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.

The National Registry

USER MANUAL



everyone deserves a better chance

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Need Help

Contact National Coordinator: Dr Jing Pang Phone: (08) 9224 0318 Email <u>fhwa@health.wa.gov.au</u>

Resources

- <u>The National Familial Hypercholesterolaemia Registry an introduction</u> (5:51 min video) (<u>https://www.youtube.com/watch?v=klkGys77fHw</u>)
 N.B. The user interface has been updated since this video was created, but it is still useful to demonstrate general concepts.
- <u>National FH Registry</u> (<u>https://fhregistry-international.com/</u>)
- <u>National FH Registry</u> Username/Password screen (<u>https://fhregistry-international.com/rdrf/login?next=/rdrf/router/</u>)
- <u>National FH Registry Charter, Protocol and Guidelines</u> (<u>http://www.athero.org.au/fh/wp-content/uploads/National-FH-Registry---Charter-Protocol-and-Guidelines.pdf</u>)
- <u>Registry Brochure</u> (<u>http://www.athero.org.au/fh/wp-content/uploads/FH-Registry-Brochure_v4.pdf</u>)
- <u>Sample Consent Form</u> (<u>http://www.athero.org.au/fh/wp-content/uploads/Sample-Consent-Form.pdf</u>)
- <u>Test site</u> (<u>https://rdrf.ccgapps.com.au/ophg/login?next=/ophg/router/)</u>
 - o 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:
 - <u>Dutch Lipid Clinic Network Score (DLCNS)</u> ≥ 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) > 0.5g/L with a DLCNS ≥ 3
- Child/adolescent INDEX with:
 - o Classification of highly probable FH
 - LDL-cholesterol > 5.0 mmol/L
 - Classification of **probable** FH
 - LDL-cholesterol > 4.0 mmol/L with a family history of premature heart disease
 - LDL-cholesterol > 4.0 mmol/L with hypercholesterolaemia or tendon xanthoma or arcus in the first-degree relative
 - o 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) > 0.5g/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 mmHg or
- Diastolic blood pressure > 90 mmHg

Hypertriglyceridaemia Criteria

Hypertriglyceridaemia is defined as:

- Triglyceride > 10 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/

National Familial Hypercholesterolaemia F	Registry		+] Registry
The Nation	Registry		
Purpos	e	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.	
Objecti	ves	To facilitate service planning by analyses and reporting of data collected by the Registry on prevalence, geographical distribution, genetic variants associated with disease, clinical features, clinical	
Click Registry			4 ⊾100% •
Rare Disease Registry Framework		\mathfrak{D} Log in $ \mathcal{C}$ Passwor	d Reset
	Welcome		
	Username:	1	
	Password:		
	Forgotten your passwo	ord? Log in	

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

- Enter your username and password
- Click Log in. The <u>Patient List</u> 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
 - o Lowercase letter
 - o Number
 - Special character (!, @, #, \$, %, ^, &, *).

Password Deactivation

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

You will need to email the <u>National Coodinator</u> to arrange reactivation.

Forgotten your Password?

Rare Disease Registry Framework		DLog in	${old C}$ Password Reset
	Welcome		
	Username:		
	Password:		
	Forgotten your password? Log in		

• If you have forgotten you password, click Forgotten your password?

Rare Disease Registry Framework	◆D Log in	${oldsymbol{\mathcal{C}}}$ 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

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.	I	Rare Disease Registry Framework	◆) Log in	${old c}$ 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.				
If you don't receive an email, please make sure you've entered the address you registered with, and check your spam folder.		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.				
		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



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

Rare Disease Registry Framework		◆) Log in	C 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 R	Registry Framework	DLog in	C Password Reset
Your password ha	as been set. You may go ahead and log in now.		
 Click Lo 	g in to take you to the <u>Log in</u> screen		

Rare Disease Registry Framework	🖺 Menu 🗸 💄 National Curator 🗸
Patient List	Apassword Reset

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:

- <u>Demographics</u> (Screen shot Demographics)
- Consents (Screen shot Consents)
- Family Linkage (Screen shot Family Linkage)
- <u>Clinical Data</u> (<u>Screen shot Clinical Data</u>)
- Genetic Data (Screen shot Genetic Data)
- Medications (Screen shot Medications)
- Imaging (Screen shot Imaging)
- Apheresis (Screen shot Apheresis)
- <u>Follow Up</u> (multiple forms) (<u>Screen shot Follow Up</u>)

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

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

	Rare Disease Registry F	Framework		🗏 Menu 👻 💄 National Curator 🗸
	Demographics ABBEY Anthea			Kave X Cancel
	Demographics	Family Linkage This patient is an index		
	Consents	Registry		
	Family Linkage	Rdrf registry 卷	FH Registry (fh)	
<	Main Clinical Data Genetic Data Medications	Centre 卷	fh Austin Health fh Royal Perth Hospital fh Royal Prince Alfred Hospital fh Flinders Medical Centre	
	Imaging Apheresis	Patients Personal Details		
	Follow Ups	Family name *	ABBEY	
	+ Add 10-8-2016 1-8-2016	Given names * Maiden name (if	Anthea	
		applicable)	ι	

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 •

C C C C C C C C C C C C C C C C C C C	ac	- 11	Contendent - A Conten		Constant Appy 1 - 2 Constant (1)	100 million (100 m	C International Contractor	
C their first	1970 Televisia		E Family Linkage		Conceptor Ferning	Karian	En Comographics A comographics	
	An and a second se		An orall and a constraint of a posterior and a constraint of a posterior and a constraint of a		Contraction of the second seco		And an	
R	elative 1 - Ima	aging	Family	Linkage	Index Dei	mographics	Index	- Imaging

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

Patient List			+ Add Patient
FH Registry V			County Innith
Patient	 Date of Birth 	Working Groups	Modules
SMITH, Anthony	1990-06-01	fh Royal Prince Alfred Hospital	Main 🗸
SMITH, Jane	2002-06-04	fh Royal Perth Hospital	Main 🗸
SMITH, Mary	1991-08-01	fh Royal Perth Hospital	Main 🗸
SMITH, Regina	1974-08-02	fh Royal Perth Hospital	Main Clinical Data
SMITH, Roger	1982-06-03	fh Royal Perth Hospital	 ✗ Genetic Data ✗ Medications ✓ Imaging
Showing 1 to 5 of 5 entries (filtered from 37 total	entries)		✓ Imaging ★ Apheresis

One ϕ r 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 <u>Follow Ups</u> and a dropdown menu will appear and you can click a specific follow up module

Rare Disease Registry Frame	ework		🚍 Menu 🗸 🔹 💄 National Curator 🗸
Patient List			+ Add Patient
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 Roxal 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 fro	om 38 total entries)		✓ 1-9-2016 ✓ 2-3-2014

Rare Disease Registry Framework	📑 Menu 🗸	👤 National Curator 👻
Demographics SMITH Roger	 FH Consents Patient List Other Clinicians Reports 	K Save X Cancel
Family Linkage Demographics	UsersDoctors	
Deinographics		

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 F	ramework		📰 Menu 🗸 🛛 👤 National Curator 🗸
Patient List Antional Curator (FH Curator	7)		
			Add Dationt
FH Registry V Show 10 V entries			Search:
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	✓ 0% Clinical Data
SMITH, John	1943-04-13	fh Royal Perth Hospital	X 0% Medications X 0% Genetic Data
Showing 1 to 3 of 3 entries			X 0% Imaging X 0% Apheresis X 0% Follow Up
upport Report a bug Version 1.1.8		Authorised by: Prof Matthew Bellgard; Director, CCG	Disclaimer & Copyright Notice © 2013-2016 Murdoch Universii Documentation Source Code Email RDR
			€,100% ◄

An Index can only be added on the Patient List page.

To add a new Index patient:

- Click + Add Patient
- A blank <u>Demographics page</u> 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:

- <u>Registry and Centre</u>
- Date Function
- Patient Address
- Add Patient Doctor
 - o Add Doctor's Details to the Database
 - o Add Patient Doctor
- Add a Relative
 - o <u>Enter a Relative in a Different Centre to the Index</u>
 - View Family Members in Different Centre
 - o Delete a Relative
 - o Delete an Index
- <u>Pedigree</u>
- Change an incorrectly entered Index patient to a Relative
- <u>Change the Index</u>

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 Framew	ork	🛢 Menu 🗸	L National Curator -
(Demographics			
	Rdrf registry *	FH Registry (fh)		K Save ★ Cancel

Demographics page BEFORE saving

• No name beside person icon

	Rare Disease Registry Framework 🗮 Menu - 👤 National Cura								
	Demograpi	nics	R Save Cancel						
	Demographics	Family Linkage This patient is an index							
٠	Consents Family Linkage	Registry Rdrf registry * (FH Registry (fh)	>						

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	🚍 Menu 🗸 💄 National Curator 🗸	
			R Save Cancel
	Demographics	Family Linkage This patient is a relative of index ABBEY Anthea (DOB May 1, 2000)))
<	Consents	Registry	
	Family Linkage	Rdrf registry * Fb Registry (fh)	

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 Regis	try Framework	🗏 Menu 🗸	L RPH Curator →
I Demographi ▲	ics		
Registry			🛱 Save
Rdrfr	eaistry * FH Registry (fh)		× Cancel
			> Next
	Centre * Th Royal Perth Hospital		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.

