HIV Stigma and Potential Lessons for TB Stigma

Reflections and Implementation Experiences from Two Decades of HIV stigma work

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"…. If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful."

– Edward Cameron, Constitutional Court Justice, South Africa

Presentation guide

- Definitions
- Key principles for stigma-reduction
- How: An example applying those to health facility stigma-reduction
- TB stigma Resources & emerging research agenda

What we Know About TB Stigma

- Harmful
  - To the individual, public health, human rights
- Universal & common at its core, yet
  - Locally shaped (context matters)
  - Often differentially experienced (e.g. by gender)
- Actionable
  - TB stigma can be reduced if deliberately addressed
  - Yet a gap remains in evaluated interventions
- Measurable
  - Growing number of tools
  - Drivers, manifestations and consequences
- Often co-occurs with/intersects with other stigmas

Growing Global Recognition of the Need to Act

- Zero suffering
  - One of the three aims of the WHO's End TB strategy
- Identified by the Global Fund as one of the most common barriers to fighting the TB epidemic
- UN agencies global call for an end to discrimination in health care
- Recognition of the potential for interventions to simultaneously reduce multiple stigmas
  - Common drivers, manifestations and consequences
  - Co-morbidity of stigmatized diseases
  - Intersectional
  - BMC Medicine collection on stigma research and global health

Definitions, Terminology & General Intervention Principles

Stigma is a Fundamental Determinant of Health and Health Inequity

- Stigma undermines three key determinants of health:
  - Access to resources
  - Access to social support
  - Psychological and behavioral responses

- Through exclusion, segregation, discrimination, stress and downward socio-economic placement

(Hatzenbuehler et al. 2013)

Stigma: a Social Process that Occurs within the Context of Power

1. Distinguishing & Labeling Differences

(TB patient, Person living with HIV, Immigrant, Adolescent)

2. Associating Negative Attributes

(dirty, irresponsible, dangerous, promiscuous, untrustworthy)

3. Separating "Us" from "Them"

(physical and social isolation)

4. Status Loss and Discrimination

(denial of health care, verbal & physical abuse, loss of respect)

Sources: Stigmatization Process: Link, B.G. and J.C. Phelan 2001. "Conceptualizing Stigma." *Annual Review of Sociology*: 363-385

The Soup of Stigma Terminology

Terminology of Stigma

Types of Stigma	
Experienced	Stigma that is enacted through interpersonal acts of discrimination
Perceived	Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g. healthcare providers)
Anticipated	Fear of stigma, whether or not it is actually experienced
Internalized (self)	Acceptance of experienced or perceived stigma as valid, justified

Terminology of Stigma Continued

Types of Stigma	
Secondary	Stigma by association, extended to family or other caregivers of stigmatized individual
Observed or Vicarious	Stigma occurring to others that is witnessed or heard about
Structural	Laws, policies, and institutional architecture that may be stigmatizing or alternatively protective against stigma
Intersectional	Convergence of multiple stigmatized identities within a person or group/intersecting of stigmas faced by individuals who are part of multiple marginalized groups

Key Principles for HIV Stigma-Reduction Interventions

Address immediately actionable drivers

Raise awareness & understanding of stigma
Attitudes: Discuss/challenge the shame and blame
Address transmission fears and misconceptions

