



# Challenges in diagnosing extrapulmonary tuberculosis in the European Union

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# Extrapulmonary tuberculosis EPTB

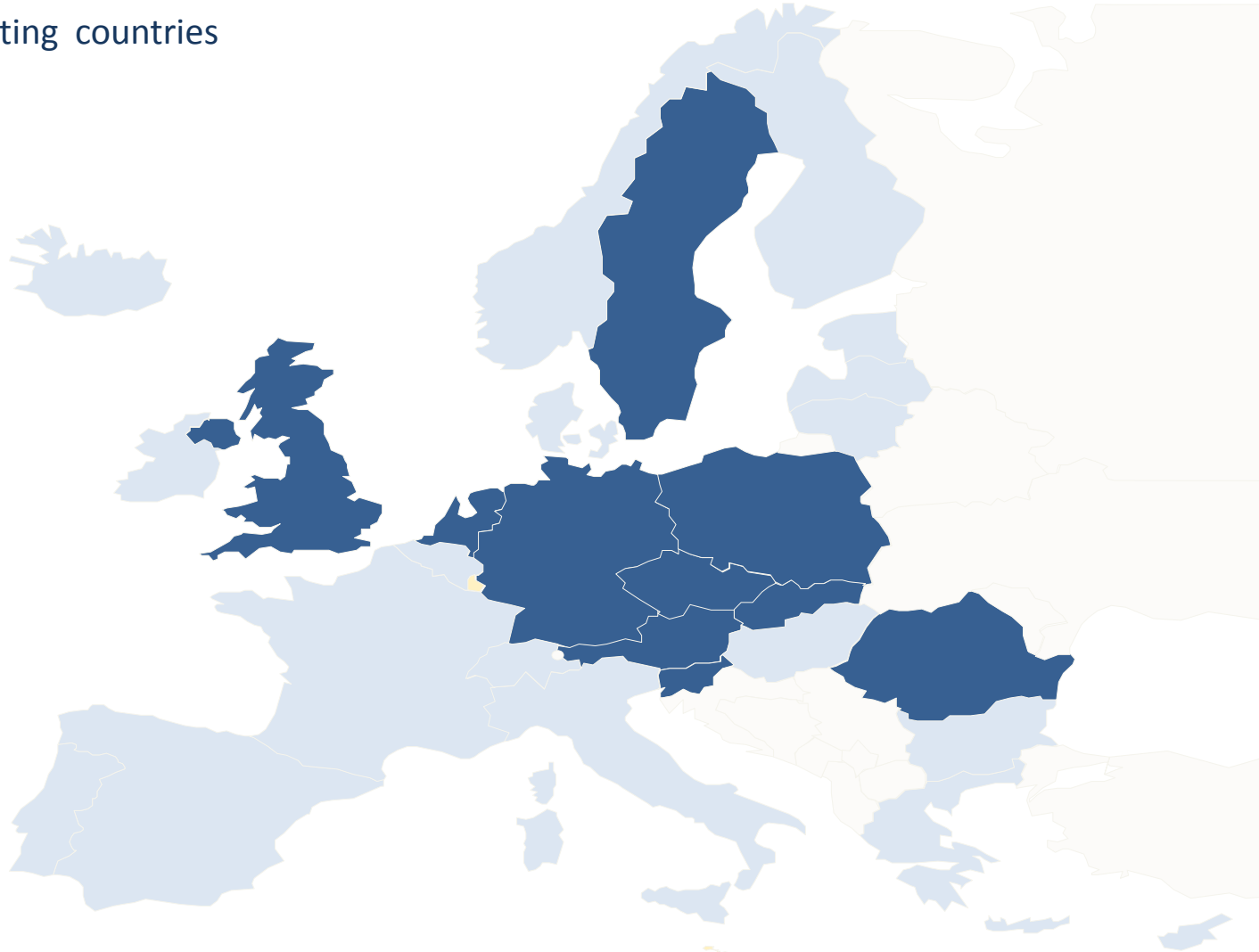
- Tuberculosis (TB) is an airborne infectious disease caused by *Mycobacterium tuberculosis*. It most commonly affects the lungs, but it can affect virtually any organ.
- A case with TB in any site other than pulmonary is considered an extrapulmonary TB case.
- In 2011, globally 6.2 million TB cases 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.*

# Map of participating countries

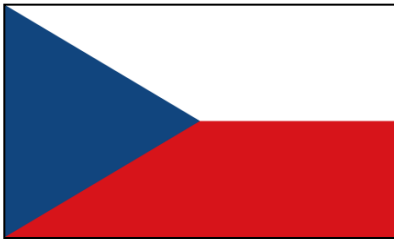
Participating countries





# 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



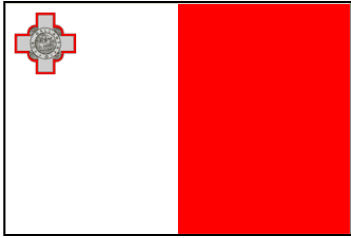
# Czech republic

- In 2011 all TB cases **600 – 5,7/100000pop.**
- EPTB **78 cases – 0,7/100000pop. 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





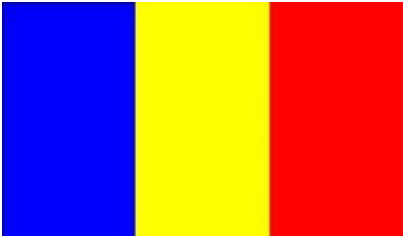
# Netherland

- 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.



