Article begins on page three of this document.

Title	Australian Health Research Alliance: national priorities in data-driven health care improvement

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Australian Health Research Alliance: national priorities in data-driven health care improvement

Unlocking the potential of health data to improve patient outcomes requires the integration of research, health care and education

Data-driven health care offers great promise in improving quality and efficiency in health care, if its value can be harnessed.[1,2] Australia has well established primary care data systems, has broad uptake of electronic medical records in the hospital sector, and has invested in My Health Record — a population-wide, opt-out, medical record. Multiple other initiatives in health data have incrementally advanced health care benefit. For example, the NPS MedicineWise Medicine Insight program — a national data initiative in primary care — has used health data to improve outcomes in a diverse range of areas, including cancer care, antibiotics prescribing, and diabetes.[3] However, in Australia, far greater opportunities exist to realise the value of data in improving health care.

In 2017, the Duckett report noted that "The health system is awash with data, but the information is poorly collated, not shared with patients, and often not given to the doctors and hospital managers responsible for keeping patients safe".[4]

To unlock the potential of these data and remove the barriers to their use, there needs to be integration of research, health care and education. Engagement of industry and government is also vital[2] and this area is a policy priority for the Australian Government.[5] Collaboration with broad industry stakeholders will provide access to experts from fields such as engineering, information technology, science and biomedicine. This expertise will accelerate the development of relevant new devices, diagnostics, therapeutics, delivery systems and clinical tools. Yet Australia has arguably lacked the collaborative platforms to bring these relevant stakeholders together and realise this potential.[5]

The Advanced Health and Research Translation Centres and Centres for Regional Health

The need to improve health care through research was highlighted in both the Strategic Review of Health and Medical Research[6] and the Australian Medical Research and

Innovation Strategy 2016–2021, which is funded through the Medical Research Future Fund (MRFF).[5,7] A key outcome to deliver on this vision of the Strategic Review of Health and Medical Research[6] was the establishment of seven Advanced Health and Research Translation Centres (AHRTCs) and two Centres for Regional Health (CIRHs) (Supporting information, table 1), which were accredited over the period 2015–2017.

The National Health and Medical Research Council (NHMRC) recognises the AHRTCs and the CIRHs as leaders in providing research-based health care and education and they are accredited by the NHMRC for this purpose.[8]

The AHRTCs and CIRHs have together been awarded $300 million in MRFF funding over 10 years from 2018.[9] The funds support rapid applied research translation projects and national system level initiatives.

Formation of the Australian Health Research Alliance

The Australian Health Research Alliance (AHRA) was established in 2015[10] and brings the AHRTCs and CIRHs together nationally across over 90% of NHMRC-funded health and medical researchers and 80% of hospitals, as well as having significant primary care reach. Each AHRA centre consists of a collaboration of organisations that include large health service providers, universities, medical research institutes, and primary health care providers. These collaborations provide a platform where integration of staff results in a blending of concepts, issues, priorities and activities both within and across each AHRTC and CIRH. These collaborations transcend traditional silos and offer unprecedented opportunities for coordinated national activities now concentrated in five national systems level initiatives, one of which is in data-driven health care improvement.

Bringing stakeholders together

The AHRA model for bringing stakeholders together aligns with that of the Strategic Review of Health and Medical Research (Box 1).

Governance

The AHRA governance structure consists of a council comprised of the director of each centre and a series of national committees bringing leading experts together (Box 2).

Establishment of the Australian Health Research Alliance data priorities

To establish agreed national data priorities, the AHRA applied a modified Delphi process and nominal group technique[11] to rank research and service priorities as determined by multiple stakeholders (Supporting information, table 2).

Previous and current work in this field was captured through stakeholder input, an evidence-based literature review, and inclusion of government priorities. The process took into consideration other national bodies of work to avoid duplication and optimise collaboration. The relevance of the priorities to AHRA objectives were also considered, including the potential for greatest measurable impact over time. This process resulted in a ranking of eight data priorities (Supporting information, table 3).

The AHRA centres have agreed to commence with a focus on the first three of these eight priorities. This work is complemented by, and integrated with, the national Digital Health Cooperative Research Centre (CRC). The Digital Health CRC program supports collaborations between industry, researchers and the community, with a view to increasing commercialisation, international opportunities, market access, and workforce development (www.digitalhealthcrc.com).

Collaboration and engagement with other existing government data activities is also emphasised.

The top three data priorities

Create virtual or actual, health data, research incubator hubs

This approach will provide a method, framework, system and structure that will improve access to, and interaction between, academics, clinicians, community, and data experts. The purpose of these hubs is to increase the use of quality data to inform decision making in the clinical setting. These will be nested within AHRA centres, across their member health care organisations, and will have a focus on community and health care benefit. These hubs will be different to conventional research hubs as they will use data to address current health care questions and priorities for community health benefit. That is, they will focus on the needs of the "demand" side of health care, which is driven by the community, public and private health service providers as well as government, where patient outcomes and benefits are paramount, unlike the "supply" side to health care, which is driven by commercial and industry interests, which are primarily financial and create the potential to have different definitions of value.

The use of AHRA infrastructure will facilitate collaboration across different stakeholders and organisations and enable rapid implementation across a large number of health care settings. The collaboration, and sharing of expertise, will also ensure that data are available quickly, in a format that is relevant to clinicians, patients and academics.

