

Draft National Health and Medical Research Strategy Consultation

Submission

Population Health Research Network

October 2025



ABOUT THE PHRN

The Population Health Research Network (PHRN) is one of Australia's premier national research infrastructures, advancing innovation through the secure linkage, management and use of high-quality health and human services data. By partnering with researchers, government, industry and the community, PHRN equips Australian researchers with a competitive edge to conduct transformative, data-driven research. Hosted by the University of Western Australia, the PHRN plays a critical role in driving health and social research excellence nationwide. The PHRN is funded by the Australian Government's National Collaborative Research Infrastructure Strategy (NCRIS).

Our Roles

- We are a respected, independent and trusted broker, valued for bringing governments, organisations, individuals and data together securely.
- We collaborate to enhance and maintain significant, innovative research infrastructure to improve the nation's data linkage capability.
- We facilitate and grow the use of linked data in the areas of health and human services.
- We advocate for an improved authorising environment for better access, use and sharing of data.
- We support the whole of government focus on accessing, sharing and using data for the national good.

Our Vision

Linking life data to improve the wellbeing of all Australians

Our Mission

To lead and enable the linking of data for world class, action-oriented research

Contact

Population Health Research Network

M320, The University of Western Australia
35 Stirling Highway
Crawley WA 6009
Australia

[+61 8 6488 7825](tel:+61864887825)

phrn@uwa.edu.au

RESPONSE TO THE GUIDING QUESTIONS FOR SUBMISSION

Vision

The proposed Vision is ambitious, but appropriate. The aspiration to improve the health and wellbeing of all Australians is framed inclusively, and its link to health and medical research is made clear. We have no suggested amendments.

Values

The PHRN generally agrees with the proposed values. However, the description of the Collaboration & Partnership value is vague and would benefit from reframing. We note that the statement: ‘A research system where collaboration and partnership achieve maximum impact for the community’ potentially encroaches into territory better covered by the ‘Impact & Sustainability’ value. We suggest the following alternative:

A collaborative and cohesive system that works seamlessly to promote and support efficient research, establishing and enabling enduring community, health, and research partnerships to the benefit of all.

Goals

The PHRN agrees with the proposed goals.

It is not, however, clear from the Draft Strategy whether the order of the goals is indicative of their priority. If so, we suggest that Goal 2 (Lead the world in health outcomes), Goal 3 (Deliver equity – no one left behind) and Goal 4 (Secure a resilient and a sustainable health system) take precedence over Goal 1 (Drive national prosperity and security). Whilst all goals are important, Goals 2 – 4 are, in our view, more directly connected to the Draft Strategy’s overarching vision of achieving better health outcomes for all Australians, and this centrality should be reflected in any potential ‘ranking’.

Focus Areas

The PHRN broadly agrees with the proposed Focus Areas. There is a clear need to coordinate priorities and investment across health and medical research (Focus Area 1) and to reduce the burden on researchers seeking to access data. Designing research processes that increase consumer engagement through the co-design of research whilst simultaneously reducing the administrative burden on researchers (Focus Area 2) will require careful coordination and planning.

With respect to Focus Area 5, greater explanation and exploration of how ‘harnessing artificial intelligence (AI) will ensure Australia has ... trust in science’ is warranted. The PHRN’s understanding is that public trust in AI is currently low (see: Australian Government, Department of Industry, Science and Resources, *Safe and Responsible AI in Australia: Proposals Paper for Introducing Mandatory Guardrails for AI in High-Risk Settings* (September 2024) 3). AI may assist to facilitate cutting-edge research, but its uptake should be dictated by more than just technical capability; it should align with community and consumer expectations and occur in step with appropriate government oversight and regulation to ensure both public trust and research benefits are maximised.

With respect to the proposed Actions, the PHRN makes the following observations:

- The proposed Actions appear generally appropriate to achieving the Focus Area objectives.
- **Build a vibrant research system that delivers for the nation:** further clarity is required as to how national priority setting and evaluation processes will coordinate and integrate with

horizon scanning mechanisms. The level of involvement of independent researchers in horizon scanning should be considered and described.

- **Embed research processes that are modern, efficient and consumer centred:**
 - The PHRN supports the unified management and oversight of the MREA and MRFF. External consultation processes should be implemented as part of this reform to ensure MREA/MRFF funded infrastructure initiatives do not duplicate existing or proposed research infrastructure initiatives of other funders, such as NCRIS Capabilities.
 - The proposed system and regulatory reform (Clinical trials, p 22) should encompass changes that enable easier access to, and use of, secondary data for clinical trials.
- **Drive impact through research translation, innovation and commercial solutions:** with respect to mechanisms that optimise research-industry exchange (p 31) – researchers, data custodians and industry would benefit from clear guidance and training regarding the ethical and legal frameworks governing the collection, use and disclosure of health data for commercial purposes.
- **Position to be ready for future needs and challenges:** continued investment in record linkage technology and infrastructure (see Case Study: CHeReL, p 34) will ensure that Australia maintains its place as a world leader in data linkage, facilitating privacy-preserving, cross-jurisdictional population health research that drives benefits for the broader Australian population.

