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Valuation of increased coordination in Australian biobanking

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Human health biobanks drive improved health outcomes by housing and providing access to human biological materials and associated data that support biomedical, clinical, public and population health research. These collections are key research infrastructure needed to maximise the impact of existing biospecimens and data, ensure that biological models represent the diversity of Australia's population, and support government decision-making.

In Australia, the total number of human health biobanks is unknown. However, there are at least 200 that collectively host and provide access to millions of biospecimens and associated data, most having emerged as local, de-centralised entities with varying levels of funding and on-going support. Absence of coordination at a national level has resulted in reduced visibility and traceability of individual collections, possible duplication of pre-existing collections, growth of biospecimen stocks without consideration of long-term demand, and inconsistent operating processes, data management systems and governance models. For example, a survey of Australian biobank users found that 62% of respondents had created their own biobank, while 64% had limited the scope of their research owing to difficulty obtaining biospecimens. These challenges impact the financial and operational sustainability of biobanks and limit their accessibility to Australian and international R&D.

To address these challenges and unlock the full potential of Australia's biobanking capabilities, this report combines expert insights with economic analysis to explore the benefits of a nationally coordinated approach to embed and sustain biobanks and cohort studies in the national research infrastructure ecosystem, and the recommendations required to pursue this future state.

Benefits of national coordination

Benefits related to improving the national coordination of Australia's biobanking capabilities can be mapped to three dependent themes, which echo the FAIR principles (findable, accessible, interoperable, and reusable) for scientific data:

- **Visibility** – Improving the visibility of available collections and biobanking services can reduce time and costs for researchers, increase biobank utilisation rates, and increase the alignment between biobank collection effort and user demands.
- **Accessibility** – Streamlining biobank governance structures and consent models, and enabling data linkage can improve risk management, support the integration of data from multiple sources, and facilitate an increase in R&D return through an increase in the number of research outputs directly enabled by Australian biobanks.
- **Harmonisation** – Harmonising protocols and professional development frameworks can facilitate improved data quality and inter-operability across collections, which is particularly valuable for studies that need to pool biospecimens or data from different sites.

A portion of these benefits – based on feasibility, mutual exclusivity, and practicality – were modelled to develop a conservative and preliminary estimate of the annual economic value that a searchable, **shared national platform** could provide. This value came to **$39 million per year**, with benefits arising from the avoided cost of biospecimen collection and increased biobank utilisation making up over two thirds of the total. While the project did not involve estimating the cost of establishing and maintaining a shared national platform, the headquarters for the European biobanking research infrastructure (BBMRI-ERIC) reports average annual operating expenses of approximately AUD 5.81 million, of which only a portion is related to maintaining their shared, cross-national search and access platform.

Recommendations to support the development of a coordinated biobanking capability in Australia

Several activities are required to increase biobanking coordination at the national level, including developing and implementing a successful shared national platform. Table 1 summarises recommendations that were developed and refined by consulted stakeholders across biobanks, research institutions and industry. Stakeholders noted that these recommendations may be best led by a governance structure with adequate decision-making power and implementation support. This requires the participation of Commonwealth government entities, state and territory health departments, and health research funders, alongside National Collaborative Research Infrastructure Strategy (NCRIS)-supported organisations, biobank networks, research institutions, and other custodians of relevant health data (see recommendation 5). Specific recommendations may be suitable for consideration as part of the upcoming 2026 National Research Infrastructure Roadmap and associated funding rounds, including the 2025 national digital research infrastructure investment round.

Table 1: Recommendations to support the development of a coordinated biobanking capability in Australia

VISIBILITY	ACCESSIBILITY	HARMONISATION
Recommendation 1: Conduct a comprehensive survey of biobanks and cohort studies hosted across Australia to identify existing collections, document their access conditions, and characterise their core operating practices.	**Recommendation 3:** Establish a national governance framework for human health biobanking that aligns custodian responsibilities and harmonises access processes across ethics, privacy, data stewardship, material transfer and data access agreements.	**Recommendation 4:** Promote a consistent quality management framework at the national level and support a stepwise process for individual entities to implement it.
Recommendation 2: Implement a shared national platform to search, and apply for access to, biospecimens and associated data across Australian biobanks and cohort studies.		**Recommendation 5:** Establish a national steering committee that guides and oversees progress of large-scale coordination initiatives to promote visibility, accessibility and harmonisation.

1 Introduction

1.1 The role of human health biobanking in a research ecosystem

Human health biobanks house and provide access to human biological materials and associated data (from specimens, donors and/or previous analyses) with the goal of improving human health via biomedical, clinical, public and population health research. These collections can:

- **Support population-scale research:** The storage, characterisation, and access that some biobanks provide enables projects of high complexity and scale, such as those exploring the interplay between genetic elements and disease across a population.[1]
- **Maximise impact of existing biospecimens and data:** Accessible collections allow scarce biospecimens and data to answer new questions, potentially reducing or eliminating the need for further costly and logistically challenging collection efforts.
- **Enable more demographically relevant models:** Collections that represent the diversity of Australia's population can become sources for more demographically relevant research models, benefitting translational research and clinical trial support.
- **Preserve information relevant to population and public health:** Long-term collections provide a temporal record that helps researchers assess segments of the Australian population over time, with implications for planning and decision-making in population and public health.
- **Provide a pathway for communities to engage with health research:** Biobanks and cohort studies function as an interface between the interests and motivations of participants, biological materials and data that are key to health research, and the evolving needs of researchers.
- **Support downstream impacts:** Access to biological materials enables research that may lead to quantifiable health gains and associated savings. For instance, a 2025 article by Victorian Cancer Biobank (VCB) and Monash University researchers estimated a return on investment of $1.59 for each $1 of public funding invested in the VCB between 2006 and 2022.[2]

1 Uffelmann E, Huang QQ, Munung NS, de Vries J, Okada Y, Martin AR, Martin HC, Lappalainen T, Posthuma D (2021) Genome-wide association studies. Nature Reviews Methods Primers 1, 59.

2 Marquina C, Lloyd M, Ng W, Hess J, Evans S, Ademi Z (2024) Evaluating Health and Well-Being Returns on Investment in a Cancer Biobank. Biopreservation and Biobanking.

1.2 Human health biobanking in Australia

Biobanks have historically emerged as local, de-centralised entities,[3] with uneven levels of funding and on-going support. An increasing number of individual biobanks without a national coordination framework can result in reduced visibility of collections, duplication of pre-existing collections to meet local research needs, growth of biospecimen stocks without consideration of long-term demand or availability in other institutions, and limited utilisation rates. For example, a survey of Australian biobank users found that 62% of respondents had created their own biobank, while 64% had limited the scope of their research owing to difficulty obtaining biospecimens.[4] These factors directly influence the financial and operational sustainability of biobanks over time,[5] and, ultimately, their capacity to efficiently support health research. Moreover, multiple high-quality biobanks can be established around a specific project or research question, without the governance structure and consent required to allow subsequent use.

Absence of a national framework has led to the proliferation of distinct operating processes (e.g., collection, processing, and storage), data management systems and governance models, particularly related to ethical approval, consent procedures and research conduct. These aspects can impact the search, access and subsequent use of existing biospecimens and data. For instance, differences across operating procedures and the associated clinical data collected can cause issues around sample quality, comparability of results, and study reproducibility. These differences also have implications for inter-operability and collaboration at state, national and global scales.[6]

Differences in data management systems, minimum data captured, and participant consents across biobanks pose a challenge to users when identifying existing materials that can both meet and be used for their research needs. Limited connectivity between data repositories also adds complexity, from technical and governance perspectives, to linking a biospecimen or dataset to additional information from other research, clinical or government sources. Further, differences in access pathways across institutions can make applications inefficient and time-consuming, resulting in unnecessary administrative effort and overall wait times. Ultimately, these challenges delay the research translation process, along with its downstream impact on the health of the represented population.

There is also limited overview and traceability of collections, biospecimens and associated data that are available at a national level. The total number of biobanks in Australia, for example, remains unknown. A 2021 analysis of 4 biobank locators from 4 different countries estimated a range of 11 to 30 biobanks per million people across the represented jurisdictions. The New South Wales (NSW) Health Pathology locator was included in the analysis, with an estimate of 9 biobanks per million people: 2 large (>1,000 participants) and 7.1 medium-small (<1,000 participants).[7] While there are limitations in extrapolating the analysis to a national estimate, such a figure infers over 200 biobanks in Australia. Separately, a 2022 analysis of large biobanks in British Columbia (Canada), estimated an average of 164,000 stored biospecimens per million people.[8] While assessed for a different setting and level of investment in health and medical research, applying this figure to the Australian context would indicate an approximate 4.3 million biospecimens in 2022.

State, local and research area-specific initiatives have been established across the country and have made advances towards coordination within their spheres of influence. However, a national framework for human health biobanking is still missing. In its absence, Australia's biobanking landscape has benefited from the support of the Australasian Biospecimen Network Association (ABNA), which provides a setting for sharing protocols, connecting biobanks, and representing the area's interests at a national level. A Biobanking National Research Infrastructure Working Group has also been established and is actively leading and contributing to national efforts to propose timely investments in both digital and physical biobanking components. This includes, for example, the Digital Biobank Australia proposal for a national biospecimen and data discovery platform.

A non-exhaustive list of Australian biobanks identified throughout the development of this study can be found in Appendix C.

3 Coppola L, Cianflone A, Grimaldi AM, Incoronato M, Bevilacqua P, Messina F, Baselice S, Soricelli A, Mirabelli P, Salvatore M (2019) Biobanking in health care: evolution and future directions. Journal of Translational Medicine 17, 172; Rush A, Matzke L, Cooper S, Gedye C, Byrne JA, Watson PH (2019) Research Perspective on Utilizing and Valuing Tumor Biobanks. Biopreservation and Biobanking 17, 219.

4 Rush A, Catchpoole DR, Reaiche-Miller G, Gilbert T, Ng W, Watson PH, Byrne JA (2022) What Do Biomedical Researchers Want from Biobanks? Results of an Online Survey. Biopreservation and Biobanking 20, 271.

