

SYDNEY HEALTH PARTNERS

2018 Biobanking Audit

SUMMARY REPORT



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December 2018

Biobanking is one of five cross-cutting themes of Sydney Health Partners (SHP). To better understand the nature and use of the existing biobanks within SHP, an audit was undertaken. This report summarises the findings.

Background

Biobanking is vital to high quality modern health and medical research. The significance of biobanks in translational research has been recognised in the NSW Health Strategic Priorities 2018-19, which identifies their importance for enabling high quality research. However, the current biobanking landscape is fragmented and not consistently regulated.

In preparation for the audit, Sydney Health Partners consulted with:

- the Leader of the Biobanking Cross-cutting theme, for background information and details about an audit of existing biobanks in the Westmead Research Hub (in 2017)
- the NSW Office of Health and Medical Research (OHMR) for existing aggregate information about biobanks in NSW (audit in 2015; biobank register 2018)
- the NSW Health Statewide Biobank for details of its remit, capabilities and available services to store and curate biobanks.

Westmead Research Hub

The Westmead precinct within Western Sydney Local Health District hosts over 30 biobanks, including several with national and international scale and recognition. In 2017, the Westmead Research Hub (WRH) conducted a survey to examine the status of biobanks within its remit. The survey identified 33 biobanks and responses from 28 were received.

The results showed that the majority of biobanks were cancer-related. The most common samples stored in the surveyed biobanks were blood and blood products. Most (72%) biobanks made their samples available for research, either through open (36%) or collaborative (36%) access.

Most biobanks (64%) relied on external peer-reviewed grant funding for support, and this was considered inadequate and unsustainable by many.

Quality assurance was identified as a major area of need across the biobanks: most (71%) did not have quality assurance programs, and 43% had no formal disaster plan in place. The survey summary report recommended a centralised streamlined quality assurance process as well as an efficient sample processing workflow.

NSW Office for Health and Medical Research

In 2013 the Office of Health and Medical Research (OHMR), in partnership with the Cancer Institute NSW, NSW Health Pathology and the Biobanking Stakeholder Network, undertook an online survey of the NSW biobanking landscape, 44 biobanks responded, it is unclear how representative they were of all biobanks in NSW at that time.

The survey aimed to identify the key issues and challenges for the NSW biobanking sector, generate relevant data to inform evidence based policy development and identify best practice biobanking procedures and quality management systems.

The survey results showed that the majority of biobanks were cancer biobanks, the range of samples stored ranged from tissue and blood samples (both normal and diseased) to whole brain and spinal cord samples. The size of the biobanks also varied, from 1000 samples to in excess of 100,000 samples. Access to these samples varied considerably, with many having restricted or limited access.

Collectively, the biobanks were highly reliant on external sources of funding, with ongoing funding being quite rare and very few of them reporting any self-generated income.

In terms of quality standards, only 13 of the 44 biobanks had formalised systems in place and six were International Organization for Standardization (ISO) accredited.

The OHMR also created a register of NSW biobanks based on these survey findings. The register is now hosted by the NSW State Biobank (<http://biobank.health.nsw.gov.au/about-the-biobank/nsw-biobank-registry/>). The register currently lists 66 biobanks.

NSW Health Statewide Biobank

The NSW Government invested \$12 million to create the NSW Health Statewide Biobank, launched in late 2017. This significant development aims to be the primary storage facility for biospecimens, and to enable access to collections of DNA, blood, tissue and tumour cells to help researchers improve the way disease is detected, diagnosed and treated. The NSW Health Statewide Biobank is the first and largest facility of its kind in Australia, incorporating advanced robotic technology to manage and retrieve samples. Other resources include: a new voluntary certification program to improve the quality of biobanking; a standardised consent process for the collection and use of samples; and standardised agreements to support transfer of samples between sites.

