What Do We Mean By Integrated, Community-Based Treatment and Support?

An Example from Romania

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The Right to Health: A Few of the Relevant International Laws and Treaties

- **Universal Declaration of Human Rights:** Guarantees the right to life (art. 3). Article 27 specifies that everyone has the right "to share in scientific advancement and its benefits". However the UDHR is not enforceable.
- **The Charter of Fundamental Rights of the European Union**
- **International Covenant on Economic, Social and Cultural Rights (ICESCR). <u>All WHO EURO region countries are legally bound by this covenant.</u>**

The ICESCR's Right to Health: Availability

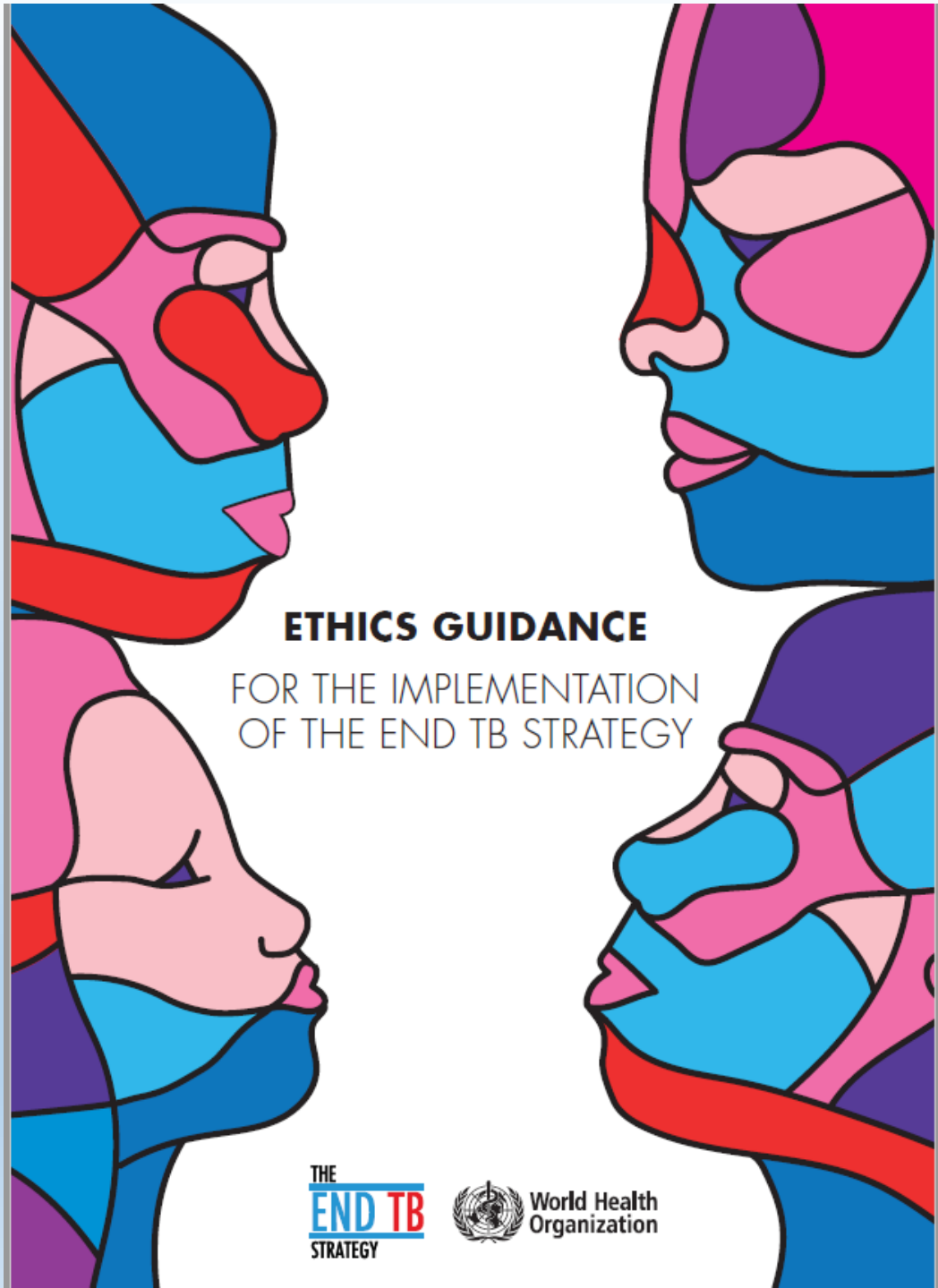
- Essential drugs (those on the WHO's Essential Medicines List (EML) which is updated every two years.
  - M/XDR-TB medicines on the EML include: bedaquiline, delaminid, linezolid, later generation fluoroquinolones, 2nd line injectables including capreomycin, PAS, cycloserine, ethionamide, etc.
- Functioning healthcare facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party
- The above are defined as "core obligations" in the ICESCR. They are non-derogable and not subject to progressive realization. States cannot justify non-compliance with core obligations under any circumstances including financial ones. There are NO excuses.

