PROTOCOL THALASSAEMIA MEDICATION THERAPY ADHERENCE CLINIC (TMTAC)
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Thalassaemia is an inherited blood disorder disease which needs lifelong therapy. Patient will develop end organ complications such as liver failure and cardiac complications if left untreated. Regular blood transfusion and iron chelation therapy are the mainly therapy for thalassaemia patients. However, adherence to iron chelation therapy is always an issue among thalassaemia patient due to unpleasant administration, potential side effect and lack of patient awareness regarding iron overload risks.

Thalassaemia Medication Therapy Adherence Clinic (TMTAC) is a service provided by pharmacists to provide optimal care to this population. It is a service to improve access of patients to recommended monitoring and treatment by establishing network of care between prescribers, pharmacists, nurses and other healthcare providers.

Pharmacists carry a stronger role to increase awareness of iron overload complications, educate our patients in managing potential side effects of iron chelators and improve their drug adherence.

I would like to congratulate all for contributing your effort in publishing this protocol. With this protocol, it can serve as a guideline to any pharmacists who wishes to initiate Thalassemia MTAC.
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A. INTRODUCTION

Thalassaemia is a genetic disorder with defective synthesis in one or more of the globin chains\(^1\). In Malaysia, the most common types are the alpha (\(\alpha\)) and beta (\(\beta\)) thalassaemias. As of 2017, the Malaysian Thalassaemia Registry showed a total of 7,509 registered patients of which 2,623 consist of the transfusion dependent \(\beta\) thalassaemia major and 2,507 hemoglobin E (HbE) \(\beta\) thalassaemia patients. The thalassaemia intermedias accounted for 754 people while hemoglobin H (HbH) affected 1,111 people and the other 514 subtypes made up the rest.

The management of \(\beta\) Thalassaemia Major comprises of regular blood transfusion with chelation therapy to prevent the effects of iron accumulation. Iron removal in transfusional iron overload is achieved by using chelation therapy with medication such as Desferrioxamine (DFO), Deferiprone (L1) and Deferasirox (DFX). \(^3\) Effective chelation is achieved when sufficient amount of accumulated iron is removed to maintain the body iron load at a non-toxic level.\(^1,2\)

Despite the availability of the drugs, compliance is still poor amongst patients. Non-compliance to iron chelators will result in the accumulation of iron leading to end-organ dysfunction, especially in the liver, myocardium, pancreas, and endocrine organs. Adherence to iron chelation therapy is a challenge among transfusion dependent thalassemia patients who are on long term transfusion management. Hence, shared responsibility between the patient and caregiver is very important and it is often associated with better adherence. In order to provide wholesome support & care, caregivers should consist of a multidisciplinary team, comprising of hematologists, nurses, dentists, dietitians, pharmacists, social workers and psychologists.\(^2\)

In Thalassaemia Medication Therapy Adherence Clinic (TMTAC), pharmacists assist thalassaemia patients in managing their iron chelation therapy, drug adherence, drug adverse effects to ensure they achieve optimum health outcomes. This protocol serves as a guide to establish and provide standardized practice in all TMTAC.
B. OBJECTIVES

1. To improve patients’ knowledge towards medications, disease(s) and its complications
2. To increase patients’ adherence towards their medications
3. To identify and prevent drug related problems including adverse effects to achieve optimum pharmacotherapy effect
4. To empower patient & caregivers about proper self-management, use of medications and devices
5. To provide continuity and enhanced patient care through close monitoring and follow-up of patients

C. SCOPE OF SERVICE

1. This service is an approach of teamwork practice consisting of doctors, pharmacists, and other relevant healthcare providers to provide better healthcare services in order to enhance patient outcomes
2. TMTAC shall provide the following services:
   a) in-depth education on medication and disease state management
   b) pharmaceutical review including
      i) medication reconciliation
      ii) medication review including drug therapy, adverse effects and adherence
   c) close follow-up on planned schedule based on individual patient needs
3. Activities at the clinic will be carried out according to the suggested workflow (refer Diagram I & II).
D. PHARMACIST REQUIREMENT

1. A minimum of one pharmacist should be stationed during TMTAC session. However, the number of pharmacists shall depend on the number of patients scheduled per day.

