Romanian Integrated Community Support Services for Tuberculosis

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List of abbreviations

ASPTMR	[Romanian] Association for Supporting MDR-TB Patients
CESCR	Committee on Economic, Social, and Cultural Rights
DOT	Directly Observed Treatment
DR-TB	Drug Resistant Tuberculosis
ECDC	European Centre for Disease Prevention and Control
EU	European Union
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
ICESCR	International Covenant on Social, Economic, and Cultural Rights
KAPs	Key Affected Populations[1]
MoH	Ministry of Health
MoL	Ministry of Labor, Family, Social Protection, and Elderly People
MDR-TB	Multi-Drug Resistant Tuberculosis
NTP	National TB Program
PCC	People (or Patient) Centered Care
SPAS	Public Social Assistance Services
TB	Tuberculosis
UDHR	Universal Declaration of Human Rights
VOT	Video Observed Treatment
WHO	World Health Organization
XDR-TB	Extensively Drug-Resistant Tuberculosis

[1] This abbreviation also commonly refers to Knowledge Attitudes, and Practices surveys, but not in this document.

Executive summary and recommendations

Although Romania currently faces serious challenges in tackling the problems of drug-susceptible tuberculosis (TB) and drug-resistant tuberculosis, having the highest burden of both these types of TB in the European Union (EU), the country has started to implement innovative programs to improve the treatment experiences and outcomes of those who are living with the disease. Chief among these is the movement towards integrated care in both the inpatient and ambulatory/community-based settings. Integrated care refers to services which are focused around the health and social needs of people with TB and which are provided in a way that allows these people to return to health, life and productivity as quickly as possible. There is a wealth of evidence from around the world and within the World Health Organization (WHO) European Region showing that integrated care for TB is not only associated with improved health outcomes but also to substantial cost savings for the health system. Early Global Fund-supported work in Romania also shows this to be the case, especially among persons with drug-resistant forms of TB (DR-TB), whose diagnosis and treatment are more complicated.

In order to develop a scale-up of and implementation plan for sustainable integrated care in Romania, relevant documents were reviewed and a series of consultations were undertaken with key stakeholders in the country, including people who have had TB, as well as doctors, nurses, psychologists, and members of civil society (see annex 1 for additional details). This report will describe the findings with a focus on barriers in three significant areas: 1) health systems; 2) people's lives and health; and 3) financing. The report, which is intended for Romanian decision makers, includes priority recommendations for addressing these barriers and providing integrated TB services in the Romanian context. Some of these recommendations are:

- It is strongly recommended that the TB program and civil society stakeholders coordinate with the Ministry of Health (MoH) and the Ministry of Labor, Family, Social Protection, and Elderly People (MoL) to develop multi-year, predictable budgeting to ensure the sustainability of these services. Sustainability without government support is unlikely.
- It is strongly recommended that integrated community-based treatment and support for TB be included into the minimum package of basic health services.
- Multi-disciplinary teams should provide *both* TB treatment and support.
- Social, economic, and psychological support are *crucial aspects* of TB care. They should be available to all people in Romania.
- A risk assessment should be done for all people diagnosed with TB disease to ensure they are able to adhere to treatment.
- People who are being treated for TB or have been in the past, as well as civil society organizations representing them, should be part of all planning, implementation, and monitoring of integrated community-based treatment and support.
- Treatment and support should include options for people, such as Video Observed Treatment (VOT), which would increase their adherence.
- People who are at an increased risk of not successfully completing treatment, or who experience negative events or "triggers" such as their sputum cultures not converting to negative after a certain point in time, or becoming smear or culture positive after

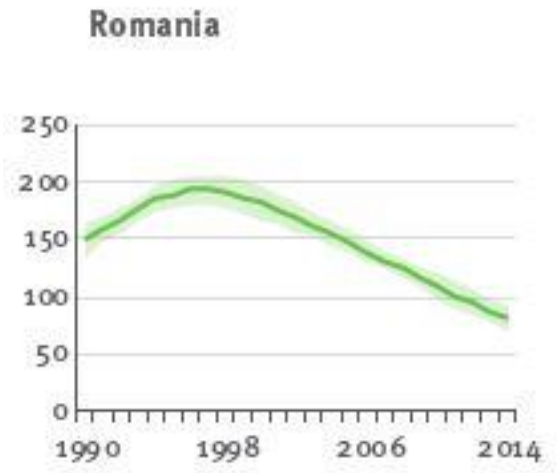
previously being negative, should receive additional monitoring and support to ensure they are successfully treated.

- A monitoring and evaluation plan should be developed which would include tracking treatment outcomes as well as the workloads of the multi-disciplinary teams, and therefore human resource requirements.
    - Monitoring should include quantitative and qualitative components and should be able to show results even among the most vulnerable populations.
- A "cascade of care" approach is recommended. It should always be clear who is responsible for the treatment and support of a person with TB—from the moment they are diagnosed until they are successfully treated.
- Outcome-based incentives are recommended for those providing support services.

These recommendations are consistent with the Romanian National Strategic Plan (NSP) for TB and with recommendations made by international normative public health bodies. They also situate integrated TB care within the legal and human rights frameworks to which the country has committed.

In order to facilitate rapid uptake of these recommendations, this document includes a draft core curriculum for training health care providers in integrated care (Annex 3). This report also considers a monitoring plan with implementation goals, and describes high level political will in the country, European Union (EU) and the global health and development communities, as well as the legal environment, including human rights and local laws which compel the provision of integrated care in Romania.

Background



TB incidence in Romania 1990-2014
Source: ECDC TB Surveillance Report 2016 [1]
X axis: Year (1990-2014)
Y axis: TB incidence (number of cases per 100,000 people)

Romania is one of the 18 countries identified by WHO Regional Office for Europe as high priority for TB control. In Romania, there are approximately 20,000 people suffering from TB at any given time, and 1,100 die every year from the disease [1]. Romania has by far the highest number of cases, incidence and prevalence rate in the European Union. This country holds 27.4% of the EU's TB burden and has a TB incidence rate that is about seven times greater than the EU average [1]. As the graph to the left indicates, there has been a downward trend in TB incidence in Romania since the late 1990s [1]. However, when compared to the rest of the EU, Romania's TB situation, even in its much-improved state, is still a serious problem.

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.			

Romania's case detection rate for drug-susceptible TB far exceeds the Millennium Development Goals benchmark of 75%, and, at almost 90%, is among the highest in the region [1]. It is the identification and treatment of people with DR-TB that has proven to be one of the greatest challenges of the Romanian TB program. Thanks to recent support from the Global Fund and the Norwegian Development Programme, this capacity for identification and treatment has been increased. However, additional investments will be necessary to ensure that everyone who is diagnosed is provided with the support they need to complete the treatment, which can last between 18 and 36 months. Only about one third of people in Romania with MDR-TB are successfully treated. This is nearly twice the rate that was recorded a few years ago, but is still much lower than the rest of the EU, and most of the world [1]. The chart on the right shows the difference between the treatment success rates within the Romanian national treatment success rates

and those within the Global Fund-supported project (approved by the Green Light Committee). This project could only enroll 20% of all people needing treatment for drug-resistant TB, but has shown more than a decade of success, which offers a promising foundation to build upon.

M/XDR-TB Treatment Success in Romania Sources [1 - 3]		
Year	National Rate	Global Fund Project Rate
2004-2011	16-25.6%	59-75%

In recent years, the Romanian TB program has struggled with low and unpredictable budgets, which have led to prolonged stockouts and shortages of the drugs used to treat multidrug-resistant and extensively drug-resistant TB (M/XDR-TB), and even to spot stockouts of first line drugs used to treat drug-susceptible TB [4]. Additionally, human resource shortages have been a persistent problem along with an aging population of doctors and an insufficient number of nurses and community health workers. Human resource problems have been exacerbated by the country's poor transportation network. In many communities, the provision of Directly Observed Treatment (DOT) is difficult, if not impossible under present conditions. All these stockouts and shortages, along with a weakness in the laboratory sector and the near absence of any manner of social, economic, and psychological support, can be blamed for much of the poor outcomes seen in people who have DR-TB, those who have been treated unsuccessfully in the past, and those who have social, economic and/or medical complications. These people are expected to particularly benefit from the integrated community-based support services discussed in this paper.

What are integrated community-based TB support services?

For the purposes of this concept paper, we use the term "integrated" to convey that TB treatment and support services are best when they are part of the health system as a whole. Integration also means that TB services are best provided as part of other health services such as HIV, hepatitis testing and treatment, diabetes care and other basic public health services. In the Romanian context, it is especially important that TB services, including community-based support, be firmly integrated within public health services and the national social welfare system because these services would be overseen and sustainably budgeted by the relevant ministries, rather than being supported by donor funding which is unpredictable and shrinking due to Romania's status as an upper-middle income country.

