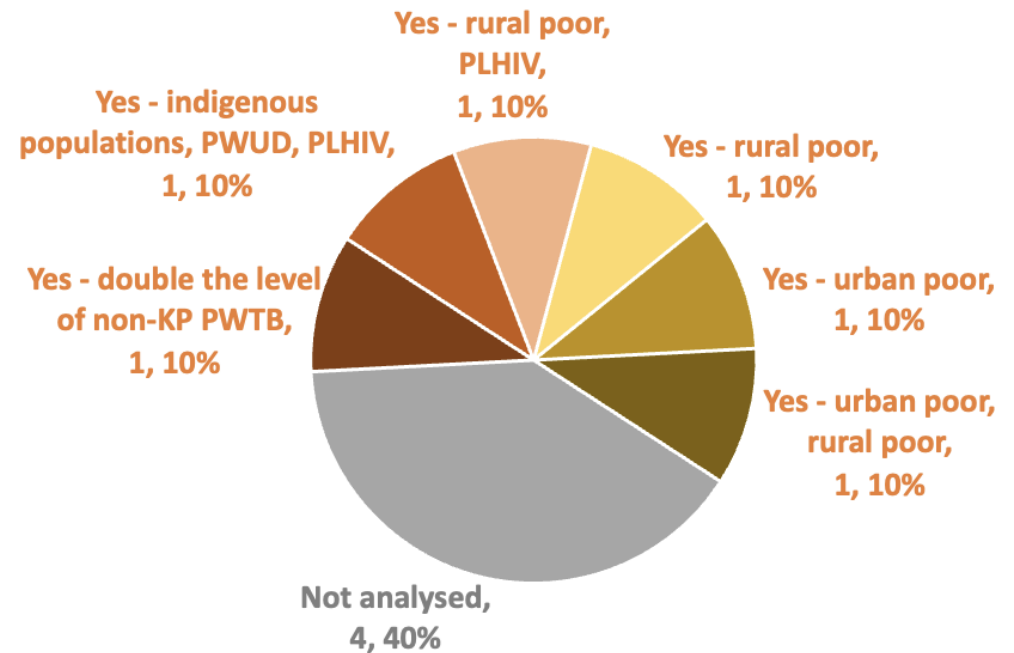
Women More Stigmatised

[mentioned in the assessment reports, 10 assessments excluding Pakistan [further analysis to be done) and Tajikistan (prisoners)]



KPs More Stigmatised

[mentioned in the assessment reports, 10 assessments excluding Pakistan (further analysis to be done) and Tajikistan (prisoners)]



* Requires statistical software (e.g., SPSS, SAS, STATA, R) beyond Stop TB Partnership's stigma assessment Excel analysis tool.