Institutional Environment

Affected groups at the center of the response

Develop and strengthen networks
Address internalized stigma

Foster Resiliency & Resistance

Empower and strengthen capacity

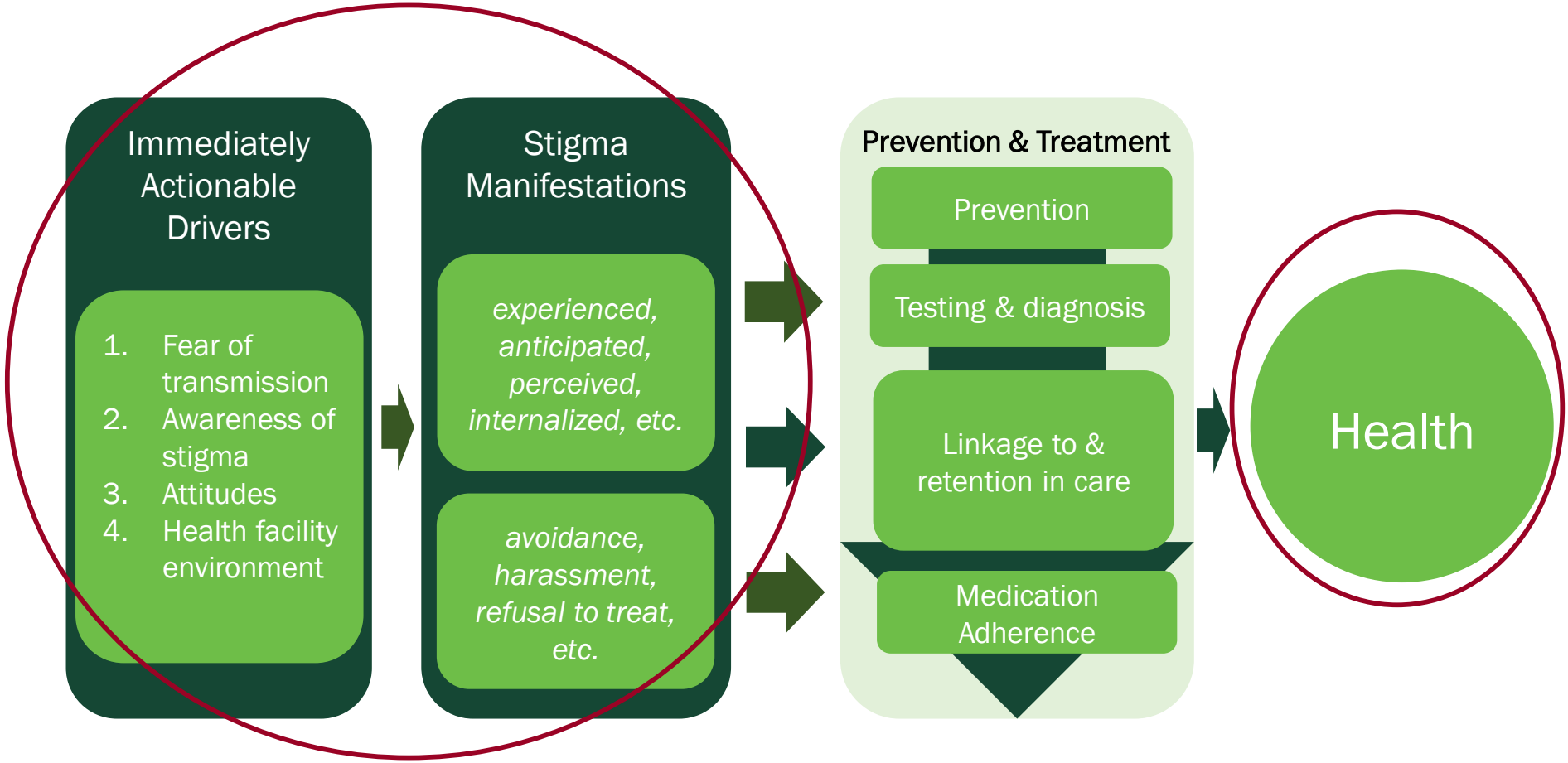
Create partnerships between affected groups and opinion leaders

Contact strategies

Build empathy
Model desirable behaviors
Recognize and reward role models

An example of a facility-focused HIV stigma reduction intervention

Why and Where We Address Stigma in Health Facilities



Source: Adapted from: Nyblade, L. and RTI International. 2016. *HIV Stigma Measurement: A Rapid Scan of Two Decades of Work.* Presentation at White House Meeting on Stigma, Washington, D.C.