Hospital/Clinic ID										Next
	_									Previou
Date of birth 🖊	03-0)2-197	6					×	J	
	0	Fe	b	× 19	976	~	0			
Country of birth	Su	Мо	Tu	We	Th	Fr	Sa	~		
	1	2	3	4	5	6	7			
Ethnic origin	8	9	10	11	12	13	14	\checkmark		
Sev #	15	16	17	18	19	20	21			
JEA +	22	23	24	25	26	27	28			
Home phone	29									
Mobile phone										

Patient Address

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

			- Remove	
	Address type 🏶	Home		
	Address 卷			
	Suburb/Town 苯			
	State \star			
	Postcode *			
•	Country *	Australia		

Add Patient Doctor

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

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

Add Doctor's Details to the Database

Rare Disease Registry Framework	≣ Modules 🚽 🖹 Menu - 🎩 National Curator -
Patient Doctor	- FH Consents
	Patient List Other Clinicians
	= Reports
Doctor *	- Users R Save
	- Doctors
Type of Medical Professional	► Next
	< Previous
Click Monu	
- Click Destant in the drandown means	

Rare Disease Registry Framework	🚍 Menu 🗸	👤 National Curator 👻	
Doctors			
L National Curator (FH Curator)			
٩.		Sat + Add	
Click + Add button			

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

Posto	:ode:						
State Territ	/Province/ Western Australia ory:	■ ∨ ∕ + ¥					
Phon	e: 0894484433]				
Email	smc@westnet.com	m.au]				
Fax:]				
¥ De	elete		Sa	ave	Save and add another	Save and continue editing	
Support Report a bug	Version 1.6.7		Disclaimer & Copyright Notice © 2013-2016 Murdoch University RDRF Project Email RDRF			Authorised by: Prof. Matth Di	ew Bellgard; rector, CCG
•	Enter doctor Click Save ~	's details.	Required fields are bolded.				

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.

	Rare Disease Registry Framework		🗮 Menu 👻 🧘 National Curator 👻
	Demographics ABBEY Anthea		K Save X Cancel
	Patien	t Doctor	🗡 🕂 Ads
٢	Type	Doctor * of Medical Professional * Mark for deletion Relative	WATTS Gerald Francis (Cardiometabolic Medicine - RPH) WARWICK Susannah (Detry Aboriginal Health Service) WASUNC Clark Matthew (Souther Regional Medical Group) WATERS Crant William (Respiratory West) WATERS Tom (Mercy Medical Centre & Nurdoch Se 17) WATERS Tom (Mercy Medical Centre & 60 5(2) WATERS Mane (Lindsframe Medical Group) WATERS Oliver (Gastoenterolog) Unit - FH) WATERS Cony James (Whitfords Avenue Medical Group) WATENS Cory James (Other Medical Centre + Murdoch Se 26) WATSON Stephen (SI John of God Medical Centre - Murdoch Se 26) WATSON Stephen (SI John of God Medical Centre - Murdoch Se 26) WATSON Stephen (SI John of God Mouse - Neurosynery) WATSON Full Manne (Noth Steen Medical Centre - Murdoch Se 26) WATSON Patter (SI John of God Mouse - Neurosynery) WATSON Faller (SI John of God Mouse - Neurosynery)
		Family name * Given names * Date of birth * Sex *	WATSON Miches Anie (Edition Heudra Game) WATSON Miches Anie (Astaliand Madda Centre) WATST Mary (South Bank Central So-Kd) WATT Mary (PreH Medical Centre) WATT Robert (Patkon Grove Hedical Centre) WATT S Gerald France (Cardiometabolic Medicine - RPH) 00-08-1990 DD-MM-YYYY Male
Support Report a bug Vere	sion 1.6.7	Disclair	Autorised by: Porf Mattew Belgard; RORF Project Lisual RORF Director, CCG

- 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 Frame	ework	≅ Menu +	👤 National Curator 👻
	Demographics BEAN Anthony			Rave Cancel
		Patient Relative		+ Add
		Family name *	Bean	- Remove
		Given names 兼	Barry	
<		Date of birth 卷	10-11-1975 DD-MM-YYYY	>
		Sex *	Male	
		Relationship 兼	Sibling (1st degree)	
		Location *	Australia - WA	
		Living status 米	Living	
		Create Patient?		
•	Go to the Index's De	emographics p	age	
•	Scroll down to Patie	ent Relative fiel	d k record will appear	
•	Complete the relativ	ve's details. All	are required fields.	
•	Check Create Patier	nt? tick box	,	
•	Click Save and set o	f modules will l	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	~	
e	Location *	Australia - WA	•	>
Ť	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 <u>National Coodinator</u> to arrange the relative to be added to the existing Index at another Centre.

- Details of index
 - Family name
 - o Given names
 - o Date of birth
- Details of relative
 - Family name
 - o Given names
 - o Date of birth
 - o Sex
 - Relationship (to the index)
 - o 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 <u>Family Linkage</u> function.

For example:

Rare Disease Registry Framework			🚍 Menu 🗸 🛛 💄 National (Curator 🗸
Patient List			+ Add	Patient
FH Registry V				
Show 10 v entries			Search: bolt	×
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)		Previous 1	Next

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.

Rare Disease Re	gistry Framework		≅ Menu - 👤 RPH Curator -
Patient Lis	st		+ Add Patient
FH Registry V Show 10 V entries	5		Search: bolt ×
Patient	 Date of Birth 	Working Groups	♦ Modules ♦
BOLT, Anna	1971-09-05	fh Royal Perth Hospital	Main -

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 v Show 10 v entries			Search: bott
Patient	Date of Birth	Working Groups	Modules
BOLT, Betty	1942-02-09	fh Royal Prince Alfred Hospital	Main - Follow Ups -
Showing 1 to 1 of 1 entries (fi	iltered 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 Fra	mework				🖺 Menu 🕇	RPH Curator 🗸 🗠
🗏 Family Linkage						Save X Cancel
	Index Lookup Type	e name to find an	index. Drag and drop rows to rea	ssign		
	Lookup Index:		Load this index and family	Add looked u	p patient to family	
	Index Patient					
	Given Names		Family Name	Patient		
RPH patient	Anna		BOLT	Demographic	S	
	Relatives					
PDAH nationt	Given Names	Family Name	Relationship	~	Link	
READ Patient					7	

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 Fra	amework		■ Menu - L National Curator -	
Demographics GOLD Anne			R Save X Cancel	
	Patient Relative		+ Add	
	Family name 🗮	Gold		
	Given names 卷	Ben		
	Date of birth 🗮	03-04-2000		
<	Sex *	Male	V	>
	Relationship 🗮	Child (1st degree)		
	Location *	Australia - WA	\checkmark	
	Living status 🗮	Living	\checkmark	
	Create Patient?	Patient in registry		
	Mark for deletion	9 7		

Only relatives can be deleted directly. To delete an Index, the Index must be changed to a relative (see <u>Change the Index</u>).

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 Framew	vork		🖴 Menu 🗸 💄 National Curator 🗸
Patient List			+ Add Patient
FH Registry V Show 10 V entries			Search: gold ×
Patient	Date of Birth	Working Groups	\Rightarrow Modules \Rightarrow
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	1 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 (<u>Change the Index</u>) and then deleted (<u>Delete a Relative</u>).

