



KEMENTERIAN KESIHATAN MALAYSIA

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MyTalasemia USER MANUAL

The screenshot shows the homepage of the MyTalasemia website. At the top, there is a navigation bar with the Malaysian coat of arms, the text 'KEMENTERIAN KESIHATAN MALAYSIA MyTalasemia', the title 'SUMBER UTAMA MAKLUMAT TALASEMIA', and a red logo. Below the navigation bar is a banner with the text 'Jalani ujian talasemia sebelum memulakan keluarga' and a 'Welcome to www.mytalasemia.net.my' message. The main content area features a grid of six user type icons: 'Lab Patient', 'Lab Professional', 'Geneticist who wants to know more about Talasemia', 'Someone who wants to go for Talasemia screening test?', 'National Talasemia Registry', and 'Lab Information System Module'. To the right, there are sections for 'Announcement', 'Watch Video', and 'Paediatric News'. A footer at the bottom contains the copyright information: 'Copyright (c) 2006-2007 Ministry of Health Malaysia'.

**OBSTETRIC & GYNAECOLOGY AND PAEDIATRIC SERVICES UNIT
MEDICAL SERVICES DEVELOPMENT SECTION
MEDICAL DEVELOPMENT DIVISION**

TABLE OF CONTENTS

| | |
|--|-----------|
| MYTALASEMIA USER MANUAL | 3 |
| 1 GETTING STARTED | 3 |
| 1.1 INTRODUCTION | 3 |
| 1.2 STARTING MYTALASEMIA | 3 |
| 1.3 NAVIGATING THE MENU | 4 |
| 2 DATA ENTRY GUIDELINES | 4 |
| 2.1 ENTERING DATE FIELD | 4 |
| 2.2 ENTERING NUMERIC FIELD | 5 |
| 2.3 SELECTING FROM DROPDOWN LIST | 5 |
| 2.4 ENTERING MYKAD NUMBER | 5 |
| 2.5 ENTERING SEARCH CRITERIA | 5 |
| 3 ONLINE HELP | 6 |
| 4 SUBMITTING NEW THALASSAEMIA CASES | 6 |
| 4.1 GENERAL DESCRIPTION OF THE FORM | 7 |
| 4.2 NOTIFICATION DETAILS PAGE | 7 |
| 4.3 PATIENT'S PARTICULARS PAGE | 7 |
| 4.4 PATIENT'S HISTORY PAGE | 9 |
| 4.5 CLINICAL DATA | 10 |
| 4.6 TREATMENT DETAILS PAGE | 11 |
| 4.7 COMPLICATIONS PAGE | 12 |
| 4.7.1 <i>Hepatitis B Investigation</i> | 13 |
| 4.7.2 <i>Hepatitis C Investigation</i> | 13 |
| 4.7.3 <i>HIV Investigation</i> | 13 |
| 4.8 COMPLICATIONS FROM THERAPY PAGE | 14 |
| 4.9 CURRENT STATUS PAGE | 14 |
| 5 ANNUAL CENSUS FORM | 15 |
| 5.1 SEARCHING FOR THE CORRECT PATIENT | 15 |
| 5.2 MEASUREMENT UPDATE PAGE | 15 |
| 5.3 COMPLICATIONS PAGE | 15 |
| 5.4 COMPLICATIONS FROM THERAPY PAGE | 16 |
| 5.5 CURRENT STATUS PAGE | 16 |
| 6 PATIENT MONITORING FORM | 16 |
| 6.1 PART 1 PAGE | 16 |
| 6.2 PART 2 PAGE | 16 |
| 6.3 PART 3 PAGE | 17 |
| 6.4 PART 4 PAGE | 17 |

| | | |
|-----------|---|-----------|
| 7 | NEW TREATMENT DATA FORM | 17 |
| 7.1 | PATIENT PARTICULARS PAGE | 18 |
| 7.2 | MEASUREMENT UPDATE PAGE | 18 |
| 7.3 | TRANSFUSION PAGE | 18 |
| 8 | DEATH/ CHANGE CENTRE FORM | 18 |
| 9 | EDIT PATIENT PARTICULARS FORM | 19 |
| 10 | VIEWING AND AMENDING PATIENT'S DETAILS | 19 |
| 10.1 | LIST OF PATIENTS REPORT | 19 |
| 10.2 | DISPLAYING PATIENTS DETAILS | 20 |
| 10.2.1 | <i>Particulars Tab</i> | 20 |
| 10.2.2 | <i>History Tab</i> | 20 |
| 10.2.3 | <i>Clinical Tab</i> | 21 |
| 10.2.4 | <i>Treatment Tab</i> | 21 |
| 10.2.5 | <i>Complication Tab</i> | 21 |
| 10.2.6 | <i>Annual Comments</i> | 21 |
| 10.3 | REPORT OF DEFERRAL PATIENTS | 22 |
| 10.4 | DISPLAYING PATIENTS FERRITIN | 22 |
| 10.5 | BREAKDOWN OF PATIENTS | 22 |
| 10.6 | THALASSAEMIA MAP | 22 |
| 10.7 | THALASSAEMIA BIRTH | 23 |
| 10.8 | SUMMARY BY STATE | 23 |
| 10.9 | TOP 5 CENTRES | 23 |
| 10.10 | DELETING PATIENTS | 23 |
| 11 | DIGITAL LIBRARY | 24 |
| 11.1 | ACCESSING VIDEO | 24 |
| 11.2 | ACCESSING EBOOKS | 24 |
| 11.3 | ACCESSING SLIDES | 25 |
| 11.4 | ACCESSING THALASSAEMIA DICTIONARY | 26 |
| 12 | REPORTING PROBLEMS | 26 |
| | SEKRETARIAT | 27 |

