AUSTRALIA'S DIGITAL HEALTH COMMUNITY

12 December 2016

Peter Harris AO
Chairman
Productivity Commission
via email: data.access@pc.gov.au

Dear Peter

Response to Productivity Commission Draft Report on Data Availability and Use; October 2016

On behalf of the HISA PC Data Availability and Use Inquiry Committee, chaired by Susan Smith, HISA welcomes the Productivity Commission's Draft Report on Data Availability and Use. We believe it is a comprehensive work covering a broad scope and we appreciate the opportunity to comment on this document with respect to the health sector and health data. We have listed several points for your consideration in the subsequent pages.

HISA's initial submission to the Inquiry constituted a report on a national survey of 101 respondents, summarising the views of professionals across the health sector who have interest and expertise in health data and who are closely associated with e-health development, delivery and application. Results from this survey are referred to in this subsequent submission.

In addition to the points covered in this submission, we would like to offer our time and expertise to the Commission to assist your ongoing work with this inquiry. We are happy to meet with you and your officers to discuss issues specific to health data, its collection, privacy, access and use.

Kindest regards

Dr Louise Schaper, PhD CHIA FACHI
CEO, Health Informatics Society of Australia

On behalf of the HISA PC Data Availability and Use Inquiry Committee:
- Susan Smith, Chair
- Jon Carrano
- Dr Peter Croll
- Dr Hugo Leroux
- Dr Dominique Gorse
- Dr Mark Santamaria

1. Management & Access - vs - Analysis & Use

The proposed directions set out in the Draft Report indicate considerable emphasis on the collection, curation and organisation of data. While this is of course important, our survey of over 100 professionals suggests that there is already an overemphasis on the preliminary phases Management and Access (left side of the figure) versus the Analysis and Use phases (right side of the figure) of information flow.

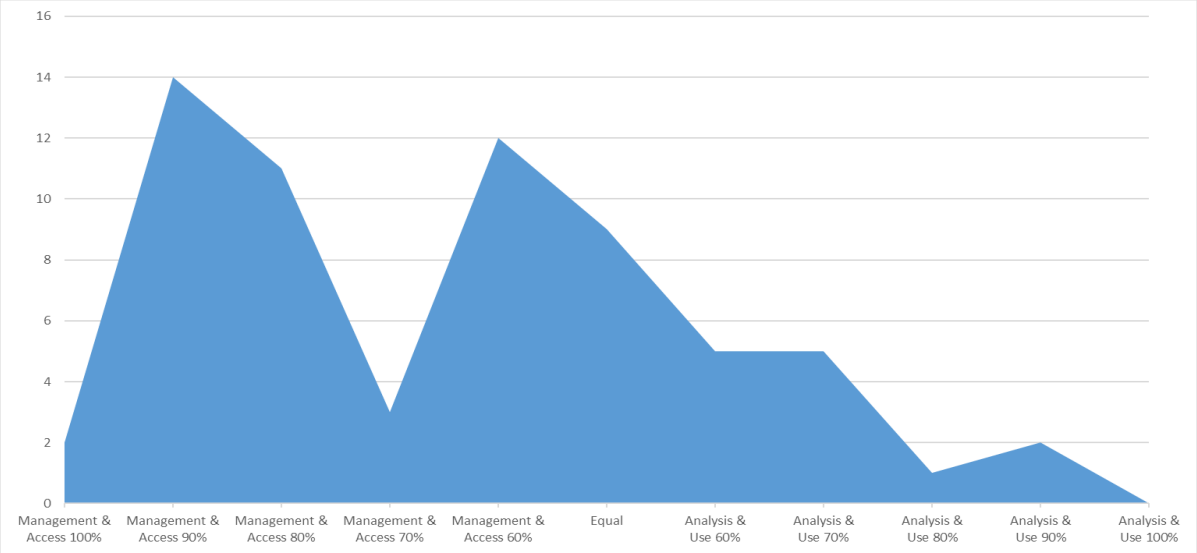

Figure: Survey indication of proportion of work resources allocated to Management and Access versus Analysis and Use.

