

Importance of engaging community and patient groups in TB care and control

Partnership for Tuberculosis Care and Control, India

National Consultation of Partners

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Journeying with Communities towards better Health and Empowerment

Introduction

Why are we still talking about importance of engaging communities and patients???



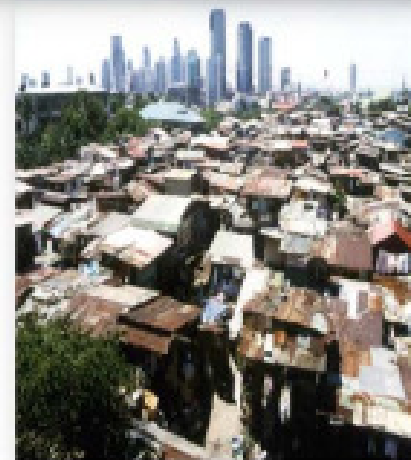
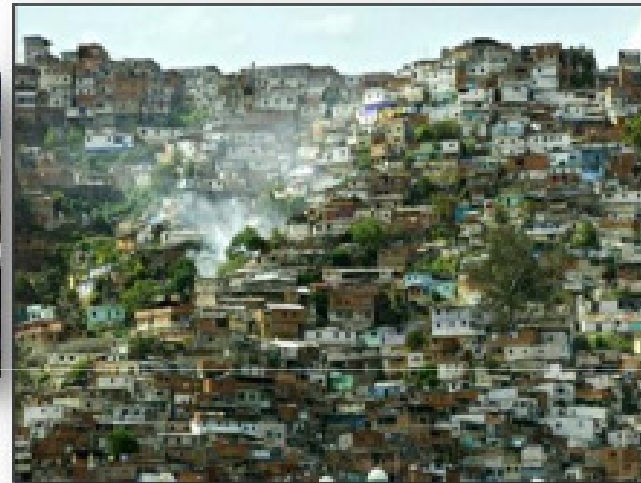
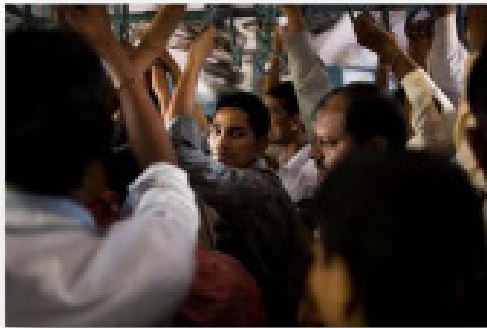
Current status

- Historically, patients and civil society groups have been involved in the development of drugs/ vaccines and diagnostics for other diseases.
- Very little involvement of patients and patient groups in TB
- Little published *patient-derived* data/operational research associated with TB

Possible reasons

- TB management systems are traditionally “top down” with clinical focus and little patient involvement
- TB seen only as a medical problem – social determinants ??
- Patient has minimal involvement with diagnosis and treatment
- Why ask?? Can't we presume we know best what patient needs

Affected community and civil society engagement is highest priority for Stop TB Partnership



- Detect the missing 3 million cases
- Expand access to existing and new diagnostics
- Save 1 million lives by implementing TB/HIV package of service
- Scale up services for drug-resistant TB
- Address the childhood TB call for action
- **Engage community in doing all of this**

Why involve community and patients?

- we haven't managed to find a way to have a world free of TB even after TB being around for hundreds of years
- for too long TB has been seen and addressed solely as a medical problem with only medical solutions
- TB is a major public health and social problem needing social along with medical interventions
- Without involving the community we cannot achieve results that are sustainable and locally rooted

Cont....

- scaling up the response to TB will not be successful without strengthened community systems
- community based organizations have evolved to fill service delivery gaps at the community level –
- role that communities and organized infected/affected community based organizations can play
 - ICF, Stigma reduction, Awareness
 - Treatment adherence and completion support
 - loss to follow up prevention and tracking
 - Advocacy for increased programmatic and research resources and implementation

Why involve community?

- reduces stigma
- all care and support comes from family or neighbours
- IC

The WHO TB screening rule for IPT among PLHIV performs well in community settings

Setting	Sensitivity (%)	Specificity (%)	NPV (95% CI) 5% TB prevalence
Community	76	61	97.3 (96.9-97.7)
Clinical	89	30	98.3 (97.5-98.8)
CD4 < 200	94	22	98.9 (95.8-99.5)
CD4 \geq 200	83	34	96.9 (95.1-98.0)

The desired results cannot be achieved if the affected communities are not part of the design, delivery, M&E Services and activities of prevention, treatment, care and support of people affected.

- improved outcomes for health
- respect for people's health and other rights
- social and financial risk protection
- improved responsiveness and effectiveness of interventions by communities
- improved responsiveness and effectiveness of interventions by health, social support, education and other services.

What is needed for this Partnership to be successful?

- Recognition that communities and patient groups are valuable Partners
- Capacity Building and empowerment
- Inclusion in National Coordinating bodies and committees
- Strong participation in CCMs
- Mechanism – CSO contribution to be reflected in the National figures
- Acceptance and space for working together with

Empowerment:

Empowerment is the process of enhancing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes.

Key elements of Empowerment include

- ❖ Access to information
- ❖ Inclusion and participation
- ❖ Accountability

We cannot address TB by adding a few extra access points to the existing system- it needs a complete paradigm shift in thinking.

We need to build a pro patient system- bottom up.

The time is now!!



Actually yesterday!!!!

Thank You!

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