# Initial work of the Wolfheze Working Group on People Centred Care (PCC)

***A review of PCC research already available in the EECA region***

***May 2019***

**Background**

At the last Wolfheze Workshop held in May 2017, a People Centred Care working group was established to:

Promote and assist the implementation of quality people-centred care across the Eastern Europe and Central Asia (EECA) region by:

- Documenting progress across the region with regards to implementation of PCC, and
- Sharing information among practitioners with regards to operational PCC practice"

As a starting point the working group collated and reviewed the research that is already available on PCC more widely and specifically relating to the EECA region.

## Research Consensus Emerging

**From the research review undertaken, the key emerging themes are detailed below.**

**Sustainability:**
*PCC is key to sustainably eliminating TB. Decentralised services improve access to treatment and together with education, awareness and ownership - a sustainable programme of care can be provided to eliminate the disease.*

**Bundled Interventions:**
*Single interventions are not effective in isolation – real benefit is generated from a number of interventions being provided together. For instance, local healthcare access, education, awareness and integration between service providers.*

**Funding structures:**
*The funding structures in countries needs to align with and support decentralised services rather than incentivising a centralised structure.*

**Change process**
*Key enablers of change include, constructing a compelling vision, aligning change with health building blocks (finance, governance, delivery), coordinating and communication with key stakeholders and enlisting the help of change agents is critical to the implementation of an effective PCC approach.*

**Ethics**:
There is an intrinsic link between PCC and ethics. An effective PCC model will be an ethical model.

**Case Studies:**
Learnings can be taken from other countries (such as Kazakhstan, Tajikistan, Ukraine amongst others) on PCC models/initiatives that have been implemented or piloted in terms of what practices have worked and any practical challenges encountered.

## Research Overview

| Organisation | Key points |
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| **KNCV**<br><br>**Finding, Diagnosing and Curing TB Patients in Central Asia**<br><br>*https://www.kncvtbc.org/uploaded/2015/10/finding_diagnosing_and_curing_tb_patients_in_central_asia_web.pdf* | • Between 2011-14 a number of policy documents and guidelines were issued for TB control under TB CARE 1 project (www.tbcare1.org) including policy regulations on psychosocial support to TB patients and scale up of ambulatory care.<br>• KNCV promotes PCC approach with the adoption of comprehensive outpatient care considering the negative social, physiological and emotional effects hospital admissions can have on TB patients (especially children) and entire families.<br>• Essential element of outpatient care is the establishment and institutional adoption of sustainable comprehensive psychosocial support system (including psychologists and social workers on staff lists).<br>• Kazakhstan successfully piloted outpatient care in Akmola region which reached 32% in 2013 compared to 10% in 2011<br>• 2013 KNCV initiated the revision of national policy for the management of TB in children in Kazakhstan to be centred around ambulatory care including home support for children<br>• Operational research studies conducted on:<br>  o The introduction of outpatient treatment of Akmola region<br>  o The effectiveness of psychosocial support in Eastern Kazakhstan. |
| **KNCV**<br><br>**Reaching Patients Worldwide**<br><br>*https://www.kncvtbc.org/uploaded/2015/11/KNCV1554_3Reaching-patients-worldwide.pdf* | • Importance of health programmes for healthcare workers, patient and community organisations to build knowledge and patient education skills.<br>• Efficiency, respect and good communication are key virtues for healthcare workers. Comfortable waiting rooms with educational material and messages and trained members from patient organisations to help patients find their way around health facilities.<br>• Involvement of ex-patients is key to help empathise to health workers the impact on patients in terms of stigma, depression and the gruelling treatment.<br>• KNCV has developed a patient centric approach package in collaboration with Royal Tropical Institute (KIT). This package assists National programmes. The package includes:<br>- Quote TB Tool<br>- Tools to estimate patient costs<br>- Patients charter for TB care |

