

# Promoting Community Empowerment for Tuberculosis Care and Prevention

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Petra Heitkamp, WHO/ Indonesia**

## Learning Objectives:

- To discuss the importance of empowering the community for tuberculosis care and prevention
- To identify and discuss the different methods/ strategies of empowering people to take actions
- To discuss the benefits of empowering people for TB care and prevention



# Outline

- What is community empowerment?
- Benefits
- Measurable interventions  
*(illustrated by Indonesian initiatives)*
- Challenges



# The Stop TB Strategy



## THE STOP TB STRATEGY

### VISION

### A WORLD FREE OF TB

### GOAL

To dramatically reduce the global burden of TB by 2015 in line with the Millennium Development Goals and the Stop TB Partnership targets

### OBJECTIVES

- Achieve universal access to high-quality diagnosis and patient-centred treatment
- Reduce the human suffering and socioeconomic burden associated with TB
- Protect poor and vulnerable populations from TB, TB/HIV and multidrug-resistant TB
- Support development of new tools and enable their timely and effective use

### TARGETS

- MDG 6, Target 8: Halt and begin to reverse the incidence of TB by 2015
- Targets linked to the MDGs and endorsed by Stop TB Partnership:
  - By 2005: detect at least 70% of new sputum smear-positive TB cases and cure at least 85% of these cases
  - By 2015: reduce prevalence of and deaths due to TB by 50% relative to 1990
  - By 2050: eliminate TB as a public health problem (<1 case per million population)

### COMPONENTS OF THE STOP TB STRATEGY

#### 1 PURSUE HIGH-QUALITY DOTS EXPANSION AND ENHANCEMENT

- a. Political commitment with increased and sustained financing
- b. Case detection through quality-assured bacteriology
- c. Standardized treatment with supervision and patient support
- d. An effective drug supply and management system
- e. Monitoring and evaluation system, and impact measurement

#### 2 ADDRESS TB/HIV, MDR-TB AND OTHER CHALLENGES

- Implement collaborative TB/HIV activities
- Prevent and control multidrug-resistant TB
- Address prisoners, refugees and other high-risk groups and special situations

#### 3 CONTRIBUTE TO HEALTH SYSTEM STRENGTHENING

- Actively participate in efforts to improve system-wide policy, human resources, financing, management, service delivery, and information systems
- Share innovations that strengthen systems, including the Practical Approach to Lung Health (PAL)
- Adapt innovations from other fields

#### 4 ENGAGE ALL CARE PROVIDERS

- Public-Public and Public-Private Mix (PPM) approaches
- International Standards for TB Care (ISTC)

#### 5 EMPOWER PEOPLE WITH TB, AND COMMUNITIES

- Advocacy, communication and social mobilization
- Community participation in TB care
- Patients' Charter for Tuberculosis Care

#### 6 ENABLE AND PROMOTE RESEARCH

- Programme-based operational research
- Research to develop new diagnostics, drugs and vaccines

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Stop TB Partnership

## Component 5:

### Empower people with TB and communities

- WHO previous work on evidence of efficacy and cost-effectiveness.
- Need to document operationalization and motivation



# STB strategy: Patient-centred approach

- ◆ Foundation of STB strategy is effective patient care which alleviates suffering and controls and prevents TB in a community
- ◆ Promote community participation and action to increase
  - (1) demand for proper care, and
  - (2) participation in patient's care



# What is Patient Empowerment?

1. TB patient's capacity to better control his own care and life;
2. TB patient's ability to assist other TB patients in improving their lives;
3. TB patient's ability to assist TB control program and health care professionals



# What is Community Empowerment?

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**Community:** people living together in some form of social organization and cohesion, sharing social, cultural, economic characteristics, common interests, incl. health.

**Community Empowerment:** Operational partnership between the health services and civil society contributing to TB care

*Scale:* motivated individuals, existing community volunteers, tribal groups/ clans, faith-based groups, NGOs, professional associations...

