NATIONAL fH REGISTRY

Core Data Entry Form – Updated 20/7/2018

AFFIX LABEL HERE

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

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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 95th percentile (for age and sex) **Father / Mother / Other:**_____		
1.3	First degree relatives with ☐ tendinous xanthomata and/or ☐ arcus cornealis	**2**	
1.4	**OR** Have children aged less than 18 years with LDL-C above the 95th 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**	

☐ UNTREATED LDL:_____mmol/L
OR
☐ TREATED LDL:_____mmol/L
Treatment:
LDL adjusted for treatment_____mmol/L

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')*	

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 ☐ Former ☐ Unknown
Hypertension*	☐ Yes ☐ No ☐ Unknown
Diabetes*	☐ Yes ☐ No ☐ Unknown
Chronic kidney disease*	☐ Yes ☐ No ☐ Unknown
Hypothyroidism*	☐ Yes – treated ☐ Yes – untreated ☐ No ☐ Unknown
Observed weight status*	☐ Underweight ☐ Healthy weight ☐ Overweight ☐ Obese ☐ 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*	☐ Yes ☐ No – service not available ☐ No – not consented ☐ No – not offered *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

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MEDICATIONS

Lipid-lowering medication* *(At time of entry into the registry)*	☐ Yes ☐ No ☐ Unknown *If yes, complete below:* Treatment (daily)*: Date of first starting any lipid-lowering medication*:
Hypertensive medication*	☐ Yes ☐ No ☐ Unknown *If yes, complete below:* ☐ Thiazide diuretics ☐ Beta blockers ☐ ACE inhibitors ☐ ARBs ☐ Calcium channel blockers ☐ Other
Diabetic medication*	☐ Yes ☐ No ☐ Unknown *If yes, complete below:* ☐ Biguanides ☐ Sulfonylureas ☐ TZDs ☐ Insulin therapy ☐ DPP-4 inhibitors ☐ GLP-1 receptor agonist ☐ SGLT-2 inhibitor ☐ Other
Antithrombotic medication*	☐ Yes ☐ No ☐ Unknown *If yes, complete below:* ☐ Aspirin ☐ Other antiplatelets ☐ Warfarin ☐ Other anticoagulants
History of drug intolerance*	☐ Yes ☐ No ☐ Unknown *If yes, complete more details. Enter as much detail as is available.*

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

IMAGING *Not all imaging is listed here. Please complete all imaging in the registry.*

Carotid ultrasonography*	☐ Yes - Normal ☐ Yes - Abnormal ☐ No ☐ Unknown *If yes, complete more details.*
Echocardiogram (resting)*	☐ Yes - Normal ☐ Yes - Abnormal ☐ No ☐ Unknown *If yes, complete more details.*
Coronary artery calcium score*	☐ Yes-0 ☐ Yes-1-99 ☐ Yes-100-300 ☐ Yes->300 ☐ No ☐ Unknown *If yes, complete more details.*
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.*

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APHERESIS*	☐ Yes ☐ No ☐ Unknown *If yes, complete more details.*