MyTalasemia USER MANUAL

1

Getting Started

1.1 Introduction

MyTalasemia is a Malaysian portal for thalassaemia. It has a comprehensive and extensive contents including the Malaysian Thalassaemia Registry (MTR). MTR is a register of all thalassaemia cases in Malaysia. This manual will focus on accessing the MTR.



Convention used in this manual:

- Data field names are displayed in ***blue bold italic***.
- Navigation buttons or navigation links are displayed ***in bold italic***

1.2 Starting MyTalasemia


MyTalasemia can be started using an internet browser such as Internet Explorer. Your computer must be connected to the internet to access MyTalasemia. If your computer is not connected to the internet, please contact the appropriate person who is in charge of ICT at your workplace.

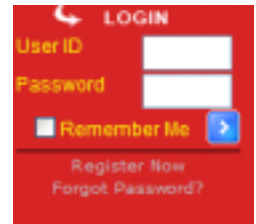
Procedure for starting MyTalasemia:

- Start Internet Explorer on your computer. This is normally done by double clicking the Internet Explorer icon on the desktop.
- On the address bar at the top of the browser, type in <http://www.mytalasemia.net.my>
- You will then get the home page of MyTalasemia
- You will have a restricted menu on the left because you have not logged on to the system. Logging on will give you more options on the menu. The options will depend on what role you have been assigned. Users with high privilege roles will get more options on the menu.



Procedure for Logging On to MyTalasemia:

- To log on to MyTalasemia, enter your username and password on the top left hand-side of the page. When typing your password, the system will display is as big dots for each character you type. Passwords are case-sensitive.
- Click the blue Login button . If you have entered your username and password correctly, you will get the welcome page.



1.3 Navigating the menu

Throughout this manual, the following convention will be used to describe menu navigation.

Menu : main menu → sub-menu1 → sub-menu 2

e.g. Menu : *Registry* → *Data Entry* → *Annual Census*



The above means:

- Click the *Registry* item in the main menu
- A sub-menu will appear. Click the *Data Entry* item in the sub-menu
- Another sub-menu will appear. Click the *Annual Census* item in the sub-menu

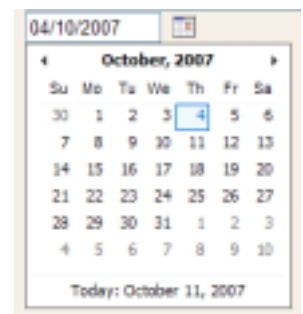
2

Data Entry Guidelines

2.1 Entering date field

Dates can be entered either by:

- Typing directly into the date box. The format of the date must be *dd/mm/yyyy* where *dd* is the day, *mm* is the month and *yyyy* is the year. For single digit day and month, please put a '0' in front e.g. for 3rd February 2007 enter 03/02/2007.
- Clicking the calendar icon to the right of the box. When the box is clicked, a calendar will appear. Navigate the calendar to the correct date and double click the date. The date will be entered automatically into the box.



2.2 Entering numeric field

Fields that require numerical values should be entered using numeric digits (0 to 9). A decimal point can be used if needed. Do not use other symbols (e.g. '<') and do not enter the unit of measurement.

Hb Analysis (Note: Do not use < or > sign. Use the best approximate value)

| | | | | | | | | | | | |
|-----|----------------------|---|--------|----------------------|---|-----|-----------------------------------|---|-----|-----------------------------------|---|
| HbA | <input type="text"/> | % | HbA2 | <input type="text"/> | % | HbF | <input type="text" value="20.3"/> | % | HbE | <input type="text" value="33.8"/> | % |
| HbH | <input type="text"/> | % | Others | <input type="text"/> | % | NA | <input type="text"/> | % | | | |

2.3 Selecting from dropdown list

The value can be selected by clicking the button on the right of the box. When clicked, a list will appear and you can select the value by clicking the appropriate item in the list.

Diagnosis

Beta thalassaemia intermedia

Beta thalassaemia intermedia

Beta thalassaemia major

Hb H disease

HbE-beta thalassaemia

Others

2.4 Entering MyKad number

You must type the all numbers into the box. When you place the cursor into the box, a template of the format will appear and you can start entering the number.

My Kad

2.5 Entering Search Criteria

On many forms that requires identification of an existing patient, the selected menu will bring up a search criteria form. The criteria has to be filled in if you want to narrow down the search.

- Select the Centre or **Hospital**. For most users, you will only have the centre name in the dropdown list
- You can optionally enter the patient name in the **Name** box. Narrow down the search by entering the first few characters of the patient's name.
- You can optionally enter the **MyKad** number. The MyKad number must be entered exactly
- The **Date of Birth** field is optional. Entering the date will narrow your search.