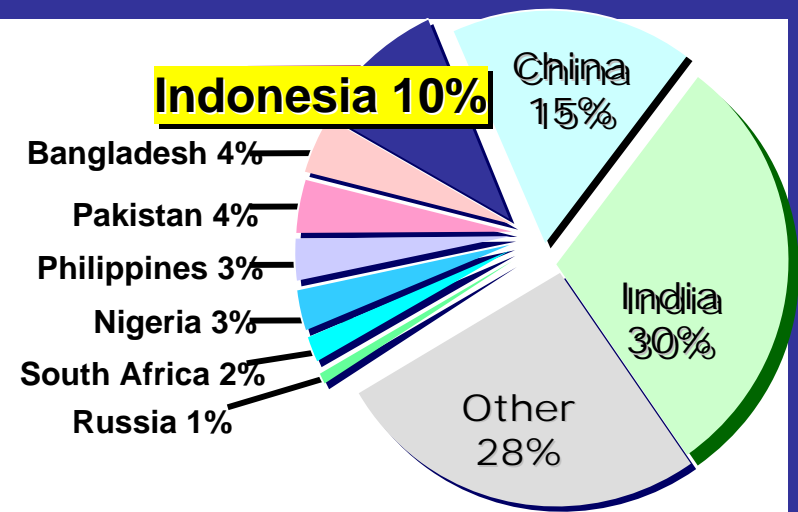


# Why Community Empowerment? (Global Taskforce)

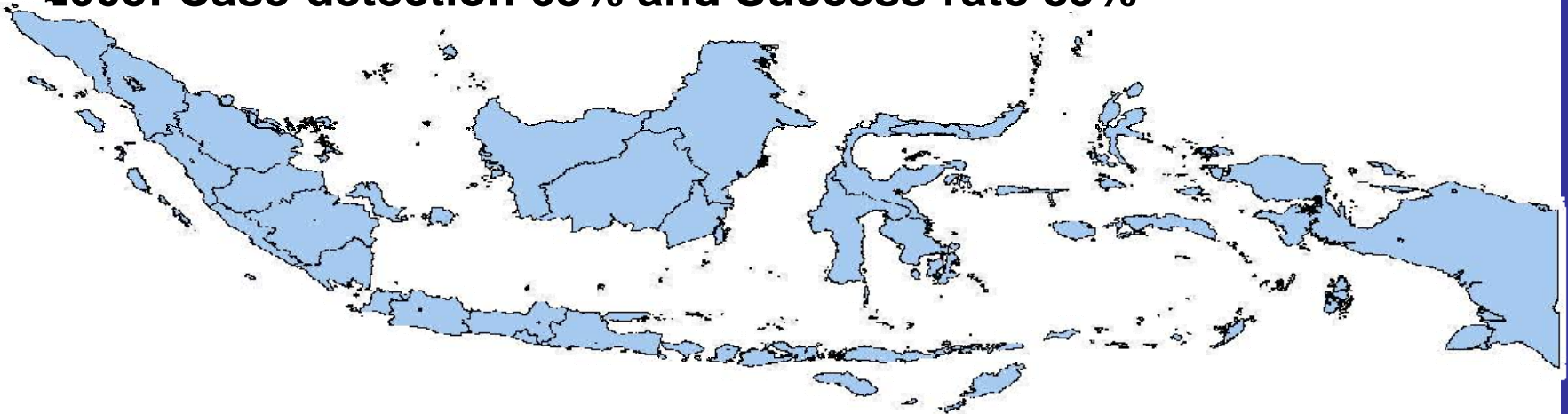
C E Areas	Benefits
Policy guidance	– Reality check, sustainability
Advocacy & communication	– Information/ dialogue (process)
Capacity building	– Additional resources
Special challenges	– Appropriate, tailored
Quality of services	– Patient satisfaction
Budgeting and financing	– Accountability
M&E and supervision	– Results and impact
Operational research	– Performance



# TB Situation in Indonesia



- Leading cause among infectious diseases (NHHS 1995)
- 583.000 new cases per year, and 100.000 deaths per year
- Ranked 3<sup>rd</sup> in TB burden Globally, following India and China
- 2005: Case-detection 68% and Success-rate 89%



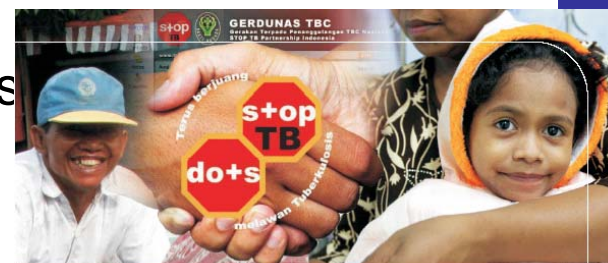
# 5yr Strategic Plan to Control TB in Indonesia 2006-2010

## EXPANSION of TB CONTROL

1. Pursue quality DOTS expansion and enhancement
2. Address TB/HIV, MDR-TB and other challenges
3. Involve all care providers
4. Engage TB patients and affected communities

