Supplementary material - Content

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### Supplementary material 1. Patient pathway survey

**CNS** Central Nervous System  
**GCS** Glasgow Coma Scale  
**General symptoms**  Fever, lethargy, weight loss, night sweats, cough, and hemoptysis.  
**Neurological symptoms**  Altered consciousness, headache, behavioral changes, vomiting (often occurring as a result of raised intracranial pressure), motor and sensory abnormalities, cranial nerve palsy, and seizures.  
**RSCM** Rumah Sakit Cipto Mangunkusumo (Cipto Mangunkusumo hospital)  
**RSHS** Rumah Sakit Hasan Sadikin (Hasan Sadikin hospital)  
**TB** Tuberculosis  
**TBM** Tuberculous Meningitis

#### PART 1. SCREENING

**Check in-and exclusion criteria**  
*If any of the questions 1-4 is answered with ‘no’, the patient is NOT eligible for participation!*

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the patient have a clinical suspicion of CNS infection, as judged by the physician?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Has the patient started TBM treatment?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Age of 18 years or older?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Informed consent signed?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Details of participation**

<table>
<thead>
<tr>
<th>Details of participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Date and time of admission to Cipto Mangunkusumo hospital or Dr. Hasan Sadikin hospital</td>
</tr>
<tr>
<td>6. Date of interview</td>
</tr>
<tr>
<td>7. Interviewer initials</td>
</tr>
<tr>
<td>8. Interviewee</td>
</tr>
</tbody>
</table>

**Can be multiple persons**  
*Specify what family member: ____________________________  
Specify what family member: ____________________________  
Specify what family member: ____________________________  
Specify what family member: ____________________________  
Specify what family member: ____________________________  
Other: ____________________________________________

#### PART 2. BASELINE DETAILS

**Patient details**

| Patient details                                                                 |     |
|--------------------------------------------------------------------------------|
| 9. What is the patient’s sex?                                                   |     |
| 10. What is the patient’s age at inclusion?                                     |     |
| 11. What is the patient’s marital status?                                       |     |

**Comorbidities and other patient history**

<table>
<thead>
<tr>
<th>Comorbidities and other patient history</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Does the patient have any other illnesses?</td>
</tr>
<tr>
<td>13. Does the patient have a history of TB treatment?</td>
</tr>
<tr>
<td>14. Does the patient currently have TB in any other organ?</td>
</tr>
</tbody>
</table>

*Specify: ____________________________

<table>
<thead>
<tr>
<th>Other comorbidities</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. HIV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Hepatitis B</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Hepatitis C</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
15. In which organ(s) does the patient currently have TB besides the meninges?

- Unknown ➔ go to Q16
- Lungs
- Other, specify: ______________________________________

16. Do you smoke?

- Yes, but only formerly
- Yes, currently
- No, I have never smoked

17. Within the past 6 months, how often did you have a drink containing alcohol?

- Never
- Monthly or less
- Weekly
- Daily

PART 3. TBM PATIENT PATHWAY

Symptoms that led patients to seek care

18. What was the date of your very first general symptom? (See the list of definitions above the survey) [__] / [__] / [__] (dd/mm/yy)

19. What was the date of your first neurological symptom? (See the list of definitions above the survey) [__] / [__] / [__] (dd/mm/yy)

20. a. What symptoms did you experience during your entire trajectory? (Check all that apply)

- Fever ____________ days ____________ months
- Headache ____________ days ____________ months
- Vomiting ____________ days ____________ months
- Altered consciousness ____________ days ____________ months
- Lethargy ____________ days ____________ months
- Behavioural change ____________ days ____________ months
- Motor abnormalities ____________ days ____________ months
- Sensory abnormalities ____________ days ____________ months
- Cranial nerve palsy ____________ days ____________ months
- Seizure ____________

Onset: ____________ days prior to presentation

- Cough ____________ days ____________ months
- Night sweats ____________ days ____________ months
- Coughing blood ____________ days ____________ months
- Weight loss ____________ days ____________ months
- Other, specify: 1. ____________ days ____________ months 2. ____________ days ____________ months 3. ____________ days ____________ months

b. How many days/months before admission to this hospital did these symptoms start?

c. Which of these is your chief complaint? Tick only one!

