NATIONAL *fH* REGISTRY

FH Australasia Network
everyone deserves a better chance

Core Data Check List (as at 15/8/2017). Please enter additional information if it is available.

Patient Name _____DoB_____

Demographics	Registry	Rdrf Registry	
		Centre	
	Patient Personal Details	Family name	
		Given names	
		Date of birth	
		Ethnic origin	
		Sex	
		Email	
	Patient Address	Address	
	Patient Doctor	Doctor (need to enter doctor details into database first)	
		Type of Medical Professional	
	Patient Relative	Link family members	
Consent	Registry Consent	Adult/child	
	Optional Consents	Clinical trials	
		Information	
	Registry Subset	FCHL	
		Hyper-Lp(a)	
	Upload consent file	Upload consent file	
Clinical Data		Date of consent	
		Date of assessment	
	Family History	All mandatory fields as indicated by *	
	Clinical History	All mandatory fields as indicated by *	
		Myocardial infarction (If **Yes** then **Age at first MI**)	
		Coronary revascularisation (If **Yes** then **Age at first revascularisation**)	
	Physical Examination	All mandatory fields as indicated by *	
	Plasma LDL-cholesterol for FH Score	Highest **ever** UNTREATED LDL-C **OR** TREATED LDL-C and Treatment (at time of assessment)	
	Biochemistry Profile	Date **Only 1 profile, closest to the date of consent is required. This profile can be untreated or treated.**	
		Lipid profile (TC, LDL-C, TG, HDL) **and other test results if available**	
		Treatment (lipid lowering only) at the time of the Lipid Profile. If **Yes** enter details otherwise select **No.** If the treatment regimen is in the dropdown list, please use the dropdown list. If not, select 'Other' and free text ALL the exact medication name(s), dose(s) and frequency i.e. do not put some in the dropdown list and some in 'Other'.	
		Compliance at the time of the Lipid Profile	

	Other CVD risk factors	Smoking	
		Alcohol	
		Hypertension	
		Diabetes	
		Chronic kidney disease	
		Hypothyroidism	
		Weight status (Observed **or** height and weight for BMI)	
	Clinical Trials	If on a trial enter details	
Genetic Data	Genetic Analysis	Has the patient had a DNA test? If **Yes** enter date, results and upload report otherwise select **No – (reason)**	
Medications	Lipid-lowering Medication	Is the patient on lipid-lowering medication (at time of entry into registry)? If **Yes** enter details otherwise select **No.** If the treatment regimen is in the dropdown list, please use the dropdown list. If not, select 'Other' and free text ALL the exact medication name(s), dose(s) and frequency i.e. do not put some in the dropdown list and some in 'Other'.	
		Date of starting medication **This is the date the patient first started ANY lipid lowering medication.**	
	Hypertensive Medication	Is the patient on hypertensive medication? If **Yes** enter details otherwise select **No**	
	Diabetic Medication	Is the patient on diabetic medication? If **Yes** enter details otherwise select **No**	
	Antithrombotic Medication	Is the patient on antithrombotic medication? If **Yes** enter details otherwise select **No**	
	Drug Intolerance (Lipid lowering drugs)	History of drug intolerance – If **Yes** enter as much detail as you have (minimum info required drug, dose and symptoms) otherwise select **No**	
Imaging		If the patient has undergone any imaging test – enter **Yes**, date, result/s and upload Report otherwise select **No** for each	
Apheresis		If the patient has ever undergone apheresis - enter **Yes** and details otherwise select **No**	