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Ministry of Health Malaysia
Pharmaceutical Services Programme

THALASSAEMIA MEDICATION THERAPY ADHERENCE CLINIC (TMTAC) PROTOCOL

SECOND EDITION

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Thalassaemia MTAC Protocol

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This edition was produced after reviewing the most recent evidence at the time of development. Every healthcare provider is responsible to make appropriate clinical judgement in consideration of each patient's condition at presentation based on treatment options available locally.

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PREFACE

Thalassaemia is an inherited blood disorder that requires lifelong therapy. Without appropriate treatment, patients are at risk of developing end-organ complications such as liver and cardiac failure. Regular blood transfusions and iron chelation therapy are the mainstays of treatment for individuals with thalassaemia. However, adherence to iron chelation therapy remains a significant challenge due to factors such as administration methods, potential side effects and limited patient awareness of the complications following iron overload.

The Thalassaemia Medication Therapy Adherence Clinic (TMTAC) is a pharmacist-led service established to optimise care for this patient population. Pharmacists play a pivotal role in evaluating medication regimens, monitoring for adverse effects, providing counselling to support treatment adherence, identifying potential drug interactions and delivering accurate medication-related information to patients and their caregivers.

This protocol has been developed to guide pharmacists within the Ministry of Health (MOH) in offering their expertise in the Thalassaemia Pharmacy Service. It ensures the standardisation of pharmacy practice and enables pharmacists to make full contributions as part of the multidisciplinary healthcare team across MOH facilities.

I extend my congratulations to all contributors for their valuable and constructive efforts in developing this protocol.

Thank you.

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ACKNOWLEDGMENT

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1. INTRODUCTION

Thalassaemia, a genetic disorder caused by faulty globin chain synthesis, is most found in its alpha (α) and beta (β) forms in Malaysia[1]. The number of patients nationwide rose from 7,984 in 2018 to 9,554 in 2023, according to the Malaysian Thalassaemia Registry[2,3]. Thalassaemia patients can be categorised into two main groups: Transfusion Dependent Thalassaemia (TDT) and Non-Transfusion Dependent Thalassaemia (NTDT). According to the Malaysia 2023 registry, 57.0% of patients are classified as TDT and 40.8% as NTDT[3]. A total of 212 TDT patients (3.9% of all TDT cases) have been cured through haematopoietic stem cell transplantation (HSCT), with the highest proportion (29.7%) originating from Sabah.

Managing β-thalassemia major requires consistent blood transfusions and iron chelation therapy[1,4]. Chelation therapy is crucial for eliminating excess iron from transfusions using drugs like Deferoxamine (DFO), Deferiprone (DFP), and Deferasirox (DFX). Effective chelation aims to remove enough accumulated iron to keep the body's iron levels at a non-toxic concentration.

Despite effective medications, transfusion-dependent thalassemia patients struggle with long-term iron chelation therapy adherence[1,4]. This is vital to prevent iron overload complications and maintain quality of life, as non-compliance leads to serious organ damage (liver, heart, pancreas, endocrine). A collaborative patient-caregiver approach and multidisciplinary team support (hematologists, nurses, dentists, dietitians, pharmacists, social workers, psychologists) are crucial for better adherence and addressing medical and psychosocial needs.

Pharmacists are crucial in the Thalassaemia Medication Therapy Adherence Clinic (TMTAC), where they support thalassaemia patients in several key areas[1,4]. These include managing iron chelation therapy, fostering drug adherence, and mitigating adverse drug effects, all with the goal of achieving optimal health outcomes. This protocol is designed to guide and standardize practices across all TMTACs.

2. OBJECTIVES

2.1 To provide structured education on medications, devices, disease(s) progression and potential complications to patients and/or their caregivers.

2.2 To promote and support patients' adherence towards their medications through individualised interventions that address treatment barriers and align with best practices in chronic disease management.

2.3 To identify, assess and address pharmaceutical care issues, such as drug-related problems, and potential or actual adverse effects.

2.4 To collaborate and provide consultative services to other healthcare providers on iron chelation therapy to ensure optimum pharmacotherapy effect.

2.5 To develop personalised care plans that are tailored to each patient's unique needs, preferences, social circumstances and life goals.

2.6 To empower patients to take an active role in their treatment and self-care practices, improving their quality of life.

3. SCOPE OF SERVICE

3.1 This service is a multidisciplinary approach consisting of doctors, pharmacists, and other relevant healthcare providers to enhance patient outcomes.

3.2 TMTAC shall provide the following services:

a. Comprehensive education on medication and disease state management
b. Pharmacotherapy review
c. Follow-up on a planned schedule based on individual patient needs

3.3 The TMTAC service shall operate at the clinic, daycare or pharmacy.

3.4 TMTAC activities shall be carried out according to the suggested workflow, refer to Appendix I & II.

4. PHARMACIST REQUIREMENT

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

4.2 TMTAC pharmacists shall be trained according to the TMTAC training module.

5. APPOINTMENT

5.1 All appointments shall be scheduled with consideration of the patient's follow-up appointment at the doctor's clinic or daycare unit.

