

The purpose of the National Familial Hypercholesterolaemia Registry is to collate data to facilitate clinical service planning and to inform clinical best practice. The Registry will also enable research on aggregated data and the identification of eligible volunteers for clinical trials.



USER MANUAL



*everyone deserves
a better chance*

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Need Help

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Resources

- [The National Familial Hypercholesterolaemia Registry - an introduction](https://www.youtube.com/watch?v=klkGys77fHw) (5:51 min video)
(<https://www.youtube.com/watch?v=klkGys77fHw>)
N.B. The user interface has been updated since this video was created, but it is still useful to demonstrate general concepts.
- [National FH Registry](https://fhregistry-international.com/)
(<https://fhregistry-international.com/>)
- [National FH Registry - Username/Password screen](https://fhregistry-international.com/rdrf/login?next=/rdrf/router/)
(<https://fhregistry-international.com/rdrf/login?next=/rdrf/router/>)
- [National FH Registry – Charter, Protocol and Guidelines](http://www.athero.org.au/fh/wp-content/uploads/National-FH-Registry---Charter-Protocol-and-Guidelines.pdf)
(<http://www.athero.org.au/fh/wp-content/uploads/National-FH-Registry---Charter-Protocol-and-Guidelines.pdf>)
- [Registry Brochure](http://www.athero.org.au/fh/wp-content/uploads/FH-Registry-Brochure_v4.pdf)
(http://www.athero.org.au/fh/wp-content/uploads/FH-Registry-Brochure_v4.pdf)
- [Sample Consent Form](http://www.athero.org.au/fh/wp-content/uploads/Sample-Consent-Form.pdf)
(<http://www.athero.org.au/fh/wp-content/uploads/Sample-Consent-Form.pdf>)
- [Test site](https://rdrf.ccgapps.com.au/ophg/login?next=/ophg/router/)
(<https://rdrf.ccgapps.com.au/ophg/login?next=/ophg/router/>)
 - Username: fhcurator
 - Password: FHcurator1*

Abbreviations used in the FH Registry

DLCNS – Dutch Lipid Clinic Network Score

Eligibility Criteria for Inclusion in the FH Registry

- Adult INDEX with:
 - Dutch Lipid Clinic Network Score (DLCNS) ≥ 6 (ie. **probable** or **definite** FH)
 - Genetic mutation that is causative of FH
 - Familial elevation of Lp(a) – *this will be a subset of the larger FH registry*
 - Defined as Lp(a) $> 0.5\text{g/L}$ with a DLCNS ≥ 3
- Child/adolescent INDEX with:
 - Classification of **highly probable** FH
 - LDL-cholesterol $> 5.0\text{ mmol/L}$
 - Classification of **probable** FH
 - LDL-cholesterol $> 4.0\text{ mmol/L}$ with a family history of premature heart disease
 - LDL-cholesterol $> 4.0\text{ mmol/L}$ with hypercholesterolaemia or tendon xanthoma or arcus in the first-degree relative
 - Genetic mutation that is causative of FH
 - Familial elevation of Lp(a) – *this will be a subset of the larger FH registry*
 - Defined as Lp(a) $> 0.5\text{g/L}$ with a family history of premature heart disease
- **All** relatives of the above including those who have tested negative
 - Classified according to age- and gender-specific LDL-cholesterol cut-offs ([link](#))

Also record Familial Combined Hyperlipidaemia (FCHL) if they coincide with the above.

Hypertension Criteria

Hypertension is defined as:

- Systolic blood pressure $> 140\text{ mmHg}$ **or**
- Diastolic blood pressure $> 90\text{ mmHg}$

Hypertriglyceridaemia Criteria

Hypertriglyceridaemia is defined as:

- Triglyceride $> 10\text{ mmol/L}$ **or**
- Mutations in LPL, APOA5, APOC2, LMF1, GPIHBP1, APOE, APOC3 **or**
- Genetic risk score indicative of hypertriglyceridaemia

Logging In

Go to <https://fhregistry-international.com/>



Click **Registry**

Rare Disease Registry Framework

Log in Password Reset

Welcome

Username:

Password:

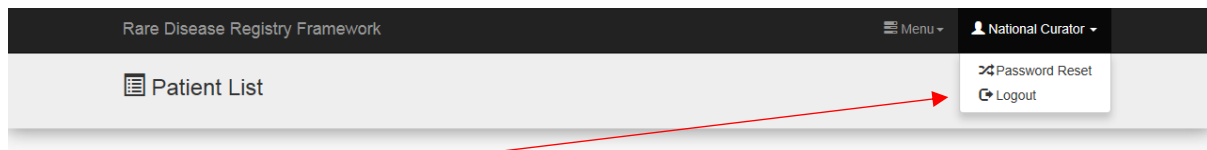
[Forgotten your password?](#)

Log in

Suggestion: Bookmark/add to favourites the page for later use.

- Enter your username and password
- Click **Log in**. The [Patient List](#) screen will appear.

Logging Out



Click **Logout**

Password Requirements

The FH Registry uses the following password policy:

- Must be at least 8 characters long
- Must contain at least one of each of the following
 - Uppercase letter
 - Lowercase letter
 - Number
 - Special character (!, @, #, \$, %, ^, &, *).

Password Deactivation

Your password will be deactivated after three months of non-use.

You will need to email the [National Coordinator](#) to arrange reactivation.

Forgotten your Password?

Rare Disease Registry Framework

Log in Password Reset

Welcome

Username:

Password:

Forgotten your password? [Log in](#)

- If you have forgotten your password, click **Forgotten your password?**

Rare Disease Registry Framework

Log in Password Reset

Forgotten your password? Enter your email address below, and we'll email instructions for setting a new one.

Email address [Reset my password](#)

- Enter your email address which was registered with the Registry
- click **Reset my password**

Rare Disease Registry Framework

Log in Password Reset

We've emailed you instructions for setting your password, if an account exists with the email you entered. You should receive them shortly.

If you don't receive an email, please make sure you've entered the address you registered with, and check your spam folder.

- Go to your email account

Password reset on fhregistry-international.com
 web=ccg.murdoch.edu.au@mg.ccgapps.com.au [web=ccg.murdoch.edu.au@mg.ccgapps.com.au] on behalf of web@ccg.murdoch.edu.au
 [web@ccg.murdoch.edu.au]

Sent: 02 June 2016 11:48
 To: [redacted]

You're receiving this email because you requested a password reset for your user account at fhregistry-international.com.

Please go to the following page and choose a new password:
<https://fhregistry-international.com/rdrf/reset/MTI/4cf-d3734b4b6108dfb4d1c6/>

Your username, in case you've forgotten:
 [redacted]

Thanks for using our site!
 The fhregistry-international.com team

- You will receive this email. Click the blue link.

Rare Disease Registry Framework

[Log in](#) [Password Reset](#)

Please enter your new password twice so we can verify you typed it in correctly.

New Password

Confirm password

Change my password

- Enter your new password and confirm
- Click **Change my password**

Rare Disease Registry Framework

[Log in](#) [Password Reset](#)

Your password has been set. You may go ahead and log in now.

- Click **Log in** to take you to the [Log in](#) screen

Rare Disease Registry Framework

Menu National Curator

Patient List

Password Reset

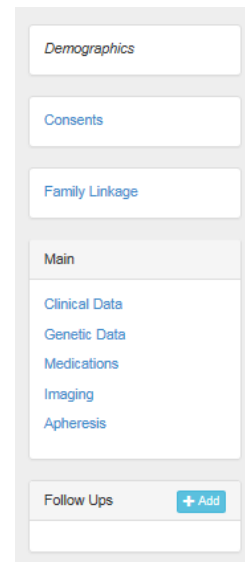
Logout

N.B. Password can be reset at any time from the dropdown menu.

Structure of the FH Registry

All patient records have the following modules:

- [Demographics](#) ([Screen shot – Demographics](#))
- [Consents](#) ([Screen shot – Consents](#))
- [Family Linkage](#) ([Screen shot – Family Linkage](#))
- [Clinical Data](#) ([Screen shot – Clinical Data](#))
- [Genetic Data](#) ([Screen shot – Genetic Data](#))
- [Medications](#) ([Screen shot – Medications](#))
- [Imaging](#) ([Screen shot – Imaging](#))
- [Apheresis](#) ([Screen shot – Apheresis](#))
- [Follow Up](#) (multiple forms) ([Screen shot – Follow Up](#))



You can move between the modules via the menu on the left or the next/previous arrows.

Rare Disease Registry Framework

Menu National Curator

Demographics

ABBEY Anthea

Save Cancel

Family Linkage

This patient is an index

Registry

Rdrf registry * FH Registry (th)

Centre * th Austin Health
th Royal Perth Hospital
th Royal Prince Alfred Hospital
th Flinders Medical Centre

Patients Personal Details

Family name * ABBEY

Given names * Anthea

Maiden name (if applicable)

