



Data Driven Healthcare Improvement

Report on MRFF deliverables 2018

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Joint Project Leaders



Melbourne Academic
Centre for Health



Monash Partners
Academic Health Science Centre



Sydney
HealthPartners

EXECUTIVE SUMMARY

Health and medical information enables clinicians, policy makers and the community to make informed decisions that will improve health care and outcomes at both the individual and population level. Typically, questions central to improving health outcomes and guiding policy decisions can only be answered by obtained and analysed quality real world data and evidence from large, heterogeneous populations, held across a range of sources.

In order for AHRA Centres and stakeholders to generate 'real-world' evidence in an efficient manner, we must facilitate the use of advanced digital technologies and nationally aligned streamlined processes that optimise data collection, linkage, management and analysis of large datasets. We must also create a governance framework that encourages and facilitates research and translation, whilst ensuring appropriate safeguards are in place that protect the rights of patients and the community.

AHRA Centres have prioritised Data Driven Healthcare Improvement (HCI) from our collective strategic Centre priorities, the Australian Medical Research and Innovation Strategy and the Medical Research Future Fund have also prioritised this area. AHRA have created a National Systems Level Initiative (NSLI) to collaborate, engage stakeholders, and create a community of practice to identify and address priorities in Data Driven HCI. This approach offers progress on previously intractable problems through large scale collaboration, transcending silos and barriers to progress.

In 2018 all Centres engaged in data activities and collaboration and these efforts are reflected in a broader report that will be co-produced and finalised early in 2019. The current report focuses on the funded deliverables under the MRFF support for the National Systems Level Initiatives. This includes formation of a national committee in Data Driven HCI, engagement of stakeholders and consumer representatives, completion of a rigorous national priority setting process: literature review, policy capture, and a modified Delphi process and nominal group technique. The priorities have been agreed across all Centres and provides a road map for collaboration nationally. These are submitted for publication.

The priorities focus on creating virtual hubs for Data Driven HCI within the Centres engaging all partners, integration of data across the continuum of care and workforce development. In 2018 deliverables have focused on integration of data and workforce development with collaboration, research, translation and leveraged partnerships to implement and scale outputs. These have been led by Monash Partners, Melbourne Academic Centre for Health and Sydney Health Partners, which are the lead Centres for Data Driven HCI and have all invested MRFF funds in 2018.

Activities included scoping of primary care data usage nationally, capturing shared learnings, hosting a national workshop, engaging PHN's and progressing a national framework for quality primary care data. Also a range of Rapid Allied Research Translation (RART) projects integrating primary and acute care data have been completed in areas such as hospital readmission prevention. RART projects have also provided exemplars of data integration including major scale up of lung cancer registries. A Data Sharing Accord and principles have been developed and are shared across Centres for adaptation and implementation as appropriate. Data sets are being aligned across Centres around Core Outcomes Sets to increase harmonisation. Meta-level learnings from these are captured to inform AHRA activities moving forward.

In workforce, considerable work has scoped activities nationally, completed a literature review, engaged and researched with stakeholders nationally, co-designed a curriculum and content and partnered with a range of government and education entities to deliver this at scale for national workforce development programs. Importantly, this MRFF funded activity has seen a new model of national collaboration with reach, collaboration and impact across silos and jurisdictions. This work, like other National Systems Level Initiatives, is proof of concept that AHRA and the AHRTC's and CIRH's can collaborate, deliver priorities, engage and complete bodies of work, reduce duplication, leverage partnerships and deliver in a short time frame.

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BACKGROUND

Data integration is one of the four Australian Health Research Alliance (AHRA) National System Level Initiatives (NSLI). These NSLIs align with the strategic platforms under the Australian Medical Research and Innovation strategy which aims for greater use of data assets and an essential integrated national health data framework supporting healthcare delivery, service improvement and best practice. Current challenges include limited health professional data literacy, ad hoc data capture, poor data quality, limited integration and linkage, major barriers to sharing and cumbersome governance requirements, with clinicians and the community generally unable to access routinely collected data to improve clinical care and health outcomes.

The Advanced Health Research Translation Centres (AHRTCs) and Centres for Innovation in Regional Health (CIRHs) are recognised leading centres of collaboration with a focus on research, practical translation, education and training and outstanding healthcare. They integrate research, healthcare and education to innovate for better health and break down silos. Embedded within health, bringing all stakeholders together and working as a national collaboration our Translation Research Centres and national collaborative AHRA are ideally positioned to address many of these challenges.

In late 2017, AHRA committed to developing a coordinated national approach to Data Driven Healthcare Improvement Research and Quality Improvement. An expert committee was formed across the Centre's with broad disciplines engaged and terms of reference established. This national systems level data initiative has engaged and encompassed all key stakeholders and leveraged:

- The Centre's workforce capabilities and platforms for data integration and usage across research, healthcare and education
- Expertise in data integration, registry science, data linkage and data driven health care improvement
- Data access across the healthcare continuum, data storage, security, access, management and analysis capability

The aims of the AHRA Data Driven Healthcare Improvement initiative are:

1. Establish national AHRA priorities through evidence synthesis, policy capture and engagement, and a formal evidence based priority setting process
2. Undertake research to scope and capture data training, literacy and harmonisation activities across AHRA
3. Engage stakeholders to co-develop and commence a multifaceted national AHRA data workforce development program
4. Optimise acute and primary care data quality improvement and governance streamlining
5. Undertake research to inform how AHRA may best enable, support and contribute to primary care data quality, linkage and sharing
6. Target clinical variation through improved:

- a. data capture (including EMR), management, harmonisation of core minimum structured outcomes
 - b. data analytics in Health Priority Areas
 - c. engagement, coordination and utilisation of registry data
 - d. identification of clinical indicators for readmissions in multi morbidity and chronic disease and data driven health care improvement
7. Identify meta-level barriers and streamlining opportunities to improve data governance and sharing, including through development of a Data Sharing Accord.

National AHRA Data Driven HCI committee and priority setting process

To optimise engagement and establish a shared vision and national work plan, an AHRA Data Driven HCI process was co-designed and completed including a national workshop in March 2018. The priority setting process was led by Monash Partners, supported by Melbourne Academic Centre for Health (MACH) and Sydney Health Partners and engaged all Centres.

Formation of AHRA Data Driven HCI Committee

Each centre (AHRTCs and CIRHs) nominated two data experts ratified by AHRA Council. Geography, discipline and regionality were all considered. Key stakeholders were identified and engaged including:

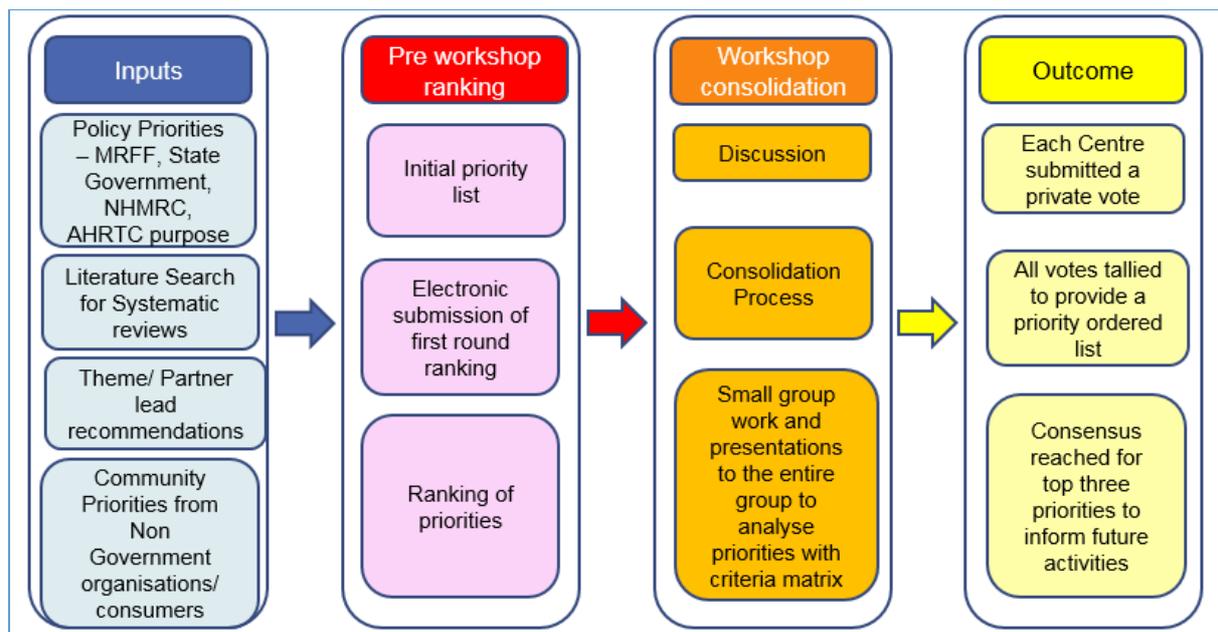
- National eResearch Collaboration Tools and Resources project (Nectar)
- Population Health Research Network (PHRN)
- Research Data Services (RDS)
- Australian Commission on Safety and Quality in Health Care
- Indigenous leaders
- International Clinical Evaluation Service (ICES)
- Department of Health and Community Services (DHHS)
- National Health and Medical Research Council (NHMRC) and
- Consumer representatives, identified through the Consumer Health Forum.

All were invited to have input into priorities and some attended the workshop (See Appendix 1).

Priority setting process

Prior to the workshop, priority areas were formulated through three strategies as outlined in Figure 1.

Figure 1: Modified Delphi and Nominal Group Technique Priority Setting Process

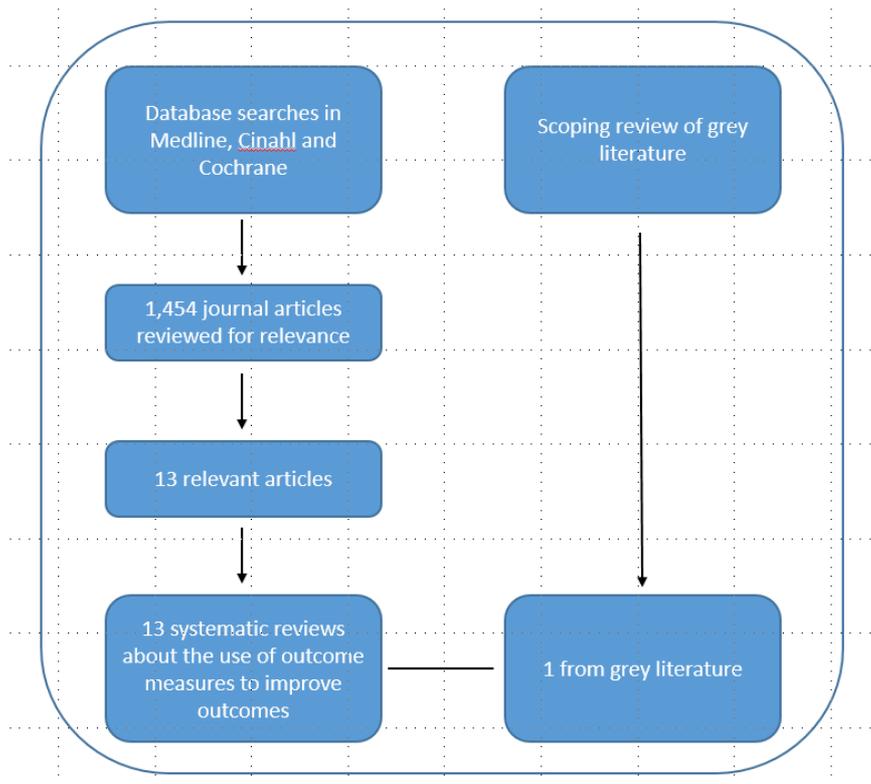


(Rankin et al. 2016; Delbecq 1975. See Appendix 2 for full references)

Inputs (figure 2) included a literature review, policy capture and priorities put forward by data committee members:

1. Literature review: A high level systematic search of the literature was completed which focused on past systematic reviews and posed the question: “How do healthcare professionals use data to improve health outcomes?” Search terms were: data and (health or outcome) and (improvement or impact) and “systematic review” with a limit to English Language and literature. Medline (1443), Cinahl (6), Cochrane (109), National Institutes of Health (NIH) (156), Canadian Institute of Health Research (CIHR), Kings Fund and the Grattan report were included in the search.

Figure 2: Literature review approach to inform the NSLI in Data Driven HCI priority setting process



2. Policy capture: Medical Research Future Fund (MRFF) priority statements from the Australian Medical Research and Innovation Priorities, and other policy statements on data including the NHMRC data sharing statement were captured. A matrix of priority areas was developed using an interactive process of document review and refinement of priorities undertaken by consensus processes.

3. Data committee members were asked to submit any additional priority areas they felt should be considered in the process.

This resulted in a list of twenty-five priorities (see Appendix 2)

The priority setting process outlined in Figure 1, can be summarised as follows:

1. First round priorities were generated from policy, evidence-based literature review and national expert committee members
2. A standard policy prioritisation framework was adapted and agreed upon via electronic communication across the national AHRA data committee
3. A modified Delphi survey was designed and the first round completed, pre-workshop to rank initial priorities across all Centres
4. Key stakeholders including consumers and representatives from national data agencies were identified and engaged

5. A facilitated national workshop was held in March 2018, applying a Nominal Group technique including review of the first round ranking, sense making and consolidation of priorities, round two and three Delphi processes were completed and small group work applied the agreed policy prioritisation framework
6. A final independent vote across each Centre and external stakeholders generated agreed priorities and consensus was obtained on the final ranked priorities.

The eight priority areas generated in round two are summarised in Table 1. Final consensus across AHRA organisations and stakeholders determined that the first three priorities would be the focus for AHRA activities from 2019-2021.

Table 1: AHRA Priorities in Data Driven Healthcare Improvement

Priority	
1	Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.
2	To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum
3	Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates)
4	Electronic Medical Records (linked to priority two)
5	Establish a strategic international collaborative in data priority areas to leverage multiple agency, discipline, national or industry investment (e.g. with Farr Institute or ICES)
6	Registries; National initiative to reduce burden and improve governance of and access to databases/ registries
7	Identify key infrastructure needs through a National data management study. With the aim of enhancing use of secure, digitised My Health Record, linked health and social data and inter-agency collaborative research
8	Develop a National framework to maximise interoperability and value of data to research and clinical practice

This work was prepared for publication and is under second round review with the Medical Journal of Australia (See Appendix 3).