Enablers

The PHRN agrees with the proposed Enablers.

Our only suggestion relates to document structure: the overview of ‘Enablers’ currently sits between ‘Focus areas’ and ‘Focus Areas and Actions’ (p 13). It would be useful to have this one-page summary replicated after the ‘Enablers & Enabling Initiatives’ title page (p 37) in some form, to provide a check point or ‘refresher’ for readers before getting into the detail of this section.

With respect to the Enabling Initiatives:

- **Workforce:**
 - Investment in the capabilities, upskilling and retention of the research infrastructure workforce is critical to ensuring the long-term support of the HMR workforce. The Workforce Enabling Initiative should recognise and reflect this.
 - Increasing opportunities for effective collaboration and dialogue between the HMR workforce and the research infrastructure workforce is likely to:
 - improve the responsiveness and effectiveness of research infrastructure, and
 - help build an adaptable HMR workforce by enhancing cross-disciplinary skills and facilitating transitions between data and research related roles.
- **Funding:** An accessible data resource that identifies all sources of health and medical research funding should include a list of the various research infrastructure initiatives (in place or prospective).
- **Data & Advanced Technology:**
 - Whilst we support a data and digital asset mapping initiative, the proposal to remove all barriers ‘currently restricting shar[ing] and open access’ warrants careful

consideration. Open access to health data is inappropriate in almost all contexts, even where data is de-identified, due to risks to patient privacy, although the PHRN does support initiatives that better facilitate data sharing and linkage between parties with security arrangements in place. The protection of patient privacy is important as both a goal in itself and to maintain the social licence of data-sharing activities.

- Legislative reform, including to Australian privacy laws, will likely be required to support the confident and ‘nationally consistent implementation of opt-out consent’.
- The proposal to develop ‘cross-Commonwealth protocols for secure data capture and sharing’ should be expanded to include input from state and territory health departments and data linkage units, noting their respective involvement in collecting, using, and disclosing health data (including to Commonwealth agencies) and frequent linkage and integration of core health-related datasets in all jurisdictions.
- **Infrastructure:**
 - The PHRN does not support the creation of a separate Australian Health and Medical Research Infrastructure Roadmap (‘AHMRI Roadmap’). Australia already has a National Research Infrastructure Roadmap (‘NRI Roadmap’), which is reviewed every 4 – 5 years, and that includes priorities for health and medical research infrastructure. Rather than creating a separate AHMRI Roadmap, which risks duplicating existing priorities leading to fragmentation and inefficiency, Australia should focus on strengthening the NRI Roadmap. At present, funders such as the MRFF and NHMRC do not systematically consult or co-invest with NRI programs such as NCRIS capabilities. As a result, Australia misses opportunities for integrated investment and efficient use of taxpayer funding. Better implementation and more effective leveraging of the NRI Roadmap to address these issues would ensure that Australia’s health and medical research infrastructure is planned and funded as part of a coordinated national effort. This would be a more sensible investment of time and resources than creating a separate, additional AHMRI Roadmap.
 - International industry investment in health and medical research infrastructure (point 2, p 45) will need to be carefully managed to maintain sovereign capability, independence, and access for Australian researchers.
 - Investment in national infrastructure must be sufficient to meet demand if the bespoke equipment and facilities of individual research groups, institutions, precincts, states and territories are replaced as the Draft Strategy suggests. Absent broad reforms, such infrastructure will need to remain responsive to discrepancies in regulatory requirements in different Australian jurisdictions.
 - Developing ‘frameworks for **guaranteed research access**’ in healthcare settings will require significant, well-considered, ethical and regulatory reform following appropriate stakeholder consultation.

Priority-ranking of Actions and Enabling Initiatives

Priority 1: Access to data, digital assets and advanced technology

Data, including data held within national linked data assets such as the recently established National Health Data Hub, are a critical resource for researchers undertaking cross-jurisdictional, population-level, health and medical research. Such data is used to supplement information from clinical trials in

a cost effective and unintrusive way, shed light on patterns and health trends that may otherwise remain hidden, and facilitates research on core priority areas at a national scale. The considered and careful breakdown of data access barriers in a way that retains public support and reduces the cost and time associated with finalising linked data research projects is a key concern of the PHRN and accords with our mandate to advocate for an improved authorising environment for better access, use and sharing of data. Streamlining data access and investing in the sensible, regulated uptake of AI so that researchers and data linkage units can leverage emerging technologies will also increase the speed of research project completion and the impact and reach of findings and outputs. Greater acknowledgment of the role and importance of observational, longitudinal, population level-data in the National Strategy is required. Such data is an invaluable resource, enabling researchers to identify trends, track health outcomes, evaluate interventions and monitor the prevalence of disease at a national scale. The National Strategy should explicitly recognise the potential of this data to contribute to horizon scanning and national priority scanning, and the opportunities that it presents to further streamline research processes and improve the scale and quality of Australian research. From our perspective, a failure to prioritise investment in existing linkage infrastructure and further enhance the robustness of population-level data assets will impede the ability of the National Strategy to successfully achieve its vision and goals.