To delete an Index with at least 1 relative:

- Use the <u>Change the Index</u> function (makes the Index a Relative)
- Use the <u>Delete a Relative</u> 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

Index Lookup Type name to find an index. Drag and drop rows to reassign Lookup Index: Patient: Arithory BROWN Demographics	👤 National Curator 👻	🗄 Menu 🗸 🔒 Nationa	=			stry Framework	Rare Disease Regi
Index Lookup Type name to find an index. Drag and drop rows to reassign It Save Lookup Index: Load this index and family Add looked up patient to family It Cancel Index Patient It Cancel It Cancel Given Names Family Name Patient It Cancel Anthony BROWN Demographics It Cancel						ages	E Family Link
Lockup Indec Loed this index and family Add looked up patient to family X Cancel Index Patient Given Names Family Name Patient Anthony BROWN Demographics	R Save	🛤 Save			and drop rows to reassign	ame to find an index. Drag a	Index Lookup Type na
Index Patient Given Names Family Name Patient Anthony BROWN Demographics	X Cancel	X Cance		nt to family	is index and family Add looked up pat	Load thi	ookup Index:
Given Names Family Name Patient Anthony BROWN Demographics							Index Patient
Anthony BROWN Demographics Relatives				Patient	Family Name		Given Names
Relatives				Demographics	BROWN		Anthony
Relatives							
							Relatives
Given Names Family Name Relationship Link			Link		Relationship	Family Name	Given Names
Ben BROWN Child (1st degree)			Demographics	~	Child (1st degree)	BROWN	Ben
Keith Brown Sibling (1st degree)			Demographics	~	Sibling (1st degree)	Brown	Keith
Martha BROWN Sibling (1st degree) V Demographics			Demographics	~	Sibling (1st degree)	BROWN	Martha
Anna BROWN Grandparent (2nd degree) V Demographics			Demographics	~	Grandparent (2nd degree)	BROWN	Anna

Family Linkage (screen shot - Family Linkage)

Rare Disease Registry Fra	amework 🗮 Menu 👻 🛓 National Cura	ator 👻
Demographics ABBEY bert	睹 Save 🛛 🗙 Car	icel
Demographics	Family Linkage This patient is a relative of index ABBEY Anthea (DOB May 1, 2000)	
Consents	Registry	
Family Linkage	Rdrf registry * FH Registry (th)	
Main	Centre * Th Austin Health	
Clinical Data Genetic Data	fn Royal Perth Hospital fn Royal Prince Alfred Hospital fn Flinders Medical Centre	
Modications		

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

Rare Disease Regi	Rare Disease Registry Framework E Menu - L National Curator -					
🗏 Family Link	ages					
Index Lookup Type na	ame to find an index. Drag	and drop rows to reassign				🛤 Save
Lookup Index:	Load t	his index and family Add looked up pati	ent to family			× Cancel
	•					
Index Patient						
Given Names		Family Name	Patient			
James		SMITH	Demographic	CS		
Relatives						
Given Names	Family Name	Relationship		Link		
Lisa	SMITH	Child (1st degree)	~	Demographics		
John	Smith	Grandparent (2nd degree)	~	Demographics		
						€ 100% -

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
- <u>Change the Index</u>

Change an incorrectly entered Index patient to a Relative

Rare Disease Registry Framework		🗏 Menu → 🛛 👤 National Curator →
Index Lookup Type name to find an index. D	rag and drop rows to reassign	
	d this index and family	
		Fi Save
Index Patient	$\langle \rangle$	
Given Names	Family Name Patient	
Anne	ABBOTT Demographics	
Relatives		
Given Names Eamily Name	Relationship	ink
Beth ABBOTT		Demographics
		€ 100% ▼

- 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 Lookup 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			🛢 Mei	nu - 👤 National Curator -
Family Linkages				
Index Lookup Type name to find an index. Drag	and drop rows to reassign			
Lookup Index: ABBOTT Cindy Load to	Add looked up patient to	family		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 <u>Patient Relative</u> field on Index's **Demographic** page and complete missing details on the added relative
- Click Save

Change the Index

Lookup Index:	Load	this index and family Add looked up pa	tient to family		
					🛱 Save
Index Patient					× Cancel
Given Names		Family Name	Patient		
Anne		ABBOTT	Demograph	lics	
Relatives					
Given Names	Family Name	Relationship		Link	
	ABBOTT	Child (1st degree)	Child (1st degree)		
Beth					

- 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 <u>Delete a Relative</u>.

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.

rtare Biocaco rtog					
Index Lookup Type n	ame to find an index. Drag	and drop rows to reassign			
Lookup Index:	Load t	his index and family Add looked	d up patient to family		R Save
Index Patient					× Cancel
Given Names		Family Name	Pa	tient	
Cindy		ABBOTT	De	mographics	
Relatives					
Given Names	Family Name	Relationship		Link	
Beth	ABBOTT	Child (1st degree)	J (1st degree) Demograph		
Anne	ABBOTT	Unknown	~	Demographics	
		\sim /			

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				📰 Menu + 🔹 💄 National Curator +	
	Main/Clinical Data ABBEY, Anthes				🕅 Sane 🛛 🛎 Cancel 🌰 Print	
		Plasma LDL-cholesterol for FH Score				
		Highest UNTREA TED LDL-cholesterol concentration, OR	10.0 mmol/L			
		TREATED LDL-cholesterol concentration	mmoi/L			
		Treatment (daily)				
		LDL-cholesterol adjusted for treatment	NaN mmol/L			
OR						
	Rare Disease Registry Framework				📰 Menu - 🔹 National Curator -	
	Main/Clinical Data ABBEY, Anthea				🗎 Save 🗶 Cancel 🌲 Print	
		Plasma LDL-cholesterol for FH Score				
		Highest UNTREATED LDL-cholesterol concentration, OR	mmol/L.			
		TREA TED LDL-cholesterol concentration	5.2 mmol/L.			
		Treatment (daily)	Atorvastatin 10mg/Ezetimibe 10mg			
		LDL-cholesterol adjusted for treatment	10.4 mmo//L	treatment	will be automatically calculate	ed

Click Save

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

Rare Disease Registry Framewo	prk	≅ Menu + 🔒 National Curator +	^ _
Main/Clinical Data ABBEY, Anthea		👫 Save 🗶 Cancel 🚔 Print	
(Biochemistry Profile	- Add	
	Date	D-MM-YYYY	
	Total cholesterol concentration	mmol.	- 1
	LDL-cholesterol concentration		
	Triglyceride concentration		
	HDL-cholesterol concentration		
	Apolipoprotein B	mmolt.	
	Apolipoprotein A1	gt.	
	Lp(a) concentration	gt	_
Support Report a bug Version 1.7.9	Discla	Isimer & Copyright Notice @ 2013-2016 Murdoch University Authorised by: Prof. Matt	thew Bellgard;

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

Rare Disease Registry Framewo	ork	🕾 Menu + 🔹 National Curator +
Main/Clinical Data ABBEY, Anthea		M Save X Cancel A Print
Clinical Data Genetic Data Medications Imaging Aphrensis	Summary Dutch Lipid Clinic Network Score (Phenotypic) PH Diagnostic Category Definite	

Depending on the type/age of the patient (see <u>Adult Index</u>, <u>Child/adolescent Index</u> or <u>Relative</u>) 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**.

Main	Index or relative	
Clinical Data Genetic Data	Summary	
Medications Imaging Apheresis	Dutch Lipid Clinic Network Score (Phenotypic) FH Diagnostic Category	
Follow Ups		

Child/adolescent Index

	Family Linkage	Index or relative
	Main	
	Clinical Data	Summary
•	Genetic Data	
•	Medications	Network Score
	Imaging	(Phenotypic)
	Apheresis	FH Diagnostic Category
	Fallow Line	

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

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	 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	Index or relative	
	Main		
	Clinical Data	Summary	
	Genetic Data	Duteh Linid Clinic	
	Medications	Network Score	
	Imaging	(Phenotypic)	
	Apheresis	FH Diagnostic Likely Category	
	Follow Ups		

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	42	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	42	4.2	4.2	42	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

	Rare Disease Registry Framewo	rk	2	Menu 🗸 🛛 👤 National Curator 🚽	
	Demographics BOLT Anna			R Save Cancel	
	Demographics	Family Linkage This patient is an index			
	Consents	Registry			
<	Family Linkage	Rdrf registry 🏶	FH Registry (ħ)	-	
	Main Clinical Data Genetic Data Medications Imaging	Centre 🏶	In Austin Heath In Royal Petric Hospital In Royal Prince Afred Hospital In Finders Medical Centre	v 	>
	Apheresis	Patients Personal Details			
	Follow Ups + Add	Family name * Given names *	BOLT		
Support Report a bug Versio	n 16.9	Disclaime	r & Copyright Holic e @ 2013-2016 Mardoch University RDRF Proget I Email RDRF	Authorised	by: Prof. Matthew Bellgard; Director, CCG

Click +Add button

	Rare Disease Registry Framewo	vrk	프 Menu - 🧘 National Curator -	·
	E Follow Up		M Save X Cancel	
		At follow-up		
	Demographics	Date of assessment *		
	Consents		DD-MM-YYYY	
	Family Linkage	Is the patient currently smoking?	♥ Yes ♥ No ♥ Unknown	
		Systolic Blood Pressure		
	Main	Diastolic Blood Pressure		
	Clinical Data Genetic Data Medications	Has the patient developed chronic kidney disease?	Ses So So Unknown Please lick Yes if chronic kidney disease has already been diagnosed previously	
	Imaging Apheresis	Observed weight status	Underweight Sealthy weight Overweight Obese	
		Height	Heinht in matrice	
	Follow Ups + Add	Weight	Weintrin kilonrams	
Support Report a bug Vers	ion 1.6.9	Disclaim	er & Copyright Notice @ 2013-2016 Murdoch University Authorised RDRF Project Email RDRF	by: Prof. Matthew Belgard; Director, CCG

