

Response ID ANON-5NKV-3M6K-5

Submitted to **National Health Information Strategy Online Consultation**

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Introduction

1 What is your email address?

Email address:

sue.mckerracher@alia.org.au

2 Are you submitting on behalf of an organisation, or as an individual?

Organisation

3 If submitting as an individual, what is your name?

Name:

4 Do you consent to the publication of your name?

Not applicable

5 If submitting on behalf of an organisation, which one?

Organisation:

Australian Library and Information Association

6 Do you consent to the publication of your organisation name?

Yes, I do consent to the publication of my organisation name

7 Which stakeholder group best describes your affiliation?

Not Answered

If other, please state::

Representing health libraries and librarians

Principles

8 When you look at the Principles in the draft Framework, is there anything missing or that should in your view not be there?

Suggested additions or changes to the Principles:

No

The Current State

9 When you look at the achievements listed in the draft Framework, are there any other essential elements of the health information system that should be listed as achievements that are starting points for future arrangements?

Achievements of the health information system:

Addressing limitations - the absence of a national framework, lack of public trust, separate collections, health workforce information and data literacy.

Librarianship is a trusted profession and across Australia, there is a strong network of specialist health librarians represented by ALIA Health Libraries Australia. We estimate there are between 350 and 400 health libraries in Australia, including hospital, community health, government department and university medical libraries, employing some 1,250 people. While each library is separately governed and funded, through informal networks and simple infrastructure, librarians facilitate sharing of best practice, research, data, information and interlibrary loans. Health librarians comprise an important part of the health information workforce, alongside health information managers and health informatics specialists. Not only are health librarians highly skilled in the field of information and data literacy, their role is also to teach these skills to other professionals in the medical field.

10 When you look at the limitations listed in the draft Framework, are there any key limitations from a national perspective that are missing?

Limitations:

1. F.A.I.R. principles for data

Academic, research and special libraries in Australia strongly support F.A.I.R. principles for data - Findable, Accessible, Interoperable and Reusable.

<https://www.force11.org/group/fairgroup/fairprinciples>

2. Open access to government-funded research

As part of the F.A.I.R. principles: "Access to research outputs will accord with international practices that are well defined, secure and trusted, and delivered through sustainable, fair, and efficient dissemination models. Publicly funded researchers will be expected, supported and rewarded to disseminate their work in such a way that anyone can find and re-use research publications and research data for further research, policy development, innovation, education and public benefit."

<https://aoasg.org.au/>

11 From your perspective, what are the top three key limitations that are creating barriers to successful use of health information in Australia?

Limitation #1:

Lack of awareness and recognition of the current role and future potential of health librarians in the health information landscape. While health professionals respect, value and make extensive use of health libraries, senior teams can be oblivious to the asset that exists within their organisation.

Limitation #2:

Absence of formal national infrastructure for the management of health information. Health libraries have developed a strong informal network but this is reliant on those with greater resources supporting others with less funding and access, to manage the gaps and inequalities across states, territories, metro, regional and remote areas.

Limitation #3:

Lack of public and consumer trust. Librarians can help overcome this lack of trust, as one of the most trusted professions. For example, the Australian Digital Health Agency has partnered with ALIA in 2019-2020 to provide training for public library staff and health librarians to support consumer use of My Health Record.

Where do we want to be; what opportunities should we grasp?

12 From your perspective, what are the three key opportunities to address the limitations and barriers to successful collection, collation and use of health data and information in Australia?

Opportunity #1:

Create an open Australian biomedical repository, providing a national health published research and evidence infrastructure, addressing the inequitable access to information currently experienced by health professionals in different parts of the country.

Opportunity #2:

Recognise and take advantage of the network of health libraries which already exists across Australia.

Opportunity #3:

Achieve open access for government-funded research.

13 Are there key health questions about health outcomes for Australians and/or Australia's health system more generally that cannot currently be answered because of current health information limitations? What is needed to answer them?

Key health questions that cannot currently be answered:

N/A

14 When you look at the opportunities listed in the draft Framework, are there any missing?

Opportunities missing from Framework:

No

How to make this happen - Priority areas for investment and implementation steps

15 When you look at the priority areas for investment/implementation listed in the draft Framework, are there any missing?

Missing priority areas:

Biomedical research in Australia is presently governed at the information management level, whereas to achieve informed decisions, synthesized knowledge is required to support action. A smarter and more efficient approach to the establishment and ongoing development of a national knowledge infrastructure is required.

Improvements to the way Australian researchers produce, manage and promulgate their research output through to the pipeline that delivers the point of care evidence for patient care is necessary.