- If there is a Status field, select the status from the dropdown list
- Click **Display List** to start the search
- If there are any patients that matches the search criteria, a list of records will appear

If you click the Print Preview List, the search results will appear as a PDF file. You must have Adobe Reader installed on your PC to view the PDF report. Printing can be done from Adobe Reader.

3

Online Help

Some fields in the data entry form have pop-up online help describing the field. Place your cursor on the field name and the description will be displayed.



4

Submitting New Thalassaemia Cases

Menu: Registry → Data Entry → MTR Notification

New cases of thalassaemia can be notified using the MTR Notification form. To avoid data duplication, please ensure that the patient's data has never been entered into MyTalasemia.

4.1 General description of the form

The form consists of several pages. To navigate from one page to the other, please use the *Next* or *Previous* button at the bottom of the page. The left column of the form consists of a list of all the pages and will highlight the current page being displayed.

4.2 Notification Details Page

Data items that have to be entered in this page are as follows:

Centre: Most users will have only 1 item in the list i.e. their centre. Your centre will automatically be selected in the drop-down list.

Notification Date: The system will automatically put today's date. You can put a different date either by typing in the box or clicking the calendar icon on the right of the box. Date should be entered in the format dd/mm/yyyy e.g. for 2nd July 2007 enter 02/07/2007 (see section 2.1 on how to enter date.)

Reported By: The system will automatically display your logon ID in the box. You can enter your name.

Click on the **Next** button at the bottom of the page to go to the next page.

4.3 Patient's Particulars Page

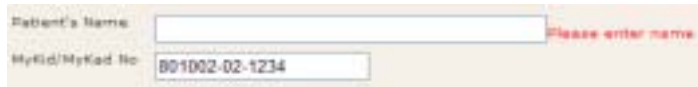
MTR Notification

Notification Details
Patient's Particulars
Patient's History
Billing mark

Patient's Name: Ali bin Ahmad
Myself/Mother No: 001800-02-1234
Other: e.g. Mother's Noted
Government's No:
Gender:
Date of Birth: 02/07/2007
Age: years months
Gender: Male
Ethnic Group: Malay
Address: 5 Jalan 1/1
Taman Bunga Raya
Postcode:
Town/City: Ipoh
State: Perak
Phone No (H): Phone No (M):
No. of Billings: 3 Billing mark: 3
Mother's Ethnic Group: Malay

Data items that have to be entered on this page are as follows:

Patient's Name: Enter the patient's full name. This data is mandatory. You will not be allowed to go to the next page if this data is not entered. If you click the **Next** button without entering the patient's name, you will get a reminder note.

A screenshot of a web form. The first field is labeled 'Patient's Name' and is empty, with a red error message 'Please enter name' to its right. The second field is labeled 'MyKid/MyKid No' and contains the text '801002-02-1234'.

MyKad/MyKid No: Enter the patient's MyKad or MyKid number if available. Enter the 3 parts of the MyKad number separately into the 3 boxes. The first box will take 6 digits, the second box 2 digits and the third box 4 digits. Do not enter the mother's MyKad number in this field. If the patient does not have a MyKad number and you wish to enter the mother's MyKad number, you can enter it in the box below. Old IC numbers should be entered as "Other Document".

Other Document's No.: For patients without a MyKad, you can enter another document number as reference e.g. the mother's MyKad.

Specify Document Type: Enter the type of document if you entered information into the **Other Document's No** box above.

Date of Birth: Enter the patient's date of birth. Please refer to section 2.1 for guideline on entering the date. This data is mandatory.

Age: This box cannot be edited. The system will automatically calculate the patient's age once the data has been saved.

Gender: Select the gender from the dropdown list.

Ethnic Group: Select the ethnic group from the dropdown list. The ethnic group of the patient is the Father's ethnic group if the parents are of different ethnic groups. If the ethnic group is not listed, please select 'Others'.

Address: A complete address can be entered in the next 5 boxes. The first 2 boxes are for filling in the first part of the address.

Postcode: Enter the postcode in the box

Town/City: Enter the town or city

State: Select the state from the dropdown list

Phone number (H): Enter the home telephone number. Please enter only 1 number

Phone number (HP): Enter the handphone number. Please enter only 1 number

No. of Siblings: Enter the number of siblings in the family. This data is mandatory.

Sibling rank: Enter the sibling ranking of the patient, the eldest has a rank of 1. This data is mandatory.

Mother's Ethnic Group: Enter the mother's ethnic group from the dropdown list.

Click on the **Next** button at the bottom of the page to go to the next page.

4.4 Patient's History Page

| Date Measurement Taken | Height (cm) | Weight (kg) |
|------------------------|-------------|-------------|
| 06/10/1998 | 126 | 23.1 |
| 06/04/1999 | 126 | 24.4 |
| 21/05/1999 | 127.5 | 25.5 |
| 25/04/2000 | 131.3 | 27.7 |

Data items that have to be entered on this page are as follows:

Desferral Status: Select the desferral status from the dropdown list. If you select a status other than 'None', then the next field must be filled in.

Date of first use of Desferral: Enter the date of the patient's first use of desferral. . Please refer to section 2.1 for guidelines on entering the date.

