

Submission

2016 National Research Infrastructure Roadmap

Capability Issues Paper

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Health and Medical Sciences

Question 15: Are the identified emerging directions and research infrastructure capabilities for Health and Medical Sciences right?

Big health data' appears, under differently named headings, under Sections 5.1 'Emerging directions', 5.2 'Current and emerging capabilities' and 5.3 'Desirable new capabilities'. It is difficult to discern how these all piece together. The table on page 20 indicates that future directions include expanding the current Population Health Research Network, and establishing a new health and medical big data capability covering e.g. infectious disease outbreaks, an Indigenous research platform and bioinformatics skills. This seems to be a piecemeal approach that does not address key deficiencies of the current infrastructure, which include duplication, fragmentation, lack of interoperability and inefficient processes and governance.

A complete redesign is needed, and a starting point would be (i) a framework for the longitudinal data that need to be integrated to build a national health big data resource that will unlock major research opportunities for Australia (e.g. Figure 1); and (ii) a set of design principles for this infrastructure, including, for example:

- data are linked (integrated) routinely at regular intervals
- de-identified linked data are held in a single, national secure repository
- the application and approval process is simple and streamlined
- metadata, code and other analysis tools are shared and freely available
- analytics environments for researchers are remotely-accessed, customisable and scalable
- governance involves researchers and consumers.

Question 15: Are there any missing or additional needed?

Infrastructure to support pragmatic clinical trials (PCTs) is an emerging capability need. PCTs aim to generate results that are relevant to patients and clinicians by comparing interventions in participants and settings that are representative of usual care. These trials present different challenges to traditional efficacy trials, which are conducted under ideal circumstances, in selected patients, and with highly controlled protocols. Infrastructure to support PCTs includes mechanisms to engage with communities and stakeholders, systems for patient recruitment and randomisation, and standardised tools for data generation, capture, and management, including infrastructure to catalog interventions and their implementation.

Figure 1: National health big data resource