The model of care advocated in this concept paper can also be described as people (or patient)-centered care (PCC). PCC is not simply a menu of choices. Instead, it is "a holistic model of care delivery that considers the patient as the central figure in the process or continuum of care" [5]. PCC "is team-based, decentralized care that requires substantial investment in human resources to provide high-quality care in settings where patients live and work, and are connected to networks of social capital and social support" [5]. It is important to note that there are substantial cost savings associated with transitioning from hospital-based to largely ambulatory treatment programs [6]. However, providing high quality integrated, community-based, people-centered care and support for TB "*where patients live and work"* will require a substantial up-front investment in human resources (emphasis added) [5].

Successful examples of people-centered, integrated care exist in many settings. In Khayelitsha, South Africa, a community-based model is in place which is showing that even the most drug-resistant

forms of TB can be treated effectively and safely in the community—even among people living with HIV/AIDS [7, 8]. The model in Khayelitsha combines top quality diagnostics and treatment with directly observed treatment (DOT) and support services provided by community health care workers.

Another example is Ethiopia, which has the highest treatment success rates recorded in Africa for drug-resistant TB (78.6% between 2009 and 2014). This success rate dwarfs those of many, far wealthier, countries and is achieved in a resource-constrained setting where many people have advanced TB disease [9]. The Ethiopian program uses a combination of "intensive treatment of adverse effects, nutritional supplementation, adherence interventions, and NGO- Ministry of Health (MoH) collaboration" [9]. Because of their success, "community-based interventions should be considered an essential component of MDR-TB treatment programs" [9]. The interventions used in Ethiopia are based on models used in Cambodia, which included monthly home visits by community health care workers, monthly visits by patients to the TB clinic, DOT provided by identified supporters, monthly food baskets, and social support for the neediest people [9]. These social support measures are recognized as increasing treatment adherence and reducing lost to follow-up (default) outcomes [9]. In Ethiopia, "roving nurses" went to the homes of a subset of people with DR-TB and provided DOT (including injections) to them [9].

Successful integrated treatment has also been seen in Tomsk, Russia, where the Sputnik project has been in place for more than ten years. Sputnik is the result of a collaboration between Partners in Health and the Russian MoH. This project provides daily comprehensive care to people who are assessed as having the greatest risk of being lost to follow-up. These are people who face the challenges of alcohol and substance addiction, and of socio-economic problems. Since 2006, TB incidence, drug-resistant TB prevalence, and TB mortality have all significantly declined in Tomsk [10]. Additionally, the rate of reoccurrence following successful treatment of drug-resistant TB has been low [11].

A further example can be found in Brazil, where the country's *Bolsa Familia* (family purse) program provides economic support to the population via cash transfers. 14% of Brazilians with TB are covered by *Bolsa Familia* and substantial numbers receive sickness benefits from the Ministry of Labor, Family, Social Protection, and Elderly People (MoL). Illness pensions for TB account for 31% of all social security payments [12]. In 2012, 85% of Brazilian states and municipalities provided social incentives such as food packages and transport vouchers to people with TB [12].

Each of the above examples shows how integrated, community-based care and support can be achieved even in settings which are resource-constrained, and with populations who face challenges such as HIV/AIDS coinfection, alcohol and drug use and socio-economic vulnerability. In a global analysis, Siroka, Lönnroth, and Ponce find a statistically significant relationship between increases in social protection spending and dropping rates of TB incidence [13]. This relationship remains significant until social protection spending exceeds 12% of GDP. According to Alston's assessment, additional reductions in TB incidence in Romania can be achieved by increasing social protection spending, which is now at 0.6% of Romania's GDP [14]. An additional benefit of such an increase is that it would lead to reductions in the costs associated with treating people who develop increased drug resistance after being lost to follow-up, as well as any additional TB infections in their contacts.

Evidence from Romania points to the value of community-based support for people with TB. Since at least 2006, pilots using varying approaches to social, economic, and psychological support have been supported in Romania by funders such as the Global Fund, USAID, and The Norwegian

Development Programme. The effectiveness of such an approach is evident, for instance, in the far greater treatment success rates seen in the Global Fund MDR-TB treatment project than within the national health system. Recently, a project involving the Association for Supporting Patients with MDR-TB (ASPTMR) has provided peer support, along with counseling and economic assistance, to people in Romania with DR-TB. This initiative is widely recognized as increasing adherence. All of these projects incorporate international best practices and are laying the foundation for what could be scaled up at the national level with predictable, sustainable domestic funding.

What is understood by the sustainability of these services?

In the section above, we note that the responsibility and ownership of the Romanian government are key to the implementation of integrated services. Oversight and funding of these projects should ideally come from the Romanian government through the relevant ministries. Over the past ten years, support projects funded by the Global Fund, USAID, Doctors of the World, the Norwegian Development Programme and others have benefited limited numbers of Romanians with TB. However, these projects, despite demonstrating increases in adherence and being highly regarded by both patients and the medical staff involved, were never adopted and scaled up by the Romanian government. One Romanian doctor described these effective integrated services as being "stuck in the pilot phase." During consultations, stakeholders mentioned specific instances that illustrate this problem. For instance, when Romania became ineligible for an HIV/AIDS grant through the Global Fund, there was a dramatic reduction in the availability of harm-reduction services, especially needle exchange. The Romanian government did not immediately provide support for these, and when it did provide syringes, the rules of Romanian state procurement resulted in the lowest bidder providing syringes which were of a quality that was unacceptable to the beneficiaries.

Probably the strongest example of the lack of sustainability of Romanian attempts to provide TB support services with the help of donor funding occurred when Round 11 of Global Fund grants was cancelled. Romania had been receiving funding from this donor to provide various forms of support and targeted interventions for vulnerable groups (these were also mentioned in Romania's Round 11 concept note). With the cancellation of Round 11, Romania began receiving funding through the Transitional Funding Mechanism, but this was scarcely enough to fund the cost of treatment for M/XDR-TB. No other funders, including the Romanian government, stepped in to provide support during this period. The end result was that Romania went years with virtually no social, economic, or psychological support for people with TB and with little outreach to vulnerable groups, until additional funding became available through the Global Fund and the Norwegian Development Programme.

There are two additional layers of sustainability apart from the national one. The first is the support of local authorities and constituencies, which can be achieved through local advocacy and educational campaigns. The second, which may contribute to a feeling of local ownership, entails that people currently being treated for TB and those who have been cured, as well as local and national groups representing and providing services, become involved in all planning, implementation and monitoring. Local support for these projects may not need to be in monetary form. It might be in-kind or even by facilitating the efforts of the implementers. This type of local support could play an important role in accessing hard to reach populations, and may reduce stigma associated with TB in the community.

Methods

This concept paper is informed by three different sources of data. The first is a desk review of relevant documents, the second is consultations with local and international stakeholders, and the third is the surveys and hundreds of interviews with medical staff and TB patients conducted by Jonathan Stillo as part of his ten-year research of TB in Romania, which included him living for six months at a Romanian TB sanatorium. Some of the consultations occurred in person or via email and Skype. The majority of them, however, took place using an online fifteen-question (mostly free answer) survey. The respondents included people who have been treated for TB, as well as doctors, nurses, psychologists, and individuals working in civil society related to TB. Overall, consultations also involved soliciting the opinions of international experts who have extensive knowledge of the Romanian situation.

Survey respondents were provided with the STOP TB Partnership's definition of integrated services, which reads "...joining together different kinds of services or operational programmes in order to maximize outcomes, e.g. by organizing referrals from one service to another or by offering one-stop comprehensive and integrated services. In the context of TB care, integrated programmes may include HIV testing, counselling, and treatment; sexual and reproductive health; primary care; and maternal and child health." [15] Respondents were asked to reflect on the challenges the Romanian TB program faces, as well as to recount their experience of Romania's past and current efforts to support people with TB. They were also asked how integrated community-based support could be made sustainable.

The online survey was bilingual (English and Romanian) and respondents were instructed to provide answers in whichever language they were most comfortable with. Survey invitations were sent to approximately 200 people using the email lists of the national TB program, of medical and civil society organizations, and of former patients. In total, twenty-nine people responded to the survey. The vast majority of responses were in Romanian. The respondents were diverse in roles as well as geographic location. The survey responses were placed in a spreadsheet and analysed by looking for main points of agreement as well as divergent opinions. The results of the survey are explained in greater detail in annex 1.

Findings

What was found as a result of the desk review, survey, individual consultations, and ethnographic data (collected by Stillo between 2009 and 2014) generally falls into three different categories: health system concerns, issues related to peoples's lives and health, and financing issues.