Combating HIV-related Stigma and Discrimination in Health Facilities

USAID FROM THE AMERICAN PEOPLE

PEPFAR

HP+ HEALTH POLICY PLUS

Acknowledgments

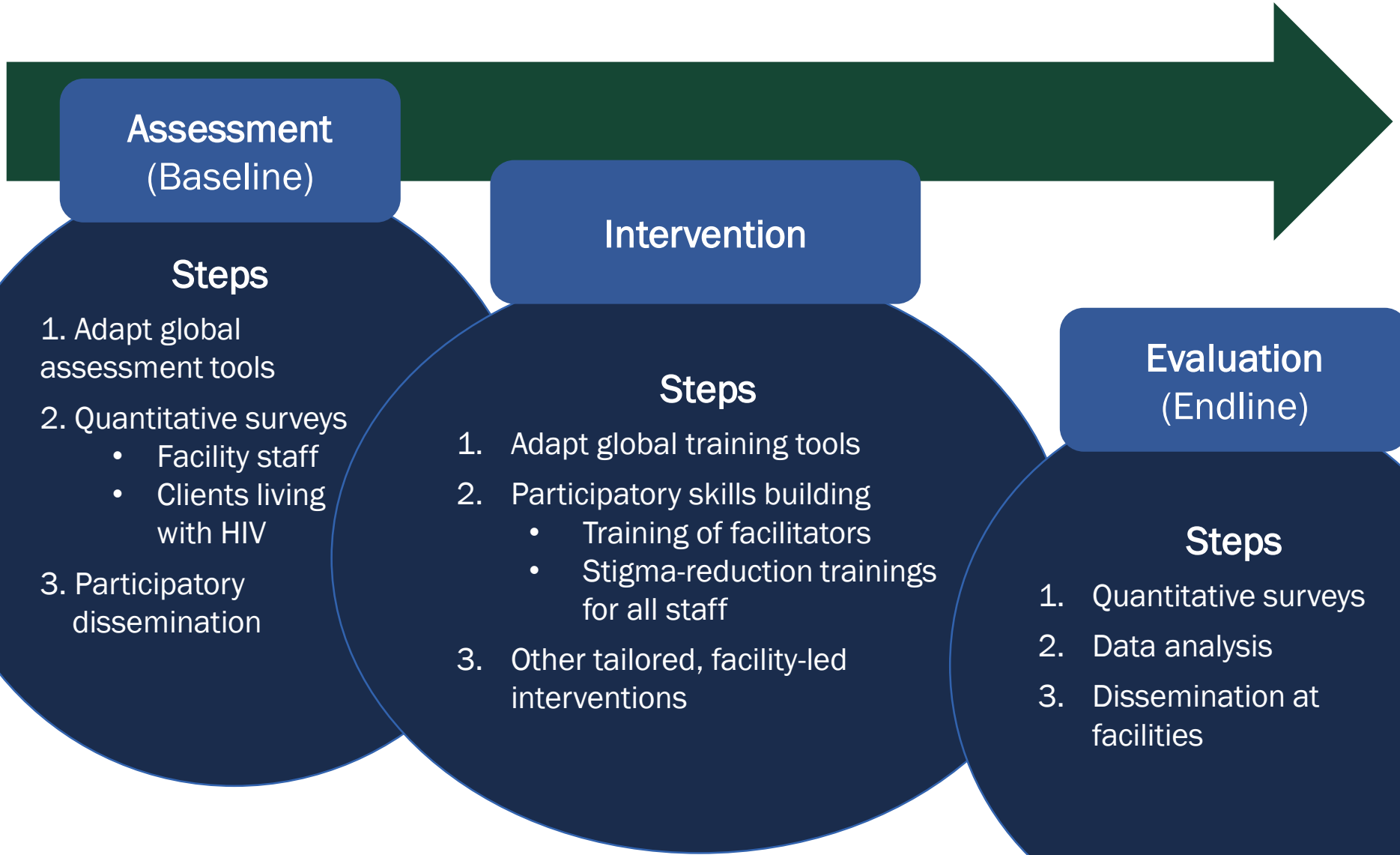
Tanzania

- Respondents, facility staff, and management
- Government of Tanzania
  - National AIDS Control Programme
  - Office of the Morogoro regional medical officer
  - Mvomero and Kilosa districts
- Local implementing partners
  - Muhimbili University for Health and Allied Sciences (Research)
  - Kimara Peer Educators (Intervention)
- USAID and PEPFAR

Ghana

- Respondents, facility staff, and management
- Ghana AIDS Commission
- National AIDS Control Programme
- Educational Assessment Research Center (local implementing partner)
- USAID and PEPFAR
- The Global Fund to Fight AIDS, Tuberculosis, and Malaria

