

# NGO INVOLVEMENT IN TB RESPONSE symposium



Perhaps none of the diseases that formed the object of medicine has ever challenged human mind more than tuberculosis. **Marius Nasta**

## CE IN RESEARCH AND DEVELOPMENT

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# WHY Community Participation in Research

- To understand TB, trial and scientific language
- To influence trial design and implementation
- To guarantee study is acceptable to community
- To ensure results are translated into policy change

# OUR FOCUS – CE IN R&D

## GOAL

Community representatives seen as research partners, not just study subjects or end users of medical advances

## CONTEXT

CE in R&D is an interactive relationship among researchers, policy makers, the community/civil society

## EFFECTIVENESS

CE in R&D should make the community more and more aware and involved in research processes and decision making

# Foundation

WHERE DO WE START

**The Good Participatory Practices (GPP) in TB research – are the core foundations of the CE in research**

Study results and scientific evidence are efficient tools for advocating to implement new technologies

Soft – new protocols/guidelines/official policies;  
Hard – new medication, new diagnostic tools etc.

# Outcomes

WHAT WE WANT TO ACHIEVE

Policy change is meant to improve quality of life for people in TB treatment by introducing the study results into practical national documents, on which any diagnostics, treatment and care is based on

CE in Research and participation in policy making fora is the best way to ensure trust and partnership among stakeholders

# RESEARCH AND DEVELOPMENT

## TB LITERACY / TB RESEARCH LITERACY

1. Information Education Communication
2. Capacity building
3. Community engagement strengthening in RESEARCH

# RESEARCH AND DEVELOPMENT

CE IN RESEARCH IS A WAY TO CHANGE THE (PERCEIVED NEGATIVE) ATTITUDE TOWARDS CLINICAL STUDIES IN THE EECA REGION, GENERATED BY YEARS OF (1) LACK OF TRANSPARENCY/LIMITED CE AND (2) LACK OF BUY IN FROM THE RESEARCHES ABOUT THE TRUE MEANING OF CE

- A collaborative approach and effective communication between researchers and the community are paramount to ensure that those representing the TB community truly understand the purpose and procedures of research.
- Partnering with community stakeholders is important to create change, build mutual trust and improve health.

Patient-oriented research – conducted with human beings (or material of human origin such as tissues, clinical samples or cognitive phenomena) for which an investigator interacts directly with patients;

Epidemiological and behavioral studies;

Research in health services: structure, processes and results.

Source: Prof. A. Ruffino-Netto, FMRP-USP, REDE-TB

New drug and regimen approvals and major changes to standard of care (SOC) should be based primarily on data from RCTs and supplemental data collected through rigorous pragmatic and operational research

Source: TAG extracted from Dreyer NA, et al, 2010,

## CLINICAL RESEARCH / STUDY

Clinical research determines the safety and effectiveness (efficacy) of medications, devices, diagnostic products and treatment regimens intended for human use.

In clinical practice established treatments are used, while in clinical research evidence is collected to establish a treatment.

# OPERATIONAL RESEARCH

Research that accompanies the transfer of knowledge, practices and technologies for clinical use.

Source: Prof. A. Ruffino-Netto, FMRP-USP, REDE-TB

Clinical use are pushed to post-marketing space where Qs are more likely to be answered using real world evidence.

Source: Lindsay McKenna, TAG

Operational studies are characterized by analysis under routine conditions, on the clinical, epidemiological and economic impact of the products used in different countries or regions.

Source: Prof. Prof. Afrânio L. Kritski, FM-UFRJ, REDE-TB

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Assessment of success in implementing new prevention interventions or therapeutic instruments;

Population-based interventions;

Study of barriers to the application of this knowledge and its implementation;

Study of how to generalize interventions that have proven effective and sustainable use;

## Examples:

Effectiveness of interventions in the real world etc.



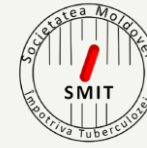
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# takeaway

- The collection of data is critical to informing guidelines
- TB R&D IS UNDERFUNDED
- CE in R&D IS UNDERFUNDED and may not even be a priority
- CE in R&D is a marathon that needs investments of different kind to build common understanding about the role of CE.
- Communities are valuable contributors to improve the policies and the quality of the services which are being provided in the country
- R&D IN COVID-19 – unprecedented joint global effort to respond to a public health issue. It's time for communities to advocate and push for similar global effort to respond to TB as well.
- A more inclusive development pathway (e.g. children, PLHIV, PWID, extra-pulmonary or severe TB), true CE would help expedite and expand uptake and promote equity.

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# Thank you!

Contact us if there are any questions.

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NGO INVOLVEMENT IN TB RESPONSE SYMPOSIUM  
СИМПОЗИУМ РОЛЬ НПО В ОТВЕТЕ НА ТУБЕРКУЛЕЗ