## Supported by Health System Strengthening:

5. Strengthened policy and ownership
6. Strengthened health system and TB control management
7. Research



Kerangka Kerja  
Strategi Pengendalian TBC  
Indonesia: 2006-2010



# **Community empowerment**

## Examples and results in Indonesia

1. TB knowledge and awareness
2. Increased case detection
3. Treatment adherence
4. Reduced stigma and discrimination



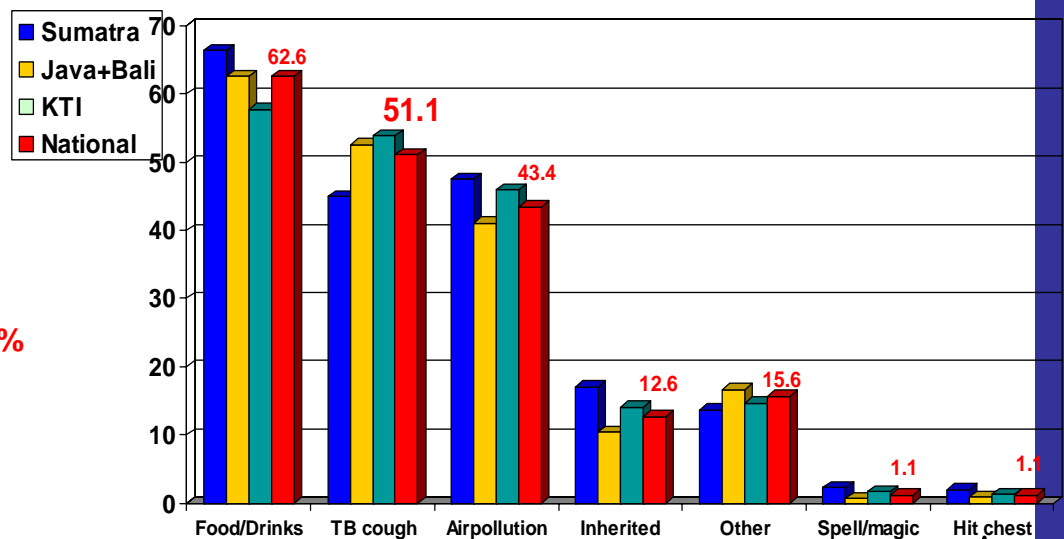
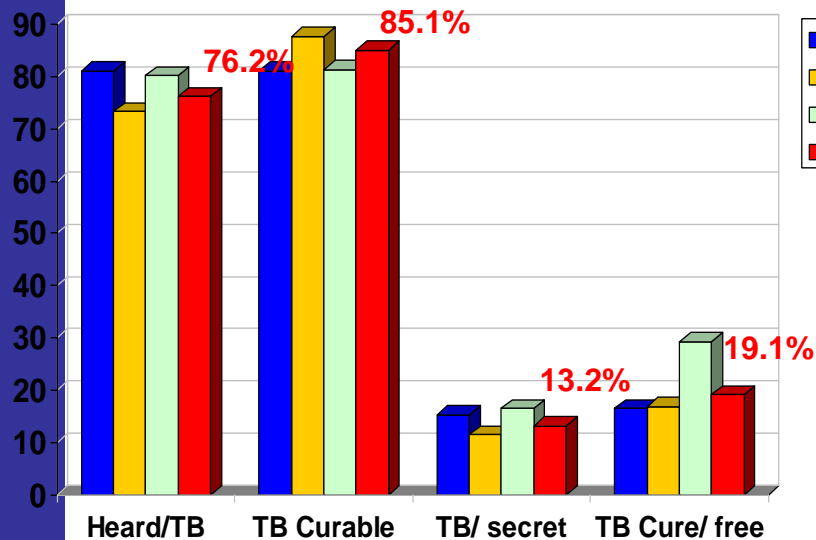
# 1. TB Knowledge and awareness

- Empower community through increasing their knowledge and understanding on:
  - 1) *how to be diagnosed;*
  - 2) *how to take treatment*
  - 3) *choosing a health facility;*
- Based on evidence:
  - Measured by KAP
  - Media mapping
- Mass media campaign launch WTBD07
  - TV/ Radio backed up by local off-air events
  - Local leadership and community led events
  - Interactive and action-oriented messages



