

RHEUMATIC HEART DISEASE REGISTER

User Guide *Expanded Database*

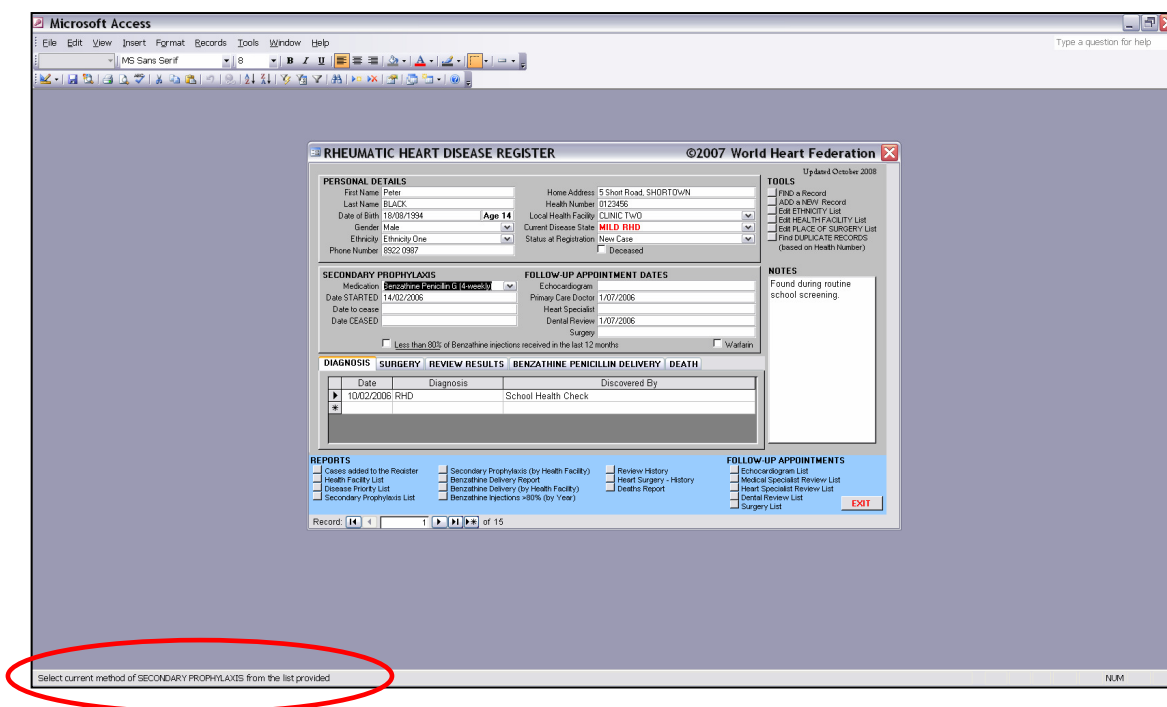
This database has been designed to be used as part of a comprehensive Rheumatic Heart Disease control programme. The main functions of this database are to

1. Identify people in the community with confirmed or suspected Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD);
2. Identify people with severe RHD and those at increased risk of developing severe disease;
3. Help monitor and improve secondary prophylaxis delivery;
4. Help coordinate ongoing medical care;
5. Report ARF/RHD epidemiology.

GENERAL INFORMATION

Database Fields

The spaces on the main form are called *fields*. Each piece of information is typed into a separate field. A new form is created for each person. Once created, a form can be updated with new information at any time. Instructions for completing each field can be found on the bottom left section of the computer taskbar (*circled below*) [E.g. click into the *Medication* field and see the instruction “*Select current method of Secondary Prophylaxis from the list provided*”]



The screenshot shows the Microsoft Access interface for the RHEUMATIC HEART DISEASE REGISTER. The form is divided into several sections:

- PERSONAL DETAILS:** Includes fields for First Name (Pete), Last Name (BLICK), Date of Birth (19/02/1994), Age (14), Gender (Male), Ethnicity (Ethnicity One), Home Address (5 Short Road, SHORTOWN), Health Number (0123456), Local Health Facility (CLINIC T140), Current Disease State (MILD RHD), and Status at Registration (New Case).
- SECONDARY PROPHYLAXIS:** Includes Medication (Benzathine Penicillin G (4weeks)), Date STARTED (14/02/2006), Date CEASED, and a checkbox for 'Less than 80% of Benzathine injections received in the last 12 months'.
- FOLLOW-UP APPOINTMENT DATES:** Includes Echocardiogram, Primary Care Doctor (1.0/07/2006), Heart Specialist (1.0/07/2006), Dental Review (1.0/07/2006), and Surgery.
- DIAGNOSIS TABLE:**

Date	Diagnosis	Discovered By
10/02/2006	RHD	School Health Check
- REPORTS:** Includes checkboxes for Cases added to the Register, Health Facility List, Disease Priority List, Secondary Prophylaxis List, Secondary Prophylaxis (by Health Facility), Benzathine Delivery Report, Benzathine Delivery (by Health Facility), Benzathine Injections >80% (by Year), Review History, Heart Surgery - History, and Death Report.
- FOLLOW-UP APPOINTMENTS:** Includes checkboxes for Echocardiogram List, Medical Specialist Review List, Heart Specialist Review List, Dental Review List, and Surgery List.