Stigmatizing attitudes

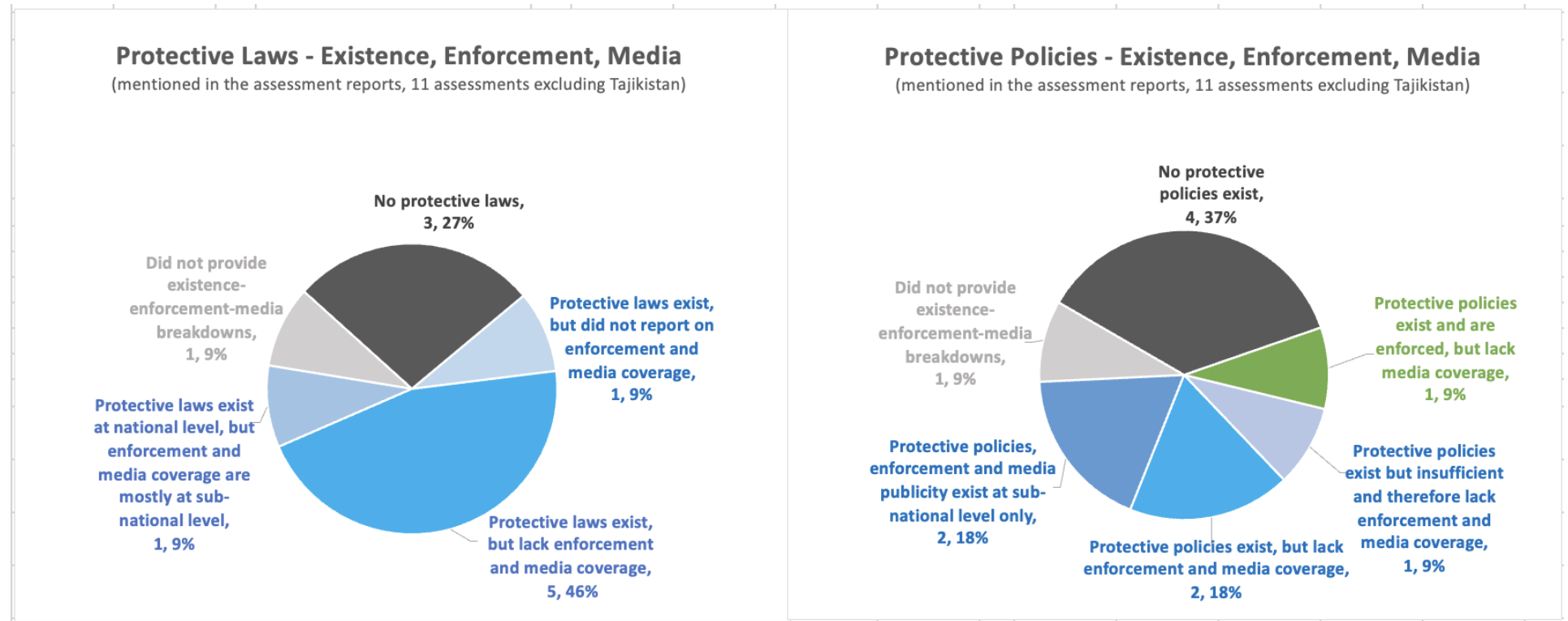
- **HCW's strong tendency to support isolation during treatment even with force while feeling pity for PWTB**
- **Neighbours very uncomfortable to be near PWTB and a strong tendency to avoid eating and drinking with PWTB**
- **PWTB family's strong tendency to hide their PWTB family members from community and other family members**
- **These 3 strong tendencies together fuel negative impact on the mental health of PWTB (self-stigma, isolation) and reinforce barriers inhibiting PWTB from accessing TB services**

Most Widespread Stigmatising Attitudes <i>(top 3 stigma scale items reported in each of the 11 assessments, excluding Tajikistan)</i>		Average (% agreed)	Number of Assessments the item in top 3
PWTB Self-Stigma	A4 - I keep a distance from others to avoid spreading TB germs.	75%	10
	A9 - I choose carefully who I tell about having TB.	69%	9
Community Stigma Towards PWTB	A2 - Some people feel uncomfortable being near to those who have TB.	77%	6
	A1 - Some people might not want to eat or drink with friends who have TB.	76%	6
HCW Stigma Towards PWTB	A9 - Some health care workers think taking TB treatment should be forced if necessary	69%	9
	A7 - Some health care workers think it would be best for TB patients to be isolated during the intensive phase of treatment.	80%	8
	A2 - Some health care workers feel pity for TB patients.	79%	5
Family Secondary Stigma	A4 - My family member hides his/her TB diagnosis from the community.	56%	9
	A10 - I am worried about becoming infected.	59%	6
	A5 - I avoid talking about TB in the presence of other family members or neighbors.	50%	6

Laws and policies

existence, enforcement, media coverage

- **Non-TB specific protective laws and policies exist at different levels in most countries**
- **But lacking in enforcement and media coverage**



No protective laws: **DRC, Nigeria, Pakistan**
Did not report on protective laws: **Azerbaijan**

No protective policies: **DRC, Nigeria, Pakistan, Lagos (state)**
Did not report on protective policies: **Azerbaijan**

Summary of findings

- Stigma inhibit PWTB accessing TB services in multiple settings (**community and health** stronger than family and work settings) and along the TB Journey (**recognising symptoms, seeking care and getting treatment adherence support** more than getting accurate diagnosis, beginning treatment, completing treatment and getting post-treatment follow up services). *→ addressing stigma during community screening and active case finding*
- **Women and KPs** are faced with more stigma than other PWTB. *→ ensuring recommendations and action plans are gender- and KP-responsive*
- Stigma against HCW were mostly in **HCWs' work place (i.e., hospitals and clinics)**, exactly where PWTB and family reported they faced most stigma during first 2 stages of the TB Journey (confirmed by community respondents). HCWs also reported sub-standard infection control at work. *→ Stigma training for HCW and infection control must go hand-in-hand*