The rest of the page consists of the height and weight of the patient. You can enter up to 4 sets of measurements. Each set consist of Date Measurement Taken, Height (cm) and Weight (kg). The system can handle the data even if the dates are not in chronological order. If you have more than 4 sets of data, you can enter them later using the "New Treatment Data" form.

Date Measurement Taken: Enter the date of when you measured the height and weight.

Height (cm): Enter the numerical value of the height in cm. Only numerical digits and decimal points are allowed e.g. 96.5 or 102. Do not enter the unit of measurement or any other characters.

Weight (cm): Enter the numerical value of the weight in Kg. Only numerical digits and decimal points are allowed e.g. 30.5 or 42. Do not enter the unit of measurement or any other characters.

Click on the **Next** button at the bottom of the page to go to the next page.

4.5 Clinical Data

Data items that have to be entered on this page are as follows:

Diagnosis: Select the diagnosis from the dropdown menu.

Other, specify: If you have selected “Others” as a diagnosis, please specify.

Basis for diagnosis:

- Tick the **Clinical** tick box if the basis for diagnosis is clinical.
- Tick the **Laboratory** tick box if the basis for diagnosis is laboratory. If you tick this box, then the rest of the page will be enabled for editing.

Basis for Diagnosis Clinical Laboratory

Hb Analysis:

Enter the numerical values for the all Hb Analysis data i.e. **HbA**, **HbA2**, **HbF**, **HbE**, **HbH**, **Others** and **NA**. Only numerical digits and decimal points should to be entered. Otherwise you will receive an error message. Do not enter any signs or units (e.g. '<' or '%'). If there is no exact value, please use the best approximate value.

| | | | | | | | | | | | |
|-----|----------------------|---|--------|--------------------------------------|---|-----|-----------------------------------|---|-----|-----------------------------------|---|
| HbA | <input type="text"/> | % | HbA2 | <input type="text" value="<3.5"/> | % | HbF | <input type="text" value="20.3"/> | % | HbE | <input type="text" value="33.8"/> | % |
| | | | | Numeric only | | | | | | | |
| HbH | <input type="text"/> | % | Others | <input type="text"/> | % | NA | <input type="text"/> | % | | | |

Molecular/DNA Analysis

Beta Thalassaemia Mutations: Tick the appropriate mutations. Each mutation value has 2 tick boxes. The tick boxes on the left column is for the first parent and the tick boxes on the right column is for the second parent.

Alpha Thalassaemia Mutations: Tick the appropriate mutations. Each mutation value has 2 tick boxes. The tick boxes on the left column is for the first parent and the tick boxes on the right column is for the second parent.

The screenshot shows a form titled "Molecular/DNA Analysis" with two main sections: "Beta Thalassaemia Mutations" and "Alpha Thalassaemia Mutations". Each section contains a grid of checkboxes for various mutations, with two columns for each parent. In the Beta section, the mutation "IVS 1-1 (G->T)" is checked in both parent columns. In the Alpha section, the mutation "--Alpha SEA" is checked in both parent columns. Other mutations listed include -88 (C->T), -29 (A->G), IVS 1-3 (G->C), IVS 11 654 (C->T), CD 19 (Asn->Ser) (A->G) / Hb Malay, CD 26 (Glu->Lys) (G->A) HbE, CD 33 (-C), CD 41/42 (-TCTT), Not Identifiable, CD 43 (GAG->TAG), CD 71/72 (+A), AATAAA->AATAGA, -PIL, -619 bp, OBeta, Hb Lepore, HPHH, and Others. The Alpha section includes -Alpha 2.7, -Alpha 4.2, --Alpha THAI, Hb Constant Spring, Hb Guan Dok, Hb Q, Hb Pakse, CD 59, and Not Identifiable.

Click on the **Next** button at the bottom of the page to go to the next page.

4.6 Treatment Details Page

Data items that have to be entered on this page are as follows:

Treatment: Select the treatment type from the dropdown list. If the "Transfusion Required" value is selected, the next field must be entered.

Transfusion Requirement: Select the transfusion requirement from the dropdown list. If the "Regular" value is selected then the next field must be entered.

The screenshot shows a form with the following fields: "Treatment" (dropdown menu with "Transfusion Required" selected), "Transfusion requirement" (dropdown menu with "Regular" selected), "Interval" (dropdown menu with "4" selected), "Others, specify" (text input field), "First Transfusion" (dropdown menu with "4" selected), "Date (First Transfusion)" (text input field with a date picker icon and the format "/YYYY"), and "Iron Chelation" (dropdown menu with "Dn") selected.

Interval (weeks): Select the transfusion interval (in weeks) from the dropdown list. If the interval is not in the list, select "0" and enter the next field.

Others (please specify): Enter the transfusion interval (in weeks) if it is not in the dropdown Interval list above.

Date of First Transfusion) : If the date of first transfusion is known, enter the date in the box. Please refer to section 2.1 for guidelines on entering the date.

Iron Chelation: Select the iron chelation type from the dropdown list.

Desferrioxamine, Deferiprone (L1), Deferasirox (Exjade): Tick the appropriate drug that has been administered on the patient. You can tick more than 1 box.

Desferrioxamine Deferiprone (L1) Deferasirox (Exjade)

Others (please specify): Enter the type of drugs administered if it is none of the above.