Priority One activities: health data research incubator hubs

In creating the hubs, a first step was to progress priority two and three activities. Evidence synthesis, stakeholder engagement, qualitative research, international partnership and hub co-design form major components of 2019-2021 planned activity.

Priority Two activities: AHRA data integration platform

2A: Primary care Data Driven HCI and quality improvement

Background

Primary care data and its uses for research and HCI in Australia has been a complex area for many years, with common issues identified in relation to data access, completeness, mapping, quality, dependability, linkage, governance and collaboration. Funding and activities are fragmented and collaboration in data use has been primarily limited to individual projects. AHRA represents an opportunity to engage and work across stakeholders and Centres nationally in this space to advance collaboration, understanding and use of primary care data to drive HCI nationally, taking a whole of systems or meta-level approach to challenges that transcend individual projects, silos and stakeholders.

AHRA NSLI activities in this area are led by MACH and in 2018, included foundational work to inform how AHRA may best contribute to this agenda. This work was aligned with AHRA Data Driven HCI priority two and included engaging stakeholders around barriers, gaps and needs. To achieve this, four principle activities were undertaken with the first three coordinated by MACH engaging across all Centres;

1. Understanding current data linkage activities utilising primary care data
 - a. AHRA coordinated a national approach to the mapping of data linkage utilising primary care data. All AHRTCs engaged and collaborated to gather and disseminate information collected from the mapping exercise.
2. Progressing understandings and trust in routinely-collected GP data
 - a. Advancing the data quality assessment framework published in 2016, by Kahn MG, et al, for practical and systematic data warehouse implementation
 - b. This advanced framework will be published and tested in a practical setting against systematically collected GP routinely-collected data for research
3. Data linkage workshop
 - a. This workshop was held in 2018 and engaged AHRA Centres and key identified stakeholders
 - b. Areas covered in the workshop included barriers and enablers and what is required nationally in developing a unified approach
 - c. The mapping project and framework were progressed during the workshop
4. Rapid applied research Translation (RART) projects engaging across acute and primary care to increase AHRTC and primary care collaboration
 - a. RART projects were completed in 2018 and learnings are being shared nationally
 - b. Collaborations across Sydney, Monash and MACH and primary care agencies were advanced and are summarised below.

Project Summary: Activity 1 – primary care quantitative and qualitative research

A research survey for primary care Data Custodians and Data Users was developed to examine three broad questions:

1. What primary care datasets are available in Australia and are they being linked to other datasets?
2. What quality frameworks are being used to assess primary care datasets?
3. What enablers and barriers should be considered to maximise the effectiveness of strategies to build benefit and capacity in primary care data?

Methods: This survey was disseminated to over 300 individuals principally via AHRA partners. A wide range of organisations were represented to maximise knowledge. These included Government health departments, universities, health and medical research institutes, government agencies, associations, councils, networks, alliances, ACCHOs, peak bodies, clinical software providers, digital health groups, data services, professional associations and societies, and health insurer research foundations. Australian Government DOH engagement was instrumental in ensuring the survey was distributed to all PHN's.

Data analysis and Results

62 surveys were completed and 7 semi-structured in-depth interviews conducted. Over 89 'primary care' data sources / types and their data linkage profiles were identified spanning research, population surveillance, needs planning and assessment, audit and reporting and clinical usage. The characteristics of these datasets and respondents' answers to questions around these datasets varied widely.

Understandings of Data Quality Frameworks varied widely with some individuals reporting tools or procedures focussed around the management and characterisation of data quality whilst others cited their data governance procedures. There was no consistency with most frameworks employed being custom or ad hoc in nature. A lack of standard coding systems, limitations of manpower and 'There is no standard data quality framework that applies to our data' were indicative responses.

Barriers to the better use of primary care data included: Appropriate de-identification (and legal interpretation), lack of funding for academic GP's / GP interpretation of data, lack of public trust, difficult access, clinicians as data clerks (or not) and limitations of clinical software systems.

This information will inform future AHRA collaborative activities on data integration.

Project Summary: Activity 2 – Routinely-collected GP data – data quality frameworks

The primary care data survey highlights a lack of consistency in approaches to managing data quality in primary care data. This finding was not unexpected as MACH have been researching data quality frameworks in advance of AHRA 2018 activities. Activity 2 was designed to explore options for the development of a practical data quality framework that may be implemented in this sector.

A practical data quality assessment framework derived in-part from the paper: 'A Harmonised Data Quality Assessment Terminology and Framework for the Secondary Use of Electronic Health Record Data' <http://repository.edm-forum.org/egems/vol4/iss1/18> was submitted to eGEMS on the 25th October 2018. Reviewer feedback is awaited (10 Dec 2018).

Implementation of the experimental data quality framework was piloted utilising the University of Melbourne Data for Decisions data repository known as 'PATRON'. This data repository contains data collected from three common GP database systems. It should be noted that the framework has been designed to be data warehouse agnostic – i.e. regardless of how a data warehouse is structured, the data quality may be assessed. The framework is extensive with full characterisation of the data warehouse beyond the remit of the project. The project limited itself to examining data commonly utilised in research projects for example the project examined patient identification, medical encounter recording, diagnosis recording and prescribing.

Data analysis and Results

An SQL database with a user interface was created to allow the compilation of the data quality characteristics of the warehouse. This database allowed for the characterisation of the data at the system, table and field level. The characterisation is highly detailed with several dozen separate tests employed in the areas of; context within the original database system; relational conformance; uniqueness and temporal plausibility; value conformance; computational conformance; data completeness; atemporal plausibility.

The data analysis resulted in the documentation of commonly identified issues such as missing data or limitations to the data due to inconsistent coding and free-text entry. Some more unusual and difficult to spot issues were identified for example in one GP computer system, a table containing medical diagnoses has a field called 'DIAGNOSIS_DATE'. This field actually contains the date the diagnosis record was saved – it is not the actual diagnosis date. The actual diagnosis date is recorded in a separate table.

This work highlighted a number of key factors:

1. We identified issues in data that are hard to spot - misconceptions are not just possible but indeed are highly likely.
2. Given the subtlety of the issues identified, it can be expected that errors will be getting made in how to interpret the data across different tool providers nationally.
3. Data is frequently incomplete – having a physical record of the nature of data errors is fundamental to epidemiology. In most cases access to information about the underlying completeness is not available to the researcher at the time of requesting access to data.
4. Data is commonly coded and these codes vary from provider to provider. Standardisation and the correct interpretation of data collected using different coding mechanisms is highly problematic.
5. Applying such a framework is very time consuming.

Project Summary: Activity 3 – Workshop

An AHRA workshop was held in Sydney on the 26th November 2018: ‘Primary Care data for healthcare improvement and research: Approaches to data quality assurance in Australia.’ Participants from across AHRA, AIHW, Primary Health Networks and other primary care data custodians with over 30 participants present in person or by video streaming. This workshop reported the findings of the primary care survey and the trial implementation of the quality assurance framework. Small group sessions gathered feedback and consensus from participants. The output of the workshop was summarised to obtain overall feedback from the participants regarding priorities for AHRA in the primary care space going into 2019.

Data analysis and Results

The workshop overall was very well received with an essential component being the focus on national issues, what the problems are and what AHRA as a national alliance may help advance into the future. Key concerns about data quality were identified including concerns about lack of documentation, funding issues, a need for the optimisation of processes, ensuring value for the GP’s and the fact that poor data quality leads to research waste and inaccurate results. Ideas to address these problems were workshopped with many ideas identified. These ideas include

1. A structured strategy with common goals
2. Development of national standardised metadata for primary care
3. Nationally available prescribing and diagnostic coding mappings
4. Progression towards standards-based primary care systems (e.g. CSIRO work)
5. A move towards the use of common data models

The findings of the workshop are being disseminated to workshop participants to elicit final comment and feedback. This work will supplement the findings of the data survey and the quality assurance framework activities.

Project Summary: Activity 4 – RART projects linking routinely-collected GP and acute service data and new collaborations across primary care data agencies and Centres.

AHRA priority two is focused on integration of data across the care continuum. Under the MRFF funded data initiative greater integration was developed at a structural level (Monash Partners data lead integrated into the primary care data governance group of Outcomes Health) and a developing partnership has emerged across Outcomes Health, Monash Partners and Sydney Partners, based on extensive engagement of Monash and Sydney catchment primary care services with the primary care data agency Outcomes Health.

Cross Centre collaborative opportunities were advanced under the AHRA umbrella. Leveraging national AHRA leadership in Data Driven HCI, Monash Partners and MACH jointly led the Victorian Government Data Grand Challenge to inform State and MRFF priorities. Here the AHRTCs engaged primary care in a comprehensive series of activities to co-design priorities in Data Driven HCI. Also, several RART projects were funded under the MRFF allocation that engaged across Centres. The learnings from this work will collectively feedback into the broader

AHRA primary care integration activities. RART project outcomes are reported under specific RART project reports.

Summary and Discussion

This work program has helped establish strong foundations for AHRA to build-on in primary care data integration in 2019. Final recommendations will be assimilated after workshop participant feedback. The findings of the data survey, the trial data quality framework implementation and the RART projects will be published in 2019 (note that these were not project deliverables for 2018). This work would not have been possible without the overarching national umbrella of AHRA and the coordination and funding of the MRFF funded NSLI data leads, to undertake this research and translation activity. Outputs will provide a foundation and guide future activities. The range of participants and the commonality of vision and agreement is a major achievement in this very fragmented space. It is clear that collaboration is difficult across disparate stakeholders and that AHRA as a national alliance will have an important role to play going forward. Joint recommendations for how AHRA can best serve the primary care data space going-forward shall be made to AHRA in Q1 2019 following the finalisation of feedback and council sign off on the outputs of here activities.

2B: Cross Centre health service data integration activities

Project Summary, Activity 1: Optimising collaboration across Centre members and across AHRA Centres in data sharing - Progressing a national data sharing accord

The aim off this work led by Sydney Partners is to bring about a data sharing relationship that facilitates safe, lawful and appropriate sharing of health data across Centre partners. By having an Accord documenting agreement on ethical principles and data handling solutions, the frustrations of having to reinvent a data extraction, encryption, storage and access solution for each adhoc individual project can be circumvented. In essence, this accord focused on meta-level issues in data sharing and integration. The objective is to facilitate the conduct of research that uses data shared across entities to measure and improve the appropriateness and quality of care across Centre partners and across AHRA Centres.

Extensive member engagement occurred across Sydney Partners. Guiding principles for the sharing of data have been agreed to by all Sydney Health Partner organisations. Appendix 4 and Appendix 5 provide further details for this agreement and are presented as the: *Accord for the Sharing of Health Data across Sydney Health Partners*, and *Data Sharing Protocol Checklist - for the Sharing of Health Data across Sydney Health Partners*.

This work has engaged AHRA data committee members and Centre directors with several other Centres looking to adopt and implement the data accord. The aim is to streamline approaches where possible, accounting for jurisdictional and Centre differences. This work will be progressed across 2019 and exemplifies how AHRA can reduce duplication of effort, lower costs, and optimise streamlined approaches nationally.

Project Summary, Activity 2: Reducing clinical variation

Harmonisation of data and reduction in clinical variation has been recognised as complex. In 2018 AHRA progressed work in this area and a road map for 2019 was developed, with targeted resources allocated to further this work.

Data capture (including EMR), management, harmonisation of core minimum structured outcomes and data analytics in National Health Priority Areas

Electronic Medical records (EMR): Centres have EMR's in place with highly variable service providers, levels of sophistication and capture and use of data for healthcare improvement. Activity to capture this information is underway currently across AHRA. This is also being linked to considerable activity at the Public Health Network and State Government levels in setting up and refining EMR capture of data.

Variation in practice: AHRA is uniquely placed to evaluate variation in practice across a wide range of services and the opportunity to compare, benchmark, improve and align with guideline recommendations to reduce practice variation is available across diverse areas. Specific collaborative exemplar projects have advanced under the AHRA national Data Driven HCI initiative in 2018 including aligning maternity outcome sets around areas of clinical variation. These include exploration of core minimum data collected across Centres, commitment to align core minimum data and to expand to guideline related outcome measures to enable benchmarking against national guideline recommendations. This work has progressed across Monash Partners, MACH, Sydney Partners and engagement with SA Translation Centre is underway with MRFF resources allocated to this activity and opportunities for engagement of other Centres planned in 2019. Joint partnership grants have been developed with State Governments engaged and co-funding and are submitted to the NHMRC. RART projects in other areas of data harmonisation and linkage have been funded under the MRFF allocation including the Obstetric Anal Sphincter Injury (OASIS) Quality of Care Improvement project: This has engaged across MACH and Monash Partners and has established agreed care assessments, patient outcome measures and benchmarks for monitoring variation in practice across health services.

Atlas for clinical variation: In collaborations with State Governments, this has been identified as an important source of priorities for AHRA moving forward.

Project Summary, Activity 3: Optimisation and utilisation of registry data

Monash Partners has prioritised registry realised activities and has funded data RART projects across Centres with shared learnings: These are reported under the RART activities. Here we note cross AHRA Centre initiatives including:

- a) Lung Cancer Clinical Quality Registry has expanded from 50% to include 80% of all new lung cancer cases diagnosed in Victoria (MACH and Monash Partners health services)
- b) The Victorian Cardiac Outcome Registry has completed a 12 month follow up evaluation for mortality rates for those following PCI and generated gender specific analysis and a healthy lifestyle adherence evaluation.

Summary of AHRA data integration activities

In 2018 AHRA has established a national committee, identified and engaged key stakeholders, reviewed relevant literature, captured policy contexts, determined agreed priorities, and progressed activities under these priorities. This has provided a road map for collaboration moving forward. We have consolidated and progressed activities around primary care data linkage, quality and usage. We have created a data sharing accord implemented in one Centre and being adapted and implemented across other Centres. We have progressed work on variation in clinical practice including with registries. Overall collaboration and engagement across all Centres nationally in Data Driven HCI has been unprecedented and has escalated at pace and scale with tangible outcomes that will promote better patient outcomes.