2. TMTAC pharmacist shall be a trained pharmacist(s) (according to TMTAC pharmacist training module).

3. TMTAC pharmacist must be able to:
   
   a) identify and develop pharmaceutical care plan
   
   b) adjust medications regimen for patients after discussion with the prescriber to achieve good clinical therapeutic outcome
   
   c) discuss and decide with prescriber and other health professionals throughout patient treatment period
   
   d) assess and identify suitable tools in order to assist with planning a good pharmaceutical care plan for patients

E. APPOINTMENT

All appointments shall be scheduled with consideration of patient’s follow-up appointment at the doctor’s clinic.

F. OUTCOME MEASURES

Every patient should be monitored and assessed during each TMTAC visit. The following indicators shall be monitored as outcome measurement of the service:

a) Understanding of medications (DFIT Score)

b) Medication adherence

c) Therapeutic outcomes:

   (i) Serum ferritin levels

   (ii) MRI T2* Cardiac Iron Concentration (If available)
G. STANDARD OPERATING PROCEDURES

1. **Patient selection** (Refer to Diagram I)

   Patients currently seen and managed in the facility.

2. **Enrollment into MTAC**

   All patients who are non-adherent to their medications or otherwise fulfil any of the criteria as below, shall be enrolled into MTAC:
   
   i) Therapeutic outcomes not achieved:
      
      • Serum Ferritin Levels > 2500ng/mL\textsuperscript{1,2}
      • MRI T2* Cardiac < 20ms\textsuperscript{1,2}
      • Liver Iron Concentration > 7mg/g\textsuperscript{1,2}

   ii) Patient with potential drug related problems

   iii) Difficulties in administering their iron chelators

   iv) Iron Overload Complications (eg. diabetes, hypothroidism)

3. **Patient Registration**

   i) All patient shall be explained about TMTAC service before enrollment

   ii) A registry of all TMTAC patients shall be maintained in the facility (Refer to Appendix I: Patient Registry Record Form)

   iii) An identification system may be put in place for follow-up patient e.g. tagging with coloured stickers

4. **Initial assessment** (Workflow as shown in Diagram I)

   During the initial visit, the pharmacist will perform an initial assessment of the patient using the Initial Visit Form (Appendix II) and Pharmacotherapy Review Form (Appendix III). The initial evaluation shall involve:

   i) Review and/or assess the following:
      
      • Personal Information

   (ii) MRI T2* Liver Iron Concentration (If available)
• Diagnosis
• Medical History
• Family History
• Social History
• Medication History
• Drug Allergies & History of Drug Adverse Events
• Disease knowledge assessment (Appendix V)
• Baseline Vital Signs & Laboratory Parameters
• Baseline DFIT Score

ii) Medication reconciliation

iii) Identify drug related problems

iv) Patient (and/or caregiver) interview

The following will also be discussed and determined with the patient:

i) TMTAC objectives

ii) Anticipated benefits to the patients or care givers

iii) Therapeutic goals to be achieved by patient

iv) Patient's specific drug therapy related needs

5. Second and subsequent visits (Workflow as shown as Diagram II)

5.1 The subsequent visits shall be scheduled (must take into consideration of patients’ need, their current health status, other clinic visits and medication refills appointments).

5.2 Evaluation at every visit shall include:

i) Review & assessment of the following as outlined in Appendix III: Pharmacotherapy Review Form and Appendix IV: Pharmacist Assessment Form:

   a) Therapeutic outcomes e.g. serum ferritin, cardiac & liver iron concentration

   b) Medication administration technique
c) Medication adherence

d) Medication understanding (DFIT)

e) Ferritin target & iron overload complications

f) Diet and lifestyle

g) Laboratory parameters e.g. RP, LFT etc.

h) Post-assessment test at 4th visit (Appendix V) to reassess patient's understanding

ii) Review and discuss pharmaceutical care plan

iii) Identify drug related problems such as adverse reaction / side effects

5.3 Education on patient empowerment and self-care management should be provided during each visit based on the education module (Appendix VI). Health advice shall be given when necessary.