5 Annaratone L, De Palma G, Bonizzi G, Sapino A, Botti G, Berrino E, Mannelli C, Arcella P, Di Martino S, Steffan A, Daidone MG, Canzonieri V, Parodi B, Paradiso AV, Barberis M, Marchiò C (2021) Basic principles of biobanking: from biological samples to precision medicine for patients. Virchows Archiv 479, 233; Rush A, Matzke L, Cooper S, Gedye C, Byrne JA, Watson PH (2019) Research Perspective on Utilizing and Valuing Tumor Biobanks. Biopreservation and Biobanking 17, 219; Tarling TE, Byrne JA, Watson PH (2022) The Availability of Human Biospecimens to Support Biomarker Research. Biomarker Insights 17.

6 Dollé L, Bekaert S (2019) High-Quality Biobanks: Pivotal Assets for Reproducibility of OMICS-Data in Biomedical Translational Research. PROTEOMICS 19; Harris JR, Burton P, Knoppers BM, Lindpaintner K, Bledsoe M, Brookes AJ, Budin-Ljøsne I, Chisholm R, Cox D, Deschênes M, Fortier I, Hainaut P, Hewitt R, Kaye J, Litton J-E, Metspalu A, Ollier B, Palmer LJ, Palotie A, Pasterk M, Perola M, Riegman PHJ, van Ommen G-J, Yuille M, Zatloukal K (2012) Toward a roadmap in global biobanking for health. European Journal of Human Genetics 20, 1105.

7 O'Donoghue S, Dee S, Byrne JA, Watson PH (2022) How Many Health Research Biobanks Are There? Biopreservation and Biobanking 20, 224.

8 Tarling TE, Byrne JA, Watson PH (2022) The Availability of Human Biospecimens to Support Biomarker Research. Biomarker Insights 17.

1.3 Drivers behind greater biobanking coordination and harmonisation

All National Research Infrastructure Roadmaps since 2006 have consistently re-iterated the importance of biobanks to Australia's research landscape, noted the current absence of coordination, and acknowledged both the need for, and benefits of, nationally coordinated and networked biobanks.[9] Current momentum for the area is also evident in the allocation of $100 million over 10 years (from 2024–25) for a 'Research data infrastructure initiative' focussed on data registries, biobanks and data linkage platforms, as a dedicated stream of the Medical Research Futures Fund (MRFF).[10] Still, relevant investments are yet to directly address national coordination of biobanking.

Australia's interest in greater coordination is aligned to other countries, however to date, the most significant progress has been seen abroad. This is illustrated by the connection and infrastructure progress made at the national level by the Finnish Biobank Cooperative (FINBB; see Box 1) and transnationally via the Biobanking and BioMolecular Resources Research Infrastructure-ERIC (BBMRI-ERIC; see Box 2). These examples highlight how visibility and increased coordination lay the foundation for integration into international networks and should inform Australia's next steps.

Box 1. National collaboration to drive large-scale biomedical research and impact

FINBB, a national node for BBMRI-ERIC, was founded in 2017 by 6 regional healthcare authorities and 8 biobanks from 6 universities in Finland. FINBB has established a digital services platform to find patients for clinical trial recruitment and to enable search and access of biospecimens, electronic health records and associated health information. In addition to FINBB and its platform, coordination and collaboration at a national scale has enabled FinnGen, a project between pharmaceutical companies, public partners, university hospitals and biobanks. FinnGen is focussed on analysing the genome and longitudinal health data from over 500,000 biobank donors, helping drive biobank and health registry utilisation, return of subsequent data to biobanks, identification of prospective targets for industry partners, and over 1,000 research articles.[11]

Box 2. A supranational entity to support international connectivity and visibility of biobanks

Originally proposed in the 2006 European Roadmap for Research Infrastructures, BBMRI-ERIC today includes 26 countries, surpassing 470 biobanks in its directory in 2025.[12] During 2023, the Directory (one of three modules in its Sample and Data Portal) had 8,924 users, while BBMRI-ERIC itself was involved in 28 projects that support digital infrastructure for transnational collaboration and research across personalised medicine, cancer, cardiovascular health, neurodegenerative diseases and rare diseases.[13]

9 NCRIS Advisory Committee (2006) National Collaborative Research Infrastructure Strategy - Strategic Roadmap February 2006. 32. Australian Government, Canberra; DIISR (2011) 2011 Strategic Roadmap for Australian Research Infrastructure - September 2011. 63 – 65. Australian Government Department of Innovation, Industry, Science and Research, Canberra; Expert Working Group (2016) 2016 National Research Infrastructure Roadmap. 71. Australian Government, Canberra; Expert Working Group (2021) 2021 National Research Infrastructure Roadmap. 54, 88. Australian Government, Canberra.

10 DoHDA (2024) Research Data Infrastructure initiative. Australian Government Department of Health, Disability and Ageing. <https://www.health.gov.au/our-work/mrff-research-data-infrastructure-initiative> (accessed 14 June 2025).

11 Tupasela A, Southerington T, Mäkelä J, Kallio L, Perälä M, Kosma V-M, Mannermaa A, Jokela T, Pitkänen K, Kontro M, Vesterinen T, Punkka E, Knopp T, Ruddock M, Serpi R, Moilanen A-M, Viiri L, Siltanen S, Makkonen E, Ingalsuo P (2025) Estimating the use of biological samples in Finnish biobanks and hospital collections. European Journal of Human Genetics; FinnGen (n.d.) Consortium. About FinnGen. <https://www.finngen.fi/en/consortium> (accessed 15 August 2025).

12 ESFRI (2006) European Roadmap for Research Infrastructures – Report 2006. 48. European Strategy Forum on Research Infrastructures, Luxembourg; BBMRI-ERIC (2025) About us. <https://www.bbmri-eric.eu/about/> (accessed 17 June 2025); Holub P, Swertz M, Reihs R, van Enckevort D, Müller H, Litton J-E (2016) BBMRI-ERIC Directory: 515 Biobanks with Over 60 Million Biological Samples. Biopreservation and Biobanking 14, 559; BBMRI-ERIC, consultation (2025).

13 BBMRI-ERIC (2024) BBMRI-ERIC® The European research infrastructure for biobanking and biomolecular resources in health and life sciences: Annual Report 2023. <https://heyzine.com/flip-book/321324e2ba.html> (accessed 31 July 2025).

2 Valuing increased coordination of Australia's biobanks

2.1 Types and benefits of national coordination

Increased visibility, accessibility and harmonisation of human biospecimen collections and associated data consistently emerged as themes needed in Australian biobanking across consulted stakeholders, echoing the FAIR principles (Findable, Accessible, Interoperable, and Reusable) for scientific data management. This section describes benefits that could be obtained from pursuing coordination initiatives in each theme. **Benefits in bold** represent those that have been quantified in section 2.2.

Visibility

Detailed information on the biological materials and data present across Australian biobanks and cohort studies is key to facilitate subsequent utilisation, particularly of collections that are beyond a user's network or local setting. Traditionally, such information has existed independently, hosted in different laboratory information management systems (LIMS) with inconsistent public searchability, reporting formats and levels of detail.

Increased visibility, particularly through a shared platform, will **reduce the time required for searching, identifying and accessing relevant biospecimens and data**, **minimise overall effort wastage by increasing the success rate for these activities**, and **allow faster redirection of efforts after unsuccessful searches ('failing fast')**. This is done by providing a central 'entry point' to Australia's biobanking landscape and enabling an early estimation of the number of biospecimens that meet quality and inclusion criteria for specific research projects, including linked, or the ability to link, additional health data. Assessing the suitability of existing collections at a national level would be particularly beneficial for research areas with comparatively small donor populations (e.g., cancer subtypes and genetic conditions of comparatively low prevalence) and projects with multiple inclusion criteria, both of which face challenges securing larger numbers of biospecimens. More broadly, estimates of available biospecimens and data could reduce the number of research projects that currently need to reduce their scope or amend original objectives due to a perceived lack of sufficient samples. This can support both research quality and the efficiency of grant opportunities, as projects maintain their intended scope.

The capacity to search at a national level can also **increase the utilisation of existing biobanks and cohort studies,** helping to enhance overall impact and support sustainability over time through collaborative funding or revenue from cost recovery. Paired with the ability to audit and report on the type, volume and characteristics of requested biospecimens and data, a national search capability can increase the alignment between biobank collection effort and user demands, helping to further address under-utilisation and sustainability challenges.[14] Moreover, information on both user demands and existing collections would enable gap analyses to inform biobank repurposing should it become appropriate.

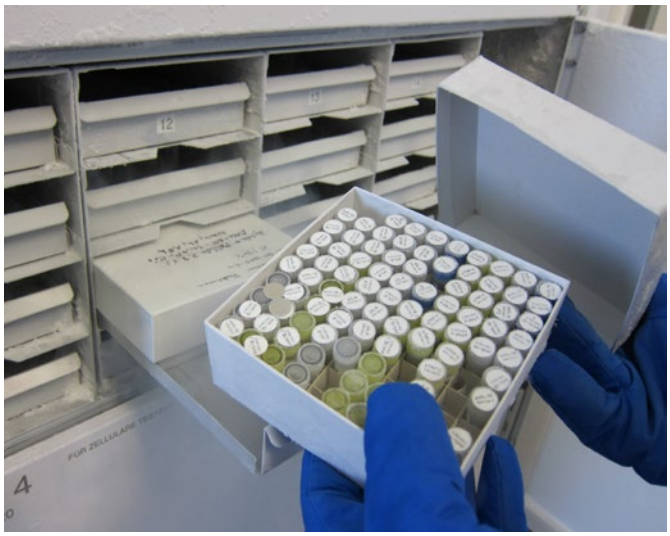
Awareness of previous sample uses, the projects they enabled, and data generated can support subsequent grant applications, highlight opportunities for collaboration, and support the participation of Australian researchers in international consortia. It can also inform decisions on collection consolidation and expansion, collaborations on large-scale initiatives, and planning to service downstream applications like the generation of induced pluripotent stem cells (iPSCs) or provision of advanced disease models (e.g., organoids).