Health system concerns

- Many communities lack access to even basic primary care.
- Ambulatory TB care is weak or inaccessible in many places.
- Since 2009, family doctors have received no compensation for providing TB services. Many no longer provide this service.
- Health resources, including human resources, are concentrated in urban areas, even though 45% of people in Romania live in rural areas.
- Much of TB treatment in rural areas is self-administered *without* the provision of adherence support and proper monitoring.

- In-home care is limited due to a lack of community health nurses and others trained to do such work, as well as to restrictions on petrol imposed by the MoH.
- Ancillary drugs (to treat TB symptoms and adverse reactions) are not free during ambulatory treatment.
- The health system is "siloed"/vertical, which requires people to seek treatment for various problems at different locations, rather than in one place where services are readily accessible. Weak infection control in many TB facilities places people there for TB treatment and staff at risk of infection and super-infection [4].
- Real and perceived expectations of corruption may delay or prevent treatment-seeking.

Romania is a large country, where 45% of residents live in rural areas. There is a general mismatch between where health and human health resources are located and where people who need them live. The United Nations Human Rights Council Special Rapporteur on Extreme Poverty and Human Rights recently visited Romania and found that "accessibility to services is especially poor in rural areas. Recent expenditures have favored hospital funding, at the expense of urgently needed improvements in primary, community, and preventative care arrangements" [14].

The accessibility of TB services was a major concern for survey respondents. The importance of this issue is also noted in the WHO and European Centre for Disease Prevention and Control (ECDC) review of Romania's TB Program [4] and in scholarly literature [16 - 18]. One respondent mentioned that, in winter months, travel becomes very difficult in many parts of Romania. Respondents stressed that, under these weather conditions, it is very important to make sure that treatment sites are connected to existing transportation networks. They also noted that the costs of transportation are prohibitive for many people with TB and that it would be helpful to those people who cannot receive in-home treatment supervision if transportation costs were covered by vouchers, or if transport were free between treatment sites and the surrounding villages. These ideas are further supported by discussions with people with TB who mentioned the economic and time costs associated with traveling to treatment sites. This burden of traveling to a treatment site, whether in rural or urban areas, is a special challenge for those who must care for children. This responsibility usually falls on women and may cause them to delay seeking treatment. It may also negatively affect their adherence [19]. Additional support may be necessary to ensure that women, and others with caregiving responsibilities, are enabled to adhere to treatment.

TB care in Romania is largely hospital-based and, even with a network of approximately 180 TB clinics (many, however, are within hospitals), basic TB services are often inaccessible to non-city residents. Romania has some of the lowest numbers of doctors, nurses, pharmacists, and psychologists per capita in the region [20, 21]. The low numbers, combined with their concentration in urban areas, makes access to even basic primary care a challenge for rural Romanians. Further complicating matters are the small numbers of community or "patronage" nurses, Roma health mediators, and community health workers. Even in communities with these workers, a MoH limit on monthly petrol subsidies constrains the number of communities that these workers can reach. This limit also applies to vehicles which transport TB-related specimens between sputum collection sites and laboratories.

One of the most important findings gathered from the survey and from other consultations is that people in Romania want options when it comes to both TB treatment and support. Several respondents commented that it is difficult to develop a uniform package of support as different people will have

different needs. Respondents also noted that there should be options for what kind of treatment supervision they would receive. They suggested that treatment observation could be done by video (VOT) using a computer or mobile phone, or through visits to their home by a treatment supporter.

Sustainability was a major concern of survey respondents. They noted that without the "ownership" and responsibility of the MoH, any improvements to TB care in Romania would not be sustainable. They also suggested that local family doctors and public health nurses should be involved whenever possible as part of multi-disciplinary teams which could provide medical care as well as economic, social, and psychological support.

After 2009, the contract between the National Insurance Program and family doctors expired. In the years that followed, family doctors received no pay for TB treatment and monitoring. Conversations with local National TB Program (NTP) managers reveal that many, if not most, of these doctors no longer provide DOT. Furthermore, since each family doctor is only allowed to register a certain number of people as patients, some communities with family doctors include people who are unable to register due to the doctor(s) having already reached their caps [4]. In many rural areas of the country, this has resulted in a standard of care based on self-administered treatment (SAT) [3, 4, 22]. Yedilbayev comments that this is "completely unacceptable" [22]. There is an ongoing debate in the TB community about whether it is necessary for every dose of TB drugs to be directly observed [23, 24]. However, self-administered treatment without treatment literacy, adherence planning and counseling, which are the conditions under which SAT occurs in Romania, is unacceptable and does not conform to international or local treatment standards.

The limited number of social workers (only 1 per 3,350 people) and their concentration in urban environments mean that many poor people in Romania never come in contact with one [14]. Some hospitals have social workers on staff, but they may be responsible for all patients and have little time to dedicate to the longer commitments required to support people with TB.

The Romanian health system is siloed (organized vertically with unnecessary physical, financial and bureaucratic separations). These separations are harmful because they make receiving care more difficult and time-consuming. Even if a person is hospitalized, he/she may be required to travel to another location for treatment or diagnosis of another condition. This has been documented in regards to TB patients who require HIV/AIDS, diabetes, psychological, dental and other types of treatment. As a result, people being treated for TB and their families experience an added burden, which may delay or prevent them from receiving all of the treatment they need. The present system for diagnosing and treating TB in Romania is not at all patient-centered. Instead "[t]hese services are, however, tailored more to the providers than to the patients with their needs for rapid diagnosis, effective treatment and support in their social vulnerability" [4].

Even in communities with health resources, some residents may delay seeking diagnosis or treatment due to the real or perceived expectations of corruption, which can include so called "envelope payments" and requests that people pay for drugs and supplies which are supposed to be provided free of charge [14, 25]. TB services, which are free of charge, seem to be less affected by this type of corruption than other specialties. However, interviews with people in Romania being treated for TB suggest that few had expected that they might have TB. Instead, they had expected diagnoses of flu, bronchitis, or pneumonia—all diseases which they would have been expected to pay for. Most people are not going to assume that TB is a possibility and may pay out of pocket for treatment of other more

common illnesses, before they are finally diagnosed with TB and can receive free treatment. The delays described above most negatively affect the vulnerable people who are the least able to pay for services.

Issues related to the lives of people with TB

- Members of vulnerable groups such as the poor, the homeless, people who use alcohol and drugs, people with HIV/AIDS or diabetes, and the Roma are all at greater risk for TB disease and face greater difficulty being cured.
- Due to a lack of economic and social support options for people in Romania with TB who are homeless, extremely poor, lacking family support, or suffering from mental illness - sometimes called “social cases” (*cazuri sociale*) - doctors are faced with the choice of either “discharging to the streets” or extending their hospitalization for social reasons.
- TB is a highly stigmatized disease in Romania. This contributes to a lack of political will to address the problem, delays diagnosis and treatment seeking, and makes supporting people with TB more difficult due to fear that others will learn they have the disease.
- It can be difficult to ensure treatment continuity for people who migrate within Romania and to other countries. There are no mechanisms to assist migrants with treatment adherence.
- The only economic assistance provided by the Romanian government to people with TB is a 100% salary benefit for one year to persons who were legally employed and salaried. This excludes many, if not most, people in Romania with TB [4, 19, 26]. It also does not last long enough to cover the entire treatment of DR-TB.
- Some of the most vulnerable people in Romania lack national ID cards. Without these, they cannot receive many social services or register with a family doctor.
- Rural people often have agricultural commitments such as harvesting and caring for animals. Many households cannot survive without the income related to these activities. The choice between these activities and treatment adherence is an impossible one.

Many people in Romania rely on migration for work. This includes internal migration, oftentimes to urban areas, and to other countries, especially in the EU. At any given time, about 15% of Romania’s population is abroad, with more than one million in Italy alone [27]. Free movement is a right of European Union citizens. However, those who migrate face challenges in adhering to TB treatment due to a lack of people-centered measures which would allow them to receive treatment and support away from their homes.

The Roma minority faces great barriers in accessing health and social welfare. Despite the existence of projects involving Roma health mediators, the Roma life expectancy is as much as sixteen years shorter than the life expectancy of other people in Romania [28].

Concerns over stigma should be taken into account when planning TB care and support. Many people with TB wish to keep their illness a secret. People in Romania have a right to keep their health information private. Highly visible services, such as the cars which were provided by the Global Fund about ten years ago and which are presently in use clearly identify them as associated with the TB program. This should be avoided in the future in order to make services more respectful of the right to privacy of people with TB.

TB Stigma in Romania:

"[TB is] The greatest shame.…Who will hire me if they find out I have this disease?" Stefan, MDR-TB, 30 years old.

"If people know you have TB, even if you are negative, and they see you in a restaurant, everyone at once will move their tables to the other side. No one wants to be near you." Mircea, XDR-TB 55 years old.

Despite being a curable bacterial infection, many people in Romania, including some medical staff and even policy-makers, still view TB as a shameful disease associated with poverty and "unbalanced" or "irresponsible" living, and often blame it on the Roma minority. These views are particularly common in rural areas, but can be heard across the country.