Blank **Follow Up** page will appear:

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

	Rare Disease Registry Frame	work ≅ Menu - L National Curat	or ▼
	Follow Up/5-5-2015	🖬 Save 🛛 🗶 Pri	nt
	Demographics	At follow-up Date of assessment	
	Consents Family Linkage	Is the patient currently • Yes • No • Unknown smoking?	
<	Main	Systolic Blood Pressure Plastolic Blood Pressure	
	Clinical Data Genetic Data Medications	Has the patient developed chrohic kidney disease? Please lick Yes if chronic kidney disease has already been diagnosed previously	
	Apheresis	Observed weight status Underweight Healthy weight Overweight Obese	
	Follow Ups + Add	Weight Weight in kilograms	
Support Report a bug Ver	rsion 1.6.9	Nisc laimer & Copyright Notice @ 2013-2016 Mundoch University Author RDRF Project Email RDRF	rised by: Prof. Matthew Bellgard; Director, CCG

Date appears in left hand menu bar and header

	Rare Disease Registry Framework			📰 Menu+ 🔹 National Curator +	
	E Follow Up/6-6-2016			Mi Save 🗶 Cancel 🌧 Print	
		Patient Anna BOLT saved successfully			
	Temperathic	At follow-up			
	Consets	Date of assessment 🌞	6-62016 00-MM-YYYY		
	Consens	is the patient currently smoking?	○ Yes ○ No ○ Unknown		
	Family Linkage	Systolic Blood Pressure			
<	Main	Diastolic Blood Pressure			>
	Clinical Data Genetic Data Medications	Has the patient developed chronic kidney disease?	○ Yes ○ No ○ Unknown Please tick Yes if chronic kidney disease has already been diagnosed previously		·
	Imaging Apheresis	Observed weight status	○ Underweight ○ Healthy weight ○ Overweight ○ Obese		
		Height	Height in metres		
	Follow Ups + Add 5-5-2015 6-6-2016	Weight	Weight in Allograms		
		BMI	NaN kgm2		

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	0 Modules 0
BOLT, Anna	05-09-1971	th Royal Perth Hospital	Main + Fotion 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)

Patient List					Add Patient
FH Registry V Show 10 V entries			Sea	Irch:	
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 -	1
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

Screen Shot – Demographics (enlarge to view)

Demographics		
L		
Registry		
Registry		
Rdrf registry 🏶	FH Registry (fh)	Save
		r+ Save
		× Cancel
Centre 卷	fh Royal Perth Hospital	> Next
		Previous
Patients Personal Details		
Eamily name #		
r anny fiame 🕷		
Given names 🏶		
Maiden name (if applicable)		
,		
Hospital/Clinic ID		
Date of birth *		
	DD-MM-YYYY	
Country of birth	<u>M</u>	
Ethnic origin	\	
Cox #		
Sex 🔹		
Home phone		
Mobile phone		
Work phone		
Email		
Living status 👋		
Living status 🖷	Living	
Patient Address	+ Add	
	- Remove	
Address type 🗮	Home	
		
Address 🗮		
Suburb/Town 🏶		
State 🌟	V	
Postcode *		
. 5310042 🛧		
Country 🗮		

Patent Doctor Doctor + Type of Medical Professiona - Patent Relative Patent Patent Relative Patent Patent Relative		
	Patient Doctor	+ Add
Doctor • Type of Medical Professional Patient Relative		- Remove
Dector •		
Type of Medical Professional Patient Relative Patient Relative Family name • Given names • Given names • Date of birth • Date of birth • Date of birth • Date of birth • Counder offect origin Create Patient? Founder effect origin Number of 1st degree relatives Number of 1st degree Number of 2nd degree Upload family pedigree Upload family pedigree Externe & Counset • Co	Doctor *	¥
Patient Relative Family name • Given names • Date of birth • Date of birth • Do MMYYYY Set • Keiationship • Location • Location • Location • Create Patient? Pedigree Founder effect origin • Number of 2nd degree relatives Number of 2nd degree Iupioad family pedigree Lipioad family pedigree	Type of Medical Professional	- V
Patient Relative Family name • Given names • Date of birth • Date of birth • Dotationship • Relationship • Location • Living status • Create Patient? Pedigree Founder effect origin	-	
Patient Relative Family name • Given names • Given names • Date of birth • Date of birth • Dot of birth • Dot of birth • Dot of birth • Counter • V Sex • Image: Create Patient? Pedigree Founder effect origin Image: Create Patient? Number of 3rd degree Indiane of 3rd degree		
Patient Relative Teamore Family name * Given names * Date of birth * Create Patient? Pedigree Pedigree Founder effect origin 		
Etense Fanily name 4 Given names 4 Given 1 Set of birth 4 Set of birth	Patient Relative	+ Add
Family name * Given names * Date of birth * Date of birth * Date of birth * Date of birth * Cease * Location * Location * Create Patient?		- Remove
Family name * Given names * Date of birth * DOMM-YYYY Sex * Relationship * Location * Location * Living status * Create Patient? Founder effect origin Number of 1st degree relatives Number of 1st degree relatives Number of 1st degree relatives Number of 3rd degree relatives Dupload family pedigree Tetatives Dupload family pedigree Browse		
Given names + Given names + Date of birth + DOMM-YYYY Sex + Relationship + Location + Location + Location + Create Patient? Pedigree Founder effect origin Number of 1st degree relatives Number of 1st degree relatives Number of 1st degree relatives Number of 1st degree relatives Number of 1st degree relatives Mumber of 1st degree relatives Dupload family pedigree Tetatives Dupload family pedigree Dupload family pedigr	Family name 🗮	
Date of birth * Do-MM-YYYY Sex * Image: Constraint of the second of the	Given names 🗯	
Do-MM-YYYY Sex * Relationship * Location * Location * Location * Create Patient?	Date of birth *	
Sex * Relationship * Relationship * Location * Location * Location * Location * Interpreted and the second a		DD-MM-YYYY
Relationship * Location * Living status * Create Patient?	Sex 🗮	V
Location *	Relationship 🗮	V
Location • · · · · · · · · · · · · · · · · · ·		
Living status * Create Patient? Pedigree Founder effect origin Number of 1st degree relatives Number of 2nd degree relatives Number of 2nd degree relatives Number of 3rd degree relatives Lupload family pedigree Browse	Location 蒂	
Create Patient? □ Pedigree	Living status 🗮	V
Pedigree Founder effect origin	Create Patient?	
Pedigree Founder effect origin Number of 1st degree relatives Number of 2nd degree relatives Number of 3rd degree relatives Upload family pedigree tt a bug Version 16.7 Disclamer & Copyright Notice @ 2013-2016 Murdoch University RDRF Project Email RDRF		
Pedigree Founder effect origin Number of 1st degree relatives Number of 2nd degree relatives Number of 3rd degree relatives Upload family pedigree Browse te bug Version 16.7 Disclaimer & Copyright Notice @ 2013-2016 Murdoch University RDRF Project Email RDRF		
Pedigree Founder effect origin		
Founder effect origin Number of 1st degree relatives Number of 2nd degree relatives Number of 2nd degree relatives Upload family pedigree Upload family pedigree Browse	Pedigree	
Number of 1st degree relatives	Founder effect origin	
Number of 2nd degree relatives Image: Comparison of the second	Number of 1st degree relatives	
Number of 3rd degree relatives Upload family pedigree Disclaimer & Copyright Notice © 2013-2016 Murdoch University RDRF Project Email RDRF	Number of 2nd degree	
Number of 3rd degree relatives Upload family pedigree Browse Browse Disclaimer & Copyright Notice © 2013-2016 Murdoch University RDRF Project [Email RDRF	relatives	
Upload family pedigree Browse Disclaimer & Copyright Notice @ 2013-2016 Murdoch University RDRF Project Email RDRF	Number of 3rd degree	
Disclaimer & Copyright Notice @ 2013-2016 Murdoch University RDRF Project Email RDRF	Telauves	
rt a bug Version 1.6.7 Disclaimer & Copyright Notice @ 2013-2016 Murdoch University RDRF Project Email RDRF	upioad family pedigree	Browse
	rt a bug Version 1.6.7	Disclaimer & Copyright Notice © 2013-2016 Murdoch University BDRF Project L Email RDRF
		· · · · · · · · · · · · · · · · · · ·

Screen Shot – Family Linkage (enlarge to view)

Rare Disease Registry Fra	mework				📰 Menu	✓ L RPH Curator ✓
🔳 Family Linkage						Save X Cancel
	Index Lookup Typ	e name to find an	n index. Drag and drop rows to reas	ssign Add looked up	o patient to family	
	Index Patient					
	Given Names Family Name Patient Anthony SMITH Demograph			Patient Demographics	\$	
	Relatives					
	Given Names	Family Name	Relationship		Link	
	Belinda	Smin	Crilia (1st degree)	~	Demographics	
Support Report a bug Version 1.6.7		Disclaimer & Cop	yright Notice © 2013-2016 Murdoch Univer RDRF Project Email RDRF	sity		Authorised by: Prof. Matthew Beilgard; Director, CCG \$ 100% -