1. Fever
2. Headache
3. Vomiting
4. Altered consciousness
5. Lethargy
6. Behavioural change
7. Motor abnormalities
8. Sensory abnormalities
9. Cranial nerve palsy
10. Seizure
11. Cough
12. Night sweats
13. Coughing blood
14. Weight loss
15. Other, specify:

21. At what place in the current hospital did the participant enter the study?

- Emergency room
- Neurological ward

The question on the next page addresses healthcare visits to previous hospitals or clinics. Please copy the next page, so that you can use one page for each of the visits separately. The table addresses the previous hospital or clinic experience (i.e. informal and formal healthcare) before reaching the current ward in RSCM/RSHS. Please specify the information of the patient’s trajectory below. Be as specific as you can be. Fill one page for each visit – even if there were several visits to the same provider. A health care provider could include a registered clinic, traditional healer, pharmacy etc). Note: that even if a patient has to go to another puskesmas for sputum then this needs to be listed separately. If the patient does not know the exact date of entering the healthcare site, please name the first day of the month or year. The table also addresses the reasons why patients visited the healthcare provider and indicates reasons why they moved from one center to the other. This is only applicable in case of a formal healthcare facility.
### Healthcare provider

<table>
<thead>
<tr>
<th>What was the type of healthcare provider?</th>
<th>What was the name of the healthcare provider? (Please be very specific!)</th>
<th>Was the patient admitted to the healthcare centre (inpatient) or not?</th>
<th>What was the approximate date of entering/visiting the healthcare site?</th>
<th>Was the patient asked the patient about HIV status or other risk factors of TB?</th>
<th>What diagnostic tests were performed during the healthcare visit?</th>
<th>What type of treatment was given to the patient?</th>
<th>For how long was the patient treated?</th>
<th>What did the treating doctor plan for the patient?</th>
<th>What was the time frame of the follow-up visit?</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] Private clinic</td>
<td></td>
<td>[ ] Inpatient</td>
<td>[ ] Day / month / year</td>
<td>[ ] Yes</td>
<td>[ ] None</td>
<td>[ ] None</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] Repeat visit</td>
<td>[ ] ___ days ___ months</td>
</tr>
<tr>
<td>[ ] Primary care</td>
<td></td>
<td>[ ] Outpatient</td>
<td>[ ] ___ minute ___ hour ___ day</td>
<td>[ ] No</td>
<td>[ ] Blood test</td>
<td>[ ] None</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] Referral for diagnosis</td>
<td>[ ] ___ days ___ months</td>
</tr>
<tr>
<td>[ ] Hospital</td>
<td></td>
<td></td>
<td></td>
<td>[ ] Don't know</td>
<td>[ ] Chest X-ray</td>
<td>[ ] Treated, but cannot recall type</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] Referral for treatment</td>
<td>[ ] ___ days ___ months</td>
</tr>
<tr>
<td>[ ] Informal care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[ ] Brain CT scan or MRI</td>
<td>[ ] TB treatment</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] Reverse referral</td>
<td>[ ] ___ days ___ months</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[ ] Lumbar puncture</td>
<td>[ ] Corticosteroids</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] No follow-up plan/ patient referred itself to the next visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[ ] Sputum test</td>
<td>[ ] Pain killers</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] ___ days ___ months</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[ ] HIV test</td>
<td>[ ] Herbal medicine</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] ___ days ___ months</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>[ ] Other:</td>
<td>[ ] Other:</td>
<td>[ ] ___ days ___ months</td>
<td>[ ] ___ days ___ months</td>
</tr>
</tbody>
</table>

**Reasons for visiting the current healthcare provider**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Order</th>
<th>Reason</th>
<th>Order</th>
<th>Reason</th>
<th>Order</th>
</tr>
</thead>
<tbody>
<tr>
<td>BPIS referral</td>
<td></td>
<td>Knowing about the expertise of the facility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free/affordable</td>
<td></td>
<td>Knew about the expertise of the facility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had used it/been there before</td>
<td></td>
<td>No faith or trust in other healthcare provider/s</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Close to home / easy accessibility</td>
<td></td>
<td>On the advice of a family member, friend or co-worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust they can cure me</td>
<td></td>
<td>On the advice of healthcare staff (e.g. nurse, not a doctor)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs are available</td>
<td></td>
<td>Not satisfied with the service of the previous provider</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostic services are available</td>
<td></td>
<td>Not satisfied with waiting time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good / better health care services</td>
<td></td>
<td>Not satisfied with accessibility of the building</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minor symptoms</td>
<td></td>
<td>Not satisfied with the costs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worried about severity of symptoms</td>
<td></td>
<td>Not satisfied with the quality of the advice given</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One-stop service: diagnostic and treatment services within the same place</td>
<td></td>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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### Supplements or non-prescribed medication

