

# 2016 National Research Infrastructure Roadmap Capability Issues Paper

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Dear Dr Finkel and colleagues

Thank you for the opportunity to contribute to the development of the National Research Infrastructure Roadmap. As a document presenting a high level view of the assets, facilities and services that should be developed for the future benefit of Australia's research and innovation community, it presents a comprehensive vision of the capabilities that should be supported. I wish to provide feedback relating to only one of the stated capabilities within Section 5: Health and Medical Sciences that being **5.2.4 Biobanking and Population Genetics**

Question 15: Are the identified emerging directions and research infrastructure capabilities for Health and Medical Sciences right? Are there any missing or additional needed?

*High quality standardised tissue collection and banking must be addressed.... Significant improvement in research effectiveness could be achieved by integrating existing tissue biobanks into collaborative networks linked to the research community. Consolidate existing efforts and create virtual networks with stable national funding.*

In 2003 the NHMRC established the Enabling Grants Special Facilities which was focussed on funding national biobank networks. In 2004 8 such networks were supported to the tune of \$14M for 5 years. In 2009 a review of the productivity of these networks led to continuation of funding for 6 groups to the value of \$10M over 5 years. In 2013 however, the NHMRC Enabling Grant program was deemed unsustainable, ineffective with respect to research outcomes with the result that ongoing funding for biobank networks ceased. Given this history, it is surprising to see 'biobanking networks' again promoted as key capabilities to be a part of our future national research infrastructure.

Despite this, the result of this decade of focus on biobanks, biobanking and biospecimen research has been to highlight the absolute necessity for systematic and specialised tissue handling for research purposes (1). Yet, finding the appropriate funding and business models to sustainably support biobanking has been difficult.

Therefore, if biobanking capabilities are to be part of the National Research Infrastructure Roadmap, the following questions need to be addressed....

- (i) How will the proposed biobanking networks be different from what was supported between 2003 and 2013?
- (ii) Are biobank networks to be considered the 'infrastructure' per se? Or, are biobank networks to be developed out of or built upon a strong biobanking infrastructure. If the latter, does a strong biobanking infrastructure exist and what would it consist of?

- (iii) As patient samples and clinical data are often obtained from within our hospitals and medical centres, will hospitals be considered a part of Australia's biobanking "Research Infrastructure" capabilities?
- (iv) How will the 'research effectiveness' of the biobanking infrastructure be determined, measured and reported to justify that the investment of funds has led to the 'significant improvements' hoped for? To date, biobank effectiveness has not been adequately addressed (2).

Whilst I am pleased that biobanking infrastructure features within this capabilities document, I hope we can learn from the lessons of the past so as to progress this field, and not regress to past unsatisfactory practices. I look forward to further opportunity to contribute to these discussions.

1. Catchpoole D., DeFazio A., Devereux L., Fleming M., Hof M., Schmidt C., Thorne H., and Zeps N., "The importance of biorepository networks: The Australian Biospecimen Network-Oncology". *Australian Journal for Medical Science*, 28(1), 16-20, 2007.

2. D.R. Catchpoole, "Biohoarding: Treasures not seen, stories not told.", *Journal of Health Services and Research Policy*, 21(2), 140-142, 2015.