

# MOVING TO PEOPLE-CENTRED CARE: Achieving better TB outcomes



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## What is people-centred care?

One important angle of **people-centred care** is the focus on the overall wellbeing, choices, convenience and safety of the individual patient. Thus, it takes account of the social and personal circumstances of the person, not just the immediate requirements of medical treatment.

People-centred care (often interchangeably referred to as ‘patient-centred care’ or a ‘patient-centred approach’) aims to ensure that the delivery of care is as close and as conveniently available to the individual as is safe and cost-effective. It considers the patient to be the central figure in the continuum of care. It also means understanding the motivations of each patient and providing them with education and counseling tailored to their circumstances, all within the context of local social, structural and cultural factors.<sup>1</sup>

**Ambulatory care** refers to treatment and care outside hospitals. In most cases people-centred care is linked to effective ambulatory models that represent the key cornerstone of care, and which support treatment at outpatient facilities and at home and take into account the social and economic vulnerabilities of the person. Such models often depend on supplementing the work of medical staff with active involvement by civil society and patient networks to give direct support to individual patients.

In TB, given that patients become non-infectious rapidly, for example, most often within two weeks of starting effective treatment, even in cases of multi-drug resistance, most individuals could be treated predominantly, if not solely, in ambulatory care.

People-centred care, however, is not limited to ambulatory models of care. There are potential health complications for any TB patient that can make hospitalisation necessary; such as some with multi-drug resistant disease or complex cases.

1. O’Donnel, Daftary et al. (2016). Re-inventing adherence: toward a patient centered model of care for drug-resistant tuberculosis and HIV. The International Journal of Tuberculosis and Lung Disease, 20(4):430-4.

## Why use people-centred care in ambulatory settings?

### Psycho-social wellbeing of individuals with TB

Outpatient treatment is more comfortable and favourable for patients and offers psychological benefits because it reduces stigma and discrimination. Isolation of TB patients in hospitals is often accompanied by stigma within communities, such as patients being considered dangerous to people, even after leaving the hospital. The social lives of individuals with TB are less disrupted in outpatient care. As they are not moved to distant hospitals, they can maintain relationships with family and friends and even continue to work if well enough, thus maintaining family income.<sup>2</sup>

### Patient and Public Safety

It is safer. From a public health perspective, inpatient (hospital-based) treatment is not necessarily an effective means of preventing the spread of TB. TB treatment in hospitals with poor airborne infection control measures too often contributes to the further spread of TB and MDR-TB.

### Non-infectiousness of patients

The risk of someone with TB infecting other people drops significantly in the first few days of effective treatment and is usually no longer a concern after 14 days at most, even for people with drug-resistant TB<sup>3</sup>. Besides, most transmission occurs before diagnosis or hospitalisation.

However, in many countries in the WHO European Region, the Eastern European and the Central Asian Country Region patients are still considered infectious until their sputum culture tests show bacterial conversion, which can take months. In many low(er) incidence countries, conversion is seen as an indicator of the success of treatment in the individual but not as an indicator of the end of infectiousness. Patients who have started treatment pose no threat to those around them even if they do not yet show bacterial conversion. This makes ambulatory care a safe and feasible option.

### Cost-effectiveness and better treatment outcomes

People-centred care in ambulatory settings provides cost-effective benefits for healthcare systems. Studies show that outpatient services are usually significantly less expensive in comparison with hospitalisation, while the effectiveness of treatment is higher once comprehensive support measures are in place.<sup>4</sup>

- In Ukraine, under the USAID *Strengthening TB Control* in Ukraine pilot project on reorganisation of TB services in Krivoy Rog city, it was estimated that Directly Observed Treatment (DOT) service in an ambulatory setting combined with active patient contact is five or more times less costly than treatment in a hospital, depending on the support arrangements employed.<sup>5</sup>
- Data on three different models of decentralized treatment in South Africa showed that depending on the intervention, savings of between 36-42% could be achieved.<sup>6</sup>

Nonetheless, while there are cost savings, implementing people-centred care in ambulatory settings has up-front costs, and it will require investment in human resources and building capacity to care where people with TB live and work.<sup>7</sup> Moreover, additional funding or funding efficiently applied to ensure that treatment and support are available through community-based, people-centred approaches must be part of any plan to reduce hospitalisation to ensure that the patient is not disproportionately burdened with costs related to treatment, such as transport, among others.



2. The section informed by the findings outlined in the report Rucsieneanu O., Andries G. (2016) "TB inpatient treatment impact on the Patient's social life". B I I, Moldova.

3. Dharmadhikari A S, Mphahlele M, Venter K, et al. (2014). Rapid impact of effective treatment on transmission of multidrug-resistant tuberculosis. *International Journal of Tuberculosis and Lung Disease*, 18:1019-1025.