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- TB Literacy toolkit<br>
- A practical guide to improving quality TB patient care.<br>
• Private sector often first point of call for patients. Can lead to poor outcomes when the wrong regime prescribed, or patients can’t afford the treatment any longer.<br>
• In Tajikistan, KNCV have successfully piloted the transition from hospital- based care to outpatient care. The country has adopted this as national policy and law. This system reduces both health care costs and patient costs and leads to better outcomes.
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<tr><td>Compendium of good practices in the implementation of the Tuberculosis Action Plan for the WHO European Region 2016–2020<br><br>Equitable access to high-quality treatment and a continuum of care for all people with TB, including DRTB, and support to facilitate adherence to treatment section Pages 47 -67<br><br>http://www.euro.who.int/en/publications/abstracts/compendium-of-good-practices-in-the-implementation-of-the-tuberculosis-action-plan-for-the-who-european-region-20162020</td><td>
• This report identifies the following areas of intervention for integrated PCC and prevention<br>
o Systematic screening of contacts and high-risk groups<br>
o Early diagnosis of all forms of TB and universal access to drug-susceptibility testing, including with rapid tests<br>
o Equitable access to high-quality treatment and a continuum of care for all people with TB, including DRTB, and support to facilitate adherence to treatment<br>
o Collaborative TB/HIV activities and management of comorbid conditions<br>
o Management of latent TB infection, preventive treatment of people at high risk and vaccination against TB<br>
• Good practices recognised in implementing the TB Action Plan 2016-20 have been evaluated against the criteria of Relevance, Sustainability, Efficiency, Ethically appropriateness, Equity/Gender, Effectiveness, Possibility for scale-up, Partnership, Community Involvement, Political Commitment.<br>
• The report provides valuable case studies on practices countries have deployed in terms of new practices on screening, contact tracing, ensuring the quality of medicines to ISO 7025 and development of new sputum transportation systems. Specific case studies on equitable access to high-quality treatment and a continuum of care for all people with TB, include:<br>
o Azerbaijan. Treatment of XDR-TB.<br>
▪ In April 2017 with support of Global Fund re-purposed anti TB drugs procured and imported into the country.<br>
▪ Before launch of XDR Treatment Programme, NTP Working group took a number of measures:<br>
▪ New protocols for DSTB and DR-TB management developed based on the most up-to-date WHO guidelines available.<br>
▪ Lead specialists trained in Latvia and Belarus, where XDR-TB treatment is successful.
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| | ▪ Special directly observed treatment (DOT) sites were established. Particular attention was paid to ensuring all infection control measures were in place.<br>▪ Criteria for inclusion in the XDR-TB treatment programme included patient consent and commitment to treatment. Given the toxicity of drugs used in XDR-TB, patients aged over 65 years, with diabetes, HIV infection, hepatitis or severe renal failure, and with reported harmful use of alcohol or substance abuse were considered with caution.<br>▪ Treatment of XDR-TB patients monitored in both inpatient and outpatient settings. Patients have the opportunity to be examined by a range of specialists including cardiologists, ear, nose and throat doctors, ophthalmologists, and neuropathologists.<br>▪ TB treatment had a positive impact on the patients' quality of life and helped reduce the risk of TB infection.<br>○ **Examples of VOTS: Georgia, Kazakhstan, Russian Federation. VOT Voronezh region**<br>▪ Lack of injectable agents in treatment regimens a prerequisite for VOT monitoring.<br>▪ Training on technologies to be use Skype, WhatsApp's, Viber...)<br>▪ In Georgia VOT was implemented with the use of mobile telephones purchased with financial support from the Global Fund and provided to the patients for their temporary use during treatment.<br>▪ Benefits of VOT's: alleviate the workload of health-care facilities, more rational use of resources; improve treatment adherence and reduce stigmatization for TB patients; save transportation costs (especially important for patients from more remote areas) and free up patients' time; avoiding the inconveniences irritability and aggression in patients associated with long trips, coupled with the side-effects experienced directly after taking drugs (e.g. on the way home), the level of confidentiality is higher with this approach to taking medications, improves patient self-esteem and gives a feeling of returning to normal life in the society.<br>▪ Patient commitment to VOT's is essential. If contact is not made, follow up through case management.<br>▪ New approaches using technologies are becoming more broadly utilized as part of a significant trend in the worldwide phthisiatric community. Given the increasing use of various mobile communication gadgets among people of all age groups, VOTS should make a positive impact on treatment adherence to anti-TB regimens.<br>○ **Examples of Mobile DOTS:** |