# Knowledge, Attitude, Practice TB Indonesia

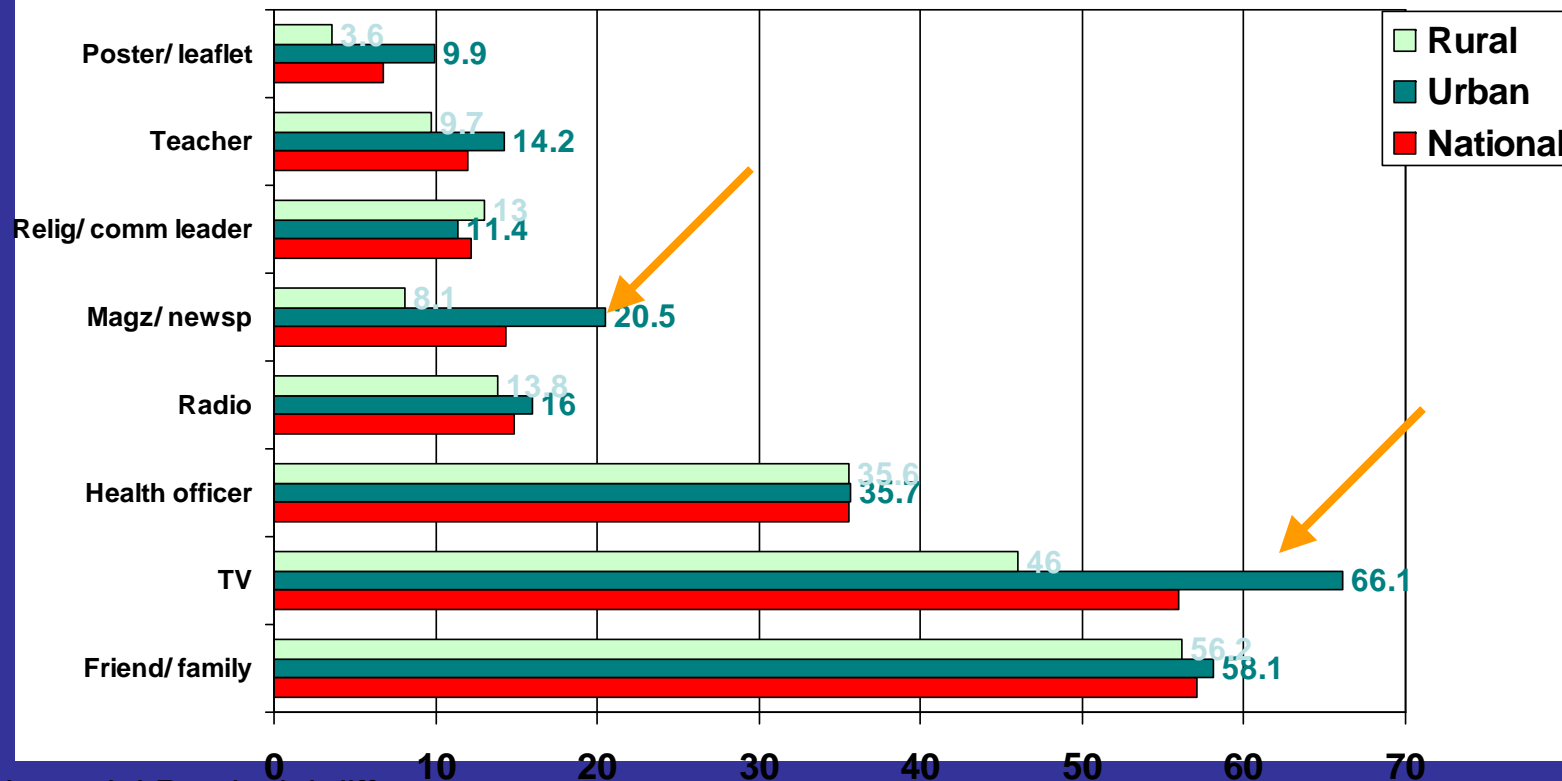
- Know about TB (76%) and know TB is curable (85%)
- **Only 16%** can mention three or more correct symptoms
- **Misconceptions** on TB dissemination thru drinks/food, air-pollution
- People do NOT know treatment is free (only 19%)



# Media mapping

## Sources of TB information

- Vast majority gets info from TV - radio 2<sup>nd</sup> most popular mass medium (*NOT print paper*)
- Family, friends, health officers play important role (word-of-mouth)
- Informal leaders, traditional media (house visits, public meetings), faith-based venues have huge potential