ICESCR Four Dimensions of Accessibility

- **Non-discrimination:** "health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds."
- **Physical Accessibility:** Goods and services in health facilities must be "within safe physical reach for all sections of the population, especially vulnerable or marginalized groups." Special mention is made of rural areas, where residents also have a right to accessible health facilities, goods and services.
- **Economic Accessibility (affordability):** The CESCR General Comment 14 states that "health facilities, goods and services must be affordable for all....including socially disadvantaged groups. Equity demands that poorer households should not be burdened with health expenses as compared to richer households."
- **Information Accessibility:** includes "the right to seek, receive and impart information and ideas concerning health issues."

New Ethics Guidance on TB from WHO

- Draws heavily from the ICESCR and General Comment 14 (the authoritative interpretation of Article 12).
- Is in plain language.
- Will help TB programs and ministries of health understand the ethical (and legal) standards that they should meet.
- Provides people with TB and their allies with information about their rights.
- One of the most important documents on TB. Should be required reading for all TB doctors.
- Affected communities and civil society organizations should read this guide and relevant local and international laws.



Methodology

- Consultation provided to the Romanian TB Program by Jonathan Stillo (Wayne State University), Nonna Turusbekova (TBC Consult), and FILHA. Funded by ECDC.
- Including:
  - Desk review of relevant documents (WHO/ECDC/GLC reviews, local and international legal documents, internal program documents etc.)
  - Online survey and interviews (2015)
  - Previous ethnographic research conducted by Jonathan Stillo (2006-2014) (patient surveys and more than 150 interviews, interviews with patients, doctors, nurses, psychologists, civil society workers, and policy-makers, participant observation at multiple sites across the country including clinics, sanatoria, pulmonology hospitals, MDR wards).
- The full concept paper can be found here: http://stop-tb.ro/wp-content/uploads/2017/05/Romania-Integrated-Community-Based-TB-Support-Services-FINAL-2.pdf

TB in the European Union: Top ten countries by number of cases Source: ECDC TB Surveillance Report 2016 [1]			
Country (in order of greatest number of TB cases)	Number of people with TB (2014 prevalence)	Deaths (2014)	MDR-TB cases among all notified TB cases (2014)
Romania	20,000	1,100	650
Poland	10,000	530	52
United Kingdom	9,600	300	59
France	7,400	370	56
Spain	6,800	230	24
Germany	6,300	330	140
Italy	4,400	260	N/A
Lithuania	2,400	220	300
Hungary	1,500	69	26
Latvia	1,100	54	84
Total EU/EEA	84,000	4,200	1,600
ECDC best estimates based on 2014 data.			

The Romanian Context

- Romania is an upper-middle income country, but has great inequality and very weak and poorly funded health and social welfare systems. TB is highly stigmatized and of little interest to most decision makers.
- A large country with 45% of residents living in rural areas that are often poorly reached by health services.
- **Self-administered treatment is the norm in rural areas, even for M/XDR-TB.**
- 27% of the European Union's TB cases each year. In 2002, Romania had the second highest rate of TB in the entire WHO-EURO region 142 per 100,000 (30,985 new and relapsed cases). Since then, the rate has been halved 71 per 100,000 in 2015 with 15,275 new and relapsed cases)
- By far, the most M/XDR-TB in the EU, >500 cases per year. Only about 50% of MDR cases are diagnosed according to WHO.
- **Some of the lowest MDR treatment success rates in the entire world (between 16 and 20% from 2008-2011. Most recently this has increased to 32%, which is still far below the global and EURO averages.**
- **Recent improvements in DST coverage (now 85%), but speed and availability varies by county.**
- **Second line drug stockouts were the norm in the government-funded system between 2009-2014. 2015-2017 MDR-TB treatment provided by Global Fund and Norwegian Development Programme. Even now, not all essential drugs are registered or able to be procured using national funds.**
- **XDR-TB treatment was basically unavailable until 2015 unless the patient purchased the medicine on their own.**
- **Very limited social/economic/psychological support available (pilot projects funded by international donors in limited locations)**

Sustainable, Integrated, People-Centered Community-Based Care

- First and foremost, TB programs must ensure that the required diagnostic technologies and medications (1st, 2nd, and 3rd line) are **available** and **accessible** in sufficient quantities.
- TB services should have strong links to other parts of the health and social welfare system—especially at the local level. Programs should not be vertical or "siloed."
- Sustainability requires domestic funding and ownership. **The age of endless donor-funded pilot projects without scale-up is over**
- Whenever possible, services should move to the patient rather than expecting a person to travel to different hospitals/clinics.
- Patient/people-centered care is care designed to best serve the needs of patients and their families—this may be less convenient for medical staff.
- Oftentimes, the most people-centered care is community-based care. This ensures that people can receive treatment close to their social networks which can provide them support and comfort.