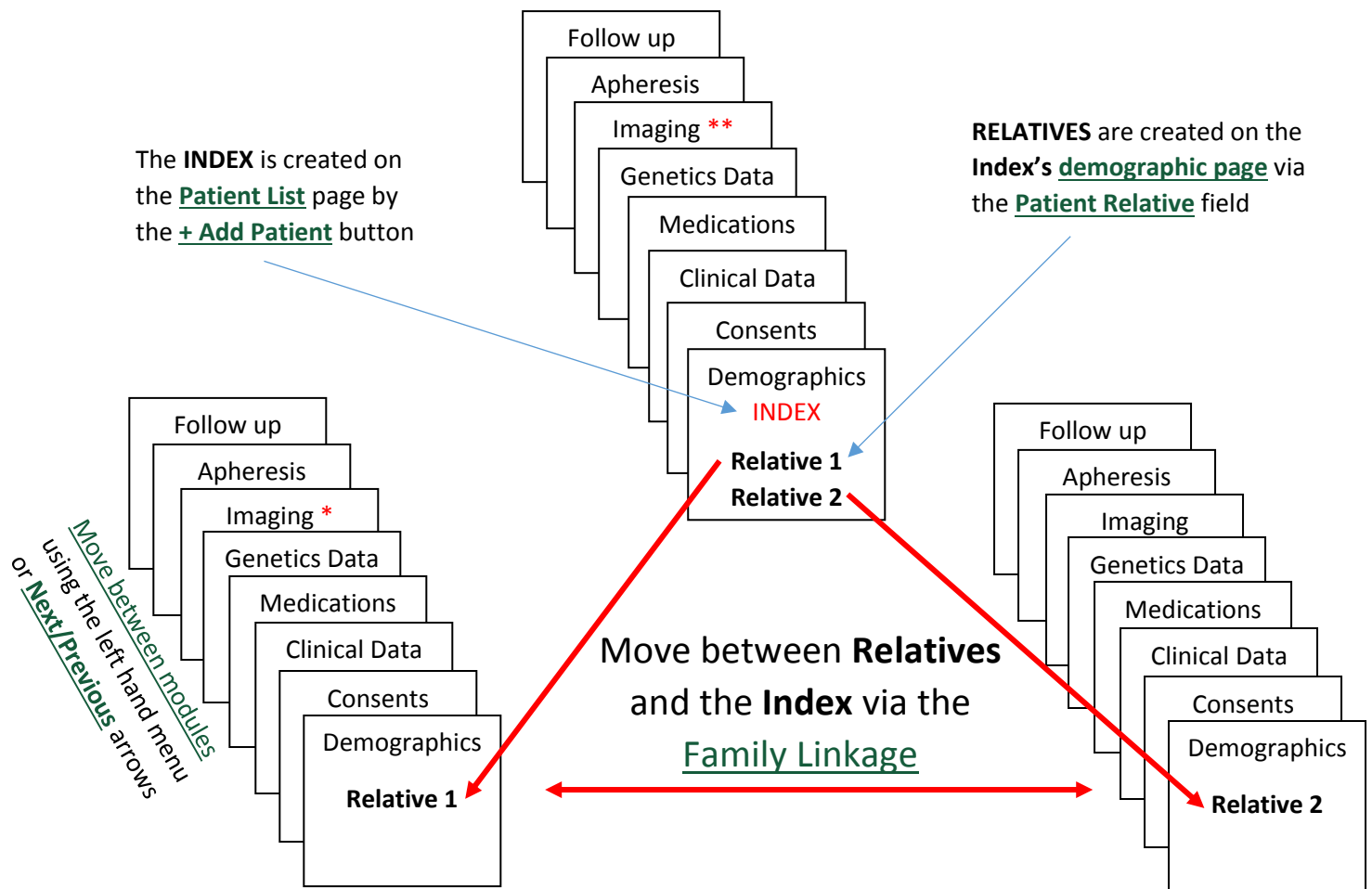
Follow Ups

+ Add

10-8-2016

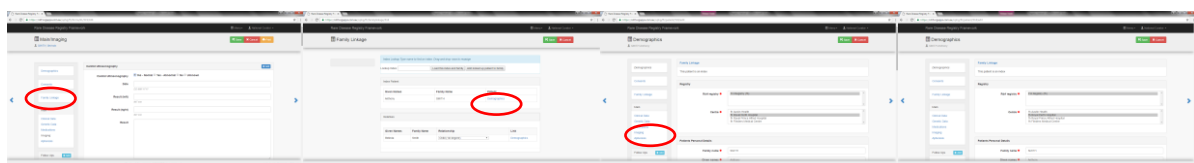
1-8-2016

Relationship between Index and Relative



If you are on Relative 1's Imaging page* and want to look at the Index's imaging**:

- Click Family Linkage link (on Relative 1 imaging page)
- Click Index's Demographics link (on the Family Linkage page)
- Click Imaging link (on Index's Demographics page)
- Index's Imaging page



Relative 1 - Imaging

Family Linkage

Index Demographics

Index - Imaging

Patient List (screen shot – [Patient List](#))

If the patient has already been entered in the FH Registry:

- Type the patient's name into the **Search** function

The screenshot shows the 'Patient List' page in the 'Rare Disease Registry Framework'. A search bar at the top right contains the text 'smith'. Below the search bar, a table lists five patients. The 'Main' module dropdown for 'SMITH, Roger' is open, showing a list of modules with status indicators (green checkmark for data entered, red cross for data not entered).

Patient	Date of Birth	Working Groups	Modules
SMITH, Anthony	1990-06-01	fh Royal Prince Alfred Hospital	Main Follow Ups
SMITH, Jane	2002-06-04	fh Royal Perth Hospital	Main Follow Ups
SMITH, Mary	1991-08-01	fh Royal Perth Hospital	Main Follow Ups
SMITH, Regina	1974-08-02	fh Royal Perth Hospital	Main Follow Ups
SMITH, Roger	1982-06-03	fh Royal Perth Hospital	Main Follow Ups

Showing 1 to 5 of 5 entries (filtered from 37 total entries)

Module Status Legend:

- ✓ Clinical Data
- ✗ Genetic Data
- ✗ Medications
- ✓ Imaging
- ✗ Apheresis

One or a list of names will then appear:

- Click the required name to take you to the patient's [Demographics](#) page
- Click **Main** and a dropdown menu will appear and you can click a specific module
N.B. The ✓ tick indicates the module has had data entered and the ✗ cross indicates the module has not had data entered.
- Click **Follow Ups** and a dropdown menu will appear and you can click a specific follow up module

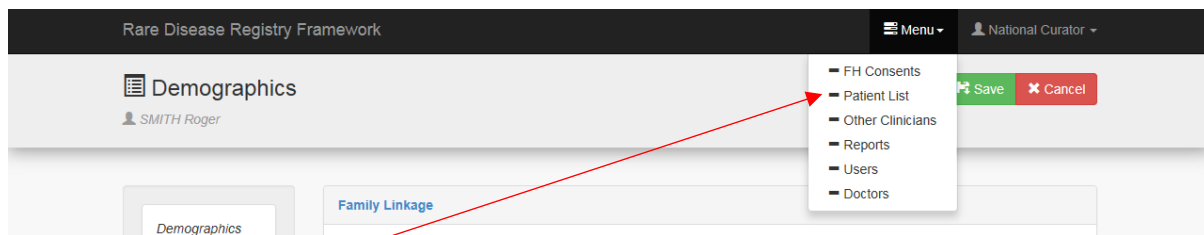
The screenshot shows the 'Patient List' page with the 'Follow Ups' dropdown menu open for 'SMITH, Roger'. The dropdown menu displays two options with status indicators (green checkmark for data entered, red cross for data not entered).

Patient	Date of Birth	Working Groups	Modules
SMITH, Anthony	1990-06-01	fh Royal Prince Alfred Hospital	Main Follow Ups
SMITH, Jane	2002-06-04	fh Royal Perth Hospital	Main Follow Ups
SMITH, Mary	1991-08-01	fh Royal Perth Hospital	Main Follow Ups
SMITH, Regina	1974-08-02	fh Royal Perth Hospital	Main Follow Ups
SMITH, Roger	1982-06-03	fh Royal Perth Hospital	Main Follow Ups

Showing 1 to 5 of 5 entries (filtered from 38 total entries)

Module Status Legend:

- ✓ 1-9-2016
- ✓ 2-3-2014



N.B. The **Patient List** can be accessed from any page using the dropdown menu.

Add an Index Patient

The first person diagnosed with FH in the family is called the Index patient. All Relatives are linked to this Index.

Rare Disease Registry Framework

Menu National Curator

Patient List

National Curator (FH Curator)

FH Registry

Show 10 entries

Patient	Date of Birth	Working Groups	Modules
SMITH, James	1976-02-03	fh Royal Perth Hospital	Show
SMITH, Lisa	2010-02-04	fh Royal Perth Hospital	
SMITH, John	1943-04-13	fh Royal Perth Hospital	

Showing 1 to 3 of 3 entries

0% Clinical Data
 X 0% Medications
 X 0% Genetic Data
 X 0% Imaging
 X 0% Apheresis
 X 0% Follow Up

1 Next

Support Report a bug Version 1.1.8

Authorised by: Prof. Matthew Bellgard, Director, CCG

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 Documentation | Source Code | Email RDRF

100%

An Index can only be added on the [Patient List](#) page.

To add a new Index patient:

- Click **+ Add Patient**
- A blank [Demographics page](#) will appear

N.B. DO NOT use the **+ Add Patient** button if you are adding a relative.

Relatives are entered on the Index's Demographics page. See:

- [Add a Relative](#)
- [Change an incorrectly entered Index patient to a Relative](#)

Demographics page (screen shot – [Demographic page](#))

Related topics:

- [Registry and Centre](#)
- [Date Function](#)
- [Patient Address](#)
- [Add Patient Doctor](#)
 - [Add Doctor's Details to the Database](#)
 - [Add Patient Doctor](#)
- [Add a Relative](#)
 - [Enter a Relative in a Different Centre to the Index](#)
 - [View Family Members in Different Centre](#)
 - [Delete a Relative](#)
 - [Delete an Index](#)
- [Pedigree](#)
- [Change an incorrectly entered Index patient to a Relative](#)
- [Change the Index](#)

When the **+ Add Patient** button (to add a new Index) on the [Patient List](#) page is clicked, a blank **Demographics** page will appear.