Substantial Provincial differences

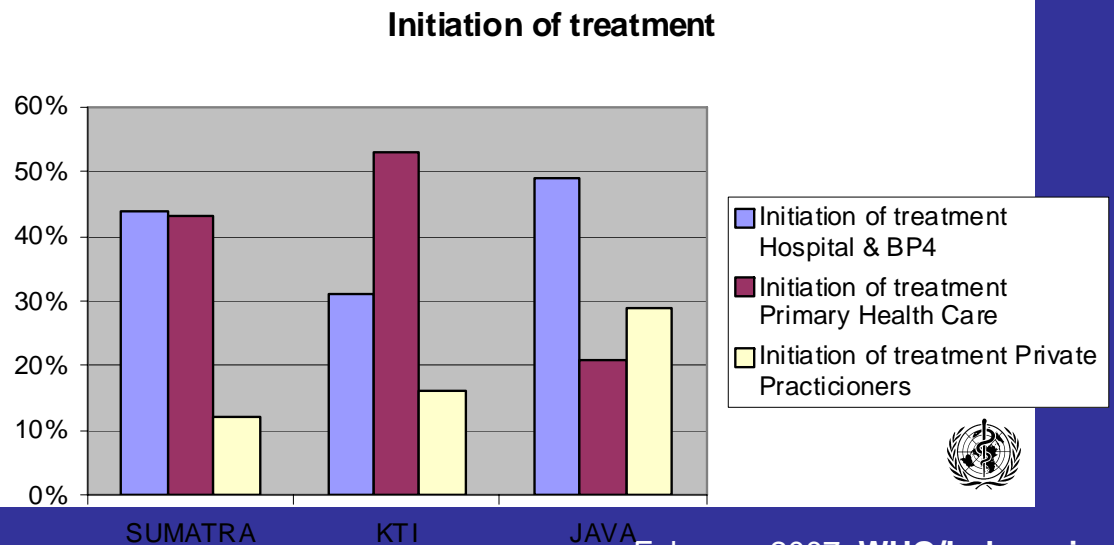
February 2007, WHO/Indonesia



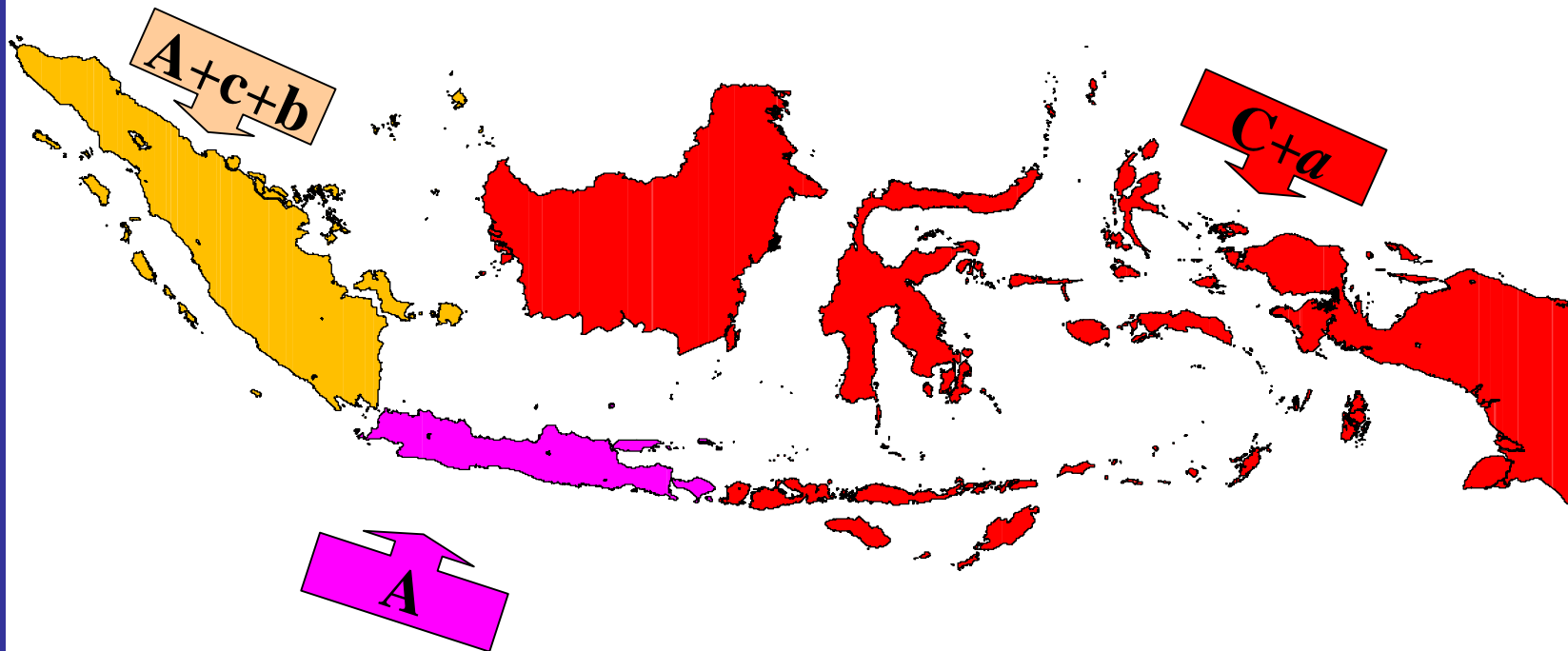
## 2. Increase Case-detection

- Increase case-detection through community participation—larger demand for quality TB diagnosis
- Evidence base:
  - Health-care seeking behaviors
  - Targeting areas for community TB care
  - Measure impact by suspect evaluation rates