6. OUTCOME MEASURES

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

a. Patient's Understanding on Medication - DFIT score should be assessed for iron chelators (mandatory) and other medications as deemed necessary.

b. Medication adherence using validated tools such as:

i. Medication Compliance Questionnaires (MCQ) for patient ≥ 9 years old (Appendix III)

ii. Malaysia Medication Adherence Assessment Tool (MyMAAT) for patient ≥18 years old (Appendix IV)

iii. Pill count or others

c. Therapeutic outcomes:

i. Serum ferritin concentration

ii. Cardiac MRI T2* (If available)

iii. Liver iron concentration (LIC) (If available)

7. STANDARD OPERATING PROCEDURES

7.1 Enrolment into MTAC

7.1.1 Patients fulfilling any one of the following criteria shall be enrolled into TMTAC:

a. Non-adherent to iron chelation therapy

b. Therapeutic outcomes not achieved:

i. Serum ferritin concentration > 1000 µg/L[1,2] **OR**

ii. Cardiac MRI T2* < 20ms[1,2] **OR**

iii. Liver iron concentration (LIC) > 7mg/g[1,2]

c. Potential drug-related problems

d. Difficulties in administering their iron chelators

7.1.1 All patients shall be explained about TMTAC service before enrolment.

7.1.2 TMTAC patients will be assigned a specific identifier or tag as part of the identification system.

7.1.3 A registry of all TMTAC patients shall be maintained in the facility. Refer to Appendix V: TMTAC Patient Registry Record & Defaulter List.

7.2 Initial Visit

7.3.1 At the beginning of each TMTAC session, the pharmacist shall:

a. Introduce themselves to the patient.

b. Explain the objectives of TMTAC

c. Outline the therapeutic plan and expected goals

d. Emphasize the importance of medication knowledge and adherence

e. Explain on patient's rights and responsibilities in TMTAC.

7.3.2 The pharmacist will document relevant clinical information based on the physician's assessment and patient interview(s) using:

a. Drug adherence assessment (Appendix III/ IV/ Pill count)

b. TMTAC Initial Visit Form (Appendix VI)

c. TMTAC Pharmacists Assessment Form (Appendix VII)

d. Parameters Monitoring Form (Appendix VIII)

e. Patient's Understanding on Medication (Appendix X)

7.3 Subsequent Visits

7.3.1 Evaluation at every subsequent visit shall include review and assessment of the patient using:

a. Drug adherence assessment (Appendix III/ IV/ Pill count)
b. TMTAC Pharmacists Assessment Form (Appendix VII)
c. Parameters Monitoring Form (Appendix VIII)
d. Patient's Understanding on Medication (Appendix X)

7.3.2 During each visit, education should be provided on patient empowerment and self-care management, utilizing the established education module outline. (Appendix XI).

7.3.3 Therapeutic goals for serum ferritin, cardiac & hepatic iron loading (if available) should be monitored as required.

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

7.3.5 Suggestions for referral to other healthcare providers for intervention should be made when necessary.

7.4 Clinic Operation

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

7.5 Patient Education

7.5.1 Patient education is an important process of ensuring safe and effective therapy.

7.5.2 Counselling should be individualised based on the patient's level of understanding and progress.

7.5.3 Each patient shall be provided with relevant information and/or adherence aids when needed.

7.5.4 Counselling should include the education module outlined in Appendix XI.

7.6 Pharmacotherapy Review

7.6.1 A pharmacotherapy review should be carried out by a TMTAC pharmacist, which consists of these activities:

a. Medication Reconciliation and Review
   i. Create the most complete and accurate list of current medications taken by the patient.
   ii. Compare the list of medications against prescribed medications.
   iii. Evaluate patients' medications to optimise drug therapy.
   iv. Monitor the patient's adherence to the plan.
   v. Identify drug-related problems e.g., drug-drug interactions, inappropriate regimen (drug, dose, and frequency), drug toxicity, adverse reactions or side effects.
   vi. Follow up on the patient's progress to ensure the achievement of desired outcomes, making modifications to the existing plan if necessary.

b. Develop a pharmaceutical care plan:
   i. Discuss individualised and achievable therapeutic goals with patients.
   ii. Suggest therapeutic alternatives for the patient (if any).
   iii. Suggest non-pharmacological therapy that may help to prevent or solve health or drug-related problems.
   iv. Take a holistic approach to patient care (i.e., consider the patient's medical, social, and financial needs) in establishing the action plan.
   v. Identify barriers to adherence and propose strategies to address non-adherence.
   vi. All relevant drug-related problems or iron chelator dosage adjustments must be discussed with the prescriber and documented.

7.7 Monitoring and Evaluation

7.7.1 The patient's response to pharmacotherapy shall be evaluated through a patient/caregiver interview, laboratory results and the patient's current clinical status.

7.7.2 Routine laboratory tests should be monitored and alerted to the prescriber if the tests are not conducted. Refer to Appendix IX for the recommended monitoring parameters and frequency of monitoring.

7.8 Immediate Referral to Prescribers

7.8.1 The following are among the conditions that require immediate referral to the prescriber:

a. Suspected severe adverse drug reactions (e.g., agranulocytosis, angioedema, or jaundice).

b. Deranged laboratory results requiring intervention (e.g., liver function derangement and progressive increment of serum creatinine concentrations).

c. Signs and symptoms (e.g., fever, sore throat, severe abdominal pain, chills, pallor) of a disease condition.

d. Any other conditions considered to warrant prescriber's intervention.

7.9 Dispensing

7.9.1 Medications may be dispensed to patients during TMTAC, subject to facility's practice and availability.

7.9.2 At the end of the session, the patient shall be provided with a summary of important information and the patient's understanding and expectations shall be reassessed, when needed.

7.10 Missed Appointment

7.10.1 Patients who have defaulted TMTAC visits will be contacted to reschedule appointments. Any contacts or attempts to contact shall be documented.

7.11 Discharge Criteria

7.11.1 Patients will be discharged from TMTAC if **one (1)** of the following criteria is fulfilled:

a. Achieved:

i. Targeted therapeutic outcomes (serum ferritin and/or Cardiac MRI T2* and/or LIC) for at least two (2) consecutive readings, **and**

ii. Patient's Understanding on Medication (DFIT) score of 100%*, **and**

iii. Good adherence to prescribed chelators over the past six (6) months.