Priority three activities: Workforce Capacity building, research and partnership for delivery

Improving Data literacy and workforce capacity for healthcare professionals and others involved in Data Driven HCI is a key priority for the improvement in quality of care and the resulting improvement in healthcare outcomes for patients. The following research and translation activities were undertaken to scope data literacy and workforce development programs across AHRA. The engagement of key stakeholders in this national system level initiative enabled completion of the following activities;

1. Scoping workforce development activities across AHRA Centres and partners inclusive of literature review on effective workforce development strategies
2. Establishing priorities for data literacy and workforce development training
3. Leveraging partner and stakeholder investment to translate and scale workforce development activities.

Activity 1: Scoping and mapping activities

A national AHRA survey scoped current activities in this area and provided a map of activities and experience. Methods are outlined under survey development below. Results included identification of:

- NSW Health and Sydney Partners activities including leadership of the \$110M digital health Collaborative Research Centre workforce development program
- ANDS workforce development funded activities
- Monash Partners international collaborative activities

The translation of AHRA workforce development activities in these areas, directly leveraged off this scoping and mapping exercise as outlined in activity 3 below.

Activity 2: Priorities for workforce development

Methods included:

1. A literature review to identify existing training opportunities, with a focus on health professionals in the first instance. This captured strategies, effectiveness and key content and delivery methods and informed the survey.

2. An evidence informed survey was co-developed, and administered to seek stakeholder input around subject areas for inclusion in a national AHRA data literacy and workforce training program primarily targeting healthcare professionals (See Appendix 6). The survey was distributed to three broad stakeholder groups:
 - a. Experts in the field (including Data Specialists from: Universities, Healthcare Networks, Primary Health, Consumers and Private/ Public Data specialist services)
 - b. University Academics with/ without Clinical affiliation
 - c. Healthcare providers with/without Academic affiliation

Results: Two hundred and eleven completed surveys were received: 110 respondents identified as a health care provider with 40 holding academic affiliation, 65 identified as academics with 49 holding a clinical appointment, and 19 surveys were received from workshop attendee data experts. Table 2 summarises the content areas included in the survey with three areas highly ranked in all three groups: security of data, data privacy and confidentiality (freedom of information, consent issues, legislation) and use of outcome measures on more than an individual basis. These are highlighted for easy identification in Table 2 below.

Table 2: Priority Areas for Data Literacy and workforce development

Data Experts	Academics	Healthcare providers
Data Privacy and Confidentiality (FOI, Consent, Legislation)	Security of data	Data Privacy and Confidentiality (FOI, Consent, Legislation)
Security of data	Data Privacy and Confidentiality (FOI, Consent, Legislation)	Systems to name and store data for easy retrieval
What large data bases are openly available for people to access?	Systems and structures to “clean” data	How do you use outcome measures on more than an individual basis?
Software analysis packages and where to get guidance	What large data bases are openly available for people to access?	Check lists and planning tools
How do you use outcome measures on more than an individual basis?	Software analysis packages and where to get guidance	Security of data
Systems to name and store data for easy retrieval	How do you use outcome measures on more than an individual basis?	What Outcome Measure collaborations exist?
What Outcome Measure collaborations exist?	Data Storage Options	Data Storage Options

Systems and structures to “clean” data	What Outcome Measure collaborations exist?	Software analysis packages and where to get guidance
What closed large data bases are available on request?	Systems to name and store data for easy retrieval	What large data bases are openly available for people to access?
Check lists and planning tools	Check lists and planning tools	Systems and structures to “clean” data
Data Storage Options	What closed large data bases are available on request?	What closed large data bases are available on request?
How to “flatten” or compress your files and then normalise again	How to “flatten” or compress your files and then normalise again	How to “flatten” or compress your files and then normalise again

Activity 3: Translation of workforce development initiatives

i) Massive Open Online Course

The literature review and survey informed content for multifaceted workforce curriculum development and across a range of offerings including a Massive Open Online Course (MOOC), ‘Using clinical health data for better healthcare’. The MOOC is a collaborative initiative between the University of Sydney and NSW Health, with active contribution and participation from AHRA Partners/Stakeholders. A MOOC is an open access web-based learning resource aimed at large-scale participation. Learners, nationally and internationally, can register and participate in the MOOC free of cost. It is asynchronous, allowing for anytime learning. Learners may choose pay a nominal fee to receive a certificate of completion. The aim of the MOOC is for learners to understand and perform information seeking, knowledge creation and decision making, utilising health data contained within digital systems. This broad scale learning resource is relevant to the health workforce and health degree graduates and focuses on foundation level digital health capabilities.

The MOOC is comprised of four learning modules targeting the following learning objectives:

1. Identify digital health technologies, health data sources, and the evolving roles of the health workforce in digital health environments.
2. Understand key health data concepts and terminology, including the significance of data integrity and stakeholder roles in the data life cycle.
3. Use health data and basic data analysis to inform and improve decision making and practice.
4. Apply effective methods of communication of health data to facilitate safe and quality care.

Monash Partners and Australian Research Data Commons have actively contributed subject matter expertise and participated in the co-design and production of two specific learning

objects (LOs) relevant to the topics identified as priorities under the MRFF funded process. The two LOs and associated learner activities form re-usable learning resources on the topics of ‘Data Governance and Privileges’ and ‘Sharing Data for Research Purposes’ (Table 3). As well as forming important curriculum components of the MOOC, these reusable LOs will be used in a variety of education and training contexts, including: organisational learning management systems and websites, staff development and on-boarding sessions, and tertiary education lectures and online learning.

Table 3: Examples of learning objects featured in ‘Using clinical health data for better healthcare’ MOOC

Learning Object Title	eHealth Capability Statement	Learning objectives
Data Governance and Privileges	Understand and describe the fundamentals of digital health legislation, policy and ethics, including privacy and security, data governance, and professional conduct.	<ul style="list-style-type: none"> • Understand basic principles of health data governance • Describe actions taken to maintain the privacy, integrity and security of data • Identify appropriate use of health data, as it complies with legislation, policy and ethics • Recognise roles, responsibilities and professional conduct when working with health data.
Sharing Data for Research Purposes	Use and share digital health appropriate to professional role, duties, and scope of practice in the provision of safe and quality care.	<ul style="list-style-type: none"> • Describe advantages of sharing research data • Identify what shared data is and its uses • Describe a data repository • Understand data ownership and licensing • Describe a data management plan and what it may include • Develop awareness of data linkage and its role

MOOC production is funded by Sydney partners and NSW Health as outlined above. It is due for completion in early 2019. A pilot, involving NSW Health workforce in the first quarter of 2019, along with further evaluation involving AHRA will inform the roll-out and production of further targeted education and training resources aimed at raising health data literacy and building

workforce capacity at pace and scale. Such resources may include micro learning opportunities and learning sets, and the development of a national repository of digital health and data analytics learning resources.

As such, AHRA is now recognised as an advocate and partner in education and workforce capacity building for digital health and data analytics. We will continue to participate and contribute to national forums relevant to this topic, including a Digital Health Cooperative Research Centre summit, involving the Australian Digital Health Agency, Departments of Health, and other key stakeholder early in 2019. This collaboration, research and translation activity across AHRA which has fed into scale up activities funded by end user organisations is a strong exemplar of the potential impact of AHRA activities.

Other Translation Activity under workforce development in Data Driven HCI

- a. The findings from the literature search and survey and the expert input from the AHRA data committee, has also informed the content of a short source and Masters of Digital Health, presently under development and funded by Monash and Warwick Universities (UK).
- b. Data Resource: An AHRA data resource is under development to address prioritised areas for the workforce survey. This is being developed in collaboration across AHRA and ANDS as a government funded nation data agency. This is planned as a live iterative resource and will be freely available on the Monash Partners Website by March 2019 linked to the AHRA website. Outputs will be accessible across Centres.
- c. Partnership with Credentialing Health Informatics Australasia (CHIA): CHIA is a unique training and credentialing program in health informatics (www.healthinformaticscertification.com). CHIA credential demonstrates that candidates meet the Health Informatics core competencies to perform effectively as a health informatics professionals in a broad range of practice settings. The certification has been designed to address training gaps and the lack of formal recognition for health informatics skills in the Australian health workforce. This program has been developed by leaders in health informatics across the health and IT sectors and academia. Monash Partners has negotiated and is trialling a partnership with CHIA to provide MRFF funded fellows and partner funded PhD students and staff the opportunity to complete the program at low cost well as opportunities for networking and support throughout the training. The program will be evaluated and if successful the collaborative model and approach will be shared across all Centres. Again, this is an example of pace, scale, reducing duplication and cost through AHRA NSLI activities.
- d. Development of a data fellow's research, translation and training program. This initiative has been informed by activities 1 and 2 with fellows recruited and funded under the 2019 MRFF funding. These fellows will undertake specific projects but will also create a network of next generation Data Driven HCI leaders. This cohort will undergo CHIA accreditation, be provided with leadership and implementation and innovation training. These fellows will progress activities under priority one including development of health data research incubator hubs undertaking literature review, qualitative research nationally and internationally and stimulating partnerships across academic, clinician, community, primary care and industry stakeholders.

Other activities will include development of:

- a data harmonisation road map to inform linkage of data to improve maternal health outcomes across State governments and Centres
- a data harmonisation road map to inform linkage of prehospital and emergency department data
- data linkage to provide near real-time monitoring of cardiac surgical performance - a pilot for a national process
- innovative artificial intelligence for application of improving patient outcomes in patients with blood cancer

e. Development of an innovative and now funded Graduate Research Industry Program: This work was supported by the NSLI lead in data driven HCI and involves \$2M of partner funding to recruit a cohort of PhD students embedded within healthcare to address health service priority areas. This program will be fully evaluated and learnings shared across AHRA Centres for adaptation and replication where appropriate.

Summary

Collectively in 2018 leveraging the MRFF NSLI funding and staff, we have scoped workforce development activities across AHRA Centres, partners and stakeholders inclusive of literature review on effective workforce development strategies. We have identified current activities and leveraged these with national coordination and integration to collaboratively develop workforce training programs. We have established priorities for data literacy and workforce development training through stakeholder engagement and informed content and translation into training programs. We have partnered and leveraged stakeholder and partner investment to translate and scale the co-designed workforce development activities nationally. This work has reduced duplication and cost and enabled pace and scale in workforce development through the AHRA NSLI.

Actions for 2019

Collectively in 2019 together we will expand work under the AHRA priority areas:

1. Incubator hubs: Research will further explore existing hub models and model these potential hubs through literature review, qualitative research and case studies. Infrastructure and co-funded capacity will be built in the lead Centres and others nationally to consolidate efforts around data driven HCI within and across AHRA and its Centres. This includes data linkage, security, governance, access and management systems linked to NCRIS and other government and Industry funded infrastructure. This is also linked to other national initiatives such as the Digital Health CRC, (leadership role from Sydney Health Partners and Monash Partners, engaging many of the other Centres), My Health Record and other partner programs.
2. Data integration: Primary care data integration will be progressed including improving data quality and generating large scale collaborations seeking MRFF funding. We will progress the data sharing principles/ accord nationally. Exemplar projects will be expanded with challenges emerging providing shared learnings on barriers and enablers to be collectively addressed. We will support, leverage and expand our world leading clinical registries program through funded RART projects. We will share and harness collective learnings across Centres and explore

streamlining activities to improve linkage and data sharing, especially in areas of major clinical variation.

3. Workforce capacity: We will build on our collective work to develop, translate, evaluate and scale up our co-designed workforce capacity building offerings. Our MRFF funded data leads will coordinate activity and ensure we leverage other large-scale opportunities, supported and mentored across the faculties of health, business and IT, to build the next generation of workforce in this area. We have partnered with national accreditation agencies in this area also and partners and funding access to this program. We are also leveraging the Digital Health CRC capacity building program with SHP and are co-developing a range of co-designed offerings that will be available nationally. Here these activities will be coordinated, shared learnings extracted and evaluation and refinement of programs completed. Finally, we are leveraging a large scale collaboration across Monash Partners and Warwick University/ UK CLAHRCs to explore workforce barriers and needs in this field and to feed this into workforce development programs and incubator hub design. Learnings will be shared across AHRA Centres. Specifically, MP has co-funded a multimillion dollar program within our AHRTC to initiate a postgraduate training program with PhD students nested within our health partners. The model, evaluation and learnings will be shared across all AHRA Centres.

