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THE UNIVERSITY OF  
**WESTERN  
AUSTRALIA**

# NATIONAL FAMILIAL HYPERCHOLESTEROLAEMIA REGISTRY

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*Data Management Plan*

**Version 3.0**

**10<sup>th</sup> February 2025**

Australian Atherosclerosis Society

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FH Registry Data Management Plan, Version 3.0, 10/02/2025

This data management plan has been developed in consultation with the University of Western Australia (UWA). The National Familial Hypercholesterolaemia (FH) Registry was created using Research Electronic Data Capture (REDCap).

## ➤ Data Storage, Access and Security

REDCap is a secure cloud-based application that supports secure research data capture and management. The FH Registry will be stored electronically in the REDCap platform provided by UWA. This service is managed by the UWA Library and maintained by UWA Information Technology Services (ITS) within secure UWA network infrastructure and services. All electronic communication between REDCap and users is encrypted. Access the FH Registry requires individual user accounts and passwords, a secure login process, and is limited to role-specific access and permissions.

### Credentials

Access and authentication to REDCap is through the UWA Single Sign On (SSO) process.

### Password Strength

Passwords must be a minimum of 9 characters long, use a combination of alphabetic, numeric, and special characters and cannot contain consecutive, repeated characters or a string of characters that match previous passwords.

### Two-factor Authentication

UWA SSO requires two-factor authentication, with a second factor, something only the user has in their possession, to provide strong identity verification.

### Data Backups and Retention

Primary data is stored and managed in REDCap. Backups are performed daily and secured at the UWA ITS Data Centre. Disaster recovery is tested annually.

### Logging

REDCap logs all user access to data at both system and project level, including page views.

## ➤ Policies and procedures

UWA staff are bound by all relevant policies and procedures, including:

- UWA Acceptable Use of IT Policy
- UWA Cyber Security Policy
- UWA Information Protection Policy

## ➤ **Contractual and licencing arrangements, and confidentiality agreements**

Confidentiality and licensing arrangements are set out in the Services Agreement with UWA.

## ➤ **Terms of use**

The terms of use are outlined here: <https://guides.library.uwa.edu.au/REDCap>

## ➤ **Training**

The FH Registry coordinator provides one-on-one user training.

## ➤ **Purpose of data storage and usage**

Purpose of data storage and data usage are outlined in the Patient Information Sheet.

## ➤ **Data access conditions**

Data access conditions are outlined in the Charter, Protocol and Guidelines document.

## ➤ **Communications**

Details of the service arrangements and data confidentiality will be communicated to potential participants via the Patient Information Sheet and the FH Australasia Network website.