The HP+ Total Health Facility Approach to Stigma Reduction: Three Phases



Participatory Skill Building

- Training of facilitators: Facility staff and clients living with HIV, including youth
  - Competitive selection of facilitators
  - Five-day offsite training and five days of mentoring/coaching (led by master trainers)

- Two days onsite, participatory skills building for facility staff (clinical and non-clinical)
  - Mix of levels and departments minimizes disruption of service delivery
  - Timing is flexible, depending on facility schedule

Participatory, Facility-Based, Two-Day Staff Training

Topic	Corresponding Exercise
Create awareness of what HIV-related stigma is in concrete terms	**Identify stigma and discrimination through pictures; analyze stigma in health facilities**
Understand and address fear of workplace HIV transmission	Partner work and quality, quantity, route of transmission tool work on non-sexual transmission; role play to review standard precautions
Gender and sexual diversity, stigma and discrimination toward key populations (Ghana)	Sexual diversity education and terminology; learn about and connect stigma to human rights
Understand and address stigma faced by youth seeking HIV and other sexual and reproductive health services (Tanzania)	Use individual reflection, small group work, and plenary discussion to explore stigma experienced by youth, provider comfort/discomfort serving youth, ways to improve service delivery for youth clients
Building empathy and reducing distance (contact strategies)	Listen to first-hand experiences from members of key populations (Ghana), youth (Tanzania), and people living with HIV; discuss experiences in health facilities; self-reflection
Working to create change	Develop realistic strategies and a code of practice and action plan

Final Curriculum: 14 participatory exercises (Ghana), 16 exercises (Tanzania)

More Tailored Interventions Designed and Implemented by Facility Staff

- **Local Solutions**
  - Champion teams
  - Public declarations to stigma-free care
    - Banners, posters, **community TV and radio spots,** loudspeaker announcements
  - Codes of conduct
  - Complaint and compliment system
- **Sustainable**
  - Integrated in existing structures and processes
- **Small seed grants** provided for stigma-reduction activities

NIULIZE MIMI ("ASK ME")

