



# Social dimensions of DRTB

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INSTITUTE FOR  
**GLOBAL  
HEALTH  
RESEARCH**

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# Acknowledgements

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# Social dimensions of DRTB

Social, political, historical and legal determinants of DRTB

Inequities and intersectionalities in DRTB

Notions and framings of resistance - illness, infection vs disease

Paradigms of and assumptions about care and caregiving

Access and other issues in prevention, diagnosis, treatment, infection control, care  
(Differential) needs and priorities of affected people and 'at-risk' communities

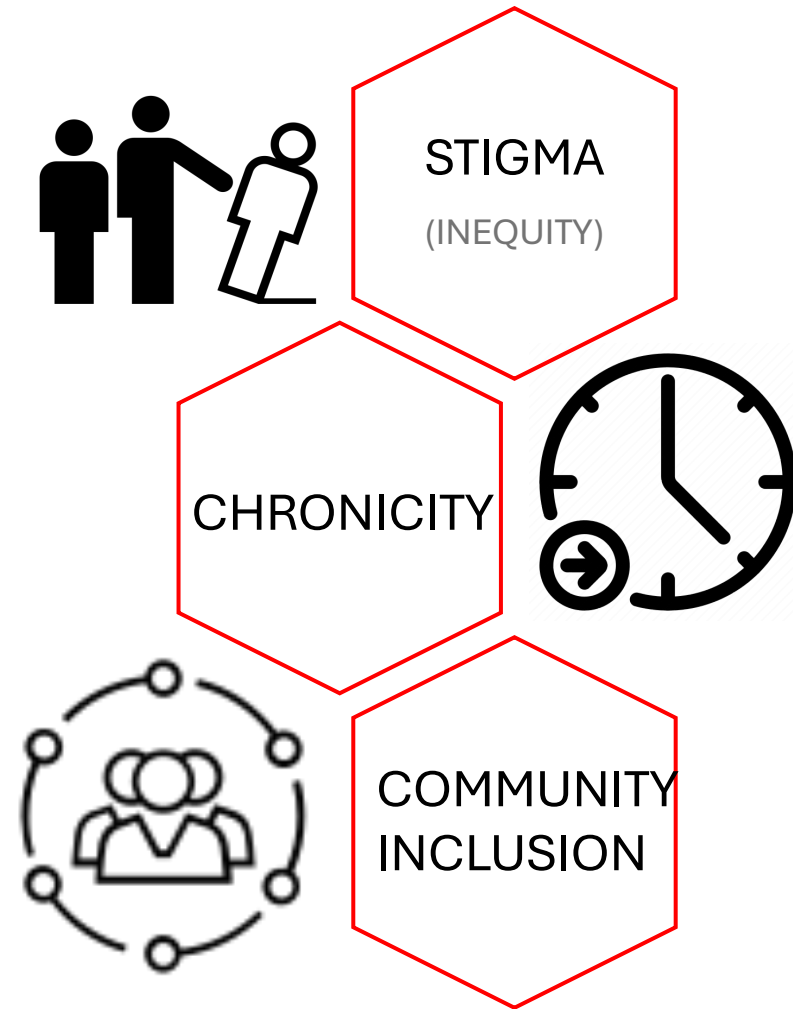
Funding, research and policy priorities and agendas in TB and DRTB

Key stakeholders and accountability

Counter narratives

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# Social dimensions of DRTB



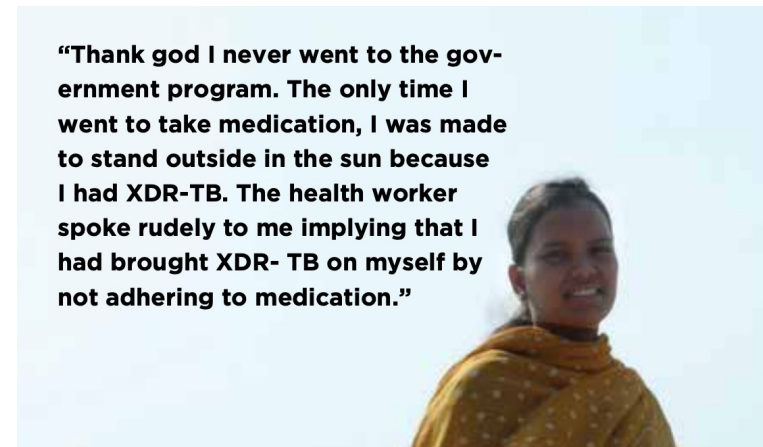
# DRTB is highly stigmatized

*There was just this sudden silence...no one came to my house... the first people who were supposed to support me left me. F*