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| | ▪ Georgia: Mobile DOT clinic used TB patients receiving treatment for DS-TB and MDR-TB. a specialized, high-tech minivan equipped with infection control measures and adapted for the adequate, on-the-spot DOT.<br>▪ This service was available for the patients residing in remote areas and those with injectable agents in their treatment regimens, disabilities or no internet access.<br>▪ With the help of new types of DOT, the TB service facilitated adherence to treatment and adapted the treatment to patient needs, thereby reducing stigma, increasing adherence and improving the quality of treatment.<br>○ **Call Centre: Russian Federation. The system of coverage of TB patients by mobile communication (call centre) enables the remote monitoring of treatment in outpatient settings.**<br>▪ The low population density and large area, the Irkutsk region has several hard-to-reach areas and territories, where access to medical care is low.<br>▪ A call centre was established in the Region Clinical Tuberculosis Hospital (IRCTH) for treatment monitoring<br>▪ A medical registrar operates the call centre, keeping records of all calls sent and received. Each patient signs an agreement with a district TB specialist to receive daily calls with a reminder of the need to take a dose of anti-TB drugs and agrees to answer the calls. Patients also have to provide telephone numbers of their close relatives or friends so that they can be contacted if information on anti-TB drug self-administration is missing. In addition to the agreement, patients receive a Memo for interaction with the call centre containing information on how to receive and reply to the telephone messages, and a questionnaire for evaluating the work of the call centre.<br>▪ Every day patients receive an automatic telephone call reminding them of the need to take their anti-TB drugs. Upon receiving the call, patients confirm the drug intake by pressing a number on the telephone keypad and use the interactive menu to confirm intake of the drug. The medical registrar analyses the list of received calls from patients. In the absence of a response from the patient, a second call (in manual mode) with a notification to self-administer the anti-TB drugs.<br>▪ Patients treated with the help of the call centre noted that they received more attention from medical staff, felt more trusted and more confident in their ability to be cured. This indicates an increased likelihood of adherence to the TB treatment.<br>○ **Ukraine. Results-based social support of outpatient DS-TB treatment** |

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| | ▪ The high TB morbidity rate in Ukraine strongly correlates with status of economic development and persistent military conflict in the country. This relationship is supported by the consistently high proportion of unemployed individuals among TB patients (52–59%).<br>▪ According to surveys and questionnaires, in 2016 the typical TB patient profile was: unemployed and indigent people and those living below the poverty line.<br>▪ Aim to establish a sustainable system to provide outpatient DOT for TB (including DR-TB and TB/HIV coinfection) to patients at risk of treatment interruption.<br>▪ Premise of model implemented on integrated people-centred approach by providing social and health-care services; daily delivery and control over taking anti-TB drugs by a DOT provider; and results-based financing.<br>▪ The integrated people-centred approach assumed a personalized approach to treating each individual patient in order to resolve socio-psychological issues such as document renewal, employment, legal advice, psychological counselling, housing, clothing and other needs, and linking these to health-care services<br>o **Ukraine. Use of international treatment protocols and best practices in care provision, including TB services, in Ukraine**<br>▪ The Ukrainian Ministry of Health made a political decision to allow the use of international clinical protocols in the work of physicians as an important component of progress towards health-care reform in Ukraine.<br>▪ International treatment protocols are people centred and their implementation help improve patient health. Protocols on the use of effective, evidence-based diagnostic and treatment methods will have an impact on the treatment success rate, ultimately leading to a reduction in morbidity and mortality rates and improvement in patient quality of life. The protocols guarantee an equally high level of care to each patient, regardless of the hospital and physician providing it. |
| **WHO**<br><br>**Ukraine to implement a new integrated approach to TB prevention and care (May 2018)** | • Ukrainian government, policy-makers and non-governmental organizations have committed to support country progress towards achieving the goals of the Tuberculosis Action Plan for the WHO European Region 2016–2020.<br>• In 2018 Ukraine started implementing a new approach to TB control aimed at improving detection, treatment and financing of tuberculosis (TB) health-care services.<br>• The most significant change, included the shift from long-term hospitalization to outpatient treatment, |

