Challenges in diagnosing extrapulmonary tuberculosis in the European Union

Ivan Solovic, Jerker Jonsson, Maria Korzeniewska-Koseła, Domnica Ioana Chiotan, Analita Pace-Asciak, Erika Slump, Rudolf Rumetshofer, Ibrahim Abubakar, Stanislav Kos, Petra Svetina-Sorli, Walter Haas, Torsten Bauer, Andreas Sandgren, Marieke J. van der Werf
Extrapulmonary tuberculosis  EPTB

• Tuberculosis (TB) is an airborne infectious disease caused by *Mycobacterium tuberculosis*. It most commonly affects the lungs, but it can affect virtually any organ.

• A case with TB in any site other than pulmonary is considered an extrapulmonary TB case.

• In 2011, globally 6.2 million TB cases were notified and 0.8 million cases with extrapulmonary TB (EPTB).
Epidemiological data

• In the European Union (EU) 16,116 extrapulmonary tuberculosis (EPTB) cases were notified in 2011.

• The percentage of TB cases with EPTB ranged from 4% to 48% in the reporting countries. This difference might be explained by differences in risk factors for EPTB or challenges in diagnosis.

• To assess the challenges in diagnosis we asked European Union/European Economic Area (EU/EEA) countries for a description of the diagnostic procedures and challenges in diagnosing EPTB.
Austria

- In 2011 all TB cases 687 – 8,2/100000pop.
- EPTB 136 cases – 1,6/100000pop. 19,8%
- Guidelines for diagnosis of EPTB - no
- Who is in charge of diagnosing and treating EPTB - majority at pulmonary in-patient clinics
- What are specific challenges in the diagnosis of EPTB - is not often considered as potential differential diagnosis
Czech republic

- In 2011 all TB cases: $600 - 5.7/100000$ pop.
- EPTB: 78 cases – $0.7/100000$ pop. 13%
- Guidelines for diagnosis of EPTB: yes
- Who is in charge of diagnosing and treating EPTB: majority by pneumologist in cooperation with relevant specialist
- What are specific challenges in the diagnosis of EPTB: low level of bacteriological confirmation
Germany

• In 2011 all TB cases **4316 – 5,3/100000pop.**

• **EPTB 926 cases – 1,1/100000pop. 21,5%**

• Guidelines for diagnosis of EPTB - **no**

• **Who is in charge of diagnosing and treating EPTB** - pulmonary or infectious diseases specialist

• **What are specific challenges in the diagnosis of EPTB** - CNS TB – lowest culture confirmation
Malta

- In 2011 all TB cases 33 – 7,9/100000pop.
- EPTB 11 cases – 2,6/100000pop. 33,3%
- Guidelines for diagnosis of EPTB - yes
- Who is in charge of diagnosing and treating EPTB - infectious diseases/TB specialist
- What are specific challenges in the diagnosis of EPTB - detection of cases in undocumented African migrants. EPTB (except thoracic EPTB) is detected by passive surveillance
Netherland

• In 2011 all TB cases 1007 – 6,0/100000pop.
• EPTB 441 cases – 2,6/100000pop. 43,8%
• Guidelines for diagnosis of EPTB - yes
• Who is in charge of diagnosing and treating EPTB - majority by lung physicians
• What are specific challenges in the diagnosis of EPTB - to maintain sufficient knowledge among clinicians to avoid diagnostic delays and the confirmation of the diagnosis of EPTB.
Poland

• In 2011 all TB cases 8478 – 22,2/100000pop.
• EPTB 599 cases – 11,6/100000pop. 7,1%
• Guidelines for diagnosis of EPTB - yes
• Who is in charge of diagnosing and treating EPTB - majority by pulmonologist
• What are specific challenges in the diagnosis of EPTB - other specialist are not aware of TB
Romania

- In 2011 all TB cases **19212** – **89,7/100000pop.**
- EPTB **2781 cases** – **13,0/100000pop. 14,5%**
- Guidelines for diagnosis of EPTB - **no**
- **Who is in charge of diagnosing and treating EPTB** - organ specific specialist, treatment by pulmonologist
- **What are specific challenges in the diagnosis of EPTB** - the involvement of different persons in the diagnosis may cause diagnostic delays.
Slovakia