*The mother of my children said so long as I am still on this pill, I should find myself another place... Go back to the hospital, you should not be with us. M*

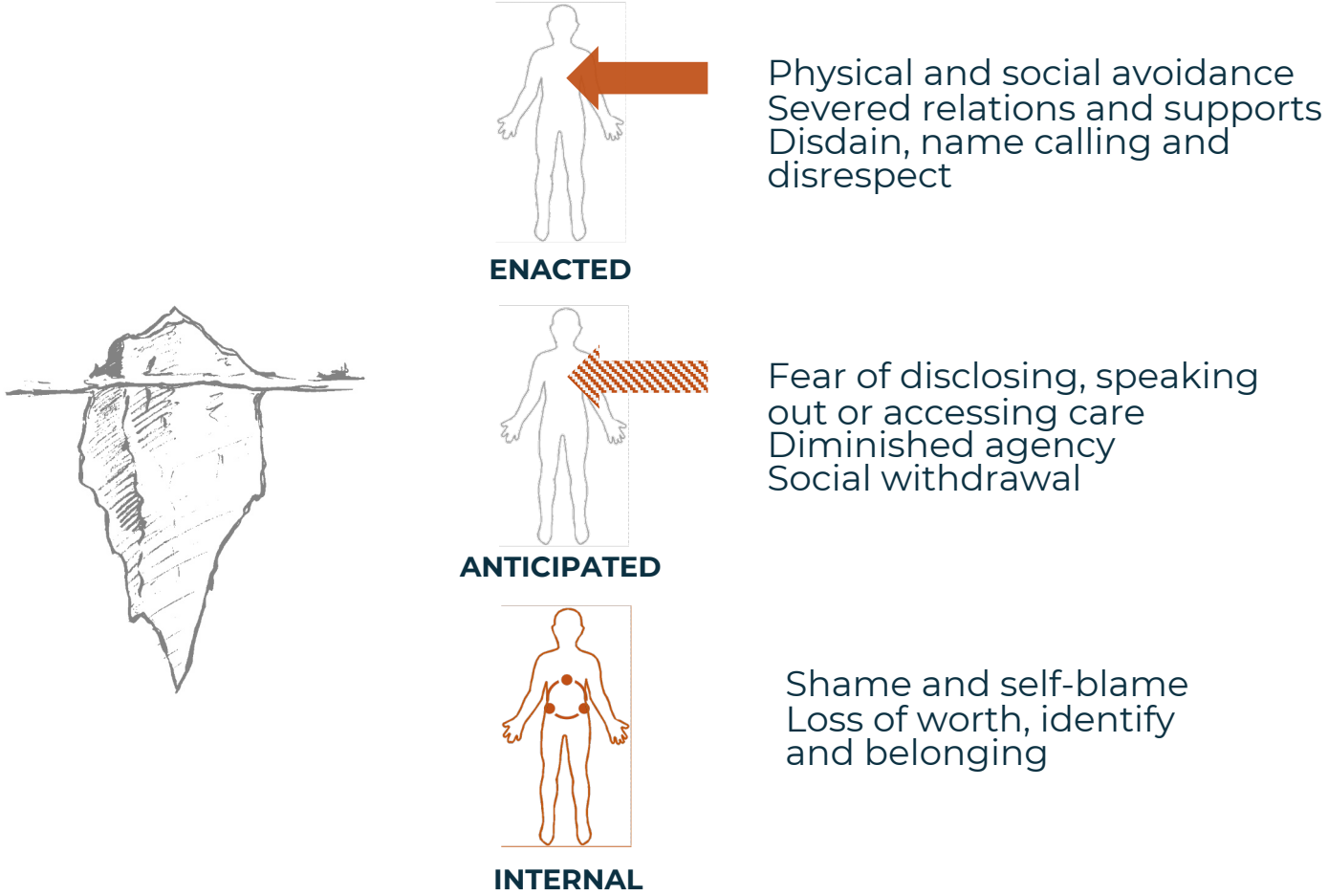
*I see myself as failure... sometimes feel like now God has given me something that is beyond my power. F*