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| *http://www.euro.who.int/en/health-topics/communicable-diseases/tuberculosis/news/news/2018/5/ukraine-to-implement-a-new-integrated-approach-to-tb-prevention-and-care* | • In Ukraine, the average hospitalization period for TB patients is 1.5 months, rising to 5 months for those with multidrug-resistant forms. This will be reduced to approximately 15 days in accordance with international standards,"<br>• Dmytro Sherembey, head of the largest national patient organization, the All-Ukrainian Network of People Living with HIV. “The old model, keeping patients in hospital for months, puts patients at risk because of exposure to potential re-infection. In addition, outpatient treatment avoids patient isolation, and helps them to maintain their work and social life.”<br><br>The Ministry of Health foresees the adoption of the new National TB Control Programme in the near future. One of its most important elements is financial security. “Starting from this year, for the first time, TB patients in Ukraine will receive state-funded treatment,” according to Deputy Minister of Health, Olga Stefanyshyna. |
| **WHO**<br><br>**WHO issues ethics guidance to protect rights of TB patients, (March 2017)**<br><br>*https://www.who.int/news-room/detail/22-03-2017-who-issues-ethics-guidance-to-protect-rights-of-tb-patients* | Five key ethical obligations for governments, health workers, care providers, non-governmental organizations, researchers and other stakeholders to:<br><br>• provide patients with the social support they need to fulfil their responsibilities<br>• refrain from isolating TB patients before exhausting all options to enable treatment adherence and only under very specific conditions<br>• enable “key populations” to access same standard of care offered to other citizens<br>• ensure all health workers operate in a safe environment<br>• rapidly share evidence from research to inform national and global TB policy updates. |
| **WHO**<br><br>**Companion Handbook, Patient Centred Care, social support and adherence to treatment (chapter 12)**<br><br>*https://apps.who.int/iris/bitstream/handle/10665/130918/9789241548809_eng.pdf?sequence=1* | *Note: [This is worth reading for real tangible action that can be taken to implement patient centred care.]*<br><br>• DR TB, advisable all patient’s complete treatment under DOTS with a strict patient centred focus adhering to sound ethics and respect for human rights.<br>• Adherence to DOT influenced by serval factors individual (knowledge, attitude, beliefs), health care system, economics (patients’ financial situation), social (community resources to prevent stigma and discrimination).<br>• Large body of evidence has shown social support is predicator of health status and mortality. |

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| | • Four social support functions fundamental to patient centred care include Information (education, awareness to communicate with not talk at patients. Where there are literacy limitations use visual and audio e-tools. Prevent the use of derogative and judgmental language, patient charter), emotional (empathy, trust), companionship (you are not alone), material (financial, assistance with daily hurdles). To be age effective and gender sensitive.<br>• Need real appreciation that TB affects all aspects of a person's life.<br>• Outlines key principles/actions on how patient centred care can be delivered.<br>• Close alignment between ethics and patient centric care. |
| **WHO**<br><br>**Guidelines for treatment of drug-susceptible tuberculosis and patient care (2017 update)**<br><br>*https://www.who.int/tb/publications/2017/dstb_guidance_2017/en/* | • DOT based treatment more effective in HIV positive patients compared to Self-Administered Treatment (SAT)<br>• DOT administered by trained healthcare workers/lay people more effective then family members.<br>• Community based DOT more effective than health care facility-based DOT<br>• DOT same level of effectiveness as VOT (Video Observed Treatment), With technology becoming widespread and the flexibility provided by VOT together with the lower levels of resource burden on health care systems this may become much more integral to treatment plans in coming years.<br>• Higher rates of treatment success when DOT or SAT's were combined with other treatment interventions such as information, material support, psychological support, staff education all factors found to improve successful treatment outcomes.<br>• A review of centralised versus decentralised treatment of MDR was examined. The analysis of the data showed treatment success was improved with decentralised care. |
| **WHO Europe**<br><br>**A People-centred model of tuberculosis care** | • Integrated health services delivery model complements the people centred models of care.<br>• TB a social disease requiring many months of treatment makes it suitable for a people centred approach. For this to work need an embedded community healthcare system which is widely accessible to patients.<br>• The accumulated evidence supports WHO's recommendations to provide TB care mainly in the ambulatory and community settings, conditional on infection control measures, patients' clinical conditions, availability of treatment support to facilitate adherence to treatment and provisions for a back-up facility to manage patients who need inpatient treatment care. |