*Assessment can be done by interviewing the patient or caregiver.

b. No further Pharmaceutical Care Issue (PCI) was identified by the pharmacist consecutively for three (3) visits.

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

d. The patient requested to be discharged from TMTAC.

e. Discharged/ transferred to either intra/ inter facilities for follow-up. In such cases, pharmacists are required to develop an individualised discharge plan using Patient Referral Note (CP4) to ensure continuity of care during the transition process.

f. Patient deceased.

7.12 Documentation

7.12.1 All activities must be documented and kept accordingly. All records must be kept at a place that is easily accessible and updated regularly by the TMTAC pharmacist.

7.12.2 The following describes the purpose of the various forms:

a. TMTAC Patient Registry Record & Defaulter List

   i. Documents the number of patients recruited into TMTAC & details such as date of recruitment, date of discharge and serum ferritin concentrations upon discharge.

   ii. Each TMTAC shall maintain a registry record for the centre.

   iii. Refer to Appendix V for details

b. TMTAC Initial Visit Form

   i. Documents patient's demographic data, disease background, and clinical summary.

   ii. Refer to Appendix VI for details

c. TMTAC Pharmacists Assessment Form

   i. This form will be filled in at every patient visit. It contains information regarding drug-related problems and the outcomes of the session.

   ii. The original form shall be attached to the patient's medical record for the prescriber's reference.

   iii. Refer to Appendix VII for details

d. Parameters Monitoring Form

i. Functions as a record for individual patients. It contains information on the patient's laboratory results.

ii. Each patient shall have his/her individual record & this record will be maintained until the patient is discharged from TMTAC.

iii. Refer to Appendix VIII for details

8. REFERENCES

1. Malaysian Health Technology Assessment Section (MaHTAS). (2024). *Clinical Practice Guidelines Management of Thalassaemia Second Edition*. Malaysian Health Technology Assessment Section (MaHTAS)

2. Ministry of Health Malaysia. (2023). *Annual Report of the Malaysia Thalassaemia Registry 2023*. Ministry of Health Malaysia.

3. Ministry of Health Malaysia. (2023). *Annual report of the Malaysia Thalassaemia Registry 2023*. Ministry of Health Malaysia.

4. Cappellini, M. D., Musallam, K. M., Farmakis, D., Porter, J. B., & Taher, A. T. (2025). *5th Edition Guidelines for the management of transfusion dependent thalassaemias.* Thalassaemia International Federation.

9. APPENDICES

Appendix I: TMTAC Workflow (Initial Visit)

Appendix II: TMTAC Workflow (Subsequent Visit)

Appendix III: Medication Compliance Questionnaires (MCQ)

Appendix IV: Malaysia Medication Adherence Assessment Tool (MyMAAT)

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Appendix VI: TMTAC Initial Visit Form

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Appendix IX: Recommended Monitoring Parameters & Frequency of Monitoring

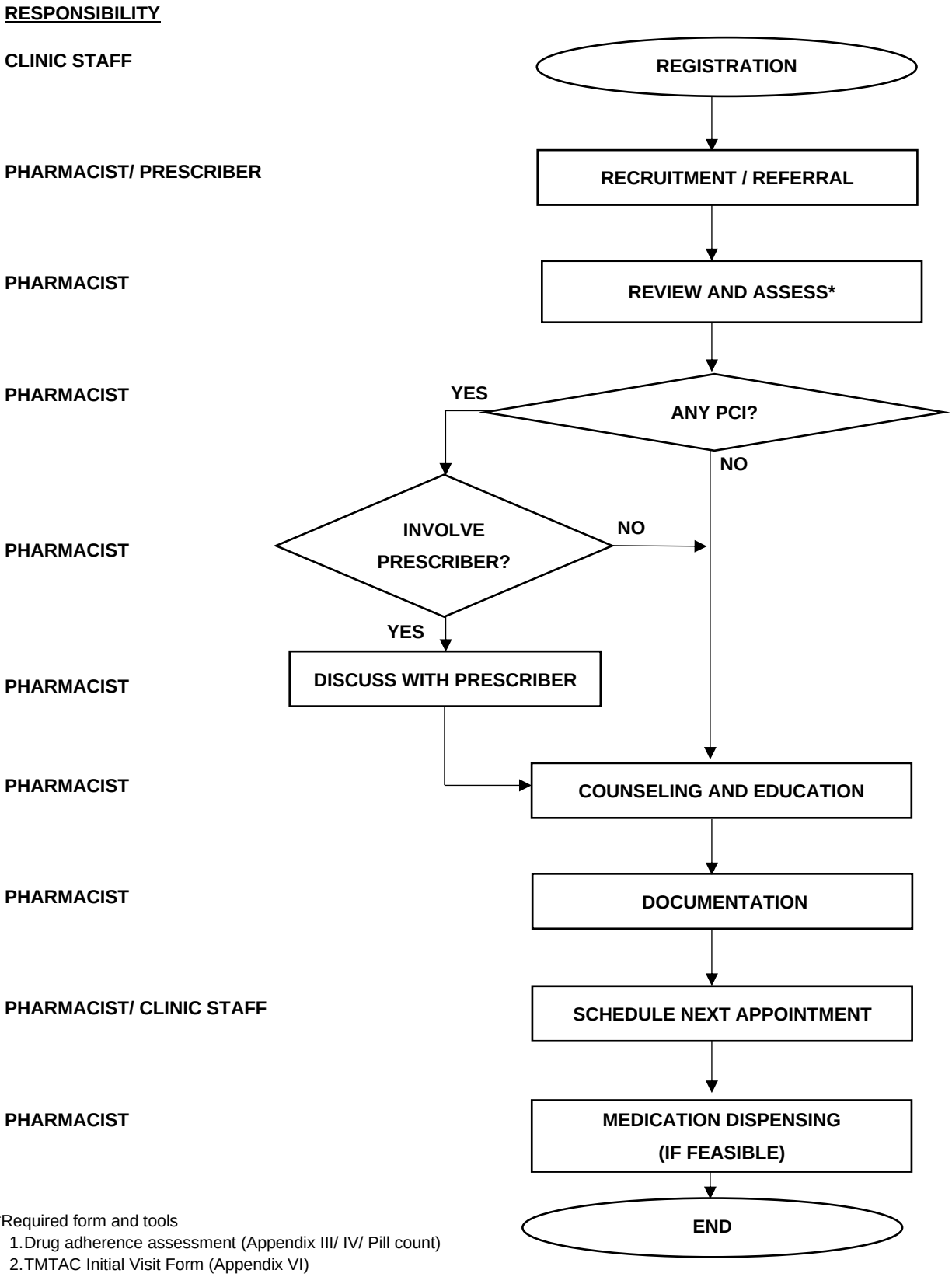
Appendix X: Patient's Understanding on Medication