Ferritin Level Test Taken: Tick this box if the ferritin level test has been taken. When this box is ticked, you can enter up to 4 sets of ferritin levels readings.

Date Ferritin Level Taken: Enter the date the test was taken

Actual S. Ferritin Level: Enter the numerical value of the measurement. Use only numeric digits and/or decimal points.

Splenectomy Done: Select one of the options from the dropdown list.

Date (splenectomy): If the splenectomy has been done, enter the date here.

Click on the **Next** button at the bottom of the page to go to the next page.

4.7 Complications Page

Hepatitis B Investigation

HbsAg: (Unknown) [v]
HbSAb: (Unknown) [v]
HbSAb: (Unknown) [v]
Vaccination given: (Unknown) [v]

Hepatitis C Investigation

Anti-HCV: (Unknown) [v]

Date of Complication (dd/mm/yyyy): 02/18/2007 [v]

| October, 2007 | | | | | | |
|---------------|----|----|----|----|----|----|
| Sa | Mo | Tu | We | Th | Fr | Sa |
| 30 | 1 | 2 | 3 | 4 | 5 | 6 |
| 7 | 8 | 9 | 10 | 11 | 12 | 13 |
| 14 | 15 | 16 | 17 | 18 | 19 | 20 |
| 21 | 22 | 23 | 24 | 25 | 26 | 27 |
| 28 | 29 | 30 | 31 | 1 | 2 | 3 |
| 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Today: October 11, 2007 [v]

Data items that have to be entered on this page are as follows:

4.7.1 Hepatitis B Investigation

Hbs Ag: Select from dropdown list and enter the date

Hbs Ab: Select from dropdown list and enter the date

HbeAg: Select from dropdown list and enter the date

Vaccination given: Select from dropdown list and enter the date

4.7.2 Hepatitis C Investigation

Anti-HCV: Select from dropdown list and enter the date

4.7.3 HIV Investigation

HIV Screening: Select from dropdown list and enter the date

HIV Confirmation: Select from dropdown list and enter the date

Short Stature: Select from dropdown list and enter the date

Delayed Puberty: Select from dropdown list and enter the date

Diabetes Mellitus: Select from dropdown list and enter the date

Cardiac Impairment: Select from dropdown list and enter the date

Hypothyroid: Select from dropdown list and enter the date

Other Complications, specify: Select from dropdown list and enter the date

Click on the **Next** button at the bottom of the page to go to the next page.

4.8 Complications From Therapy Page

The form is divided into the following categories:

- Complications from Desferrioxamine (Desferal)
- Complications from Deferiprone (L1)
- Complications from Deferasirox (Exjade)

Tick all complications that apply.

Click on the **Next** button at the bottom of the page to go to the next page.

The screenshot shows three overlapping form panels. The top panel is titled 'Complications from Desferrioxamine (Desferal)' and lists symptoms like Abdominal pain, Anemia, and Arterial hypertension. The middle panel is titled 'Complications from Deferiprone(L1)' and lists symptoms like Abdominal pain, Agranulocytosis, and Amenorrhea. The bottom panel is titled 'Complications from Deferasirox(Exjade)' and lists symptoms like Abdominal distension, Abdominal pain, Anorexia, and Anxiety. Each symptom has a checkbox next to it.

4.9 Current Status Page

Patient's Current Status: Select the status from the dropdown list. If 'Dead' is selected, the next field must be entered.

If deceased, please specify date of death: Please refer to section 2.2 for guidelines on entering the date.

Click on the **Next** button at the bottom of the page to go to the next page. This will take you to the Summary page. To save all the information that you have entered, click the **Finish** button.

The screenshot shows the 'Patient's Current Status' form. The 'Patient's Current Status' dropdown menu is set to 'Dead'. Below this, there is a section for 'If deceased, please specify' with a 'Date of Death' field containing '01/07/2007'. Underneath is the 'Cause of Death' section, which includes several checkboxes for different causes: Cardiac causes, Infections, Arrhythmias, Liver disease, Endocrine complications, Thrombosis, Tumors, Cholelithiasis, and Unknown. There is also an 'Others' checkbox with a text input field next to it.

Annual Census Form

The Annual Census form is used to update information on patients who have previously been entered into MyTalasemia. It cannot be used for patients whose information have not been previously entered. For patients who have not been notified, please use the MTR Notification form (see Section 4).

5.1 Searching for the correct patient

Menu: Registry → Data Entry → Annual Census

To access the Annual Census form, you must first do a search on the patient. Navigate the menu. Then:

- A form for the search criteria will appear
- Select the Centre or **Hospital**. For most users, you will only have your centre name in the dropdown list
- You can optionally enter the patient name in the **Name** box. Narrow down the search by entering the first few characters of the patient's name.
- You can optionally enter the **MyKad** number. If entered, the MyKad number must be entered in full.
- The **Date of Birth** field is optional. Entering the date will narrow down your search.
- Click **Search** to start the search
- If there are any patients that match the search criteria, a list will appear.
- Select the patient you want to update by clicking the patient name.
- A page with the patient's particulars will appear. Please ensure that it is the correct patient before clicking the **Next** button to get to the next page.

5.2 Measurement Update Page

This page allows you to enter up to 4 sets of height and weight measurement and up to 4 sets of Actual Serum Ferritin Level. All sets must be accompanied by the date the measurement was taken.