- Complete all the required fields as indicated by *
- Click **Save**

Rare Disease Registry Framework

Menu National Curator

Demographics

Registry

Rdrf registry * FH Registry (fh)

Save Cancel

Demographics page BEFORE saving

- No name beside person icon

Rare Disease Registry Framework

Menu National Curator

Demographics

ABBEY Anthea

Save Cancel

Demographics

Consents

Family Linkage

Family Linkage

This patient is an index

Registry

Rdrf registry FH Registry (th)

The **Index's** Demographic page AFTER saving:

- A set of modules has been created for this Index
- Patient name now next to person icon
- Family Linkage and **This patient is an index** now visible

Rare Disease Registry Framework

Menu National Curator

Demographics

ABBEY bert

Save Cancel

Demographics

Consents

Family Linkage

Family Linkage

This patient is a relative of index ABBEY Anthea (DOB May 1, 2000)

Registry

Rdrf registry FH Registry (th)

The **Relative's** Demographic page AFTER saving:

- A set of modules has been created for this relative
- Patient's name appears next to person icon
- **Family Linkage** and **This patient is a relative of index.....**
- Clicking the Index's name will take you to the Index's Demographics page

Registry and Centre

Rare Disease Registry Framework

Menu RPH Curator

Demographics

Registry

Rdrf registry * FH Registry (fh)

Centre * fh Royal Perth Hospital

Save Cancel Next Previous

- Click **FH Registry (fh)**
N.B. Provision has been made for multiple registries to be linked in the future.
- Click **Centre** the patient is attending
N.B. One or more Centres may be visible depending on your permissions.

Date Function

The date can be entered manually as 3-2-1976 or 03-02-1976.

The dropdown function is based on a calendar:

- The year must be selected first (the months for the selected year will then be loaded)
- Then the month selected (the days for the selected month will then be loaded)
- Finally the day selected

Once the day is selected the date will be entered automatically.

The screenshot shows a patient registration form with the following fields and options:

- Hospital/Clinic ID**: Text input field.
- Date of birth ***: Dropdown menu showing "03-02-1976". A calendar popup is visible, showing the month "Feb" and the year "1976". The calendar grid shows days 1 through 29.
- Country of birth**: Dropdown menu with a checkmark icon.
- Ethnic origin**: Dropdown menu with a checkmark icon.
- Sex ***: Dropdown menu with a checkmark icon.
- Home phone**: Text input field.
- Mobile phone**: Text input field.

Navigation buttons: "Next" and "Previous" are located on the right side of the form.

Patient Address

The **Country** must be selected before the **State** can be selected.

The screenshot shows the "Patient Address" form with the following fields and options:

- Address type ***: Dropdown menu showing "Home".
- Address ***: Text input field.
- Suburb/Town ***: Text input field.
- State ***: Dropdown menu with a checkmark icon.
- Postcode ***: Text input field.
- Country ***: Dropdown menu showing "Australia".

Navigation buttons: "Add" and "Remove" are located at the top right of the form. A blue arrow button is located on the right side of the form.

Red arrows indicate the selection order: one arrow points from the "Country" field to the "State" field, and another arrow points from the "State" field to the "Postcode" field.

Add Patient Doctor

Add **Patient Doctor** occurs in two steps:

1. Doctor's details are added to the database. Details are only added once.
2. Add Patient Doctor on the patient's demographics page

Add Doctor's Details to the Database

- Click **Menu**
- Click **Doctors** in the dropdown menu

- Click **+ Add** button

N.B. You are able to search for a doctor and change details via the search function.

- Enter doctor's details. Required fields are bolded.
- Click **Save**

N.B. The doctor's details can be deleted by clicking **Delete**.

Add Patient Doctor

Once added to the database the doctor's name will automatically appear in the **Doctor** dropdown menu.

The screenshot shows the 'Demographics' page for a patient. The 'Patient Doctor' section is highlighted with a red arrow pointing to the '+ Add' button. Another red arrow points to the 'Doctor' dropdown menu, which is open, showing a list of doctors. A third red arrow points to the 'Type of Medical Professional' dropdown menu, which is also open, showing a list of medical professionals. The 'Patient Relative' section is visible below, with fields for Family name, Given names, Date of birth, and Sex.

- Go to the patient's **Demographics** page
- Scroll down to **Patient Doctor**
- Click **+ Add** button
- Click the dropdown menu next to **Doctor**. Click the doctor's name or start typing the doctor's name, the doctor's name will appear in the box.
- Click the dropdown menu next to **Type of Medical Professional**. Click **Type of Medical Professional** and the details will appear in the box.
- Click **Save**

If you wish to delete the Doctor:

- Check the **Mark for deletion** box
- Click **Save**
- Doctor's details will be deleted

Add a Relative

The Index patient's demographic page has an additional **Patient Relative** field, where all relatives are entered.

Rare Disease Registry Framework

Menu National Curator

Demographics

BEAN Anthony

Save Cancel

Patient Relative

+ Add

- Remove

Family name * Bean

Given names * Barry

Date of birth * 10-11-1975
DD-MM-YYYY

Sex * Male

Relationship * Sibling (1st degree)

Location * Australia - WA

Living status * Living

Create Patient? ☒

- Go to the Index's **Demographics** page
- Scroll down to **Patient Relative** field
- Click **+ Add** button and a new blank record will appear
- Complete the relative's details. All are required fields.
- Check **Create Patient?** tick box
- Click **Save** and set of modules will be created for this relative

The relative then can be accessed via the:

- [Family Linkage](#) or
- **Patient in registry** link which will appear after saving

Relationship * Unknown

Location * Australia - WA

Living status * Living

Create Patient? [Patient in registry](#)

Mark for deletion ☐

Enter a Relative in a Different Centre to the Index

Relatives are automatically created with the same **Centre** as the Index.

If the index is not your patient you will not be able to access the index's demographics page to add your relative.

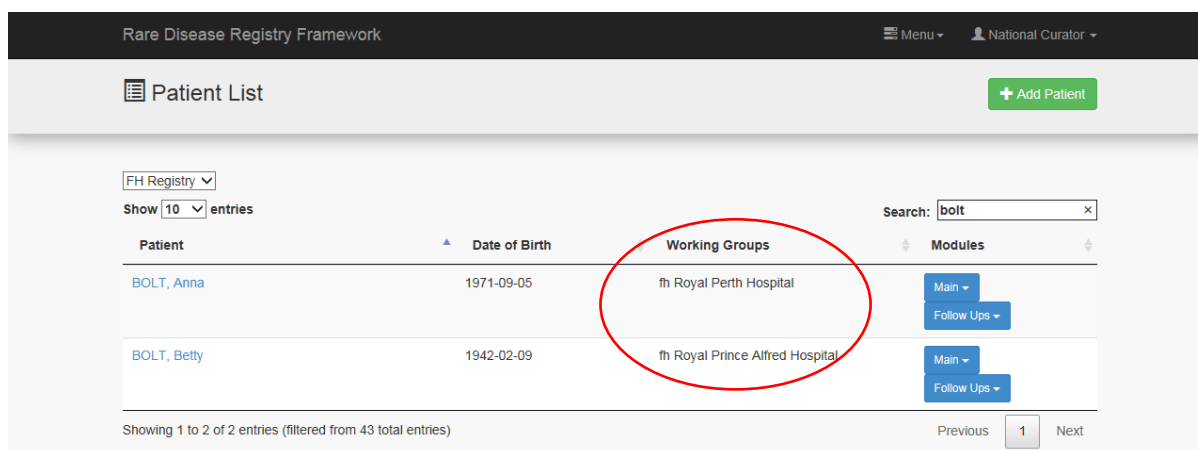
You will need to email the following details to the [National Coordinator](#) to arrange the relative to be added to the existing Index at another Centre.

- Details of index
 - Family name
 - Given names
 - Date of birth
- Details of relative
 - Family name
 - Given names
 - Date of birth
 - Sex
 - Relationship (to the index)
 - Location
 - Living status

View Family Members in Different Centres

You will only be able to view patients in **Centres** you have permission to access, unless your patient has family members in other **Centres** and then they can be viewed via the [Family Linkage](#) function.

For example:



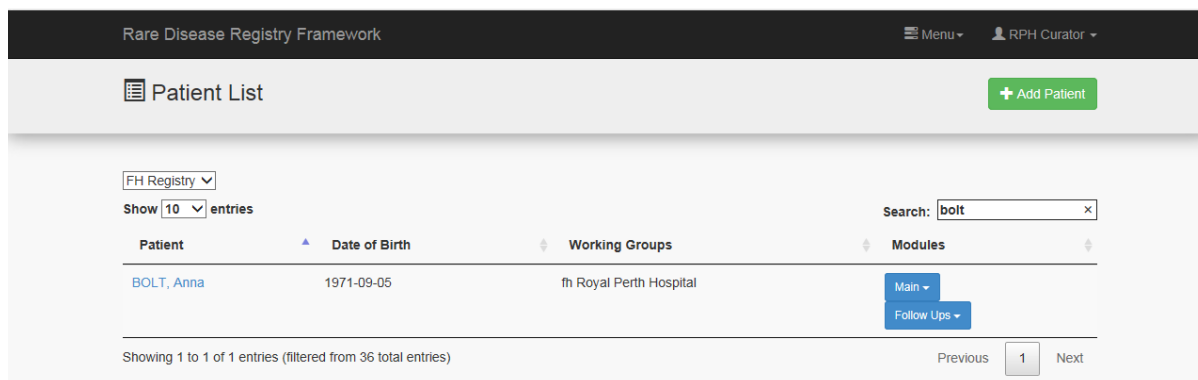
Patient	Date of Birth	Working Groups	Modules
BOLT, Anna	1971-09-05	fh Royal Perth Hospital	Main Follow Ups
BOLT, Betty	1942-02-09	fh Royal Prince Alfred Hospital	Main Follow Ups

Showing 1 to 2 of 2 entries (filtered from 43 total entries)

Anna Bolt (Index) is a patient at Royal Perth Hospital (RPH).

Her mother Betty Bolt (Relative) is a patient at Royal Prince Alfred Hospital (RPAH).

Only the National Coordinator can see this view.



Patient	Date of Birth	Working Groups	Modules
BOLT, Anna	1971-09-05	fh Royal Perth Hospital	Main Follow Ups

Showing 1 to 1 of 1 entries (filtered from 36 total entries)

The RPH coordinator can only see Anna Bolt (RPH patient) on their **Patient List** page.