Appendix 1

AHRA Data Driven HCI committee members and stakeholders who were Workshop attendees:

Professor John Attia - New South Wales Regional Health Partners

Assoc. Professor Douglas Boyle – Melbourne Academic Centre for Health

Mr Adrian Burton – Australian National Data Service (Now Australian Research Data Commons)

Mr Ian Duncan – Research Data Services (Now Australian Research Data Commons)

Ms Robyn Dunphy – Consumer Representative

Professor Peter Eastwood – Western Australian Health Translation Network

Dr Sue Evans – Monash Partners Academic Health Science Centre

Dr Felicity Flack - Population Health Research Network

Ms Aisling Forrest – Sydney Health Partners

Ms Areti Gavrilidis – Brisbane Diamantina Health Partners

Prof Gary Geelhoed - Western Australian Health Translation Network

Dr Stephen Grey - Consumer Representative

Mr David Henry – Institute for Clinical Evaluative Sciences

Mr Michael Inouye – Central Australia Academic Health Science Centre

Mr Gary Jennings - Sydney Health Partners

Ms Alison Johnson - Monash Partners Academic Health Science Centre

Dr Angela Jones - Monash Partners Academic Health Science Centre

Professor Cheryl Jones - Melbourne Academic Centre for Health

Professor Louisa Jorm – Sydney Partnership for Health, Education, Research and Enterprise

Ms Karyn Joyner - Sydney Partnership for Health, Education, Research and Enterprise

Ms Wendy Keech – South Australian Academic Health Science and Translation Centre

Mr Christopher Levi - Sydney Partnership for Health, Education, Research and Enterprise

Mr Chips Mackinolty - Central Australia Academic Health Science Centre

Professor Rod McClure – New South Wales Regional Health Partners

Professor Jonathan Morris - Sydney Health Partners

Professor Terry Nolan - Sydney Health Partners

Mr Gerry O’Callaghan - South Australian Academic Health Science and Translation Centre

Professor Tim Shaw - Sydney Health Partners

Dr Merran Smith – Population Health Research Network

Dr Clair Sullivan - Brisbane Diamantina Health Partners

Professor Helena Teede - Monash Partners Academic Health Science Centre

Ms Jodie Wall - Melbourne Academic Centre for Health

Mr Steve Wesselingh - South Australian Academic Health Science and Translation Centre

Dr Ross Wilkinson - Australian National Data Service (Now Australian Research Data Commons)

Appendix 2

Data driven HCI priorities
To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum
Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.
Identify key infrastructure needs through a National data management study. With the aim of enhancing use of secure, digitised My Health Record, linked health and social data and inter-agency collaborative research
Establish a strategic international collaborative in data priority areas to leverage multiple agency, discipline, national or industry investment (e.g. with Farr Institute or ICES)
Data integration to reduce clinical variation; co-morbidity; and health inequities
Develop a National framework to maximise interoperability and value of data to research and clinical practice
Use of MBS, PBS and other large administrative data sets
NHMRC Data Practitioner Fellowships to increase engagement of data research-focused clinicians
Investment in disease or therapy-focused clinical registries
PhD/ postdoc fellowships to build capacity and talent exchange, across health, industry, government to stimulate entrepreneurial and translation activities
Enhance data activity around disruptive technologies such as artificial intelligence and wearable devices
Use of data to enhance research on national surveillance of and response to current and emerging infectious diseases and antimicrobial resistance
Use of data to measure and report on economic returns from investments
National scheme that enables access to existing high cost data infrastructure to maximise hardware use and foster collaboration. This may include the creation of data hubs or warehouses/ market places within the Centres
EMR integration of clinical guidance/ decision support. Evidence shows success with order sets, pharmacy prescribing and lab tests
National initiative to increase patient reported outcomes measures in registries and data sets
EMR - extraction of data from unstructured data
EMR – integrated harmonised core minimum data sets agreed and implemented into the EMR to enable cross sectional and longitudinal benchmarking and ongoing evaluation of care for quality improvement
Patient self-reported/ collected data linked to clinical teams that enhances self-management
Enhancing use of registry data to improve healthcare delivery and outcomes
Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates)
Registries; National initiative to reduce burden and improve governance of and access to databases/ registries
Promotion of real time data to enhance clinical decision making – outcome measures available at point of care
Data/ Cyber security as major barrier to health data translation
Increase researchers integrated into clinical services/ teams to increase data use

Yellow: Australian Medical Research and Innovation Priorities for MRFF funding

Green: Literature search **Blue:** Expert recommendations.

Appendix 3

Publication for Medical Journal of Australia

Australian Health Research Alliance: National priorities in data driven healthcare improvement.

Helena Teede^{1,2}, Alison Johnson¹ Jim Buttery^{1,2} Cheryl Jones^{3,4} Douglas Boyle^{3,4} Garry LR Jennings^{5,6} Tim Shaw^{5,6} On behalf of all the national Australian Health Research Alliance data driven healthcare improvement committee.

1Monash Partners Academic Health Science Centre, 2Monash University, 3Melbourne Academic Centre for Health, 4 The University of Melbourne, 5Sydney Health Partners, 6The University of Sydney

Abstract:

Objectives

The Australian Health Research Alliance (AHRA) aimed to undertake a rigorous process to generate strategic national collaborative priorities in data-driven healthcare improvement.

Setting and Participants

AHRA encompasses National Health and medical Research Council accredited Advanced Health Research Translation Centres and Centres for Innovation in Regional Health, covering the vast majority of Health and Medical Researchers and acute health care services, engaging significantly with primary care and across geographical diversity nationally. Funded through the Medical Research Future Fund, we integrate research and healthcare to deliver better health outcomes. Data Driven Healthcare Improvement is a Strategic Health and Medical Research Priority and here we outline our national priority setting processes.

Intervention

We established a national committee, engaged broad stakeholders, used modified Delphi and Nominal Group techniques in a multi-step process, and generated priorities from policy, evidence synthesis, experts and stakeholders. Online voting generated preliminary priorities which were refined at a national workshop. Sense making, consolidation and a co-designed prioritisation framework preceded final voting for agreed priorities.

Results

Three priorities emerged: 1) Create virtual or actual health data research incubator hubs within the NHMRC accredited Centres to stimulate partnerships across academic, clinician and industry stakeholders, 2) Integrate large scale data sets to undertake research and quality improvement across the care continuum 3) Build workforce capacity in data driven health care improvement through training of undergraduates and postgraduates.

Conclusion

We identified AHRA's stakeholder driven, strategic, data driven healthcare improvement priorities to inform our national shared approach, with alignment across our accredited Centres nationally.

The Known: Healthcare Improvement is a key health and medical research priority.

The New: The Australian Health Research Alliance encompasses NHMRC accredited Advanced Health Research Translation Centres and Centres for Innovation in Regional Health used evidence based processes to generate priorities from policy, evidence synthesis, experts, consumers and data agencies.

The Implications: National strategic data driven healthcare improvement priorities generated are:

- 1) Create virtual or actual health data research incubator hubs
- 2) Integrate large scale data sets for research and quality improvement across the care continuum
- 3) Build workforce capacity in data driven healthcare improvement

Introduction

Data driven healthcare improvement offers great promise in improving quality and efficiency in healthcare, if its value can be harnessed (1, 2). Australia has a well-established primary care data system, has invested widely in electronic medical records in the hospital sector and also in “My Health Record”: a population wide, opt out, medical record. We are poised to realise the value of data in improving health. However, The Duckett report (2017) noted “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” (3). Major barriers exist, and in order to unlock the potential of health data, integration of research, healthcare and education; alongside industry and government engagement is vital (2) and must be a policy priority (4). Others, such as the Scottish node of Health Data Research UK, have unleashed, at scale, the power of health service and wider administrative data (1). Yet until recently, Australia has arguably lacked the collaborative platforms to bring relevant stakeholders together to deliver on the potential (5).

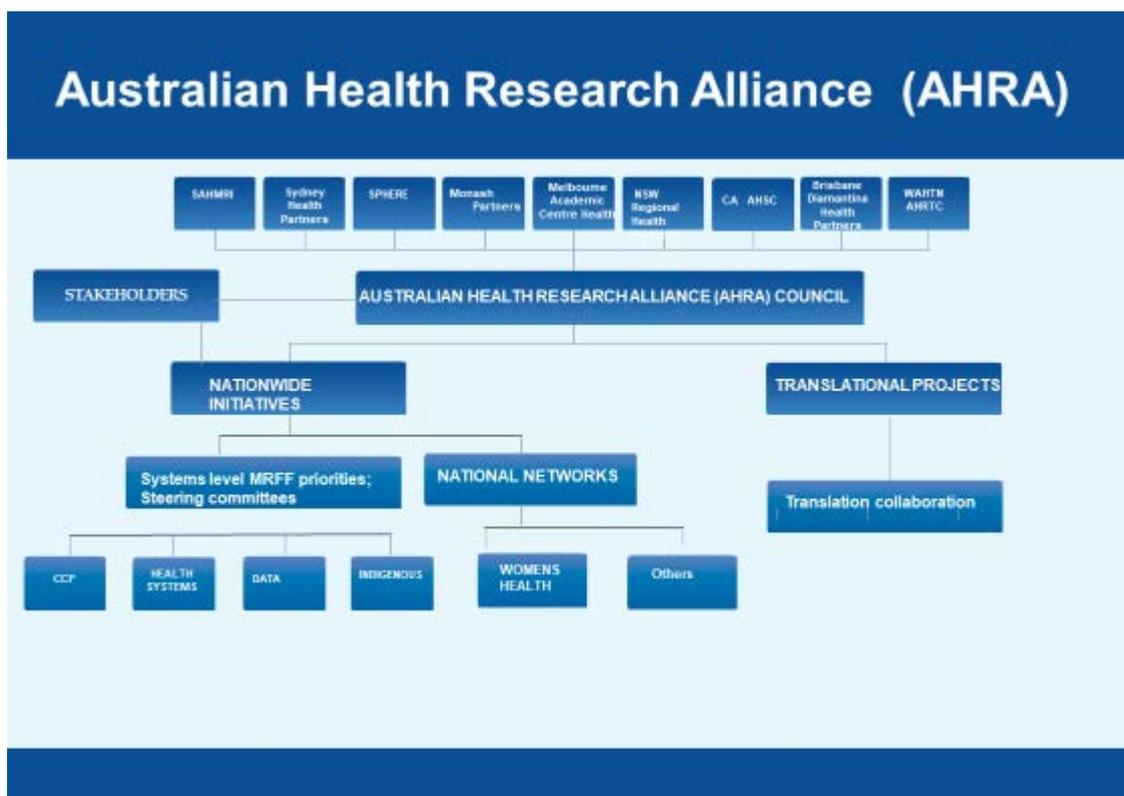
The need to improve healthcare through research was highlighted in the *Strategic Review of Health and Medical Research* (5, 6) and the *Australian Medical Research and Innovation Strategy 2016–2021* (‘the Strategy’) which is funded through the *Medical Research Future Fund* (MRFF), (4, 6). Together these aim to deliver on the vision of Better Health through Research. The national Australian Health Research Alliance (AHRA), which through its collaboration with seven Advanced Health and Research Translation Centres (AHRTCs) and two Centres for Regional Health (CIRHs) brings together approximately 90% of NHMRC-funded health and medical researchers and 80% of hospitals could provide an ideal platform to achieve this vision. The AHRTCs and CIRHs were established following the McKeon review (5) to integrate research, education and healthcare across sectors and have been accredited by the National Health and Medical Research Council (NHMRC) (fig 1).

Figure 1: AHRA model bringing stakeholders together for better health through research (adapted from (5)).



The governance structure consists of a national Council of Centre directors and a network of national committees (fig 2). The Centres have together been awarded \$95M in MRFF funding up to 2021. The funds support rapid applied research translation projects and national system level initiatives in the areas of i) data driven healthcare improvement, ii) consumer and community engagement in research and translation iii) Indigenous capacity building and iv) health services research and system sustainability (fig 2).

Figure 2: AHRA governance



In this paper, we describe the process to establish agreed national priorities and a path forward for data driven health care improvement for the nation, that is firmly public benefit, community and outcome focused.

Methods

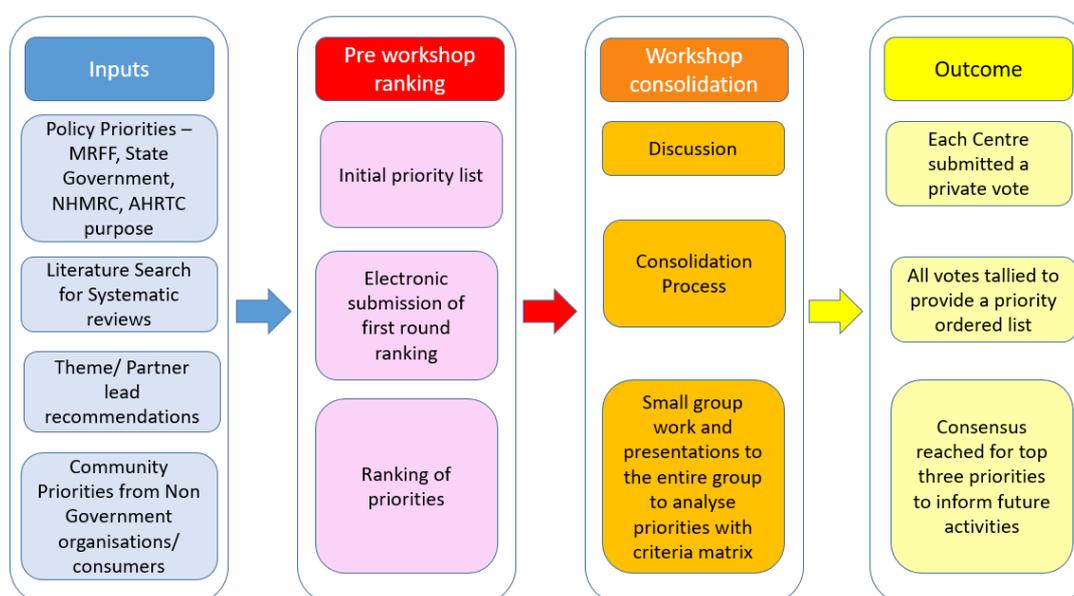
We applied a modified Delphi process and Nominal Group technique previously used to rank research and service priorities by multiple stakeholders (7). Our adapted multistep process is outlined in box 1 and figure 3.

Box 1: Multistep process to engage stakeholders and establish national AHRA priorities for data driven healthcare improvement.

1. Representative experts were identified and nominated by AHRA NHMRC accredited Centres, considering discipline, geography and expertise and supplemented with key stakeholders including consumers and representatives from national data agencies
2. A literature review was completed
3. First round priorities were generated from policy, evidence-based literature review and national expert committee members
4. A policy prioritisation framework was adapted and agreed upon via electronic communication across the national AHRA data committee
5. A pre-workshop modified Delphi survey was circulated to rank first round priorities with instructions to utilise the policy prioritisation framework when considering each priority
6. A facilitated national workshop was held in March 2018, applying a Nominal Group technique including review of the first-round ranking, sense making and consolidation of priorities and small group work to apply the agreed policy prioritisation framework
7. A final independent vote across each Centre and external stakeholders generated agreed priorities and consensus was obtained on the final ranked priorities

Figure 3: The Prioritisation process for AHRA priorities in data driven healthcare improvement

Prioritisation Process – Data Driven Healthcare Improvement



AHRA: National data driven healthcare improvement committee

Each centre (AHRTCs and CIRHs) nominated two data experts ratified by AHRA council. Other invited stakeholder organisations included: National eResearch Collaboration Tools and Resources project (Nectar), Population Health Research Network (PHRN), Research Data Services (RDS), Australian Commission on Safety and Quality in Health Care, Indigenous Issues (Professor Marcia Langton AM), International Clinical Evaluation Service (ICES), Department of Health and Community Services (DHHS), National Health and Medical Research Council (NHMRC) and consumer representatives, identified through the consumer health forum.

