

## MDR-TB stakeholders meeting: 27<sup>th</sup>-28<sup>th</sup> October 2013

### ***Discussion notes: Breakout group on developing a Patient Centred Approach (PCA) to TB management***

28<sup>th</sup> October: 14h00-15h30

#### **Participants:**

<b>Name, Surname</b>	<b>Country</b>	<b>Organisation</b>
Dozin Rotazu	Moldova	Ministry of Health
Temitayo Odusote	Nigeria	USAID
Muluken Malese	Ethiopia	MSH
Francois Romain	Haiti	
Essam Elmoghazy	Egypt	GLC-EMRO
Khann Sokhan	Cambodia	WHO
Will Morose	Haiti	NTP MOH
Dr Claudio Marra	SA	URC
Gini Williams	UK	ICN (facilitator)
Ernesto Jaramillo	Geneva	WHO
Manfred Danlovits	Estonia	Tartu Uni Hospital, NTP co-ordinator

#### **Background**

This impromptu break out discussion was called to start a dialogue relating to a number of the issues raised during the presentations given on the first day of the meeting. These included questions regarding the definition of patient-centred care, the cost associated with it and most importantly the examples from countries, where excellent results were achieved during pilot MDR-TB projects with strong patient support and the subsequent decline following scale up when patient support was reduced.

PLEASE NOTE: From the beginning it was agreed that the term TB would cover all forms including smear positive, smear negative, pulmonary, non-pulmonary and X/M/DR-TB. If you are working with TB the chances are you will be working with MDR-TB

#### **Summary**

The participants came from a variety of backgrounds and had different experiences and perspectives which led to a very fruitful discussion. Some shared valuable examples of PCAs and a local or country-level and others had questions about what it means and what can be funded. These notes have been compiled as a summary of the discussions around the questions raised with a brief description of the examples given.

The question at the heart of the group's discussion was that we are treating too few people with MDR-TB and we need to treat more – why can't we? We need a fundamental change in our approach and we need to invest in it – the cost of not doing so is too high.

## **Next steps**

1. Recommend to GDI that PCA needs to be an integral part of its work plan
2. Write up and distribute notes from the discussion to the participants and the meeting organisers and rapporteurs
3. Advocate a cost-effective study to demonstrate value of PCA and the cost of not using it (to patients, communities, health systems and national economies)
4. Advocate for investment in operational and implementation research to gather strong evidence regarding effective models of care required to achieve a PCA
5. Submit proposals for a post-graduate course and a symposium for the Union's Conference in 2014
6. Define indicators for the purposes of monitoring and evaluation

## **Discussion**

### ***What constitutes a patient-centred approach?***

While acknowledging the need for new drugs and diagnostics, the obsession with these elements at the expense of investment in PCA have been to the detriment of the quality of TB programmes as seen by the levels of drug resistance.

While the DOTS approach is followed the needs of the patient leads the response rather than the needs of the health system. This can be achieved with health providers such as family workers plus listening to and following patient preferences when at all possible.

PCA is linked to rights and responsibilities set out in the Patient's Charter. Public health principles still need to be followed in order to prevent the spread of a communicable disease but this can be done better if patients are recognised and empowered as partners. There is an emphasis on trust

There is no one-size fits all. All countries are likely to need different levels of hospital, out-patient, community-based and home-based care (plus palliative care) organised in a way which is appropriate for the local context.

There is an understandable concern about cost but we need to find various sources of support – i.e. not all support needs to come from the NTP or hospital administration – to enable the patient to complete treatment. The bottom line however is that we need to make the

WHO is laying out a clear framework for patient-centred care in the post 2015 StopTB Strategy.

PCA requires a behavioural change and this in turn requires transformational training focused on the human elements of TB, practice development and problem-solving in addition to technical guidance regarding clinical aspects of the disease.

It was agreed that the least important intervention is financial aid and the most important are mutual respect and complete information.

### ***How can you officially adopt a PCA at a national level?***

Dozin Rotazu, NTP manager from Moldova, gave a good example of how interventions are being explored to ensure the TB Control Programme is patient-centred and how this has the support of the

Ministry of Health. Interventions include piloting the provision of mobile phones to enable communication between patients, health care providers and relatives.