- Most Indonesians when sick go to health-centres (60%-urban and 70% rural) where TB services are available



# Areas-specific planning & targeting

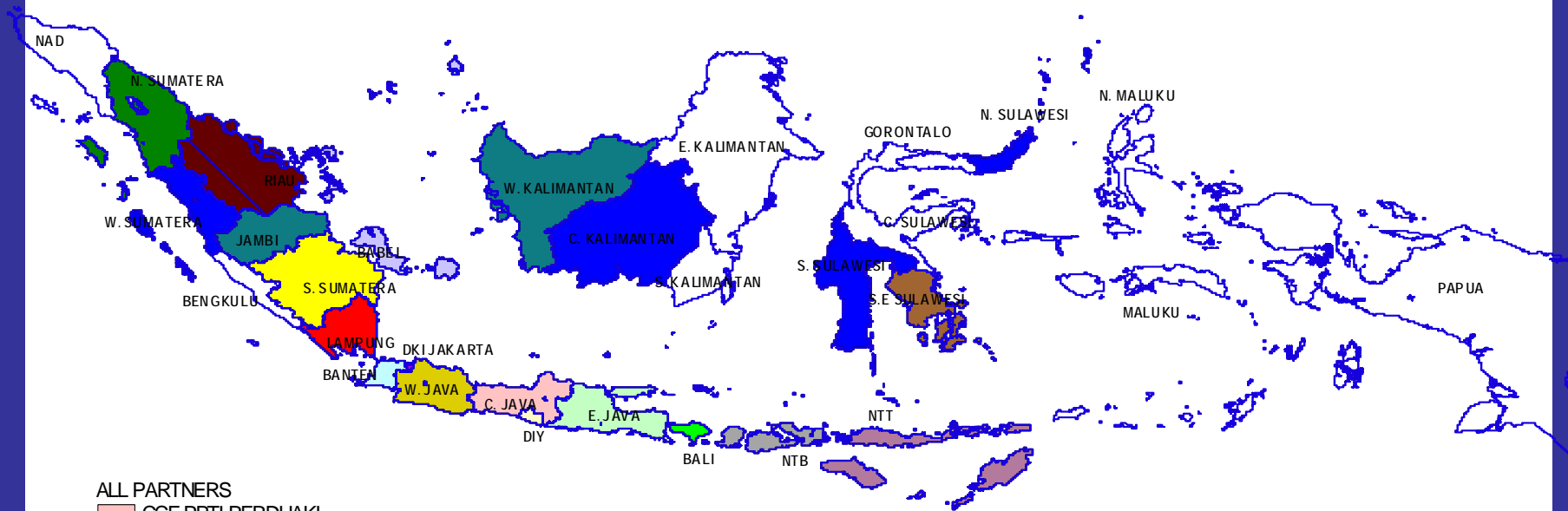


Area of work A: strengthening of hospital referral & networking system

Area of work B : expansion of hospital involvement

Area of work C: strengthening and optimising peripheral PHC system (*puskesmas pustu, bidan desa, ngo support/involvement*)  
community involvement

# Where are the TB partners?



- ALL PARTNERS
- CCF,PPTI,PERDHAKI
  - KUIS,CCF
  - KUIS,FHI
  - KUIS,MSH,PERDHAKI,Muhammadiyah
  - KUIS,PPTI,PERDHAKI
  - KUIS,PPTI,PERDHAKI,FHI
  - PKK,PROKAMI,LSM Peduli Perempuan
  - PPTI
  - PPTI,CCF
  - PPTI,HOPE,YSA
  - PPTI,KUIS
  - PPTI,KUIS,CCF
  - PPTI,KUIS,CCF,MSH,FHI
  - PPTI,KUIS,CCF,MSH,YSA,Muhammadiyah,PERDHAKI
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  - PPTI,KUIS,PERDHAKI
  - WVI