A red circle at the bottom of the window highlights the instruction: "Select current method of SECONDARY PROPHYLAXIS from the list provided".

Search the Database

- Open the database;
- Click the **Find a Record** button under TOOLS;
- Type any known information [e.g. surname or health number] in the *Find What* box;
- Click *Find Next* and continue to click *Find Next* until the correct record has been found;
- When the correct record has been found [or not found] click *Cancel*.

Add a New Record

- Open the database;
- Click the **Add NEW Record** button under TOOLS;
- Add any available information for this person.

NOTE: Each person has a separate form to record personal and medical information. Unique information including health number and name must be included when adding a new record.

Date Fields

All *dates* are entered as 6 letters, and will appear according to the computer's date format setting.

To enter 4th October 1990: type **041090** (day, month, year), **or** Type 100490 (month, day, year).

NOTE: For all dates, if exact date is unknown, enter year known as default date: e.g. if 1990, enter as 1st July 1990.

Option Fields

Option fields have a small arrow on the right and allow selection from a list of set options. Most option fields have standard options [e.g. *Gender* options are MALE and FEMALE]. Only options in the list can be selected.

Text Fields

Text fields require information to be typed. There are no rules for these fields and care must be taken with spelling and accuracy [e.g. *Name*, *Health Number*].

Tick Box

A *tick box* indicates 'NO' when not ticked and 'YES' when ticked. A black tick appears when selected.

DATABASE FUNCTIONS

Filter Information

Filtering allows the user to select all records that have exactly the same information. For example, filtering is a quick method to count the number of males registered in the database.

EXAMPLE: To filter the total number of males in the database:

- Click into a *Gender* field where MALE has been selected
- Click the FILTER BY SELECTION icon in the toolbar (see right)



The number of males will be displayed at the bottom of the database screen, e.g. "*of 10 (filtered)*". This indicates that there are 10 males currently registered in the database.

To remove the filter, click the **Remove Filter** icon.



Prevent Duplicate Records

IMPORTANT: Name and Health Number MUST be entered for every record. Together, this information will prevent the same person being registered more than once.

To find DUPLICATE RECORDS

- Open the database;
- Click the **Find DUPLICATE RECORDS (based on Health Number)** button under TOOLS;
- View the list of possible duplicates.

This report lists all records where the same Health Number is entered more than once. The list is a guide to check and correct records that may have been entered with incorrect information.

CREATING / EDITING OPTION LISTS

ETHNICITIES list

Ethnicity groups are unique to each region. To create or edit a list of Ethnicities:

- Open the database;
- Click on the **Edit ETHNICITY List** button under TOOLS;
- Type the names of Ethnicities as instructed on the form;
- Click the **Close this list** button.

NOTE: Only Ethnicities typed into this list can be selected from the list on the main form.

HEALTH FACILITIES list

The names of Health Facilities [including hospitals and clinics] are unique to each region. To create or edit a list of Health Facilities:

- Open the database;
- Click on the **Edit HEALTH FACILITY List** button under TOOLS;

- Type the names of local Health Facilities as instructed on the form;
- Click the **Close this list** button.

NOTES: Only Health Facilities typed into the list can be selected on the main form.

The Health Facility where secondary prophylaxis is usually received and primary health care usually given should be selected from the list for each person.

PLACES OF SURGERY list

The locations where cardiac surgery is done are unique to each region. To create a Places of Surgery list:

- Open the database;
- Click on the **Edit PLACE OF SURGERY List** button under TOOLS
- Type the places of surgery as instructed on the form
- Click the Close this list button
- Only Places of Surgery typed into this list can be selected on the MAIN FORM

DATABASE REPORTS

Information typed into the database is reproduced in the Reports. All reports can be viewed; however a printer must be connected to the computer to print reports.

Cases added to the Register

This report lists individuals registered at each Health Facility within a specified time (including those who are deceased).

EXAMPLE: To view individuals added to the register in 2005:

- "Enter Start Date" – type **1/1/05** [i.e. 1st January 2005] ... Click OK
- "Enter End Date" – type **31/12/05** [i.e. 31st December 2005] ... Click OK

Age at Registration and Age at Death are calculated automatically.