There is a need for research on how to optimise integration across relevant sectors, and to move beyond health data to also link in social data.[1,12] Internationally, data hubs such as the nodes of Health Data Research UK[12] link under the broader umbrella into a United Kingdom-wide platform, including the recently announced and funded UK health system data hubs.[13] These hubs integrate stakeholders, especially policy makers, academics and health care providers, to move beyond research use of data, to optimise the application and benefit of health data. The AHRA centres are ideally positioned to align values and skills and maximise benefits from health data. These hubs could both leverage considerable infrastructure housed within universities and health services and link nationally through AHRA to share findings and to translate evidence into practice. As an example, in this priority area, Monash Partners is applying internal and MRFF funding in leading and collaborating on a literature review and national and international research and partnership scoping and codesigning an Australian virtual or actual Learning Health System data hub. This approach aligns with the Australian Medical Research and Innovation Priority on a national data management study, and will inform an evidence-

based, consistent framework to inform AHRA centres nationally.[14]

Integrate large scale datasets

There is a need to integrate data across the primary, acute and subacute care continua to enable research that will drive health care improvement. While the value of integrating and linking health data is recognised, many barriers remain on sharing, integrating and securely storing, accessing, analysing and applying health data to improve health outcomes.[15]

Examples of progress in this area so far include a national AHRA data sharing accord developed by one of the AHRA centres, Sydney Health Partners, and a project lead by the Melbourne Academic Centre for Health to engage all AHRA centres in the joint development of a national framework for improving data quality and linking primary care data. This involves building on understanding of the data currently available in Australia and helping to establish collaborations and working relationships with principal stakeholders in this space, including Primary Health Networks, the CSIRO and the Australian Institute of Health and Welfare. We will use the collaborative strengths and nature of AHRA to work towards harmonisation of data in areas such as the establishment of frameworks for data quality assessment, data linkage, common data modelling, terminology mapping and governance. Other AHRA centre projects that provide exemplars of data integration include projects aimed at reducing clinical variation (eg, a major scale-up of a lung cancer registry and linkage, alignment and harmonisation of maternal health data, hospital pre-admission prevention initiatives) and providing pilot hubs for implementing and optimising the use of My Health Record. Issues related to public willingness and confidence to share personal data need to be considered when linking datasets, particularly in relation to data privacy, consent for access and transparency regarding secondary use and who can access data and for what purpose.[16] Legislative changes are currently being explored in these areas across state and federal governments; however, lack of harmonisation of effort across governments remains a key barrier for streamlined application of data for health benefit and is an area AHRA is collaborating on to aim to improve nationally.[17]

Build workforce capacity

The building of workforce capacity will be done by providing multidisciplinary training for undergraduates and graduates in the use of data for health care improvement.[18] The Topol review for the National Health Service (NHS) in the UK states that "within 20 years, 90% of all jobs in the NHS will require some element of digital skills. Staff will need to be able to navigate a data-rich health care environment. All staff will need digital and genomics literacy".[19] We, along with federal data agencies, understand this also applies to the Australian health care workforce[20] in their aim to deliver safe seamless and secure use of data to improve health. AHRA activities include developing the vision and priorities, scoping current workforce development activities nationally, a literature review on priorities and effective strategies in workforce development, and a survey on priorities, needs and delivery methods across diverse stakeholders.

A Massive Open Online Course on digital health is now available online (www.coursera.org/learn/healthcare-data). This was led by the University of Sydney and Sydney Health Partners and supported by the Digital Health CRC and Monash Partners. More training programs have been collaboratively developed throughout AHRA centres, with both state and Commonwealth government support. Continuing professional development in health data science is an emerging field, with many universities developing a range of training options from postgraduate degrees and individual subjects to short courses and openly available online resources.

Some AHRA centres have engaged with accredited training bodies, for large-scale, low cost, access to accredited training programs and data fellowships, which have been codesigned in health service priority areas. Monash Partners, for example, has developed a partnership with federal data agencies to scale current informatics training programs and has a multimillion dollar funded partnership supporting doctoral students and fellows in the use of data for health care improvement. This includes AHRTC health partner organisations as well as the university faculties of Information Technology, Business, and Medicine and Nursing and Health Sciences at Monash University, and is now engaging with the Digital Health CRC and government to expand this further. All priority areas here come from the health system, rather than the academic sector, as an exemplar of demand-driven activities.

Strengths of the AHRA activities to date include the rigorous process; the diverse range of stakeholders, including consumers, health professionals, and health services; the multidisciplinary national experts and agencies involved; and the collaboration and leveraging of learning nationally and internationally.[11] While input from state jurisdictions is increasing, expansion of opportunities here is needed. Implementation is well progressed and three AHRTCs have now engaged in pilot data hub development, most centres are engaged in data integration and harmonisation activities and all are involved in workforce development activities. Implementation will continue to evolve with parallel evaluation that is codesigned and includes clear health impact and workforce development measures.

Conclusion

We propose that the AHRA is uniquely placed to collaborate and drive the optimal use of data collected across the health care system in Australia and that implementing these joint agreed data priorities — collaborating with all relevant agencies and learning and coordinating nationally — is a vital step in delivering improved patient outcomes.

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[Insert boxes]

[Box 1; tee_mja18.01017_gr1]

1 The Australian Health Research Alliance model for bringing stakeholders together

[Box 1 foot]

MRIs = medical research institutes. Figure adapted from McKeon et al.[6]

[Box 2; tee_mja18.01017_gr2]

2 Governance structure of the Australian Health Research Alliance (AHRA)

[Box 2 foot]

MRFF = Medical Research Future Fund.

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