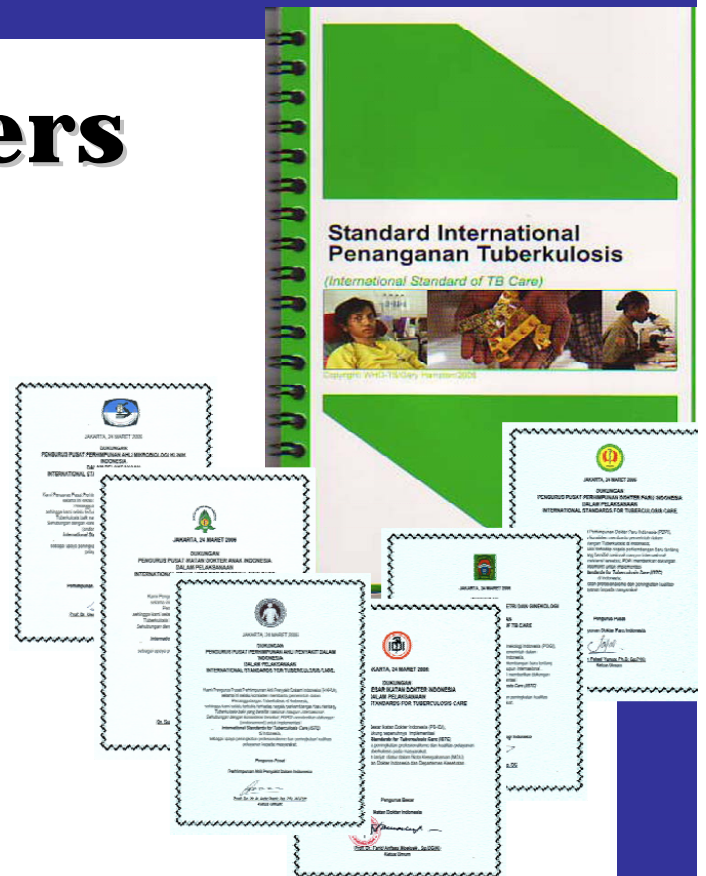


# Involve all care providers

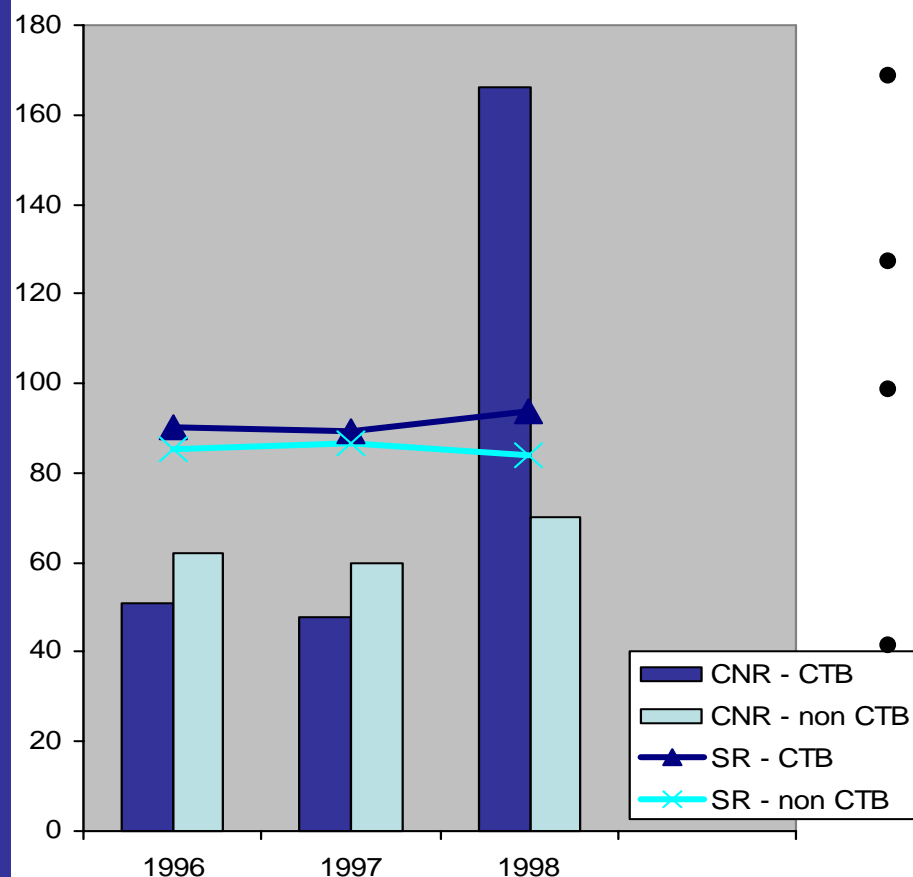
All public and private care providers in providing quality DOTS services, endorsing the International Standards of TB Care (ISTC)

## Program interventions:

- Scaling up TB case management in public-private sectors
- Scaling up hospital DOTS linkages
- Scaling up NGO and community services



