

The Australian Society for Medical Research comment on the OHMR proposed framework for NSW biobanking consultation Paper.

1. Why is it in New South Wales' interest to possess a nationally and internationally attractive biobanking sector? Please provide a one or two sentence vision statement in response.

Biobanks provide the vital resources that enable translational research discoveries. The development of a nationally and internationally biobanking sector in NSW will:

- Improve researcher access to larger sample sets
- Strengthen research results
- Accelerate translation to clinic
- Economic benefit to NSW through improved health outcomes and attracting increased investment to the sector.

2. What would you consider the best use of NSW biobanking infrastructure for achieving sustainable funding and operational efficiency?

Biobanking must be considered an essential part of the research effort which underpins health in NSW.

The establishment of a world-class biobanking sector is the responsibility of government in its provision of world -class health care to the people of NSW. Part of this responsibility is the establishment and implementation of a centralised governing body to support the development of standardised consent, ethics, collection and storage and open access processes and policies, preferably in conjunction with a national body such as NHMRC with a view unified national guidelines.

The bulk of the information in this consultation paper is cancer centric, it will be important to ensure that other specimens of value, particularly from rare diseases, are not overlooked. An audit of current biobanks and sample collections should be undertaken to determine any niche areas that may be capitalised on.

A central world class Biobank network will attract international interest and support particularly if a wide range of quality data and diverse biospecimens are available.

3. How can NSW biobanking be better managed to optimise the translation of health and medical research into improved healthcare?

Centralised standardised governance, processes and data repository with full recognition that biobanking underpins the research which underpins improved health outcomes.

Investing in key personnel (Biobanking Officers responsible for patient consent and sample collection, processing and storage) in hospitals as to facilitate communication between pathologists, clinicians, researchers and patients to develop the trust which is needed to allow full exploitation of the process.

The hub and spokes model is preferred as it capitalises and bolsters existing biobanks.

4. What is your perception of the quality of NSW biobanking operations and outputs, and what do you consider the key mechanisms to improve this quality?

The quality of biobanks in NSW varies greatly.

- Collections can be disease / research project centric and small scale
- Quality of samples varies greatly
- Clinical data patchy
- Governance and access not standardised

The establishment of central standardised governance, processes and an IT platform to support linked data facilitate improved researcher access.

5. **Other comments**

It is crucial to understand that biobanking is an essential element allowing research to be conducted. Health is underpinned by research which saves lives and money. Biobanking must be viewed as part of the 'whole of health'.... It is not a cost, it is an investment which brings exceptional returns¹.

1. Access Economics. Exceptional returns: The Value of Investing in Health R&D in Australia II. In: 2008, <http://www.asmr.org.au/Publications.html>