Health Facility List

This report lists all individuals registered as receiving care at any specified Local Health Facility.

EXAMPLE: To individuals receiving care at HOSPITAL ONE:

- "Please Enter name of Health Facility" – **HOSPITAL ONE** ... Click OK

The name of the Health Facility must be entered as it appears in the Local Health Facility list.

RHD Priority List

This report identifies individuals at all Health Facilities at a specified stage of disease.

EXAMPLE: To view persons with 'Severe RHD':

- "Please Enter 'Current Disease State' category e.g. ARF (no RHD)" – type **Severe RHD** ... Click OK

Secondary Prophylaxis

This report lists all people registered to receive regular secondary prophylaxis by Health Facility.

This report includes the tick box that indicates whether or not the individual received less than 80% of planned injections in the previous 12 months.

Secondary Prophylaxis (by Health Facility)

This report lists people registered to receive regular secondary prophylaxis at a specified Health Facility.

EXAMPLE: To individuals registered to receive secondary prophylaxis at HOSPITAL ONE:

- "Please Enter name of Health Facility" – **HOSPITAL ONE** ... Click OK

This report includes the tick box that indicates whether or not the individual received less than 80% of planned injections in the previous 12 months.

Benzathine Delivery Report

This report shows the proportion of injections received for each calendar year for individuals at all Local Health Facilities.

This report includes the tick box that indicates whether or not the individual received less than 80% of planned injections in the previous 12 months.

Benzathine Delivery (by Health Facility)

This report shows the proportion of injections received for each calendar year for individuals at a specified Local Health Facility.

EXAMPLE: To view individuals scheduled to receive secondary prophylaxis at HOSPITAL ONE:

- "Please Enter name of Health Facility" – type **HOSPITAL ONE** ... Click OK

This report includes the tick box that indicates whether or not the individual received less than 80% of planned injections in the previous 12 months.

Benzathine Injections >80% (by Year)

This report automatically produces a graph to show the proportion of all people requiring Benzathine injections who received 80% or more of injections each year.

Review History

This report provides a history of persons undergoing review [i.e. echocardiogram assessment or medical review].

EXAMPLE: To view persons undergoing Echocardiogram in 2005:

- "Please Enter Start Date" – type **1/1/05** [1st January 2005] ... Click OK
- "Please Enter End Date" – type **31/7/05** [31st July 2005] ... Click OK
- "Please Enter type of review" – type **Echocardiogram** ... Click OK

Heart Surgery – History

This report provides a history of persons who have undergone previous cardiac surgery.

EXAMPLE: To view all persons who had surgery in 2005:

- "Please Enter Start Date" – type **1/1/05** [1st January 2005] ... Click OK
- "Please Enter End Date" – type **31/7/05** [31st July 2005] ... Click OK

Deaths Report

This report describes deaths and causes of death for individuals registered on the database.

EXAMPLE: To view a list of persons with a date of death in 2004 and 2005:

- "Enter Start Date" – type **1/1/04** [i.e. 1st January 2004] ... Click OK
- "Enter End Date" – type **31/12/05** [i.e. 31st December 2005] ... Click OK

Age at death is calculated automatically.

Echocardiogram Appointments, Medical Specialist Appointments, Dental Appointments, Surgery List

These reports list individuals who have future dates entered for echocardiogram, medical review and surgery. The following method is used to generate these reports.

EXAMPLE: To view individuals who require an Echocardiogram between January and July 2007:

- Click the *Echocardiogram Appointments* report button
- "Enter Start Date" – type **1/1/07** [i.e. 1st January 2007] ... Click OK
- "Enter End Date" – type **31/07/07** [i.e. 31st July 2007] ... Click OK