Appendix XI: Education Module Outline

Appendix XII: Prescriber Referral Form

Appendix XIII: Thalassaemia Medication Diary

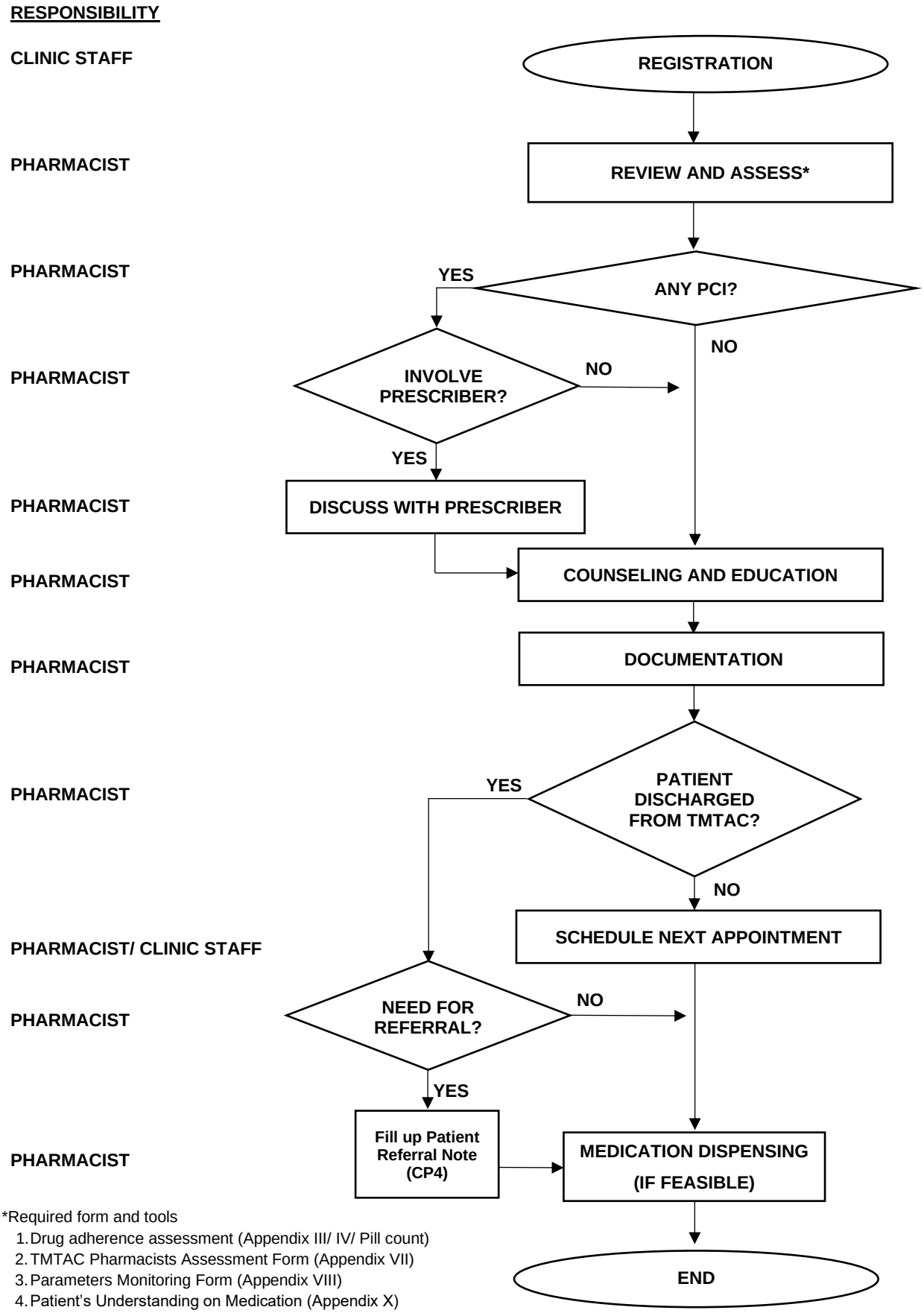
Appendix I: TMTAC Workflow (Initial Visit)