*[Only] once everyone had eaten and gone out for work... was I permitted to enter the hall or my room. F*

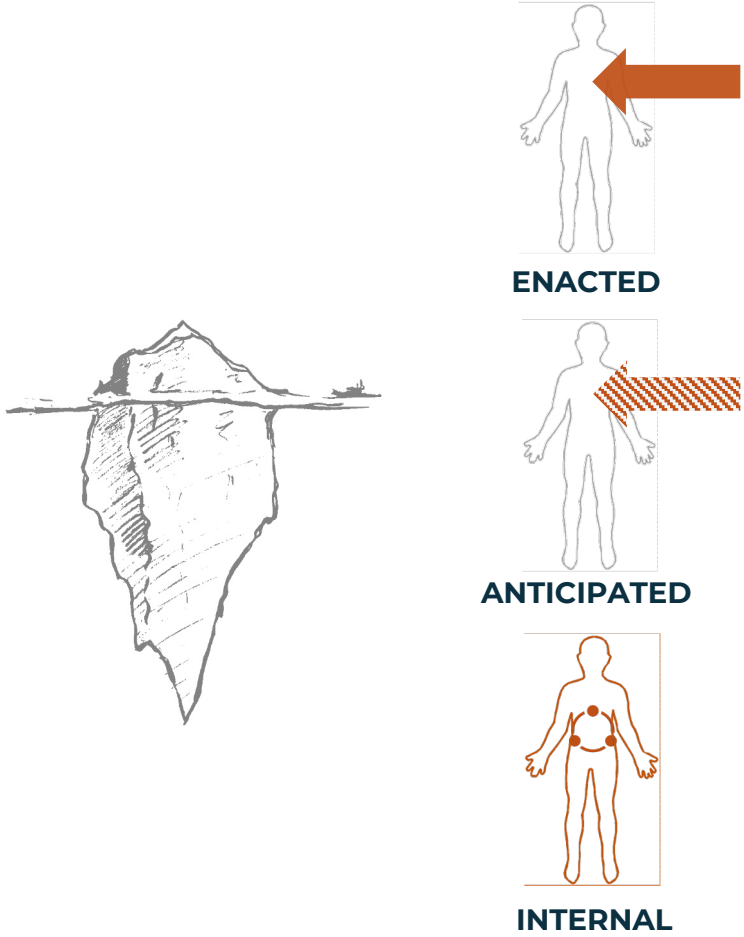




# Stigma is multidimensional, intersectional and persistent



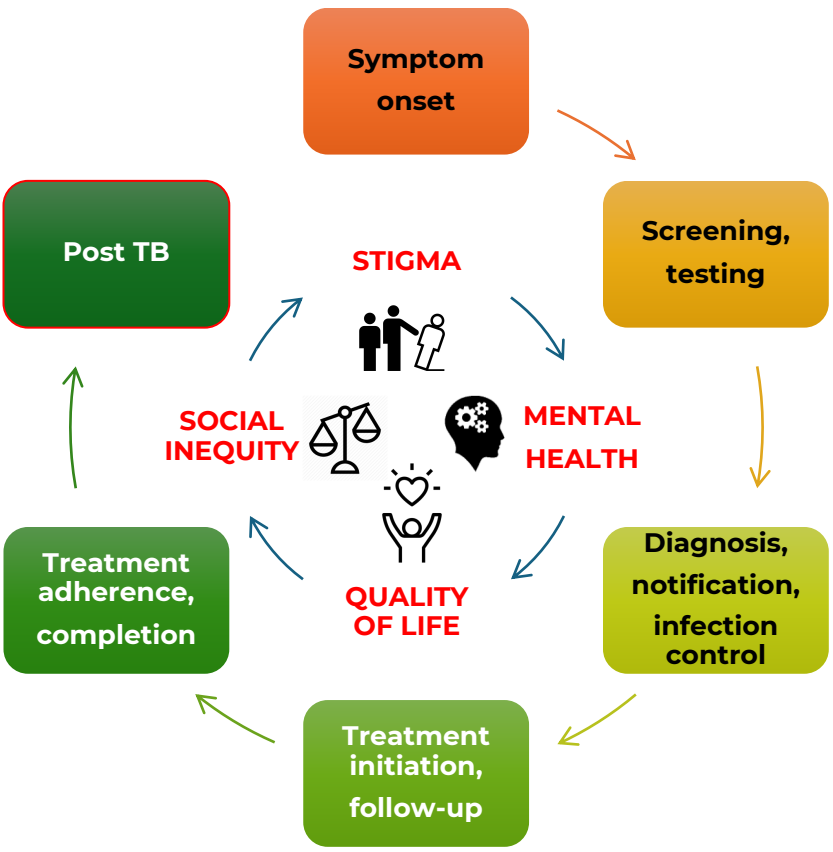
# Stigma is multidimensional, intersectional and persistent