The production of biomedical knowledge transcends organisational boundaries. A big picture perspective of Australia's complex healthcare environment and the organisations that are part of the system will help to identify the gaps and the barriers to be removed. At present the "poor coordination of people, methods, data and technology results in a wasteful disconnect between evidence production, synthesis and use that impairs decision making across the entire health system – from individual treatments to major health program spending." (From: The need for living evidence in the region, summed up so eloquently in the submission:

<https://livingevidence.org.au/alec-aboutus#what-we-aim-to-do>)

A National Health Information Strategy provides an opportunity within the health sciences information library sector to better utilize library experts. With the development of a national health information system Australian health sciences librarians and library services can work outside of the silos that presently restrict their effectiveness. Removing the barriers to accessing research content and establishing a national biomedical knowledge management approach would help to avoid the vast amount of duplicate effort that occurs throughout organisations and in particular libraries.

For biomedical researchers, the openly available PubMed, MEDLINE and PMC are the foundation, primary research repositories. As funders, such as the ARC and the NHMRC, have open access policies that require researchers adhere to openly publishing articles, considering an Australian open biomedical repository for reporting on research performance is a means to achieve funding body compliance. Institutional executives and open access leaders view the PMC system, such as the Europe PMC, as a means to manage and review the output of biomedical research linked to grant details and a means to help avoid duplication of research and link related findings.

A proposed Australian open biomedical repository, potentially as a member of PMC International <https://www.ncbi.nlm.nih.gov/pmc/about/pmci/>, has the potential to achieve a number of goals. Reducing the duplication of effort, and the fragmented and incomplete access to health research output that presently exists with institutional repositories are major incentives. Establishing an open national biomedical repository for sites without repositories and expanding the corpus of knowledge within PMC International are other goals. In addition, preserving health research and associated data for present and future generations of users throughout the world by becoming a node of an internationally proven PMC system, which produces quality metadata that is widely discoverable, are other important incentives.

16 What are your top three priorities for investment and implementation?

Priority #1:

An Australian open biomedical repository

Priority #2:

Formal recognition of, and investment in, the network of Australian health libraries as a national asset

Priority #3:

Open access to government-funded research

Summary

17 When you look at the suggested approach to governance of health information in the draft Framework is there anything missing or wrong?

Missing elements:

No

18 Are you aware of other strategies for health information in Australia or elsewhere that could inform this strategy?

Other health information strategies:

The National Library of Australia's Trove and National eDeposit (NED) platforms provide examples of how national infrastructure can be applied to dispersed collections.

<https://trove.nla.gov.au/>

<https://ned.gov.au/portal/>

In the US and Europe, PMC International (PMCI) is a collaborative effort between: NIH / NLM; publishers and US funding agencies that contribute content to the PMC archive; and funding organisations in other parts of the world that also wish to preserve and provide free access to journal articles authored by the researchers they support. The collaboration helps funding organisations build national or regional repositories of funded research articles, which they may supplement with other materials of particular interest to their respective communities. It also makes possible the exchange of journal articles between repositories in the PMCI network, subject to copyright and related permissions. The PMCI network currently comprises (U.S. / NLM) PMC and Europe PMC. NLM's collaboration with Europe PMC is based on a formal agreement between NLM and Europe PMC's sponsors concerning the management of any content the center gets from PMC. The agreement protects the rights of those who deposited the content in PMC, and ensures the integrity of that content by requiring each center to use NCBI's pPMC software.

<https://www.ncbi.nlm.nih.gov/pmc/about/pmci/>

19 Do you have 1-2 high profile examples where data has made a clear contribution to a successful health outcome that you are willing to share?

Example #1:

SGS Economic produced a report on the return on investment in health libraries in 2013. The result was \$9 of benefit for every \$1 invested.

<https://www.alia.org.au/sites/default/files/Worth-Every-Cent-and-More-FULL-REPORT.pdf>

Example #2:

In 2012, ALIA/HLInc published a report based on a survey of health professionals, which found that:

83% said it had helped them improve health outcomes for their patients

76% said it had changed their thinking and improved their diagnosis or treatment plan

<http://www.hlinc.org.au/images/Projects/Advocacy/hli-aliavaluinghealthinformationservicesreport2012final.pdf>

20 Do you have any further suggestions or comments?

Further comments:

The underlying principles of the National Health Information Strategy are well thought through, simple, clear and provide an excellent structure for organisations such as ALIA HLA to provide feedback.

Health libraries are particularly relevant to four realms: 'A trusted and transparent environment', 'Data are accessible', 'The health workforce is data-enabled' and 'Health information infrastructure is agile and innovative'.

We welcome this opportunity to contribute and will be pleased to support the next stage of this strategy development.