Policy Priority Areas

Prior to the workshop, priority areas were formulated through three strategies (box 1). A high level systematic search of the literature was completed which focused on past systematic reviews and posed the question “How do healthcare professionals use data to improve health outcomes?” Search terms were: data and (health or outcome) and (improvement or impact) and “systematic review” with a limit to English Language and literature over the past 3 years (given the rapidly growing field). Medline (1443), Cinahl (6), Cochrane (109), National Institutes of Health (NIH) (156), Canadian Institute of Health Research (CIHR), Kings Fund and the Grattan report were included in the search.

Medical Research Future Fund (MRFF) priority statements were extracted by two team members (AJ, HT) from the Australian Medical Research and Innovation Priorities (4). A matrix of these priority areas was developed that linked the priorities to the one or more references from which they were drawn. An interactive process of document review and refinement of priorities was undertaken by consensus processes including two authors (AJ, HT).

Expert data committee members were asked to submit any additional priority areas they felt should be considered in the process (fig 3).

This process resulted in a list of twenty-five priorities.

Priority setting framework

	Criteria	Explanation
1	Prevalence or burden relevant to the proposal	Consider prevalence/ attributable burden of the problem and implications/ complications to be addressed. Is the problem a major issue for the community, health system/ stakeholders? Or will it address national health priority areas
2	Prevention	Is there significant potential to prevent the problem/ complications or secondary impacts in the broader population or specific vulnerable cohorts?
3	Position	Consider geographical/ regional issues and location of services/ expertise. Are there inequities that can be improved by this initiative? Is there potential to improve health for regional populations and /or vulnerable cohorts?
4	Provision	Does the current approach (or use of data) align with evidence-based best practice? Is there a gap to address?
5	Potential	Is there a strong rationale/evidence base for the proposed approach to improved health care and outcomes? Is there evidence for the proposed approach to addresses the evidence practice gap? Is it feasible to institute?

6	Participation	Is engagement/ collaboration critical to success? Are there clear drivers for stakeholders to engage and collaborate? Are there existing relationships between stakeholders that can be leveraged? Is there potential for strong engagement in the proposed initiative, and why AHRTCs/ CIRHs or AHRA?
7	Policy	Does the problem or the potential solution align with current policy directions at a local, state or national level including MRFF priorities?
8	Proposed Strategy	Does the proposal align with the purpose of the AHRTC's and CIRHs priority areas
9	Proposed Transformation	Will addressing this problem/ taking this approach collaboratively, lead to a transformational change in health care and outcomes?

Table 1: Agreed Priority setting framework

A Priority setting framework was adapted from a Victorian Policy Prioritisation Framework. This generated nine criteria that were adapted, refined, and endorsed by the committee members electronically beforehand and applied at the workshop. Explanations were provided for nine criteria (the 9 P's) which are outlined in table 1.

Pre-workshop

One week prior to the workshop all attendees were sent a list of the twenty-five priorities. They were also provided with the agreed prioritisation setting framework to guide consideration of each item. Attendees were asked to rate their top ten priorities and submit these prior to the workshop. Ten would indicate the priority of most importance and one the least. All AHRA member centres submitted priority lists.

Workshop

Participants discussed the twenty-five priorities in small groups (group allocation was not controlled). Groups were instructed to review the priorities and consolidate and integrate where appropriate. This was followed by a whole group discussion to consolidate and integrate working group inputs.

Once a consolidated list of priorities was agreed, an independent confidential vote was conducted. One vote for each AHRTC/ CIHR centre and one vote from invited stakeholders, which included consumers. The nine AHRTC/ CIHR votes were amalgamated and compared with the stakeholder vote.

The prioritised list was presented to the workshop participants and consensus was reached that the top three priorities would form the data driven healthcare improvement priorities for the AHRA.

Results

The systematic literature review identified 1454 articles after removal of duplicates with 1422 excluded through a review of titles and abstracts. Thirty full text articles were reviewed for priority area formulation. Fourteen provided evidence based potential priority areas which have been included in table 2.

Five submissions from AHRA data committee members were received prior to the workshop for consideration in the priority setting process.

The adapted and agreed policy priority framework is presented in table 1.

Table 2: Pre-workshop priorities from MRFF policy, literature review and expert recommendations

Ranked order	Policy	Total score	Median (IQR)
1	To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum	128	8 (7 to 9)
2	Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.	77	5 (2 to 10)
3	Identify key infrastructure needs through a National data management study. With the aim of enhancing use of secure, digitised My Health Record, linked health and social data and inter-agency collaborative research	75	7.5 (3 to 9)
4	Establish a strategic international collaborative in data priority areas to leverage multiple agency, discipline, national or industry investment (e.g. with Farr Institute or ICES)	69	7.5 (6 to 9)
5	Data integration to reduce clinical variation; co-morbidity; and health inequities	68	6 (4 to 8)
6	Develop a National framework to maximise interoperability and value of data to research and clinical practice	67	6 (4 to 9)
7	Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates)	57	5 (4 to 8)
8	Use of MBS, PBS and other large administrative data sets	55	6.5 (5.5 to 8.5)
9	Registries; National initiative to reduce burden and improve governance of and access to databases/ registries	43	6 (2.5 to 8)
10	NHMRC Data Practitioner Fellowships to increase engagement of data research-focused clinicians	36	6 (4 to 8)
11	Investment in disease or therapy-focused clinical registries	35	6 (3 to 9)
12	PhD/ postdoc fellowships to build capacity and talent exchange, across health, industry, government to stimulate entrepreneurial and translation activities	34	4.5 (1.5 to 7)
13	Enhance data activity around disruptive technologies such as artificial intelligence and wearable devices	32	5 (3 to 8)
14	EMR integration of clinical guidance/ decision support. Evidence shows success with order sets, pharmacy prescribing and lab tests (15-19)	30	4 (2 to 7)
15	National initiative to increase patient reported outcomes measures in registries and data sets (20, 21)	29	6 (4 to 7)
16	Promotion of real time data to enhance clinical decision making – outcome measures available at point of care (22)	29	3 (2 to 5)
17	Use of data to enhance research on national surveillance of and response to current and emerging infectious diseases and antimicrobial resistance	25	3 (2 to 6)
18	EMR - extraction of data from unstructured data (19, 23)	25	5.5 (4.5 to 8)
19	Use of data to measure and report on economic returns from investments	21	2 (2 to 3.5)
20	EMR – integrated harmonised core minimum data sets agreed and implemented into the EMR to enable cross sectional and longitudinal benchmarking and ongoing evaluation of care for quality improvement (19)	21	4 (4 to 4)
21	National scheme that enables access to existing high cost data infrastructure to maximise hardware use and foster collaboration. This may include the creation of data hubs or warehouses/ market places within the Centres	20	3.5 (2 to 5)
22	Enhancing use of registry data to improve healthcare delivery and outcomes (24, 25)	18	6 (3 to 9)
23	Data/ Cyber security as major barrier to health data translation	16	6 (3 to 7)
24	Increase researchers integrated into clinical services/ teams to increase data use (26)	11	3 (2 to 6)
25	Patient self-reported/ collected data linked to clinical teams that enhances self-management (27, 28)	4	4 (4 to 4)

Possible score was 1 to 10 with 15 priorities not scored per voting contribution. Hence the median may be relatively high with a lower total score due to a relatively small number of votes.

Pre-workshop results

Twentyone participants submitted pre-workshop ranking scores. The prioritised list is provided in table 2. All AHRA centres responded. External stakeholders and consumers submitted pre-workshop priorities that were included in the prioritisation process. Scores for each of the 25 priorities were added to create a total score for each priority.

Tables 2 and 3 show the pre-workshop ranked priorities. Australian Medical Research and Innovation Priorities (4) and Government priorities indicated as orange in tables 2 and 3, provided 8 of the top 10 priorities ranked in the first pre-workshop round. Green fields were sourced from the literature review with blue provided by participants prior to the day.

Table 3: Workshop consolidation and sense making discussion.

Top 10 Pre-Workshop	Consolidation and Sense making
To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum	To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum
Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.	Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.
Identify key infrastructure needs through a National data management study. With the aim of enhancing use of secure, digitised My Health Record, linked health and social data and inter-agency collaborative research	Identify key infrastructure needs through a National data management study. With the aim of enhancing use of secure, digitised My Health Record, linked health and social data and inter-agency collaborative research
Establish a strategic international collaborative in data priority areas to leverage multiple agency, discipline, national or industry investment (e.g. with Farr Institute or ICES)	Establish a strategic international collaborative in data priority areas to leverage multiple agency, discipline, national or industry investment (e.g. with Farr Institute or ICES)
Data integration to reduce clinical variation; co-morbidity; and health inequities	Develop a National framework to maximise interoperability and value of data to research and clinical practice
Develop a National framework to maximise interoperability and value of data to research and clinical practice	Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates)
Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates)	Registries; National initiative to reduce burden and improve governance of and access to databases/ registries
Use of MBS, PBS and other large administrative data sets	Electronic Medical Record
Registries; National initiative to reduce burden and improve governance of and access to databases/ registries	
NHMRC Data Practitioner Fellowships to increase engagement of data research-focused clinicians	

Yellow: Australian Medical Research and Innovation Priorities for MRFF funding, **Green:** Literature search
Blue: Expert recommendations

Workshop Consolidation

Attendees included two to three representatives from each AHRTC and CIRH. Also represented were: PHRN, RDS, ICES, and consumer representatives. These together represented clinicians, consumers, and academics; public, private and primary health care providers; Universities and Research Institutes and government data agencies.

The Nominal Group technique process was undertaken to consolidate the top ten priorities. This resulted in seven priorities. The lower ranked priority topics were then discussed and amalgamated into the top seven priorities, where appropriate. A group decision was made to “pool” the results for the three electronic medical record (EMR) items and include EMR as a single listing to be added to the top seven priorities. Table 3 presents the consolidation process and sense making results, which resulted in agreement on eight priorities.

Final vote

These top eight consolidated priorities were then tested against the policy framework (table 1). Each AHRTC and CIRH and external stakeholders discussed this in small groups and submitted one consolidated second round Delphi ranking on the priority order of the eight priorities. These results are presented in ranked order in table 4. External stakeholders, including consumer representatives and experts from government data agencies were asked to vote as a collective. Their priority ranking largely aligned with the top three AHRA ranked priorities as 2, 1 and 4 (table 4). They did, however, rank workforce (third priority) as sixth. When the stakeholder rankings were integrated with the nine centres the overall agreed priority order was unaltered. EMR was noted as important, yet also felt to integrate into priorities 1 and 2. International engagement was felt important but likely to progress alongside development of priorities 1-3. Registries were also noted as important, but were felt to best coordinated by Centres of excellence supported by the AHRA members rather than embedded across all Centres.

A final group discussion process resulted in an agreement that the top three priorities noted in table 4, would inform activity for all AHRTCs and CIRHs for the next three years.

Table 4: Final Priorities

	Priority	Total	Median (IQR)
1	Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.	63	7 (7 to 7)
2	To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum	55	7 (5 to 8)
3	Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates)	52	6 (4 to 7)
4	Electronic Medical Records	41	5 (3 to 5)
5	Establish a strategic international collaborative in data priority areas to leverage multiple agency, discipline, national or industry investment (e.g. with Farr Institute or ICES)	30	4 (2 to 4)
6	Registries; National initiative to reduce burden and improve governance of and access to databases/ registries	29	3 (2 to 4)

7	Identify key infrastructure needs through a National data management study. With the aim of enhancing use of secure, digitised My Health Record, linked health and social data and inter-agency collaborative research	28	3 (2 to 4)
8	Develop a National framework to maximise interoperability and value of data to research and clinical practice	26	2 (1 to 5)

Statistical Analysis

The score for each of the eight final priorities was totaled. As the data was not normally distributed, the Median and Interquartile range were calculated. These results are presented in table 4.

The two results have not been statistically compared, as the voting system was not consistent at time one and two (twenty-five priorities vs eight, with only a subset numbered at time one) and some of the priorities from pre-workshop were grouped to form one of the final eight priorities. This prevented statistically compare the two groups.

Discussion

AHRA priorities for Data Driven Healthcare Improvement were generated through a multistep transparent stakeholder engagement and modified Delphi and Nominal Group technique. The top three agreed priorities were:

- 1) Create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs to stimulate partnerships across academic, clinician and industry stakeholders;
- 2) To integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum and;
- 3) Building workforce capacity in data use for health care improvement through training (undergraduates/ graduates). These consensus priorities are now being utilised to provide strategic direction to future AHRA and member Centre data driven healthcare improvement activities, funding allocations and advice to government.

The first AHRA priority is to create virtual or actual health data research incubator hubs within the AHRTCs/ CIRHs leveraging our partnerships across academic, clinician, health service, community, government and industry stakeholders (figure 2). It is recognised that stakeholders involved in the supply side of health technology and data (industry and technology companies) and those in the demand side (community, public and private health service providers and government) are not well aligned, with differing definitions of value (2). Suppliers may value profit over usefulness and public benefit, with little consideration of cost effectiveness. The need for a more proactive role of universities and public research funders In driving “responsible innovation” has also been recognised (2). There is clearly a need for research into how to optimise integration across relevant sectors, and to move beyond health data to link in social data (1, 8). Internationally, data hubs such as the nodes of Health Data Research UK (8) link under the broader umbrella into a UK wide platform. The institute integrates stakeholders, especially policy makers, academics and healthcare providers to optimise the application and benefit of health data. The NHMRC accredited Centres, designed to integrate research,

healthcare and education and bring stakeholders together in a community of practice (figure 1 and 2), are ideally positioned to align values and skills and maximise benefits from health data. Our Centres would be well positioned as hubs, leveraging considerable infrastructure housed within our universities and linked nationally through AHRA to share learnings and translate evidence into practice. In this priority area, Monash Partners is applying MRFF funding in leading and collaborating on a literature review and national and international research to scope and co-design an Australian virtual or actual “hub” to inform next steps. This approach aligns with the *Australian Medical Research and Innovation Priority* on a “National data management study”.

