Patient – Survey

General information through lung association [without patient]

1. Patient-ID:

2. Written consent form:

☐ 1 Yes
☐ 2 No → stop the interview

3. Sex:

☐ 1 Female
☐ 2 Male

4. Birth date:

5. Canton:

☐ 1 Aargau
☐ 2 Basel-Land
☐ 3 Geneva
☐ 4 Solothurn
☐ 5 Vaud
☐ 6 Zurich

6. Language of interview:

☐ 1 German
☐ 2 French
☐ 3 English
☐ 4 Other

7. Carried out with translation service:

☐ 1 Yes
☐ 2 No
A. Background Data

8. In which country were you born?

☐ 1 Switzerland → Please go to question 12
☐ 2 Other, please specify______________________________

9. Since when do you live in Switzerland [Date of Entry]?

<table>
<thead>
<tr>
<th>Day</th>
<th>Month</th>
<th>Year</th>
<th>Don’t know</th>
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</thead>
<tbody>
<tr>
<td>☐ 1 Beginning</td>
<td>☐ 2 Mid</td>
<td>☐ 3 End</td>
<td>☐ 99</td>
</tr>
</tbody>
</table>

10. Have you ever been an asylum seeker in Switzerland?

☐ 1 Yes
☐ 2 No → Please go to question 12
☐ 99 Don’t know / Prefers not to answer this question

11. What is the actual situation or result of your asylum seeking request in Switzerland?

☐ 1 Pending
☐ 2 It was accepted
☐ 3 It was denied/rejected
☐ 99 Don’t know / Prefers not to answer this question

12. What is/are your nationality/-ies?

[Multiple answers]

Nationality/ies ________________________________

13. For how many years did you attend school?

<table>
<thead>
<tr>
<th>Years</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐ 99</td>
</tr>
</tbody>
</table>
B. Start of the [Tuberculosis] disease

14. How did you notice your illness?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

Interviewer: if the patient has taken note of his illness due to symptoms then go to question 16

15. When did you notice your illness? Please tell me the day, month and year as accurately as possible.

<table>
<thead>
<tr>
<th>Day</th>
<th>Month</th>
<th>Year</th>
<th>Don't know</th>
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</thead>
<tbody>
<tr>
<td></td>
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<td>☐ 3 End</td>
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<tr>
<td>☐ 99</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
16. Have you had the following symptoms when suffering tuberculosis disease or have these symptoms worsened due to your tuberculosis disease? If yes, when was that?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Date [dd/mm/yyyy]</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.1</td>
<td>Coughing, with or without sputum from the lung</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.2</td>
<td>Haemoptysis (spitting blood/vomiting blood)</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.3</td>
<td>Fever</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.4</td>
<td>Weight loss</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.5</td>
<td>Increased sweating (particularly at night)</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.6</td>
<td>Tiredness and/or feeling weak</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.7</td>
<td>Chest pain and/or shortness of breath</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
<tr>
<td>16.8</td>
<td>Others; please specify</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
17. When did you realise that you should consult a doctor [because of these symptoms]? Please tell me the day, month and year as accurately as possible.

<table>
<thead>
<tr>
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<th>Year</th>
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</tr>
</thead>
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<td>☐ 2 Mid</td>
<td>☐ 3 End</td>
<td>☐ 99</td>
</tr>
</tbody>
</table>

C. Initial contact with doctor and medication to treat the tuberculosis disease

18. Had you consulted a doctor outside Switzerland because of the [increasing] symptoms (for instance when travelling, in your home country, at your work place)?

☐ 1 Yes
☐ 2 No → Please go to question 20
☐ 99 Don’t know / Prefers not to answer this question → Please go to question 20.

19. When was the first time that you consulted a doctor outside Switzerland due to your [increasing] symptoms? Please tell me the day, month and year as accurately as possible.

<table>
<thead>
<tr>
<th>Day</th>
<th>Month</th>
<th>Year</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
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<td>☐ 2 Mid</td>
<td>☐ 3 End</td>
<td>☐ 99</td>
</tr>
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</table>

20. Under which circumstances did the first contact with a doctor in Switzerland take place that was related to the symptoms of your [tuberculosis] disease [where? why?]?

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
21. When was the first time that you consulted a doctor in Switzerland due to your [increasing] symptoms? Please tell me the day, month and year as accurately as possible.