**ENACTED**  
 Physical and social avoidance  
 Severed relations and supports  
 Disdain, name calling and disrespect

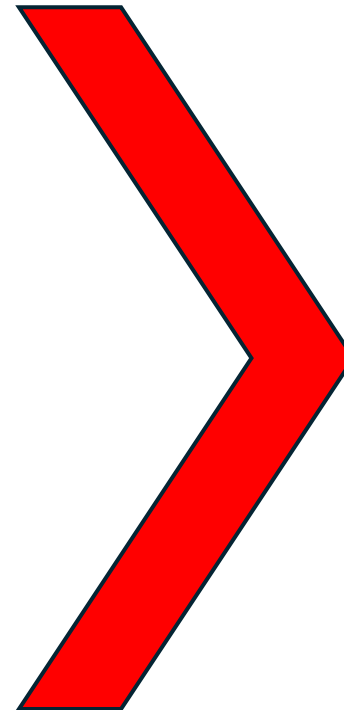
**ANTICIPATED**  
 Fear of disclosing, speaking out or accessing care  
 Diminished agency  
 Social withdrawal

**INTERNAL**  
 Shame and self-blame  
 Loss of worth, identify and belonging



# Stigma has multilevel impacts

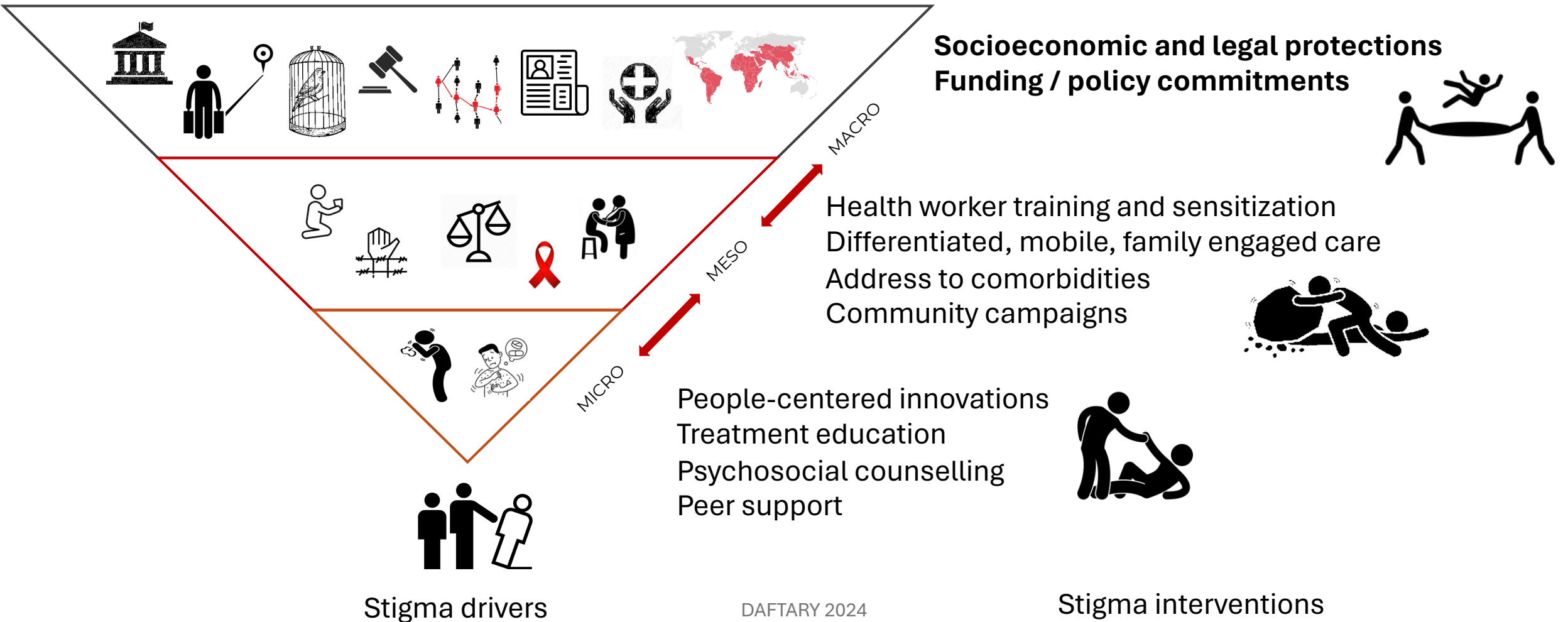
Compromised health seeking  
Inequitable and coercive care practices  
Delayed diagnosis  
Poor adherence and retention in care  
Poor infection control practices  
Disrupted relations and supports  
Disrupted identity and quality of life  
Mental health ...