5.4 Therapeutic goals for serum ferritin, cardiac & hepatic iron loading. Referrals to other healthcare providers for intervention should be done when necessary.

5.5 Regular discussion with the prescriber should be done pertaining to patient’s condition and treatment.

6. Clinic Operation

A designated area with the relevant documents and necessary items shall be made available. The area should have minimal interruptions to ensure patient’s privacy and confidentiality.

7. Patient Education

Education of the patient is an important process of ensuring safe and effective therapy. All counselling should be individualized based on the patient’s level of understanding and progress. Each patient shall be provided with relevant information and/or adherence aids when needed.

Education during each visit should be based on the education module (Appendix VI). Counselling should follow the checklist as outlined in Appendix VII.
8. Pharmaceutical Review

Pharmaceutical review should be carried out by TMTAC pharmacist, which consisting of these activities:

8.1 Medication Reconciliation
   a) Create the most complete and accurate list of current medications taken by the patients
   b) Compare list of medications against prescribed medications

8.2 Medication review
   a) Evaluate patients’ medications to optimize drug therapy
   b) Monitor patient’s adherence to the plan
   c) Identify any drug related problem e.g. adverse reaction or side effects
   d) Follow up on patient’s progress to ensure the achievement of desired outcomes, making modifications to the existing plan if necessary

8.3 Identification of drug related problems
   a) Carefully assess the patient and obtain all information required to ascertain if any intervention or recommendation has to be made.
   b) Identify patient-specific disease or medication related problem e.g. drug-drug interactions, inappropriate regimen (drug, dose, frequency).

8.4 Develop pharmaceutical care plan:
   a) Discuss individual, achievable therapeutic goals with patients
   b) Suggest therapeutic alternatives for the patient (if any)
   c) Suggest non-pharmacological therapy that may help to prevent or solve health or drug related problem.
   d) Refer to other healthcare professionals when necessary
   e) Take a holistic approach to patient care (i.e. consider patient’s medical, social, and financial needs) in establishing the action plan.
8.5 Pharmacist’s recommendation

All relevant drug related problems must be discussed with prescriber and documented.

9. Monitoring and Evaluation

Patient’s response to pharmacotherapy shall be evaluated through patient interview, laboratory results and patient’s current clinical status.

Routine laboratory tests should be monitored and alerted to prescriber if result is not available. (Refer to Appendix VIII for the recommended monitoring parameters & frequency of monitoring).

10. Immediate referral to prescribers

Following are among the conditions that require immediate referral to the prescriber:

i) Suspected severe adverse drug reaction, e.g. angioedema, jaundice

ii) Deranged laboratory results requiring intervention, e.g. liver function derangement, progressive increment of serum creatinine

iii) Signs and symptoms of disease condition eg. sign & symptoms of infection, pallor due to severe anemia

11. Iron Chelator Dosage Adjustments

All intervention/dosage adjustment on medication regime must be discussed & endorsed by the prescriber.

All adjustments must be documented in patient’s profile for future reference.

12. Dispensing

Medications may be dispensed during TMTAC to the patients.

At the end of the session, patient shall be provided with a summary of important information and patient’s understanding and expectations shall be reassessed, when needed.
13. Missed appointment

Patient who has defaulted visits would be contacted to reschedule appointments. Any contacts or attempts to contact shall be documented.

14. Discharge criteria

Discharges could be discussed with prescriber. Patients will be discharged from TMTAC if one of the following criteria is fulfilled:

a) Achieved:
   i. targeted therapeutic outcomes for at least two (2) consecutive readings, and
   ii. good medication knowledge score (DFIT) 100%*, and
   iii. good disease knowledge (Appendix V)*

   *Assessment can be done by interviewing patient or care-giver.

b) No further PCI identified by pharmacist after 4 visits

c) Defaulted six (6) months or two (2) consecutive appointments, whichever is longer, despite intervention being done.

d) Patient requested to be discharged from TMTAC / not interested to remain in TMTAC

e) Discharged/ transferred to other facilities for follow-up (issue form CP 4 and inform the respective facility)

15. Documentation

All activities must be documented and filed accordingly. All record must be kept at a place that is easily assessable and updated regularly by the TMTAC pharmacist.