Rare Disease Registry Framework

Menu RPA Curator

Patient List [+ Add Patient](#)

FH Registry

Show 10 entries

Search: bolt

Patient	Date of Birth	Working Groups	Modules
BOLT, Betty	1942-02-09	th Royal Prince Alfred Hospital	Main Follow Ups

Showing 1 to 1 of 1 entries (filtered from 3 total entries)

Previous 1 Next

The RPAH coordinator can only see Betty Bolt (RPAH patient) on their **Patient List** page.

Rare Disease Registry Framework

Menu RPH Curator

Family Linkage [Save](#) [Cancel](#)

Index Lookup: Type name to find an index. Drag and drop rows to reassign

Lookup Index: [Load this index and family](#) [Add looked up patient to family](#)

Index Patient

Given Names	Family Name	Patient
Anna	BOLT	Demographics

RPH patient

Relatives

Given Names	Family Name	Relationship	Link
Betty	BOLT	Parent (1st degree)	Demographics

RPAH patient

On the **Family Linkage** page:

- The RPAH coordinator can click the **Demographics** and access Anna Bolt's (RPH patient) results N.B. Anna Bolt's results will be a 'view only' access for the RPAH coordinator.
- The RPH coordinator can click the **Demographics** and access Betty Bolt's (RPAH patient) results N.B. Betty Bolt's results will be a 'view only' access for the RPH coordinator.

Delete a Relative

Rare Disease Registry Framework

Menu National Curator

Demographics

GOLD Anne

Save Cancel

Patient Relative

Family name * Gold

Given names * Ben

Date of birth * 03-04-2000
DD-MM-YYYY

Sex * Male

Relationship * Child (1st degree)

Location * Australia - WA

Living status * Living

Create Patient? Patient in registry

Mark for deletion ☒

Only relatives can be deleted directly. To delete an Index, the Index must be changed to a relative (see [Change the Index](#)).

To delete a relative:

- Go to the Index's Demographics page
- Scroll down to the **Patient Relative** section
- Check the **Mark for deletion** box on the relative you wish to delete
- Click **Save**

Rare Disease Registry Framework

Menu National Curator

Patient List

+ Add Patient

FH Registry

Show 10 entries

Search: gold

Patient	Date of Birth	Working Groups	Modules
GOLD, Anne	1980-09-15	fh Royal Perth Hospital	Main Follow Ups
GOLD, Ben (Archived)	2000-04-03	fh Royal Perth Hospital	Main Follow Ups

Showing 1 to 2 of 2 entries (filtered from 41 total entries)

Previous 1 Next

The deleted patient is now shown as **(Archived)** on the **Patient List** page.

The deleted patient will no longer appear on the **Family Linkage** or in the **Patient Relative** field.

All archived patients will be deleted periodically by the database administrator.

Delete an Index

Only relatives can be deleted directly.

To delete an Index, the Index must first be changed to a Relative ([Change the Index](#)) and then deleted ([Delete a Relative](#)).

To delete an Index with at least 1 relative:

- Use the [Change the Index](#) function (makes the Index a Relative)
- Use the [Delete a Relative](#) function

To delete an Index with no relatives:

- Change the **Family name** to 'DELETE'
- Change the **Given name** to 'DELETE'
- Email details to the [National Coordinator](#)
- Database administrator will delete the patient

Pedigree

Pedigree

Founder effect origin: No ☒

Number of 1st degree relatives: 5

Number of 2nd degree relatives: 3

Number of 3rd degree relatives: 1

Upload family pedigree: [Browse...](#)

The pedigree indicates the number of possible relatives.

When compared with the [Family Linkage](#) (the number of family members already in the Registry) you can see:

- For 1st degree relatives you have consented 3 out of the possible 5 relatives
- For 2nd degree relatives you have consented 1 out of the possible 3 relatives
- For 3rd degree relatives you have consented 0 out of the possible 1 relative

Rare Disease Registry Framework Menu National Curator

Family Linkages

Index Lookup Type name to find an index. Drag and drop rows to reassign

Lookup Index: [Load this index and family](#) [Add looked up patient to family](#) [Save](#) [Cancel](#)

Index Patient

Given Names	Family Name	Patient
Anthony	BROWN	Demographics

Relatives

Given Names	Family Name	Relationship	Link
Ben	BROWN	Child (1st degree)	Demographics
Keith	Brown	Sibling (1st degree)	Demographics
Martha	BROWN	Sibling (1st degree)	Demographics
Anna	BROWN	Grandparent (2nd degree)	Demographics

Family Linkage (screen shot – [Family Linkage](#))

The **Family Linkage** can be accessed via the menu on the left or the **Family Linkage** link.

On the **Family Linkage** screen you can:

- Move between family members by clicking on the **Demographics** links
- See family relationships
- Load another Index and Relatives by typing in the name of the Index in the **Lookup index** field and clicking **Load this index and family** button
- [Change an incorrectly entered Index patient to a Relative](#)
- [Change the Index](#)

Change an incorrectly entered Index patient to a Relative

Rare Disease Registry Framework

Menu National Curator

Index Lookup Type name to find an index. Drag and drop rows to reassign

Look up Index: ABBOTT Cindy x Load this index and family Add looked up patient to family

Save Cancel

Index Patient

Given Names	Family Name	Patient
Anne	ABBOTT	Demographics

Relatives

Given Names	Family Name	Relationship	Link
Beth	ABBOTT	Unknown	Demographics

- Load the family you wish to add the incorrect Index patient to. This can be done by going to any member of the family and clicking on the **Family Linkage**.
- Typing in the name of the incorrect Index in the **Look up index** field and click **Add looked up patient to family** button
- The incorrect **Index** will now be a **Relative**
- Enter **Relationship**
- Click **Save**

Rare Disease Registry Framework

Menu National Curator

Family Linkages

Index Lookup Type name to find an index. Drag and drop rows to reassign

Look up Index: ABBOTT Cindy Load this index and family Add looked up patient to family

Save Cancel

Index Patient

Given Names	Family Name	Patient
Anne	ABBOTT	Demographics

Relatives

Given Names	Family Name	Relationship	Link
Beth	ABBOTT	Unknown	Demographics
Cindy	ABBOTT	Unknown	Demographics

- Go to **Patient Relative** field on Index's **Demographic** page and complete missing details on the added relative
- Click **Save**

Change the Index

Rare Disease Registry Framework Menu National Curator

Index Lookup Type name to find an index. Drag and drop rows to reassign

Lookup Index:

Index Patient

Given Names	Family Name	Patient
Anne	ABBOTT	Demographics

Cindy ABBOTT

Relatives

Given Names	Family Name	Relationship	Link
Beth	ABBOTT	Child (1st degree)	Demographics
Cindy	ABBOTT	Child (1st degree)	Demographics

100%

- Go to the **Family Linkage** page
- Drag the **Relative** you wish to become the new index to the **Index Patient** field
- Click **Save**
- The old index is now a relative and can now be deleted from the Registry if required. See [Delete a Relative](#).

Warning: Changing the Index should be avoided and only used in rare cases of the Index withdrawing from the Registry. Note the **Relationships** will now be incorrect and will need to be re-entered. Multiple fields in the **Patient Relative** section will also be lost and need to be re-entered.

Rare Disease Registry Framework Menu National Curator

Index Lookup Type name to find an index. Drag and drop rows to reassign

Lookup Index:

Index Patient

Given Names	Family Name	Patient
Cindy	ABBOTT	Demographics

Relatives

Given Names	Family Name	Relationship	Link
Beth	ABBOTT	Child (1st degree)	Demographics
Anne	ABBOTT	Unknown	Demographics

100%

Clinical Data (screen shot – [Clinic Data](#))

Calculate the DLCNS

To calculate the DLCNS:

- Complete all the required fields (marked with an *****) including the **Date of assessment**
- Complete the **Plasma LDL-cholesterol for FH Score** section. **Complete either:**
 - Highest UNTREATED LDL-cholesterol concentration (on record)
 - OR**
 - TREATED LDL-cholesterol concentration AND Treatment (daily)

Rare Disease Registry Framework

Main/Clinical Data

ABBEY, Anthea

Save Cancel Print

Plasma LDL-cholesterol for FH Score

Highest UNTREATED LDL-cholesterol concentration, OR mmol/L

TREATED LDL-cholesterol concentration

Treatment (daily) ☒

LDL-cholesterol adjusted for treatment mmol/L

OR

Rare Disease Registry Framework

Main/Clinical Data

ABBEY, Anthea

Save Cancel Print

Plasma LDL-cholesterol for FH Score

Highest UNTREATED LDL-cholesterol concentration, OR

TREATED LDL-cholesterol concentration mmol/L

Treatment (daily) ☒

LDL-cholesterol adjusted for treatment mmol/L

N.B. The LDL-cholesterol adjusted for treatment will be automatically calculated

- Click **Save**

N.B. If both the UNTREATED and TREATED LDL-cholesterol are entered the **UNTREATED LDL-cholesterol** will be used for the calculation of the DLCNS.

Rare Disease Registry Framework

Menu National Curator

Main/Clinical Data

ABBEY, Anthrea

Biochemistry Profile

+ Add

Date

DD-MM-YYYY

Total cholesterol concentration

mmol/L

LDL-cholesterol concentration

mmol/L

Triglyceride concentration

mmol/L

HDL-cholesterol concentration

mmol/L

Apolipoprotein B

g/L

Apolipoprotein A1

g/L

Total concentration

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N.B. Enter current lipid profile in the **Biochemistry Profile** section

Rare Disease Registry Framework

Menu National Curator

Main/Clinical Data

ABBEY, Anthrea

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Summary

Dutch Lipid Clinic Network Score (Phenotypic)

9

FH Diagnostic Category

Definite

Depending on the type/age of the patient (see [Adult Index](#), [Child/adolescent Index](#) or [Relative](#)) a **Dutch Lipid Clinic Network Score (Phenotype)** and/or **FH Diagnostic Category** will automatically appear in the **Summary** section.

Adult Index

Adult INDEX will be given a **DLCNS** and an **FH Diagnostic Category**.