The second agreed priority was to integrate large scale data sets to undertake research and quality improvement across the primary care, acute and sub-acute continuum. In Australia with complex health system funding from federal and state governments and the private sector with community co-contribution, the imperative to link data across these often poorly integrated parts of our health system is vital and well recognised. Our fragmented system leads currently to poor communication, adverse health outcomes and drives duplication and costs (3). Whilst 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 (9). The NHMRC accredited Centres, designed to encompass care across the continuum, are ideally positioned to work together and with other stakeholders to deliver on this priority. Implementation in this area includes progress on a data sharing accord developed by Sydney Partners and now being explored across other Centres with a vision for a single national data sharing accord or set of principles. Melbourne Academic Centre for Health are leading and engaging all Centres to jointly develop a national framework for linking primary care working closely with our primary care to inform next steps in this priority area. This work will be informed by a national workshop in late 2018. Our Centres also support data linkage studies and clinical quality registries through our MRFF funded Rapid Applied Research Translation grants. Centres are also providing pilot hubs for implementing and optimising use of My Health Record.

The third priority is building workforce capacity in data use for health care improvement through training undergraduates and graduates (10). This aligns with health service, government and international data agency priorities including the Australian Digital Health Agency’s key objective for a workforce confidently using digital health technology in the delivery of health care. With our AHRTC’s and CIRH’s accredited to integrate research, healthcare and education (11), we are well placed to work with stakeholders to build capacity in the multifaceted workforce needed to harness the power of health data. Implementation has included input from the national AHRA data committee and Centre workforce development advisory groups 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. Co-design of open online introductory training programs in data driven healthcare improvement, designed for pace and scale, are underway and supported by the Digital Health Cooperative Research Centre, with input from a wide variety of stakeholders including the Australian Digital Health Agency and the Australian Research Data Commons. More in-depth training programs are also being developed with State and Commonwealth government support, and continuing professional development training in health data science is better my integrated into University education offerings. In some Centres engagement with accredited training bodies has enabled large scale low cost access to accredited training programs and data fellowships have been co-designed in health service priority areas and will commence in 2019. Monash Partners, for example, has developed a multimillion dollar funded partnership supporting PhD students in

data driven health care improvement with supervision from health partners, and the Faculties of **IT, Business and Medicine, Nursing and Health sciences. Learnings from this and other Centre initiatives will be shared nationally with all other Centres.**

These priorities were generated via a robust process and took into consideration other national bodies of work to avoid duplication and optimise collaboration. The relevance of the priorities to the purpose and strengths of the Centres and to the AHRA collaboration was also considered, including the potential for greatest measurable impact over time. This process of priority setting was chosen given the diverse national stakeholders involved. The nominal group technique is “designed to increase the creative productivity of group action, facilitate group decision, help stimulate the generation of critical ideas, give guidance in the aggregation of individual judgements” (1, 12).

Limitations of this work include that not all invited agencies engaged in the priority setting process and individual State jurisdictions were not engaged due to challenge managing the number of stakeholders through the process. The AHRA data driven healthcare improvement committee is engaging with these agencies and State jurisdictions to inform the implementation of these priorities. The systematic literature search focused on recent systematic reviews, rather than primary literature. Strengths include the rigorous process and the diverse range of stakeholders and multidisciplinary national experts (7).

Conclusion

It is clear that greater integration of research, healthcare and other stakeholders is vital to deliver on the promise of data driven healthcare improvement. The Australian Health Research Alliance of Advanced Health Research Translation Centres and Centres of Innovations in Regional Health, have together, with key stakeholders, identified three national priorities in data driven healthcare improvement. These are the creation of virtual data research data research incubator hubs within each centre, linked nationally; large scale data integration across the health care continuum, and to build workforce capacity and training in use of data to improve health care. Funded by renewed MRFF funding to our centres, we are now working together with our stakeholders to implement these priorities aligned with the Australian Medical Research and Innovation Strategy and Priorities.

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Accord for the Sharing of Health Data across Sydney Health Partners

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Authors: Dr Felicity Gallimore & Professor Jonathan Morris
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FOREWORD

Health and medical information enables clinicians and policy makers to make informed decisions that will improve health care at both the individual and population level. Typically, questions central to improving health outcomes and guiding policy decisions can only be answered by obtained data from large, heterogeneous populations.

In order for Sydney Health Partners to generate this type of 'real-world' evidence in an efficient manner, it must facilitate the use of advanced digital technologies that streamline data collection, management and analysis of large datasets. It must also create a governance framework that encourages and facilitates these types of studies, whilst ensuring appropriate safeguards are in place that protect the rights of patients whose data is being used.

Sydney Health Partners (SHP) wish to develop a Data Sharing Accord across the Partnership's local health districts, Sydney Children's Hospitals Network and University of Sydney. The aim is to bring about a data sharing relationship that would facilitate safe, lawful and appropriate sharing of health data across the SHP facilities. By having an Accord documenting agreement on ethical principles and data handling solutions, the frustrations of having to reinvent a data extraction, encryption, storage and access solution for each individual project can be circumvented. The objective is to facilitate the conduct of studies that use data shared across SHP to measure and improve the appropriateness and quality of care across the partnership.



SYDNEY HEALTH PARTNERS SIGNATURES OF ENDORSEMENT

On behalf of our respective SHP Organisations, we accept and endorse this Accord.

*Signed for and on behalf of the Northern Sydney Local Health District
(Name)*

..... Date

*Signed for and on behalf the Sydney Local Health District
(Name)*

..... Date

*Signed for and on behalf of the Western Sydney Local Health District
(Name)*

..... Date

*Signed for and on behalf of the Sydney Children's Hospitals Network (Westmead)
(Name)*

..... Date

*Signed for and on behalf of the University of Sydney
(Name)*

..... Date

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- Mr D May, Commercial Manager, North Shore Private Hospital
- Mrs J Tang, Health Information Manager, North Shore Private Hospital
- Mr S, Philip, Finance Director, North Shore Private Hospital
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- Ms K Hanson, Research Office Manager, Research and Education Network, WLHD
- Ms L Attwood, Research Governance Manager, Research and Education Network, WLHD
- Ms S Lee Clinical Trials Manger, Research and Education Network, WLHD
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GLOSSARY/DEFINITIONS

DSP Checklist	Data Sharing Protocol Checklist
eMR	electronic medical record
HREC	Human Research Ethics Committee
SHP	Sydney Health Partners
SHP Organisation	Sydney Health Partner Organisation. A formally affiliated organisation of Sydney Health Partners.

The SHP Organisations are: Northern Sydney Local Health District (NSLHD), Sydney Local Health District (SLHD), Western Sydney Local Health District (WSLHD), Sydney Children's Hospitals Network (Westmead), University of Sydney, ANZAC Research Institute, Asbestos Diseases Research Institute (ADRI), Chris O'Brien Lifehouse, Woolcock Institute of Medical Research, George Institute, Centenary Institute, Heart Research Institute (HRI), Children's Medical Research Institute and the Westmead Institute.

The SHP Organisations covered by the Data Sharing Accord are: Northern Sydney Local Health District (NSLHD), Sydney Local Health District (SLHD), Western Sydney Local Health District (WSLHD), Sydney Children's Hospitals Network (Westmead) and the University of Sydney.

1. INTRODUCTION AND PURPOSE

Sydney Health Partners (SHP) is one of the first four Advanced Health Research and Translation Centres in Australia, recognised by the National Health and Medical Research Council in 2015 for being a world leader in translating research into better health outcomes for our community.

Patient and public benefit is at the core of what we do. Through our Partnership we are committed to fostering cutting edge collaboration and using the outcomes of health and medical research to improve the lives of our patients and community faster and more consistently.

The purpose of the Accord is to enable SHP's network of health organisations to share health data between them in a **lawful, safe and informed way**. At the same time, it aims to help **streamline** the governance process enabling the **swifter acquisition and interpretation** of valuable population data contained within the electronic Medical Record (eMR) and/or other unit record information with the aim of transformative health care improvement.

The purpose of data sharing can include but is not restricted to:

- Clinical quality and safety
- Health research
- Service delivery and improvement (key performance indicators).

This Accord aims to provide a guideline of consistency under which information can be shared and outlines the safeguards that should be implemented. The Accord exists to ensure that data can be shared in a way which satisfies the ethical and legal obligations of the Partners, their respective staff, and the legitimate expectations of the patients whose data has been collected.

The conditions, obligations and requirements set out in this Accord and supporting documentation will apply to all appropriate staff, agency workers, volunteers and others working on behalf of the SHP Organisations, including agents and sub-contractors.

2. THE FRAMEWORK FOR SHARING HEALTH DATA

The Accord identifies the suggested commitments by each SHP Organisation to enable sharing of health data. It is a statement of the **principles and assurances** which govern the activity of information sharing. It ensures that the rights of all those who are involved in the process are protected.

The **Accord** will be supported within the named SHP Organisations by a **Data Sharing Protocol (DSP) Checklist** for project-specific requirements

The DSP Checklist focuses on the **processes** underlying the sharing of specific sets of information between multiple SHP Organisations. It is intended for operational use and to guide the mechanisms for safely sharing de-identified health data across Sydney Health Partners. It documents the processes for selecting specific data for specific purposes, data extraction and handling, data storage and security, access for analysis and data retention and destruction.

3. THE SCOPE OF THE ACCORD

The Accord provides a framework for the sharing (including disclosure from SHP Organisations) of de-identified health data across SHP. See Section 6.2 for detail on de-identification. The Accord is a living document to be updated to reflect the future requirements of the Partnership

This Accord covers guidelines for:

Studies where personal health information is extracted from health data sources within SHP Organisations and de-identified prior to sharing outside of the source LHD/Organisation.

4. ADOPTION OF THE ACCORD

Adoption of this Accord is the responsibility of the Chief Executive or Chief Officer for each signatory SHP Organisation.

Each signatory SHP Organisation agrees to support the adoption, dissemination, implementation, monitoring and review of this Accord and its requirements in accordance with its own internal and any other jointly agreed and authorised information governance standard and/or operational policies and procedures.



To facilitate this, it is recommended that each SHP Organisation identifies a 'Designated Person' or Data Steward (See Section 5.1) who will have responsibility for this Accord.

Each SHP Organisation will have a copy of this Accord which can be obtained from its respective Research Office at any time.

5. SYDNEY HEALTH PARTNER ORGANISATION COMMITMENTS

This section outlines the suggested principal commitments for each SHP Organisation to ensure that the SHP Organisation's treatment of patient eMR or other unit record information is compliant with current best practice.

5.1 DESIGNATED PERSON or DATA STEWARD

It is recommended that each SHP Organisation should appoint a "Designated Person"¹ or Data Steward who will support the adoption and dissemination of the Accord within the SHP Organisation.

The Data Steward will be responsible for monitoring and reviewing compliance with the principles of the Accord within their organisation and dealing with any concerns or complaints received. The Data Steward will escalate any material risks or issues to the Data Custodian for review (see Section 5.2 and 7.1)

The Data Steward will usually be the person with overall responsibility for personal information within the SHP Organisation; for example, the Director of Clinical Governance or the Chief Information Officer.

The Data Steward may delegate day-to-day responsibility to individuals with operational responsibility for Information Governance eg personnel within the HREC/governance site office.

¹https://www.nhmrc.gov.au/_files_nhmrc/file/research/research-integrity/r39_australian_code_responsible_conduct_research_150811.pdf

5.2 DATA CUSTODIAN

Each SHP Organisation should have a Data Custodian who is responsible for data storage and disposal, compliance of data with relevant legislation and policies, administration, quality assurance and data access. It is recommended that the Data Custodian is the Health Information Services Manager (district level) for each SHP Organisation.

The Data Custodian will escalate any material risks or issues to the Data Owner (Chief Executive) for review and resolution. (See Section 7.1)

5.3 DATA OWNER

The Chief Executive of each SHP Organisation is the Data Owner. The authority for disclosure outside of the SHP Organisation is vested in the Chief Executive. The Chief Executive may authorise a Tier 2 position (e.g. Director of Clinical Governance) within the SHP Organisation to exercise this delegation provided the authority is in writing and is limited to information that does not identify any individual to whom the information relates. Assessment and approval of the project by a HREC committee will precede sign off from the Chief Executive (or delegate) for disclosure of data outside of the SHP Organisation.

5.4 PATIENTS' RIGHTS

Each SHP Organisation should comply with the rights of the patient in a fair and consistent manner and in accordance with any specific legislative requirements, regulations or guidance. Each SHP Organisation should ensure that they have appropriate policies and procedures in place to facilitate both the protection and the exercising of these and other rights.

It is a fundamental principle of privacy law that personal data are processed in a transparent manner in relation to the patients to whom the data relates. Patients should be made aware of risks, rules, safeguards and rights in relation to the processing of their personal data and how to exercise their rights in relation to such processing

Each SHP Organisation should be clear and open with patients about how their information will be used. In general terms, a patient should be told the identity of the SHP Organisation collecting and recording the data, the reasons or purposes for doing so (including any statistical or analytical purposes), and any extra information that a patient needs in the circumstances to ensure that their information is being processed appropriately. This information is usually provided through the Organisation's "Privacy leaflet"² and "Privacy Policy".

Each SHP Organisation should also inform patients about their additional rights, with respect to State Privacy legislation and how these rights may be exercised. This will include the provision of appropriate support in order that patients may best exercise those rights e.g. providing information in alternative formats or languages, providing support in the form of advocacy or assisting them to make an access request.

² <http://www.health.nsw.gov.au/patients/privacy/Documents/privacy-leaflet-for-patients.pdf>

5.5 PATIENT CONSENT FOR SECONDARY USE OF DATA

As stated in Section 5.4 above, each SHP Organisation must inform patients about how their health information can be used. This information is usually provided through the SHP Organisation's "Privacy leaflet" and "Privacy Policy".

The Information Privacy Leaflet for Patients (NSW Health)² covers the obligations, collection, security and use or disclosure of personal health information. It makes clear that the law allows health information to be disclosed to third parties under certain circumstances. This includes disclosure to researchers for public interest research projects as approved by a Human Research Ethics Committee (HREC).

In relation to this Accord, the HREC will decide whether a 'waiver of consent' is appropriate for research projects involving de-identified data on a case-by-case basis.