The following describes the purpose of the various forms:

a) Patient Registry Record (Appendix I)
   i) Documents the number of patients recruited into TMTAC & details such as date of recruitment, baseline levels & date of discharge
   ii) Each TMTAC Clinic shall maintain one registry record for the centre.
b) Initial Visit Form (Appendix II)
   i) Documents the patient’s demographic data, disease background, clinical summary and baseline disease knowledge of the patient.

c) Pharmacotherapy Review Form (Appendix III)
   i) Functions as a record for individual patients. It contains information of patient’s laboratory results & patient’s understanding on medication.
   ii) Each patient shall have their own individual record & this record is maintained until the patient is discharged from the MTAC.

d) Pharmacist’s Assessment Form (Appendix IV)
   i) This form will be filled in at every patient visit. It contains information regarding drug related problems identified & the outcomes of the session.
   ii) The original form shall be attached to the patients’ medical record & the copy should be attached together to the Pharmacotherapy Review Form, for the pharmacist’s reference.
H. REFERENCES


Thalassemia Medication Therapy Adherence Clinic (TMTAC)
Workflow (Initial Visit)

1. **Patient Registration**
   - **Responsibility**: Nurse

2. **Doctor Review & Treatment**
   - **Responsibility**: Doctor

3. **Referral to Pharmacist**
   - **Responsibility**: Doctor/Nurse

4. **Pharmacist Review**
   - **Responsibility**: Pharmacist

5. **TMTAC Criteria**
   - **Decision Point**: Yes or No

   - **Yes**: **Recruitment, Review & Assessment**
     - **Responsibility**: Pharmacist

   - **No**: **Counselling and Documentation**

6. **Recruitment, Review & Assessment**
   - **Responsibility**: Pharmacist

7. **Education (Based on Patient’s Need and Understanding)**
   - **Responsibility**: Pharmacist

8. **Documentation**
   - **Responsibility**: Pharmacist

9. **Schedule Next Appointment**
   - **Responsibility**: Pharmacist/Nurse

10. **End**
    - **Responsibility**: End

---

**Diagram I**

PROTOCOL THALASSAEMIA MTAC (TMTAC)

PHARMACY PRACTICE & DEVELOPMENT DIVISION, MOH
Thalassemia Medication Therapy Adherence Clinic (TMTAC)
Workflow (Subsequent visits)

1. **Patient Registers for Follow Up**
   - **Responsibility:** Pharmacist

2. **Retrieve Patient’s File From Clinic**
   - **Responsibility:** Pharmacist

3. **Pharmacist’s Review & Assessment**
   - **Responsibility:** Pharmacist

4. **Patient’s Education**
   - **Responsibility:** Pharmacist

5. **Develop Pharmaceutical Care Plan**
   - **Responsibility:** Pharmacist

6. **Need Further Discussion With Prescriber**
   - **Responsibility:** Doctor/Pharmacist

   - **Yes**
     - **Documentation & File MTAC Report In Patient’s Clinic Folder**
       - **Responsibility:** Pharmacist

     - **No**
       - **Schedule Next Appointment**
         - **Responsibility:** Pharmacist/Nurse

7. **End**
<table>
<thead>
<tr>
<th>No</th>
<th>Name</th>
<th>IC Number</th>
<th>Date Recruited by</th>
<th>Baseline Ferritin &amp; Date</th>
<th>Ferritin &amp; Date at Discharge</th>
<th>Discharged by</th>
<th>Reason for Discharge / Notes</th>
<th>Date Discharged</th>
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**APPENDIX I**
# Protocol Thalassaemia Medication Therapy Adherence Clinic (TMTAC)