<table>
<thead>
<tr>
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<td>☐ 3 End</td>
<td>☐ 99</td>
</tr>
</tbody>
</table>

22. In which health structure did this first doctors’ consultation in Switzerland take place?

☐ 1 Family doctor
☐ 2 Clinic of the Reception Centre or clinic of an institution (jail, prison, nursing home)
☐ 3 Medical practice for child and adolescent medicine
☐ 4 Medical practice for pulmonary disease (pneumology)
☐ 5 Permanence/Ambulatory/Drop in Clinic (24/7)/ Emergency practice
☐ 6 Hospital, please specify_____________________________________________
☐ 7 Other, please specify________________________________________________
☐ 99 Don’t know / Prefers not to answer this question

23. Which diagnostic tests were conducted during this first consultation with a doctor in Switzerland?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 99</td>
</tr>
</tbody>
</table>

23.1 Taking of a blood sample.................................................................
23.2 Clinical examination (e.g. stethoscope, physical examination)...........
23.3 Palpation of the lymph nodes ......................................................
23.4 Getting an X-ray...........................................................................
23.5 Submission of a sputum sample .....................................................
23.6 Other, please specify_____________________________________________
24. What was the outcome of this first doctor’s consultation in Switzerland?

- Prescription of medication………………………………………………………………………….. ☐ 1 ☐ 2 ☐ 99
- Wait, if no improvement then 2nd consultation…………………………………………………….. ☐ 1 ☐ 2 ☐ 99
- New appointment for 2nd consultation …………………………………………………………….. ☐ 1 ☐ 2 ☐ 99
- Referral for X-ray……………………………………………………………………………………………….. ☐ 1 ☐ 2 ☐ 99
- Referral to lung specialist……………………………………………………………………………….. ☐ 1 ☐ 2 ☐ 99
- Referral to a hospital……………………………………………………………………………………………….. ☐ 1 ☐ 2 ☐ 99
- Other, please specify______________________________________________________________

25. When did you start taking the tuberculosis medication? Please give me the day, month and year as accurately as possible.

- ☐ 1 Beginning
- ☐ 2 Mid
- ☐ 3 End

Day Month Year

- Don’t know ☐ 99

26. Where have you been prescribed the [tuberculosis] medication?

- ☐ 1 Family doctor
- ☐ 2 Reception Centre (of migrants) or an institution (jail, prison, nursing home)
- ☐ 3 Medical practice for child and adolescent medicine
- ☐ 4 Medical practice for pulmonary disease (pneumology)
- ☐ 5 Permanence/Ambulatory/Drop in Clinic (24/7)/ Emergency practice
- ☐ 6 Hospital, please specify________________________________________________________
- ☐ 7 Other, please specify__________________________________________________________
- ☐ 99 Don’t know / Prefers not to answer this question

27. In total, how many doctors did you see in Switzerland from the onset of the symptoms of the [tuberculosis] disease until you started treatment with tuberculosis medication?

- Number
- Don’t know ☐ 99
28. How many doctors’ appointments did you have in Switzerland from the onset of the symptoms of the [tuberculosis] disease until you started treatment with tuberculosis medication?

☐ 1. 1 or 2 doctor appointments
☐ 2. 3 to 5 doctor appointments
☐ 3. More than 5 doctor appointments
☐ 99. Don’t know / Prefers not to answer this question

D. Personal situation when the symptoms began

29. Which illnesses did you have when the symptoms began?
   [Multiple answers]

☐ 1. COPD / bronchitis /asthma
☐ 2. Diabetes mellitus
☐ 3. Treatment with immune suppressing medication (e.g. rheumatoid arthritis, organ transplantation, multiple sclerosis)
☐ 4. Cancer
☐ 5. Alcoholism / inappropriate consumption of alcohol
☐ 6. Smoker’s cough
☐ 7. Drug addiction
☐ 8. HIV-Infection
☐ 9. Others, please specify __________________________________________________________

30. In what type of accommodation did you live when the symptoms began?

☐ 1. Flat or house (rented (by themselves) or own property)
☐ 2. Institution [e.g. Reception Centre (of migrants) (EVZ); Temporary centre for asylum seekers, home for asylum seekers (house or flat); Shelter for homeless]
    ☐ 2. Single room
    ☐ 3. Shared room
☐ 4. Detention Centre („prison“)
☐ 5. Hospital
☐ 6. Other, please specify: __________________________________________________________
☐ 88. Don’t know / Prefers not to answer this question
E. Personal situation, when you realised that you should seek medical care from a doctor or when entering into Switzerland

31. What were the reasons why you did not immediately seek care from a doctor?
   [Multiple answers possible]

   Financial Aspects
   □ 1. No health insurance / unclear situation with health insurance
   □ 2. Unclear situation on who pays for treatment costs
   □ 3. Fear of high treatment costs