Click on the **Next** button at the bottom of the page to go to the next page.

5.3 Complications Page

This page will allow you to update details of the patient's complications. Please refer to Section 4.7 for more information.

Click on the **Next** button at the bottom of the page to go to the next page.

5.4 *Complications From Therapy Page*

This page will allow you to update the details of the patient's complications from the therapy. Please refer to Section 4.8 for more information.

Click on the **Next** button at the bottom of the page to go to the next page.

5.5 *Current Status Page*

This page will allow you to update the patient's status. Please refer to Section 4.9 for more information.

Click on the **Next** button at the bottom of the page to go to the next page. This will take you to the Summary page. To save all the information that you have entered, click the **Finish** button.

6

Patient Monitoring Form

Menu: Registry → Data Entry → Patient Monitoring

Navigate the menu. Then:

- A search criteria form will appear.
- Enter the search criteria as in Section 5.1
- Select the patient from the list of results by clicking the patient name.
- The Patient Monitoring form will appear, displaying the first page i.e. the patient's particulars.

6.1 *Part 1 Page*

Data items that have to be entered on this page are as follows:

- General
- Laboratory
- Transfusion record
- Chelation record

6.2 *Part 2 Page*

Data items that have to be entered on this page are as follows:

- Vaccination record
- Growth
- Physical examination
- Average Hb pre-transfusion

- Average serum ferritin
- Liver function test
- Virology
- Glucose tolerance
- Calcium level
- Thyroid function
- Cardiac review
- Endocrine review
- Audiometry
- Ophthalmology

6.3 Part 3 Page

Data items that have to be entered on this page are as follows:

- Liver iron
- Cardiac
- Bone scan
- Biochemistry blood test
- Heart assessment record
- Hormone record
- Bone density record
- Vaccination and virus testing record

6.4 Part 4 Page

Data items that have to be entered on this page are as follows:

- Annual comments

Click on the **Next** button at the bottom of the page to go to the next page.

New Treatment Data Form

Menu: Registry → Data Entry → New Treatment Data

This form is for adding the following data to existing patients:

- Height and weight data
- Ferritin level data
- Transfusion data

7.1 Patient Particulars Page

This page cannot be updated. Please ensure that you have the correct patient before clicking the **Next** button to go to the next page.

7.2 Measurement Update Page

This page allows you to enter up to 4 sets of height and weight measurements and up to 4 sets of Actual Serum Ferritin Level. All sets must be accompanied by the date the measurement was taken.

Click on the **Next** button at the bottom of the page to go to the next page.

7.3 Transfusion Page

This page will display the last 10 transfusion records, if available. You can add up to 4 sets of new transfusion records. Each set of data comprises of the transfusion date and the volume.

Click the **Next** button to get to the next page and the click the **Finish** button to save the data.

Death / Change Centre Form

Menu: **Registry** → **Data Entry** → **Death / Change Centre**

8

This form is for updating the patient's information in cases of death or change of centre.

- A search criteria form will appear.
- Enter the criteria and click search. For information on entering the search criteria, please refer to Section 5.1.

Data items that can be entered on this page are as follows:

Patient's Current Status: Select from the dropdown list and enter the date. If the status 'Dead' is selected, then the date of death and cause(s) of death have to be entered.

Date of Death: Please refer to section 2.1 for guidelines on entering the date.

Cause of Death: Tick the relevant cause(s) or enter the reason in Others if it is not caused by any of the preset reasons.

Transfer to new Centre: Tick this to assign the patient to a new centre. When the box is ticked, the **Date of Last Follow Up at the old centre** and the **Name of Centre transferred to** must be entered.

If “Lost, to follow up” is selected, please specify date of last contact with patient. Please refer to section 2.1 for guidelines on entering the date.

Comments: Enter additional information

Click the **Finish** button to save the data.

9

Edit Patient Particulars Form

Menu: *Registry → Data Entry → Edit Patient Particulars*

This form is provided for changing the patients particulars only. No medical data can be added or mended on this form.

Navigate the menu:

- A search criteria form will appear.
- Enter the search criteria as in Section 5.1
- Select the patient from the result list by clicking the patient name.
- The Patient Particulars form will appear.

To edit the particulars, click the **Edit** button at the bottom of the screen.

Click the **Save** button after making any amendments.

Viewing and Amending Patient’s Details

Reports for viewing and amending patients details can be accessed from the Reports sub-menu.

10.1 List of Patients Report

Menu: *Registry → Reports → Patients*

A report on the list of patients can be obtained by navigating the menu as below:

Navigate the menu:

- A search criteria form will appear.
- Enter the search criteria as in Section 2.5. There is an extra criterion i.e. Status of the patient. Select the status from the dropdown list.
- To view the list on screen, click the Display List button. This will search MyTalasemia for all records that match the criteria and display them in a list.