Coordination to increase visibility also facilitates communication of information relating to relevant services provided by biobanks themselves or their host institutions. This may include management of prospective collections, integration with clinical pathways for access to specialised or scarce samples, bioinformatic analyses, or preclinical testing of drug candidates.

Importantly, the discoverability and visibility of human biospecimens and data can also be supported, as done in other countries, by frameworks established by government and funding bodies. This includes requirements to register new and existing data collections in a publicly accessible directory and legislation to provide for biobank registration and oversight (see Box 3).

Box 3. Additional strategies to increase the discoverability and visibility of human biospecimens and data

A shared platform facilitates the identification of suitable biospecimens and associated data across providers, at a national level. However, in other jurisdictions, efforts to increase visibility have been complemented by explicit requirements from medical research funders and legislative frameworks governing the use of human biospecimens. For instance, the 2011 UK Funder's Vision for Human Tissue Resources outlined requirements to register new and existing collections in a publicly accessible directory and provide existing sample metadata on request.[15] Similarly, in Finland, the 2001 Tissue Act enabled the National Authority for Medicolegal Affairs to issue permits for human biospecimen use, resulting in relevant national data. This was complemented by a dedicated Biobank Act in 2013, which set biobank registration and oversight responsibility in the Finnish Medicines Agency; combined access permits for specimens and data; and established pathways for the transfer of legacy collections without re-consent.[16]



14 Henderson MK, Goldring K, Simeon-Dubach D (2019) Advancing Professionalization of Biobank Business Operations: Performance and Utilization. Biopreservation and Biobanking 17, 213.

15 Health Research Authority (2025) Registration of research tissue banks. Research registration and research project identifiers. <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/#tissue> (accessed 4 August 2025); Medical Research Council (MRC), National Cancer Research Institute (2011) UK Funders' Vision for Human Tissue Resources. UKCRC, London. <https://www.ukcrc.org/wp-content/uploads/2014/03/Vision+for+human+tissue+resources.pdf> (accessed 4 August 2025).

16 Tupasela A, Southerington T, Mäkelä J, Kallio L, Perälä M, Kosma V-M, Mannermaa A, Jokela T, Pitkänen K, Kontro M, Vesterinen T, Punkka E, Knopp T, Ruddock M, Serpi R, Moilanen A-M, Viiri L, Siltanen S, Makkonen E, Ingalsuo P (2025) Estimating the use of biological samples in Finnish biobanks and hospital collections. European Journal of Human Genetics.

Accessibility

Utilisation of existing biospecimens and data depends on users successfully navigating the access requirements and constraints of an existing collection. In the absence of a nationally coordinated approach, collections have adopted different access pathways, application formats and assessment timelines, posing a challenge to projects that seek to access multiple collections or link data from separate sources.[17]

Aligning governance and core operating principles can improve overall risk management across Australian biobanks and cohort studies, including compliance with safety requirements, privacy and confidentiality, Indigenous data sovereignty, and culturally safe practices. This is key to maintaining the social licence and trust needed for collecting and re-using human biospecimens and data. Over time, nationally consistent risk management practices may help streamline the overall access process. This includes reducing the timeline for ethics and project reviews and facilitating the development of transfer and access agreements.

A national approach to accessibility, including consistent informed consent models, could maximise the ability to use collected biospecimens and data in future unspecified research. Complemented by increased visibility, this can **reduce duplication of collection efforts and analyses that may already be adequately covered by the biospecimens, data or outputs of existing biobanks.**

Further, nationally consistent governance and access pathways can facilitate the large-scale linkage of new biospecimens and research data with information from medical and clinical sources (e.g., hospital or local health network databases). Connectivity between separate data repositories can enable traceability of biospecimens, technologies used to generate data, and data gaps, all of which are relevant to strategic provision and use. Greater access to biomedical data of various formats (from omics to imaging) that is linked to relevant health information also supports the growth of digital biobanking and the transition to a just-in-time model in which available data sources are used to guide prospective collection efforts, highlighting the specimens that are required as health and research contexts change.[18]

Combined with greater collection visibility and transparency of access processes, coordination to facilitate accessibility can **improve overall R&D return via an increase in the number of research outputs directly enabled by Australian biobanks** (e.g., research publications, guidelines, patents and medical products). Such outputs are a key link to increased representation of Australia's diverse population in biomedical research, faster progress in prevention, diagnosis and treatment of disease, and downstream outcomes in terms of quality of life and/or cost of healthcare.

17 Byrne J, ANZCHOG Biobanking Network (2019) The Australian and New Zealand Children's Haematology/Oncology Group Biobanking Network. Biopreservation and Biobanking 17, 95.

18 Mullan J, Hubbard E (2022) *Letter to the Editor:* A Data-Driven Journey to Just-in-Time Biobanking. Biopreservation and Biobanking 20, 467.

Harmonisation

Distinct operating conditions have resulted in the adoption of different practices across Australian institutions, which can compromise comparability and reproducibility between studies and locations. Adoption of a consistent quality management framework at the national level ensures the use of best practices across biospecimen collection, pre-analytical processing, storage, analysis and data processing, helping minimise and document sources of variability.

For instance, harmonisation of protocols, metadata and minimum data standards will result in more consistent data quality and inter-operability across collections. This can support larger cohort studies that need to pool biospecimens or results from different sites, help achieve sufficient statistical power (e.g., in large-scale genomic studies), and promote conditions that benefit study reproducibility. Establishing larger cohorts across institutions enables the validation of results against the Australian population itself, minimising the need to rely on proxy data from other countries. This capability is key to ensure accurate representation of Australia's history and current diversity, both of which have a direct impact on clinical translation of research findings and medical products.

Similarly, adopting a national framework for career development and progression specific to biobanking can help harmonise core roles and functions, position descriptions, and associated salaries across institutions. This promotes formal recognition of the area and employment pathways across different biobanks. Moreover, it encourages specialised training and education in operating protocols, best practices in data management, privacy and consent. Expertise in most or all these areas is required in some biobanking roles given funding limitations.

Finally, harmonisation of both protocols and professional development frameworks could create efficiencies of scale for conducting specialised analyses (e.g., long-read genomic sequencing) and help reduce establishment and maintenance costs for new collections within existing biobanks, by leveraging shared infrastructure, established practices and qualified personnel.

2.2 Estimating the direct financial value of increased coordination via a shared national platform for biospecimen and data search and access

This section focusses on the concept of a shared national platform for biospecimen and data search and access. Within this narrower context, six of the benefits outlined in section 2.1 were selected for quantitative assessment based on feasibility, mutual exclusivity, and practicality within the time constraints of the project (see Table 2). As such, the findings represent only a partial estimate of the true value of a shared national platform.

The analysis compares the current state and a future state. In the current state, biobanks operate as locally managed, decentralised entities. In the future state, these individual biobanks are coordinated through a shared national platform. Table 2 presents a description of the benefits and an estimate of their annual economic value to Australia. The totalled modelled benefits came to $39 million per year, with benefits arising from avoided cost of biospecimen collection and increased biobank utilisation making up over two thirds of the total.

Model assumptions were developed based on data collected from stakeholder interviews and were supplemented with benchmarking against available literature where applicable. As such, the findings should be interpreted as preliminary 'order of magnitude' estimates and used to facilitate further conversations and analyses. A more detailed methodology can be found in Appendix B.

While the project did not involve estimating the cost of establishing and maintaining a shared national platform, the annual benefits can be better contextualised when considered alongside the operating costs of entities with large-scale platforms for searching and accessing biospecimens. For example, BBMRI-ERIC reports an average annual operating expense of approximately AUD 5.81 million for its headquarters.[19] Only a portion of this amount relates to the operation and maintenance of their cross-national search and access platform.[20]

Finally, as described in Appendix B, there are limitations to the analysis that future research can help address. Subsequent analyses could assess the rate of adoption, explore its associated challenges, and use a larger sample size that accounts for user clusters to more accurately estimate modelled benefits.

Table 2: Quantified benefits findings

BENEFIT	DESCRIPTION	ANNUAL VALUE
Reduction in search and access time for successful searches	Occurs when usable biospecimens or data are successfully accessed in both the current and future state, but the effort required to search for and access them is reduced in the future state.	**$7.64m**
Avoided time wastage from failed searches	Occurs when time wastage from unsuccessful searches is avoided in the future state. In the current state, users may spend time searching for biospecimens or data but fail to find what they need, despite it existing, resulting in unproductive effort.	**$0.29m**
Avoided cost of biospecimen collection	Occurs when duplication of collection efforts is avoided in the future state. In the current state, limited visibility can lead users to collect biospecimens and data that are adequately covered by existing biobanks.	**$19.15m**
Faster failing	Occurs when a usable biospecimen is unavailable in both states, but this can be more quickly and confidently determined in the future state, allowing researchers to fail faster and redirect efforts.	**$0.69m**
Additional R&D projects	Occurs when increased data visibility in the future state enables additional R&D benefits by allowing projects to proceed that would have been discontinued in the current state.	**$3.62m**
Increased biobank utilisation	Occurs when usable biospecimens or data are not accessed by the researcher in the current state but are found and accessed in the future state due to increased visibility, leading to greater biospecimen utilisation.	**$7.91m**
Total		**$39.31m**

19 Based on a five-year average (2019–2023) of annual operating expenses for BBMRI-ERIC headquarters, compiled from the annual report 2023 and converted to AUD $ 2024. National nodes and individual biobanks have separate operating costs. The report is publicly available: BBMRI-ERIC (2024) BBMRI-ERIC® The European research infrastructure for biobanking and biomolecular resources in health and life sciences: Annual Report 2023. <https://heyzine.com/flip-book/321324e2ba.html> (accessed 31 July 2025).

20 The total expense includes operation and maintenance of their searchable platform (the Sample and Data Portal), core management and executive functions, and services across Quality Management; Ethical, Legal and Social Issues (ELSI); and Biobanking Development. BBMRI-ERIC (2025) Consultation.