*Required form and tools

1. Drug adherence assessment (Appendix III/ IV/ Pill count)
2. TMTAC Initial Visit Form (Appendix VI)
3. TMTAC Pharmacists Assessment Form (Appendix VII)
4. Parameters Monitoring Form (Appendix VIII)
5. Patient's Understanding on Medication (Appendix X)
6. Prescriber Referral Form (Appendix XII)

Appendix II: TMTAC Workflow (Subsequent Visit)



*Required form and tools

1. Drug adherence assessment (Appendix III/ IV/ Pill count)
2. TMTAC Pharmacists Assessment Form (Appendix VII)
3. Parameters Monitoring Form (Appendix VIII)
4. Patient's Understanding on Medication (Appendix X)

Appendix III: Medication Compliance Questionnaires (MCQ)

English version

Please circle (O) the answer that suit you the most (for the past 2 months) based on the following scale:

Items		Never	Seldom	Sometimes	Frequent	Very frequent
1)	You take medication(s) as prescribed by doctor.	1	2	3	4	5
2)	You take medication(s) only when you feel unwell.	5	4	3	2	1
3)	You feel difficult to take/ swallow medication(s) daily.	5	4	3	2	1
4)	You forget to take medication(s).	5	4	3	2	1
5)	When you forget to take medication(s), you take double the medications (s) that are prescribed by doctor.	5	4	3	2	1
6)	You change the timing of taking medication without doctor's advice.	5	4	3	2	1
7)	You take less medication when you feel well or fresh.	5	4	3	2	1
8)	You stop taking medication when you feel it is not effective.	5	4	3	2	1
9)	You stop taking medication when you experience unpleasant effect from the medication.	5	4	3	2	1
10)	You stop taking medication when you feel well or fresh.	5	4	3	2	1

Score: [ ] /50 X100%= [ ] %, score ≥ 75% good compliance.

Reference:

Chai, A. S. C., Draman, N., Mohd Yusoff, S. S., Azman, N. F., Mohd Zulkifli, M., Yaacob, N. M., Mohamad, N., Hassan, R., Abdullah, W. Z., & Zilfalil, B. A. (2021). *Non-compliance to iron chelation therapy in patients with transfusion-dependent thalassaemia*. *Pediatric Hematology Oncology Journal*.

Appendix III: Medication Compliance Questionnaires (MCQ)

Versi Bahasa Melayu

Sila bulatan (O) jawapan yang paling sesuai bagi anda (dalam masa dua bulan yang lepas) mengikut skala tersebut:

Item		Tidak Pernah	Jarang	Kadang-kadang	Kerap	Sangat Kerap
1)	Anda mengambil/ memakan ubat seperti yang dipersetujui dengan doktor.	1	2	3	4	5
2)	Anda mengambil/ memakan ubat hanya apabila anda merasa kurang sihat.	5	4	3	2	1
3)	Anda merasa sukar/ susah untuk mengambil/memakan ubat setiap hari.	5	4	3	2	1
4)	Anda terlupa mengambil/ memakan ubat.	5	4	3	2	1
5)	Bila anda terlupa mengambil/memakan ubat, anda makan ubat yang seterusnya dua kali ganda dari yang dipersetujui dengan doktor.	5	4	3	2	1
6)	Anda ubah masa mengambil/ memakan ubat tanpa nasihat doktor.	5	4	3	2	1
7)	Anda kurangkan pengambilan/ memakan ubat apabila merasa sihat atau segar.	5	4	3	2	1
8)	Anda berhenti mengambil/memakan ubat apabila merasa ubat itu tidak berkesan.	5	4	3	2	1
9)	Anda berhenti mengambil/ memakan ubat apabila mengalami kesan yang tidak enak dari ubat yang dimakan/ diambil.	5	4	3	2	1
10)	Anda berhenti mengambil/memakan ubat apabila merasa sihat atau segar.	5	4	3	2	1

Markah: [ ] /50 X100%= [ ] %, markah ≥ 75% kepatuhan baik.

Rujukan:

Hassan, N. B., Hasanah, C. I., Foong, K., Naing, L., Awang, R., Ismail, S. B., Ishak, A., Yaacob, L. H., Harmy, M. Y., Daud, A. H., Shaharom, M. H., Conroy, R., & Rahman, A. R. A. (2006). *Identification of psychosocial factors of noncompliance in hypertensive patients*. *Journal of Human Hypertension, 20*(23–29).

Appendix IV: Malaysia Medication Adherence Assessment Tool (MyMAAT)

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ALAT PENGUKURAN TAHAP KEPATUHAN PESAKIT TERHADAP PENGAMBILAN UBAT DI MALAYSIA
MALAYSIA MEDICATION ADHERENCE ASSESSMENT TOOL (MyMAAT)

Hospital/ *Hospital*			
Nama Pesakit/ *Patient's Name*		**No. Pendaftaran/** *Reg. No.*	
		Tarikh/ *Date*	
No. KP/ *IC No.*		**Lokasi/** *Location*	

Bahagian I	:	**Persepsi Tahap Kepatuhan Pesakit Terhadap Pengambilan Ubat-Ubatan**
Part I	:	***Perception on Patient's Adherence Towards Medication***

Soal selidik ini dijalankan untuk mendapatkan maklumat mengenai amalan pengambilan ubat oleh pesakit dan sebaik-baiknya diisi oleh pesakit/ penjaga.
***Sila tandakan (√) pada kotak yang berkenaan.**

This survey will ask about your current practice related to medication taking and preferably to be filled by patient/ care taker.
** Please tick (√) in the appropriate boxes.*