Screen Shot – Consents (enlarge to view)

En Consents A startH, Anthony FH Registry Consent Consents Family Linkage Main Clinical Data Clinical Data Consent given to be contacted about clinical trials or other studies. FH Optional Consents	
Demographics FH Registry Consent Consents Adult consent Consents Consent given to be part of the registry and have data retained and shared in accordance with the information provided to them. Main FH Optional Consents Clinical Data Clinical trials Genetic Data Consent given to be contacted about clinical trials or other studies.	
Adult consent Consents Family Linkage Main Clinical Data Genetic Data Clinical trials Consent given to be contacted about clinical trials or other studies.	
Consents Consents 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 Data Genetic Data Clinical trials Consent given to be contacted about clinical trials or other studies.	
Main FH Optional Consents Clinical Data Clinical trials Genetic Data Clinical trials Consent given to be contacted about clinical trials or other studies.	20
Clinical Data Genetic Data Clinical trials Consent given to be contacted about clinical trials or other studies.	
Modications	
Imaging Information Apheresis Consent given to be sent information.	
Follow Ups FH Registry Subset	
FCHL Familial Combined Hyperlipidaemia	
Hyper-Lp(a) Familial Elevation of Lipoprotein(a)	
Upload consent file (if requested)	+ Add
I Report a bug Version 1.6.7 Disclaimer & Copyright Notice © 2013-2016 Murdoch University RORF Project Email RORF	

Screen Shot – Clinical Data (enlarge to view)

Rate Disease Registry F	Tamework		Smenu + A RPH Curator +
Main/Clinical D	ata		🛱 Save 🗶 Cancel 🚔 Print
SMITH, Anthony			
Demographics	Consent date		
		DD-MM-YYYY	
Consents	Date of assessment *		
Family Linkago		DD-MM-YYYY	
Tanny Linkage	Index or relative	index	
Main	index of relative		
Clinical Data	0		
Genetic Data	summary		
Medications	Dutch Lipid Clinic Network Score		
Apheresis	(Phenotypic)		
	FH Diagnostic Category		
Follow Ups			
	Family History		
	Family biotest of		
	hypercholesterolaemia	>95th percentile for age and gender	
	(first-degree adult relative) *	* 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-	 Men <55, Women <60 years of age	
	degree relative) *	* This field is required.	
	Family history of		
	tendon xanthoma (first-degree relative) *	* This field is required.	
	Family history of		
	to 45 years of age (first-	* This field is required.	
	degree relative) 🛧		
	Oliniaal Ulintary		
	Clinical History		
	Personal history of premature coronary	 Men <55 Women <60 years of are	▼
	heart disease 卷	* This field is required.	
	Myocardial infarction	○ Yes ○ No ○ Unknown	
	Age at first MI		
		years	
	Coronary		
	revascularisation		

premature cerebral or	
peripheral vascular	men so, women < ou years or age
disease 🗮	* This field is required.
Aortic valve disease	○ Yes ○ No ○ Unknown
Supravalvular disease	○ Yes ○ No ○ Unknown
Premature non-	○ Yes ○ No ○ Unknown
coronary vascular	
disease	
Physical Examination	
Tendon xanthoma ቾ	- •
	* This field is required.
Arcus cornealis prior	
to age 45 years 兼	* This field is required.
Xanthelasma	○ Yes ○ No ○ Unknown
Plasma LDL-cholesterol for F	TH Score
Highest UNTREATED	
LDL-cholesterol	mmol/L
concentration, OR	
TREATED LDL-	
cholesterol concentration	mmol/L
Treatment (daily)	
(ually)	
LDL-cholesterol	NaN
adjusted for treatment	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	mmol/L.
Apolipoprotein B	mmoVL
Apolipoprotein B Apolipoprotein A1	mmol/L.
Apolipoprotein B Apolipoprotein A1	mmol/.

Lp(a) concentration		
	g/L	
Aspartate transaminase		
(AST)	UL.	
(ALT)		
Creatine kinase (CK)		
Albumin		
	g/L	
Creatinine		
	umol/L_	
C-reactive protein (CRP)		
	mg/L	
Treatment (daily)		
freathent (daily)		•
If other, enter medication		
name(s), dose(s) and		
regime		
Compliance		~
	If intolerant, please enter details into Medication Module - Drug Intolerance	
Mark for deletion		
Smoking	○ Yes ○ Never ○ Ex-smoker	
Indicate pack years		
smoked	Pack years = (number of cigarettes smoked per day/20) x number of years smoked	
A1		
Alconol		
Hypertriglyceridaemia	○ Yes ○ No ○ Unknown	
Unertension		
Hypertension	If ves and on hypertensive medication, please complete the Medication Module	
Systolic Blood		
Fressure		
Diastolic Blood		
11033010		
Heart rate		
neartrate	bpm	
Diabetes		~
Diabetes	 If yes and on diabetic medication, please complete the Medication Module	•
Diabetes Blood glucose	If yes and on diabetic medication, please complete the Medication Module	
Diabetes Blood glucose concentration	If yes and on diabetic medication, please complete the Medication Module mmol/L.	
Diabetes Blood glucose concentration	If yes and on diabetic medication, please complete the Medication Module mmo//L	
Diabetes Blood glucose concentration HbA1c	If yes and on diabetic medication, please complete the Medication Module mmol/L.	
Diabetes Blood glucose concentration HbA1c	If yes and on diabetic medication, please complete the Medication Module mmol/L. (%)	
Diabetes Blood glucose concentration HbA1c		
Diabetes Blood glucose concentration HbA1c Chronic kidney disease	If yes and on diabetic medication, please complete the Medication Module	
Diabetes Blood glucose concentration HbA1c Chronic kidney disease	If yes and on diabetic medication, please complete the Medication Module mmol/L (%) Yes O No O Unknown	
Diabetes Blood glucose concentration HbA1c Chronic kidney disease eGFR	If yes and on diabetic medication, please complete the Medication Module mmol/L (%) Yes O No O Unknown mi/min/1.73m2	
Diabetes Blood glucose concentration HbA1c Chronic kidney disease eGFR	If yes and on diabetic medication, please complete the Medication Module mmol/L. (%) Yes O No O Unknown m/min/1.73m2	

TSH	
	mU/L
Hepatic steatosis	○ Yes ○ No ○ Unknown
Observed weight status	\bigcirc Underweight \bigcirc Healthy weight \bigcirc Overweight \bigcirc Obese
Height	
-	Height in metres
Weight	Weight in kilograms
	weight in Kilografits
BMI	NaN
	kg/m2
Waist circumference	
	cm
Please list any other significant medical	
conditions	
Clinical Trials	_
Cinical mais	Add 🛨
Cinical mais	+ Add
Trial name	+ Add
Trial name Expect length	
Trial name Expect length	+ Add
Trial name Expect length Start date	+ Add
Trial name Expect length Start date	+ Add
Trial name Expect length Start date Trial status	
Trial name Expect length Start date Trial status	
Trial name Expect length Start date Trial status Mark for deletion	
Trial name Expect length Start date Trial status Mark for deletion	Add
Trial name Expect length Start date Trial status Mark for deletion	

Screen Shot – Genetic Data (enlarge to view)

Rare Disease Registry F	ramework	Benu → L RPH Curator →
Imain/Genetic D	ata	Restance Save X Cancel Print
	Genetic Analysis	
Demographics Consents	Has the patient had a DNA test? *	 ○ Yes ○ No - service not available ○ No - not consented ○ No - not offered * This field is required.
Family Linkage	Genetic Analysis	
Main	Genetic test date	DD-MM-YYYY
Clinical Data Genetic Data Medications	Genotype	• No variant identified • Heterozygous • Compound Heterozygous • Homozygous If "Compound Heterozygous" selected, enter two mutations below, otherwise only enter one.
Apheresis	Gene Variant	+ Add
Follow Ups	Gene variant	○ LDLR ○ APOB ○ PCSK9 ○ Other
+ Add	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	
ug Version 1.6.7	Disclaimer	Copyright Notice © 2013-2016 Murdoch University RORF Protect Email RORF

Screen Shot – Medications (enlarge to view)