3 Recommendations to support the development of a coordinated biobanking capability in Australia

This section describes recommendations that would be required to pursue the coordination themes and associated benefits identified in section 2. These recommendations – summarised in Table 3 – have natural synergies and were developed and refined by consulted stakeholders. Implementation of the recommendations may be best led by a governance structure with adequate decision-making power and representatives from key stakeholder groups. This will require the participation of Commonwealth government entities, state and territory health departments, health research funders, NCRIS-supported organisations, biobank networks, research institutions, and other custodians of relevant health data.

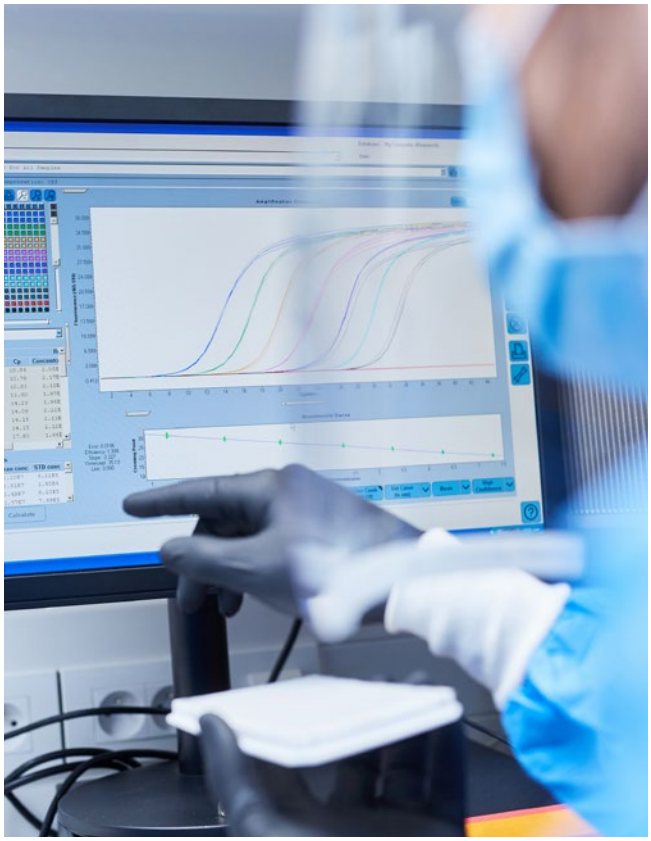


Table 3: Recommendations to support the development of a coordinated biobanking capability in Australia

VISIBILITY	ACCESSIBILITY	HARMONISATION
Recommendation 1: Conduct a comprehensive survey of biobanks and cohort studies hosted across Australia to identify existing collections, document their access conditions, and characterise their core operating practices.	**Recommendation 3:** Establish a national governance framework for human health biobanking that aligns custodian responsibilities and harmonises access processes across ethics, privacy, data stewardship, material transfer and data access agreements.	**Recommendation 4:** Promote a consistent quality management framework at the national level and support a stepwise process for individual entities to implement it.
Recommendation 2: Implement a shared national platform to search, and apply for access to, biospecimens and associated data across Australian biobanks and cohort studies.		**Recommendation 5:** Establish a national steering committee that guides and oversees progress of large-scale coordination initiatives to promote visibility, accessibility and harmonisation.

Visibility

Providing a unified pathway to explore Australia's biobanking capabilities requires updated information on collections across the country, a reliable environment for handling sensitive data and a centralised setting that maximises data availability.

Recommendation 1: Conduct a comprehensive survey of biobanks and cohort studies hosted across Australia to identify existing collections, document their access conditions, and characterise their core operating practices.

This activity could leverage existing information and established relationships from local and statewide locators, state-based networks and working groups, research area-specific consortia, and ABNA.

A comprehensive survey of Australia's biobanking landscape would also support Recommendations 2 and 3 and inform state and Commonwealth initiatives, by:

- Documenting needs across locations and institutional settings.
- Identifying barriers to participation in visibility and accessibility coordination efforts across restricted- and open-access collections.
- Informing a national strategy and governance framework for the area.
- Assessing data availability for a shared national platform.

Recommendation 2: Implement a shared national platform to search, and apply for access to, biospecimens and associated data across Australian biobanks and cohort studies.

Leveraging the insights collected in Recommendation 1, this will require close engagement with Australian biobanks, national biobanking networks, national research infrastructures, cohort studies, data custodians and international consortia to ensure that the platform is inter-operable and capable of detailed querying and comparison of existing resources. Functional aspects considered important by consulted stakeholders include:

- Advanced search functionality to allow querying at the individual biospecimen and dataset level, based on demographic, clinical, and analytical parameters.
- Public preview of the specific variables and data types available in the national platform. The Dementias Platform UK Data Portal is an example of this design, providing a summary of sociodemographic data, physical and mental health status, lifestyle, and genomics data available. Its publicly available overview facilitates search and consideration by prospective users, which can use dedicated matrix tools and a data explorer for comparisons across cohorts.[21]
- Provision of suitable templates for material transfer and data access agreements. This would help address one of the most time-intensive segments of the access pathway for end-users, reducing both unnecessary duplication of effort and administrative processing timelines across institutions.
- Identification and traceability of individual biospecimens throughout their management lifecycle, including collection, processing, and provision for subsequent use. This would help record procedures undertaken, maintain up-to-date information on availability, and link research outputs resulting from use.
- Linkage of biospecimens and datasets with relevant health information present in clinical, administrative and research sources (including other Australian biobanks and studies) wherever possible given consent, ethics and privacy compliance.
- Provision of both raw and processed data in internationally standardised formats after approval of access.

Suitable governance and technical structures will also be needed to implement a shared national platform. This could involve:

- Developing a hybrid funding and governance mechanism for the platform. This would leverage inputs from research institutions, government, and industry to facilitate long-term sustainability; maintain a balance between the needs, priorities and interests of each stakeholder group; help address participation barriers for small and regional institutions; and facilitate access for commercial projects where viable given custodian restrictions.
- Promoting and facilitating adoption of a secure, federated digital research environment capable of both interacting with the information management systems used by different institutions and enabling cross-institutional and cross-jurisdictional data sharing. A relevant digital research environment to support interoperability across a national network of sites is BioGrid (BioGrid Australia). Secure research workspaces for individual institutions are available from Australian institutions, including ERICA (E-Research Institutional Cloud Architecture, UNSW) and SURE (Secure Unified Research Environment, Sax Institute).[22]
- Adopting a common framework, terminology and minimum set of fields covering demographic, clinical, biological and sample information to be linked to the biospecimens or data collected. The Minimum Information About Biobank Data Sharing (MIABIS) Core is a relevant example, being developed and maintained for use within BBMRI-ERIC.[23]

21 DPUK (2022) DPUK Data Portal Annual Report 2022. Dementias Platform UK. <https://portal.dementiasplatform.uk/wp-content/uploads/2023/07/DATA_PORTAL_ANNUAL_REPORT-FINAL.pdf> (accessed 21 July 2025); DPUK (n.d.) Discovery Tools. <https://portal.dementiasplatform.uk/data/discovery-tools/>

22 BioGrid Australia (2025) How does BioGrid work? <https://www.biogrid.org.au/how-biogrid-works> (accessed 21 July 2025); Sax Institute (2025) Safely share data with SURE. Solutions. <https://www.saxinstitute.org.au/solutions/sure/safely-share-data-with-sure/> (accessed 21 July 2025).

23 Eklund N, Engels C, Neumann M, Strug A, van Enckevort E, Baber R, Bloemers M, Debucquoy A, van der Lugt A, Müller H, Parkkonen L, Quinlan PR, Urwin E, Holub P, Silander K, Anton G (2024) Update of the Minimum Information About Biobank Data Sharing (MIABIS) Core Terminology to the 3rd Version. Biopreservation and Biobanking 22, 346.

Accessibility

The impact of biobanks and cohort studies relies not only on the visibility of biospecimens and data available but also on the implementation of reliable access pathways and trusted practices.

Recommendation 3: Establish a national governance framework for human health biobanking that aligns custodian responsibilities and harmonises access processes across ethics, privacy, data stewardship, material transfer and data access agreements.

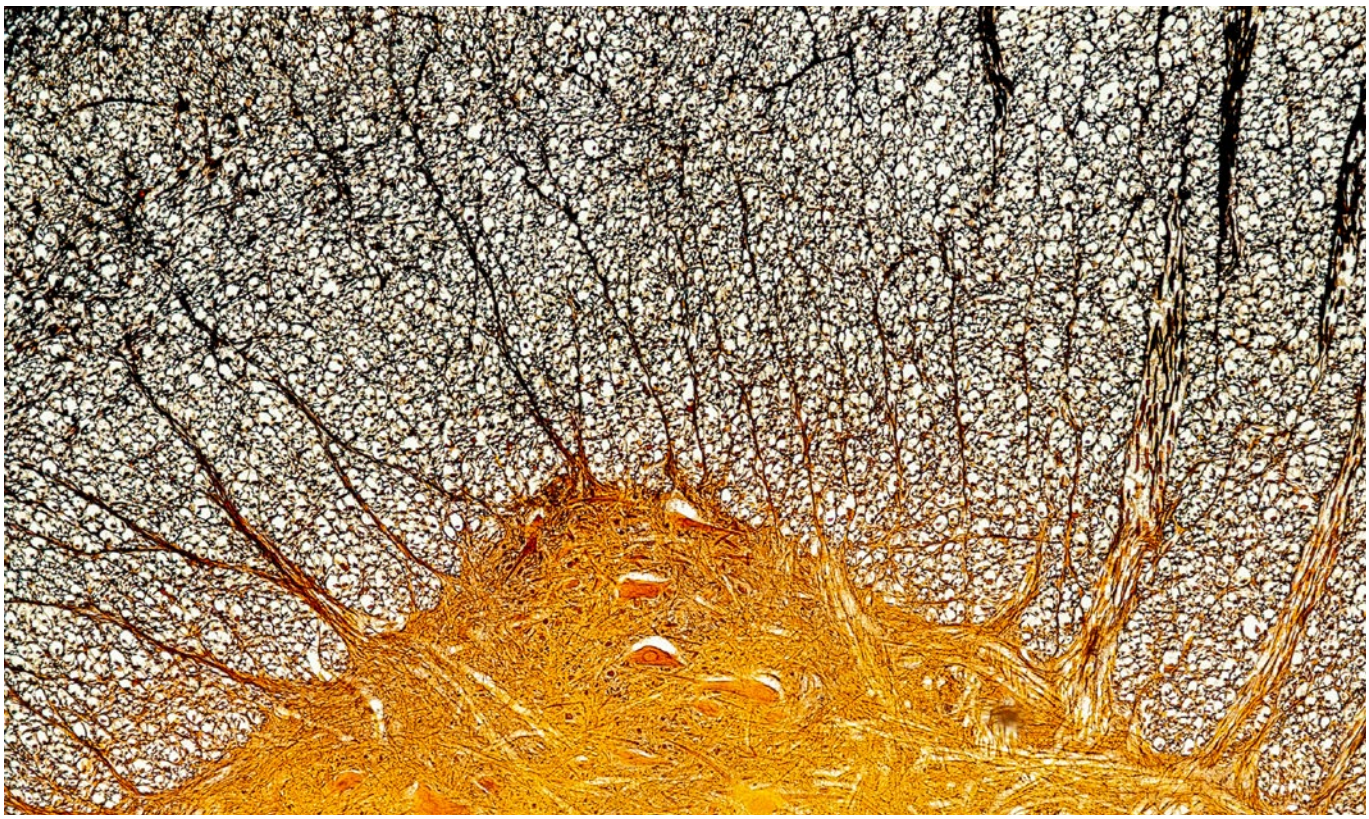
A national governance framework can promote a consistent approach to quality, streamline interactions between institutions, and simplify access to multiple collections. Supported by the information obtained via Recommendation 1 and the stakeholder engagement provided by Recommendation 5, such a framework will require a collaborative effort to:

- Promote transparency and clear communication of the access processes currently implemented in each collection. This can serve as an initial step towards harmonisation and helps potential users understand the specific pathway and requirements to access biospecimens and data from existing collections.
- Standardise the access process across Australian institutions. This includes defining consistent process steps, document requirements, submission formats, and baseline access or transfer agreements for biospecimen and dataset owners and prospective users.
- Harmonise the process for ethics and privacy assessment of projects seeking access and use of biospecimens and data hosted by Australian biobanks and cohort studies. To support this, the framework could promote the adoption of consistent requirements, biobanking-specific guidelines (see Recommendation 5), and a single application format, such as the National Health and Medical Research Council (NHMRC) Human Research Ethics Application (HREA).[24]
- Adopt a broad consent model with nationally standardised terms, that explicitly accounts for unspecified future use of biospecimens and data for research purposes and provides an opt-out mechanism to participants. Integrating the consent model as part of the NHMRC registration for human research ethics committees (HRECs) could support the adoption process. Existing biospecimens and data under pre-existing consent models will also require a nationally consistent mechanism to update possible uses and limitations, while ensuring donor and community consultation.
- Develop provisions that ensure Indigenous data sovereignty, First Nations-led governance, and culturally safe biobanking practices.
- Establish the legislative, ethics and consent arrangements needed for expedited application review and access during public health emergencies, to enable a streamlined and collaborative national response.
- Select and promote a well-defined certification structure to be used and recognised nationally for Australian biobanks, to ensure consistency, clear communication of requirements, and progression towards the international biobanking standard where appropriate.

Given the differences in relevant legislation and oversight structures between states and territories, implementation of this recommendation and its underlying actions at the state-level may be a beneficial first step. Further, adoption of a nationally aligned governance framework, including harmonisation of access processes, may be done prospectively for new biobanks, cohort studies and networks. However, retrospective adoption in existing collections is more challenging and may require a mechanism that supports and incentivises the transition.

Given the shift from the current state, the governance aspects presented in this recommendation need to be considered, planned and implemented in a way that mitigates the barrier to change for all institutions involved.

24 NHMRC (n.d.) Human Research Ethics Application form. Research Policy. <https://www.nhmrc.gov.au/research-policy/ethics/human-research-ethics-application-form> (accessed 14 August 2025).



Harmonisation

Activities performed across the biospecimen and data management lifecycle vary between projects and institutions. Without a consistent approach to quality and documentation of procedures, differences can affect the ability to use existing resources in subsequent projects, driven by considerations of comparability of results and study reproducibility.

Recommendation 4: Promote a consistent quality management framework at the national level and support a stepwise process for individual entities to implement it.

An international standard specific to biobanking is available (ISO 20387:2018), with accreditation to it representing an ideal and an important consideration for integration with international networks and industry collaborations. However, direct accreditation can be time and resource intensive, potentially being out of reach for entities that operate under funding constraints. A stepwise process that begins with a nationally available biobank certification program can support the overall pathway. The certification program, which may be scaled up from existing state equivalents (e.g. NSW Health Biobank Certification Program), [25] can promote a consistent approach to quality, while providing a base for Australian entities to advance to the international standard for quality management, and ultimately the biobank-specific standard. The latter two, could be considered based on relevance to each entity's objectives and resource availability.

As noted in Recommendation 2, harmonisation also relies on adequate documentation and transparent communication of the protocols used across collection, handling, quality control and storage, with direct linkage to each biospecimen or dataset.

25 NSW Health Statewide Biobank (2025) Biobank Certification Program. <https://biobank.health.nsw.gov.au/certification/> (accessed 15 August 2025).

Finally, consulted stakeholders noted the need for a national governance mechanism to guide large-scale coordination initiatives such as those described in the other recommendations.

Recommendation 5: Establish a national steering committee that guides and oversees progress of large-scale coordination initiatives to promote visibility, accessibility and harmonisation.

Given its national scope, the steering committee would benefit from being led by a Commonwealth government entity with oversight of human health research, to ensure formalised responsibilities and funding. Further engagement will be required to identify the appropriate entity and develop a framework that establishes and empowers the committee.

The Biobanking National Research Infrastructure Working Group, which is co-chaired by, and includes members from, senior leaders of key biobanking and national research infrastructure entities, offers a strong basis for the proposed steering committee. This working group is actively engaged with the Commonwealth government in developing investment proposals for national digital research infrastructure (including the Digital Biobank Australia proposal), with the 2026 national research infrastructure roadmap consultations, and the preparation of this report. A new steering committee could leverage work undertaken by this Biobanking Working Group, the NCRIS Health Group and others to develop a more coordinated approach to biobanking in Australia.

The steering committee would include representatives of key stakeholder groups, including state and territory health departments, health research funders, biobanks, community participants, biobanking networks, cohort studies, NCRIS-supported organisations, universities, medical research institutes, and other custodians of relevant health data.

In addition to enacting the Recommendations outlined in this report, a national steering committee could guide cross-institutional and cross-jurisdictional collaboration to:

- Develop and promote consistent guidance on long-term sustainability for Australian biobanks and appropriate cost recovery models for academic and commercial users.
- Develop a strategic, coordinated approach to funding and investment in human health biobanking that is aligned to areas of national interest, unmet need, benefit for vulnerable communities, and opportunity to advance and support key research infrastructure.
- Consider formats for the explicit inclusion of costs and benefits of biobank use in grant applications and funding mechanisms to promote utilisation of existing collections to answer new research questions.
- Consolidate and disseminate lessons from previous state and national coordination initiatives, particularly on barriers to implementation, country-wide and state-specific challenges, successful approaches, and relevant progress to build upon.
- Design, develop and implement platforms for data integration across different modalities and sources (e.g., omics data obtained from a biospecimen, health information from follow-up surveys, and imaging data from clinical sources).
- Inform the update and harmonisation of Human Tissue Acts across states and territories for consistency on key definitions and conditions for the use of human biospecimens in research, accounting for current differences based on source (e.g., biospecimens obtained from a donation intended for transplantation or from an activity with a valid clinical purpose).[26]
- Support the development of ethical guidelines and legislative pieces specific to the use and access of biospecimens and data available in Australian biobanks and cohort studies.
- Explore increased integration of biobanks with routine clinical practice and a shift in national strategy towards a population-based biobanking capability, supported by reliable digital infrastructure, data linkage and just-in-time collection approaches.

26 ALRC (2025) Review of Human Tissue Laws: Issues Paper. Australian Law Reform Commission Issues Paper 51, 2025. <https://www.alrc.gov.au/wp-content/uploads/2025/05/HT-issues-paper-2025.pdf> (accessed 25 July 2025).

Appendices

Appendix A – Consulted stakeholders

CSIRO would like to thank the following organisations for their contributions to the project through interviews and reviews. The insights expressed throughout this report were developed by considering the collective views obtained alongside independent economic and qualitative research. They may not always align with the specific views of one of the consulted individuals or organisations. This list is not to be interpreted as an endorsement or promotion of this report.

- Australasian Biospecimen Network Association (ABNA)
- Biobanking and BioMolecular Resources Research Infrastructure-ERIC (BBMRI-ERIC)
- Busselton Population Medical Research Institute (BPMRI)
- CSIRO
- GeneSeq Biosciences
- Kolling Institute
- Mark Hughes Foundation Centre for Brain Cancer Research
- Mater Research
- Monash University
- NSW Health
- NSW Health Statewide Biobank
- Olivia Newton-John Cancer Research Institute (ONJCRI)
- Peter MacCallum Cancer Centre
- Queensland Health
- Queensland University of Technology (QUT)
- RhythmBio
- Tissue Repository of Airway Cancers for Knowledge Expansion of Resistance (TRACKER)
- University of Adelaide
- University of Melbourne
- University of New South Wales (UNSW)
- University of Newcastle
- University of South Australia
- University of Sydney
- University of Tasmania
- Victorian Cancer Biobank
- Walter and Eliza Hall Institute (WEHI)

Appendix B – Economic analysis methodology

CSIRO Futures conducted an economic analysis to quantify the value of coordinating existing biobank collections in Australia through a shared national platform. This appendix summarises the results, parameters and methodology used to produce the estimates presented in this report.

The analysis compares two states – the current state and a future state. In the current state, biobanks operate as locally managed, decentralised entities. In the future state, these individual biobanks are coordinated through a shared national platform. It is assumed that the volume and type of biospecimens and data remain the same in both states except where duplication of collection efforts occur.