These attitudes are against Romanian law. However, patients have reported losing their jobs after employers learned they had TB. Others have stated in interviews that they chose not to apply for the 100% salary benefit for fear that their employer would find out they had the disease and fire them. For these reasons, it is crucial to respect the confidentiality of people with TB and to make services and support available to them in non-stigmatizing ways, which do not reveal their TB infection to the public.

While ending catastrophic economic costs for people with TB and their families is a target in the WHO's END TB Strategy [29], based on interviews with former and current patients, catastrophic costs are the norm for families in Romania. People report selling livestock and other possessions as well as taking out high-interest loans in order to pay for costs related to their TB treatment and to help support their family while they are hospitalized and unable to earn a wage. These costs affect the poorest people in Romania the most. Furthermore, since the 100% salary benefit only covers salaried employees working under formal contracts, the large numbers of people with TB who work on small scale agriculture, or are employed "off the books" (*la negru)* or by the day (*cu ziua*) are ineligible to receive it. This means that, outside of donor-funded projects which are limited in time and location, most people in Romania with TB have no access to economic support. Some of the most vulnerable people have little to no possessions and may not have families who can support them. They are called "social cases" (*cazuri sociale)* by medical staff. Rather than "discharge" such people "to the streets," as some doctors describe it, they extend these patients' hospitalization times [16, 17, 30, 31]. This shifts costs which should be the responsibility of the social welfare system to the already underfunded health system and may expose the same people these doctors seek to protect to additional risk of nosocomial TB infection.

Several survey respondents specifically stressed the importance of multi-disciplinary teams in providing community-based TB treatment and support. Some noted the importance of social workers and psychologists on these teams, who would address social, economic, and psychological aspects of

adherence. These suggestions are in keeping with international best practices. Respondents' focus on these types of support is likely related to the success of two recent projects funded by the Global Fund and the Norwegian Development Programme. These projects have supported multi-disciplinary teams and a community support-based approach in six counties, as well as a peer mentoring project where people who used to have TB have provided psychological services and peer counseling in person or by phone. Respondents – among them people who have completed TB treatment – specifically mentioned both of these projects and described them as facilitating treatment adherence, including by helping them cope with adverse effects of drug-resistant TB medications.

Financing issues

- Overall, in Romania there are low levels of both health and social services spending when compared to other European countries [32]
- Social welfare spending is inefficient and completely misses some of the poorest people [33].
- Since 2010, TB has been excluded from the illness pensions provided by the MoL.
- Budgets are unpredictable and there is a heavy reliance on donor funding for major parts of the TB program, including for drugs and laboratory supplies.
- Perverse incentives in hospital financing encourage longer hospitalizations and the mixing of people who have TB with people who do not [4].
- Ancillary medicines (used to treat TB symptoms and ease adverse reactions to TB drugs) are not free except to people who are hospitalized.

Romanian investment in social welfare has been low since the 1980s. The amount which is invested has a disproportionately small impact on Romania's poor and vulnerable. The total amount of social welfare spending, as well as the percentage of public expenditure dedicated to it, are among the lowest in the European Union [33]. In fact, at just 0.6% of GDP, it is only one quarter of the EU average [14]. Alston also notes that "[t]he County Directorates of Social Assistance and Child Protection, municipalities and NGO providers, do not have sufficient funds to finance adequate social services. Although the law (Law 292/2011) requires every municipality to establish public social assistance services (SPAS), many smaller municipalities in rural areas do not offer such services." [14, 34]

Beyond the low levels of funding, it is also important to note how ineffective Romanian social welfare spending is at addressing poverty. The World Bank Country Partnership Report found that "[o]nly a few safety net programs perform well, while the overall system of social assistance cash benefits performs less well than in other EU countries in reaching the vulnerable and providing them with adequate protection....Most of the social assistance benefits have low adequacy, representing only 10-20 percent of the minimum wage and cover less than 30 percent of the household consumption of the poorest beneficiaries….only 17 percent of the social assistance benefits reach the poorest quintile, 29 percent of the poor are excluded from the system… and half of the funds spill to the wealthier quintiles. Spending on poverty targeted programs has decreased relative to GDP in recent years. Well-targeted programs such as the Guaranteed Minimum Income Program (GMI) or income-tested family allowances are underfunded, leaving out 60 percent of the rural poor and 77 percent of the urban poor" [33].

Recent research in Romania has shown that people with DR-TB are more likely to have been unemployed [26]. Additionally, a survey of people being treated for TB at one large Romanian sanatorium found that unemployment was significantly correlated with delays in seeking treatment for TB after the onset of symptoms [35]. Based on this data, as well as on the difficulties vulnerable people in Romania describe in trying to be cured of TB [4, 16, 17, 18, 19, 26], we identify poverty as a major barrier to effective TB care in Romania. We also find that the social assistance available through the MoL is largely unavailable to the most vulnerable people in Romania. This leaves them with only the smallest social welfare benefits, namely those available through their local mayor's office. These are among the "low adequacy" benefits described by the World Bank as providing only ten to twenty percent of minimum wage. People with TB are usually unable to work during all or part of their treatment. At the same time, they receive little support. Under these conditions, they cannot provide for their families [33].

Iulian: A "lose-lose situation"

"Here in Romania, if you don't work, you starve to death. There are two options: You take the TB pills and get better, but starve or you work and have to come back to the sanatorium. So it's a lose-lose situation." Iulian.

In 2012, Iulian died at age 42 of XDR-TB. In 2010, he had been diagnosed with MDR-TB, but had been unable to complete treatment. He and his family were extremely poor. Ill with TB, he could no longer work. His wife had been laid off from her job as a seamstress. They worried about how they would feed their little girl with only the small social welfare payment from the mayor's office. Iulian chose to leave the hospital and return to work. He developed additional drug-resistance and died shortly thereafter.

For people like Iulian, there is no way to both care for one's family and complete TB treatment, especially for drug-resistant TB. For more about Iulian see [36] and [37].

Current and future national and international funding landscape for TB in Romania

At least since the 1989 revolution, Romania's TB program has never received enough funding to accomplish its mission. Virtually every international review since the start of Romania's modern NTP has raised concerns over inadequate funding and an overreliance on unsustainable external donor funding [3, 4, 38, 39, 40]. In recent years, Romania has seen the exit of large funders such as USAID, as well as the retreat of organizations such as Doctors without Borders, and Doctors of the World. Funding issues greatly limited the NTP's ability to provide diagnosis of DR-TB, and delayed the widespread introduction of modern, rapid diagnostic methods until 2015, when external donors provided funding for these technologies. While external donors have funded diagnostic technologies and even the purchase of second- and third-line drugs to treat DR-TB, as well as pilot projects aimed at increasing the social, economic, and psychological support of people with TB, it is not feasible for external donors to fund and organize Romania's ambulatory TB treatment and support because this external funding depends upon local political and legal constraints. To paraphrase a member of the Romanian NTP: this is an issue which requires a Romanian response. There needs to be a broad base of support from the MoH, MoL, the National Insurance Program, the public health authorities, and, importantly, local and national civil society, especially people who are being treated or who have completed treatment for TB.

One positive development is that Romania may now be diversifying its sources of TB funding. Recent years have seen Romania receive TB funds through the Norwegian Development Program, the EU, and the US Department of Defense. Better still, domestic funds are to make up the majority of TB funds for the activities in the 2015-2020 National Strategic Plan. However, Romania will need to reduce its reliance on external donors due to its increasing economic success. It is now classified as an upper-middle income country by the World Bank, and is the 31st wealthiest country in the world. Romania's eligibility for HIV funding from the Global Fund has ended and Romania's TB allocation for 2017-2019 from this external donor is only $4,052,972. This is *less than one third* of the $12.8 million that the Global Fund allocated for the 2014-2016 period. The continued availability of Norwegian Development Programme funds may also be limited for the same reasons. Based on the approach that the Global Fund has taken with HIV/AIDS funding in middle-income countries, and its efforts to phase out TB grants to other middle-income countries, it is likely that this type of funding will be reduced and will only be available for supplementing domestic funding for specific risk groups. In other words, Romania could qualify for funding to implement innovative projects to better serve vulnerable groups, but is unlikely to remain eligible for the broad type of funding which it is currently receiving through the Global Fund and the Norwegian Development Programme.

Lessons learned from the recent community support projects

The current Global Fund grant is funding a pilot project in six counties in Romania. These counties have revised their laws and reimbursement practices to facilitate the greater use of ambulatory care and to provide supports such as modest cash payments, psychological and peer support, and treatment literacy services to people with TB. Multi-disciplinary teams are providing these services. An output of this project will be "protocols and guidelines for outpatient and inpatient care, including criteria for hospitalization and outpatient care" [3].