It is essential for a PCA to be understood by governments in particular with regard to often stigmatised conditions such as TB, HIV and mental health problems. There needs to be a recognition of the repercussions on the economy of the country through poor outcomes if this approach is not adopted.

Another good example reported was Estonia where the system was changed to deliver PCA. This is well-developed and is showing very good results

***What specific things can be funded?***

Temitayo Odusote from USAID Nigeria explained that when donating funds for HIV interventions she invites tenders from NGOs who provide a variety of support for patients for instance home-based care. She suggested that this could also happen for TB especially as the workload is reducing in the HIV field as the need has reduced due to ARTs. Investing in these same NGOs to work with people affected by TB makes sense as they are experienced, have capacity and are motivated to work with stigmatised and 'risky' patient groups.

In Moldova, NGOs are contracted to provide support services to patients.

***Why as a donor, should I invest in PCA and not intensified case finding (e.g in Nigeria where prevalence has been found to be higher than originally estimated)?***

Demonstrates need to be very clear with our messaging and what we are asking for. Also demonstrates need for measurable indicators as well as research to underpin the theory

***Who decides the most important aspect of care for the patient?***

Need to engender the concept of partnership between patients and providers. This requires a paradigm shift from active provider and passive recipient to a collaborative model of working together

***How does the PCA relate to the Patient's Charter?***

Clarification that adopting a PCA is a significant move towards implementing the patient's charter. Key concepts include partnership, empowerment, rights and responsibility

**Examples of PCA**

***South Africa***

Move towards decentralising MDR-TB care to the home. Need to develop patient-centred model of care.

Home-based care is included in the new model – health service (nurses) enters the home to work with patient and offer, treatment, counselling, support advice infection control, and contact tracing

***Moldova***

National commitment to transition to ambulatory care from a largely hospital-based system for TB care.

Emphasis on PCA

- MOH contracting NGOs to offer a variety of services to patients
- Setting up community centres which can provide clinical care, psychological care and legal assistance

Part of this approach involves piloting

- the provision of mobile phones to people with MDR-TB with free communication to relatives, nurses and doctors
- prizes for sticking with treatment (in collaboration with UNDP)

### **Haiti**

In an NGO run (private not-for-profit) hospital a PCA has been developed for patients with MDR-TB. This takes account of a wide range of needs including:

- Medical – provision of drugs, management of side effects, daily follow up, free non-TB drugs
- Emotional – listening, answering questions, counselling
- Nutritional – food to assist with recovery and toleration of treatment
- Social – training, information, communication (phone access), books, games, TV, CD player with a choice of CDs, literacy courses, parental/family visits at weekends, money for family to visit, more active occupational activities as people make progress, growing ‘fast’ crops e.g. tomatoes,
- Financial

The patients are very happy in this context BUT this is an NGO-run hospital with greater resources than the government programme

**Estonia** (Additional information received following the distribution of the discussions notes)

Comments from Estonia ( example of country where Government took full responsibility of all TB control activities since 1998. We do not have any donor support)

NTP started prioritizing ambulatory care in 1998 and according to our experience there were five main issues at first stage to solve:

1. To change the staff (both for TB specialist and family doctors) thinking and understanding about possibility, usefulness of outpatient care for TB patients
  - Why ?-during previous 50 years only TB specialists have been dealing with these patients

- Long hospitalization was priority; mode of financial allocations supported the hospitals. Public opinion was against to treated TB as ambulatory disease

2. To justify ( give the detailed financial and epidemiological data ) to MoH that ambulatory treatment with full package of DOT is cost-effective and not cause the worsening of treatment outcome results and will not cause danger for society.

3. To carry out comprehensive training programs for all categories of medical staff and social workers (we started with pulmonary specialist, then administration of hospitals and following family doctors and nurses together with social network)

4. To get confirmation from authorities (in our case from MoH) that the financial resources given earlier to hospitals will not go to “other fields but stay with TB “

5. To work out the legal bases (written contract based system) between health care providers and different levels of medical staff/administration

**We have three levels contracts system for providing DOT: between NTP/National Institute of Health Development-central hospitals-family doctors/nurses-social workers**

**All it** took 2-3 years for a small country with only 1.3 million people.