# Community Participation Indonesia, Central Sulawesi



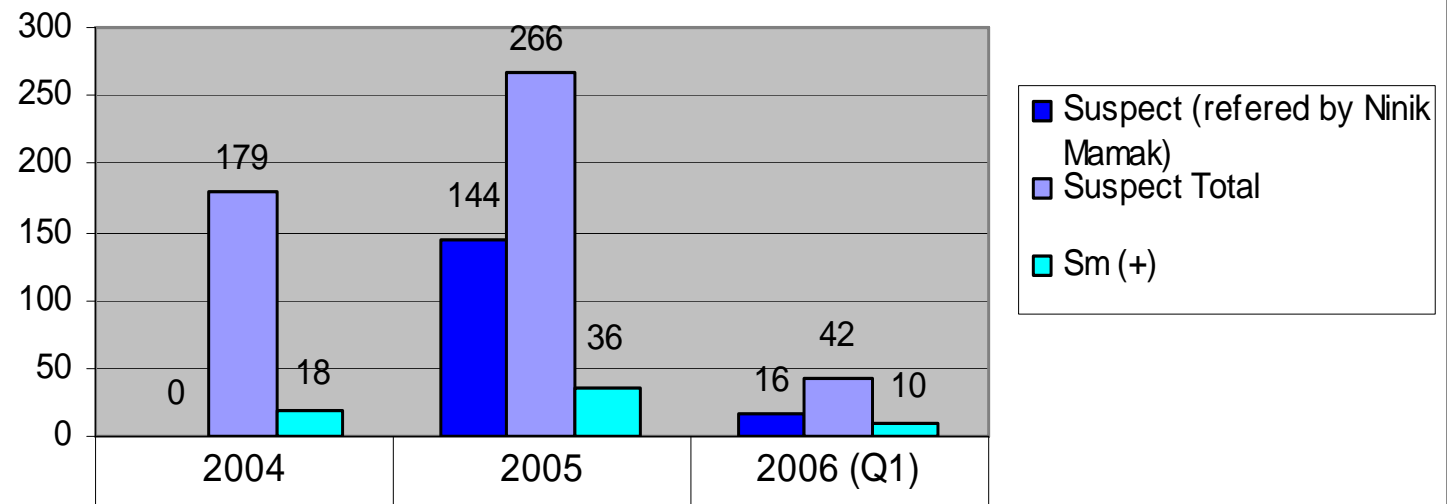
- TB case notification increases in a community based tuberculosis program (CTB) after start in 1997
- Results before and after introduction of the program
- Comparison with area where the program was and was not introduced.

- *Maintain high treatment success rates and sputum conversion rates*



# Effectiveness of Clan leaders involvement

## Ninik Mamak–West Sumatra



### Support from Ninik Mamak:

- Increase of TB suspect thanks to Ninik Mamak (54%: 2005 and 38%: Q1 2006)
- Proportion of Sm+ among suspect examined > 10% → identify TB patient
- TB knowledge increased → people come themselves



## 3. Treatment Adherence

- Increasing knowledge of TB patients/ community on importance of treatment adherence
- Direct community support to TB patients during treatment course
- Evidence base:
  - Drop-out rates and profiles of DO patients



# Indonesia treatment success

- TB program success-rates 85% since 2001
  - > 20% drop-out within 2mnts after feeling better
  - Hospital drop-outs up to 60%
  - Drop-out patient profiles (young, male, urban)
- We need better patient-communication tools (toolkit)
- Mobilise patient support groups (ex-patient and community-based groups)

**Lindungi Keluarga Anda Dari Bahaya TBC !!**




# 4. Stigma & discrimination

Fundamental violations of human dignity:

- Stigma is a mark or blemish on someone or something, leading to a negative impression or value;
- Discrimination is the taking of specific action towards the stigmatized.

Indonesia:

- Stigma is low (only 13% keep TB a secret if a family member had TB)
- Patients have family DOT supporters mainly
- Vulnerable, stigmatized communities (migrant population, etc)
- Adapt the Patient Charter to local context



# Operational Challenges

- Area specific burden (diverse approaches)
- Equitable access for un-reached (need for targeting)
- Scarcity of information (guidance)
- Lack of capacity in ACSM
- Decentralisation/ Low local commitment to health (15-20% of population)
- Non-activist culture for health issues
- Weak systematic implementation
- Incentives/ enablers (needs equal implementation)
- Consistent and measurable surveillance and monitoring



# Community Empowerment: Conclusion

- New area within Stop TB - requires more attention
- Guidance to countries needed
  - Community Empowerment Taskforce
  - ACSM Country level group
  - TB determinants (riskfactors and TB prevention)
  - Technical assistance GFATM implementation
- Build the evidence base
  - Documentation and peer review
  - Operational Research
- Need to make transition to scale and expand community partnerships at all levels, all areas



# *TB patients: Save lives, reduce suffering*

