

People Research Data Commons

FEEDBACK FROM CONSULTATIONS

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The Australian Research Data Commons
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BACKGROUND



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The Australian Research Data Commons (ARDC) has undertaken consultations with national stakeholders for the People Research Data Commons (or ‘People RDC’). The purpose of these consultations was to:

- identify the key data challenges in health and biomedical research as well as the associated priorities
- help define the value proposition of the People RDC
- learn where initial efforts need to be focused in establishing the People RDC.

The consultations were done in phases, with initial feedback sought from national committees that have the breadth and depth of representation across sectors and jurisdictions, including from health research, research funding bodies, national digital/research infrastructure organisations and the community.

Detailed feedback was received from the ARDC’s [Health Studies Australian National Data Asset \(HeSANDA\) Advisory Committee](#) and [Research and Technology Advisory Committee](#). Recommendations and comments were also received from the [Chairs of the Australian Academy of Health and Medical Sciences Data Steering Committee](#) and the [Advanced Health Research and Translation Centres National Data Driven Healthcare Committee](#).

BACKGROUND

Two roundtable consultations on 1 and 2 June 2022 were open to all stakeholders. There were 161 registrations for the 2 sessions. The attendees were predominantly researchers, institutional research infrastructure providers and representatives from NCRIS facilities. There were also representatives from industry, health services, government agencies, NHMRC, philanthropic research funding organisations, consumer groups and Learned Academies.

The focus of the initial consultations was on *“What the People RDC needs to deliver”* and *“Why the challenges addressed by the People RDC would be transformative for research.”* The next stage of the discussions with NCRIS facilities and research infrastructure providers will cover the question of *“How can the People RDC deliver infrastructure to address the identified challenges by building on existing capabilities, both within the ARDC and across the sector?”*

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This report summarises the insights gained from the stakeholder discussions and roundtables. Generally, the consistent feedback from the consultations has been that **the ARDC’s vision is big and the proposed challenges are difficult, but it is also important to address the identified challenges on a national scale; with a focus on early wins towards this long term vision.**

WHAT - CHALLENGES AND PRIORITIES

The People RDC consultations tested the relevance and priorities of the following data challenges in health and biomedical research, which were detailed in the [People RDC Briefing Paper](#):

1. Data discovery across distributed national data assets
2. Data collaborations across diverse data sharing and analysis environments
3. Application of advanced analytics over distributed data
4. Data linkage at scale

At each consultation roundtable, the attendees were polled to determine the relevance of the 4 proposed data challenges and their priority.

The results from these polls showed that all the 4 challenges were relevant and there was no consensus about additional challenges. This indicates that the right challenges have been identified.

How Relevant Are These Data Challenges?