10.2 Displaying Patients Details

To display patients details, Select the patient from the list of results by clicking the patient name. The Patient Details form will appear. The form has many tabs at the top. Each tab will display different group of information.

| Particulars | History | Clinical | Treatment | Complications | Annual Comments |
|---------------------|--|----------|-----------|---------------|-----------------|
| Patient's Name | <input type="text"/> | | | | |
| MyKid/MyKad No | <input type="text"/> - <input type="text"/> - <input type="text"/> | | | | |
| Other Document's No | <input type="text"/> e.g. Mother's MyKad | | | | |

If you want to edit any information in any of the tabs, click the **Edit** button at the bottom of If you want to edit any information in any of the tabs, click the **Edit** button at the bottom of the page. This will enable the edit mode so that changes can be made. To save the edited data, click the **Save** button next to the **Edit** button.

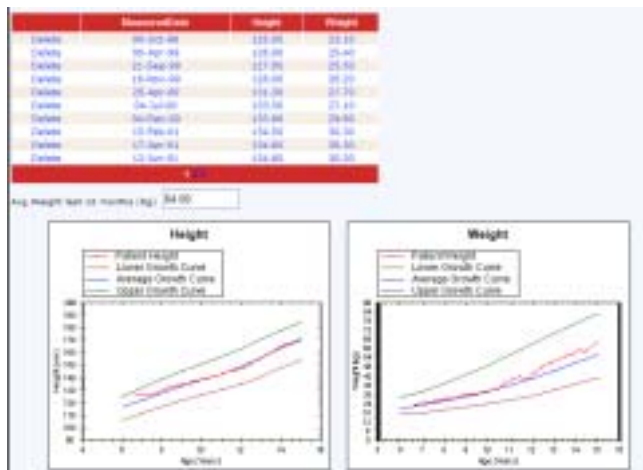
10.2.1 Particulars Tab

This tab contains the patient's particulars as in Section 4.3.

10.2.2 History Tab

This tab contains information as entered in Section 4.4, History page of the MTR Notification form. The system will also display extra information:

- Desferral usage period
- Age at first using desferral
- Average weight for the last 12 months
- Plot of height chart with reference of growth chart
- Plot of weight chart with reference of growth chart



10.2.3 Clinical Tab

This tab contains information as entered in Section 4.5.

10.2.4 Treatment Tab

This tab contains information as entered in Section 4.6.

Particulars History Clinical **Treatment** Complications Annual Comments

TRANSFUSION

Treatment: Total Volume Transfused (past 1 yr):

Transfusion requirement: Ratio Vol / Avg Weight (past 1 yr):

Interval (weeks):

Others, specify:

Date of First Transfusion:

Age at first transfusion: years months

Last 20 Transfusion Records

| | Date | Volume of Blood Transfused/Kg |
|--------|-------------|-------------------------------|
| Delete | 30-May-2007 | 780 |
| Delete | 14-Feb-2007 | 720 |
| Delete | 28-Dec-2006 | 600 |
| Delete | 28-Dec-2006 | 600 |
| Delete | 27-Nov-2006 | 300 |
| Delete | 23-Nov-2006 | 320 |
| Delete | 24-Aug-2006 | 630 |
| Delete | 24-Aug-2006 | 630 |
| Delete | 31-May-2006 | 550 |
| Delete | 31-May-2006 | 550 |

FERRITIN

Mean Ferritin Level:

| | Date Measured | Ferritin Level |
|--------|---------------|----------------|
| Delete | 31-May-06 | 1,185.00 |
| Delete | 28-Aug-05 | 1,050.30 |
| Delete | 23-Feb-05 | 7,026.80 |
| Delete | 23-Feb-05 | 7,026.80 |
| Delete | 28-Jul-04 | 2,482.70 |
| Delete | 05-Jul-04 | 2,452.70 |
| Delete | 25-Jan-04 | 3,946.20 |
| Delete | 19-Jan-04 | 3,846.20 |
| Delete | 28-Aug-03 | 2,228.75 |
| Delete | 28-Aug-03 | 2,228.75 |

Ferritin Level

10.2.5 Complication Tab

This tab contains information as entered in Section 4.7.

Particulars History Clinical Treatment **Complications** Annual Comments

Complications

| Category | Complication | Status | Date Completion |
|---------------------------|---------------|--------------|-----------------|
| Hepatitis B Investigation | HBsAg | Non-reactive | 30-Jan-07 |
| Hepatitis C Investigation | Anti-HCV | Negative | 30-Jan-07 |
| HIV Investigation | HIV screening | Non-reactive | 30-Jan-07 |

Complications from Therapy

No Complications from Therapy

10.2.6 Annual Comments

This tab contains information as entered in Section 6.4.

10.3 Report of Desferral Patients

Menu: **Registry** → **Reports** → **Desferral Patients**

The report on desferral patients can be obtained by navigating the menu. Then enter the search criteria as in Section 2.5.

10.4 Displaying Patients Ferritin

Menu: **Registry** → **Reports** → **Patients Ferritin**

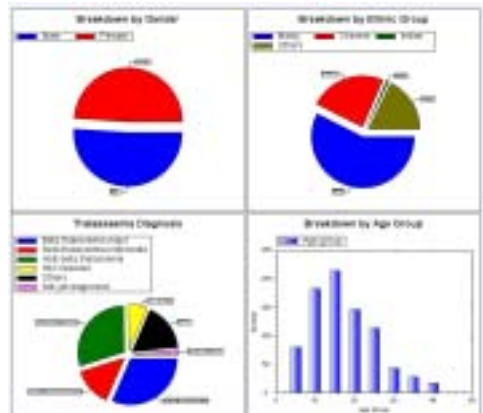
The report on desferral patients can be obtained by navigating the menu. Then enter the search criteria as in Section 2.5.

