

# Patients' perspective

Results of in-depth interviews conducted  
by TBpeople within the TB-REP project

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# Characteristics of respondents

- Sample size: 12 respondents
- Countries: Belarus (1), Georgia (1), Kazakhstan (1), Kyrgyzstan (1), Moldova (1), Russia (4), Ukraine (2), Uzbekistan (1)
- 8 women, 4 men
- Age groups: 20-30 y.o. (2), 31-45 y.o. (7), 46 and older (3)
- Types of TB: DS TB, MDR TB, XDR TB
- 5 respondents – repeated treatment

# Definition

*person-centered TB care means providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions*

# Diagnosis

- Up to 4 months from first contact with doctor to the diagnosis (2 respondents)
- Wrong initial diagnosis: 6 respondents (pneumonia, allergic bronchitis); 4 respondents were hospitalized
- TB detected “accidentally”: 5 respondents
- Counselling: 8 respondents received counselling, 6 respondents were not counselled
- Counselling rating – from 0 to 5

*“I had to pull out information out of doctors. I felt – and based on what I know now – doctors were probably not very competent. And clearly not interested to give counselling. There are so many patients – a real flood”*

*“I got information from Internet and not from the doctor”*

# Treatment

- Treated in the hospital: 11 respondents
- Assess hospitalization positively: 3
- Side effects: 12 respondents; informed the doctor: 12; help received: 4; help not received: 9
- Adherence: 10 respondents
- Types of support received:
  - Financial incentives (1)
  - Counselling (7)
  - Support from other people on treatment (7)
  - Family support (8)
  - Transportation costs covered (2)
  - Food parcels (4)
  - Other: support from friends (1)
- Did not get any support: 2 respondents

*«Even though I had a smear negative TB and I was not infectious, they wanted to admit me to the hospital... I understand that the minute I cross the doorstep of the TB hospital, I get into an environment that is dangerous for me. Dangerous for cross infection*

*«If to compare, in hospital is better, because I am always supervised by a physician. In the ambulatory it is challenging with tests. Until you get one, is an issue.*

# Co-morbidities

- HIV (5)
  - Diabetes (2)
  - Drug use (2)
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- Challenges in diagnosing comorbidities
  - Service integration is necessary

# Psychosocial support, stigma and discrimination

- The need of psychosocial support has been stated by 10 respondents, just 1 said s/he did not needed it
- All respondents mentioned stigma in the society towards TB patients. When a patient said he did not face stigma, was because he did not disclose the TB diagnosis.
- 4 respondents, were confronted with discrimination related to TB diagnosis

*«Support is needed so that person first starts the treatment then finalizes it. An not just **completed treatment but cured.**»*

*«... the psychologist came and discussed with patients. I think this was the best time of my ambulatory treatment.»*

*«I needed a psychologist, but I did not see one»*

*«My doctor told me: «Do not tell anyone, you will be labeled, and you are young woman»»*

*«I had to not disclose, because I saw the attitude of people towards TB. Literally, we are perceived as **outcasts**»*

*«With only social workers nothing will be changed. Global projects are needed to decrease stigma and discrimination»*

# Patient involvement

- Respondents have mentioned the importance of involvement in response to TB:
  - Patient support
  - Advocacy
  - Fighting stigma
  - Information campaigns
- Needs:
  - Funding
  - Acknowledging patients as partners in the fight against TB; interaction with state
  - Introducing peer counselors