HEIGHTENING  
RISK OF RESISTANCE  
  
...TO ANY TB DRUG



# Beyond fear of TB, stigma is rooted in inequities facing TB affected communities and unjust policies and care practices



# Lessons learned from other programs



<b>WHEN</b>	<b>WHERE</b>
Monthly Every 2 months Every 3 months Every 6 months	HIV clinic / hospital Primary care clinic Other clinic Community Home
<b>WHO</b>	<b>WHAT</b>
Physician Clinical officer Nurse Pharmacist Community health worker Client / peer / family member	ART initiation / refill Clinical monitoring Adherence support Laboratory tests GI treatment Psychosocial support



**SASSA**  
How to apply for COVID-19 R350 Social Relief Grant

**STAY HOME**  
SAVE SOUTH AFRICA

- Who can apply?**
  - An unemployed person
  - Must be over 18 years old
  - Not receiving social grants, UIF OR NSFAS stipend
- What you need?**
  - Identity Document
  - Banking details
  - Contact Number – Cellphone number
  - Proof of residential address
- Apply via...**
  - Send message to: 082 046 8553
  - USSD Code: \*134\*7737#
  - Email: srd@sassa.gov.za

Payments will be made through direct deposits into bank accounts or a money transfer to a mobile phone.

WHATSAPP SUPPORT: 0600 423 456  
EMERGENCY NUMBER: 0800 020 398  
SASSA: 0800 020 398

Choice can be integrated into standardized treatment

Social, legal, mental health protections can be delivered via multisectoral actions



Infection control can be normalized and anonymized

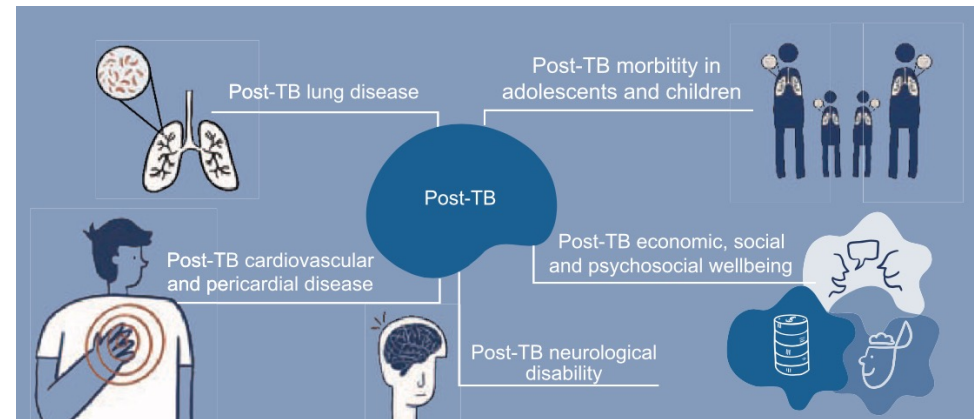
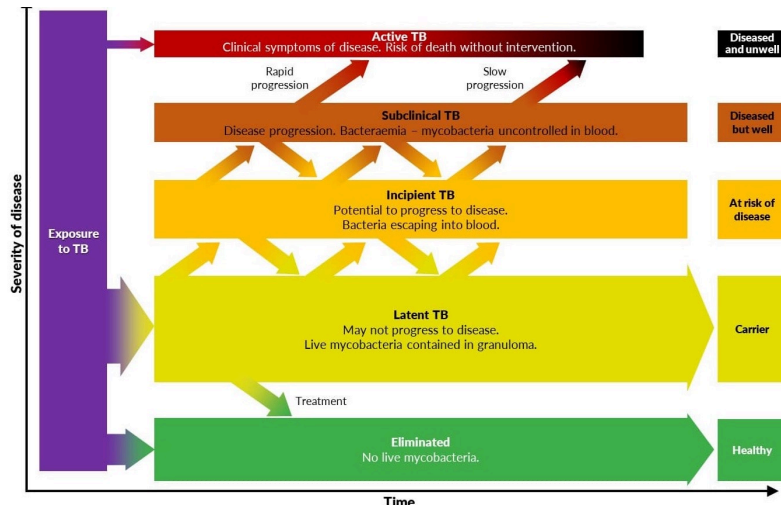