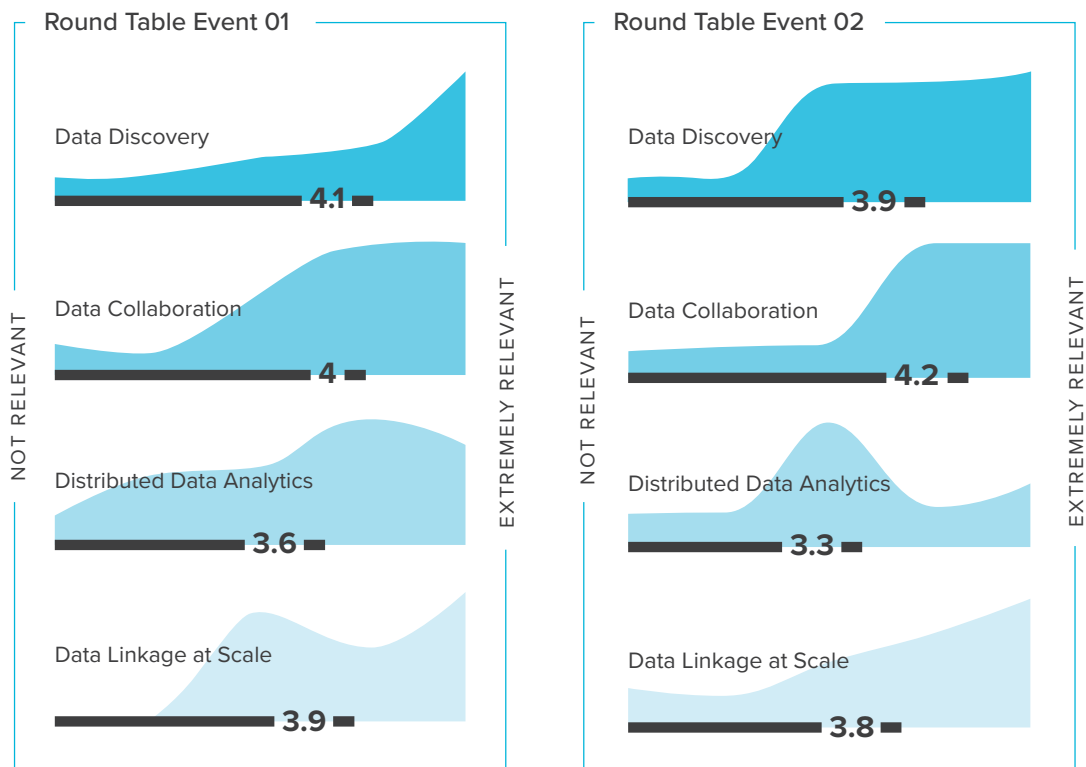


Fig. 1: Poll results for “How relevant are these data challenges” from the 2 public consultation sessions. The first poll had 42 respondents, and the second had 33 respondents

WHAT - CHALLENGES AND PRIORITIES

The challenges in order of priority were:

- i. Data collaboration across diverse analysis environments
- ii. Data discovery across distributed national data assets
- iii. Data linkage at scale
- iv. Applying advanced analytics over distributed datasets.

This priority also aligned with the top 3 priorities suggested by representatives from the national committees.