Index or relative

Index

Main

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Follow Ups

+ Add

Summary

Dutch Lipid Clinic Network Score (Phenotypic)

24

FH Diagnostic Category

Definite

Child/adolescent Index

Child/adolescent INDEX will be given an **FH Diagnostic Category** only.

The screenshot shows the National FH Registry interface. On the left is a sidebar with navigation links: Family Linkage, Main, Clinical Data, Genetic Data, Medications, Imaging, Apheresis, and Follow Ups. The main content area has a header 'Index or relative' with a dropdown menu currently set to 'index'. Below this is a 'Summary' section with two rows: 'Dutch Lipid Clinic Network Score (Phenotypic)' and 'FH Diagnostic Category'. The 'FH Diagnostic Category' row shows 'Highly Probable'. Red circles highlight the 'index' dropdown and the 'Highly Probable' category.

To be included in the registry as an INDEX, a child/adolescent must have a **highly probable** or **probable** category.

Category	Inclusion as an INDEX	Criteria
Highly probable	Yes	LDL-cholesterol concentration > 5.0 mmol/L
Probable	Yes	<ul style="list-style-type: none"> • LDL-cholesterol concentration > 4.0 - 5.0 mmol/L + family history of premature CHD or • LDL-cholesterol concentration > 4.0 - 5.0 mmol/L + hypercholesterolaemia or tendon xanthoma or arcus in first-degree relative
Possible	No	LDL-cholesterol concentration 4.0 - 5.0 mmol/L
Unlikely	No	LDL-cholesterol concentration < 4.0 mmol/L

Relative

All relatives including children and adolescents will be given an **FH Diagnostic Category** only, based on their LDL-cholesterol level for their age and gender (see tables below).

Family Linkage

Main

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Follow Ups

Index or relative

relative

Summary

Dutch Lipid Clinic Network Score (Phenotypic)

FH Diagnostic Category

Likely

Likely - red
Uncertain - grey
Unlikely – green

LDL-C FEMALES

Age					
0 To 14	15 To 24	25 To 34	35 To 44	45 To 54	55 and Older
5.5	5.5	5.5	5.5	5.5	5.5
5.4	5.4	5.4	5.4	5.4	5.4
5.3	5.3	5.3	5.3	5.3	5.3
5.2	5.2	5.2	5.2	5.2	5.2
5.1	5.1	5.1	5.1	5.1	5.1
5.0	5.0	5.0	5.0	5.0	5.0
4.9	4.9	4.9	4.9	4.9	4.9
4.8	4.8	4.8	4.8	4.8	4.8
4.7	4.7	4.7	4.7	4.7	4.7
4.6	4.6	4.6	4.6	4.6	4.6
4.5	4.5	4.5	4.5	4.5	4.5
4.4	4.4	4.4	4.4	4.4	4.4
4.3	4.3	4.3	4.3	4.3	4.3
4.2	4.2	4.2	4.2	4.2	4.2
4.1	4.1	4.1	4.1	4.1	4.1
4.0	4.0	4.0	4.0	4.0	4.0
3.9	3.9	3.9	3.9	3.9	3.9
3.8	3.8	3.8	3.8	3.8	3.8
3.7	3.7	3.7	3.7	3.7	3.7
3.6	3.6	3.6	3.6	3.6	3.6
3.5	3.5	3.5	3.5	3.5	3.5
3.4	3.4	3.4	3.4	3.4	3.4
3.3	3.3	3.3	3.3	3.3	3.3
3.2	3.2	3.2	3.2	3.2	3.2
3.1	3.1	3.1	3.1	3.1	3.1
3.0	3.0	3.0	3.0	3.0	3.0

LDL-C MALES

Age					
0 To 14	15 To 24	25 To 34	35 To 44	45 To 54	55 and Older
5.5	5.5	5.5	5.5	5.5	5.5
5.4	5.4	5.4	5.4	5.4	5.4
5.3	5.3	5.3	5.3	5.3	5.3
5.2	5.2	5.2	5.2	5.2	5.2
5.1	5.1	5.1	5.1	5.1	5.1
5.0	5.0	5.0	5.0	5.0	5.0
4.9	4.9	4.9	4.9	4.9	4.9
4.8	4.8	4.8	4.8	4.8	4.8
4.7	4.7	4.7	4.7	4.7	4.7
4.6	4.6	4.6	4.6	4.6	4.6
4.5	4.5	4.5	4.5	4.5	4.5
4.4	4.4	4.4	4.4	4.4	4.4
4.3	4.3	4.3	4.3	4.3	4.3
4.2	4.2	4.2	4.2	4.2	4.2
4.1	4.1	4.1	4.1	4.1	4.1
4.0	4.0	4.0	4.0	4.0	4.0
3.9	3.9	3.9	3.9	3.9	3.9
3.8	3.8	3.8	3.8	3.8	3.8
3.7	3.7	3.7	3.7	3.7	3.7
3.6	3.6	3.6	3.6	3.6	3.6
3.5	3.5	3.5	3.5	3.5	3.5
3.4	3.4	3.4	3.4	3.4	3.4
3.3	3.3	3.3	3.3	3.3	3.3
3.2	3.2	3.2	3.2	3.2	3.2
3.1	3.1	3.1	3.1	3.1	3.1
3.0	3.0	3.0	3.0	3.0	3.0

Add Follow Up Form

Click **+Add** button

Blank **Follow Up** page will appear:

- Complete **Date of assessment** (required field)
- Complete other data
- Click **Save**

Rare Disease Registry Framework

Menu National Curator

Follow Up/5-5-2015

BOLT, Anna

Save Cancel Print

Demographics

Consents

Family Linkage

Main

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Follow Ups + Add

5-5-2015

At follow-up

Date of assessment 5-5-2015
DD-MM-YYYY

Is the patient currently smoking? ☐ Yes ☐ No ☐ Unknown

Systolic Blood Pressure

Diastolic Blood Pressure

Has the patient developed chronic kidney disease? ☐ Yes ☐ No ☐ Unknown
Please tick Yes if chronic kidney disease has already been diagnosed previously

Observed weight status ☐ Underweight ☐ Healthy weight ☐ Overweight ☐ Obese

Height
Height in metres

Weight
Weight in kilograms

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Date appears in left hand menu bar and header

Rare Disease Registry Framework

Menu National Curator

Follow Up/6-6-2016

BOLT, Anna

Save Cancel Print

Demographics

Consents

Family Linkage

Main

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Follow Ups + Add

5-5-2015

6-6-2016

At follow-up

Date of assessment 6-6-2016
DD-MM-YYYY

Is the patient currently smoking? ☐ Yes ☐ No ☐ Unknown

Systolic Blood Pressure

Diastolic Blood Pressure

Has the patient developed chronic kidney disease? ☐ Yes ☐ No ☐ Unknown
Please tick Yes if chronic kidney disease has already been diagnosed previously

Observed weight status ☐ Underweight ☐ Healthy weight ☐ Overweight ☐ Obese

Height
Height in metres

Weight
Weight in kilograms

BMI
NaN
kg/m²

Patient Anna BOLT saved successfully

With multiple forms dates will appear in chronological order

Rare Disease Registry Framework

Menu National Curator

Patient List

+ Add Patient

FH Registry

Show 10 entries

Search: bolt

Patient	Date of Birth	Working Groups	Modules
BOLT, Anna	05-05-1971	th Royal Perth Hospital	Main Follow Ups
BOLT, Betty	09-02-1942	th Royal Prince Alfred Hospital	5-5-2015 6-6-2016

Showing 1 to 2 of 2 entries (filtered from 55 total entries)

Previous 1 Next

Patient List page will show Follow Ups in dropdown menu

Screen Shot – Patient List (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Patient List
Add Patient

FH Registry
Show 10 entries
Search:

Patient	Date of Birth	Working Groups	Modules
ABBEY, bert	1980-08-08	fh Royal Perth Hospital	Main Follow Ups
ABBOTT, Anthony	1990-01-01	fh Royal Perth Hospital	Main Follow Ups
ABBOTT, Ben	1990-09-09	fh Royal Perth Hospital	Main Follow Ups
BEAN, Anthony	1970-02-01	fh Royal Perth Hospital	Main Follow Ups
BLUE, Anna	2000-09-01	fh Royal Perth Hospital	Main Follow Ups
BLUE, Bert	1970-09-01	fh Royal Perth Hospital	Main Follow Ups
BOLT, Anna	1971-09-05	fh Royal Perth Hospital	Main Follow Ups
BROWN, Angela (Archived)	1990-01-01	fh Royal Perth Hospital	Main Follow Ups
BROWN, Bret	1970-01-01	fh Royal Perth Hospital	Main Follow Ups
BROWN, Sue (Archived)	1960-08-10	fh Royal Perth Hospital	Main Follow Ups

Showing 1 to 10 of 36 entries
Previous
1
2
3
4
Next

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100%

Screen Shot – Demographics (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Demographics

Registry

Rdrt registry * FH Registry (fh)

Centre * fh Royal Perth Hospital

Save
Cancel
Next
Previous

Patients Personal Details

Family name *

Given names *

Maiden name (if applicable)

Hospital/Clinic ID

Date of birth * DD-MM-YYYY

Country of birth

Ethnic origin

Sex *

Home phone

Mobile phone

Work phone

Email

Living status * Living

Patient Address
Add
Remove

Address type * Home

Address *

Suburb/Town *

State *

Postcode *

Country *

Patient Doctor

+ Add

- Remove

Doctor *

Type of Medical Professional *

Patient Relative

+ Add

- Remove

Family name *

Given names *

Date of birth *

DD-MM-YYYY

Sex *

Relationship *

Location *

Living status *

Create Patient?

☐

Pedigree

Founder effect origin

Number of 1st degree relatives

Number of 2nd degree relatives

Number of 3rd degree relatives

Upload family pedigree

Browse...

