

## **Scaling-up patient and community participation in response to MDR/XDR TB**

### **Summary of Case Studies:**

Two case studies were presented in relation to this topic. To recap briefly, the first was presented by myself looking at the potential to use patient communities as advocates for TB patient management in Ukraine. The knowledge, attitudes and behaviours of patients currently receiving TB treatment was documented, as was their perception of being discriminated, and their overall confidence in health and social systems. Against this backdrop, a vision for establishing a TB patients-advocate lobby where no such organisation exists at the current time, was outlined. The identified projects include:

- Media advocacy
- Health education tools
- Research and community consultations
- Working relationships.

The second case study was presented by Mamel Quelapio, which described the current status of patient participation and community mobilisation currently in place in the Philippines. Mamel showed how patients are supported and empowered in a participatory health model that features:

- Psychosocial support
- Group therapy
- General assemblies (for health education purposes and confirmation of successful milestones)
- Skills training
- Housing options (organic farming, poultry raising, cooking)
- Involvement in creative activities
- Sharing their experiences by participating in World TB Day, writing their stories, talking at TB-related media events

**Break-Out Session Discussion:**

Chair: Natalie Taranec (Ukraine)

Facilitators: Case Gordon (France), Simon Lobo (India)

Rapporteur: Mamel Quelapio (Philippines)

The importance of MDR-TB community advocacy in promoting optimal patient outcomes was hopefully adequately highlighted in context of building civil society processes. The break-out session, by generating a discussion of community advocacy issues, hoped to capture the current collective experience, as well as identifying challenges for the future.

**Definitions:**

While it was difficult to identify recovered TB patients because they may simply want to resume their old life, it was debated, that there is a huge human resource of recovered MDR-TB patients who could be used as advocates because MDR-TB is such an unforgettable, life-changing experience.

There was also some debate over whether to use the terms *TB control* or *TB care*, as the first seemed to support the rationale of a top-down prescriptive approach, while the second seemed to lend itself to a more participatory meaning. One particular perception was that the system is not primarily designed as a care system: *it is there for the prevention of transmission more so than to cure the patient*. Another interpretation from the floor indicated that it was important to *control the disease in order to care for the patient*.

(i). Is MDR patient participation the way to promote political commitment to scale-up MDR-TB management?

There was agreement from the floor that it is important to use patient as advocates, but also a necessity to feature community participation. It was suggested to include everybody as a whole under the definition of community in this sense: medical doctors and other health workers, medical associations and donors, local officials, and ordinary community people partnering TB patients. It was also noted that it was important to build alliances with opinion makers such as the media and union organisations.

Another speaker noted that whilst this is a given, there is greater sense of social solidarity in some societies (such as Peru, and the Philippines) than others. However, even in authoritarian states, community groups have been able to mobilize a health agenda.

A strategy by which political will was suggested to be engaged, is by advocating that TB is more than a clinical condition, but also a question of development: the investment in effective TB treatment, but better still prevention, will lead to better health outcomes, and higher productivity.

(ii). Is community participation the response to the lack of adequate and sufficient human resources to scale-up MDR-TB management?

In Namibia and Indonesia, where health care workers were unable to dedicate adequate time (due to lack of human resource), difficult patients who were at risk of failing treatment were *intercepted pre-consultation by volunteer staff*, whose role was to inform and motivate the patient in an informal setting (a chat over a coffee).

In the Philippines experience, patients have become more empowered, by the *social mobilisation of ordinary people as volunteer advocates* on special task forces. This results in building a motivated community to support a program, and it is this membership that will advocate for political commitment. It was considered that a dedicated community was more valued than a paid, untrained (and perhaps uninitiated) worker.

It was considered important to evaluate whether community participation is *acknowledged as a feature of the National Health Plan*, and does this also mean that it is a natural part of the TB programme.

(iii). How to promote community participation in countries where civil society is not strong enough?

The Global Fund proposed the need to strengthen the TB community. Concerns were raised that in a country like Ukraine, where there is a weak TB community (essentially a TB organisation does not exist), how do you do this?

The Philippines example showed that unlike HIV, where patients were predominantly young, financially secure and prominent, TB patients are predominantly poor, unaware of their rights, and feel stigmatised. Patients hesitate in participating in such processes, and it was felt that *addressing stigma of patients* was important in moving them into a phase of greater participation.

The *setting up of NGO's* (perhaps under an umbrella organisations such as KNCV) was seen as an important way of initiating, supporting local initiatives. It was also important to have the whole community (health workers, local council authorities, workplaces and professional/trade unions, society leaders, media) involved, otherwise advocacy effort may be too weak. The strength and resources of an organisation (or organisations) was thought to be able to provide counselling and support to combat stigma, as well resources (information, funding, advice).

Another suggestion included an *analysis on priority needs* (resources, training, an education process whereby patients are taught the importance of participation and advocacy).

Initially, it is suggested due to the relationship of poor socioeconomic status and stigma, patients could benefit *from in-house education sessions* (support mechanisms for the patient, about the treatment process, examples of successes) provided by health workers. The organisation and facilitation of the sessions would be initiated by the health workers/health facility.

It was suggested that it was important to collect individual patients together in a group, purely at social level at first, but with increasing levels of counselling, support, training to *coach them into an organisation*, that is finally empowered to advocate to the TB community, public and the media. It was felt behavioural research could be used as an important resource which could provide sound methods that were effective in this sort of process: from a social club (which may even have originated in a waiting room) to a union complex.

(iv). Should social support be an essential part of MRD-TB management?

It was noted that an important form of social support was access for financial assistance. Currently, there is public and private financing of TB care for patients and workers.

However, whilst TB treatment and access to tuberculosis medications are free of charge, the opportunity costs of the patient being treated may compromise their treatment. For example, in Ukraine where inpatient treatment of 6-8 months is the norm, if the patient is the main breadwinner, they may sign out and therefore default on their treatment, as a result of an inadequate income to sustain their family in their absence, and a lack of social support systems.

The Green Light Committee, it has been acknowledged, has identified that social support is integral to TB management.

The Omsk experience (Russia, 2000) has shown that social support services are effective in improving successful treatment rates. The pilot study of MDR-TB in the penitentiary system, which managed to reduce MDR-TB failure rates from 25% down to 10-15%, featured such social support services:

- Incentive food packages to reward proper and daily medication use;
- Provision of hygiene packages;
- Daily visit by psychologists who provided treatment, support and discussion of social problems.

**Issues for Consideration:**

- (i). Promote *community participation* as an element that countries consider adopting in their National Health Plans
- (ii). Support the setting up of NGO's where no such organisation previously exists in a community
- (iii). Sustain free-of-charge diagnostics, treatment and access to pharmaceuticals for TB patients, and the advocacy for social support for TB patient families, where no financial safety net exists.

(Recommendation provided separately)