Rare Disease Registry Framework	■ Menu + L RPH Curator +
Main/Medications SMITH, Anthony	🛱 Save 🗶 Cancel 🚔 Print
Linid-Jowering Medication	
Is the patient on lip lowering medicatio	ld- ○Yes ○No ○Unknown n?
Treatment (dai	V) V
lf other, en	ter
medication name(dose(s) and regin	s), ne
Date of starti	ng
medicati	DD-MM-YYYY
Hypertensive Medication	
Is the patient hypertensi medicatio	on O Yes O No O Unknown ve n?
Medication	(s) Thiazide diuretics
	Beta blockers
	Calcium channel blockers
	□ Other
If other, en medication name	ter (s)
Diabetic Medication	
Is the patient diabetic medicatio	on OYes ONo OUnknown n?
Medication	(s) 🗌 Biguanides
	Sulfonylureas
	ITZDs Insulin therapy
	DPP-4 inhibitors
	GLP-1 receptor agonist
	SGLT-2 inhibitor Other
If other, en	
medication name	(2)

Antithrombotic Medication	
is the patient on	○ Yes ○ No ○ Unknown
antithrombotic medication?	
Mediastics(a)	
medication(s)	☐ 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	
regime	
How long was the patient	
intolerance was observed?	Enter a number or 'Several'
Time frame	V
	Select a time frame
Specify type of muscle	Fatigue
	Muscle years
	Muscle tenderness Gramps
	CK elevation
	Myalgia, tolerable Myalgia intolerable
	☐ Myopathy
	Severe myopathy Rhabdomvolvsis
	Necrotizing myositis
Specify type of hepatic intolerance	Hepatotoxicity Increased activity of liver enzymes
Specify type of gastrointestinal tract	Constipation Diarrhoea
intolerance	Dyspepsia
	□ Flatulence
	□ Nausea
	└ Vomiting
Specify type of neurologic	Aggressive behaviour
intolerance	 Headache Asthenia
	 □ Fatigue □ Severe irritability
	 Insomnia
	□ Somnolence

		Agitation	
		☐ Nightmares	
		_ memory road	
		Inner respiratory tract infection	
	Specify type of		
	respiratory intolerance		
		□ Rhinitis	
	Specify type of endocrine	☐ New onset diabetes	
	intolerance		
	Specify type of skin	Rash	
	intolerance		
	Specify type of eye	□ Cataract	
	intolerance	Diplopia, ptosis and ophthalmoplegia	
	Specify type of repair	Acute renal failure	
	intolerance	Proteinuria	
		Erectile dysfunction	
	Specify type of		
	reproductive intolerance	Decrease libido	
		☐ Gynecomastia	
		Reduced testosterone levels	
	Specify type of bones and	Tendinitis	
	joints intolerance	Arthralgia	
		Arthritis	
	If other enter type of		
	intolerance/s		
	Additional comments		
	Mark for deletion		
	Disclaimer &	Copyright Notice © 2013-2016 Murdoch University Authorised hv: Pr	of. Matthew Bellgard:
port a bug Version 1.6.7		RDRF Project Email RDRF	Director, CCGV

Screen Shot – Imaging (enlarge to view)

Main/Imaging Carcial Ultrasongraphy Result (right) Mark for deleton Data Carcial Artery Calclum Score Carcial Artery Calclum Score Carcial Carcial Calcian Score Carcial Calcian Score Carcial Artery Calclum Score Carcial Calcian Score Carcial		■ Menu - 👤 RPH Curator -
LastATY, Annoy Corrographis Result (left) Apheresis Polion Ups Result Corrographis Result Result Result Result Corrographis Result Result Result Result Corrographis Result Corrographis Result Result <th>Main/Imaging</th> <th>🛱 Save 🗮 Cancel 🚔 Print</th>	Main/Imaging	🛱 Save 🗮 Cancel 🚔 Print
Carolid Ultrasonography Carolid Ultrasonography ○ Yes - Normail ○ Yes - Abnormail ○ No ○ Unknown Consents Date DotAll YYYY Fanity Linkage Result (ent) Mari m Main Result (ent) Mari m Concertions Result (ent) Mari m Genetic Data Result (ent) Mari m Matin Result (right) Mari m Medications Result Ebocardiogram (Resting) Follow Ups Result Ebocardiogram (Resting) Echocardiogram (Resting) ○ Yes - Normail ○ Yes - Abnormail ○ No ○ Unknown Date Date Date Coronary Artery Calcium Score Contary Yrr Result (corn) Ebocardiogram (Resting) ○ Yes - Normail ○ Yes - Abnormail ○ No ○ Unknown Data Data Data Data Coronary Artery Calcium Score Ext Ext Coronary Artery Calcium Score Ext Ext Data Data Data Data Data Data Data Data Data Data Data Data Data Data	VITH, Anthony	
Cancid Ultrasonography		
Consents Carotis Ultrasonograph ○ Yes - Normal ○ Yes - Abnormal ○ No ○ Unknown Consents Date Date Date Date Date Christ Data Result (right) Main Result (right) Christ Data Result Mark for deletion Itrame Follow Upset Report Echocardiogram (Resing) Ext Echocardiogram (Resing) Ext Echocardiogram (Resing) Ext Echocardiogram (Resing) Ext Coronary Artery Calclum Score Ext Mark for deletion Itrame	Carotid Ultrasonography	+ Add
Consents Date Family Linkage Result (ieth) Main Result (ieth) Main Result (ieth) Marine Marine Christ Data Result Context Data Result Medicators Marine Maging Report Entocardiogram (Resting) Yes - Normal O Yes - Abnormal O No O Unknown Date Date Entocardiogram (Resting) Yes - Normal O Yes - Abnormal O No O Unknown Mark for deletion Date Mark for deletion Booxee	Carotid Ultrasonography	\odot Yes - Normal \odot Yes - Abnormal \odot No \odot Unknown
Family Linkage Result (ieth) Main Result (ieth) Main Result (ieth) Main Result (ieth) Mark atons Mark me Modelatons Mark me Mark for deletion Bouse Echocardiogram (Resting) Yes - Normal O Yes - Abnormal O No O Unknown Date Date Date Date Mark for deletion Bouse Mark for deletion Bouse Mark for deletion Coronary Artery Calcium Score Mark for deletion Coronary Artery Calcium Score Mark for deletion Coronary Artery Calcium Score Date Date	Consents Date	
Family Linkage Result (int) Main Result (int) Clinkal Data Result (int) Clinkal Data Result Main Result Main Clinkal Data Boose. Main Clinkal Data Personal O Yes - Abnormal O No O Unknown Data Dote Dote Dote Data Coronary Attery Calclum Score Data Dote Data<		DD-MM-YYYY
Main Result (right) Cincuit Data Result Medications Result Main for deletion Boxse Polov Ups Report Mark for deletion Over - Abnormal O No O Unknown Date Dommy YYYY Result Coronary Aftery Calclum Score Coronary Aftery Calclum Score Coronary aftery calclum score Coronary Aftery Calclum Score Coronary aftery calclum score Coronary Aftery Calclum Score Coronary Aftery Calclum Score	Family Linkage Result (left)	
Anim Cincal Data Genet: Cota Medications maging Apheresis Fellow Ubs Report Browsee Mark for deletion Echocardiogram (festing) Echocardiogram (resting) O'Yes - Normal O'Yes - Abnormal O No O Unknown Date Dotato Yrry Result Coronary Artery Calclum Score Coronary artery calclum Score Date Date Dotato Yrry Result Coronary artery calclum Score Date <	Pasult (right)	
Cincia Data Genetic Data Medications Imaging Apheresis Follow Ups Report Browse. Mark for deletion Echocardiogram (Resting) Echocardiogram (Resting) Cenocardiogram (resting) Ces. Normal O Yes - Abnormal O No O Unknown Date DAMA YYYY Result Report Coronary Artery Calcium Score Coronary Artery	Main Result (fight)	IMT mm
Corenary Artery Calcium Score Coronary Artery Calcium Score Coronary Artery Calcium Score Date Doutley YYYY Result Coronary Artery Calcium Score Doutley YYYY Result (score)	Clinical Data Result	
Imaging Report	Medications	
Apheresis Follow Ups Report Mark for deletion	Imaging	
Follow Ups Mark for deletion Mark for deletion Echocardiogram (Resting) Ves - Normal O Yes - Abnormal O No O Unknown Date DDMM-YYYY Result Mark for deletion Mark for deletion Coronary Artery Calcium Score Coronary artery calcium score DDMM-YYYY Result (score)	Apheresis	
Report Mark for deletion Echocardiogram (Resting) Echocardiogram (Resting) Coronary Artery Calclum Score Mark for deletion Coronary artery calclum score Date Dotate	Eollow Line	
Mark for deletion Echocardiogram (Resting) Echocardiogram (resting) Date Date Do MM- YYYY Report Mark for deletion Mark for deletion Coronary Artery Calcium Score Coronary artery calcium score Date Date Date Date Coronary Artery Calcium Score Ceronary artery calcium score Resut (score)	+ Add Report	Browse
Echocardiogram (Resting) Echocardiogram (resting) Date Date DoML-YYYY Result Mark for deletion Coronary Artery Calcium Score Coronary artery calcium score Date Date Date Date Browse	Mark for deletion	
Echocardiogram (Resting) Yes - Normal O Yes - Abnormal O No O Unknown Date		
Echocardiogram (resting) Yes - Normal O Yes - Abnormal O No O Unknown Date		
Echocardiogram (resting) O Tes - Abhormal O No O Unknown Date DD-MM-YYYY Result Report Report Mark for deletion Coronary Artery Calcium Score Date DD-MM-YYYY Result (score) Coronary artery calcium C	Echocardiogram (Resung)	
Date DD-MM-YYYY Result Report Report Mark for deletion Coronary Artery Calcium Score Coronary artery calcium score Date DD-MM-YYYY Result (score)	Echocardiogram (resting)	
Result Report Mark for deletion Coronary Artery Calcium Score Coronary artery calcium score Date Date Date Date	Date	DD-MM-YYYY
Report Browse Mark for deletion	Result	
Report Browse Mark for deletion Image: Coronary Artery Calcium Score Coronary artery calcium score Image: Coronary artery calcium score Date Do-MME YYYY Result (score) Image: Coronary score s		
Report Browse Mark for deletion Browse Mark for deletion Image: Coronary Artery Calcium Score Image: Coronary artery calcium Score Coronary artery calcium score Image: Coronary artery calcium Score Image: Coronary artery calcium Score Date Image: DD-MM-YYYY Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Date Image: DD-MM-YYYY Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Date Image: DD-MM-YYYY Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Date Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Date Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Image: Coronary Artery Calcium Score Date Image: Coronary Artery Calcium Score Date Image: Coronary Artery Calcium Score Date Image: Coronary Artery Calcium Score Image: Coron		
Report Browse Mark for deletion		
Report Browse Mark for deletion Image: Coronary Artery Calcium Score Coronary Artery Calcium Score Image: Coronary artery calcium Score Date Image: Coronary Artery Calcium Score		
Mark for deletion		
Coronary Artery Calcium Score Coronary artery calcium score Date Dot Result (score)	Report	Browse
Coronary Artery Calcium Score	Report Mark for deletion	Browse
Coronary artery calcium score Date DD-MM-YYYY Result (score)	Report Mark for deletion	Browse
Date DD-MM-YYYY Result (score)	Report Mark for deletion	Browse
Date DD-MM-YYYY Result (score)	Report Mark for deletion Coronary Artery Calcium Sc Coronary artery calcium	ore + Add
Result (score)	Report Mark for deletion Coronary Artery Calcium Sc Coronary artery calcium score	ore
	Report Mark for deletion Coronary Artery Calcium Sc Coronary artery calcium score Date	ore + Add
	Report Mark for deletion Coronary Artery Calcium Sc Coronary artery calcium score Date	
Result (percentile)	Report Mark for deletion Coronary Artery Calcium Sc Coronary artery calcium score Date Result (score)	Image: Control of the second secon
Report Browse	Report Mark for deletion Coronary Artery Calcium Sc Coronary artery calcium score Date Result (score) Result (percentile)	Image: Image
Mark for deletion	Report Mark for deletion Coronary Artery Calcium Score Date Result (score) Result (percentile) Report	□ Browse □ □