Healthcare is a data-rich industry, and a strength of health informatics is extracting value from health data – this can be at an individual, organisation or population health level. However, despite high value propositions at all three levels, healthcare is notoriously inefficient and does not analyse and use its data wisely. HISA strongly advocates for the strengthening of the health Informatics workforce and the data captured in the above graph, as well as other survey results, suggests that more prominence and resources should be directed to the data analysis and use aspect of the information chain.

The PC Draft Report proposals are not likely to effectively support this direction towards analysis and use, with more emphasis being placed on data management and growing national data repositories. Funding of education and workforce development strategies and development of competencies directed towards the data sciences is likely to produce more long-term beneficial use of data and increase confidence in the appropriate use of data. Such competencies embedded in the work environment will drive further refinement of data resources, capture and use.

2. National Data Repositories

The suggested collection of additional national data repositories simply indulges the status quo. Our survey indicates agreement among respondents that Australia already has numerous data collections in place, *but they are not being used well*. Sizeable funding already supports many of these national data collections available through the ABS, AIHW, Medicare, etc. Furthermore, over the last decade in excess of $80 million has been deployed to the development of the Public Health Research Network

data linkage hubs to facilitate linkage of such health data repositories, with undoubtedly useful outcomes. However, as mentioned in your report, the inability of being able to move patient data from one hospital ward to another for patient care, let alone integrate and use such data for research and quality improvement at the coalface, is critically absent. This fundamental inability to use patient clinical data productively will not be remotely improved by curating National data collections. In fact, the suggested collection and curation of further data collections will slow the agile use of data and information in health systems for local improvement and benefit. Potential funding will be diverted from grants or resources that might otherwise have gone to these activities.

3. Proposed National Data Custodian

Such a new position is likely to reinforce the status quo of data custody rather than data use. The term "Custodian" simply reinforces the current situation of keeping data (instead of sharing it). Definitions for custodian include:

- Guardian, keeper, curator, conservator, overseer, superintendent;
- one that guards and protects or maintains; especially: one entrusted with guarding and keeping property or records or with custody or guardianship of prisoners or inmates

The terminology used in this job title and the role's description is an opportunity to relay a shift in focus to consolidation and sharing of data, while maintaining high quality of data usability, protection and communication. A title such as 'custodian' is not in keeping with a new direction of increasing data liquidity and use. A potential new term such as National Data Marshall suggests bringing together, organisation, guidance, deployment as well as leadership and would better convey a change in purpose from the current situation (although 'marshall' also has authoritarian connotations). Alternatively National Data Steward or Curator also better reflects a role supporting consolidation, management and fitness of data; helping provide business users with high-quality data that is easily accessible in a consistent manner; with no implications about constraining access; while at the same time ensuring it is presented appropriately, protected and used properly.

4. Commonwealth Data Sharing and Use Legislation

The proposed Commonwealth Data Sharing and Use legislation is welcomed, however this is likely to have minimal impact on *public* health data, the majority of which is under State jurisdiction. This is evidenced in that recent changes to the Commonwealth Privacy Act have not been successful in significantly unifying State Privacy legislation, which remain a patchwork of infinitely nuanced regulations nigh impossible for knowledge workers in health to navigate. Rationalisation of jurisdictional Privacy and Information legislation, within and between Governments is required for data use reform.

5. Secondary use of health data

HISA members advocate for any proposed legislation to allow for the secondary use of deidentified healthcare data. This is vital for research purposes. An example that resonates is that soon individual genomic data will be captured as a matter of course and this data will be used to deliver precision medical care, which will have significant impacts for the individual, the organisation and the community. To advance medical research, the sharing of deidentified health data amongst researchers is vital.

Additionally, in the same way that financial and transport data have allowed for disruptive changes in those sectors we feel that there are endless opportunities for development of healthcare and wellness

apps which can improve healthcare delivery, disease prevention and enhanced wellbeing. There are already many anecdotal cases of app developments overseas drawing from healthcare data to achieve such objectives. Identifiable healthcare data has an additional layer of complexity and sensitivity compared to commercial data; however, there is no difference in privacy and security for deidentified data which preclude such use with the implementation of appropriate and already available controls and safeguards. Indeed, access to state and national data sources, including the government's My Health Record data offer unique opportunities in Australia to enhance healthcare delivery.