Because this project is still ongoing, there is no formal data available to include in this paper. However, several people involved in it responded to the survey and provided feedback in person and via Skype in August and October of 2016. They stressed that Romania does not have the local public health resources necessary to provide these services in all places. The initial six counties were selected, in part, because they had community health nurses. One respondent pointed out that, even between the six purposefully selected counties, there are wide variations in local political will and health resources. Two additional possible challenges to scaling up this project nationwide were identified. The first is that visiting people with TB in their homes or communities is hard work that not all community nurses will be eager to do. Secondly, community nurses are supervised by local authorities. It can be expected that their interests may not perfectly align with national ones. It is reported that, in some communities, community nurses may not be doing as much outreach work as this project has designated them to do and may be doing other tasks instead. For these reasons, the support of local authorities is crucial, as is a clear mechanism for ensuring that the multi-disciplinary teams are providing treatment and support as intended.

One insight garnered from a similar project in the Republic of Moldova is that special attention should be paid to the composition of the multi-disciplinary teams. One such team consisted of a doctor who was also fulfilling the role of psychologist (without appropriate training). At the same time, the team included a full-time driver, as well as clerical staff. If resources are limited, as they are expected to be in the Romanian case, it will be more cost-effective to ensure that there are enough licensed drivers

among the nurses, psychologists, and others, rather than employing a driver who adds no additional benefit. If the services of a driver are required, it is recommended to hire someone who formerly had TB so they can also participate in peer support.

Cost data

The exact direct and indirect costs of TB in Romania are unknown. The WHO Regional Office for Europe is currently providing Romania with technical assistance to determine these costs. The results were not available at the time of this writing. Conservative calculations done by Diel et al (2013) found that the economic burden of TB to the EU was more than 500 million Euros each year [41]. While the direct and indirect costs of TB in newer EU states such as Romania are lower due to subsidized medications provided through the Global Drug Facility and overall lower costs of living, the fact that Romania alone accounts for 27% of the total number of TB cases in the EU, and has the largest number of people with much more expensive to treat MDR and XDR-TB means that Romania is bearing a substantial amount of the 500 million Euro yearly cost. TB costs the Romanian economy much more than just the direct costs of treating this disease. People with TB and their families are usually responsible for the costs of transportation to and from treatment sites, and sometimes must purchase their own medicines out-of-pocket due to drug shortages and a lack of free ancillary medicines during the ambulatory phase of treatment [3, 4]. Finally, the loss of wages and the inability to care for children and sick relatives due to the disease most heavily affect the poorest and most vulnerable people in Romania. These people are also the least likely to qualify for the salary benefit provided by the MoL. The most vulnerable people have little ability to endure the catastrophic economic costs associated with having TB in a country such as Romania which lacks social protections for underprivileged groups. Reducing these catastrophic economic costs to zero is a main objective of the WHO's END TB Strategy [29].

Because of the high costs of TB diagnosis and treatment, as well as the significant burden the disease creates for national economies, a report published by the World Bank has identified TB interventions as being one of the most cost-effective means of health spending [42]. It is important to note that TB tends to affect people in their most active working years. This prevents them from working, and can also reduce their family consumption. This decreases both their economic output and the taxes they would otherwise pay to the government on their income and consumption (VAT) According to the WHO, people with TB who are not successfully treated can spread the disease to between ten and fifteen other people each year [43]. This means that the cost of not correctly treating and supporting people with TB can be very large. The value of investing in a sustainable, integrated system of community-based TB support can be further enhanced by linking these services to as many elements of the health and social welfare system as possible. If TB was approached as one of several public health priorities, TB services could be delivered in conjunction with other extremely important ones, such as reproductive health, childhood vaccinations, harm reduction services for alcohol and drug-users, and services for people living with HIV/AIDS or diabetes. These are the same services which have been identified as missing or inadequate in many places, especially poor rural areas and Roma communities [14, 44].

Recent cost analysis research in South Africa reveals that the transition from a hospital-focused TB treatment model to one of three ambulatory-focused alternatives resulted in a cost savings of between 36 and 42% [6]. While there will certainly be cost savings, it is important to note that Romania

will need to make a substantial investment up front in order to ensure an adequate level of human resources and quality treatment options, as well as a robust set of social, economic, and psychological supports which would enable people to adhere to treatment.

Proposed solutions

The solutions presented here focus specifically on the sustainability of initiatives for integrated, community-based support for people with TB. However, it is assumed that this support will be integrated *according to* a people-centered approach.

- It is strongly recommended that integrated, community-based treatment and support for TB be included into the minimum package of basic health services that is freely available to everyone in Romania.
- Multi-disciplinary teams should provide *both* TB treatment and support.
- Social, economic and psychological supports are crucial aspects of TB care. They should be available to all people in Romania with TB.
- Public/private partnerships to sponsor some aspects of support for people with TB should be considered. Seeking both material and in-kind support from religious organizations should be taken into account. The Romanian Orthodox Church could be an especially appropriate partner because of its presence in most Romanian communities.
- A risk assessment is recommended for all people diagnosed with TB disease to ensure they are enabled to adhere to treatment. This could aid sustainability by reducing overall costs.
- People currently and formerly under treatment for TB, as well as civil society organizations representing them, should be part of all planning, implementation and monitoring of integrated, community-based treatment and support.

- In order to increase people's adherence, treatment and support should include options for them. One of these options could be VOT.
- People who are at increased risk of not successfully completing treatment, or who experience negative events or "triggers", such as not having their sputum cultures convert to negative after a certain point in time, or becoming smear or culture positive after previously being negative, should receive additional monitoring and support to ensure they are successfully treated.
- A monitoring and evaluation plan should be developed which would include tracking treatment outcomes, as well as the workloads of the multi-disciplinary teams, and therefore human resource requirements.
    - Monitoring should include quantitative and qualitative components and should be able to show results even among the most vulnerable populations.
- A "cascade of care" approach is recommended. It should always be clear who is responsible for the treatment and support of a person with TB—from the moment they are diagnosed until they are successfully treated.
- Outcome-based incentives should be created for those providing support services.
- There should be a publication plan to ensure that the results of these interventions are shared with the rest of the region and with other countries trying to develop integrated, community-based support for TB. The publication of results may also aid in sustainability by providing evidence of success, or by revealing opportunities for increasing quality and efficiency of services.

Video Observed Treatment (VOT)

- VOT is an option that can offer flexibility to people with TB as well as cost-savings to the TB program.
- VOT was studied in a randomized control trial in the UK [45]. The results of this study are promising, especially because it included people with multiple vulnerabilities such as homelessness, drug and alcohol use, and a history of migration.
- 90% of those in the VOT arm of the study have successfully completed or are on track to successfully complete TB treatment.
- A personal mobile phone can be used, or a low-cost one (<50 Euros) can be provided. Through software developed by California State University at San Diego, USA, a video can be recorded and uploaded by the patient, and then watched asynchronously by a treatment observer.
- This method is feasible for people whose schedules do not allow other methods of DOT, as well as for rural people who lack treatment observation options.
- Because video recording and treatment observation can occur asynchronously, even communities without reliable internet could use this option as long as the phones were periodically taken to a place with internet service where the videos could be uploaded.
- People receiving VOT will still need counseling and other forms of support. Much of this support, however, can also be done remotely, as the ASPTMR peer support project has demonstrated in Romania.

Romania's legal obligations related to TB

There are several national and international frameworks that impose legal obligations upon Romania to provide for the rights of its residents (see Annex 2 for additional details). These include the Romanian Constitution [46] and local laws such as the Romanian Patients Law (46/2003) [47]. They also include non-binding international treaties and conventions, such as the Universal Declaration of Human Rights [48], and legally binding conventions to which Romania is a signatory, such as the International Convention on Social, Economic, and Cultural Rights (ICESCR) [49], and the European Union Charter of Fundamental Rights [50]. The legal environment within Romania provides a number of rights to people with TB. However, these rights are not well-known. These rights could be strengthened and more work could be done to ensure that legally required support, such as the economically and physically accessible TB services described below, is available to all people in Romania.

While this document cannot provide a complete analysis of the national and international legal landscape related to TB, Annex 2 contains most of the relevant provisions. The ICESRC [49] and its companion document, General Comment 14 [51], are described here in the main text due to their specificity, relevance to the Romanian context, and legally binding nature.