   Other financial aspects, please specify
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

   Aspects related to health provider
   □ 4. Did not get an appointment with a doctor / The appointment I got with a doctor was not timely, meaning it was only after a rather long time.
   □ 5. I did not know to which doctor I should go
   □ 6. Bad experience with doctors

   Other aspects related to the health provider, please specify
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

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1 In case the patient was aware of the need to seek care before immigrating into Switzerland.
**Personal aspects / fears**

☐ 9 Fear of the diagnosis

☐ 10 Fear that I could be diagnosed with tuberculosis

☐ 11 Fear of stigmatisation / exclusion / isolation

☐ 12 Fear of impact on my [legal] residence status / fear of deportation

☐ 13 No time

☐ 14 Language barrier

☐ 15 Thought that the symptoms might still disappear by themselves

**Other personal aspects, please specify**

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

32. Did you think yourself or did someone else mention to you that you could be sick from tuberculosis?

☐ 1 Yes

☐ 2 No

☐ 99 Don’t know / Prefers not to answer this question

33. What did you know about tuberculosis at that time or which experiences did you have with tuberculosis?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
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</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐ 99</td>
</tr>
</tbody>
</table>

33.1 I knew that people can die of tuberculosis ....................... ☐ 1 ☐ 2 ☐ 99

33.2 I knew that tuberculosis can be treated .......................... ☐ 1 ☐ 2 ☐ 99

33.3 I knew that tuberculosis is an infectious disease ............... ☐ 1 ☐ 2 ☐ 99

33.4 I had been sick with tuberculosis previously .................... ☐ 1 ☐ 2 ☐ 99

33.5 I knew people who had fallen ill of tuberculosis .................. ☐ 1 ☐ 2 ☐ 99

33.6 I knew people who had died of tuberculosis ....................... ☐ 1 ☐ 2 ☐ 99

Other, please specify____________________________________________________________

____________________________________________________________________________
34. What [legal] residence status did you have when you realised that you should seek medical care from a doctor or when entering into Switzerland

☐ 1 Swiss
☐ 2 Residence category: L; B; C; C1; G
☐ 3 Residence category: N or F or S
☐ 4 Legal stay <3 months („Tourist“)
☐ 5 No residence permit (illegal stay/ Sans Papiers)
☐ 6 Other, please specify: ________________________________
☐ 88 Don’t know / Prefers not to answer this question

35. I will now read a couple of possible answers. Please tell me which situations applied to you at that time.

[Multiple answers possible]

☐ 1 In employment
☐ 2 Pupil or student
☐ 3 Housewife/househusband
☐ 4 In military service/civil service (more than 12 weeks)
☐ 5 Retired
☐ 6 In receipt of IV or SUVA pension or social support or unemployment support
☐ 7 In asylum process
☐ 8 Unemployed
☐ 9 Contributing family member (in the family business with/without pay)
☐ 10 Other, please specify ________________________________
☐ 88 Don’t know / Prefers not to answer this question

We are now at the end of the questionnaire.

36. Do you still have a question [for me] or would you still like to share something with me?
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

Thank you very much for your participation.
F. Information given by Lung Association [without the patient]

37. What is the specialisation of the first consulted doctor?  
   [Multiple answers possible]
   ☐ 1  GP / General Internal Medicine  
   ☐ 2  Child and Adolescent Medicine  
   ☐ 3  Lung diseases (pneumology)  
   ☐ 4  Infectious diseases (infectiology)  
   ☐ 5  Other speciality, please specify ____________________________________________  
   ☐ 99  Unclear / unknown

38. What is the specialisation of the doctor who prescribed the tuberculosis medicine?  
   [Multiple answers possible]
   ☐ 1  GP / General Internal Medicine  
   ☐ 2  Child and Adolescent Medicine  
   ☐ 3  Lung diseases (pneumology)  
   ☐ 4  Infectious diseases (infectiology)  
   ☐ 5  Other speciality, please specify ____________________________________________  
   ☐ 99  Unclear / unknown

39. Which diagnostic results were available when the medication for the tuberculosis disease was initiated?  
   [Multiple answers possible]
   ☐ 1  IGRA-Test (i.e. TB-Spot Test) / Tuberculin skin test Mantoux  
   ☐ 2  Chest X-ray  
   ☐ 3  Microscopy  
   ☐ 4  Amplification (PCR)  
   ☐ 5  Culture  
   ☐ 6  Other, please specify ____________________________________________  
   ☐ 99  Unclear / unknown
Other information / summary of health seeking path