DATA DICTIONARY

Field Name	Description	Data type	Field Format
First name	All known given names	Text	50 characters
Last name	Family name/s	Text	
Date of Birth	Date of birth (if exact date is unknown, default to year – e.g. 1/01/1987)	Date	00/00/00
Gender	Gender	Option List	OPTIONS: Male; Female
Ethnicity	Racial group to which the person identifies	Option List	20 characters <i>Generated by Database User</i>
Phone number	Phone number (mobile number if applicable)	Text	100 characters
Home Address	Contact information including residence, region	Text	
Health Number	Clinic or Hospital registration number (<i>unique for each person</i>)	Text	20 characters
Local Health Facility	The Local Health Facility where the person received regular secondary prophylaxis or medical care if not prescribed secondary prophylaxis	Option List	50 characters <i>Generated by Database User</i>
Current Disease State	Current type and severity of disease (update as disease progresses)	Option List	OPTIONS: ARF (no RHD); Mild RHD; Moderate RHD; Severe RHD
Status at Registration	The person had a known ARF or RHD diagnosis, or diagnoses was unknown (new) at the time of registration on the database	Option List	Known case; New case
Deceased	When ticked this indicates that the person is deceased	Tick Box	1 character
Medication	Method of secondary prophylaxis (if any) currently prescribed by a Medical Specialist	Option List	OPTIONS: Benzathine Penicillin (3weekly); Benzathine Penicillin (4weekly); Penicillin V (2 daily); Erythromycin (2 daily); No Prophylaxis
Date STARTED	Date secondary prophylaxis was started by a Medical Specialist following initial diagnosis of ARF or RHD	Date	00/00/00
Date to Cease	The expected future date to cease secondary prophylaxis as determined by a Medical Specialist	Date	00/00/00
Date CEASED	Date secondary prophylaxis was ceased by a Medical Specialist	Date	00/00/00
Less than 80% of Benzathine injections received in last 12 months	When ticked, indicates that less than 80% of Benzathine injections were received during the last calendar year (as indicated in Injection Delivery sub form)	Tick Box	1 character

Warfarin	When ticked, this indicates that this person has been prescribed Warfarin for anticoagulation therapy	Tick Box	Tick if requires Warfarin
Echocardiogram	Scheduled date for next Echocardiogram	Date	00/00/00
Primary Care Doctor	Scheduled date for next review with a primary care doctor	Date	00/00/00
Medical Specialist	Scheduled date for next review with a Medical or Heart Specialist	Date	00/00/00
Dental Review	Scheduled date for next dental review	Date	00/00/00
Heart Valve Surgery	Date for proposed future heart valve surgery	Date	00/00/00
DIAGNOSIS			
Date	Date that diagnosis was made from clinical assessment, serology and/or echocardiogram.	Date	00/00/00
Diagnosis	The current diagnosis as determined by a Medical Specialist. NOTE: <i>ARF Recurrence</i> should be selected for an ARF illness in any person with RHD (previous ARF has been missed, and any ARF with existing RHD is a recurrence).	Option List	OPTIONS: ARF; ARF(not confirmed): ARF recurrence; ARF with chorea; RHD; RHD(not confirmed)
RHD Discovered by	How the current diagnosis was discovered.	Option List	OPTIONS: Associated ARF; Clinical Presentation; Coincidental Finding; Post Mortem; Pregnancy/Labour; School Health Check; Screening Program
SURGERY			
Date	Date of surgical procedure	Date	00/00/00
Procedure	The type of surgical procedure performed. NOTE: For multiple procedures on one date, enter the date and individual procedures on separate lines.	Option List	OPTIONS: Aortic Repair; Aortic Replacement; Aortic Valvoplasty; Aortic Valvotomy; Mitral Repair; Mitral Replacement; Mitral Valvoplasty; Mitral Valvotomy; Pulmonary Repair; Pulmonary Replacement; Pulmonary Valvoplasty; Pulmonary Valvotomy; Tricuspid Repair; Tricuspid Replacement; Tricuspid Valvoplasty; Tricuspid Valvotomy
Place of Surgery	Location where surgery was performed (e.g. country, city or specific hospital).	Option List	50 characters <i>Generated by Database User</i>
REVIEW RESULTS			
Review Date	The date the person was reviewed by a Heart Specialist or Primary Care Doctor, or date an echocardiogram was undertaken.	Date	00/00/00

Assessed by	How / by whom the person was assessed	Option List	OPTIONS: Echocardiogram; Heart Specialist; Primary Care Doctor; Dentist
Findings	Results of review or echocardiogram (including heart and valve function, patient well-being)	Text	225 characters
BENZATHINE PENICILLIN DELIVERY			
Year	Calendar year (Jan to Dec) for which secondary prophylaxis delivery is being calculated (NOTE: prophylaxis must be prescribed for the full year)	Text	4 characters
Required (Jan-Dec)	The number of injections required for this person for the year (enter 13 for 4- weekly injections and 17 for 3- weekly injections)	Option List	17 (3 weekly); 13 (4-weekly)
Given (Jan-Dec)	The total number of injections given to this person over the full year Enter '0' if no injections were given during the year.	Text	2 characters
<i>Received (%)</i>	AUTOMATED field calculation using <i>Injections REQUIRED</i> and <i>Injections RECEIVED</i>	<i>Automated field</i>	----
DEATH			
Date of Death	Date the person died	Date	00/00/00
Cause of Death	The primary cause of death in a person with a history of ARF or RHD	Option List	OPTIONS: Other Cause(Not RHD); RHD-Endocarditis; RHD-Haemorrhage; RHD-Heart Failure; RHD-Stroke; Unknown Cause
Notes	Important notes, comments and reminders about diagnosis or ongoing management	Text	255 characters