The International Covenant on Cultural, Economic, and Social Rights (ICESCR)

The right to health is contained in the International Covenant on Economic, Social and Cultural Rights (ICESCR) [49]. It is further elaborated in the Committee on Economic, Social, and Cultural Rights General Comment 14 (CESCRG 14) [51], which is considered to be the authoritative interpretation of the Covenant. The ICESCR's article 12.1 states that the countries which are party to this Covenant "recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." It continues by stating that the full realization of this right shall include, among others, "(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;" and "(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness." [49]

The CESCRGC 14 is considered the authoritative interpretation of the content and scope of the international right to health. It establishes the availability of:

"the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs." [51]

The CESCRGC 14 also considers accessibility to health care. It states: "Health facilities, goods and services have to be accessible to everyone without discrimination." According to the CESCRGC 14, there are four overlapping dimensions of accessibility. The first stipulates that "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." The CESCRGC 14.30 declares that "States parties have immediate obligations in relation to the right to health, such as the guarantee that the right will be exercised without discrimination of any kind (art. 2.2)." Secondly, goods and services in health facilities must be physically accessible—that is, "within safe physical reach for all sections of the population, especially vulnerable or marginalized groups." Special mention is made of rural residents' right to accessible health facilities, goods and services. The third dimension of

accessibility is economic affordability. The CESCRGC 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." The fourth dimension is information accessibility. [51]

Another aspect of the right to health as defined in the ICESCR and elaborated on in the CESCRGC 14 is that of quality [49, 51]. The General Comment 14 states that "[a]s well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment." [51]

The provision of access without discrimination is a core obligation of countries which are party to the ICESCR [49] and the failure to provide it is defined by the CESCRGC 14.47 as a violation [51]. The CESCRGC 14.47 declares that

> "A State which is unwilling to use the maximum of its available resources for the realization of the right to health is in violation of its obligations under article 12. If resource constraints render it impossible for a State to comply fully with its Covenant obligations, it has the burden of justifying that every effort has nevertheless been made to use all available resources at its disposal in order to satisfy, as a matter of priority, the obligations outlined above. It should be stressed, however, that a State party cannot, under any circumstances whatsoever, justify its non-compliance with the core obligations set out in paragraph 43 above, which are nonderogable." [51]

Given Romania's obligations under the ICESCR [49], it is important to develop an integrated, community-based TB treatment and support system which reaches all people, regardless of whether they live in rural areas or are members of other vulnerable groups. Additionally, in order to respect article 12 of the ICESCR, it is necessary to ensure that these services are equitably accessible and do not burden people with TB and their families with direct and indirect economic costs [49]. The proposals in this concept paper take this into account.

Concluding thoughts

This concept paper and the vision of sustainable, integrated, community-based support for people with TB are in keeping with a human rights-based approach to TB, are people-centered, and are fully compatible with Romania's National Strategic Plan to Fight TB. In recent years, Romania has made considerable progress against TB but, without funding and oversight from the MoH, these gains are not sustainable. In order to consolidate these gains and fully reap the benefits of recent improvements in diagnostic and treatment capacity, now is the time for bold action. Anti-Microbial Resistance (AMR) is one of the world's greatest public health threats. TB is already the infectious disease responsible for the most deaths globally. People in Romania with unsuccessfully treated TB, especially drug-resistant varieties, will contribute to the spread of AMR unless they are treated and supported correctly. AMR infections are expected to cost the world between 40 and 120 trillion US dollars by 2050 [52]. Addressing TB is not only good public health policy, but it also makes good economic sense. Romania is presently bearing a great economic cost due to the lost economic productivity of people with TB and their caregivers.

The Romanian TB program, when provided with the required resources, has shown great success. The high rates of treatment success against DR-TB seen in the Global Fund project are proof of this. If Romania invests in TB elimination, it too can join the rest of the European Union in discussing the possibility of TB elimination in the region. By investing in bold, evidence-based TB control measures, such as those contained in the National Strategic Plan and in this concept paper, Romania's TB crisis and especially the unnecessary deaths and economic burden of drug-resistant TB can be ended. All of this is possible. We have the utmost confidence in the dedicated doctors, nurses, psychologists, social workers, and others who will be part of this effort. Countries such as South Africa, which face TB burdens much worse than Romania's, have shown that even the worst epidemics can be ameliorated through the work of a dedicated Ministry of Health and appropriate national investment. Romania has more than halved its TB rate in the past decade. However, this trend cannot be expected to continue unless additional measures are taken which will ensure that people with drug-resistant TB and those belonging to vulnerable groups and needing additional support are cured. Stakeholders ranging from members of the Romanian NTP to civil society and former patients all conveyed the same sentiment: the sustainability of these past successes, especially in the face of dwindling prospects for donor funding, require greater ownership and implication on the part of the Romanian state. This is a view which we also support. We urge Romanian decision-makers to provide assistance and oversight in order to ensure that integrated, community-based support for people with TB will be sustainable.

Annexes

Annex 1. Summary of the consultation survey results

An email invitation was sent out in the summer of 2016 to a broad group of stakeholders. In addition, the survey was posted on Facebook and distributed locally by civil society. The survey was widely distributed in order to engage stakeholders beyond the NTP and main NGOs, which are all based in Bucharest. One objective of the survey was to elicit the opinions of stakeholders (including local and international experts and advocates) on the challenges that Romania faces in providing community-based TB care and support, and on the optimal form of sustainable, integrated, community-based TB care and support. The second objective was to collect the experiences of individuals who have benefited from, or been involved in recent community support projects for people with TB in Romania.

In total, 29 people responded. These individuals came from all areas of TB. Some had previously been treated for TB, others were NTP staff, doctors, nurses, psychologists, laboratory managers, and civil society workers and volunteers. Among the respondents were also several international experts who have experience with the Romanian TB situation. Most of the respondents to the survey were doctors, who accounted for 56% of responses. People who had been treated for TB, Romanian civil society, and international civil society members each accounted for about 15% of responses (individuals could select more than answer for this question, so the percentages do not add up to 100%).

There was a good degree of agreement among the respondents regarding the desired qualities of integrated, community-based TB support. Several respondents noted that the MoH, the National Insurance Program and public health authorities should be involved. Some cautioned that, without the involvement of such organizations, the care would not be sustainable. Some respondents pointed out the importance of family doctors and suggested that they be implicated in integrated community support. Others noted that people who had been successfully treated for TB should be providing peer support in a manner similar to the recent pilot projects. Many respondents stressed the importance of a holistic approach to TB that includes social, economic, and psychological support. They cited past pilot projects funded by the Global Fund and Norwegian Development Programme as successful examples of this approach, but noted that these projects were always geographically and time-limited due to funding constraints.

One important finding of the consultation is the desire for multiple options to be available to people with TB for their ambulatory treatment and support. Several respondents commented that it is difficult to develop a uniform package of support as different people may have very different needs. Others argued that the interventions should be the same. There was therefore a lack of agreement on this point. The form that treatment supervision should take was another area where there was a plurality of opinions. Some respondents suggested that patients should be presented with the option of having their daily treatment supervised via video conferencing through a mobile phone or computer. Other people advocated for visits to patients' homes by treatment supporters.

One point which multiple respondents raised was the importance of an easily accessible treatment center. By "access" the respondents referred to several things: physical proximity, accessibility during the winter months when travel is much more difficult, and affordability of transport. One respondent suggested that any treatment center should be located on already existing transit lines.

Another suggestion was to have a dedicated shuttle which would provide free transport to and from nearby villages.

Respondents were asked to identify the qualities that treatment supporters should have. The most common responses mentioned empathy and good communication skills. Other answers stressed knowledge about TB. When asked who should be involved in providing these services, respondents expressed a plurality of opinions. Most commonly, respondents suggested multi-disciplinary teams while several mentioned involving NGOs and volunteers for some aspects. It is important to note that even those respondents who suggested the involvement of NGOs did not argue that NGOs should be solely responsible for these services. Rather, they saw them as complementing and filling in gaps within services which are funded and supervised by the Romanian government. There was a high level of acceptance of the concept of multi-disciplinary teams as well as the use of outcome-based incentives for these teams as a way of encouraging success.

There was disagreement among respondents regarding the qualifications necessary for people to be members of treatment teams. Some answered that formal studies were necessary, such as nurse's training or a social work degree. Others, however, suggested that the level of formal training was less important than knowledge, good communication skills, empathy and even personal experience with TB. This divergence of responses reflects the different levels of training that members of a multi-disciplinary team might have. As some respondents mentioned, these teams could consist of doctors, nurses, psychologists, social workers, Roma health mediators, former patients doing peer-support, and other lay health workers who have specific training to complete certain tasks. As there is a range of jobs for such a team, it makes sense that there would be a range of preparation required.