- In 2011 all TB cases **399** – **7,3/100000pop.**
- EPTB **62 cases** – **1,1/100000pop.**  **15,5%**
- Guidelines for diagnosis of EPTB - **yes**
- Who is in charge of diagnosing and treating EPTB - majority by pulmonologist
- What are specific challenges in the diagnosis of EPTB - is too often diagnosed empirically without microbiological confirmation and for this reason often over- and under-diagnosed.
Slovenia

• In 2011 all TB cases **192 – 9,4/100000pop.**
• **EPTB 27 cases – 1,3/100000pop. 14,1%**
• Guidelines for diagnosis of EPTB - **yes**
• **Who is in charge of diagnosing and treating EPTB** - majority by pulmonologist
• **What are specific challenges in the diagnosis of EPTB** - all patients suspected of EPTB should be confirmed by culture before starting treatment
Sweden

• In 2011 all TB cases **586 – 6,2/100000pop.**
• EPTB **228 cases – 2,4/100000pop.  38,9%**
• Guidelines for diagnosis of EPTB  - **yes**
• *Who is in charge of diagnosing and treating EPTB*  - infectious diseases clinics
• *What are specific challenges in the diagnosis of EPTB*  - 70% of EPTB is bacteriologically confirmed
United Kingdom

• In 2011 all TB cases 8963 – 14,3/100000pop.
• EPTB 4313 cases – 6,9/100000pop. 48,1%
• Guidelines for diagnosis of EPTB - yes
• Who is in charge of diagnosing and treating EPTB - organ specific specialist
• What are specific challenges in the diagnosis of EPTB - patients with EPTB are managed with support from experts with knowledge of TB
Country reports

• In the majority of the participating EU countries EPTB is diagnosed by a pulmonologist, sometimes in collaboration with the doctor that is specialized in the organ where the symptoms presented.
• In most countries a medical history and examination is followed by invasive procedures, puncture or biopsy, to collect material for confirmation culture/histology/cytology of the disease.
• Some countries also use the tuberculin skin test or an interferon-gamma-release-assay. A wide variety of radiological tests may be used.
Country reports

• Countries that reported challenges in the diagnosis of EPTB reported that EPTB is often not considered because it is a rare disease and most medical professionals will not have experience in diagnosing EPTB.
• The fact that EPTB can present with a variety of symptoms that may mimic symptoms of other pathologies does pose a further challenge in diagnosis. In addition, obtaining an appropriate sample for confirmation of EPTB was frequently mentioned as a challenge.
Major site of EPTB in 2011 in 11 participating countries

- Lymphatic: 13.5%
- Pleural: 1.3%
- Spinal: 1.9%
- Urogenital: 3.1%
- Bone: 2.7%
- Gastrointestinal: 6.7%
- Meningitis: 7.3%
- Disseminated: 10.3%
- Other Extrapulmonary: 49.4%
Country reports

• In most countries, **the treatment of EPTB is the responsibility of the pulmonologist**. In some countries, such as Sweden and the UK, **infectious disease specialists** are involved or responsible for treatment of EPTB cases. **Paediatricians** are involved in the treatment of **EPTB in children**.

• Since TB and EPTB is a rare disease in most EU/EEA countries **not all clinicians have experience with the treatment**. To guarantee adequate treatment and treatment support TB treatment should be provided by clinicians with ample experience in treating and supporting EPTB patients.
Country reports

• Countries reported large differences in the percentage of EPTB cases that is confirmed, from 10% in Romania to 80% in Sweden.

• **Confirmation of EPTB was frequently mentioned as a challenge** - for a number of reasons: the difficulty to obtain an adequate sample; the apportioning of the sample for various diagnostic tests resulting in non uniform distribution of microorganisms

• **Diagnoses of EPTB without microbiological confirmation may result in over-diagnosis.**
Summary

• **Diagnosis of EPTB** poses challenges due to the diversity of symptoms with which EPTB may present, the low level of suspicion among clinicians, and the difficulty in obtaining an adequate sample for confirmation.

• Raising awareness among non pulmonary physicians about EPTB and guidelines for diagnosis and treatment of EPTB may result in more timely and adequate diagnosis.
Thank for the participation in the Euroroundups