Bil./ *No.*	**Perkara/** *Item*	**Skor/***Score*				
		Sangat Tidak Setuju/ *Strongly Disagree*	**Tidak Setuju/** *Disagree*	**Neutral/** *Neutral*	**Setuju/** *Agree*	**Sangat Setuju/** *Strongly Agree*
		5	**4**	**3**	**2**	**1**
1.	**Dalam sebulan yang lepas, saya kerap tidak mengambil ubat seperti yang diarahkan oleh doktor.** *In the past one month, I frequently failed to take my medication in accordance with the doctor's instruction.*					
2.	**Dalam sebulan yang lepas, saya mengurangkan pengambilan ubat apabila berasa sihat.** *In the past one month, I reduced my medication intake when I felt better.*					
3.	**Dalam sebulan yang lepas, saya mengambil ubat secara berselang-seli.** *In the past one month, I took my medication alternately.*					
4.	**Saya sering terlewat/terlepas untuk temujanji pengambilan ubat susulan di kaunter farmasi.** *I was often late on / missed the appointment date to get the supplies of my follow-up medication at the pharmacy counter.*					

Bil./ *No.*	Perkara/ *Item*	Skor/*Score*				
		Sangat Tidak Setuju/ *Strongly Disagree*	**Tidak Setuju/** *Disagree*	**Neutral/** *Neutral*	**Setuju/** *Agree*	**Sangat Setuju/** *Strongly Agree*
		5	**4**	**3**	**2**	**1**
5.	**Daripada bekalan ubat yang diterima, saya mempunyai banyak lebihan ubat di rumah.** *I have excess supply of the prescribed medication at home.*					
6.	**Saya hanya mengambil sebahagian sahaja daripada ubat yang diberikan kerana merasakan ianya tidak perlu/tidak penting.** *I did not fully comply with the prescriptions because I felt it was unnecessary/insignificant.*					
7.	**Dalam sebulan yang lepas, saya sering terlupa untuk mengambil ubat saya.** *In the past one month, I frequently failed to remember to take my medication.*					
8.	**Saya sering mengurangkan pengambilan ubat kerana bimbang akan kesan sampingnya terhadap badan.** *I regularly take less medication than prescribed for fear of the side effects to my body.*					
9.	**Saya tidak mengambil ubat apabila tiada sesiapa mengingatkan saya.** *I will miss/not take my medication if no one reminds me to do so.*					
10.	**Saya tidak begitu pasti tentang dos ubat yang perlu diambil setiap hari.** *I am uncertain about my daily medication doses.*					
11.	**Saya tidak boleh menguruskan pengambilan ubat saya dengan baik.** *I am unable to manage my medication intake properly.*					
12.	**Ketiadaan sokongan atau pertolongan dari orang tersayang menyebabkan saya tidak bermotivasi untuk mengambil ubat yang diberikan oleh doktor.** *Without support or help from the loved ones, I lack motivation to take my medication as prescribed by the doctor.*					
	JUMLAH/ *TOTAL* **Skor minimum = 12; Skor maksimum = 60** *Minimum score = 12; Maximum score = 60*					

SOAL SELIDIK TAMAT/ *END OF SURVEY*

TERIMA KASIH/ *THANK YOU*

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ALAT PENGUKURAN TAHAP KEPATUHAN PESAKIT TERHADAP PENGAMBILAN UBAT DI MALAYSIA
MALAYSIA MEDICATION ADHERENCE ASSESSMENT TOOL (MyMAAT)

Bahagian II	:	**Kategori Kepatuhan Pesakit Terhadap Pengambilan Ubat-Ubatan**
Part II	:	***Category of Patient's Adherence Towards Medication***

Kategori kepatuhan mengikut jumlah skor adalah seperti berikut:
Patient's adherence category based on total score as stated below:

Kategori/ *Category*	**Jumlah Skor/** *Total Score*
Kepatuhan baik/ *Good adherence*	≥ 54
Kepatuhan sederhana dan lemah/ *Moderate and poor adherence*	< 54

Bahagian III	:	**Rumusan Tahap Kepatuhan Pesakit Terhadap Pengambilan Ubat-Ubatan**
Part III	:	***Summary on Patient's Adherence Towards Medication***

Untuk diisi oleh pegawai farmasi/ *To be filled by pharmacist.*

Jumlah Skor/ *Total Score*	
Kategori Kepatuhan/ *Adherence Category*	☐ **Kepatuhan baik/** *Good adherence* ☐ **Kepatuhan sederhana dan lemah/** *Moderate and poor adherence*
Nota Pegawai Farmasi/ *Pharmacist's Note*	

Tandatangan & Cop Pegawai Farmasi/ :
Pharmacist's Signature & Stamp

Tarikh/ :
Date

Appendix V: TMTAC Patient Registry Record & Defaulter List

No.	Name	ID/RN	Date of Recruited	TMTAC Visit		Discharge		Missed Appointment			
				Visit Number	Date	Date of Discharge	Reason for Discharge	Date of Missed Appointment	Reason For Default	Action Taken	New Appointment Date

Note: The format provided in this protocol serves as a guideline. Facilities may rearrange or customise the format as needed, provided that all required information is retained.

