

Submission

2016 National Research Infrastructure Roadmap

Capability Issues Paper

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Background

Brain Cancer Biobanking Australia (BCBA) – a consortium of clinical and laboratory researchers, neurosurgeons, oncologist, neuropathologists, and representatives for legal, ethical and consumer issues - was established in 2015 to network and harmonise Australia’s geographically and operationally disparate brain cancer biobanking operations. The main objective being to realise the inherent value of these individual collections and maximise the materials available to accelerate for both paediatric and adult brain cancer research. Acting as a virtual hub for a network of 17 brain tumour biobanks, BCBA is working to harmonise brain cancer biobanking operations and facilitate researcher access to the amount, quality and type of tissue and associated data they need to build their projects, recently establishing Australia’s first national registry of brain tumour biospecimens available for research. Our goal is for that registry to become the world’s largest. According to international expert in brain cancer research, Dr Timothy Cloughesy (Director UCLA Neuro-Oncology Program, USA) Australia has the potential to create the largest centralised registry of brain cancer tissue and data in the world and simply by allowing global access to that register could do more than Europe or the US to advance brain cancer research.

BCBA has engaged with well-established biobanks and biobanking consortiums, such as the Kathleen Cuninghame Foundation Consortium for research into Familial Breast cancer, Australian Breast Cancer Tissue Bank, Australian Brain Bank Network, Victorian Cancer Biobank, and internationally with Brain UK. We are also aligned with the activities of the Australasian Biospecimen Network Association, the Cancer Institute NSW Biobanking Stakeholder Network (BSN), NSW Health Pathology Biobanking Reference Group, and the International Society for Biological and Environmental Repositories (ISBER). BCBA has recently formed an important, association with the Neurosurgical Society of Australasia in an effort to increase brain tumour biobanking and the subsequent tissue accrual rates Australia-wide.

BCBA has close ties and strong support from the brain cancer consumer community. Indicating the importance of biobanking to the general public, BCBA was founded by a brain cancer consumer advocate, understanding that donated tumour tissue is key to advancing brain cancer research.

While significant progress has been made in a very short timeframe, Australia’s state-based funding model has been a serious impediment to BCBA’s development as an integrated platform for Australian brain cancer research. BCBA has no government support and relies totally on small industry and charitable donations, therefore would welcome the establishment of a framework and funding model to support biobanking infrastructure at a national level.

BCBA is an example of how the integration of **“existing tissue biobanks into collaborative networks linked to the research community”** can achieve a **“significant improvement in research effectiveness”** as outlined in Section 5.2.4 of the Issues Paper, and would fully endorse the identified

need for “**stable national funding**” to support the collaborative effort of this virtual network in providing the much needed “**step change in managing patients with cancers.... of the brain.**”

As such we are addressing questions 15 & 16 within the 2016 National Research Infrastructure Roadmap Capability Issues Paper.

Health and Medical Sciences

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

Biobanking is a key research infrastructure capability that is essential for Health and Medical Sciences as identified in research infrastructure capability issues paper (5.2.4 Biobanking and population genomics). Biobanking underpins medical research and is an investment in the overall health of the Australian population. Biobanks facilitate medical research by supplying annotated clinical samples and associated data which allows researchers to conduct studies to understand human health and diseases. This can ultimately lead to prevention of diseases and improvements in patient care. In the current era of precision medicine, biobanks are the essential driver, supplying the resources that allow researchers to identify new molecular information of clinical and therapeutic relevance. In order to provide the number and diversity of samples that are required to study the complexity and heterogeneity of diseases such as brain cancer, a relatively uncommon group of tumours and one in which the amount of available material is often limited, there is a need (as recognised in Sect 5.2.4. of the Issues Paper) to integrate individual biobanks into collaborative, virtual networks.

A national biobanking infrastructure framework with a certification ‘hub’ overseeing disease specific virtual network ‘spokes’ supported by stable funding would certainly assist in advancing Australian biomedical research. We are aware of the Australian Cancer Biobank Network (ACBN) model (a distributed model with central coordination) developed by the NHMRC working group in 2011 consisting of the NHMRC enabling grant recipients and others, and we are supportive of such a model. Such a distributed network model will help to harness existing expertise, experience and resources and reduce costs and unnecessary duplication of effort. It will also allow the committed clinicians, researchers and consumers experienced and interested in a particular tumour type to maintain biobanks, utilise materials and/or data stored and promote tumour specific research programs nationally and internationally. Collection of samples and/or data for research can be challenging logistically and requires considerable effort and in kind support, which can in many instances only be achieved with the support of committed individuals with an invested interest.

A national model should also encompass a certification framework for Australian biobanking similar to the program being developed by NSW Health Pathology, which is based on, and has been developed in conjunction with, the Canadian Tissue Repository Network (CTRNet). A national biobank certification program will help to harmonise biobanking activities and enhance pooling and sharing of materials and/or data from biobanks to accelerate translational research. A national investment in best practice biobanking supported at all levels from patient consenting and sample collection to researcher access and materials transfer will allow:

- Standardised consenting forms and processes

- Standardisation of general operations, sample and data collection and material transfer agreements
- Data mapping between biobank and health databases and between biobanks
- The infrastructure for data linkages for biobanks
- Certification procedures for existing and new biobanks
- Improved biobank governance and administrative processes
- Reduction in duplication of effort and administration
- Provision of infrastructure for study specific collections
- Transparent, equitable and peer reviewed access to samples based on scientific merit
- Maximal use of samples and data collected
- Promotion of national and international research collaborations
- Active engagement with international biobanking developments
- Increased public awareness and patient participation in biobanking
- Clinical trials to tap into biobank infrastructure for collection and storage of clinical samples at local sites before shipment to the central site
- Ability to leverage state, industry, not-for-profit and philanthropy partnerships

Question 16: Are there any international research infrastructure collaborations or emerging projects that Australia should engage in over the next ten years and beyond?

NSW is currently engaging with the Canadian Tissue Repository Network (CTRNet) via the NSW Health Pathology Biobank Certification Program, which provides support to biobanks through education and access to a comprehensive range of recommended and standard operating procedures based on best practices. Another prime example of an international biobanking collaboration is the European BBMRI-ERIC (Biobanking and Biomolecular resources Research Infrastructure- European Research Infrastructure Consortium). In 2008, the European Commission provided 5M€ to fund the development of the pan-European health research infrastructure BBMRI, which over the next three years, grew into a 54-member consortium with more than 225 associated organisations (largely biobanks). The BBMRI-ERIC is now one of the largest research infrastructure projects in Europe. There are great opportunities for Australia and Australian research to benefit through collaborations with BBMRI-ERIC, and to adopt biobanking platforms and solutions that have already been proven to function at a trans-national scale. However a national commitment to advancing science through biobanking is needed to promote such high level international engagement. For Australia to be competitive in this field and align with global initiatives it must find the political will and invest in a national approach to biobanking.