Rank the challenges in order of priority

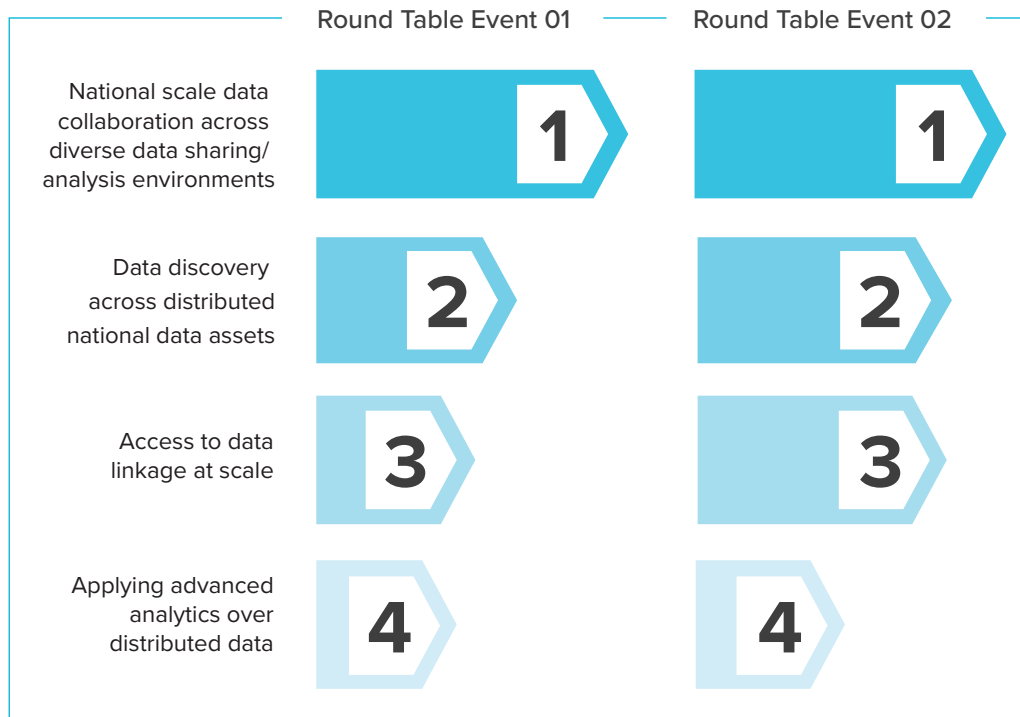


Fig. 2: The poll results for “Rank the challenges in order of priority” from the 2 public consultation sessions.

WHY - IMPACT AND VALUE PROPOSITION

The feedback from the consultations highlighted that some of the benefits from addressing the identified data challenges would include:

- breaking down barriers to data sharing while protecting sensitive data
- building public trust
- building bigger and richer data collections
- enabling “cradle to grave research”
- partnerships with commercial entities
- personalised care with improved outcomes for patients
- answering questions about national health challenges that are multifactorial
- reducing resource wastage
- identifying interventions which will have the largest impacts
- faster application of research advances into clinical practice
- increased patient access to clinical trials
- more equitable access to healthcare.



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Example: Improved access to healthcare in rural and regional areas

The New South Wales Rural Doctors Network is a not-for-profit, non-government organisation that seeks to support better health and wellbeing for people living in remote, rural, regional, Aboriginal and disadvantaged communities.

The network has been working with the communities for over 30 years and has valuable data related to the health of these communities. Having access to data infrastructure through a People RDC would enable research on these valuable data assets while also supporting healthcare delivery.

WHO - NATIONAL STAKEHOLDERS

The range of national stakeholders for health and biomedical research and translation is diverse across sectors, including research, research infrastructure, government, industry, health services and the consumer community. Consequently, the feedback received from across these sectors reflects their particular challenges, risks and opportunities with health data.

The table below summarises the feedback and comments mapped to the stakeholder categories.



WHO - NATIONAL STAKEHOLDERS

GOVERNMENT

Federal, States and Territories



STRENGTHS

Data legislation - default position of the government is to make data available to benefit society

Significant initiatives underway at federal and state levels

AIHW and ABS collaborating on a data linkage spine ANDI - that builds on NIHSI & MADIP



CHALLENGES

Alignment between the various initiatives underway nationally



RISKS

Lack of easy access to government linked data is a critical risk for research



OPPORTUNITIES

Government initiatives primarily focus on the data requirements for government. The People RDC can help bridge the gap for research engagement with government data initiatives

HEALTH SERVICES



STRENGTHS

Data from primary care, hospital and aged care is very useful for research



CHALLENGES

Health services do not fully appreciate the value of their own data for national-scale research and translation

Lack of access to infrastructure for secure data collaborations



RISKS

Without access to appropriate infrastructure, the adoption of best practices in data collaboration is difficult leading to data silos



OPPORTUNITIES

Accelerating research translation

Building trust with the community

Enabling adoption of common data models and data standards

FUNDERS



STRENGTHS

MRFF infrastructure program is heading in the same direction as the People RDC

NHMRC interest in lowering the barriers to research data collaborations



CHALLENGES

Alignment between organisational initiatives



RISKS

Duplication or divergent efforts in infrastructure development



OPPORTUNITIES

Effectively leveraging infrastructure investments across MRFF and NCRIS

Funding rules can incorporate the use of capabilities in the Commons

WHO - NATIONAL STAKEHOLDERS

INDUSTRY



STRENGTHS

Significant investment in data capabilities
Big data assets in pharma (e.g. clinical trials data)



CHALLENGES

Need to define the value proposition of a commons for industry



RISKS

Lack of a strategic long term approach to building industry engagement



OPPORTUNITIES

Important to consider industry stakeholders for clinical research (e.g. clinical trials)

