

Registry Establishment Cost Drivers

1. Determine the scope.

- Consider including the following roles when determining the scope of the registry:
 - i. Senior Manager Registry Science
 - ii. Head of ICT
 - iii. Strategic Director Registry
 - iv. Senior Statistician
- Hours will vary based on the request and the role each person plays

2. Build the platform.

- Determine the complexity of the registry and its requirements
- Discuss this with the Head of ICT to evaluate the best solution
- Ensure there is adequate budget allocated for the build and ongoing maintenance
- Consider the following options
 - i. Option 1 – REDCap
 - Most organisations have a free licence to use REDCap however, there may be costs associated with custom builds and hosting.
 - As an indication a recent build for a simple REDCap Registry is around \$50,000. (Not including clinician data entry and follow-up).
 - ***NOTE: time and cost will vary based on complexity*
 - ii. Option 2 - Other/bespoke
 - Can include external ICT companies
 - May require internal server hosting and ongoing ICT support including secure data storage
 - Bespoke would need to be determined
 - *** NOTE: Time and costs would need to be determined*

3. Staffing.

- Registry roles may include:
 - i. Strategic Director
 - Steering Committee participation governance oversight
 - ii. Senior Manager Registry Science
 - Registry Science Oversight
 - iii. Registry Project / Registry Manager
 - Project management/operations
 - Staff management and professional development oversight of ethics and governance, Stakeholder engagement of clinicians + data collections sites, Profile/promotion, budget, funding, risk management.
 - iv. Ethics Officer
 - HREC and site governance depending on number of sites and if FQAA (Federal Qualified Privilege) sought/achieved.

- v. Administration Officer
- vi. Research/Publication Officer
 - Optional or maybe required once the registry is mostly established
- vii. Data Officer / Data Manager
 - Data Structure and collection
 - Analytics Design
- viii. Senior Statistician
 - During the build phase and ongoing is critical to success.
 - Analytics and reporting
- ix. Principal Investigator / Clinician Researcher (variable)
 - Can be voluntary, part of the organisation or paid role

4. Corporate Infrastructure.

- These will be organisation specific but could include Charges are specific to each organisation HR, ICT, Finance, Insurances, Legal and Marketing in addition to office space, office expenses, ICT maintenance and support etc

5. Licencing and other costs.

- This may include licences such as R Studio or Power BI

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