CT Coronany Angiogram	
or coronary Anglogram	+ Add
CT coronary angiogram	\bigcirc Yes - Normal \bigcirc Yes - Abnormal \bigcirc No \bigcirc Unknown
Date	
Result	DD-MM-YYYY
Result	
Report	Browse
Mark for deletion	
Invasive Angiogram	+ Add
Invasive angiogram	○ Yes - Normal ○ Yes - Abnormal ○ No ○ Unknown
Date	
Result	
Report	Browse
Report Mark for deletion	Browse
Report Mark for deletion	Browse
Report Mark for deletion	Browse
Report Mark for deletion Stress Echo	Browse Browse
Report Mark for deletion Stress Echo Stress echo Date	Browse
Report Mark for deletion Stress Echo Stress echo Date	Browse
Report Mark for deletion Stress Echo Stress echo Date Result	Browse Browse Browse
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Report Mark for deletion Stress Echo Stress echo Date Result	Browse □ ▲ Add ○ Yes - Normal ○ Yes - Abnormal ○ No ○ Unknown □ □ □
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Report Mark for deletion Stress Echo Date Result Result Report	Browse Browse Browse Browse Browse Browse Browse Browse

	+ A00
Stress ECG	\bigcirc Yes - Normal \bigcirc Yes - Abnormal \bigcirc No \bigcirc Unknown
Date	
Result	
Report	Browse
Mark for deletion	
Nuclear Perfusion Coon	
Nuclear Ferrusion Scan	+ Add
Nuclear perfusion scan	⊖ Yes - Normal ⊖ Yes - Abnormal ⊖ No ⊖ Unknown
Date	D.MILVVV
Result	
Result	
Report	Browse
Report Mark for deletion	Browse
Report Mark for deletion Intravascular Ultrasound	Browse Browse Yes - Normal O Yes - Abnormal O No O Unknown
Report Mark for deletion Intravascular Ultrasound Intravascular ultrasound Date	Browse Browse
Report Mark for deletion Intravascular Ultrasound Intravascular ultrasound Date	Browse Browse Add Yes - Normal O Yes - Abnormal O No O Unknown DD-MM-YYYY
Report Mark for deletion Intravascular Ultrasound Intravascular ultrasound Date Result	Browse Browse Browse O Comman O Yes - Abnormal O No O Unknown DO-MM-YYYY
Report Mark for deletion Intravascular Ultrasound Intravascular ultrasound Date Result	Browse Browse DD-MME-YYYY DD-MME-YYYY
Report Mark for deletion Intravascular Ultrasound Intravascular ultrasound Date Result	Browse Browse Browse Ores - Normal ○ Yes - Abnormal ○ No ○ Unknown DD-MM+YYYY
Report Mark for deletion Intravascular Ultrasound Intravascular ultrasound Date Result	□ □ ● <t< th=""></t<>
Report Mark for deletion Intravascular Ultrasound Date Result	Image: Stress of the second secon

	Optical Coherence Tomography			
	Optical coherence tomography	○ Yes - Normal ○ Yes - Abnormal ○ No ○ Unknown		
	Date			
		DD-MM-YYYY		
	Result			
	Report	Browse		
	Mark for deletion			
pport Report a bug Version 1.6.7	Disclaimer 8	8 Copyright Notice © 2013-2016 Murdoch University Authorised by: Pro RDRF Project Email RDRF	of. Matthew Bellga Director, C	
			at 100% -	

Screen Shot – Apheresis (enlarge to view)

	Tamework		
SMITH, Anthony			Fi Save 🗙 Cancel 🖶 Print
	Apheresis		
Demographics	Has the patient had apheresis?	○ No ○ Yes	
Consents	Apheresis		+ Add
Family Linkage			
Main	Date apheresis started	DD-MM-YYYY	
Clinical Data Genetic Data	If not currently on apheresis, date apheresis stopped	DD-MM-YYYY	
Medications	Type of apheresis		\checkmark
Apheresis	Duration of an episode of		
	apheresis	hours	
Follow Ups	Frequency of apheresis		~
	Have there been any complications?		
	Pre-apheresis LDL-		
	cholesterol concentration	mmol/l	
	cholesterol reduction	mmol/l	
	Pre-apheresis Lp(a) concentration	a/L	
	Interval mean Lp(a)	y ~	
	reduction	g/L	
	Mark for deletion		
minn 1.6.7	Disclaimer	& Copyright Notice © 2013-2016 Murdoch University	Authorised by:

Screen Shot – Follow Up (enlarge to view)

Rare Disease Registry Framework		≅ Menu + 👤 RPH Curator +
E Follow Up		R Save X Cancel
Demographics		
Date of	assessment 卷	DD-MM-YYYY
Consents Is the pa	atient currently	○ Yes ○ No ○ Unknown
Family Linkage Systolic E	Blood Pressure	
Main Diastolic E	Blood Pressure	
Genetic Data Has the pat Medications chronic ki	ient developed dney disease?	○ Yes ○ No ○ Unknown Please tick Yes if chronic kidney disease has already been diagnosed previously
Imaging Observed Apheresis	l weight status	○ Underweight ○ Healthy weight ○ Overweight ○ Obese
Follow Ups	Height	Height in metres
+ Add	Weight	Weight in kilograms
	BMI	NaN kg/m2
Has th disch	is patient been arged from the clinic?	
Events		
Has the event since	patient had an the last visit?	○ Yes ○ No ○ Unknown
Муоса	rdial infarction	○ Yes ○ No ○ Unknown
	Age at MI	years
rev	Coronary ascularisation	
Age at rev	vascularisation	years
Coronary	artery disease	Defined by imaging/functional test(s) (if checked, please enter results into Imaging Module) Angina pectoris