Summary of findings – cont'd

- The single most common theme among PWTB self-stigma, family secondary stigma and stigmatising attitudes against PWTB of community/neighbours and HCWs is **“Stay Away”**. This means PWTB not only have internalised isolation but are constantly reminded at home, in the community and health care settings they should be isolated, negatively impacting their mental health and reinforcing self-stigma. This explains why most stigma (both experienced and observed) occurred at the early stage of the TB Journey. The isolation messaging is so strong that PWTB find it very challenging to recognise symptoms and seek care. *→ be specific for the targeted audience for anti-stigma messaging (e.g., focus on specific issues such as neighbours do not want to eat and drink with PWTB; HCW training to include isolation should be the last resort infection control measure when other treatment support measures are already in place)*
- While they exist to different extent in different countries, **protective laws and policies lack enforcement and the media coverage.** *→ address first law enforcement and media coverage of specific rights, then legal reforms, particularly in countries where protective non-TB-specific laws and policies exist*

Observations on assessments' recommendations

- Recommendations made by these assessments included:
 - Legal and policy reform
 - Media campaign
 - TB survivors support groups
 - Community leader education
 - HCW training
- These high-level recommendations largely reflected the key findings:
 - Laws and policies exist but lack enforcement and media coverage
 - High level of self-stigma (isolation) among PWTB reinforced by high levels of stigmatising attitudes against them in the community and health care settings
 - PWTB experienced and observed most stigma in both community and health settings
- ***However, none of the recommendations highlighted which stages of the TB Journey, which settings, which stigmatising attitudes and which rights and their corresponding existence/enforcement/media coverage these recommendations should target.***
- ***And despite gender and KPs differences documented by the majority of the assessments, none of the recommendations were gender and KP-sensitive.***

Observations on action plans

- A significant minority of the assessments (2 out of 11*) did not provide an action plan.
- The interventions in the action plans reflect the high-level recommendations but lack specificity (missed opportunities to make anti-stigma interventions more targeted and effective):
 - ***Not gender- and KP-responsive***
 - ***Not targeting specific TB journey stages and settings where barriers were most widespread***
 - ***Not targeting specific stigmatising attitudes need to be addressed***
 - ***Not targeting specific rights and corresponding enactment, enforcement or media coverage***
- Five out of the 9 action plans provided were not costed. The lack of costing (or implementation details such as how many, who and where to support costing), together with a significant minority (4 out of 11) of the assessments did not document NTPs' participation in the Core Groups, can potentially undermine the realisation of these action plans (only 3 out all 11 assessments reviewed had both costed action plans and NTPs involved in the Core Groups).

* *Excluding Pakistan – its action plan currently under development.*

What Need to be Addressed?

Stigma in Community

- *TB stages where PWTB experienced and observed most stigma in community (also confirmed by neighbours)*
 - Recognising symptoms
 - Seeking care
 - Getting treatment adherence support
- *Community leaders/neighbours' stigmatising attitudes against PWTB*
 - Uncomfortable being near PWTB
 - Not drinking or eating with PWTB

PWTB Self-Stigma

- *Self-stigmatising attitudes*
 - Keeping a distance from others
 - Choosing carefully who they tell about having TB

Stigma in Health Facilities

- *TB stages where PWTB experienced and observed most stigma in health setting (also confirmed by neighbours)*
 - Recognising symptoms
- *HCWs' stigmatising attitudes against PWTB*
 - Forced treatment in isolation
 - Feeling pity for PWTB
- *Setting where HCWs reported*
 - Most stigma against HCWs are at hospitals and clinics where they work
 - A lack of infection control at hospitals and clinics where they work

What Need to be Addressed – Cont'd

Stigma at Home/Family

- *TB stages and settings PWTB family experienced stigma that stopped them from supporting their family members with TB accessing TB services*
 - Recognising symptoms (health and community settings)
 - Getting treatment adherence support (community setting)
- *Family secondary stigma*
 - Family members with TB hide TB diagnosis from community
 - Avoid talking about TB with family and neighbours

Laws and Policies

- *Protective relevant laws and policies, including non-TB specific ones, exist but lack enforcement and media coverage*
 - Legal and societal impunity for violation of protective laws/policies, indirectly condoning such violations to continue

Thank You!