4. Andrews, Jason R., Stout, Jason E. (2015). Treating multidrug-resistant tuberculosis in community settings: a wise investment. *International Journal of Tuberculosis and Lung Disease*, 19(2):127-2015; retrieved from <http://dx.doi.org/10.5588/ijtld.14.0761>

5. Retrospective analysis on economic effectiveness of the organizational models of provision of TB care in the city of Krivoy Rog, Ukraine (2014), retrieved from [http://stbcu.com.ua/wp-content/uploads/2015/05/FI-NAL\\_Звіт-досл.-ек-еф.-но-ТБ-з-додатками\\_12-05-2015.pdf](http://stbcu.com.ua/wp-content/uploads/2015/05/FI-NAL_Звіт-досл.-ек-еф.-но-ТБ-з-додатками_12-05-2015.pdf)

6. Sinanovic E. et al. (2015). Impact of reduced hospitalization on the cost of treatment for drug-resistant tuberculosis in South Africa. *The International Journal of Tuberculosis and Lung Disease*, 19(2):172-178; retrieved from <http://dx.doi.org/10.5588/ijtld.14.0421>

7. 8. O' Donnell, Daftary et al. (2016). Re-inventing adherence: toward a patient centered model of care for drug-resistant tuberculosis and HIV. *The International Journal of Tuberculosis and Lung Disease*, 20(4):430-4.

## How can we achieve quality people-centred care?

Traditionally, individuals with TB in many Eastern European and Central Asian countries with a high TB burden have been routinely treated in hospital on an in-patient basis for long periods. This is often unnecessary. In most cases, ambulatory TB treatment delivers similar or better treatment outcomes.

However, simply shifting from hospital-based to ambulatory care is not going to improve treatment outcomes overnight. For example, if the only change is that patients have to frequently collect drugs at a Polyclinic, without support measures in place and without addressing the needs of the individual, no significant improvement will have been made. For ambulatory models to provide quality people-centred care there needs to be:

**Strong Primary Health Care (PHC) systems in place**, which can deliver services close to patients and communities. In preparing to play a larger role in TB treatment, PHC services can and should expand their capacity to address more than medication delivery. They should be more active in other aspects of TB, such as prevention, detection, support through the process of diagnosis, and infection control. Effective TB programmes located in PHC settings should promote better TB/HIV coordination and address other health and social issues often associated with TB, particularly management of the adverse effects of TB treatment.

**Appropriate financing instruments** are developed to ensure that ambulatory services providers have access to resources allocated for TB treatment and care. In most EECA countries, TB services are funded through National TB Programs where the horizontal linkages between the providers are rather weak. A more optimal model is when defined TB services can be purchased by a national purchaser (such as Health Finance Agency, Insurance Funds, etc.) from service providers, including from PHC providers and CSOs, utilising performance based payment methods. Linkage of the new model of TB services to broader healthcare finance system reform is essential to achieve people-centred care.

**Clinical interventions backed by psychosocial support:** People-centred care for TB and M/XDR-TB patients still includes directly observed treatment (DOT) as a cornerstone of TB treatment, helping the patient with the burden of taking handfuls of pills daily for many months. Clinical interventions alone, however, will not suffice to ensure successful treatment outcomes. Different types of psychosocial (e.g. peer support from others who have had the personal experience of being a patient, psychological help, referral to welfare services if needed, etc.) and financial (e.g. transport or food vouchers, cash incentives for adherence, etc.) support schemes should be available to patients based on individual needs. For patients on long-term MDR/XDR treatment, training on how to find work and education (during treatment) as well as direct assistance to arrange this, helps patients to stay connected with social life and to retain a belief in a positive future after treatment completion.

### Fitting the provision of care to patient needs:

Provision of ambulatory care should be flexible, depending on the individual patient's needs. This may include initiatives such as patronage (home) visits, arrangement of daily delivery of medicines to a location that is convenient to the patient, DOT within the primary healthcare network, video observed treatment (VOT), etc. All these options can constitute effective people-centred care and should be accompanied by robust measures to support the patient and his/her family.

### Strong partnerships between all providers of medical and social services:

An important element of people-centred care is collaboration between all care providers including government agencies, civil society and – where they exist – private providers. Effective referral systems between different medical and social care providers are needed to fit the individual needs of patients.

If a person with TB also needs social welfare services he/she should be referred and followed up. A team-based approach that includes access to trained mental health workers, social workers and behavioural counsellors can engage with patients more holistically, as well as facilitating treatment decisions that encompass the full range of clinical, socio-economic and structural issues confronting patients.<sup>8</sup>



### Civil society and community involvement:

As well as advocacy efforts, the added value of civil society in people-centred models is provision of person-to-person and community support. This means effective psycho-social services that help to ensure both that the individual takes their drugs on time for the entire duration of treatment and remains confident throughout that they will be cured. As well as working with patients, civil society can be extremely effective in increasing awareness of TB in communities and in delivering health education to groups at high risk of TB. They can also provide a bridge between healthcare staff and hard-to-reach groups, including implementation of the active case-finding strategies for early TB detection in key populations.