Annex 2. Additional information on Romania's legal obligations in regards to TB

National legislation

Romanian Constitution [46]

Within the Romanian Constitution there are several articles which support the right to health of people in Romania. Article 16 guarantees that "[c]itizens are equal before the law and public authorities, without any privilege or discrimination." Article 22 states that "[t]he right to life, as well as the right to physical and mental integrity of person are guaranteed." According to Article 34, "[t]he right to the protection of health is guaranteed" and "[t]he State shall be bound to take measures to ensure public hygiene and health." While not going into detail about these rights, the Romanian Constitution establishes in article 20.1 that "[c]onstitutional provisions concerning the citizens' rights and liberties shall be interpreted and enforced in conformity with the Universal Declaration of Human Rights, with the covenants and other treaties Romania is a party to." It continues in article 20.2 by stating that, where there are inconsistencies between national and international laws, "international regulations shall take precedence, unless the Constitution or national laws comprise more favourable provisions." [46] While there are several international treaties which apply to Romania's TB situation, there is also Romanian legislation which is relevant to this issue, such as the Romanian Anti-Discrimination Law (48/2002) [53] and the Romanian Patient's Law (46/2003) [47].

The Romanian Anti-Discrimination Law [53] and the Romanian Patient's Law (46/2003) [47]

Romania has an anti-discrimination law (48/2002) which can be applied to health matters. It specifically mentions access to legal, administrative, and public health services [53]. This law could be used to support the claims of people in Romania who face unequal access to health facilities, goods and services. These individuals include rural residents, people living with HIV/AIDS, the Roma, and several other protected groups. There is also a Romanian law establishing the rights of patients, which contains provisions guaranteeing "the highest quality care which society is able to provide in accordance with human, financial and material resources." [47] In Romania, people with TB have few specific protections and benefits. While people living with HIV/AIDS have benefitted from a special law guaranteeing basic supports and protections since 2002 (584/2002) [54], no such protection exists for people in Romania with TB. In 2014, the Swiss-Romanian Cooperation Program funded a project which produced a draft law protecting the rights of people with TB, including their right to diagnosis, quality treatment and information about their condition. It also included provisions aimed at ensuring that people with TB have economic and social support. [55] Many of these rights are already established in other laws and treaties, such as the Romanian Patient's law 46/2003 [47]. However, these do not mention the sorts of social, economic, and psychological support provided for in the Romanian HIV/AIDS patient's law [54] and the draft TB patient's law [55]. This law was not passed by the parliament when it was submitted for approval in 2016. However, already existing Romanian legislation and, in particular, international conventions which are binding for Romania, guarantee a higher level of care than what is presently available to many people in Romania, especially to those from vulnerable groups and those living in rural communities.

International conventions, declarations, and treaties

The Universal Declaration of Human Rights (UDHR) [48]

The third article of the Universal Declaration of Human Rights (UDHR) guarantees the right to life. Article 27 of the same document specifies that everyone has the right "to share in scientific advancement and its benefits" [48]. The UDHR is non-binding. However, as mentioned above, the Romanian Constitution specifically acknowledges it [46]. Article 27 should be of concern to Romanian policy makers as it is clear that it has not been upheld with regards to access to diagnosis and treatment for M/XDR-TB since the beginning of Romania's MDR-TB (formerly DOTS plus) pilot.

The TB Patients' Charter [56], the International Standards for TB Care (ISTC) [57], and the European Union Standards of Tuberculosis Care [58]

Although not legally binding, the TB Patients' Charter [56] and the International Standards for TB Care (ISTC) [57] are two internationally recognized documents that provide guidance on how quality, equitable TB care should look. The TB Patients' Charter states that patients have "[t]he right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness." [56] The standards endorsed by the WHO and contained in the ISTC [57] define minimal, internationally accepted approaches to combating TB, and are based on the best available evidence. The European Union Standards [58], which apply to Romania, are somewhat different from the ISTC [57], which is explained by the fact that most countries in the EU have low burdens of TB and decentralized health systems.

The Charter of Fundamental Rights of the European Union

There are several articles in the Charter of Fundamental Rights of the European Union which pertain to health care. These include Articles 31.1, 32, and 35 (2000) [50]. Article 35 states that "Everyone has the right of access to preventative health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all of the Union's policies and activities" [50].

Annex 3. Outlines of the training modules

The approach to be used:

1. There are two types of training modules: required and optional. Members of the multi-disciplinary teams must follow all the required training modules.
   Training organizers should:
2. Conduct training needs assessment for the prospective training participants to determine the appropriate optional training modules.
3. Based on the results of the training needs assessment offer a combination of the required and optional training modules.
4. The target group for all the optional modules are the multi-disciplinary team members who are in need of passing the training module based on the results of the training needs assessment. Thus target audience can include but is not limited to nurses, psychologists, community or "patronage" nurses, Roma health mediators, community health workers, social workers, people who had been previously treated doing peer-support, and other types of (lay) health workers.
5. Ensure supportive supervision (on-the-job) to reinforce the learning after the training.

REQUIRED TRAINING MODULES

Module A1

Title: The principles of the integrated community TB support

Duration: 4-5 hrs.

Objective: to lay the foundation for the rest of the modules by embedding the principles of the integrated community TB support into outreach work.

Target group: Members of the multi-disciplinary teams.

Expected Outcomes:

- Participants can recall the principles of integrated community TB support.

Content:

- Components of integrated community TB support in Romania.
- Principles of integrated community TB support:
  - Inclusiveness;
  - Patient-centered approach;
  - Client empowerment;
  - Client confidentiality.

Methodology:

- Lecture presentation.
- Case studies and small group work on the principles of integrated community TB support. Four cases studies should be prepared, highlighting each of the principles: inclusiveness, patient-

centered approach, client empowerment, client confidentiality. When the four small groups are formed, each group works on one case study/one principle, thereafter the group makes a presentation and formulates this principle (in their own words) at the end of their presentation.
- The facilitator summarises the principles of integrated community TB support.
- Discussion of the framework for the integrated community TB support by the facilitator with a short presentation of the principles by the facilitator.

Materials:

- Projector and computer.
- Case studies.
- Space for breakout groups.
- A flipchart or a computer per group to make presentations.

Module A2

Title: Key TB affected populations and the process of integrated community TB support

Duration: ~5-6 hrs.

Objective: to deepen the participants' knowledge of the key affected populations (KAPs) relevant to their work location and to link KAPs with the process of integrated community TB support.

Target group: Members of the multi-disciplinary teams.

Expected Outcomes:

- Participants can identify their KAPs.
- Participants can describe the processes of integrated community TB support.
- Participants can conduct a client assessment.

Content:

- Key TB affected populations (KAPs)
- Process of integrated community TB support:
    - Opening of a case.
    - Assessment of client social and health situation and need for support.
    - Providing support (informing and educating the client and their family about TB, DOT, knowledge of the actions of TB medications including their associated adverse reactions, promoting treatment literacy and adherence, client empowerment).
    - Closing a case.

Methodology:

- Short lecture on KAPs and an exercise 1: to identify existing KAPs in the localities of the training participants followed by a plenary discussion.
- Facilitator gives a lecture on the process of integrated community TB support.
- Group work on the exercise 2: opening a case, assessment and closing a case. The emphasis is on the assessment of client social and health situation and need for support.

- Exercise 3: participants (working in groups of three) have to describe the process of integrated community TB support to different audiences e.g. 1) a TB patient, 2) a TB patient's family, 3) at a city council meeting, 4) to a prospective supporter. One participant acts as the care provider, one as audience, one makes notes and gives feedback; then they rotate the roles.

Materials:

- Projector and computer.
- Space for breakout groups.
- Instructions for the exercises 1-3.

Resources:

- Stop TB micro guides on key affected populations. http://www.stoptb.org/resources/publications/ [59]
- Providing Comprehensive, Patient-Centered Care. A Conceptual Framework for Social Support of TB Patients, URC (emphasis on chapter "Support needs for vulnerable groups"). http://www.urc-chs.com/sites/default/files/Providing%20Comprehensive%20Care.pdf [60]

OPTIONAL TRAINING MODULES

Module B1

Title: Dealing with emotions and burnout prevention

Duration: ~4-5 hrs.

Objective: to improve the participants' communication skills and help prevent burnout. The idea is to give advice and tools to prevent negative emotions at work.

Expected Outcomes:

- Participants can identify the symptoms of burnout, how it can impact them as caregivers and their clients and what to do to prevent it.

Content:

- Dealing with emotions: changing attitude and behavior, optimistic thinking (LHL manual [61]).
- Causes of burnout and symptoms.
- How to deal with stress and prevent burnout (LHL manual).

Methodology:

- Lecture presentation: lecture part will be very brief only to introduce the principles of positive psychology, optionally also "How to become a more optimistic and solution-oriented thinker" and "coping with different types of problems".
- Facilitated discussion on (1) changing attitude e.g. using "How to make the patient cover his mouth when coughing", communication skills e.g. using "'the traffic light' to deal with anger" (2) the causes of burnout and symptoms, e.g. using "Sharing advice for stress-reduction".

- Exercises “How do you react when you experience a problem/something positive?”

Materials:

- Projector and computer.
- Instructions for the exercises.
- Space for the exercises, including quiet places for meditation practice.