Ade at andina	
. ge ar angilla	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	
	eg. multiple events or number of stents/by-passes
Hypertension	
Line the netions developed	
hypertension?	Please tick Yes if hypertension has already been diagnosed previously
If yes, is the patient on hypertensive medication?	○ Yes ○ No ○ Unknown
Medication(s)	☐ Thiazide diuretics
	Beta blockers ACE inhibitors
	Calcium channel blockers Other
If other, enter medication name(s)	
Diabetes	
Diabetes Has the patient developed diabetes?	○ Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously
Diabetes Has the patient developed diabetes?	Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication?	 ○ Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously ○ Yes ○ No ○ Unknown □ Biguanides
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s)	 Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown Biguanides Sulfonylureas
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s)	 Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown Biguanides Sulfonylureas TZDs Insults thereau
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s)	 Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown Biguanides Sulfonylureas TZDs Insulin therapy DPP-4 inhibitors
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s)	 Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown Biguanides Sulfonylureas TZDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s)	 Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown Biguanides Sulfonylureas TZDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s)	 Yes ○ No ○ Unknown Please tick Yes if diabetes has already been diagnosed previously Yes ○ No ○ Unknown Biguanides Sulfonytureas TZDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other
Diabetes Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s) If other, enter medication name(s)	Yes No Unknown Please tick Yes if diabetes has already been diagnosed previously Yes No Unknown Biguanides Sulfonylureas TZDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SULT-2 inhibitor Other
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s) If other, enter medication name(s) Antithrombotic	 Yes No Unknown Please tick Yes if diabetes has already been diagnosed previously Yes No Unknown Biguanides Sulfonylureas T2Ds Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other
Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s) If other, enter medication name(s) Antithrombotic	 Yes No Unknown Please tick Yes if diabetes has already been diagnosed previously Yes No Unknown Biguanides Sulfonylureas TZDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other
Diabetes Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s) If other, enter medication name(s) Antithrombotic Has the patient been prescribed antithrombotic medication?	<pre> Yes No Unknown Please tick Yes if diabetes has already been diagnosed previously Yes No Unknown Biguanides Sulfonylureas TzDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other</pre>
Diabetes Diabetes Has the patient developed diabetes? If yes, is the patient on diabetes? If yes, is the patient on Medication(s) If other, enter medication Antithrombotic Has the patient been prescribed antithrombotic Medication(s)	Yes ○ No ○ Unknown Piease tick Yes if diabetes has already been diagnosed previously ○ Yes ○ No ○ Unknown □ Biguanides □ Sulfonylureas □ TzDs □ Insulin therapy □ DPP-4 inhibitors □ GLP-1 receptor agonist □ SGL T-2 inhibitor □ Other
Diabetes Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication? Medication(s) If other, enter medication ft other, enter medication Has the patient been prescribed antithrombotic medication; Medication(s)	\Yes ○ No ○ Unknown Please lick Yes if diabetes has already been diagnosed previously \Yes ○ No ○ Unknown Biguanides Sulfonylureas □ DP-4 inhibitors □ GLP-1 receptor agonist □ SGL T-2 inhibitor □ Other
Diabetes Diabetes Has the patient developed diabetes? If yes, is the patient on diabetes? If yes, is the patient on diabetes whether medication(s) Medication(s) If other, enter medication name(s) Antithrombotic Has the patient been prescribed antithrombotic medication(s)	Yes No Unknown Please tick Yes if diabetes has already been diagnosed previously Yes No Unknown Biguanides Sulforylureas TZDs Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other Yes No Unknown Aspirin Other antiplatelets Warfarin Other antiplatelets Warfarin Other antiplatelets
Diabetes Diabetes Has the patient developed diabetes? If yes, is the patient on diabetic medication(s) Medication(s) If other, enter medication for the patient been prescribed antithrombotic Has the patient been prescribed antithrombotic medication(s) If other, enter medication	\Yes \No \Unknown Please tick Yes if diabetes has already been diagnosed previously \Yes \No \Unknown Biguanides Sulfonylureas T2Ds Insulin therapy DPP-4 inhibitors GLP-1 receptor agonist SGLT-2 inhibitor Other

Biochemistry Profile				
Date				
	DD-MM-YYYY			
Total cholesterol				
concentration	mmol/L			
I DI -cholesterol				
concentration	mmol/L			
Triphospide				
concentration	mmol/L			
HDL-cholesterol concentration	mmol/L			
Lp(a) concentration	a4			
	g -			
Blood glucose				
concentration	mmol/L			
HbA1c				
	(%)			
Apolipoprotein B				
	g/L			
Apolipoprotein A1				
	g/L			
Aspartate transaminase				
(AST)	U/L			
Alanine transaminase				
(ALT)	UL			
Creatine kinase (CK)				
	U/L			
Albumin				
	g/L			
Creatinine				
	umol/L			
C-reactive protein (CRP)				
	mg/L			
Treatment (daily)	-			
(2003)				
If other, enter medication				
regime				
Compliance	-			
	Fintelerent, please enter details into Mediaction Mediule. Drug Intelerence			

Death		
Date of de	eath	
Age at de	bathyears	
Cause of de	eath	
Please specify of cause of de	ther tath	
Support Report a bug Version 1.6.7 Disc	laimer & Copyright Notice © 2013-2016 Murdoch University RDRF Project Email RDRF	Authorised by: Prof. Matthew Bellgard, Director, CCGV
		a 100% 👻 💡

NATIONAL f_H registry



Core Data Entry Form – Updated 20/7/2018

DEMOGRAPHICS							
Doct	tor*:		Hospital ID:				
Туре	e of M	edical Professional*:	Family name*:				
Hom	ne:		Given names*:				
Mob	oile:		Address*:				
Ema	il:				PC:		
Ethn	ic ori	gin:	Sex*: DOB*:				
	NDEX	RELATIVE – Name of index/relationship:					
Click t	he gree	n 'Save' button, then use the blue arrow on the right to move to	the next form >				
CON	ISENT						
A	dult	Child Clinical trials Information	FCHL Hyper-Lp(a)	pload co	nsent file		
Click t	he gree	n 'Save' button, then use the blue arrow on the right to move to	the next form >				
CLIN	ICAL	DATA					
Date	e of co	onsent*: [Date of assessment*:				
	CLIN	IICAL DATA – FH Score		Score	Patient Score		
	1.0	Family History					
	1.1	First degree relatives with known premature coron (Men < 55 years, Females < 60 years) Father / M	1				
	1.2	OR First degree relatives with known LDL-cholest (for age and sex) Father / M					
	1.3	First degree relatives with 🗌 tendinous xanthoma	2				
	1.4	OR Have children aged less than 18 years with LD and sex)	2				
	2.0	Clinical History					
	2.1	Patient with premature coronary artery disease (MI: age at first CABG: age at first	Men < 55 years, Females < 60 years) PCI: age at first	2			
	2.2	Patient with premature cerebral or peripheral vasc (Men < 55 years, Females < 60 years)	1				
	3.0	Physical examination		1			
	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 (mmo	I/L)				
	4.1	LDL-C ≥ 8.5	mmol/L	8			
	4.2	LDL-C 6.5-8.4 OR	mmol/l	5			
	4.3	LDL-C 5.0-6.4 Treatment:		3			
	4.4	LDL-C 4.0-4.9	ntmmol/L	1			
		FH Diagnostic Categories: Definite >8, Probable 6-8, Possible 3-5, Unlikely 0-2 FH Score:					
Plas	ma LC	DL-cholesterol for FH Score					
	HIG	HEST UNTREATED LDL-C*					

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



	U a ur ital ID. ≥					
DEMOGRAPHICS						
Dr:	Family name:					
Date":	Given names:					
Home:						
Fracile	PC. Sex. DOB.					
INDEX RELATIVE Index/relationship:						
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 wei	ghtOverweightObese					
Height (m): Weight (kg):	BMI:					
Patient discharged: Yes – to GP Yes – to spe						
No – remains in clinic	o – but lost to follow up					
Event since last visit: Yes No Unknown						
Myocardial infarction: Yes No Unknown	Age at MI (years):					
Coronary revascularisation: PCI CABG Both	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:	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 recepto	r 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	CURRENT MEDI	ICATION (L	.ipid lower	ing)			
Date	Name				Dose	Frequency	Commenced
ТС							
LDL							
Glucose							
HbA1c							
АроВ							
ApoA1							
AST							
Alb							
Creat							
CRP	Compliance:]Full 🗌 I	rregular	Non	-complia	nt 🗌 Intoler	ant 🗌 N/A
Details if intolerant - Enter details into	Medication Module -	– Drug intoler	ance:				
DEATH							
Date of death:		A	ge at deat	h (years):		
Cause of death: CAD Cerd	ebrovascular disea n death 🛛 Heai	ase - ischen rt failure	nic ∐Co ∏Acute	erebrova aortic sv	ascular d vndrome	isease - haemo	orragic Other
Specify other cause of death:					ynaronne		
ADDITIONAL NOTES							