Heterogeneous community insights can be systematically included and prioritized



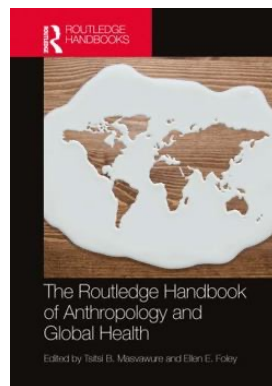
Recovery (non infectivity) can be emphasized alongside risk

# (DR)TB may not be experienced as an acute illness



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<http://dx.doi.org/10.5588/ijtld.22.0514>

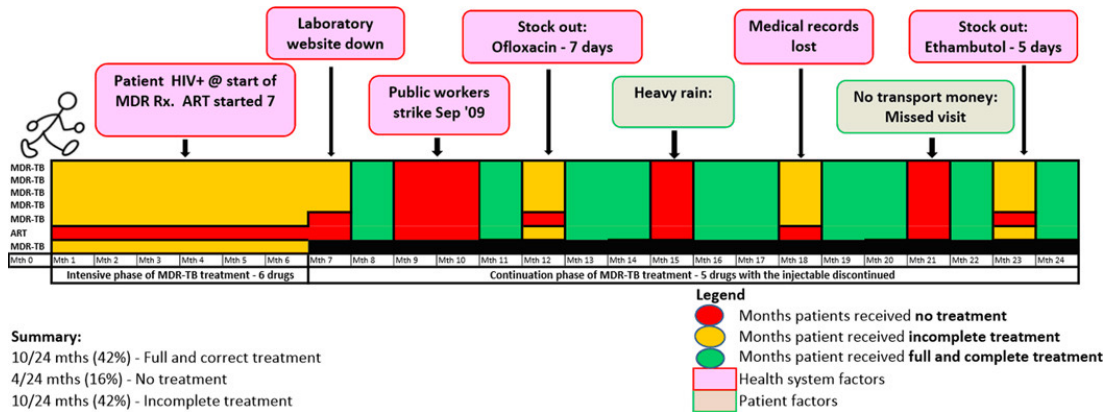
## Post-TB health and wellbeing



## THE NEGLECTED CHRONICITY OF TB

*Dillon T. Wademan and Amrita Daftary*

# A chronic framing may be especially relevant in DRTB



**Stage 1: diagnosis and hospitalisation—the first crisis**

- Urgent care
- Stigmatising treatment (masks, queue)
- Admission to centralised hospital
- Renunciation of social commitments
- Fear of the unknown, illness disclosure
- No information, no notice, no choice

**Stage 4: treatment continuity—no end in sight**

- Persisting, un concealable side-effects
- Fragmented health care
- Social obligations, unmet family expectations
- Financial debt
- Stigma, loss of self worth