Researchers can use or disclose personal health information without the consent of the person (subject to approval from ethics), for the secondary purpose of research or statistics if all the following four criteria are met:

Criteria 1: *The use or disclosure is reasonably necessary for research, or the compilation or analysis of statistics, in the public interest.*

Criteria 2: *Reasonable steps have been taken to de-identify information, or the purpose of the research cannot be served by using or disclosing de-identified information and it is impracticable to seek the consent of the person to the use or disclosure.*

Criteria 3: *If the information could reasonably be expected to identify individuals, the information is not published in a generally available publication.*

Criteria 4: *The use or disclosure of the health information is in accordance with the Statutory Guidelines on Research⁴.*

The four criteria with definitions of key terms and examples are described in the Statutory Guidelines on Research (Information and Privacy Commission NSW)⁴

²Information Privacy Leaflet for Patients (NSW Health)

<http://www.health.nsw.gov.au/patients/privacy/Documents/privacy-leaflet-for-patients.pdf>

³Health Records and Information Privacy Act (2002) NSW Handbook to Health Privacy. Health Privacy Principles 10(1)(f) or 11(1)(f) https://www.ipc.nsw.gov.au/sites/default/files/file_manager/hripa_health_handbook.pdf

⁴Statutory Guidelines on Research. Information and Privacy Commission NSW. Health records and information Privacy Act 2002

https://www.ipc.nsw.gov.au/sites/default/files/file_manager/privacy_statutory_guidelines_research.pdf

5.6 RECORDS MANAGEMENT

Inaccurate, incomplete or out-of-date information can have a detrimental effect on patients, therefore each SHP Organisation is responsible for the quality and accuracy of the personal information and its processes (see Section 5.1).

If it is discovered that information held is inaccurate, SHP Organisations should take reasonable steps to ensure that their records/case management systems are corrected or updated accordingly. The SHP Organisation should also take reasonable steps to advise any other party known to have received or to be holding that information about any change that it is necessary to make.

All participating SHP Organisations should have policies and procedures in place which will make clear their approach to retention, storage and disposal of records. Details of the *State Records Act 1998 (NSW)* and key obligations including *General Retention and Disposal Authority (Health Services, GDA17)* can be found on the NSW State Archives & Records website⁵.

⁵<https://www.records.nsw.gov.au/recordkeeping/rules/legislation/key-obligations-under-the-act>

5.7 INFORMATION SECURITY

Each SHP Organisation should have in place a level of security commensurate with the sensitivity and classification of the information to be stored and shared.

Each SHP Organisation should ensure that mechanisms are in place to address the issues of physical security, security awareness and training, security management, systems development, role-based security/practitioner access levels, receiving and transfer of data and system specific security policies.

It is accepted that each SHP Organisation will vary in size and complexity and this will be reflected in any processes and levels of security put into place.

Generalised expectations of levels of security for data handling, extraction, storage and transfer will be dealt with in Section 6 (see below). Project-specific data handling details will be approved on a case-by-case basis in accordance with the requirements of the project's HREC and site authorisation/s.

Each SHP Organisation should have procedures in place that will be invoked if a member of staff is found to have breached the privacy of a patient, or to have shared information in a manner in contravention of this Accord. E.g. *NSW Policy Directive 2018_001, Appendix 4, Procedure for response to a breach of conditions by a researcher or contractor flowing disclosure of unit record data*⁶ See Section 7.1.

⁶http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2018_001.pdf. NSW Policy Directive 2018_001 *Disclosure of unit record data by LHDs for research or contractor services*

6. DATA HANDLING PRINCIPLES

6.1 DEFINITIONS OF 'ACCESS TO' AND 'DISCLOSURE OF' HEALTH DATA (DE-IDENTIFIED)

The Accord provides guidelines for sharing of data that are extracted from a SHP Organisation's eMR and/or other unit record information and then **de-identified** before being transferred out of the SHP Organisation. The point of legal **disclosure** occurs when such de-identified data **leaves** the SHP Organisation (e.g. LHD).

Access to this data occurs when data are being 'processed' e.g. extracted, cleaned and de-identified **within** the SHP Organisation. This is not the same as 'disclosure'.

6.2 DE-IDENTIFICATION OF DATA

Data should be sufficiently de-identified to satisfy legal thresholds and protect individual privacy. Resources for this purpose include the Office of the Australian Information Commissioner publication: *De-identification and the Privacy Act*⁷. The OAIC and CSIRO's Data61 have released the *De-Identification Decision-Making Framework*⁸ and the Australian National Data Service (ANDS) have published a *De-identification Guide*⁹.

The resources listed below provide important guidance for choosing and documenting the most appropriate de-identification process prior to submission to a HREC for the necessary approval.

⁷De-identification and the Privacy Act. <https://www.oaic.gov.au/agencies-and-organisations/guides/de-identification-and-the-privacy-act>

⁸OAIC and CSIRO's Data61 De-Identification Decision-Making Framework. <https://publications.csiro.au/rpr/download?pid=csiro:EP173122&dsid=DS2>

⁹ANDS De-identification guide. https://www.ands.org.au/_data/assets/pdf_file/0003/737211/De-identification.pdf

6.3 AUTHORITY FOR ALLOWING 'ACCESS TO' eMR DATA WITHIN A SYDNEY HEALTH PARTNER ORGANISATION

Authority for consenting to access to eMR data lies with the eMR Data Custodian for each SHP Organisation. It is recommended that this Data Custodian is the Health Information Services Manager (district level) for each SHP Organisation.

6.4 AUTHORITY FOR ALLOWING 'DISCLOSURE' OF DE-IDENTIFIED HEALTH DATA FROM A SHP ORGANISATION

Permission is required from each SHP Organisation that will disclose health data¹² as part of the HREC approval process for data sharing projects. The authority for disclosure rests with the Chief Executive of a SHP Organisation (as Data Owner). The Chief Executive may authorise a Tier 2 position (e.g. Director of Clinical Governance) within the SHP Organisation to exercise this delegation provided the authority is in writing and is limited to information that does not identify any individual to whom the information relates.

¹²NSW Health Policy Directive PD2018_001 Disclosure of unit record data by Local Health Districts for research or contractor services. http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2018_001.pdf

6.5 USE OF THIRD PARTY CONTRACTORS (WITH CONTINGENT WORKER STATUS) FOR eMR DATA AND/OR OTHER UNIT RECORD INFORMATION EXTRACTION WITHIN A SHP ORGANISATION

It is recognised that there may be circumstances when the expertise of third party contractors for extraction of data is necessary. These contractors need to access eMR and/or other unit record information within the SHP Organisation.

Each SHP Organisation will already have in place processes to accommodate contingent workers and safeguard data security and privacy. The processes should be detailed in the HREC and site assessment applications and be approved prior to any data being accessed.

These processes may include:

1. Signing a Confidentiality Agreement, e.g. *Appendix 3, NSW Policy Directive 2018_001, Disclosure of unit record data by LHDs for research or contractor services*¹⁰
2. Signing the *NSW Health Code of Conduct*¹¹
3. Undergoing a criminal record check
4. Providing project specific details e.g. time period, number of records being accessed, data fields being extracted etc. These will be specified in the **project protocol** and assessed by the relevant HREC on a project-by-project basis. (See DSP Checklist for further guidance.)

¹⁰PD2018_001, *Disclosure of unit record data by LHDs for research or contractor services*
http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2018_001.pdf

¹¹ NSW Health Code of Conduct

http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2015_049.pdf

6.6 APPOINTMENT OF A PROJECT DATA MANAGER

A Data Manager should be appointed for each project. The Project Data Manager (who is not the Data Custodian) should be an employee of the SHP Organisation disclosing the data AND a member of the project research team. The Project Data Manager is involved in validating, cleaning and de-identifying data prior to transfer out of the SHP Organisation. It is expected that the Project Data Manager would work in conjunction with the data extraction team.

The Project Data Manager has custody of any encryption key involved in the de-identification of data.

It is envisaged that it may be necessary for a researcher (analysing de-identified data outside of the SHP Organisation) to query the field value of a specific piece of data. Such queries can be answered by the Project Data Manager who has access to the encryption key, and thus the source data, without revealing any identifiable information to the researcher.

6.7 SECURE STORAGE OF HEALTH DATA WITHIN AND OUTSIDE OF A SHP ORGANISATION

It is suggested that:

- In accordance with the principles of *PD2018_001 Disclosure of unit record data by Local Health Districts for research or contractor services*¹³, health data originating from a SHP organisation must be stored securely at all times. Acceptable secure storage includes storage on physically secure file servers that are configured in such a way that password protection is universally enforced, or in files that are encrypted by “strong” encryption software such as PGP, provided that the passwords used for encryption are also kept secure. The encryption offered by PkZip and other file compression utilities or by word processors, spreadsheets and other software that is not specifically designed to offer high-level encryption are inadequate and can be easily broken.
- Storage on portable media (e.g. mobile devices, USBs, laptops etc) and desktop computer hard-drives is not considered acceptable.
- Details of storage to be provided in project-specific protocol (see DSP Checklist for guidance) and assessed by the HREC and site governance officer on a project-by-project basis.
- Data will be de-identified prior to transfer out of the SHP Organisation.

¹³NSW Policy Directive *PD2018_001. Disclosure of unit record data by Local Health Districts for research or contractor services*. http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2018_001.pdf

6.8 TRANSFER OF DE-IDENTIFIED DATA OUT OF A SHP ORGANISATION

De-identified, encrypted data must only be transferred using secure file transfer technologies.

Two options are listed below – **other secure file transfer options also exist** and can be used provided they are approved on a case-by-case basis by a HREC.

Accellion¹⁴ Secure File Transfer is a secure web portal that allows data to be uploaded and downloaded.

CloudStor¹⁵ is provided by AARNET (Australia's Academic and Research Network). It is a file sharing and cloud storage solution for the research and education sector. Most Australian Universities and research institutes have access to Cloudstor. Encryption is applied during transition and if required, also at rest.

¹⁴<https://www.accellion.com/platform/simple/secure-file-sharing>

¹⁵<https://www.aarnet.edu.au/network-and-services/cloud-services-applications/cloudstor>

7. GOVERNANCE OF NEWLY CREATED COMBINED, DE-IDENTIFIED DATA SETS

It is proposed that the Data Owner of the newly created, combined dataset is the Chief Investigator listed on a data sharing project .

It is proposed that the Data Custodian of the newly created combined data set should have ICT expertise within the institution storing the combined de-identified dataset. The data custodian has responsibility for data storage, access and disposal. Only project personnel approved by the relevant HREC would have access to the combined data set.

Storage location possibilities include a server in one of the SHP Organisations contributing data, eHealth NSW server, University of Sydney server, cloud-based storage. Currently SHP Organisations are involved in projects with both cloud-based and local data storage. The results of these projects will inform future guidance in this area. In the meantime, the storage location of a combined data set will be agreed upon on a project-by-project basis and be given Ethics approval by the HREC assessing the project. The storage facility will need to satisfy the security principles detailed in Section 6.7.

Ownership of data, data custodianship of the newly formed dataset and location of data storage would all be agreed upon and specified prior to HREC approval of any such data sharing project.

Best practice dictates that any new information arising from the combined dataset will be reported back to the contributing SHP Organisations prior to dissemination of any findings.

7.1 PROCEDURE FOR RESPONSE TO A BREACH OF CONDITIONS OF DATA USE

A wide range of circumstances might potentially represent a breach of conditions of data use. Breaches may range from minor infringements, such as failure to report changes in named staff working on a project, to serious breaches such as data being sold for commercial gain or data being unlawfully linked with personal information from another source to re-identify an individual.

The following standards¹⁶ are put forward as a guide:

On becoming aware of any actual or possible breach of conditions, the Data Custodian will:

- Make enquiries to ensure the full facts of the situation are available for consideration; and
- Provide the information to the relevant SHO Organisation Data Owner.

The SHP Organisation Data Owner (Chief Executive or their delegate) will consider each situation on its merits, taking into account any previous breaches of conditions, and make a determination on one or more of the following actions:

1. No action because the conclusion is that no breach took place
2. A request for rectification of the circumstances causing the breach within a specified timeframe.
3. Counselling in the form of a warning.
4. A sanction, which may include:
 - Revision of the project approval so as to require stricter conditions;
 - Revoking project approval (with the requirement that all data files are returned or destroyed immediately);
 - Barring the individual or employer responsible for the breach from future access to data held by the SHP Organisation for a period of time or indefinitely;
 - Revision of any other project approvals where the individual or employer is a named party, so as to require stricter conditions, or revoking approval;
 - Reporting the individual responsible for the breach to employer(s) with a complaint of misconduct;

- Reporting the individual responsible for the breach to the funding agency that has supported the project with a complaint of misconduct; or
- Where applicable, reporting the individual(s) responsible for the breach to the appropriate statutory registration board (such as a medical, dental, nurses or psychologists board) with a complaint of misconduct; or
- Reporting the individuals(s) responsible for the breach to the Ministry of Health Legal Branch with a recommendation to take legal action.

The SHP Organisation Chief Executive will be advised where a breach of conditions has occurred involving the possible or actual breach of individual privacy.

If a breach of individual privacy has occurred, the Data Owner will coordinate a response in line with the most current New South Wales Information and Privacy Commission's guidelines for handling data breach notifications, as detailed on their website <https://www.ipc.nsw.gov.au/data-breach-guidance>

¹⁶http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2018_001.pdf. NSW Policy Directive 2018_001 *Disclosure of unit record data by LHDs for research or contractor services*

8. DATA SHARING PROTOCOL CHECKLIST (SEE ATTACHED)

It is recognised that every project wishing to use health data shared across SHP Organisations faces similar challenges and requires similar safety and technical processes to be developed. It is recommended that the Data Sharing Protocol Checklist is used as a step by step guide to ensure that the necessary operational processes are developed in each case.

The Data Sharing Protocol Checklist is divided into eight sections:

1. Project Overview
2. Consent
3. Data selection
4. Data extraction and handling
5. Data storage and security
6. Disclosure and secure transfer of de-identified data
7. Storage and access to de-identified data for data analysis
8. Data retention and destruction schedule.

As projects start to anticipate these operational requirements and develop a consistency in method, confidence in the safety of such data sharing projects will rise. This in turn will facilitate approvals for future projects and health improvements across Sydney Health Partners.

9. DURATION AND REVIEW OF ACCORD

This Accord will remain in effect until December 2021 at which time the SHP Organisations will review the Accord and the DSP checklist via the Data Sharing Accord Steering Group. During the review, the Accord will remain in effect until either a new Accord has been signed off or formally terminated.