### Support from family members, relatives, friends and neighbours:

With people-centred care, the individual can remain within their family and friendship support circles. Thus, the ability of those closest to the patients to contribute to their care is maximized. It is especially helpful if at least one family member can be trained to monitor, care, and support the person with TB.

Given the overall burden that TB causes for families, support to families from relatives, friends, and neighbours is also helpful, and can be encouraged by identifying community resources available to them. Furthermore, information campaigns that reduce stigma and the social exclusion of families can facilitate positive and supportive action within communities.

## To whom do we need to explain the value of people-centred care?

### **Government decision-makers**

Advocacy aimed at government remains important. Although a few countries have adopted ambulatory care policies as part of integrated care, many Eastern European and Central Asian countries still have a long way to go in moving from hospital-based/inpatient care to quality people-centred care.

Governments need to play an important role in extending TB care in ambulatory settings and, for instance, in setting up social contracting mechanisms to help provide funding for more efficient civil society engagement.

### **Civil society organizations and local communities**

If CSOs are to play an important role in people-centred care, they need to be persuaded of the benefits of this approach so that within their communities they can explain and support this. They also need to see how they can be potential providers of TB services as part of a people-centred approach. Once their interest is secured, TB training programmes on advocacy and service provision should be offered to them.

### **Members of Parliament**

With development of the Global TB Caucus<sup>9</sup>, we are engaging more with parliamentarians. Members of Parliaments, however, can be very sensitive to what they hear from doctors and patients in their own constituencies. They need to be well-informed about the benefits and key defining principles of people-centred care from the perspectives of both the patient and the healthcare system.

Members of Parliament who are engaged in their country's budget or health committees can ensure that reallocation mechanisms are in place so that funds saved through reductions in hospital bed numbers are shifted towards more ambulatory TB care, and can be available for TB care delivery in ambulatory settings.

### **Healthcare workers**

Much greater attention to advocacy aimed at doctors and other healthcare workers is necessary to overcome their professional and employment concerns. In particular, concerns about the infectiousness of patients need to be addressed by pointing to the evidence that patients, even those with MDR, become non-infectious within a few days of starting a proper treatment regimen.

There is a need to emphasise the benefits of people-centred TB care and the nature of *quality* people-centred care.

It is also important to advocate for both results-based incentives to be made available for healthcare workers as they begin to provide people-centred care in ambulatory settings and to convince governments to ensure that TB hospital doctors do not suffer due to reductions in the number of hospital beds. They should be offered re-training and continued employment within health services.

9. [www.globaltbcaucus.org](http://www.globaltbcaucus.org)

## What needs to change/be in place?

*Public awareness campaigns* are needed to counter stigma and to explain the non-infectiousness of individuals with TB within days of starting treatment. Stakeholders and service providers should acknowledge and take into account the experience, concerns and needs of individuals who have suffered or are suffering from TB when developing people-centred models of care. Health care providers and communities should understand why people-centred care is preferable for TB patients, public health more broadly, and for health system efficiency; educational and awareness-raising campaigns are needed for this.

*Integration with PHC:* People-centred TB treatment needs to be integrated into primary health care (PHC). In doing so, the capacity of local PHC systems to assume this role has to be assessed; policy-makers and health care providers need to treat PHC and community-level services as central components of national TB programmes. In countries where large-scale PHC management of TB treatment is not yet feasible, an appropriate interim measure is for health authorities to develop and apply clear and strict hospitalisation and discharge criteria for patients who have been referred to specialized TB services.

*Enhanced referral systems:* In conjunction with these efforts, referral systems between health, social and community care providers must be strengthened, financial resources redirected and health services expanded and tailored to meet patient needs.

*Policy action:* In many countries, there is still a long way to go in reducing often unnecessarily high TB hospital bed numbers. This requires policy change and a step-by-step approach so that the concerns and needs of doctors, other healthcare workers, patients and communities are taken into account.

*Use 'savings' to ensure quality people-centred care:* A continuing battle will be to ensure that funds released by reducing hospital-based TB care provision are not relocated to other healthcare needs but instead are used to build up good quality people-centred care in ambulatory settings. Results-based incentives for healthcare workers as well as patient incentives for treatment adherence, when appropriate, should be seen as part of this approach.

*Engage civil society and community organizations* in all aspects of these activities ranging from advocacy to service provision. Their support can greatly speed up progress. Furthermore, NTP Managers will be more sympathetic to CSO advocacy and engagement if they see those CSOs being active on the ground and providing services that bolster effective delivery of people-centred TB care.

For more information on TBEC and people centred care, get in touch with us at [coordinator@tbcoalition.eu](mailto:coordinator@tbcoalition.eu) or visit our website <http://www.tbcoalition.eu>

Text: Fanny Voitzwinkler, Paul Sommerfeld, Jonathan Stillo, Nonna Turusbekova, Safarali Naimov, Ksenia Schchenina, Oxana Rucsineanu, Yuliya Chorna

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