

Building community support for TB-HIV research

Symposium 22 –
TB-HIV community activism : key
components of a health system response

39th IUATLD Conference
Paris, France

Consciousness

Are people living with HIV and AIDS *aware* they are particularly **vulnerable** to tuberculosis?

Do people living with HIV and AIDS *know* what is **tuberculosis**?

Priorities

Being people with HIV and AIDS mostly living in poverty is it likely they will consider education and research **first** to other priorities?

Roles

How do researchers, clinicians, services see affected people:

Patient or **person**?

Are researchers truly considering the needs and conditions of people affected?

Are people affected *object* or **subject** of the studies?

Consent

If people affected by TB would **understand** the benefits of research; if they would be actively participating in the **design** of clinical studies they would rather be *requiring participation* than giving consent.

HIV/AIDS

Fear of the unknown, fear of death...

Fear of **discrimination**, of annihilation...

Urgency leading to advocate for research, funding

Urgency scaling up studies, anticipating protocol approvals, making diagnostics and drugs available

VIDDA

Add **V**alue, **I**ntegrate, **D**ignify those **D**iseased of **A**IDS...
...mostly with TB!

Recuperate or conquer **citizenship**.

Be recognized as equal, *annihilate* stigma.

Objective

What do we want, what do we **need**?

- New *diagnostics*,
- New tools,
- New *drugs*.
- An effective vaccine.

*Are we **doing** right?*

*Are we talking to the **right** people?*

*Are we doing **enough**?*

Appropriate

Of *knowledge*, of science

Occupy spaces

Go *beyond* diagnostics, of the patient's role



Plan

How to get **there**?

Implementing

Some local recent experiences:

TB Network / ICORHTA: professionals , activists *doing* research

REDE TB, UFRJ-USP-UFES International Clinical, Operational, and Health Services Research Training Award for AIDS and Tuberculosis

THRio / CREATE: *sensitizing* professionals and activists on IPT

TB-HIV in Rio Consortium to Respond Effectively to the AIDS-Tuberculosis Epidemic

Seminar “**Community and Research**”, Rio, May 2007

Increasing CAB, ethics commissions participation

Expanding

- CCM Brazil TB Project to the GFATM
 - New campaigns... *visibility*
 - New projects of intervention... *amplifying*
 - New spaces... *Metropolitan Committees*

*New **opportunities** for Operational Research
Patients' satisfaction, treatment compliance,
services*



more

Internacional experiences:

- **Monitoring** TB Policies (OSI)
- TB-HIV *Advocacy* Project (TAG-ICW)
- Mapping and documenting **innovative** control activities in Latin America (PAHO)

Evaluate

Efficacy and **impact** of insertion of new community actors in TB control policies.

Survey on the TB-HIV *Advocacy Project*
(TAG-ICW; TCC)

Further...

“Empowering communities on TB, TB-HIV: to overcome resistance”

Stop-TB Brazil (GPV-RJ, Rede-TB, NTP, THRio), adding Lilly



Obrigado.