

MACH Clinical Trials Consortium

HeSANDA Node

Contribute to the Health Studies Australian National Data Asset (HeSANDA)

Dataset Provider Instructions - How to register your clinical trial dataset in 2 steps

1. Ensure your trial is registered in [ANZCTR](#) and Section 11. data sharing statement is current.
2. Complete the additional clinical trial dataset description (metadata) form via REDCap [here](#) (approx. 5-10mins)

Tip: Dataset Description is a description containing easily read and understood information about the dataset, not the trial itself - this information is captured in ANZCTR. The purpose is to enable users not involved in the original study to find and evaluate the applicability of a dataset for their research question.



Example dataset description

This dataset includes 384 participants (from 18 years old, 190 males / 194 females) receiving in-centre or home-based hemodialysis or peritoneal dialysis recruited into the EXEMPLAR study from six local health districts in the Greater Sydney region, New South Wales, Australia. Baseline data includes demographics, dialysis history, cognitive status, health literacy and self-efficacy scores. Follow-up data were collected at 3, 6 and 12 months and includes patient reported outcomes (quality of life, knowledge, confidence, health behaviour and self-management) and clinical outcomes (symptom burden (Palliative care Outcome Scale) and nutritional status (Patient-generated Subjective Global Assessment). The file type is .XLS.



After steps 1 & 2 are complete

- The REDCap form will feed metadata into [figshare](#) and a DOI (Digital Object Identifier) will be created.
- The combined records (ANZCTR & the trial dataset description) will be harvested into the [Health Data Australia](#) platform within 72 hours.
- Search the [Health Data Australia](#) platform to browse other clinical trial metadata and request access to datasets via the platform.



FAQ: Why use the MACH node to register your clinical trial dataset description?

- Secure – REDCap and figshare are secure applications which feeds metadata into Health Data Australia.
- Identifiable – Figshare mints a DOI for each published metadata record.
- Discoverable – As a unique identifier the DOI is captured by major research repositories and libraries globally.
- Controllable – Researchers always maintain control over their research datasets and Individual Participant Data (IPD), only sharing the metadata through the catalogue. Researchers can control and approve requests for access to their datasets once your individual governance requirements are met.