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Change zoom level

Screen Shot – Family Linkage (enlarge to view)

Rare Disease Registry Framework

Menu RPH Curator

Family Linkage

Save Cancel

Index Lookup Type name to find an index. Drag and drop rows to reassign

Lookup Index: Load this index and family Add looked up patient to family

Index Patient

Given Names	Family Name	Patient
Anthony	SMITH	Demographics

Relatives

Given Names	Family Name	Relationship	Link
Belinda	Smith	Child (1st degree)	Demographics

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Screen Shot – Consents (enlarge to view)

Rare Disease Registry Framework

Menu RPH Curator

Consents

SMITH, Anthony

Save Cancel

Demographics

Consents

Family Linkage

Main

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Follow Ups

+ Add

FH Registry Consent

Adult consent

Consent given to be part of the registry and have data retained and shared in accordance with the information provided to them.

Child consent

Parent/guardian consent on the child/ward's behalf to be part of the registry and have data retained and shared in accordance with the information provided to them.

FH Optional Consents

Clinical trials

Consent given to be contacted about clinical trials or other studies.

Information

Consent given to be sent information.

FH Registry Subset

FCHL

Familial Combined Hyperlipidaemia

Hyper-Lp(a)

Familial Elevation of Lipoprotein(a)

Upload consent file (if requested)

+ Add

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Screen Shot – Clinical Data (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Main/Clinical Data
Save Cancel Print
SMITH, Anthony

Demographics
Consents
Family Linkage
Main
Clinical Data
Genetic Data
Medications
Imaging
Apheresis
Follow Ups
Add

Consent date
DD-MM-YYYY
Date of assessment *
DD-MM-YYYY
* This field is required.
Index or relative
index

Summary
Dutch Lipid Clinic Network Score (Phenotypic)
FH Diagnostic Category

Family History
Family history of hypercholesterolaemia (first-degree adult relative) *
>95th percentile for age and gender
* This field is required.
Family history of hypercholesterolaemia (child aged <18 years) *
>95th percentile for age and gender
* This field is required.
Family history of premature CVD (first-degree relative) *
Men <55, Women <60 years of age
* This field is required.
Family history of tendon xanthoma (first-degree relative) *
* This field is required.
Family history of arcus cornealis prior to 45 years of age (first-degree relative) *
* This field is required.

Clinical History
Personal history of premature coronary heart disease *
Men <55, Women <60 years of age
* This field is required.
Myocardial infarction
Yes No Unknown
Age at first MI
years
Coronary revascularisation
Age at first revascularisation
years

Personal history of premature cerebral or peripheral vascular disease *

Men <55, Women < 60 years of age

* This field is required.

Aortic valve disease

☐ Yes

☐ No

☐ Unknown

Supravalvular disease

☐ Yes

☐ No

☐ Unknown

Premature non-coronary vascular disease

☐ Yes

☐ No

☐ Unknown

Physical Examination

Tendon xanthoma *

* This field is required.

Arcus cornealis prior to age 45 years *

* This field is required.

Xanthelasma

☐ Yes

☐ No

☐ Unknown

Plasma LDL-cholesterol for FH Score

Highest UNTREATED LDL-cholesterol concentration, OR

mmol/L

TREATED LDL-cholesterol concentration

mmol/L

Treatment (daily)

LDL-cholesterol adjusted for treatment

NaN

mmol/L

Biochemistry Profile

+ Add

Date

DD-MM-YYYY

Total cholesterol concentration

mmol/L

LDL-cholesterol concentration

mmol/L

Triglyceride concentration

mmol/L

HDL-cholesterol concentration

mmol/L

Apolipoprotein B

g/L

Apolipoprotein A1

g/L

Lp(a) concentration	<input type="text"/>	g/L
Aspartate transaminase (AST)	<input type="text"/>	U/L
Alanine transaminase (ALT)	<input type="text"/>	U/L
Creatine kinase (CK)	<input type="text"/>	U/L
Albumin	<input type="text"/>	g/L
Creatinine	<input type="text"/>	umol/L
C-reactive protein (CRP)	<input type="text"/>	mg/L
Treatment (daily)	<input type="text" value="---"/>	<input type="button" value="v"/>
If other, enter medication name(s), dose(s) and regime	<input type="text"/>	
Compliance	<input type="text" value="---"/>	<input type="button" value="v"/>
	<i>If intolerant, please enter details into Medication Module - Drug Intolerance</i>	
Mark for deletion	<input type="checkbox"/>	

Other CVD Risk Factors

Smoking	<input type="radio"/> Yes <input type="radio"/> Never <input type="radio"/> Ex-smoker
Indicate pack years smoked	<input type="text"/>
	<i>Pack years = (number of cigarettes smoked per day/20) x number of years smoked</i>
Alcohol	<input type="text" value="---"/>
Hypertriglyceridaemia	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Hypertension	<input type="text" value="---"/>
	<i>If yes and on hypertensive medication, please complete the Medication Module</i>
Systolic Blood Pressure	<input type="text"/>
Diastolic Blood Pressure	<input type="text"/>
Heart rate	<input type="text"/>
	bpm
Diabetes	<input type="text" value="---"/>
	<i>If yes and on diabetic medication, please complete the Medication Module</i>
Blood glucose concentration	<input type="text"/>
	mmol/L
HbA1c	<input type="text"/>
	(%)
Chronic kidney disease	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
eGFR	<input type="text"/>
	ml/min/1.73m ²
Hypothyroidism	<input type="text" value="---"/>

TSH

mU/L

Hepatic steatosis

☐ Yes

☐ No

☐ Unknown

Observed weight status

☐ Underweight

☐ Healthy weight

☐ Overweight

☐ Obese

Height

Height in metres

Weight

Weight in kilograms

BMI

NaN

kg/m2

Waist circumference

cm

Please list any other significant medical conditions

Clinical Trials

+ Add

Trial name

Expect length

Months

Start date

DD-MM-YYYY

Trial status

☐ Completed

☐ Withdrawn

☐ Ongoing

Mark for deletion

☐

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Screen Shot – Genetic Data (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Main/Genetic Data
Save Cancel Print
SMITH, Anthony

Demographics
Consents
Family Linkage
Main
Clinical Data
Genetic Data
Medications
Imaging
Apheresis
Follow Ups
Add

Genetic Analysis
Has the patient had a DNA test?
Yes No – service not available No – not consented No – not offered
This field is required.

Genetic Analysis
Genetic test date
DD-MM-YYYY
Genotype
No variant identified Heterozygous Compound Heterozygous Homozygous
If "Compound Heterozygous" selected, enter two mutations below, otherwise only enter one.

Gene Variant
Add
Gene variant
LDLR APOB PCSK9 Other
Description of variant
Pathogenicity
Pathogenic Not pathogenic Variant of uncertain significance
Mark for deletion

Next Generation Sequencing
Has this patient had Next Generation Sequencing?
Yes No Unknown
Genetic test date
DD-MM-YYYY
Details

Laboratory Data
Add
Laboratory Report
Browse...
Mark for deletion

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Screen Shot – Medications (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Main/Medications
SMITH, Anthony
Save Cancel Print

Lipid-lowering Medication

Is the patient on lipid-lowering medication? ☐ Yes ☐ No ☐ Unknown

Treatment (daily)

If other, enter medication name(s), dose(s) and regime

Date of starting medication DD-MM-YYYY

Hypertensive Medication

Is the patient on hypertensive medication? ☐ Yes ☐ No ☐ Unknown

Medication(s) ☐ Thiazide diuretics ☐ Beta blockers ☐ ACE inhibitors ☐ ARBs ☐ Calcium channel blockers ☐ Other

If other, enter medication name(s)

Diabetic Medication

Is the patient on diabetic medication? ☐ Yes ☐ No ☐ Unknown

Medication(s) ☐ Biguanides ☐ Sulfonylureas ☐ TZDs ☐ Insulin therapy ☐ DPP-4 inhibitors ☐ GLP-1 receptor agonist ☐ SGLT-2 inhibitor ☐ Other

If other, enter medication name(s)

Antithrombotic Medication

Is the patient on antithrombotic medication? ☐ Yes ☐ No ☐ Unknown

Medication(s) ☐ Aspirin
☐ Other antiplatelets
☐ Warfarin
☐ Other anticoagulants

If other, enter medication name(s)

Drug Intolerance

History of drug intolerance ☐ Yes ☐ No ☐ Unknown

Specific Lipid-lowering Drug Intolerance

[+ Add](#)

Date drug intolerance first observed

DD-MM-YYYY

Drug

Dose

If other, enter medication name(s), dose(s) and regime

How long was the patient on medication before intolerance was observed?