## Initial Visit

### Patient’s Profile and Assessment Form

#### i. Demographic Data

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<tr>
<th>Name:</th>
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<tr>
<td>Age:</td>
<td>Gender: Male/ Female</td>
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<tr>
<td>Race:</td>
<td>Weight:</td>
</tr>
<tr>
<td>Contact No.:</td>
<td>Date of recruitment:</td>
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#### ii. Disease Background

- **Diagnosis:**
  - [ ] Transfusional Dependant Thalassaemia (TDT)
  - [ ] Non-Transfusional Dependant Thalassaemia (NTDT)
- **Please specify:**
  - [ ] Thalassaemia Major
  - [ ] Hb E Beta Thalassaemia
  - [ ] Hb H Constant Spring
  - [ ] Others: ____________________________
- **Past Medical/Surgical History:**
- **Age at Diagnosis:**
- **Social History:**
- **Family History:**
- **Allergies & History of Drug Adverse Events:**
- **Disease Knowledge Assessment (Baseline):**
- **Past Medication History:**

### C. Pharmacist’s Notes

Pharmacist’s Stamp & Signature: ...........................................  Date: ........................
### Laboratory Investigations:

**Weekly:** FBC  
**3 Monthly:** LFT, Renal Profile  
**6 Monthly:** Hep B, Hep C, RVD Screening  
**Annually:** Cardiac MRI T2*, Thyroid TSH / T4, Serum Cortisol, Testosterone, FSH, LH, Serum Magnesium, Phosphate, Calcium, Alkaline Phosphatase, Fasting Blood Glucose or OGTT

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<tr>
<td>Hemoglobin</td>
<td>11.5-16.5 g/dL</td>
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<tr>
<td>Neutrophils</td>
<td>2-6.9</td>
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<td>Platelet</td>
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</tr>
<tr>
<td>Serum Cr.</td>
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<tr>
<td>UFEME (Proteinuria)</td>
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<td>AST</td>
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<td>Total Bilirubin</td>
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### Endocrine Monitoring

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<td>TSH</td>
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### Infectious Screen

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### Annual Screening

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<td>Visual</td>
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### Iron Burden Monitoring

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<th>Target</th>
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<tr>
<td>Serum Ferritin (ng/mL)</td>
<td>± 1000 ng/mL</td>
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<tr>
<td>MRI T2* (Heart)</td>
<td>&gt;20ms</td>
</tr>
<tr>
<td>MRI T2* (Liver)</td>
<td>&lt;7mg/g</td>
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<tr>
<td>Normal</td>
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<tr>
<td>Assessment</td>
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<td>Assessment</td>
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<tr>
<td>Medication (Include Doses)</td>
<td>Visit 1</td>
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<td>---------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>D</td>
<td>F</td>
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**Key:**
- D = Dose
- F = Frequency
- I = Indication
- T = Method of Administration

**APPENDIX III (Cont')**
<table>
<thead>
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<th>Name:</th>
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<td>Diagnosis</td>
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<tr>
<td>Serum Ferritin Level (ng/ml)</td>
<td>MRI T2 Level</td>
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<td></td>
<td>Heart (ms):</td>
<td>Liver (mg/g):</td>
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</tbody>
</table>

### Iron Chelation Therapy

**Desferoxamine**

Mean daily dose = \( \text{mg/kg/day} \)

Therapeutic Index = \( \frac{\text{Mean daily dose (mg/kg)}}{\text{Serum ferritin (μg/L)}} \) < 0.025

**Infusion technique:**

- Independence: 
- Dose administered: 
- Dilution: 
- EMLA use: 
- Injection site: Arm/ Abdomen/ Thighs 
- Rotation of injection site: Yes/ No 
- Change & disposal of needles: 
- Machine Settings: 
- Time setup: 
- Infusion Duration: 
- Vitamin C administration: 
- Frequency of missed doses per week: 

---

APPENDIX IV
### Deferiprone

- **Dose (mg/kg):**
- **Method of administration:**
- **Neutrophil count:**

### Deferasirox

- **Dose (mg/kg):**
- **Method of administration:**
- **Dose & diluent:**
- **Timing:**
- **Renal Profile, Scr =**
- **Urine proteineuria:**
- **Liver Profile, ALT =**
- **AST =**