COMMUNITY



STRENGTHS

Community support for research
Consumer interest in understanding how data is being used and how it delivers societal benefit



CHALLENGES

Building and maintaining trust
Need for transparency and accountability in handling personally identifiable data



RISKS

Data breaches and the significant risk they pose for consumers



OPPORTUNITIES

Big data
Active consumer involvement in determining data use and delivering impact

HOW - IMPLEMENTATION FACTORS



Image — Love the wind - 215484326 / stockadobe.com

The feedback from the consultations related to the delivery of the People RDC can be summarised as follows:

- As the challenges identified in the People RDC represent a big and long-term vision, the delivery of the RDC correspondingly requires long term investment
- Given the diversity in the data/digital landscape, federation is the most viable approach
- It's important to have a consistent approach to the architecture and the messaging - with a focus on both FAIR and CARE principles
- There is a need for consistency and standards in data governance, ethics, data quality
- There is a need for alignment between data infrastructure initiatives across MRFF and NCRIS
- Understand the current state of national initiatives and the current gaps as well as the alignment opportunities
- Recognition of industry as a technology provider/partner
- Importance of identity and authorisation framework
- The common confusion between privacy and security concerns when dealing with sensitive data
- Lowering the barriers to bridging the cultural shift from protecting data by securing it in locked down environments to secure data collaborations across institutions/sectors

HOW - IMPLEMENTATION FACTORS

At the roundtables, stakeholder input was sought on the secure collaboration platforms currently being used across the sector. Platforms like SeRP, SURE, ERICA, XNAT and Data Lab are commonly used. But it was notable that several participants highlighted the lack of access to an appropriate secure collaboration platform as a challenge, with several projects adapting a data collection tool like REDCap to support data collaboration.

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The roundtable attendees also identified high value data assets that should be brought into the commons. This included data from primary care, hospital, aged care, biobanks, cohort/longitudinal studies, clinical trials, AIHW/ABS linked datasets, birth and death records, indigenous datasets, CALD data, education/social/justice datasets and imaging/omics datasets.

GLOSSARY

TERM	DESCRIPTION
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ANDI	Australian National Data Integration infrastructure led by AIHW and ABS developing a national linked data spine with an initial focus on national disability data assets
ABS DataLab	Secure data analysis environment for ABS data
ARDC	Australian Research Data Commons
CALD	Culturally and Linguistically Diverse
CARE	Collective benefit, Authority to control, Responsibility, Ethics
ERICA	E-Research Institutional Cloud Architecture - cloud computing infrastructure for sensitive data
FAIR	Findable, Accessible, Interoperable, Reusable
MADIP	Multi-Agency Data Integration Project from ABS is a secure data asset combining information on health, education, government payments, income and taxation, employment and population demographics over time
MRFF	Medical Research Future Fund
NCRIS	The Australian Government National Collaborative Research Infrastructure Strategy
NHMRC	National Health and Medical Research Council
NIHSI	National Integrated Health Services Information Analysis Asset contains de-identified data from all participating jurisdictions from 2010-11 onwards
People RDC	People Research Data Commons
RDC	Research Data Commons
SeRP	Secure eResearch Platform
SURE	Secure Unified Research Environment is an online workspace for analysing and sharing health and human services data
XNAT	XNAT is an open source imaging informatics platform

MORE INFORMATION

For more information, please visit the [ARDC website](#). For updates on the People RDC, please [subscribe to our newsletter](#).

FEEDBACK

We welcome your feedback on this document. Please email contact@ardc.edu.au with any comments or questions.

ABOUT THE AUSTRALIAN RESEARCH DATA COMMONS

The Australian Research Data Commons (ARDC) enables the Australian research community and industry access to nationally significant, data intensive digital research infrastructure, platforms, skills and collections of high quality data.

The ARDC is supported by the Australian Government through the National Collaborative Research Infrastructure Strategy (NCRIS).



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