23. Did the patient buy any supplements for his/her diet or any other kind of non-prescribed medication because of the TBM illness?  
For example vitamins, energy drinks, special food or drinks, Panadol.  
- □ Yes  
- □ No → Go to Q24

23.1. What kind of items?  
Check all that apply  
- □ Fruits  
- □ (Energy) drinks  
- □ Vitamins  
- □ Herbal medicine  
- □ Panadol  
- □ Other: ________________________________________

### PART 4. SOCIO-ECONOMIC SITUATION

#### Insurance

24. What type of insurance do you have?  
Check all that apply  
- □ BPJS (Government insurance)  
- □ Private insurance  
  Specify: ________________________________________  
- □ No insurance → Go to Q26  
- □ Other: ________________________________________

25. Did you use your insurance in the process of getting a TBM diagnosis?  
- □ Yes  
- □ No → Go to Q26

25.1. If ‘yes’, what type of insurance did you use?  
- □ BPJS (Government insurance)  
- □ Private insurance → Go to Q26  
- □ BPJS and Private insurance

25.1.1. If ‘BPJS (government insurance)’: did you know that you can go directly to RSCM/RSHS if your disease was categorized as an emergency?  
- □ Yes  
- □ No

#### Socioeconomic information (individual situation and income)

26. Who is the primary income earner in the household?  
Check only one!  
- □ TBM patient  
- □ Partner  
- □ Parent  
- □ Son/daughter  
- □ Other extended family  
- □ Other: ________________________________________

27. What is the patient’s highest level of education?  
Check only one!  
- □ No formal schooling  
- □ Less than primary school  
- □ Primary school completed  
- □ Secondary school completed  
- □ High school completed  
- □ College/university completed  
- □ Post-graduate completed

28. What is the patient’s normal work situation?  
Check only one!  
- □ Full or part time work for pay  
- □ Student at school/university → Go to Q28.4  
- □ Housewife/husband → Go to Q28.4  
- □ Retired → Go to Q29  
- □ Unemployed/looking for work (no wages) → Go to Q29  
- □ Other: ________________________________________

28.1. In case the patient works: what is his/her main occupation?  

28.2. How regularly did the patient work before he/she became ill with TBM?  
- □ Throughout the year  
- □ Seasonal / part of the year  
- □ Day labour  
- □ Other: ________________________________________

28.3. When was the last time the patient was working?  
- □__/__/__ (dd/mm/yy)

28.4. Has the patient ever stopped working/going to school/university/doing housework due to your TBM?  
- □ Yes  
- □ No → Go to Q29

28.4.1. If ‘yes’, for how long?  
- □ <1 week

---

## Have symptoms affected the patient’s social or private life in any way until now? (Check all that apply)

- [ ] No effect/problems → Go to Q30
- [ ] Separated from spouse
- [ ] Discriminated at work
- [ ] Stopped socialising with family and friends
- [ ] Affected self-esteem
- [ ] Unable to go to work
- [ ] Unable to do daily activities
- [ ] Other: _________________________________________

### If ‘yes’, has this resulted in a financial burden?
- [ ] Yes
- [ ] No → Go to Q30

## PART 5. ADMISSION TO CIPTO MANGUNKUSUMO OR HASAN SADIKIN HOSPITAL

### Admission

30. What was the patient’s GCS score at admission?

31. What was the patient’s TBM grade at admission?

32. At what date and time was the patient seen by the neuroinfection team in the study hospital?

33. Has an LP been performed?

33.1. If “Yes”: at what date and time is the LP performed?

34. What was the date of (presumptive) TBM diagnosis?

35. What was the date of initiation of TBM treatment?

### Discharge

36. What was the patient’s diagnosis at discharge?

37. What was the outcome of the patient at the end of hospital admission?

38. What was the patient’s GCS score at discharge?

39. What was the patient’s TBM grade at discharge?

40. What was the patient’s GOS score at discharge?

41. What was the patient’s MRS score at discharge?
## Supplementary material 2. Diagnostic capacity survey

1. What is the name of the hospital where you work?

2. How many neurology specialists work at your hospital?
   - None
   - 1
   - 2
   - 3
   - 4
   - 5
   - >5

3. Is equipment for lumbar puncture (spinal needle) available at the hospital where you work?
   - Yes
   - Yes, but not always
   - No, never