In the current state, researchers commonly search for usable biospecimens and data by leveraging professional networks or contacting biobanks directly via email. In the future state, it is assumed that all users would instead utilise the national searchable platform to streamline this process. For this to hold, biobanks would need well-functioning inventory management systems that are compatible with and integrated into the national platform to ensure visibility and coordination. While this assumption reflects how the platform is intended to be used, it is acknowledged that in practice, some users may continue to rely on informal channels.

Estimating demand for domestic biobanks and cohort studies

To assess the potential benefits for users, it is necessary to estimate the current level of demand for domestic biobanks and cohort studies (i.e., collections). Figure 1 illustrates the approach used to estimate current demand in terms of research activity.

Figure 1: Estimate of current demand for biobanks and cohort studies in terms of research counts

A bibliometric analysis was performed to estimate the average number of publications involving domestic biobanks and cohort studies over the past 10 years (2015–2024), as a baseline indicator of demand for existing collections. Top-down and bottom-up search strategies were used in the Web of Science (WoS) Core Collection to identify publications that (i) are related to biobanking or cohort studies and (ii) are linked either to authors with an Australian affiliation or to a reliably identified Australian biobank or cohort study.

The top-down approach used the Medical Subject Headings (MeSH) associated with 'biobank' and 'cohort study' as search terms to capture outputs without direct linkage to a specific entity (biobank or cohort study), and to account for entities not explicitly included in the bottom-up search. Secondary outputs (e.g., review articles), non-human health areas and outputs with non-Australian affiliations were excluded from the initial dataset via the Document Type, Research Area and Countries/Regions filters, respectively. The Countries/Regions filter was used as a strict criterion, where any non-Australian affiliation resulted in exclusion. This minimises outputs from biobanks and cohort studies that are in other jurisdictions but also results in a more conservative estimate of overall Australian outputs.

The bottom-up approach used two separate lists of known biobank and cohort study names. The first list covered Australian biobanks (and their relevant name variants), as identified via domestic biobank locators, desktop review, and stakeholder engagement. The second list covered Australian cohort studies and biobanks present in the dataset used by Dorantes-Gilardi et al. (2025).[27] Names in each list were used as search terms, with secondary outputs and non-human health areas excluded from the resulting dataset via filtering. The Countries/Regions filter was used as a soft criterion, to refine the dataset to outputs with at least one Australian affiliation. This allowed the inclusion of outputs resulting from international collaboration while accounting for similar names in other jurisdictions.

The datasets from each approach were merged in WoS to eliminate duplicates, with the result filtered in the same way as the bottom-up approach to obtain the yearly number of publications.

While consulted stakeholders indicated that a proportion of research using existing collections might not acknowledge the use of a biobank in a consistent way, a reliable estimate of this potential under-attribution was not identified and so the analysis assumed it to be 0%. In addition, biospecimen and data use in industry-supported research is likely under-represented in the published literature, as not all research conducted results in a publication.[28]

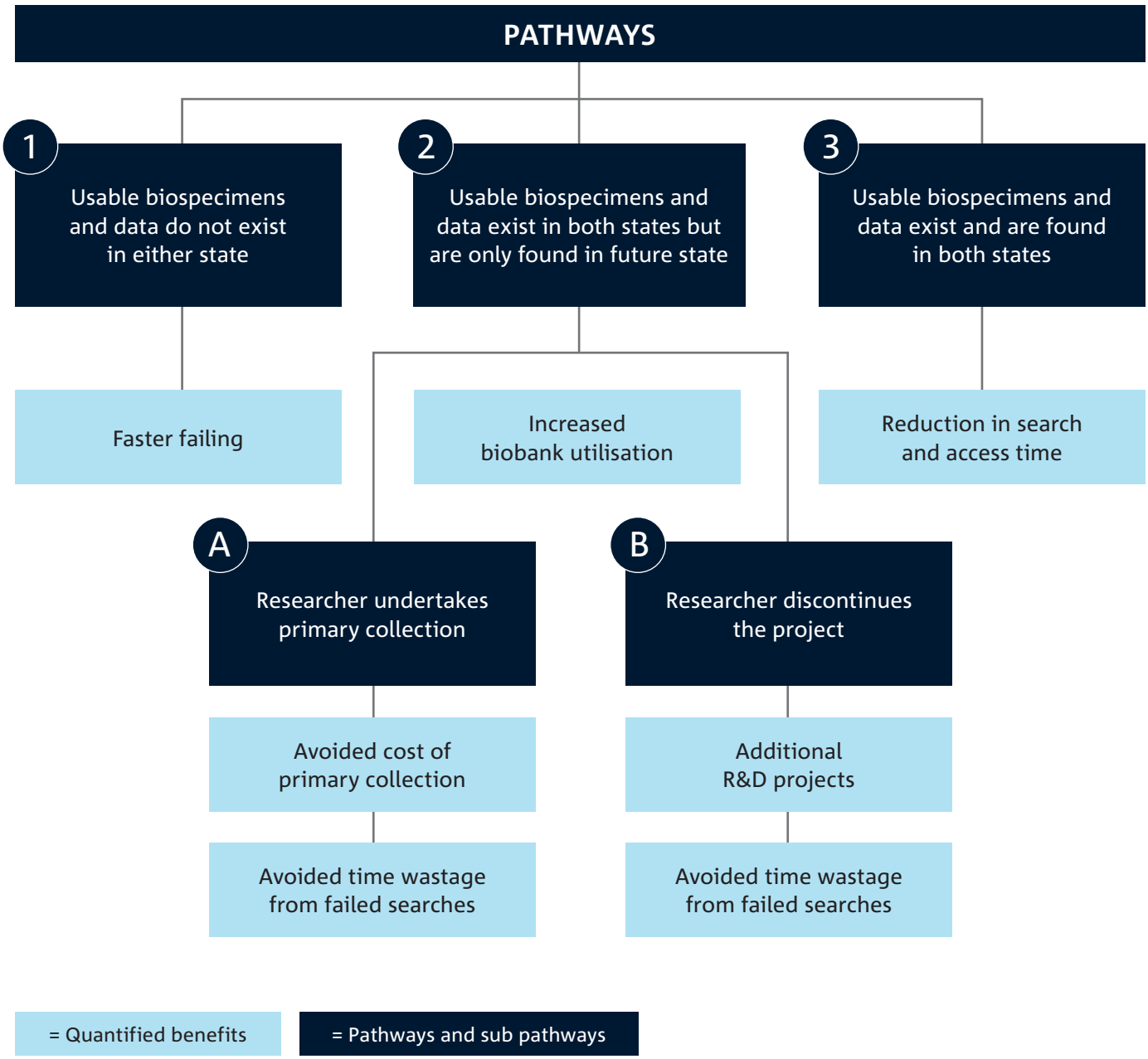
27 Dorantes-Gilardi R, Ivey KL, Costa L, Matty R, Cho K, Gaziano JM, Barabási A-L (2025) Quantifying the impact of biobanks and cohort studies. Proceedings of the National Academy of Sciences 122.

28 Tarling TE, Byrne JA, Watson PH (2022) The Availability of Human Biospecimens to Support Biomarker Research. Biomarker Insights 17.

To reflect this, an adjustment is applied to account for collection use in unpublished research. It is also recognised that some research projects may have intended to use existing collections but ultimately did not, because relevant biospecimens or data were either unavailable or unsuitable. To capture this unmet demand, an additional adjustment is included to account for research that failed to access collections for these reasons. Together, these adjustments provide a more comprehensive estimate of current demand.

The current annual demand for biobanks and cohort studies, measured by the number of research projects, is estimated at n **= 2385**. The benefit was estimated based on this current demand for domestic biobanks and cohort studies. While demand may increase in the future state due to reduced search and access times, potentially attracting users who previously relied on international biobanks, this potential uplift was not captured in the model due to a lack of supporting evidence.

Figure 2: Pathways through which the quantified benefits of a national shared platform can arise



Estimating benefits of a shared national platform

Benefits can emerge through three primary pathways as illustrated in Figure 2; each associated with an estimated probability of occurrence.

Pathway 1: The required biospecimens and data do not exist in either the current or future state and therefore cannot be found by the researcher. In the future state, a searchable platform enables faster determination of unavailability, leading to time savings compared to the current state.

Pathway 2: The required biospecimens and data exist in both the current and future state but remain unfound in the current state due to limited visibility, while a searchable platform in the future state facilitates their discovery. This leads to greater utilisation of existing resources and increased cost recovery for biobanks.

In this pathway, the researcher typically faces two options in the current state: (A) initiate their own primary collection, or (B) abandon the project. These decisions are influenced by factors such as funding availability, ease of collecting required biospecimens or data (e.g. challenging for rare diseases), and the complexity of ethical or regulatory approvals, which may act as a barrier to initiating new collection efforts. If the researcher undertakes their own primary collection in the current state despite a usable biospecimen or dataset existing, the future state results in avoided collection costs and time savings. Alternatively, if the project is discontinued in the current state, the future state enables the project to proceed, thereby avoiding the loss of R&D returns and saving time.

Pathway 3: Usable biospecimens and data exist and are accessed in both the current and future state. Similar to pathway 1, the future state yields a benefit through reduced search time compared to the current state. Additionally, it is assumed that the future state will reduce access times through streamlined and potentially harmonised application processes across biobanks, further enhancing efficiency.

In all three pathways, time savings arising from using the new platform is assumed to accrue to both the requester (i.e. the biobank user) and their contact (either someone in their professional network or a biobank). When professional networks are used, the search burden is assumed to be symmetric.[29] When biobanks are contacted, it is assumed that a searchable platform would reduce a portion of the time otherwise spent by biobank staff on manual responses.

The assumptions used to estimate the magnitude of benefits under each pathway are outlined in Table 4 below, along with the corresponding calculations in Table 5. The assumptions in this analysis were primarily informed by stakeholder consultations. The relatively small sample size may limit the representativeness of the responses. Future work could involve a broader survey with a larger and more diverse sample, accounting for different user clusters that interact with the platform.