What Was Measured and Addressed

Ghana

Tanzania

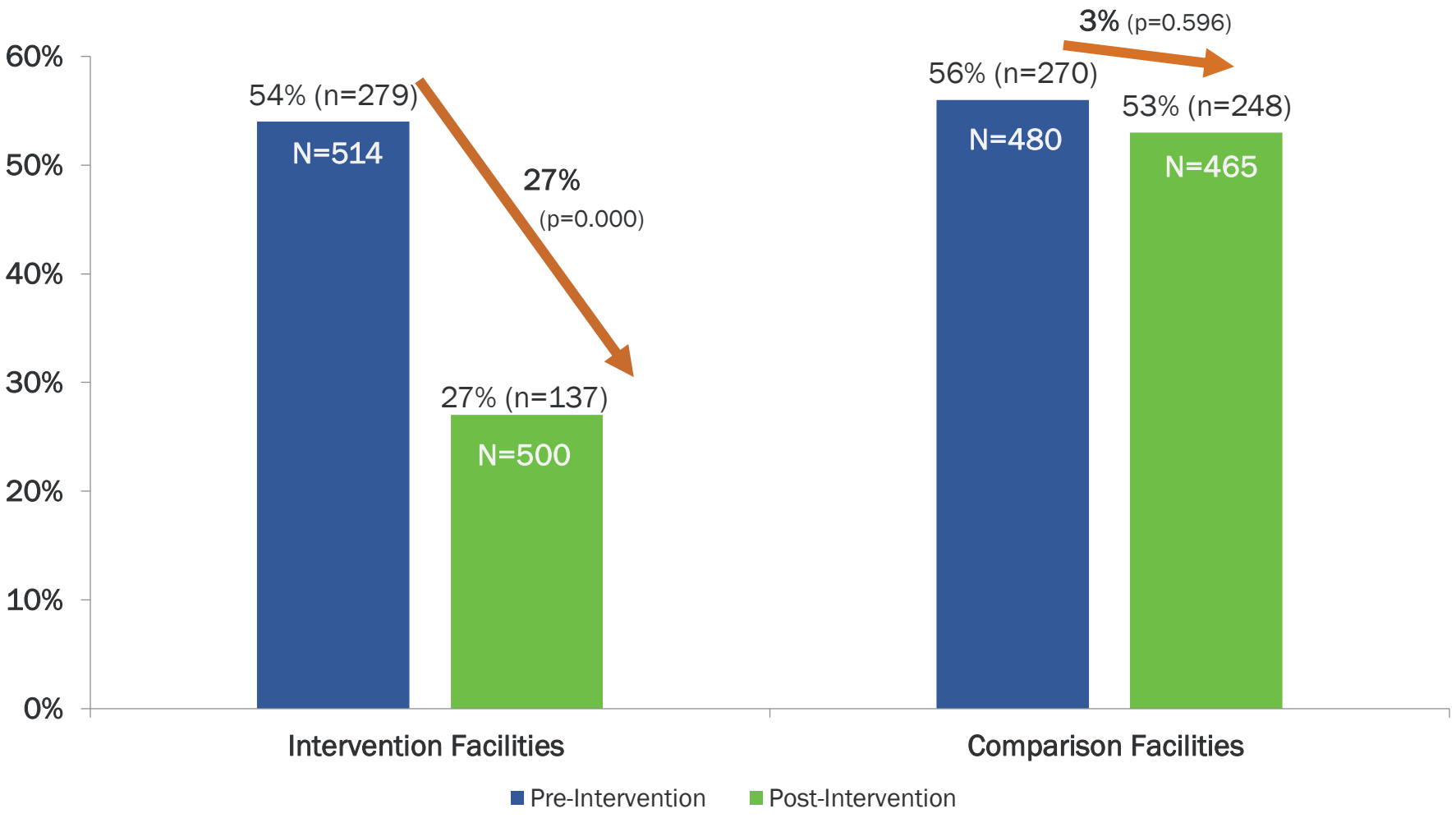
HIV-related stigma

- Immediately actionable drivers
  - Fear, attitudes, health facility environment/influence of stigma on health facility staff
- Stigmatizing avoidance behaviors (self-reported)
- Observed discrimination (behaviors observed in other staff)
- Willingness to care