Resources:

- Health Communication for Health Workers Working with TB, LHL [61]

Module B2

Title: Good communication

Duration: ~4-5 hrs.

Objective: to improve the participants’ communication skills.

Expected Outcomes:

- The participants communicate better with their clients and know how to use the “5 minute” communication model.

Content:

- Basic communication skills
    - Becoming aware of our own communication habits
    - Paying attention to non-verbal communication
    - Providing constructive feedback
    - Asking open-ended questions
    - Using active listening
- The “5 minute” communication model
    - Step 1 - How to establish trust
    - Step 2 - How to ensure understanding
    - Step 3 - How to ensure remembering
    - Step 4 - How to ensure motivation

Methodology:

- Lecture presentation: introduction of the “5 minute” communication model.
- Facilitated discussion: what is good communication, potential barriers to good communication and how to overcome them.
- Group exercises: constructive feedback, active listening; practice of the “5 minute” communication model.

Materials:

- Projector and computer.

- Instructions for the exercises.
- Space for the breakout groups.

Resources:

- Health Communication for Health Workers Working with TB, LHL [61]

Module B3

Title: Basic TB

Duration: ~8 hrs.

Objective: to teach practical information about TB that the participants can also use to communicate relevant TB messages to their clients.

Expected Outcomes:

- The participants can take infection control precautions to increase their work safety.
- The participants can explain basic TB information to their clients.

Content:

- TB epidemiology and pathogenesis.
- Drug-resistant TB.
- TB infection control in the community.
- Myths and misconceptions.

Methodology:

- Lecture presentations.
- Practical (group) exercises follow each lecture segment, during these exercises the participants "translate" basics of TB to a simplified form, limited to the essential key points to allow for clear understanding by the prospective clients and prevent information overload.

Materials:

- Existing materials for patients in Romanian.
- Projector and computer.
- Instructions for the exercises.
- Space for the breakout groups.

Module B4

Title: Participation in case management

Duration: ~6 hrs.

Objective: to inform the participants about case management as it applies to their roles as treatment supporters.

Expected Outcomes:

- The participants can describe their role/tasks related to case management.
- The participants practice addressing the clients' housing, addiction, welfare benefits and other social care needs.

Content:

- Practical aspects of case management (including adherence plans and how they are aligned with treatment and monitoring plans of the patient; coordinating with allied providers; patient education and counseling; addressing psycho-social barriers; referrals).

Methodology:

- Lecture presentations on the basics of case management.
- Plenary discussions: the role/tasks related to case management and the relevant Romanian guidelines and protocols.
- Exercises: addressing the clients' social care needs.

Materials:

- Relevant Romanian guidelines and protocols.
- Projector and computer.

Module B5

Title: Side effects of anti-TB treatment

Duration: ~4 hrs.

Objective: to inform the participants about the side effects of anti-TB treatment.

Expected Outcomes:

- The participants can recall the main potential side effects, especially those relevant to the KAPs, know where to find information about side effects and when to escalate care to a higher level.

Content:

- Protocols for assessing adverse reactions, including:
    - Side effects what they mean and how they are manifested.
    - Drug interactions with Antiretroviral Therapy and Opioid Substitution Therapy.

Methodology:

- Lecture presentations: potential side effects/drug interactions, their identification, referral and follow-up.

- Plenary discussion on the necessity of finding out from the TB doctors about the possible side effects/interactions for all clients.
- Individual work and group exercises on communicating about possible side effects/drug interactions with the client (increasing client awareness).

Materials:

- A table of anti-TB drugs used in Romania with their side effects and possible interactions.
- Using the available job aids and simplified protocols, mechanisms that cue the HCW on when and how to perform a task (lists, decision trees, wallet cards and flipbooks)
- Existing materials for patients in Romanian.
- Projector and computer.
- Instructions for individual work and group exercises.

Module B6

Title: Counseling

Duration: ~8 hrs.

Objective: to provide the participants with information and skills to counsel their clients.

Expected Outcomes:

- The training participants can provide different sessions to their clients, using the adherence plan.

Content:

- Adherence plans and steps.
- Counseling sessions:
    - Treatment initiation counseling sessions (treatment literacy, adherence steps).
    - Completion of intensive phase counseling session (revision of treatment literacy messages, revisit adherence steps).
    - Treatment interruption counseling session and follow up support (treatment literacy).
    - M/XDR – TB counseling session (treatment literacy).
    - Palliative care counseling session (conditions, prognosis, practical information).
- Ad hoc counseling and support activities.

Methodology:

- Lecture presentation: adherence plans, basics of counseling.
- Role-plays to practice each counseling session.

Materials:

- Existing materials for patients in Romanian.
- Projector and computer.
- Instructions for the role-plays.

- Space for the breakout groups.

Resources:

- Médecins sans Frontières Khayelitsha, Patient support interventions to improve adherence to drug resistant tuberculosis treatment. Counselling toolkit http://samumsf.org/documents/2014/06/khayelitsha_dr-tb-pt-support.pdf [62]
- Checklists for Patient education/counselling sessions for those with active TB disease, Including drug-resistant TB, MSF OCB, February 2013 https://www.dropbox.com/s/97biu9qbu71897h/PEC%20checklists_TB%20incl%20DR%20TB_Eng_2013.pdf [63]

Module B7

Title: Nutrition health education

Duration: ~3-4 hrs.

Objective: to inform the participants about nutrition and TB

Expected Outcomes:

- The participants can identify symptoms and signs of malnutrition.
- The participants can provide their clients with practical advice on nutrition and on preventing and managing malnutrition.

Content:

- Nutrition and TB:
    - Nutritional requirements of TB clients;
    - Symptoms and signs of malnutrition;
    - Causes and consequences of malnutrition in TB Clients.
- Practical advice on nutrition
- Practical advice on preventing and managing malnutrition.

Methodology:

- Lecture presentation: nutritional requirements, malnutrition.
- Role-play: work in pairs (one on one session) or in small groups (a client and a multi-disciplinary team) to practice giving advice to different types of clients e.g. people who use drugs, rural poor, breast-feeding mothers, children.

Materials:

- Projector and computer.
- Instructions for the role-plays.
- Space for the role-plays.

Resources:

- Nutritional care and support for patients with tuberculosis, Guideline, WHO, 2013 http://apps.who.int/iris/bitstream/10665/94836/1/9789241506410_eng.pdf [64]
- Ghana Nutrition Assessment, Counselling, and Support (NACS): Training Materials for Facility-Based Service Providers http://www.fantaproject.org/countries/ghana/nacs-training-materials [65]

Module B8

Title: Addressing stigma and discrimination

Duration: ~4 hrs.

Objective: to inform the participants about addressing stigma and discrimination throughout their work with the clients.

Expected Outcomes:

- The participants understand what causes stigma and discrimination.
- The participants have the skills to empower their clients in overcoming stigma and addressing discrimination.

Content:

- Forms, effects and causes of TB stigma.
- TB and human rights.
- Addressing stigma and discrimination.
- Client empowerment.

Methodology:

- Lecture presentation.
- Exercises (1) on forms, effects and causes of TB stigma and (2) on client empowerment.
- Plenary discussion.

Materials:

- Projector and computer.
- Materials and instructions for the exercises.

Resources:

- Understanding and challenging TB stigma Toolkit for action, International HIV/AIDS Alliance, 2009. http://targets.lshtm.ac.uk/resources/Publications/TB_and_Stigma_Eng2.pdf [66]

Module B9

Title: self-help groups

Duration: ~6-8 hrs.

Objective: to give the participants practical information on how to engage the TB patients in self-help groups.

Expected Outcomes:

- The participants develop the skills to do mapping.
- The participants understand how to form a self-help group.
- The participants develop/strengthen the skills to conduct a self-help group meeting.

Content:

- Self-help groups: principles;
- Practice:
    - Mapping,
    - Groups initiation,
    - Inter-personal communication and facilitation,
    - Group sessions,
    - Monitoring and evaluating self-help groups.

Methodology:

- Lecture presentation.
- Plenary discussions.
- Group work/exercise (mapping, conducting a self-help group session).

Module B10

Title: Relevant information technology skills

Duration: ~3-4 hrs.

Objective: to teach the participants skills related to recording and reporting of their work as treatment supporters and information technology skills related to the content of their work.

Expected Outcomes:

- The participants can maintain the necessary records.
- The participants know how to operate the relevant equipment e.g. for Video DOT.

Content:

- Relevant reporting and recording forms and guidelines.
- How to provide video DOT.

Methodology:

- Lecture presentation: to explain the recording and reporting requirements for outreach workers and multi-disciplinary teams.
- Practical exercises: (1) recording and reporting, (2) a video DOT session.

Materials:

- Required reporting and recording forms.
- Relevant equipment e.g. for Video DOT.

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