Priority 2: Collaborative platforms and networks:

As the Draft Strategy recognises, ‘by facilitating data sharing, resource pooling and coordinated research efforts on a larger scale and for longer time periods, platforms and networks accelerate innovation, reduce duplication and enhance the translation of research outcomes’. Collaborative relationships and consultation between funders of both research projects and research infrastructure is a priority for the PHRN and is critical to ensuring that the PHRN’s NCRIS funds are invested wisely, with maximum return and impact. A cooperative approach to network and platform building is also likely to increase system and output interoperability, reduce custodian and researcher costs and minimise data waste. It aligns well with the PHRN’s priorities and would enable us to better support researchers to conduct data-driven research, as well as contributing to the durability and increased functionality of the research system as a whole.

Priority 3: Clinical trials

The PHRN is invested in supporting a vibrant clinical trials sector and is in the process of developing guidance and training materials for researchers interested in linking clinical trials data to administrative data. We are also engaged in the development of supportive infrastructure such as the National One Stop Shop for health and medical research (NOSS), which will streamline approvals and reduce the regulatory burden on researchers undertaking multi and cross-jurisdictional projects. The effectiveness of these initiatives will be reduced in the absence of similar projects to streamline ethical approvals and reduce variation and inconsistency in HREC decision making; consequently, the PHRN also supports the proposed Human Research Ethics Committee Quality Standard and Accreditation Scheme. Successful implementation of these Strategy Action items will assist the PHRN to better support researchers to use linked data to conduct transformative research.

Governance

The PHRN supports, in principle, the establishment of a National Strategy Advisory Council. It appears to be an appropriate mechanism through which to implement and oversee the National Strategy; however, further information regarding the Council’s proposed makeup, functions, and powers is required.

Metrics

From the PHRN's perspective, the success of the Strategy will be reflected through:

- An increase in the efficiency and use of existing research infrastructure, including data linkage infrastructure, measured through project approval times, the number of (linkage) applications, and researcher satisfaction survey results
- The establishment of new infrastructure that supports research using emerging technologies within the Strategy's lifetime
- Changes in government released disease and morbidity statistics, including for Aboriginal and Torres Strait Islander peoples
- Positive community, industry, and researcher feedback regarding streamlined research processes and increased community engagement
- Workforce statistics indicating retention and growth (research sector)
- An increase in peer reviewed publications on topics relevant to priority areas or horizon scanning
- Evidence of increased research translation – e.g. quantitative measurements tracking new medications and treatments
- Increased registration of clinical trials
- Reduced pressure (longer term) on metropolitan and regional and remote hospitals (tracked through quantitative measures such as reduced patient wait times).

We suggest annual review of quantitative measurements, as this will allow for easier and earlier 'course correction'. Qualitative measurements may need to take place every 2-3 years noting the additional logistical coordination these measurements often require.

Strategy impact

A well-designed National Health and Medical Research Strategy would have a significant positive influence on our activities as an NCRIS capability. By articulating clear national priorities for health and medical research, the Strategy would guide us in targeting our investments in research infrastructure so that they directly support those national priorities.

Most importantly, a single, coordinated Strategy would help align the goals and funding decisions of both infrastructure funders (such as NCRIS and related programs) and research funders (such as the MRFF and NHMRC). This alignment would:

- Enable co-investment in nationally prioritised infrastructure, avoiding duplication and gaps.
- Ensure that researchers have access to fit-for-purpose infrastructure without needing to build and operate it themselves.
- Allow researchers to focus their grant applications on funding for research activities, rather than for building or sustaining infrastructure.
- Promote the long-term sustainability of critical infrastructure, reducing the current problem where researcher-built infrastructure is often under-resourced and difficult to maintain.

For the Strategy to achieve this, it must:

1. Reaffirm a single, unified NRI Roadmap

The Strategy should explicitly support the use of one national NRI Roadmap that includes health and medical research priorities, rather than proposing a separate health-specific infrastructure roadmap.

2. Strengthen implementation of the existing Roadmap

The Strategy should include measures that ensure research funders (MRFF, NHMRC) consult and co-invest with NCRIS and other NRI stakeholders in line with the Roadmap.

3. Align funding and policy levers

The Australian Government should provide the policy direction and funding mechanisms needed to align research and infrastructure funding to the priorities in the single Roadmap.

4. Improve access and sustainability

By embedding health and medical infrastructure within the national NRI framework, the Strategy can ensure reliable, equitable access for researchers and reduce the sustainability issues that arise when infrastructure is project-based.

Conclusion

The PHRN thanks the Department of Health, Disability and Ageing for the opportunity to contribute to the Draft National Strategy. Should you wish to discuss our submission please do not hesitate to contact us.