Appendix VI: TMTAC Initial Visit Form

THALASSAEMIA MEDICATION THERAPY ADHERENCE CLINIC (TMTAC) HOSPITAL/ HEALTH CLINIC: _____			INITIAL VISIT FORM
PATIENT'S PROFILE AND BACKGROUND			
Patient's Profile			
Name:		**ID/RN:**	
Age:	**Gender:** **Male/ Female**	**Race:**	**Weight:**
Contact No.:		**Date of recruitment:**	
Disease Background			
Diagnosis: ☐ **Transfusional Dependent Thalassaemia (TDT)** ☐ **Non-Transfusional Dependent Thalassaemia (NTDT)** **Please specify:** ☐ **Thalassaemia Major** ☐ **Hb E Beta Thalassaemia** ☐ **Hb H Constant Spring** ☐ **Others:**_____ **Frequency of transfusion:**			
Past Medical/ Surgical History:		**Age at Diagnosis:**	**Social History:**
Family History:		**Allergies & History of Drug Adverse Event/ Reaction:**	
Past Medication History:			
Pharmacist's Notes			
Pharmacist's Stamp and Signature:			**Date:**

Appendix VII: TMTAC Pharmacists Assessment Form

THALASSAEMIA MEDICATION THERAPY ADHERENCE CLINIC (TMTAC) HOSPITAL/ HEALTH CLINIC: _____		PHARMACIST'S ASSESSMENT FORM
Name:	**ID/RN:**	**Weight:**

A. Current Medication/Supplements/OTC

B. Iron Chelation Therapies

1.DESFEROXAMINE

Dosage

Dose Administered: _____ mg x___ days/week

Mean daily dose:_____mg/kg/day

Therapeutic Index: Mean daily dose (mg/kg): _____
(<0.025) Serum ferritin (µg/L)

Frequency of missed doses per week:

Preparation & Administration

Dilution done by: ☐ self ☐ caregiver:_____ Volume of WFI per dose:

Infusion done by: ☐ self ☐ caregiver:_____

Infusion rate : Time start/stop infusion : Infusion Duration :

Injection Site Management

Local anaesthesia use: ☐ Yes ☐ No

Injection site: ☐ Arm ☐ Abdomen ☐ Thigh Single use of needles: ☐ Yes ☐ No

Rotation of Injection Site: ☐ Yes ☐ No Correct disposal of needles: ☐ Yes ☐ No

Injection site issues: ☐ Yes ☐ No

Barriers encountered during injection:

Adjunct Therapy

Vitamin C intake: ☐ Yes ☐ No

If yes, correct intake of Vitamin C: ☐ Yes ☐ No
*One hour after start of desferoxamine infusion

2.DEFERIPRONE

Dosage form: Syrup / IR / PR
Daily dose (mg/kg/day):

Frequency of missed dose:

3.DEFERASIROX

Daily dose (mg/kg/day):

Frequency of missed dose:

Method of administration: Crush / Swallow whole

C. Drug Adverse Event/ Reaction Monitoring

1.General
☐ Signs and symptoms of infections

2.Desferoxamine
☐ Injection site reaction ☐ Neurotoxicity (visual and auditory) ☐ Yersinia and mucor infections ☐ Growth disturbance
☐ Others

3.Deferiprone
☐ Arthropathy ☐ Agranulocytosis ☐ Raised liver enzymes ☐ Others

4.Deferasirox
☐ Rash ☐ Proteinuria ☐ Renal impairment ☐ Neurotoxicity (visual and auditory) ☐ Others

5.Others
☐ _____

D. Lifestyle and Dietary Information

Adherence to low-iron diet: ☐ Yes ☐ No

Physical activity:

E. Adherence Score

Tool(s):

Score:

F. Pharmacist's Notes

Pharmacist Plan

Next TCA: **Date:**

Pharmacist's Stamp and Signature:

Appendix VIII: Parameters Monitoring Form

Anthropometric Measurements:

Parameters/Date												
Height (cm)												
Weight (kg)												

Laboratory Investigations:

Blood Counts													
Parameters	Normal Range/ Date												
Hemoglobin	11.5-16.5 g/dL												
Absolute Neutrophil Count	2-6.9												
Platelet	150-400 x 10^9/L												
Renal Profile													
Parameters	Normal Range/ Date												
Serum creatinine	45-84 µmol/L												
eGFR													
Liver Function Test													
Parameters	Normal Range/ Date												
ALT	<35 U/L												
AST	<35 U/L												
ALP	33-98 U/L												
Total bilirubin	5-21 µmol/L												

Endocrine													
Parameters	**Normal Range/ Date**												
TSH	**< 12 years old: 0.79-5.85 uIU/mL 12 - 18 years old: 0.68 - 3.35 uIU/mL > 18 years old: 0.38 - 5.33 uIU/mL**												
fT4	**< 20 days: 17.37 - 57.66 20 days - <3 years: 9.52 - 17.76 3 - <18 years old: 7.85 - 13.64 ⩾18 years old: 7.86 - 14.41**												
FSH	**Refer to individual laboratory reference range**												
LH													
Testosterone													
Serum cortisol													
FBS	**4.4 - 7.0 mmol/L**												
Corrected calcium	**2.20 -2.65 mmol/L**												
Magnesium	**0.73 - 1.06 mmol/L**												
DEXA bone scan	**T score: ≥ -1 or Z score > -2**												
Vitamin D	**>50ng/mL**												
Phosphate	**0.81 - 1.45 mmol/L**												
Infectious Screening													
Parameters	**Normal Range/ Date**												
HBsAg	**Non-reactive**												
Anti-HBs	**>10**												
HIV Ab/Ag	**Non-reactive**												
Anti-HCV	**Non-reactive**												

Total Iron Burden													
Parameters	**Normal Range/ Date**												
Serum ferritin (ug/L)	**< 1000 ug/L**												
Cardiac MRI T2*	**Normal: > 20 ms Mild: 16-20 ms Moderate: 10-15 ms Severe: <10 ms**												
Liver Iron Concentration (LIC)	**Normal: < 2 mg/g Mild: 2-7 mg/g Moderate: 7-15 mg/g Severe: >15 mg/g**												
***Rate of iron loading (ROIL)**	**Average: 0.3-0.5 mg/kg/day**												

***ROIL (mg/kg/day) = $\frac{\text{ml of blood transfused x 1.08}}{\text{Weight x days over which the blood was administered}}$**

Others													
Parameters	**Normal Range/ Date**												
Auditory	**Normal**												
Visual	**Normal**												
Echocardiography	**LVEF > 50%**												
Hepatic Ultrasound	**NAD**												

Note: Reference ranges derived from local hospital laboratory which may varies between different facilities.