**Stage 2: treatment initiation—displaced and confined**

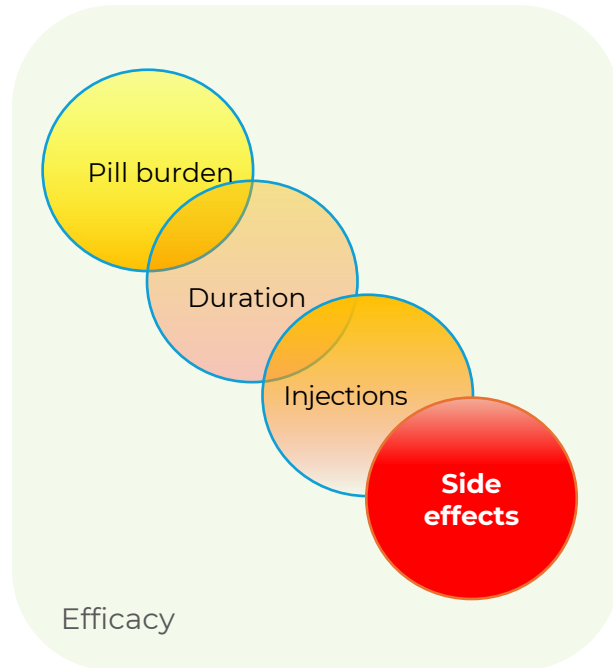
- Side-effects, pill burden
- Prolonged hospitalisation
- Disconnection from social networks
- Provider apathy and stigma
- Fear of dying, witnessing death
- No information, no mobility, no agency

**Stage 3: discharge home—reprieve and resurgent disruption**

- Self care, pill burden, pill management
- Side-effects, physical and mental debilitation
- Fragmented health care
- Social obligations, unmet family expectations
- Financial insecurity
- Stigma (clinic, community, household)

Emerging drug resistance implies people affected by TB and DRTB will have repeated and/or prolonged encounters with TB

# Patient priorities in DRTB should not be assumed



SURVIVOR PREFERENCES FOR THE IDEAL DRTB DRUG REGIMEN

## SURVIVOR PERSPECTIVES ON SIDE EFFECTS OF DRTB DRUG REGIMENS



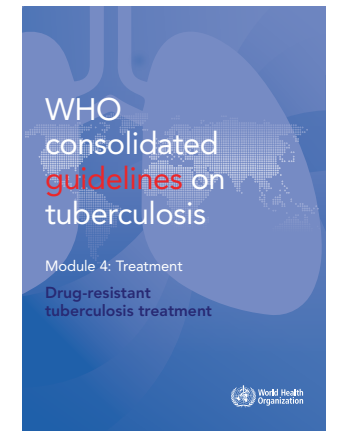
Tinnitus  
Dizziness  
Mild depression  
Disturbed sleep  
Nausea  
Mild vomiting  
Appetite loss  
Fatigue  
Aches and pains

COULD BE TOLERATED



Hearing loss  
Vision loss  
Severe mental illness  
Skin changes  
Jaundice / yellowing  
Irreversible organ damage  
Severe burning  
Severe vomiting

NOT ACCEPTABLE

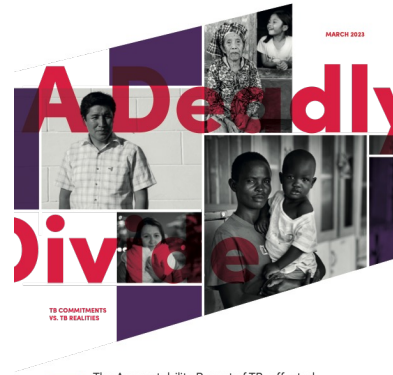


WHO 2020



# A way forward – community inclusion

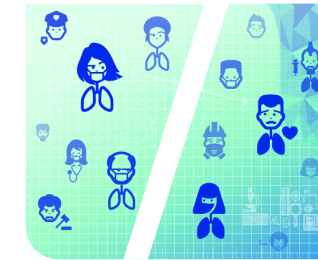
Amplifying the perspectives of TB champions and affected communities



The Accountability Report of TB-affected Communities & Civil Society:

**Priorities to Close the Deadly Divide**

Stop Partnership Community Deligation Stop Partnership Accountability 2023 Progress Stop Partnership Stop Partnership 2023 Progress



**TB Stigma**  
Measurement Guidance



 Nothing About us, Without us  
DETERMINANT INFLUENCES ON TB CARE AND CONTROL







# Thank you

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sshiftb.org