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| **A blueprint for Eastern European and central Asian countries, first edition (prepared in connection with the TB-Rep project)**<br><br>http://www.euro.who.int/__data/assets/pdf_file/0004/342373/TB_Content_WHO_PRO_eng_final.pdf | • A people-centred model of TB care should be designed to ensure that, services meet patients' and their families' needs and expectations;<br>-social determinants of health are taken into consideration;<br>-services, tasks and responsibilities are defined for each setting and within different facilities, while recognizing the need for flexibility to respond to the needs of individual patients;<br>-well functioning systems for referral are in place across various settings and facilities;<br>-the model of care is acceptable to service users; a robust data-reporting system is in place to monitor performance, including diagnostic delay and loss to follow-up; patients and their families are protected from catastrophic financial expenses.<br>• Misconceptions from some stakeholder groups:<br>-all TB patients are infectious irrespective of their treatment stage;<br>-patients with TB cannot contribute to the community (i.e. they are unable to work);<br>-hospitalization of patients with TB is necessary to ensure adherence to treatment and infection control.<br>• Any delay in treatment initiation increases the possibility of transmission and of losing patients to follow-up. Consequently, a high level of awareness of TB among the population and health care professionals is essential.<br>• Incentives traditionally provided to hospitals need to change so that community-based care is more heavily incentivised.<br>• Countries are advised to adopt fee-for-service programmes for screening, diagnosis and provision of treatment at ambulatory care, as these can provide financial incentives to reduce delays in diagnosis and treatment access. A pay-for-performance programme, such as rewarding completion of TB treatment, should also be implemented to enhance the incentive to reduce TB-related hospitalization and, as a result, total treatment costs. All countries could use non-financial incentives, such as presenting awards to the best performing providers and publishing performance data on each provider.<br>• Funding models – If ambulatory care is part of the hospital set up, incentivising per TB patient regardless of whether care is provided as inpatient or outpatient. If separate, outpatient to control budgets and if in patient care is required, the hospital provider to claim from the outpatient provider.<br>• To facilitate PCC – moving delivery from in patient to out-patient care (task shifting) is required with this movement of delivery appropriately reflected in patient care pathways.<br>• Capacity building and education through CPD whereby health professionals can collect credits for training activities which are ultimately tied to certification and licensing. |

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| | • Policy-makers, professionals and citizens are increasingly recognizing that the current models of care and vertical orientation of health systems are no longer sustainable, from cost, quality and patient satisfaction perspectives. Instead, taking steps towards implementing people-centred health systems and services is becoming a high priority.<br>• “Health system transformation: making it happen” workstream identified some of the critical enablers of change are the following:<br>- Articulate long term vision to unite stakeholders<br>- Use a systems perspective and ensuring where possible change is aligned with health building blocks (finance, governance, delivery)<br>- Stakeholder mapping to identify factors which may inhibit, enable or engage influential stakeholders<br>- communicating a strategic vision and inspirational narrative can be important in bringing stakeholders together.<br>- integration of high-quality evidence in the development of health policies and management critical to ensure policies are best suited to desired outcomes.<br>- Change agents can engage a critical mass of stakeholders promoting transformational agenda.<br>- Keeping stakeholders informed and energized by communicating and disseminating early successes<br>- combining top-down with bottom-up implementation, is important to generate innovation and sustainable investment.<br>- balancing big bang and incremental change – the old and new<br>- complex large-scale shifts in health policy must spread across many stakeholders and sectors, institutionalizing change – boundary spanners<br>- Change agents will need to take time and space to think through the right vision and narrative for change, to develop trust between partners and to answer questions to reassure stakeholders. |
| **ECDC**<br><br>**Interventions in vulnerable groups are the key to eliminating tuberculosis in Europe** | • The challenge to eliminating TB is in the pockets of TB that exist with vulnerable groups<br>• Crucial that TB is identified and treated in these groups to stop the spread of MDR TB and the spread to wider population.<br>• Tailored intervention is key to reach these groups and could consist of outreach teams and mobile units, incentives such as food coupons, covering travel costs, involvement of key partners such as peers from community, DOTs/VOTs, integrated services between providers, promoting awareness and training. |