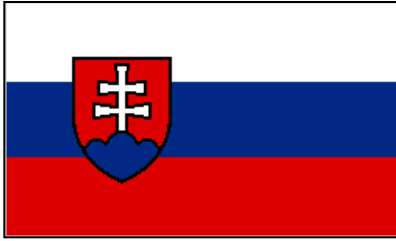
# Poland

- In 2011 all TB cases **8478 – 22,2/100000pop.**
- EPTB **599cases – 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



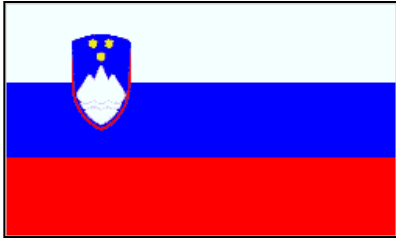
# Romania

- 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- under-diagnosed.



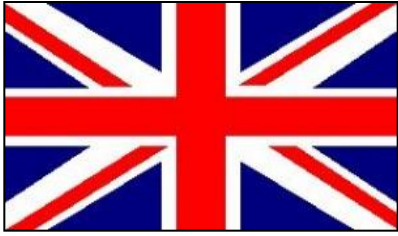
# Slovenia

- 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

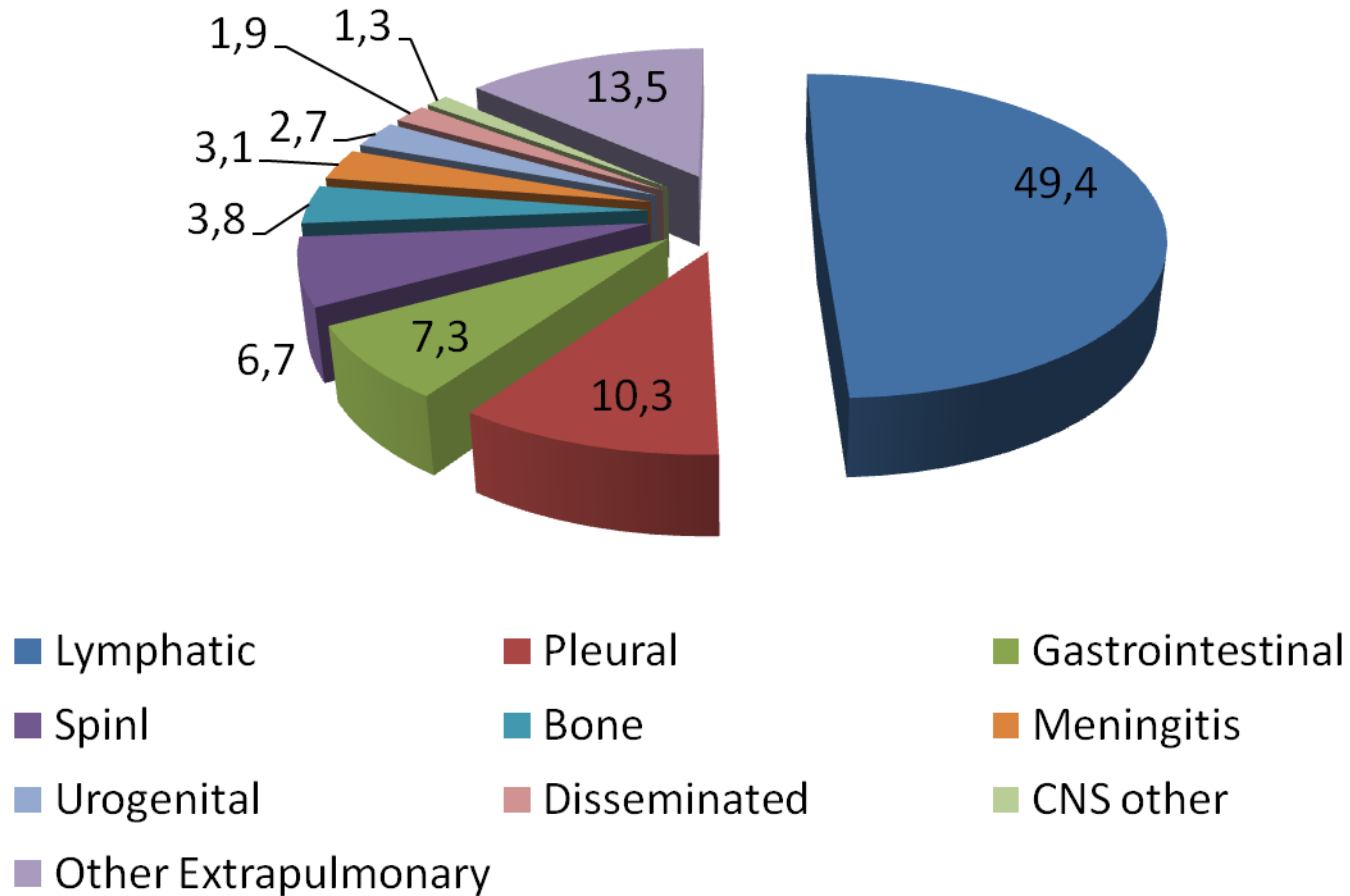
- **In the majority of the participating EU countries EPTB is diagnosed by a pulmonologist**, sometimes in collaboration with the doctor that is specialized in the organ where the symptoms presented.
- In most countries a **medical history and examination is followed by invasive procedures**, puncture 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



# 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