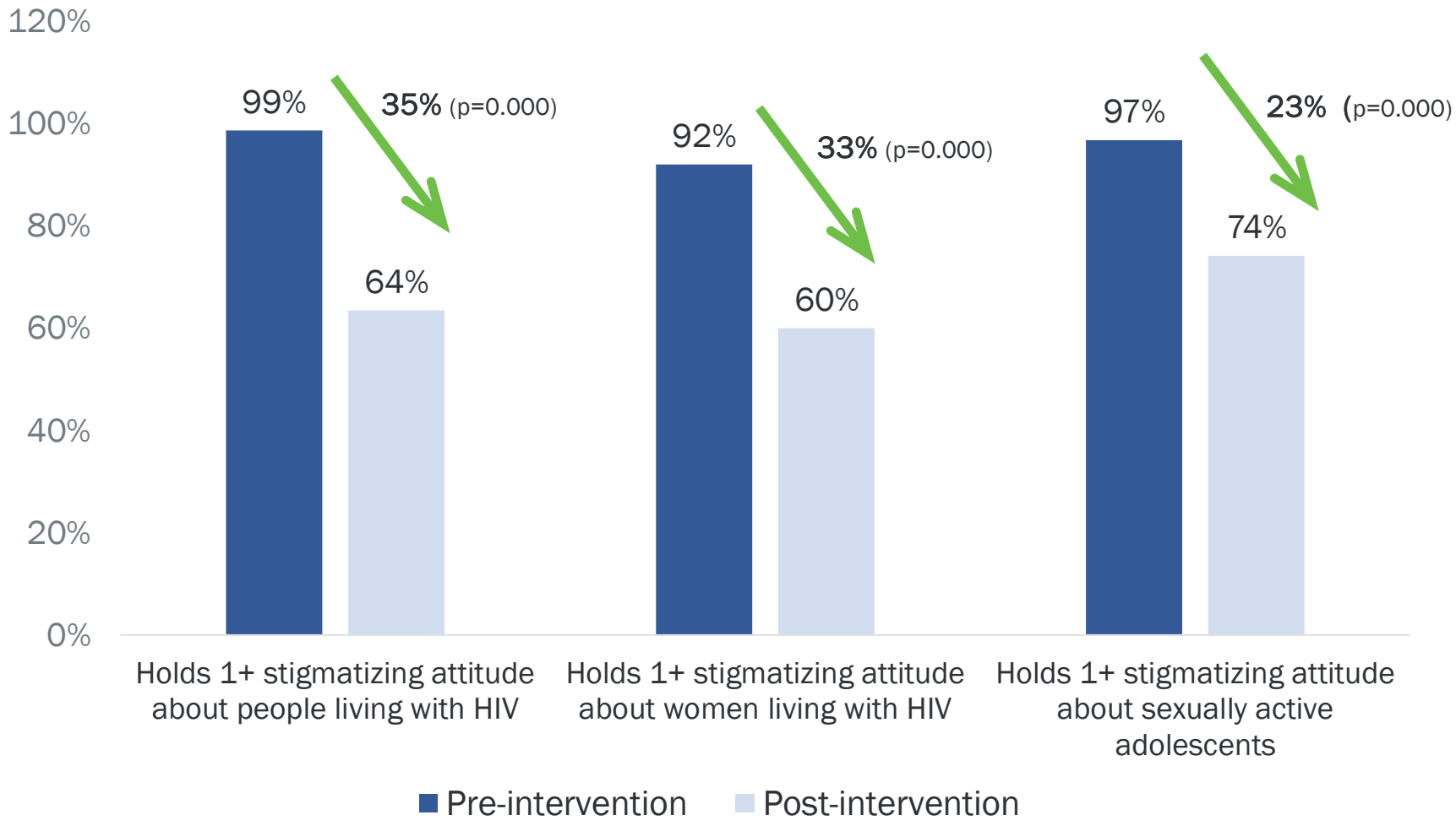
- Stigma toward key populations
  - Men who have sex with men, sex workers, people who inject drugs
- Costing analysis

- Stigma toward youth (ages 15-24)
- First adaptation to generalized epidemic setting

Worry About HIV Transmission While Caring for Clients Living with HIV: Composite (Ghana)



Stigmatizing Attitudes: Composite (Tanzania)



Provider Understanding of and Interactions with Key Populations Improved (Ghana, Pre/Post)

- Own preference **not** to treat men who have sex with men (MSM)
  - 15% decline (p=0.000)
  - Greater change in intervention facilities
    - Difference-in-differences: 14.2% (p=0.001)

Since the training, we have seen an increase in MSM living with HIV coming for services. We think this is mostly due to the change in our staff and how they interact with key populations. We also see MSM coming freely for their medicines during regular facility hours. Before they preferred coming after hours, to avoid being seen by staff."

— Mr. Kofi Atakorah-Yeboah Jnr,
Champion Team Member, Bekwai Hospital

Key Elements of the Total Facility Approach

- Evidence-based, building on two decades of work
  - Immediately actionable drivers
  - Adaptation of validated measurement and participatory training tools
  - Data-driven
- Builds ownership of the response by facilities
  - Recognition that all facility staff have a role to play
  - Early and ongoing engagement of facility management
- Strengthens stigma-reduction capacity in facilities
  - Participatory approaches to learning and behavior change
  - Participatory stigma-reduction trainings led by staff and clients
  - Facility champion teams

Participation leads to ownership and lays foundation for success and sustainability

"Training facility staff as facilitators led to much better results… Because they were our own staff, they were able to go and learn and then prepare sustainable trainings for their colleagues … Trainings were easier to understand and better received, because the facilitators know their fellow staff members and understand the facility context and were able to plan the content accordingly"