### Compliance & Knowledge Assessment

- **DFIT Score:**
- **Pill Count Score:**
- **Ferritin target:**

### Supplements:

### Dietary Compliance:

### Pharmacist’s Notes:

### Plan:

---

**Next TCA:**

**Reviewed By:**

**Date:**
## Thalassaemia Knowledge Assessment

### Part 1: Knowledge about Thalassaemia/

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What is your Thalassaemia type?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Apakah jenis penyakit Talasemia anda?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>a. Beta Thalassaemia Major</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. Hb E Beta Thalassaemia</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c. Beta Thalassemia Intermediate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>d. Hb H Constant Spring</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>e. Others: _______________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Thalassaemia is a genetic blood disorder.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Talasemia ialah kecacatan darah disebabkan faktor genetik.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Thalassaemia is inherited from both parents who carry the thalasemia gene.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Penyakit talasemia diwarisi daripada ibu dan bapa yang merupakan pembawa gen talasemia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Thalassaemia can be prevented by doing premarital screening and avoid marriage between two carriers.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Penyakit Talasemia boleh dicegah dengan menjalani ujian saringan darah pra perkahwinan dan mengelakkan perkahwinan antara pembawa Talasemia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Blood transfusion, iron chelation therapy and bone marrow transplants are among the thalassaemia treatments.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Transfusi darah, penyingkiran zat besi dan pembedahan adalah antara rawatan Talasemia.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Part 2: General Knowledge/

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.</td>
<td>Regular blood transfusion is the main cause of iron overload in thalassaemia patients.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Pemindahan darah secara kerap merupakan sebab utama kelebihan zat besi dalam pesakit talasemia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Iron removal in thalasemia patient can be done through injection, oral pills and surgery.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Penyingkiran besi untuk pesakit Talasemia boleh dilakukan melalui suntikan, makan ubat dan pembedahan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Splenomegaly is defined as enlargement of the spleen caused by inadequate blood transfusion.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Splenomegaly bermaksud pembesaran limpa disebabkan rawatan transfusi yang tidak mencukupi.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Thalassaemia patient has to practice high iron diet.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Pesakit talasemia perlu mengamalkan diet tinggi zat besi.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Part 3: Treatment/ Rawatan

10. What is your hemoglobin level when you are getting your transfusion? (before transfusion)
   Apakah tahap hemoglobin anda pada hari menerima transfusi darah? (sebelum transfusi)

11. I am currently using these iron chelators:
   Pengelat besi yang saya gunakan sekarang adalah seperti berikut:
   Deferasirox
   Dose:
   Deferoxamine
   Dose:
   Deferiprone
   Dose:

12. I know the side effects of the iron chelators I am taking. Please mention:
    Saya tahu kesan sampingan pengelat besi yang saya ambil. Sila nyatakan:

Part 4: Complications/ Komplikasi

13. Iron overload will be harmful to the internal organs such as liver, heart, thyroid gland and sex organs.
    Pengumpulan besi dalam badan boleh menyebabkan kerosakan organ-organ dalaman badan seperti hati, jantung, kelenjar endokrin dan organ seksual.
    Yes
    No

14. Patient with spleen removed are prone for infections and advised to receive necessary vaccinations as advised by your doctor.
    Sekiranya limpa anda dikeluarkan, anda lebih cenderung untuk mendapat jangkitan dan dinasihatkan untuk menerima vaksin seperti yang disarankan oleh doktor anda.
    Yes
    No

Part 5: Psychosocial Support/ Sokongan psikososial

15. Do emotional stresses need help?
    Adakah tekanan emosi perlukan bantuan?
    Yes
    No

16. I can get emotional support by sharing problems with my family/ close friends or meeting with Psychologist/ counselors.
    Saya boleh mendapat sokongan emosi dengan berkongsi masalah dengan keluarga/kawan-kawan rapat saya atau berjumpa pegawai Psikologi/ kaunselor.
    Yes
    No