Enter a number or "Several"

Time frame

Select a time frame

Specify type of muscle intolerance

- ☐ Fatigue
- ☐ Muscle pain
- ☐ Muscle weakness
- ☐ Muscle tenderness
- ☐ Cramps
- ☐ CK elevation
- ☐ Myalgia, tolerable
- ☐ Myalgia, intolerable
- ☐ Myopathy
- ☐ Severe myopathy
- ☐ Rhabdomyolysis
- ☐ Autoimmune-mediated
- ☐ Necrotizing myositis

Specify type of hepatic intolerance

- ☐ Hepatotoxicity
- ☐ Increased activity of liver enzymes

Specify type of gastrointestinal tract intolerance

- ☐ Constipation
- ☐ Diarrhoea
- ☐ Dyspepsia
- ☐ Flatulence
- ☐ Heartburn
- ☐ Nausea
- ☐ Vomiting

Specify type of neurologic and psychological effects intolerance

- ☐ Aggressive behaviour
- ☐ Headache
- ☐ Asthenia
- ☐ Dizziness
- ☐ Fatigue
- ☐ Severe irritability
- ☐ Insomnia
- ☐ Somnolence

	<input type="checkbox"/> Agitation
	<input type="checkbox"/> Confusion
	<input type="checkbox"/> Nightmares
	<input type="checkbox"/> Memory loss
Specify type of respiratory intolerance	<input type="checkbox"/> Upper respiratory tract infection
	<input type="checkbox"/> Pharyngitis
	<input type="checkbox"/> Rhinitis
Specify type of endocrine intolerance	<input type="checkbox"/> New onset diabetes
Specify type of skin intolerance	<input type="checkbox"/> Rash
Specify type of eye intolerance	<input type="checkbox"/> Cataract
	<input type="checkbox"/> Diplopia, ptosis and ophthalmoplegia
Specify type of renal intolerance	<input type="checkbox"/> Acute renal failure
	<input type="checkbox"/> Proteinuria
Specify type of reproductive intolerance	<input type="checkbox"/> Erectile dysfunction
	<input type="checkbox"/> Decrease libido
	<input type="checkbox"/> Gynecomastia
	<input type="checkbox"/> Reduced testosterone levels
Specify type of bones and joints intolerance	<input type="checkbox"/> Tendinitis
	<input type="checkbox"/> Arthralgia
	<input type="checkbox"/> Arthritis
If other, enter type of intolerance/s	<div></div>
Additional comments	<div></div>
Mark for deletion	<input type="checkbox"/>

Screen Shot – Imaging (enlarge to view)

Rare Disease Registry Framework

Menu RPH Curator

Main/Imaging

SMITH, Anthony

Save Cancel Print

Demographics

Consents

Family Linkage

Main

Clinical Data

Genetic Data

Medications

Imaging

Apheresis

Follow Ups

+ Add

Carotid Ultrasonography

+ Add

Carotid Ultrasonography ☐ Yes - Normal ☐ Yes - Abnormal ☐ No ☐ Unknown

Date
DD-MM-YYYY

Result (left)
IMT mm

Result (right)
IMT mm

Result

Report Browse...

Mark for deletion ☐

Echocardiogram (Resting)

+ Add

Echocardiogram (resting) ☐ Yes - Normal ☐ Yes - Abnormal ☐ No ☐ Unknown

Date
DD-MM-YYYY

Result

Report Browse...

Mark for deletion ☐

Coronary Artery Calcium Score

+ Add

Coronary artery calcium score

Date
DD-MM-YYYY

Result (score)

Result (percentile)

Report Browse...

Mark for deletion ☐

CT Coronary Angiogram

+ Add

CT coronary angiogram

Yes - Normal

Yes - Abnormal

No

Unknown

Date

DD-MM-YYYY

Result

Report

Browse...

Mark for deletion

Invasive Angiogram

+ Add

Invasive angiogram

Yes - Normal

Yes - Abnormal

No

Unknown

Date

DD-MM-YYYY

Result

Report

Browse...

Mark for deletion

Stress Echo

+ Add

Stress echo

Yes - Normal

Yes - Abnormal

No

Unknown

Date

DD-MM-YYYY

Result

Report

Browse...

Mark for deletion

Stress ECG

Stress ECG

Yes - Normal

Yes - Abnormal

No

Unknown

Date

DD-MM-YYYY

Result

Report

Browse...

Mark for deletion

Nuclear Perfusion Scan

Nuclear perfusion scan

Yes - Normal

Yes - Abnormal

No

Unknown

Date

DD-MM-YYYY

Result

Report

Browse...

Mark for deletion

Intravascular Ultrasound

Intravascular ultrasound

Yes - Normal

Yes - Abnormal

No

Unknown

Date

DD-MM-YYYY

Result

Report

Browse...

Mark for deletion

[RETURN TO MENU](#)

Optical Coherence Tomography		+ Add
Optical coherence tomography	<input type="radio"/> Yes - Normal <input type="radio"/> Yes - Abnormal <input type="radio"/> No <input type="radio"/> Unknown	
Date	<input type="text"/>	
	<i>DD-MM-YYYY</i>	
Result	<input type="text"/>	
Report	<input type="text"/> <input type="button" value="Browse..."/>	
Mark for deletion	<input type="checkbox"/>	

Screen Shot – Apheresis (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Main/Apheresis
SMITH, Anthony
Save Cancel Print

Demographics
Consents
Family Linkage
Main
Clinical Data
Genetic Data
Medications
Imaging
Apheresis
Follow Ups
Add

Apheresis

Has the patient had apheresis? ☐ No ☐ Yes

Apheresis

Add

Date apheresis started
DD-MM-YYYY

If not currently on apheresis, date apheresis stopped
DD-MM-YYYY

Type of apheresis ---

Duration of an episode of apheresis
hours

Frequency of apheresis ---

Have there been any complications?

Pre-apheresis LDL-cholesterol concentration
mmol/l

Interval mean LDL-cholesterol reduction
mmol/l

Pre-apheresis Lp(a) concentration
g/L

Interval mean Lp(a) reduction
g/L

Mark for deletion ☐

Support Report a bug Version 1.6.7
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Authorised by: Prof. Matthew Bellgard;
Director, CCG
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Screen Shot – Follow Up (enlarge to view)

Rare Disease Registry Framework
Menu
RPH Curator

Follow Up
SMITH, Anthony
Save
Cancel

Demographics
Consents
Family Linkage
Main
Clinical Data
Genetic Data
Medications
Imaging
Apheresis
Follow Ups
Add

At follow-up

Date of assessment *
DD-MM-YYYY

Is the patient currently smoking? ☐ Yes ☐ No ☐ Unknown

Systolic Blood Pressure

Diastolic Blood Pressure

Has the patient developed chronic kidney disease? ☐ Yes ☐ No ☐ Unknown
Please tick Yes if chronic kidney disease has already been diagnosed previously

Observed weight status ☐ Underweight ☐ Healthy weight ☐ Overweight ☐ Obese

Height
Height in metres

Weight
Weight in kilograms

BMI
kg/m2

Has this patient been discharged from the clinic?

Events

Has the patient had an event since the last visit? ☐ Yes ☐ No ☐ Unknown

Myocardial infarction ☐ Yes ☐ No ☐ Unknown

Age at MI
years

Coronary revascularisation

Age at revascularisation
years

Coronary artery disease ☐ Defined by imaging/functional test(s) (if checked, please enter results into Imaging Module)
☐ Angina pectoris

Age at angina	<input type="text"/>
	years
Stroke	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Age at stroke	<input type="text"/>
	years
TIA	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Age at TIA	<input type="text"/>
	years
Other vascular surgery	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Other comments	<input type="text"/>
	<i>eg. multiple events or number of stents/by-passes</i>

Hypertension

Has the patient developed hypertension?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	<i>Please tick Yes if hypertension has already been diagnosed previously</i>
If yes, is the patient on hypertensive medication?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Medication(s)	<input type="checkbox"/> Thiazide diuretics <input type="checkbox"/> Beta blockers <input type="checkbox"/> ACE inhibitors <input type="checkbox"/> ARBs <input type="checkbox"/> Calcium channel blockers <input type="checkbox"/> Other
If other, enter medication name(s)	<input type="text"/>

Diabetes

Has the patient developed diabetes?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
	<i>Please tick Yes if diabetes has already been diagnosed previously</i>
If yes, is the patient on diabetic medication?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Medication(s)	<input type="checkbox"/> Biguanides <input type="checkbox"/> Sulfonylureas <input type="checkbox"/> TZDs <input type="checkbox"/> Insulin therapy <input type="checkbox"/> DPP-4 inhibitors <input type="checkbox"/> GLP-1 receptor agonist <input type="checkbox"/> SGLT-2 inhibitor <input type="checkbox"/> Other
If other, enter medication name(s)	<input type="text"/>

Antithrombotic

Has the patient been prescribed antithrombotic medication?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Medication(s)	<input type="checkbox"/> Aspirin <input type="checkbox"/> Other antiplatelets <input type="checkbox"/> Warfarin <input type="checkbox"/> Other anticoagulants
If other, enter medication name(s)	<input type="text"/>

Biochemistry Profile

Date

DD-MM-YYYY

Total cholesterol
concentration

mmol/L

LDL-cholesterol
concentration

mmol/L

Triglyceride
concentration

mmol/L

HDL-cholesterol
concentration

mmol/L

Lp(a) concentration

g/L

Blood glucose
concentration

mmol/L

HbA1c

(%)

Apolipoprotein B

g/L

Apolipoprotein A1

g/L

Aspartate transaminase
(AST)

U/L

Alanine transaminase
(ALT)

U/L

Creatine kinase (CK)

U/L

Albumin

g/L

Creatinine

umol/L

C-reactive protein (CRP)

mg/L

Treatment (daily)

If other, enter medication
name(s), dose(s) and
regime

Compliance



If intolerant, please enter details into Medication Module - Drug Intolerance

Death

Date of death

DD-MM-YYYY

Age at death

years

Cause of death

Please specify other cause of death

Support Report a bug Version 1.6.7

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Authorised by: Prof. Matthew Bellgard:
Director, CCG

100%

NATIONAL FH REGISTRY



Core Data Entry Form – Updated 20/7/2018

DEMOGRAPHICS

Doctor*:	Hospital ID:		
Type of Medical Professional*:	Family name*:		
Home:	Given names*:		
Mobile:	Address*:		
Email:	PC:		
Ethnic origin:	Sex*:	DOB*:	

☐ INDEX ☐ RELATIVE – Name of index/relationship:

Click the green 'Save' button, then use the blue arrow on the right to move to the next form >

CONSENT

☐ Adult ☐ Child ☐ Clinical trials ☐ Information ☐ FCHL ☐ Hyper-Lp(a) ☐ Upload consent file

Click the green 'Save' button, then use the blue arrow on the right to move to the next form >

CLINICAL DATA

Date of consent*: Date of assessment*:

CLINICAL DATA – FH Score		Score	Patient Score
1.0	Family History		
1.1	First degree relatives with known premature coronary and vascular disease (Men < 55 years, Females < 60 years) Father / Mother / Other: _____	1	
1.2	OR First degree relatives with known LDL-cholesterol (LDL-C) above the 95 th percentile (for age and sex) Father / Mother / Other: _____		
1.3	First degree relatives with <input type="checkbox"/> tendinous xanthomata and/or <input type="checkbox"/> arcus cornealis	2	
1.4	OR Have children aged less than 18 years with LDL-C above the 95 th percentile (for age and sex)		
2.0	Clinical History		
2.1	Patient with premature coronary artery disease (Men < 55 years, Females < 60 years) MI: age at first_____ CABG: age at first_____ PCI: age at first_____	2	
2.2	Patient with premature cerebral or peripheral vascular disease (Men < 55 years, Females < 60 years) Age at first_____	1	
3.0	Physical examination		
3.1	Tendinous xanthomata Right / Left / Bilateral	6	
3.2	Arcus cornealis prior to age 45 years Right / Left / Bilateral	4	
4.0	Low Density Lipoprotein Cholesterol, LDL-C (mmol/L)		
4.1	LDL-C ≥ 8.5	8	
4.2	LDL-C 6.5-8.4	5	
4.3	LDL-C 5.0-6.4	3	
4.4	LDL-C 4.0-4.9	1	

FH Diagnostic Categories: Definite >8, Probable 6-8, Possible 3-5, Unlikely 0-2

FH Score:

Plasma LDL-cholesterol for FH Score

HIGHEST UNTREATED LDL-C*
OR TREATED LDL-C and Treatment
(Closest to the 'Date of consent')

AFFIX LABEL HERE

CLINICAL DATA – Biochemistry Profile <small>Enter one profile closest to the 'Date of consent'. This profile can be treated or untreated.</small>					
Date*					
Total cholesterol*:	LDL-cholesterol*:	Treatment (daily)*: <small>(At time of lipid profile)</small>			
Triglyceride*:	HDL-cholesterol*:				
Compliance*		<input type="checkbox"/> Full <input type="checkbox"/> Irregular <input type="checkbox"/> Non-compliant <input type="checkbox"/> Intolerant <input type="checkbox"/> N/A <input type="checkbox"/> Unknown			
CLINICAL DATA – Other CVD Risk Factors					
Smoking*	<input type="checkbox"/> Yes <input type="checkbox"/> Never <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Unknown				
Alcohol*	<input type="checkbox"/> Yes – daily <input type="checkbox"/> Yes – once/twice a week <input type="checkbox"/> Yes – occasional <input type="checkbox"/> Never <input type="checkbox"/> Former <input type="checkbox"/> Unknown				
Hypertension*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Systolic:		Diastolic:	
Diabetes*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Glucose:		HbA1c (%):	
Chronic kidney disease*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	eGFR:			
Hypothyroidism*	<input type="checkbox"/> Yes – treated <input type="checkbox"/> Yes – untreated <input type="checkbox"/> No <input type="checkbox"/> Unknown				TSH:
Observed weight status*	<input type="checkbox"/> Underweight <input type="checkbox"/> Healthy weight <input type="checkbox"/> Overweight <input type="checkbox"/> Obese <input type="checkbox"/> Unknown				
	Height (m):		Weight (kg):		
Lp(a)*					
Other significant medical conditions:					
Click the green 'Save' button, then use the blue arrow on the right to move to the next form >					
GENETIC DATA					
DNA test*	<input type="checkbox"/> Yes <input type="checkbox"/> No – service not available <input type="checkbox"/> No – not consented <input type="checkbox"/> No – not offered <small>If yes, complete sections below.</small>				
Date					
Genotype	<input type="checkbox"/> None identified <input type="checkbox"/> Hetero. <input type="checkbox"/> Compound Hetero. <input type="checkbox"/> Homozygous				
Gene Variant	<input type="checkbox"/> LDLR <input type="checkbox"/> APOB <input type="checkbox"/> PCSK9 <input type="checkbox"/> Other				
Description					
Pathogenicity	<input type="checkbox"/> Pathogenic <input type="checkbox"/> Non-pathogenic <input type="checkbox"/> Uncertain <input type="checkbox"/> Upload report				
Click the green 'Save' button, then use the blue arrow on the right to move to the next form >					
MEDICATIONS					
Lipid-lowering medication* <small>(At time of entry into the registry)</small>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete below:</small> Treatment (daily)*:				
	Date of first starting any lipid-lowering medication*:				
Hypertensive medication*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete below:</small> <input type="checkbox"/> Thiazide diuretics <input type="checkbox"/> Beta blockers <input type="checkbox"/> ACE inhibitors <input type="checkbox"/> ARBs <input type="checkbox"/> Calcium channel blockers <input type="checkbox"/> Other				
Diabetic medication*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete below:</small> <input type="checkbox"/> Biguanides <input type="checkbox"/> Sulfonylureas <input type="checkbox"/> TZDs <input type="checkbox"/> Insulin therapy <input type="checkbox"/> DPP-4 inhibitors <input type="checkbox"/> GLP-1 receptor agonist <input type="checkbox"/> SGLT-2 inhibitor <input type="checkbox"/> Other				
Antithrombotic medication*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete below:</small> <input type="checkbox"/> Aspirin <input type="checkbox"/> Other antiplatelets <input type="checkbox"/> Warfarin <input type="checkbox"/> Other anticoagulants				
History of drug intolerance*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details. Enter as much detail as is available.</small>				
Click the green 'Save' button, then use the blue arrow on the right to move to the next form >					
IMAGING <small>Not all imaging is listed here. Please complete all imaging in the registry.</small>					
Carotid ultrasonography*	<input type="checkbox"/> Yes - Normal <input type="checkbox"/> Yes - Abnormal <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				
Echocardiogram (resting)*	<input type="checkbox"/> Yes - Normal <input type="checkbox"/> Yes - Abnormal <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				
Coronary artery calcium score*	<input type="checkbox"/> Yes-0 <input type="checkbox"/> Yes-1-99 <input type="checkbox"/> Yes-100-300 <input type="checkbox"/> Yes->300 <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				
CT coronary angiogram*	<input type="checkbox"/> Yes - Normal <input type="checkbox"/> Yes - Abnormal <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				
Invasive angiogram*	<input type="checkbox"/> Yes - Normal <input type="checkbox"/> Yes - Abnormal <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				
Other:	<input type="checkbox"/> Yes - Normal <input type="checkbox"/> Yes - Abnormal <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				
Click the green 'Save' button, then use the blue arrow on the right to move to the next form >					
APHERESIS*	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <small>If yes, complete more details.</small>				

NATIONAL *fH* REGISTRY



AFFIX LABEL HERE

DEMOGRAPHICS

Dr:	Hospital ID:
Date*:	Family name:
Home:	Given names:
Mobile:	Address:
Email:	PC: Sex: DOB:

☐ INDEX ☐ RELATIVE Index/relationship:

Currently smoking: ☐ Yes ☐ No ☐ Unknown

Hypertension: Systolic Blood Pressure:

Diastolic Blood Pressure:

Chronic kidney disease: ☐ Yes ☐ No ☐ Unknown Tick yes if chronic kidney disease has been diagnosed previously.

Observed weight status: ☐ Underweight ☐ Healthy weight ☐ Overweight ☐ Obese

Height (m):

Weight (kg):

BMI:

Patient discharged: ☐ Yes – to GP ☐ Yes – to specialist

☐ No – remains in clinic ☐ No – but lost to follow up ☐ Unknown

EVENTS

Event since last visit: ☐ Yes ☐ No ☐ Unknown

Myocardial infarction: ☐ Yes ☐ No ☐ Unknown

Age at MI (years):

Coronary revascularisation: ☐ PCI ☐ CABG ☐ Both
☐ No ☐ Unknown

Age at revascularisation (years):

Coronary artery disease: ☐ Defined by imaging/functional test(s) If checked enter results into Imaging Module.

☐ Angina pectoris

Age at angina (years):

Stroke: ☐ Yes ☐ No ☐ Unknown

Age at stroke (years):

TIA: ☐ Yes ☐ No ☐ Unknown

Age at TIA (years):

Other vascular surgery: ☐ Yes ☐ No ☐ Unknown

Other comments e.g. multiple events or number of stents/by-passes:

HYPERTENSION

Hypertension: ☐ Yes ☐ No ☐ Unknown Tick yes if hypertension has been diagnosed previously.

Hypertensive medication: ☐ Yes ☐ No ☐ Unknown

Medications: ☐ Thiazide diuretics ☐ Beta blockers ☐ ACE inhibitors ☐ ARBs ☐ Calcium channel blockers ☐ Other

If other, enter medication name(s):

DIABETES

Diabetes: ☐ Yes ☐ No ☐ Unknown Tick yes if diabetes has been diagnosed previously.

Diabetic medication: ☐ Yes ☐ No ☐ Unknown

Medications: ☐ Biguanides ☐ Sulfonylureas ☐ TZDs ☐ Insulin therapy

☐ DPP-4 inhibitors ☐ GLP-1 receptor agonist ☐ SGLT-2 inhibitor ☐ Other

If other, enter medication name(s):

ANTITHROMBIC

Antithrombic medication: ☐ Yes ☐ No ☐ Unknown

Medications: ☐ Aspirin ☐ Other antiplatelets ☐ Warfarin ☐ Other anticoagulants

If other, enter medication name(s):

BIOCHEMISTRY PROFILE

Date	
TC	
LDL	
TG	
HDL	
Lp(a)	
Glucose	
HbA1c	
ApoB	
ApoA1	
AST	
ALT	
CK	
Alb	
Creat	
CRP	

CURRENT MEDICATION (Lipid lowering)

Name	Dose	Frequency	Commenced

Compliance: ☐ Full ☐ Irregular ☐ Non-compliant ☐ Intolerant ☐ N/A

Details if intolerant - Enter details into Medication Module – Drug intolerance:

DEATH

Date of death: Age at death (years):

Cause of death: ☐ CAD ☐ Cerebrovascular disease - ischemic ☐ Cerebrovascular disease - haemorrhagic
☐ Cardiac sudden death ☐ Heart failure ☐ Acute aortic syndrome ☐ Cancer ☐ Other

Specify other cause of death:

ADDITIONAL NOTES