Draft 2016 National Research Infrastructure Roadmap Submission

The PHRN is pleased that the draft Roadmap recognises the high value of data and data linkage/integration infrastructure to Australian research.

To better reflect the broad role that data linkage/integration plays in human research and its applications in the future, wording changes to five focus areas are suggested.

Digital Data and eResearch Platforms

The PHRN is pleased to be recognised as an existing infrastructure in this focus area. We suggest that the specific requirements of research using personal health information could be acknowledged in the "What we have" section with reference to the PHRN's Secure Unified Research Environment which is a virtual laboratory designed to meet the privacy and confidentiality needs of researchers using linked personal health information.

The PHRN is very supportive of the development of an Australian Research Data Cloud. It will be essential that it is developed to meet the requirements of researchers using personal health information. The PHRN has substantial experience with management of personal health information and can assist in this regard.

Platforms for Humanities, Arts and Social Sciences

Linked/integrated data is a valuable resource for social scientists to research a range of complex social, economic and environmental issues. We suggest that existing data linkage infrastructure is acknowledged by the addition of a paragraph entitled "Data linkage and integration" to the "What we have" section on Page 29. The wording of the paragraph could be "*The Population Health Research Network provides a national data linkage infrastructure with the capability to link personal information across a broad range of sources e.g. education and child development, in privacy-preserving ways.*"

The PHRN data linkage infrastructure has also been used for a range of indigenous research[1,2]. The PHRN is an important platform for indigenous research and should be included in the list of indigenous platforms in Paragraph 6 on Page 29.

The inclusion of more state and national data collections relevant to the humanities, social sciences and indigenous research in the PHRN infrastructure should be mentioned in the "What we need" section of this focus area.

[1] Freemantle J et al. Am J Public Health. 2015 Apr;105(4):644-52.

[2] Gibberd A. J, ANZJPH. 2016 Aug. 40:388-394

Characterisation

Access to linked biomedical imaging, longitudinal health and outcome data will contribute to understanding health and disease and evaluation and monitoring of new therapies. This should be included in the "What we need – Biomedical Imaging" section on Page 33. A final sentence in this section is suggested to read "*Processes to link biomedical imaging data (collected both for research and clinical purposes) into the national data linkage infrastructure should be established*".

Complex Biology

The PHRN supports the coordination of existing biobanks and establishment of a population biobank. These initiatives would benefit from linkage to the decades of population level administrative data available through the PHRN infrastructure. An amendment is suggested for Paragraph 5 Page 57, final sentence. It could read "Inclusion of genomics, proteomics and metabolomics data with health ***(****such as available through the PHRN****)***, lifestyle and clinical data (*including clinical registries*) *…..*". Table 10, Row 3 could also be amended as follows:

Elements	NRI Response
Networked biobanks	Explore opportunities to establish a national network to coordinate and enhance current biobank capability *including data linkage and integration through the PHRN.*

Therapeutic Development

While the importance of data linkage/integration infrastructure is recognised, the focus is on discovery, testing and production of biological molecules. The PHRN suggests that the title is changed to better encompass the range of activities mentioned in the text. A title such as "*Improving Health*" would cover therapeutic development as well as effective health services, interventions and policies. This would be consistent with the Australian Science and Research Priorities[3] which focus on building healthy communities through a range of strategies including improvements to the health care system.

Changes to the summary paragraph are also proposed as follows:

"*This National Research Infrastructure is required to progress the development of new therapeutic agents, medical devices, therapies and preventive strategies to improve health at both the individual and population levels. The aim is to better support approaches to the prevention and treatment of disease and to more quickly translate research findings into new commercially viable products, changed clinical practice and improved health and well-being outcomes*".

In keeping with a more inclusive approach to the focus area and in recognition of the existing NCRIS infrastructure, a section on data linkage/integration should be added to the "What we have" section. Suggested wording is as follows:

[3] Australian Government Science. Health Capability Statement [Internet]. Canberra ACT: Australian Government Department of Industry Innovation and Science [updated 2015 November; cited 2016 Aug 14]. Available from: http://www.science.gov.au/scienceGov/ScienceAndResearchPriorities/Pages/Health.aspx

"*Australia has a unique combination of high quality population level data collections and a coordinated national data linkage infrastructure (PHRN). This provides researchers with the opportunity for long term follow up of clinical trials participants, post-market surveillance of therapeutics and devices as well as monitoring and evaluation of health services and policies".*

Amendments to the list in the "What we need" section on Page 62 are also suggested.

- "*Expansion of the national, coordinated data linkage infrastructure to include a broader range of data collections including clinical data (e.g. pathology and imaging), clinical quality registries, omics and biobank data*."

It is suggested that the heading "Integration" on Page 63 is changed to "*Data linkage and integration*". In this section Paragraph 1, Sentence 2 could read "This could be achieved through expanding data linkage platforms, for example PHRN, to enable *near* real-time *administrative,* clinical, biobanking and *omics* data linkage and integration."

Paragraph 3, Sentence 2 could read "Data from all patient admissions should ideally *be linked* and available for research and policy making *in a de-identified form*".

Table 11, Row 1 could be amended as follows:

Elements	**NRI Response**
High throughput methods for candidate discovery, manufacturing and testing	Enhance capability to coordinate discovery activities and enhance the existing national and candidate (both small and large molecule) management capability**.** BPA is currently contributing to this capability on a national level. *PHRN should be enhanced to support post-market surveillance.*