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| https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/tb-interventions-vulnerable-populations-policy-briefing.pdf | • Examples outside of EECA include VOTs used in the UK London-based Find & Treat team, outreach team and integrated services in France provided by Equipe Mobile de Lutte centre la Tuberculosis (EMLT) and involving key partners in Slovakia with the Roma Community.<br>• Useful graphics included showing TB is the second highest burden infection disease, how it is concentrated amongst vulnerable groups and also the extensive cost of treating MDR cases. |
| **ECDC**<br><br>**Guidance on TB control in vulnerable and hard to reach populations**<br><br>https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/TB-guidance-interventions-vulnerable-groups.pdf | • When developing communications, education programmes consider barriers such as organisation barriers, lack of access to services, lack of understanding and trust between health providers.<br>• Emphasises the importance of addressing structural determinants such as poverty and overcrowding as well as TB specific interventions.<br>• As TB incidence drops in countries, the disease becomes concentrated in the lower end of socio-economic populations.<br>• The cost of treating TB in vulnerable groups can be high due to the human resource effort required which has implications for public health spending. As rates decline the funding should not decline at the same rate as the cost of reaching the vulnerable groups can be relatively high.<br>• Guiding principles when working with vulnerable groups: reduce poverty and social exclusion, equitable access to healthcare & social services, Patient centred approach, reach beyond health sector, integration of services, gender and cultural sensitivity, non-stigmatisation and respect, empowerment and participation.<br>• Moderate evidence for promoting early diagnosis through the use of mobile x-ray units. Moderate evidence on uptake in screening if financial incentives offered and use of peer/community individuals to help with promoting screening.<br>• Moderate evidence that reminder systems helped improve treatment outcomes, moderate evidence that financial incentives to aid adherence to DOTS for drug users helped. Moderate evidence that treatment completion can be improved through enhanced case management for drug users and the engagement of non-clinical professionals in outreach work.<br>• Barriers to diagnosis include – lack of knowledge about TB and the fear of death. Inadequate compliance to treatment due to the long duration, feeling better quickly. Access to healthcare also cited as a barrier with regards to lack of information on the available centres and also communication/language barriers. A perceived lack of confidentiality also showed moderate evidence to indicate lack of compliance. |

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| **Medecins Sans Frontieres and Stop TB Partnership**<br><br>**Out of Step in EECA. Nov 2017**<br><br>http://www.stoptb.org/assets/documents/outofstep/TB_Report_OutOfStepInEECA_ENG_2017.pdf | • Report considers TB diagnosis and treatment challenges in 12 EECA countries and presents results on 8 country (Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Russian Federation, Tajikistan and Ukraine) survey of national TB policies and practices to identify where they need to focus their efforts to be more effective.<br>• Research undertaken in the form of desktop research, policy review and questionnaires sent to NTP's. The questionnaire had 2 parts with the first part focused on whether national policies were aligned with the WHO guidance and the 2nd part about the implementation.<br>• Report advocates once diagnosed, on going care must be patient centric. WHO recognised this to be the case 50 years ago - ambulatory care was best use of limited resources. Decentralising treatment removes a bottleneck, is more cost effective, is preferred by patients and is as effective as hospital-based approaches.<br>• Shift from compulsory hospitalisation to ambulatory care has been stalled by the slow pace of much needed health reform.<br>• Drug susceptible TB at primary healthcare level only recommended in policies by 37% (3 EECA countries) with only Kazakhstan implementing this policy widely.<br>• Of the 63% (5 countries) that initiate DR TB at the district level, only 60% implemented it widely.<br>• Although hospital-based treatment should be reserved for the sickest patients 75% (6 countries) required hospital treatment for nearly all patients.<br>• Patient centred care should match services to the needs of patients and their families, taking into account social determinants, adapt services to different settings, recognise the need for flexibility, ensure well-functioning referral systems, robust data reporting and protect patients/families from financial loss.<br>• Common myths: hospitalisation is necessary to ensure adherence and that all people with TB are infectious.<br>• A single day of hospital care can cost 15 times more than an out-patient visit.<br>• Compulsory hospital stay can facilitate the spread of TB because of lengthy delays prior to treatment and poor infection control in hospitals.<br>• TB services should be integrated into broader health and social systems HIV/Aids, diabetes.<br>• Overall goal of TB-REP is to reduce burden of TB and halt the spread of resistance by increasing political commitment and translating evidence into the implementation of people centred care model of TB care. Blueprint for EECA builds on the TB REP framework. |