Upon conducting a sensitivity analysis, the result was found to be most sensitive to the assumption regarding the success rate of finding usable biospecimens and data under the current state.

Table 4: Summary of parameters[30]

PARAMETERS	UNITS	VALUE	SOURCE
A. Success rate of finding usable biospecimens and data under the current state	%	70	Biobank user consultations
B. Success rate of finding usable biospecimens and data under the future state	%	77.9	Biobank user consultations
C. Median search time under the current state if successful	*Days*	0.833	Biobank user consultations
D. Median time spent on an unsuccessful search in the current state	*Days*	2.50	Biobank user consultations
E. Median search time under the future state if successful	*Days*	0.458	Biobank user and biobank consultations
F. Median time spent on an unsuccessful search in the future state	*Days*	1.00	Biobank user consultations
G. Search Method: Probability of reaching out to your existing professional network to find usable biospecimens and data	%	64.7	Biobank user consultations
H. Search Method: Probability of contacting biobanks directly via email or formal enquiry to find usable biospecimens and data	%	23.5	Biobank user consultations
I. Excess time spent searching by a biobank in the absence of a shared national platform	*Days*	0.683	Biobank consultations

Table 4 continued over page

29 For example, if a researcher spends three hours of active time drafting emails to three contacts in search of suitable biospecimens and/or data, it is assumed that the three contacts collectively spend a similar amount of active time responding.

30 All monetary values are presented in Australian dollars (AUD), adjusted to 2024 prices when possible.

Table 4 continued

PARAMETERS	UNITS	VALUE	SOURCE
J. Probability of initiating primary collection	%	95	Biobank user consultations
K. Probability of discontinuing the project	%	5	Biobank user consultations
L. Median active time required to access one biobank[31]	*Days*	0.60	Biobank user consultations
M. Median total access time in the current state	*Years*	0.417	Biobank user consultations
N. Median total access time in the future state	*Years*	0.288	Reference 32
O. Median cost recovery per sample	*AUD* $	157	Reference 33
P. Median cost of collection per sample	*AUD* $	400	Biobank user and biobank consultations
Q. Average number of biospecimens or data samples required per research study[34]	#	269	Biobank user consultations
R. Average researcher salary per day	*AUD* $	400	Reference 35
S. Average R&D return for biomedical research	%	290	Reference 36
T. Average investment per research publication	*AUD* $	266,666	Reference 37
U. Lag time between investment and research benefits	*Years*	10	Reference 36
V. Discount rate[38]	%	5	Reference 39
W. Proportion of users accessing more than one biobank to meet their research requirements	%	53	Reference 40
X. Median number of biobanks accessed if accessing > 1	#	2.75	Biobank user consultations
Y. Average salary of biobank staff per day	*AUD* $	396	Reference 41
Z. Percentage of additional benefits that would have resulted from the project not being undertaken	%	50	CSIRO assumption[42]

31 Active access time is the time actively spent by a biobank user to obtain access to biospecimens and data, which may include completing application forms, material transfer agreements (MTAs), follow-ups, and related tasks. The median active time required to access a single biobank is assumed to remain the same in both the current and future state.

32 UK Biobank (2024) How soon do I get access to the data after I have submitted my application? Categories – Get started with UK Biobank. <https://community.ukbiobank.ac.uk/hc/en-gb/articles/15006910060317-How-soon-do-I-get-access-to-the-data-after-I-have-submitted-my-application> (accessed 18 August 2025); UK Biobank (2011) ACCESS PROCEDURES: Application and review procedures for access to the UK Biobanks Resource. UK Biobank Coordinating Centre, Version 1.0, Stockport, UK.

33 A weighted median cost was calculated using fee data for academic and commercial archival samples from the Victorian Cancer Biobank, assuming that academics comprise 88% of biobank users and commercial entities 12%. It was also assumed that for each biospecimen, associated data on staging, diagnostic markers, treatment, medications, and comorbidities is often procured simultaneously. Victoria Cancer Biobank (2025) Archival samples. Our services. <https://viccancerbiobank.org.au/services/archival> (accessed 18 August 2025).

34 Although researchers typically have to settle for smaller sample sizes when collecting prospective biospecimens and data compared to accessing retrospective samples, for simplicity we assumed the sample size would be equal in both cases.

35 The average annual salary for a researcher or biobank user was estimated based on the average wages of positions relevant to biobank users listed on Seek and Glassdoor. This figure was then divided by the total number of working days in a year to estimate a daily salary rate.

36 Association of Australian Medical Research Institutes (2018) Economic Impact of Medical Research in Australia. KPMG. <https://aamri.org.au/wp-content/uploads/2018/10/Economic-Impact-of-Medical-Research-full-report.pdf> (accessed 18 August 2025).

37 Expenditure per health and medical research publication is used as a proxy for average research investment per publication. This is considered reasonable given the assumption that, in academic research, funding closely approximates actual expenditure. Mendis K, Bailey J, McLean R (2015) Tracking Australian health and medical research expenditure with a PubMed bibliometric method. Australian and New Zealand Journal of Public Health 39, 227.

38 The discount rate is used to calculate the present value (PV) gain from shorter access times in the calculation steps table.

39 CHERE (2022) Review of the Discount Rate in the PBAC Guidelines. University of Technology Sydney Centre for Health Economics Research and Evaluation. <https://ohta-consultations.health.gov.au/ohta/review-of-discount-rate-in-the-pbac-guidelines-pha/supporting_documents/Review%20of%20the%20Discount%20Rate%20%20Report.pdf> (accessed 4 September 2025).

40 Rush A, Catchpoole DR, Reaiche-Miller G, Gilbert T, Ng W, Watson PH, Byrne JA (2022) What Do Biomedical Researchers Want from Biobanks? Results of an Online Survey. Biopreservation and Biobanking 20, 271.

41 The median average wage for the positions of Biobank Project Officer and Research Officer, based on data from Seek, was used under the assumption that these roles would undertake the searching in biobanks. This figure was then divided by the number of working days in a year to estimate a daily rate.

42 It is assumed that the biobank user will always begin with the project expected to yield the highest research benefit. In practice, this may not occur due to irrational behaviour or because the researcher may not be aware of the potential findings until the research is undertaken. An arbitrary assumption has been made that the project given up would have generated 50% more benefit.

Table 5: Calculation Steps[43]

BENEFITS	CALCULATIONS
Faster failing	$= \mathrm{P}(pathway\ 1) \times n \times [Time\ saved\ by\ the\ researcher + Time\ saved\ by\ professional\ networks + Time\ saved\ by\ biobanks]$ $= (1 - B) \times n \times \{[(D - F) \times R] + [G \times D \times R] + [H \times I \times Y]\}$
Increased biobank utilisation	$= \mathrm{P}(pathway\ 2) \times n \times Average\ cost\ recovery\ per\ research$ $= (B - A) \times n \times [O \times Q]$
Avoided cost of primary collection	$= \mathrm{P}(pathway\ 2) \times \mathrm{P}(subpathway\ A) \times n \times Average\ cost\ of\ collection\ per\ research$ $= (B - A) \times J \times n \times [P \times Q]$
Avoided time wastage from failed searches	$= \mathrm{P}(pathway\ 2) \times n \times [Time\ saved\ by\ the\ researcher + Time\ saved\ by\ professional\ networks + Time\ saved\ by\ biobanks]$ $= (\mathrm{B} - \mathrm{A}) \times n \times \{[(D - E) \times R] + [G \times D \times R] + [H \times I \times Y]\}$
Additional R&D projects	$= \mathrm{P}(pathway\ 2) \times \mathrm{P}(subpathway\ B) \times n \times Average\ investment\ per\ project \times Average\ R\&D\ return$ $= (B - A) \times K \times n \times T \times S \times Z$
Reduction in search time	$= \mathrm{P}(pathway\ 3) \times n \times [Time\ saved\ by\ the\ researcher + Time\ saved\ by\ professional\ networks + Time\ saved\ by\ biobanks]$ $= A \times n \times \{[(C - E) \times R] + [G \times C \times R] + [H \times I \times Y]\}$
Reduction in active access time[44]	$= \mathrm{P}(pathway\ 3) \times n \times [P(accessing > 1\ biobank) \times Additional\ \#\ of\ biobanks\ accessed \times active\ time\ spent\ accessing\ 1\ biobank]$ $= A \times n \times [W \times (X - 1) \times L \times R]$
Present value gain from shorter access times	$= \mathrm{P}(pathway\ 3) \times n \times [PV\ of\ R\&D\ benefits\ in\ the\ future\ state\ (shorter\ access\ times) - PV\ of\ R\&D\ benefits\ in\ the\ current\ state]$ $= A \times n \times (1 + S) \times T \times \left[\frac{1}{(1 + V)^{(U + N)}} - \frac{1}{(1 + V)^{(U + M)}} \right]$

43 The reduction in search time, reduction in active access time, and the present value gain from shorter total access times were aggregated to calculate the total benefit from reduced search and access times, as presented in Figure 2 above.

44 It is assumed that the active time required to access a single biobank remains the same in both the current and future state. However, in the current state, accessing multiple biobanks requires additional active time (e.g. contacting two biobanks takes twice as long). In the future state, a streamlined application process is assumed to reduce the additional time burden when researchers need to access multiple biobanks.

Appendix C – Australian biobanks and cohort studies

The Australian biobanks and cohort studies listed below were identified as part of the background research phase of this analysis. The list was compiled through desktop research, bibliometric analysis, interviews, and state-based registries. It is not an exhaustive list of all Australian biobanks and cohort studies and is likely to be a significant under-representation of the actual number that exists in Australia. The list is intended to demonstrate the scale of the coordination required.