Sydney Health Partners' Biobanking Survey

Development of the SHP biobanking survey included extensive consultations with various stakeholders including Professor Christine Clarke, Sydney Health Partners' Biobanking theme leader, Simon Cooper, COO of the NSW Statewide Biobank, staff of the OHMR, and researchers hosting biobanks. As part of the consultation, a contact list of known biobanks was developed; this identified 53 biobanks within Sydney Health Partners' remit. This contact list was then crosschecked with existing contact lists from the OHMR's biobank registry, Westmead Research Hub and the NSW Statewide Biobank.

The recent survey by the WRH of biobanks in the Westmead precinct helped inform the design of the SHP survey. Many of the same questions were included. Given the recency of the WRH survey, it was agreed those biobanks would not be re-surveyed. This left a survey sample of 25 biobanks within SHP.

The SHP survey was distributed to the 25 biobanks through REDCap, an online survey tool. The survey was open for three weeks and two reminders to complete the survey were sent.

Participating biobanks

Organisation	LHD/MRI
NSW Brain Tissue Resource Centre	USYD
MS Research Australia Brain Bank	USYD
Sydney Sleep Biobank	USYD
Brain Cancer Biobanking Australia (BCBA)	USYD
Sydney Heart Bank	USYD
The Australian Arthritis and Autoimmune Biobank Collaborative (A3BC)	NSLHD/USYD
Woolcock Centre for Lung Cancer Research	MRI
Woolcock Institute Lung Disease	MRI
Neuropathology Tumour and Tissue Bank	SLHD
Australian Sports Brain Bank	SLHD
Sydney Brain Bank *	MRI

*Serves researchers outside Sydney Health Partners' area

Survey Response Rate

In total, 11 biobanks responded to the survey, giving a response rate of 44 per cent (see Appendix 1). The biobanks that did not respond were followed up by phone calls and email and/or redistributed as hard copies by our project officers. Through the follow up process, the following issues were identified to explain the low response rate:

- 1) Feelings of being over-surveyed
- 2) Not interested in completing the survey
- 3) Errors in institutional affiliations (three biobanks were affiliated with SPHERE)
- 4) Problems with contact information - incorrect or outdated details
- 5) Inconsistent naming conventions for some biobanks, making identification difficult (e.g., one biobank was listed under three different names in three different locations)
- 6) Historical information about the biobanks was not known by current staff.

“Biobanking provides a source of samples available to a multitude of researchers to enhance medical research and create new medical knowledge to enhance future health care and health outcomes.”

Summary of Survey Findings

The specimens collected by the 11 SHP biobanks were highly varied, with the most common being fresh/frozen disease samples (n=6). Specimen numbers ranged from <1000 biospecimens to more than 10,000. The number of employees per biobank also varied, ranging from 0.2 FTE to 8.0 FTE. The main purpose for establishing the biobanks was to support scientific research, both for specific and unspecified projects. Of the 11 biobanks, eight indicated they were open to external applications for access, provided that relevant ethics and governance approvals were in place. Of these eight, six had access committees in place to assess incoming applications. Obtaining necessary

ethics and governance approvals, and having the appropriate patient consents were identified as significant barriers to using biobank samples for research.

The majority of the biobanks (n=8) had Standard Operating Procedures (SOPs) in place, although only five had completed compliance audits, and three indicated they were formally accredited.

“Basic biobanking is unlikely to advance research innovation. However, when high-quality biospecimens are integrated with a broad range of clinical, patient-reported and population health data, big data analytics has the potential to uncover unknown associations for more holistic, safe and effective evidence-based strategies in preventive and precision medicine.”

Conclusions

While the response rate in the SHP survey was lower than expected, the results of this survey are consistent with those conducted in recent years by WRH and the OHMR. The combined results of these surveys show that biobanks in NSW are of variable size, of variable or unknown quality, with inconsistent quality management systems and in many cases, insecure funding sources.

The NSW Health Statewide Biobank has been established to develop a coordinated high quality biobanking service in NSW and beyond that encompasses consistent, well-documented sample storage, centralised streamlined quality assurance process as well as efficient sample processing workflow. Its size and available resources could accommodate one or more biobanks within Sydney Health Partners. It appears well placed to support better access and use of biospecimens for research.