Appendix IX: Recommended Monitoring Parameters & Frequency of Monitoring

Monitoring Parameter	Frequency
BLOOD COUNTS	
Hemoglobin	Pre-transfusion
Absolute Neutrophil Count	
Platelet	
RENAL PROFILE	
Serum creatinine	3-6 monthly (monthly in DFX toxicity)
eGFR	
Urine analysis (protein)	
LIVER FUNCTION TEST	
ALT	3 monthly (monthly in DFX toxicity)
AST	3 monthly
ALP	
Total bilirubin	
ENDOCRINE	
TSH	Annually
fT4	
FSH	
LH	
Testosterone	
Serum cortisol	
Serum calcium	
Phosphate	
Magnesium	
FBS	10-18 years: 2 yearly >18 years: annually
25-OH Vitamin D	6 monthly
DEXA bone scan	1-2 yearly, starting 10 years old
INFECTIOUS SCREENING	
HBsAg	Annually, in unvaccinated patients
Anti-HBs	Annually, in vaccinated patients
HIV Ab/Ag	Annually
Anti-HCV	
IRON BURDEN	
Serum ferritin	3-6 monthly, with the start of transfusion therapy
Cardiac MRI T2*	Normal: 2 yearly Mild to Moderate: Annually* Severe: 6 monthly* *After intensification of chelation

LIC	Normal-Mild: 2 yearly Moderate to Severe: Annually* *After intensification of chelation
ROIL	6-12 monthly
ANNUAL SCREENING	
Auditory	Annually in DFO toxicity
Ophthalmology	
Echocardiography	Annually
Hepatic ultrasound	Annually 6 monthly (advanced liver disease, severe LIC, cirrhotic, age >45 years, chronic viral hepatitis)

Note: The recommendation serves as a general guide. Adjust accordingly for patients with comorbidities.

References:

Malaysian Health Technology Assessment Section (MaHTAS). (2024). *Clinical Practice Guidelines Management of Thalassaemia Second Edition*. Malaysian Health Technology Assessment Section (MaHTAS)

Cappellini, M. D., Musallam, K. M., Farmakis, D., Porter, J. B., & Taher, A. T. (2025). *5th Edition Guidelines for the management of transfusion dependent thalassaemias.* Thalassaemia International Federation.

Appendix X: Patient's Understanding on Medication

Review of Patient's Understanding on Medication (DFIT Scoring)																				
Medication	**Visit:** **Date:**				**Visit:** **Date:**				**Visit:** **Date:**				**Visit:** **Date:**				**Visit:** **Date:**			
	D	**F**	**I**	**T**	**D**	**F**	**I**	**T**	**D**	**F**	**I**	**T**	**D**	**F**	**I**	**T**	**D**	**F**	**I**	**T**
Score (%)																				

Key : D = Dose , F = Frequency, I = Indication, T = Method of Administration

Appendix XI: Education Module Outline

***Education module should be delivered following patient's understanding and needs**

CHAPTER	MODULE OUTLINE
Chapter 1	• Brief Thalassaemia Overview • Pathophysiology of Thalassaemia • Genetic basis of Thalassaemia • Blood transfusion basics • Role of the patient in their own care
Chapter 2	• Therapeutic goals (serum ferritin, Cardiac MRI T2*, LIC) • Drug counselling (types of iron chelators, DFIT, toxicity and adverse drug reactions, sick day management, injection site management and needle disposal) • Importance of adherence to iron chelators • Iron control during pregnancy and lactation
Chapter 3	• Complications of iron overload, eg, osteopenia/osteoporosis, DM, hypothyroidism, cardiovascular, liver disease • Infective complications - transfusion-related, splenectomy-related & iron chelator-related • Splenectomy (vaccination and chemoprophylaxis)
Chapter 4	• Basic nutrition and supplements • Lifestyle advice (including bone health) • Benefits of relaxation techniques/ support groups • Long-term plans (overcoming barriers, family planning, managing schools/ work) • Transition to adult care

Appendix XII: Prescriber Referral Form

PRESCRIBER REFERRAL FORM
THALASSAEMIA MEDICATION THERAPY ADHERENCE CLINIC
HOSPITAL/ HEALTH CLINIC_____

Dear Pharmacist,

The following patient is referred to Thalassaemia Medication Therapy Adherence Clinic (TMTAC)

Date :

Patient's Name :

ID/RN :

Diagnosis :

Current Medications:

Please see this patient for the following reason:

- ☐ Newly started
- ☐ Non-adherence
- ☐ Switching of regimen
- ☐ Drug related problems
- ☐ Difficulties in administration
- ☐ Other:_____

Prescriber's Signature and Stamp:

_____

_____

For Pharmacist's Use

Received by :

Notes :

Appendix XIII: Thalassaemia Medication Diary

The Thalassaemia Medication Diary is a bilingual tool designed to help patients with thalassaemia manage their treatment and overall health. It includes sections for iron chelation therapy, daily medication intake, and any side effects. The diary also provides educational information and practical tips to encourage adherence and self-care. By supporting accurate tracking and improving communication with healthcare providers, the diary helps patients take an active role in their care journey.

**Thalassaemia Medication Diary is provided as a supplementary document.*

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