

Supplementary material for

Biobank networking and globalisation: perspectives and practices of Australian biobanks

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Australian Health Review: “Biobank networking and globalisation: Perspectives and practices of Australian biobanks” (AH20063)

APPENDIX: Biobank survey – recruitment overview

Sample/sources

Association of Australian Medical Research Institutes

- Public list of 47 MRI members and websites
- Each MRI website visited and manually searched for information on “biobank/s” (and “repository/ies”), and contact details of individuals associated with any biobanks, and/or institute research units, and/or institute general inquiry contact

National Health and Medical Research Council (NHMRC)

- Public list of national research facilities and networks, including 28 “Biobanking and clinical services”
- Websites visited and searched for up to date contact details/individuals

Australian and New Zealand Clinical Trial Registry

- online registry of clinical trials being undertaken in Australia, New Zealand and elsewhere (results include international studies registered on ClinicalTrials.gov, US National Library of Medicine database of privately and publicly funded clinical studies conducted around the world)
- registry search function used to find “biobank” or “tissue repository”, manually search results for biobanks, details and contact persons at Australian-based/partnered trials
 - biobank result = 9 studies (one inactive NZ study, one inactive/unverified Belgian-international study)
 - tissue repository result = 11 studies (one excluded, one duplicate from “biobank” results, four local-led studies, six US-led international studies with Australian collaborators)

The Australasian Biospecimen Network – Oncology (ABN-Oncology)

- national network of biobanks established to collect, process and disseminate biospecimens for cancer research, ranging from basic laboratory projects through to clinical trials
- provides links to websites of (26) Australasian biobanks
 - cross checked against above lists for additional biobanks (and their contact details)
 - members might circulate invitation to participate

NSW Biobank Registry / NSW Office for Health and Medical Research

- *Biobank registry*: Listing drawn from earlier survey of NSW organisations regarding biobank infrastructure in 2015, contains information about 44 participating biobanks, including contact names, details and websites (if available)
 - Cross-checked against above lists for additional biobanks (and their contact details)
 - Information is hosted by NSW Office for Health and Medical Research (OHMR). Email to staff/representatives from the NSW OHMR with survey information.

Biobank Certification Program – biobank locator

- “aims to improve and harmonise biobanking standards through education and communication of best practices and SOPs”, part of the NSW Health Statewide Biobanking Framework.

- Currently lists 31 biobanks in “locator” – cross check against above lists for additional biobanks and contacts: <https://nsw.biobanking.org/locator>

NSW Health Statewide Biobank

- NSW Health Statewide Biobank launched November 2017
- Estimates more than 50 resources in NSW that can be defined as a biobank, of varying size, scope, facilities, operating models and governance
- Survey sent to project manager

Cancer Biobanks

- Website resources include "biobank catalogue", including a list of 22 biobanks: <https://cancerbiobanksnsw.org/biobank-catalogue/>
 - Cross checked against above lists for additional biobanks (and contact details)

University of Sydney Tissue Banks

- Listing of tissue banking activity at the University of Sydney and affiliated bodies
- Provides links and contact details for nine (9) banks
- Cross checked against above lists for additional biobanks (and their contact details) <http://sydney.edu.au/cancer-research/resources/bio.php>

Australian Genomics Health Alliance

- Australian Genomics is made up of more than 70 partner organisations committed to integrating genomic medicine into healthcare across Australia.
- AGHA Lead is Murdoch Children's Research Institute director, and already listed in survey contacts list. AGHA Program Manager also forwarded survey invite for network.

Recruitment/invitations to participate

From the sources outlined above, a list of potential survey participants was produced.

- 139 contacts at 102 biobanks, biobank networks, clinical trials and/or other projects involving biobanks or potentially involving biobanks were emailed an invitation to participate in the survey
- 19 general inquiry contacts at medical research institutes were also emailed a request to advise research team of any internal biobanks and with invitation to participate

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