10.5 Breakdown of Patients

Menu: **Registry** → **Reports** → **Breakdown**

This graphical report produces the breakdown of patients according to:

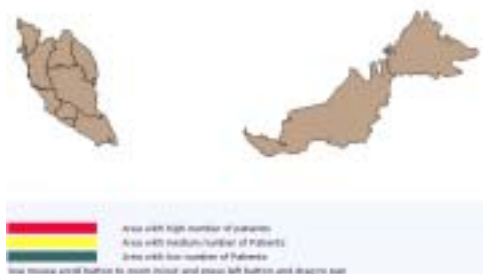
- Gender
- Ethnic group
- Diagnosis
- Age group



10.6 Thalassaemia Map

Menu: **Registry** → **Reports** → **Thalassaemia Map**

This graphical report produces the breakdown of Thalassaemia patients by states.



Digital Library

The Digital Library contains online resource that are useful for health professionals. They are categorised under:

- Videos
- eBooks
- Slides
- Articles
- Thalassaemia dictionary

11.1 Accessing Video

Menu: *Digital Library* → *Video*

To view the videos, you must have Windows Media player installed on you PC. If you do not have them, then click “Download Media Player 11”. This will install Media Player on your PC.

The contents of the library are updated as new materials are received.




11.2 Accessing eBooks

Menu: *Digital Library* → *eBook*







Most eBooks are published as PDF documents. PDF documents can be viewed using Adobe Reader. If you do not have Adobe Reader installed on your PC, please click Download Adobe Reader to install it.

The eBooks are organised as a tree hierarchy. If a branch contains many items, the right-pointing triangle symbol on the left of the item will be black. Click on the triangle symbol and the branch will open up, displaying the items under it and also changing the triangle to a downwards-pointing triangle. Clicking the triangle again will hide the items under the branch.

The eBooks are available in 2 formats:

- PDF format: You must have a Adobe reader to view documents in this format. Click on the heading next to the  to start viewing.
- HTML format: This is the normal web page version of the document.

▼ eBook

- ▼  Guideline for Clinical Management of Thalassemia
 - ▶ The Thalassemias: Overview
 - ▶ Genetic Basis and Pathophysiology
 - ▶ Blood Transfusion Therapy in β -Thalassemia Major
 - ▶ Splenectomy in Thalassemia Major
 - ▶ Iron Overload
 - ▶ The Management of the Cardiac Complications of Thalassemia Major
 - ▶ Endocrine Complications In Thalassemia Major
 - ▶ Infections in Thalassemia Major
 - ▶ Bone Marrow Transplantation
 - ▶ Psychological Support of Thalassemia
 - ▶ Thalassemia Intermedia
 - ▶ β -Thalassemia/Hb E
 - ▶ Alternative Approaches for Thalassemia Treatment
 - ▶ General Health Care and Lifestyle in Thalassemia
- ▶  Compliance to Iron Chelation Therapy
- ▶  Pediatric Protocol for Malaysian Hospitals
- ▶  Drug Doses
- ▶  Growth Charts.pdf
- ▶  FALS Algorithms.pdf

11.3 Accessing Slides

Menu: **Digital Library** → **Slides**

Slides are available in up to 2 formats i.e. PDF and Powerpoint. If you do not have Powerpoint installed on your PC, you can download a Powerpoint viewer by clicking the Download Powerpoint Viewer link. This will bring you to the Microsoft site where you can download the viewer.

Presentation slides are available in up to 3 formats:

- PDF format: You must have a Adobe reader to view documents in this format. Click on the heading next to the  to start viewing.
- Microsoft Powerpoint format.
- Streaming video i.e. video recording of the presentation will be put into the library if it is available.

- ▼ Issues In Thalassemia
 - ▶  PDF
- ▼ Management of Thalassemia 1
 - ▶  PDF
 - ▶  Powerpoint
- ▼ Management of Thalassemia 2
 - ▶  PDF
 - ▶  Powerpoint
- ▼ Management of Thalassemia 3
 - ▶  PDF
 - ▶  Powerpoint
- ▼ Thalassemia Program Update 1 Jul 05
 - ▶  PDF
 - ▶  Powerpoint
- ▼ Thalassemia for Policy Makers
 - ▶  PDF
 - ▶  Powerpoint
- ▼ Export Master
 - ▶  PDF

11.4 Accessing Thalassaemia Dictionary

Menu: **Digital Library** → **Thalassaemia Dictionary**

The Thalassaemia Dictionary contains explanations of thalassaemia-related terms used in MyTalasemia. Only high privilege users can add, edit or delete the entries.



12

Reporting Problems

Menu: **Contact Us**

Please use the feedback form to report any problems. Please include the following information:

- Name
- Email
- Logon username
- Centre
- Description of problem

A screenshot of a feedback form. It contains the following fields: 'Name:' (text input), 'Email:' (text input), 'Type of comment:' (dropdown menu with 'Suggestion' selected), and 'Comments:' (text area). At the bottom, there are two buttons: 'Send Feedback' and 'Clear'.



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