Score/Markah /16

Adapted from:

1. Upadhyay J, Chatterjee S. Assessment of the knowledge of Thalassaemia in the thalassemia patients and treatment received by them. The Internet Journal of Hematology. 2008 Volume 5 Number 2.
## EDUCATION OUTLINE FOR TMTAC PATIENTS

(*)Education module should be delivered following patient’s understanding and needs

<table>
<thead>
<tr>
<th>VISIT</th>
<th>MODULE OUTLINE</th>
</tr>
</thead>
</table>
| **Visit 1** | • Brief Thalassaemia Overview  
• Therapeutic goals (serum Ferritin, MRI T2*, R2*)  
• Specific discussion on medication use/adverse effects  
• Patient’s concerns  
• Transfusion –benefits & complications  
• Benefits, risks and options for improving the iron overload with Iron Chelators |
| **Visit 2** | • Other therapeutic goals (blood glucose, hormones)  
• Drug counselling  
• Importance of adherence to Iron Chelators  
• Infections  
• Patient’s concerns |
| **Visit 3** | • Basic nutrition  
• Benefit of relaxation technique/support group  
• In-depth discussion of iron overload  
• Drug counselling  
• Prevention and detection of complication  
• Patient’s concerns |
| **Visit 4** | • Health benefits of good iron control  
• Tailoring dosage to rate of iron loading  
• Long term plans (overcoming barriers)  
• Genetic counselling  
• Managing schools/work  
• Patient’s concerns |
## Counselling Checklist

### Introduction
- Introduce Self & Purpose of Counselling
- What medications are you currently taking?
- Do you know what these medications are for?
- Are you taking any other supplements?
- What is the ideal ferritin target?

### Deferrioxamine
- Who helps you prepare your infusion? (Pediatric Patients)
- How many vials of Deferrioxamine are you taking per dose?
- How many times a week are you using your Deferrioxamine?
- How do you dilute your Deferrioxamine?
- How long do you apply EMLA before inserting injecting the medicine?
- Where do you inject the medicine?
- Do you have difficulty in performing the SC Injection?
- Do you rotate the injection site?
- Do you inject on areas which have wounds or areas which are ‘hard’?
- How frequently do you change your needles?
- How do you dispose your needles?
- What time do you start the infusion? How long is your infusion duration?
- Do you have any problems with your infusion machine?
- When do you take your Vitamin C tablet?
- Have you experienced any unwanted side effects with Deferrioxamine?
<table>
<thead>
<tr>
<th>Question</th>
<th>Deferiprone</th>
<th>Deferasirox</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many times a week do you miss using your medication?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times a day do you take your tablets?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many tablets do you take at each dose?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you experienced any unwanted side effects with Deferiprone?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times a week do you miss using your medication?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many tablets of Deferasirox do you take daily?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What time do you take your tablets? Do you take it before or after meals?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What diluent do you use for your tablets?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use any metal utensils to prepare your Deferasirox?</td>
<td></td>
<td></td>
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<tr>
<td>Do you re-suspend the sediments and swallow it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you experienced any unwanted side effects with Deferasirox?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times a week do you miss using your medication?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Conclusion**

Is there anything else you would like to know about your therapy?
## Monitoring Parameters & Frequency of Monitoring

<table>
<thead>
<tr>
<th>Category</th>
<th>Measurement</th>
<th>Frequency of checking: Every</th>
<th>Monitoring Indication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1mo</td>
<td>3mo</td>
</tr>
<tr>
<td>Growth</td>
<td>Height</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Weight</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Hematology</td>
<td>CBC</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Iron Burden</td>
<td>Serum Ferritin</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Liver Iron Concentration</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>*Cardiac Iron Concentration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chelators</td>
<td>Audiology Evaluation</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ophthalmology Evaluation</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>LFT (Includes ALT, AST, Bilirubin)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Renal Profile (SCR, Proteinuria)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Viral Screening</td>
<td>VDRL, HepBsAg, HepBsAb, HIV, HCV</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*The monitoring frequency may differ between different facilities*