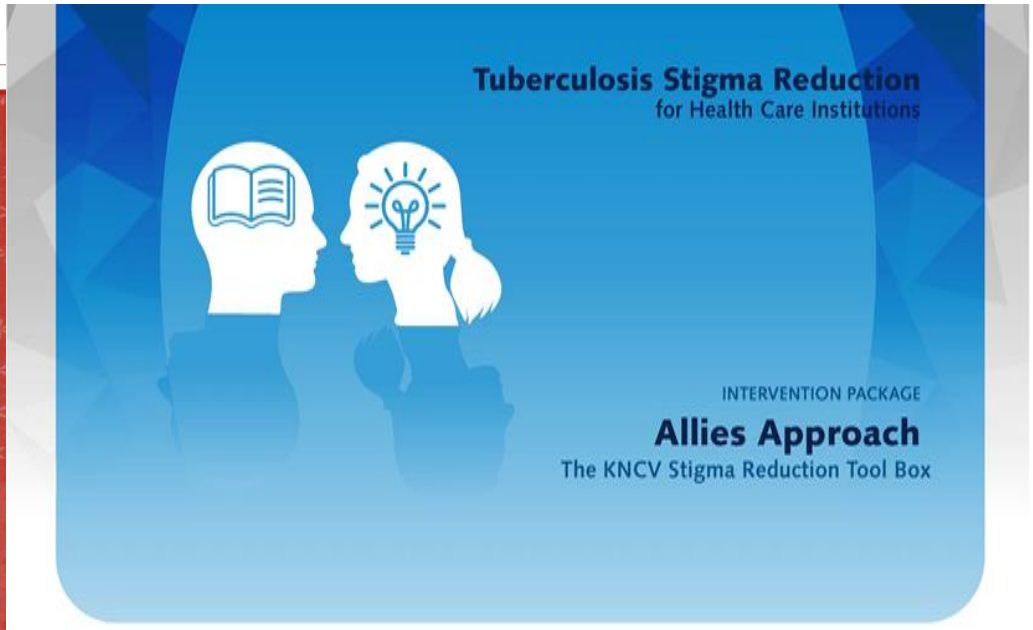
–Joseoh Ngimba, Medical Officer-In-Charge, Turiani

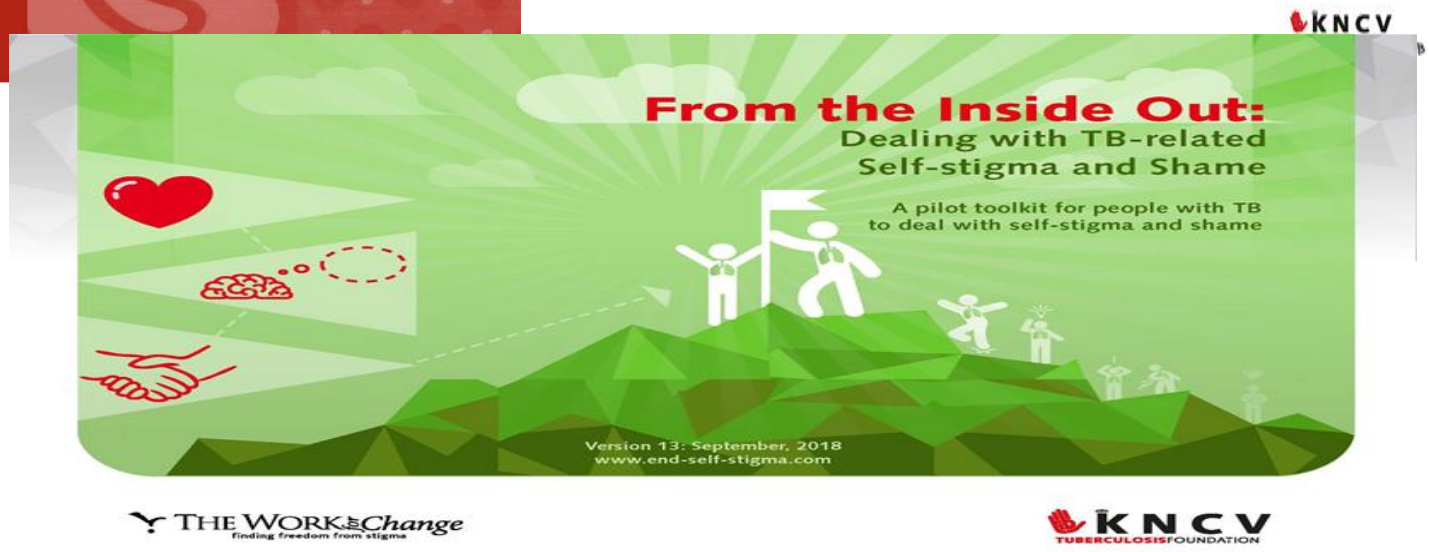
"This interaction is different from anything else we have experienced so far—we defined the response; we owned it."