- 45 and Up Study Biobank
- A follow-up of the WA Kidskin Study
- ACT Brain Cancer Biobank
- Alcohol and Other Drug Dependence
- Alfred Brain Tumour Bio-databank
- Alfred Cancer Biobank
- Alfred Neuroscience Bio-databank
- ANZgene
- Asbestos Diseases Research Institute (ADDRI) Biobank
- ASCOT-ADAPT: The Australasian COVID-19 Trial
- ASPREE Healthy Ageing Biobank
- AusDiab
- AusME Registry & Biobank
- Aussie Ear Bank
- Austin Health Tissue Bank (VCB member)
- Australasian Gastro-Intestinal Trials Group Biobank (AGITG GI Cancer Biobank)
- Australasian Hearing Registry and Biobank
- Australasian Interstitial Lung Disease Registry
- Australasian Leukaemia & Lymphoma Group (ALLG) Biobank
- Australia New Zealand Gynaecological Oncology Group Biobank (TR-ANZGOG Network Biobank)
- Australian & New Zealand Children's Haematology/Oncology Group (ANZCHOG) Biobanking Network
- Australian Arthritis & Autoimmune Biobank Collaborative (A3BC)
- Australian Autism Biobank
- Australian Biobank for Chromosome 15 Imprinting Disorders
- Australian blood donor study biobank (ABDS biobank)
- Australian Brain Injury Biobank and Registry (ABIBaR)
- Australian Breast Cancer Tissue Bank
- Australian Childhood Diabetes DNA Repository
- Australian CTE Biobank
- Australian Donation and Transplantation Biobank (ADTB)
- Australian Health Biobank
- Australian Inherited Retinal Disease Registry and DNA Bank
- Australian Institute of Tropical Medicine (AITHM) Biobank
- Australian IPF Registry
- Australian IRDs and HONs DNA Bio-Bank
- Australian Lupus Registry and Biobank
- Australian Ocular Bank
- Australian Parkinson's Disease Registry
- Australian Prostate Cancer BioResource
- Australian Schizophrenia Research Bank
- Australian Scleroderma Cohort Study (ASCS) Biobank
- Australian Sports Brain Bank
- Australian Veterans Brain Bank
- BANK CF: The Respiratory Centre BIOBANK
- Biobanking Victoria
- Biomarkers for diagnosis and prognosis of cancer
- Biospecimen Research Services group
- Bladder and Urothelial Cancer Data and Biobank (BLADDA Project)
- Brain Cancer Biobanking Australia
- Brain Tumour Bio-databank
- Breast Origin Cancer tissue DonatEd after death
- Brisbane Breast Bank
- Burns & Reconstructive Surgery Skin Biobank
- Busselton Population Medical Research Institute Biobank
- Canberra Brain Cancer Collaborative
- Cancer Collaborative Biobank
- Cancer Evolution Biobank
- Centre for Eye Research Australia (CERA) Biobank
- Centre for Oncology Education Research Translation (CONCERT) Biobank
- Centre for population genomics
- Charles Day Tissue Bank
- Charlie Teo Foundation Tumour Biobank
- Children's Cancer Centre Biobank
- Children's Cancer Institute Tumour Bank (The Tumour Bank)
- CKD.QLD
- CMV & CVD
- Colorectal Oncogenomics Group
- Colour Vision Deficiency study
- COMBINE Biobank
- Concord Colorectal Cancer Tissue Bank
- COVID Research Biobank
- Critical Illness and Shock Study
- Critical Illness, Inflammation and Immunology (CI3) Biobank
- Curtin Centre of Clinical Research and Evaluation Biobank
- David Serisier Research Biobank
- Dermatology Bio-Specimen Bank (Derm Bio-Bank)

- Digestive Health Biobank
- Donor Tissue Bank of Victoria
- Dream Trial Biobank
- ENDORIGINS endometriosis tissue biobanking project
- Environmental determinants of islet autoimmunity (ENDIA) Biobank
- Eye Protection Study
- eyePSC Bank
- Fiona Elsey Cancer Research Institute Tissue Bank
- Flinders Tissue Bank
- Fremantle Diabetes Study
- GenV biobank
- Glaucoma Inheritance Study in Tasmania (GIST)
- Gold Coast Biobank
- Griffith Institute for Drug Discovery (GRIDD) NeuroBank
- Gynaecological and Breast Cancer Biobank
- Gynaecological Oncology Biobank at Westmead (GynBiobank)
- Head and Neck BioBank
- Health in Men Study (HIMS)
- Health Science Alliance Biobank
- Helicobacter Research Biobank
- Hudson-Monash Children's Cancer biobank and Living Biobank
- Human Studies Unit
- ICAD Study
- Illawarra-Shoalhaven Cancer Biobank
- Infective Endocarditis Queensland (ieQ) Research Group Biobank
- Inherited Kidney Disease Biobank
- Justin Cameron Sarcoma Collection
- kConFab
- Kidney canceR Australian registry and Biobank
- Kids Heart BioBank
- Kolling Breast Cancer Biobank
- Kolling Institute Tumour Bank
- Lifelong impact of burn injury
- Lifepool Research Project
- Liquid Biopsy BioBank for Paediatric Solid Cancers
- Liver Biobank
- Macquarie University Cancer Biobank
- Mark Hughes Foundation Biobank
- Mater Inflammatory Bowel Disease Biobank
- MCRI COVID Biobank
- Melanoma Institute Australia (MIA) Biospecimen Bank
- Melanoma Research Database (MRD2)
- Melanoma Research Victoria Biobank
- Melbourne Biobank for Eye Disease
- Melbourne Femur Research Collection
- Melbourne Health Tissue Bank (VCB member)
- Monash Centre for Health Research and Implementation (MCHRI) Biobank
- Monash Children's Cancer Biobank
- Monash Public Health Biorepository
- Motor Neuron Disease Research Centre Biobank
- Multiple Sclerosis (MS) Australia Brain Bank
- National Centre for Asbestos Related Diseases (NCARD) Biobank
- National Centre for Neuroimmunology and Emerging Diseases (NCNED) Biobank
- National Muscle Disease Bio-databank
- National Survey of High Impact Psychosis
- Nepean Cancer Research Biobank
- Nepean Intensive Care Biobank
- Neurodegenerative Disease Biobank
- Neurological Brain Bank
- Neuropathology Tumour and Tissue Bank
- New South Wales Brain Bank
- New South Wales Research Centre for Peripheral Vascular Disease Biobank
- NHMRC Chronic Kidney Disease (CKD) Centre of Research Excellence
- Nicotine Dependence Study
- Northern Centre for Health Education and Research (NCHER) Reproductive Health Biobank
- NSW Brain Tissue Resource Centre (BTRC)
- NSW Health Statewide Biobank
- NSW Kawasaki Disease Biobank
- NSW Regional Biospecimen Research Services
- NSWRCPVD Vascular Biobank
- Oesophageal and gastric blood and tissue bank
- Ophthalmic Western Australian Biobank
- ORIGINS Biobank
- PEBBLES Study Biobank
- Perkins Cancer Biobank
- Perron Genomics Biobank
- Perth Bone & Tissue Bank Inc
- Perth Children's Hospital Tumour Bank
- Perth Longitudinal Study of Ageing Women
- Peter MacCallum Cancer Centre Tissue Bank (VCB member)
- PlusLife
- Princess Alexandra Hospital Kidney Cancer Biobank
- QCell Resource
- Queensland Brain Tumour Bank
- Queensland Children's Tumour Bank
- Queensland Family Cohort Biobank
- Queensland Research Centre for Peripheral Vascular Disease (QRC-PVD) Peripheral Vascular Biobank
- Rheumatology Research Laboratory
- Riordan Haematology Tissue Bank
- Royal Brisbane and Women's Hospital (RBWH) Brain Cancer and Cell Culture Bank
- Royal Melbourne Hospital (RMH) Neurosurgery Brain and Spine Tissue Bank
- Royal Women's Hospital (RHW) Tissue Bank

- South Australian Brain Bank
- South Australian Cancer Research Biobank (SACRB)
- South Australian ENT Bank
- South Australian Neurological Tumour Bank
- South Australian Paediatric Brain Cancer Biobank
- St Vincent's Institute (SVI) Medical Research Biobank
- St. Vincent's Centre for Applied Medical Research (AMR), Trials and Biorepository
- STROKE Biobank
- Sydney Brain Bank
- Sydney Brain Tumour Biobank
- Sydney Children's Hospitals Network (SCHN) biobanking services
- Sydney Cord Blood Bank
- Sydney Heart Bank
- Sydney Sleep Biobank
- TARRGET Glaucoma Study
- Tasmanian CNS Biobank
- The Australian Imaging, Biomarker and Lifestyle (AIBL) Study of Aging Biobank
- The Elevated Risk of Ovarian Cancer (EROC) Biobank
- The Kids Cancer Biobank
- The Prince Charles Hospital (TPCH) Lung Tissue Biobank
- The Raine Study
- The Respiratory Centre BIOBANK
- The Rheumatology Synovial Tissue Research Group
- The University of Adelaide (Biobank)
- Tissue Repository of Airway Cancers for Knowledge Expansion of Resistance (TRACKER) Biobank
- Treatment-resistant Schizophrenia Cohort
- Twins Eye Study
- Type 1 and 2 Diabetes DNA Bank
- Type 1 and 2 Diabetes Plasma and Serum Repository
- UNSW Biospecimen Services
- UNSW Health Precincts Biobank
- Vascular Surgery Biobank Flinders Medical Centre
- Victorian Brain Bank
- Victorian Cancer Biobank (VCB)
- Victorian Critical Vaccinees Collection (VC2)
- Victorian Heart Institute (VHI) Biobank
- Victorian HIV Blood and Tissue Storage Bank
- Victorian Immune Diseases Biobank (VIDBioB)
- Victorian Pancreatic Cancer Biobank
- WA COVID-19 Immunity Collaborative (WACIC)
- WA Family Study of Schizophrenia
- WA Gynaecologic Oncology Biospecimen Bank
- WA Research Team Biobank of Anogenital Neoplasia and Condylomata (WARTBANC)
- Wesley Medical Research Biobank
- Western Australia DNA Bank
- Western Australia Retinal Degeneration (WARD) Biobank
- Western Australian Pregnancy Biobank
- Westmead Biobank
- Westmead Oral Health Biobank
- Women and Children's Hospital Tumour Bank
- Women's Healthy Ageing Project
- Woolcock Institute of Medical Research BioBank

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