People-Centered Care Can Be Less Expensive

- If people say that long hospitalization is bad for them, and recent data shows that concerns over patient infectiousness are overblown, then why do we insist on this outdated and expensive approach which creates hardship for patients?

- Studies from across the world (South Africa, Ethiopia, Ukraine, Moldova, etc.) show that ambulatory treatment is less expensive, more acceptable to most patients, and at least as effective as hospital-based care.

- If people-centered ambulatory treatment was introduced, cost-savings could be used to strengthen local health care and to fund treatment adherence support. Stronger local health systems and community-based care benefit everyone.

We Already Know What Works…


Photo: MSF


Photo: Elena Devyashina for PIH

MSF Khayelitsha, South Africa

- Strong M/XDR-TB regimens (including BDQ, DEL, LZD, CFZ).
- A decentralized model of care.
- Community nurses, and counselors used for treatment initiation and adherence support.
- High treatment success even among HIV positive people with XDR-TB!

Partners in Health's Sputnik Project Patient Centered Accompaniment in Tomsk, Russia

- Meets people with TB as who they are, where they are. Enables them to adhere to treatment.
- High treatment success even for the most vulnerable people.

Issues Raised During the Consultation

- Long wait times and incomplete DST results delay appropriate treatment and create economic hardship.
- Need for complete, continuous supplies of drugs for M/XDR-TB treatment ***throughout the country*** (not just at the 2 GFATM sites).
- Need for alternatives to long hospitalization and dispensary-based DOT. Rural people need *realistic* options for treatment supervision.
- Need for ancillary drugs to be provided free of charge during outpatient treatment. Many people can't afford to buy them
- Need for economic, social, and psychological support for all people with TB, especially M/XDR-TB.
  - Economic support is complicated in RO. Social welfare is poorly funded and according to the World Bank, is inadequate and misses the poorest 29% completely!

Recommendations Based on the Consultation, Local and International Best Practices

- Same day GeneXpert for all followed by full 1st and 2nd line DST for everyone with rif. resistance.
- Multi-disciplinary teams should provide *both* treatment and support.
- Adherence risk assessment for all people diagnosed with TB.
- A minimum package of social, economic, and psychological support for everyone and additional support if needed (i.e. alcohol/addiction services, chilcare, job-retraining, etc.)
- Video-Observed Therapy (VOT)- Traditional DOT is a burden on people—major time and travel costs, interferes with work and family life, also it is embarrassing/demeaning. The option of VOT could help reach rural people and could be integrated with remotely located peer-support.
- Transportation assistance to enable people to get to TB care sites.
- Treatment monitoring and support can be contracted to civil society organizations with appropriately trained staff as we have seen in Bulgaria.
- Telephone-based peer support, education, and psychological services
  - Successfully piloted in Romania by ASPTMR. Provided by people who were cured of M/XDR-TB.
- People want treatment options! This should include the possibility of outpatient treatment for DS and DR TB. A Moldovan trial recently showed fully ambulatory MDR treatment was non-inferior to traditional treatment.

Recommendations (cont.)

- A cascade of care beginning closest to the patient and escalating to higher levels of care (Lay health worker->community nurse->primary care doctor->TB doctor). Adverse reactions or not meeting treatment milestones (negative culture) would trigger the involvement of higher levels of care. If all is going well, why require them to travel unnecessarily to a hospital when even EKG and blood draws can be done in home or locally?
- A monitoring and evaluation plan:
  - Workloads of the multidisciplinary teams should be monitored to determine if additional human resources are needed.
  - Treatment progress and outcomes should be tracked.
    - Progress and outcomes for vulnerable groups should be disaggregated and analyzed to be sure that the most vulnerable people are being well-served.

Failing the "Iulian Test"

- He has been dead for 5 years now. Could Romania cure him today?
- Are we curing people with multiple social and economic barriers?
- Who is collecting AND analyzing the data to let us know?
- My personal goal for this project was to offer solutions that could have helped Iulian, and the 1000 other people who die of TB in Romania each year.

Special thanks to all the patients and medical personnel who shared their lives with me. We will beat TB in the European Region.