—Dr. Akosua Osei Manu, Tema General Hospital

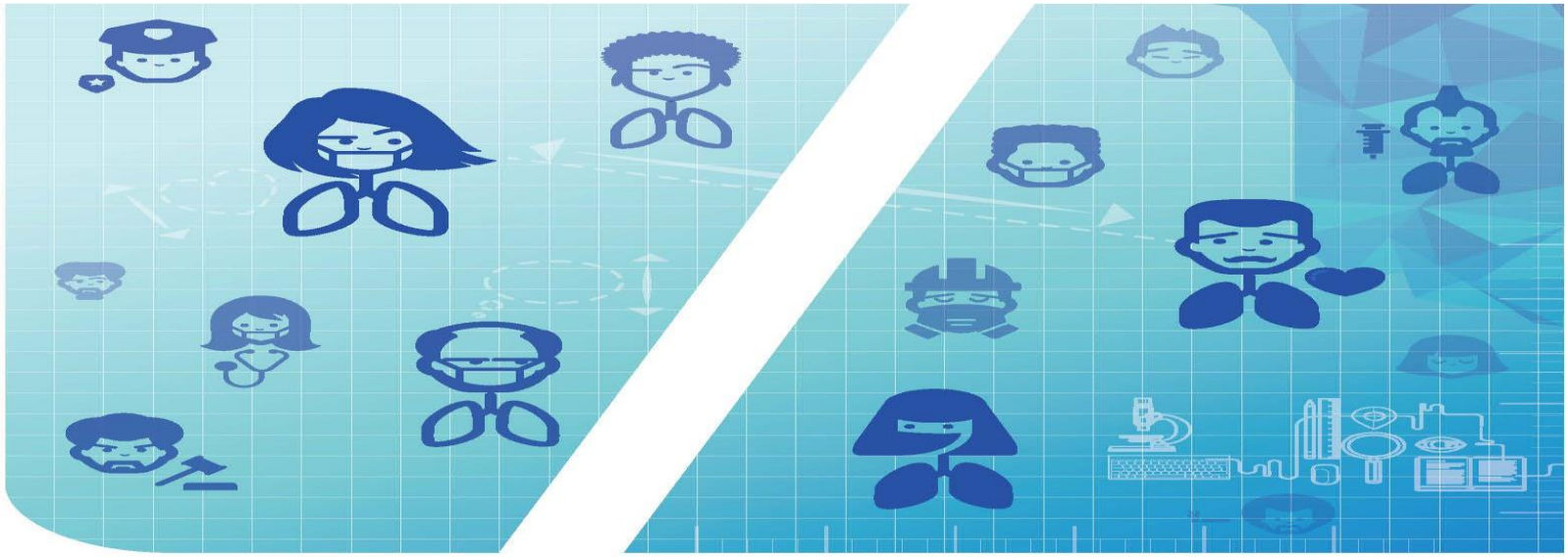
TB Stigma Focused Resources

TB Stigma Reduction Intervention Tools





TB Stigma Measurement Toolkit



- Companion Curriculum: http://www.challengetb.org/publications/tools/ua/TB_Stigma_Companion_Curriculum.pdf

International Journal Tuberculosis and Lung Disease
Special Supplement on TB stigma
Volume 21, Supplement 1, November 2017

Defining the research agenda to measure and reduce tuberculosis stigmas *Macintyre et al*

1) Drivers: what are the main drivers and domains of TB stigma(s)
2) Consequences: how consequential are TB stigmas and how are negative impacts most felt?
3) Burden: what is the global prevalence and distribution of TB stigma(s) and what explains any variation?
4) Intervention: what can be done to reduce the extent and impact of TB stigma(s)?

Stigma-Reduction: A key ingredient to finding and treating the estimated 4 million missing TB cases?

- The ripple effect will impact across prevention and treatment, contributing to better health outcomes across populations & TB control