The Data Sharing Accord Steering Group will consist of appropriate stakeholder representation including:

- Representatives from Health Information Services from each signatory SHP Organisation
- Representative from Privacy and Confidentiality Audit Service
- Representatives from Ethics/Governance Office from each signatory SHP Organisation
- Representative from a SHP Organisation Performance Unit
- Representative from SHP Organisation Clinical Operations
- Representative from Medical/Clinical Services



Data Sharing Protocol Checklist

for the Sharing of Health Data across

Sydney Health Partners

October 2018

Authors: Dr Felicity Gallimore & Professor Jonathan Morris

Version: 3.1

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DRAFT

GLOSSARY/DEFINITIONS

DSP Checklist	Data Sharing Protocol Checklist
eMR	electronic medical record
HREC	Human Research Ethics Committee
SHP	Sydney Health Partners
SHP Organisation	Sydney Health Partner Organisation. A formally affiliated organisation of Sydney Health Partners (see below)
SSA	Site Specific Assessment

The **SHP Organisations** are: Northern Sydney Local Health District (NSLHD), Sydney Local Health District (SLHD), Western Sydney Local Health District (WSLHD), Sydney Children's Hospitals Network (Westmead), University of Sydney, ANZAC Research Institute, Asbestos Diseases Research Institute (ADRI), Chris O'Brien Lifehouse, Woolcock Institute of Medical Research, George Institute, Centenary Institute, Heart Research Institute (HRI), Children's Medical Research Institute and the Westmead Institute.

The Data Sharing Accord and Data Sharing Protocol Checklist cover sharing between NSLHD, SLHD, WSLHD, Sydney Children's Hospitals Network (Westmead) and the University of Sydney.

FOREWORD

This **Data Sharing Protocol Checklist** (DSP Checklist) is intended to be used in conjunction with the **Accord for the Sharing of Health Data across Sydney Health Partners** (SHP). The Accord is a statement of the principles involved. It covers requirements for:

Studies where personal health information is extracted from health data sources within SHP Organisations and de-identified before being disclosed from the SHP Organisation.

It is recognised that every project wishing to use health data shared across SHP Organisations faces similar challenges and requires similar safety and technical processes to be developed. It is recommended that this **Data Sharing Protocol Checklist** (DSP Checklist) is used as a guide to ensure that the necessary operational processes are developed in each case.

The DSP Checklist aims to put forward a comprehensive list of the steps that need to be considered in order to achieve the goal of safe and effective data sharing across Sydney Health Partners. In order to make this document as useful as possible, it has been structured to follow the path of the data as it is selected, accessed, extracted, stored, transferred and analysed.

Inevitably, the components and team structures of data sharing projects vary and they need to satisfy the Human Research Ethics Committee (HREC) and Site Specific Assessment (SSA) (Governance) requirements of the individual SHP Organisations that are involved. The line between Ethics and Governance requirements is not always clear cut. However, by following this DSP Checklist, all the important steps in safe data sharing will have been considered, streamlining the process of information provision for the Project Protocol, Ethics submission and Site-Specific Assessment.

The Data Sharing Protocol Checklist is divided into eight sections:

1. Project Overview
2. Consent
3. Data selection
4. Data extraction and handling
5. Data storage and security
6. Disclosure and secure transfer of de-identified data
7. Storage and access to de-identified data for data analysis
8. Data retention and destruction schedule.

As projects start to anticipate these operational requirements and develop a consistency in method, confidence in the safety of such data sharing projects will rise. Ethical and Governance approvals will

be easier to obtain. This in turn will facilitate approvals for future projects and health improvements across Sydney Health Partners.

1.0 PROJECT OVERVIEW

Is this a project that involves <u>obtaining</u> health data across two or more Sydney Health Partner Organisations (SHP Organisations)?	
Is this a project where personal health information is extracted from health data sources within SHP Organisations and de-identified before being disclosed outside of the SHP Organisation?	

If answering yes to both these questions, the **Accord for the Sharing of Health Data across Sydney Health Partners** provides principles supporting the SHP Organisations' ability to share such data. The following Data Sharing Protocol Checklist will cover areas that need to be considered prior to the submission of applications for Ethics and Governance approval for such studies.

2.0 CONSENT (for disclosure of de-identified data)

Can you confirm that data will be de-identified prior to disclosure from the SHP Organisation?	
If the above answer is yes, can apply to HREC for a Waiver of Consent for secondary use of data.	See Accord, Section 5.3 for details of the four criteria that need to be satisfied.

3.0 DATA SELECTION and ACCESS

Which source SHP Organisation(s) will be providing the data?	
Which Information system(s) from within the above SHP Organisations will be accessed to provide the data? eg eMR, eMaternity, Auslab etc.	
Obtain written authority to access the Information systems from the above SHP Organisations This authority rests with the Data Custodian for each involved organisation (Health Information Services Manager – district level).	
What are the main personal identifiers being used to identify the patient? E.g. Surname, First Name, DOB, Medicare number, MRN, Address, Postcode, etc.	
Approximately how many records will be accessed?	

Which data fields will be extracted? Data fields to be listed in study Protocol for review by a HREC.	
Specify over which time period the records are being accessed. E.g. 5 years, from January 2013 to December 2017	

4.0 DATA EXTRACTION & HANDLING

What date or over what time period will the data extraction/download occur? le overnight, or 5th-7th January 2018	
What is the frequency of extraction? Will there be a single extract, or multiple extracts (e.g. daily, weekly, monthly)	
Who will perform the data extraction? e.g. an employee of the SHP Organisation or a third-party contractor?	
Have the members of the data extraction team: <ul style="list-style-type: none"> • Signed an ICT Business Change Request Form? • Signed a Service Agreement? • Signed a Network and Application Access Form? 	
If a third-party contractor is involved, has a contract been signed between the contractor organisation extracting the data and the funding organisation?	See Accord, Section 6.3
If a third-party contractor is involved, has the contractor: <ul style="list-style-type: none"> • Been granted Category B contingent worker status for the SHP Organisation site of extraction? • Signed a Confidentiality Agreement? • Signed the NSW Health Code of Conduct? • Undergone a criminal record check? • Provided project specific details about extraction process, records and data fields being accessed? (to be described in Protocol for HREC review) 	See Accord, Section 6.3
Has a Project Data Manager been appointed? The Project Data Manager should be an employee of the source SHP Organisation AND a member of the research team.	See Accord, Section 6.4.

5.0 DATA STORAGE AND SECURITY

Describe the Data Storage Facility of extracted data within the source SHP Organisation(s). Details to be listed in Study Protocol for HREC review.	See Accord, Section 6.6 for storage security standards.
Data must be de-identified prior to disclosure from the SHP Organisation. The following minimum details will need to be listed in Study Protocol for HREC review: <ul style="list-style-type: none"> • Describe the de-identification/encryption process • Describe how/where the encryption key will be stored (if key is being used) • List who has access to the encryption key (eg Project Data Manager) 	See Accord, Section 6.2 for De-identification resources

6.0 DISCLOSURE AND SECURE TRANSFER OF DE-IDENTIFIED DATA

Obtain authority for disclosure of de-identified data from the source SHP Organisation(s). This authority rests with the SHP Organisation Chief Executive. The Chief Executive may authorise a tier 2 position (eg Director of Clinical Governance) within the Organisation to exercise this delegation.	See Accord, Section 6.4
Describe how data will be securely transferred from the above site. E.g. Accellion Secure File Transfer, CloudStor, other secure method approved by HREC.	See Accord, Section 6.8
Who will perform this data transfer?	

7.0 STORAGE AND ACCESS TO DE-IDENTIFIED DATA FOR DATA ANALYSIS

Describe the Data Storage Facility of extracted de-identified data after disclosure and transfer from the source SHP Organisation(s). Details to be listed in Study Protocol for HREC review.	See Accord Section 6.7 for storage security standards.
Describe the Governance structure of the newly formed de-identified data set: Who owns the data? (eg Chief Investigator of data sharing project) Who is the data custodian? (eg Responsible for data storage, access and disposal - with ICT expertise within the Organisation storing the combined data set)	See Accord, Section 7.0
Detail who will have access to the de-identified data for performing	

analysis of data	
What hardware/software will be used to analyse the data and where is it located? Check if additional on-site permission is required to use this data analysis infrastructure.	

8.0 DATA RETENTION AND DESTRUCTION SCHEDULE

Specify the agreed time period for retaining the data and the data disposal plan. For guidelines, see Appendix B, Statutory Guidelines on Research, IPC	https://www.ipc.nsw.gov.au/sites/default/files/file_manager/privacy_statutory_guidelines_research.pdf
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Draft

Appendix 6

Data Driven HCI workforce capacity building AHRA national survey

Data Driven Healthcare Improvement - Data Literacy and workforce capacity building

* 1. What roles/ expertise do you have? (One or more)

- Health professional
- Academic
- Undergraduate University Student
- Clinical Researcher
- Manager of Service/ Clinicians
- Data literacy: experience in collecting, aggregating, storing and analysing data
- Data use: experience in using data (including local data) to inform health care or to implement change
- If other, please specify

* 2. What Centre (Advanced Health Research Translation Centres and Centres for Innovation in Regional Health) are you affiliated with?

- Brisbane Diamantina Health Partners
- Central Australia Academic Health Science Centre
- Melbourne Academic Centre for Health
- Monash Partners
- NSW Regional Health Partners
- South Australian Academic Health and Medical Research Institute
- Sydney Health Partners
- The Sydney Partnership for Health, Education, Research and Enterprise
- Western Australian Health Translation Network
- I don't know
- I am not associated with an Advanced Health Research Training Centre

3. The aim of the Data Driven Healthcare Improvement initiative is to improve the use of data by health professionals to optimise health care and outcomes. We aim to start with a short co-designed module this year and expand over time.

With this in mind please provide us with your views on the following:
Would you target a particular group of health professionals?

- Yes No

Page 2 - Survey to co-design training in data driven healthcare improvement

4. Which health professionals would you target for data training?

- Senior medical staff
- Junior Medical staff
- Nursing staff
- Allied Health Practitioners
- Undergraduate health professional trainees
- Multidisciplinary / interdisciplinary training
- Not Sure/ Other, please specify

Page 3 - Survey to co-design training in data driven healthcare improvement

5. Please rank these areas of training you feel relevant from most useful (1) to least (12)

Rank the following items using numbers from 1 to 12.

Data Privacy and Confidentiality (FOI, Consent, Legislation) _____

Data Storage Options _____

Security of data _____
Check lists and

planning tools _____

Systems to name and store data for easy

retrieval _____

Systems and structures

to "clean" data _____

Software analysis packages and where to

get guidance _____

How to "flatten" or compress your files and

then normalise again _____

What Outcome

Measure collaborations

exist? _____

How do you use outcome measures on more than an individual basis?

What large data bases are openly available for

people to access? _____

What closed large data bases are available on

request? _____

6. Please provide any other suggested training areas that we have missed

7. The best mode of delivery of any training program should be: (1 most preferred, 5 least)

Rank the following items using numbers from 1 to 5.

Face to face _____

PDF – paper training

guide _____

Online training

module/s _____

Webinar _____

Multimodal _____

8. If you ranked Multi modal highly, please comment on mode preferences. Any other suggestions- please comment

9. Whilst this year we will design a short introductory module we would like your views for long term training design.

The optimal total duration for any training program would ideally be:

< or = to 2

- 2-5
- 6-10
- >10 hrs

10. **The duration of each session for health professionals would ideally be:**

- 30 minutes
- 1 hour
- 90 minutes
- If other, please specify

Page 4 - Survey questions for existing resources

11. **Are you aware of any data training or data literacy activities in your organisation?**

- Yes No

Additional Comments

12. **Have you attended any data training or data literacy activities in the past 12 months, not offered within your organisation?**

- Yes No

Additional Comments

13. **Did you answer No to both of the previous two questions (Q11 and Q12)?**

- Yes No

Page 5 - Survey questions for existing resources

14. **If you answered yes to questions 11 and 12 please choose the best quality course, in your opinion, and answer the following questions with that in mind:**

Who is/was the training targeting?

- University undergraduate health professional students
- Academic Staff
- Medical staff
- Allied health staff
- Nursing
- Service managers
- Senior management
- Open
- If other, please specify

15. **What is/was the purpose of this training?**

- Research Activity
- Healthcare improvement activity
- Quality initiative
- Productivity and performance
- Improving health outcomes
- If other, please specify

16. **Is/was the training?**

- Mandatory
- Optional

Additional Comments

17. Was the program evaluated?

- Yes
- No
- Don't know

Page 6 - Survey questions for existing resources

18. What evaluation strategies were used to evaluate the training program?

- Number of people completing training/ uptake
- Increase in access to data bases
- Less variation in file naming and systems on audit
- Accreditation evidence that data has been used to inform service delivery changes
- Inclusion in regular team meetings/ case conference discussions
- Inclusion of data/ outcome measures in patient files as per audit review

19. What mode of delivery is/was used?

- Face to face
- Online training module/s
- Webinar
- PDF/ Paper training guide
- If other, please specify

20. Is/was this program....?

- Open (widely available)
- Closed (only organisation members have access)

Additional Comments

21. What intensity is/was the program? How many hours in total?

- < or = to 2 hours
- 2-5 hours
- 6-10 hours
- If >10, please specify

22. How many sessions?

- < or = to 2
- 2-5
- 6-10
- If >10, please specify

23. Is/was this time limited? Do the participants need to complete modules in a specific and limited time frame, once commenced?

- Yes No

Please specify time limits/time frames

24. Is/was there a cost to the organisation?

- Yes
- No
- Not sure

Please state cost if relevant:

25. Is/was there a cost to the individual?

- Yes No

Please state cost if relevant:

Page 7 - Survey questions for existing resources

26. Do/did participants receive a certificate of attendance?

- Yes
- No
- Not sure

Additional Comments

27. Is the course recognised by any professional organisations to accrue CPD points?

- Yes
- No
- Not sure

Please note which professional organisation

28. Is the training accredited by a University and/or link into a University course?

- Yes
- No
- Not sure

Please note which University if relevant

29. Please rate the course

- Would not recommend
- Is/was adequate
- Marvelous

Please provide details of the course