4. Is a CT scan or MRI of the head available at the hospital where you work?
   - Yes
   - No
   - Don’t know

5. Does the hospital have facilities for cerebrospinal fluid (CSF) analysis?
   - Yes
   - No → go to Q6
   - Don’t know → go to Q6

5.1. If “yes”, which of the following cerebrospinal fluid analysis tests can be done at the hospital where you work?
   - (You can choose more than one)
   - Routine cerebrospinal fluid analysis (proteins/leukocytes/glucose)
   - AFB (acid-fast bacilli) smear microscopy on cerebrospinal fluid
   - GeneXpert MTB/RIF on cerebrospinal fluid
   - TB culture on cerebrospinal fluid
   - TB PCR on cerebrospinal fluid
   - India Ink (for diagnosis of cryptococcal meningitis)

6. Based on your experience, what challenges do you experience in diagnosing and treating patients with TB meningitis at the hospital where you work?
Supplementary material 3. Patient flowchart

RSCM Jakarta
May 2020-May 2022

Patients started on TBM treatment
n=165

Interviewed
n=105

Included
n=90

Total
n=175

RSHS Bandung
January 2020-June 2021

Patients started on TBM treatment
n=104

Interviewed
n=79

Included
n=76

Exclusion
Could not be contacted (n=14)
Refused to participate (n=11)

Exclusion
Diagnosis other than TBM at discharge \(^a\) (n=3)

Exclusion
Could not be contacted (n=5)
Refused to participate (n=3)
Sequelae/not newly
Diagnosed as not TBM before
recruitment (n=26)
Diagnosed as not TBM before
interview (n=20)

Discharge diagnoses other than TBM included cerebral toxoplasmosis, stroke, cytomegalovirus encephalitis, stroke sequela, toxic metabolic encephalopathy, toxoplasma encephalitis, autoimmune encephalitis, and neuroleptic malignant syndrome.

\(^a\) Discharge diagnoses other than TBM included cerebral toxoplasmosis, stroke, cytomegalovirus encephalitis, stroke sequelae, toxic metabolic encephalopathy, toxoplasma encephalitis, autoimmune encephalitis, and neuroleptic malignant syndrome.
Supplementary material 4. Individual patient pathways

Events of patients' pathways over time (x-axis) for each individual study participant (y-axis).
**Supplementary material 5. Diagnostic capacity in 40 hospitals visited by patients in this study***

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private hospital</td>
<td>24 (60.0)</td>
</tr>
<tr>
<td>Number of beds</td>
<td></td>
</tr>
<tr>
<td>&lt;100</td>
<td>4 (10.0)</td>
</tr>
<tr>
<td>100-250</td>
<td>20 (50.0)</td>
</tr>
<tr>
<td>≥250</td>
<td>16 (40.0)</td>
</tr>
<tr>
<td>Number of neurologists</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>1-2</td>
<td>11 (27.5)</td>
</tr>
<tr>
<td>3-5</td>
<td>17 (42.5)</td>
</tr>
<tr>
<td>&gt;5</td>
<td>9 (22.5)</td>
</tr>
<tr>
<td>Availability of LP kits</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>19 (47.5)</td>
</tr>
<tr>
<td>Yes, but not always</td>
<td>11 (27.5)</td>
</tr>
<tr>
<td>No</td>
<td>10 (25.0)</td>
</tr>
<tr>
<td>Availability of brain CT / MRI scan</td>
<td>31 (77.5)</td>
</tr>
<tr>
<td>Availability of lab analyses on CSF</td>
<td></td>
</tr>
<tr>
<td>Routine analysis (protein, leukocytes, glucose)</td>
<td>26/38 (68.4)</td>
</tr>
<tr>
<td>AFB smear microscopy</td>
<td>20/38 (52.6)</td>
</tr>
<tr>
<td>GeneXpert MTB/RIF</td>
<td>6/38 (15.8)</td>
</tr>
<tr>
<td>TB culture</td>
<td>13/38 (34.2)</td>
</tr>
<tr>
<td>PCR</td>
<td>7/38 (18.4)</td>
</tr>
<tr>
<td>Indian ink test for diagnosis of cryptococcal meningitis</td>
<td>10/38 (26.3)</td>
</tr>
</tbody>
</table>

* visited by ≥ 2 patients in this study. LP = lumbar puncture, CT = computed tomography, MRI = magnetic resonance imaging, CSF = cerebrospinal fluid, AFB = acid-fast bacilli, TB = tuberculosis, PCR = polymerase chain reaction.