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Lowitja
INSTITUTE

Australia's National Institute
for Aboriginal and Torres Strait
Islander Health Research

*Incorporating the Cooperative Research Centre
for Aboriginal and Torres Strait Islander Health*

Aboriginal and Torres Strait Islander Health Data Linkage Roundtable

Melbourne, 31 October 2013

Report

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An Australian Government Initiative



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Acronyms

AIATSIS	Aboriginal and Torres Strait Islander Studies
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal medical services
NACCHO	National Aboriginal Community Controlled Health Organisation
NTCorp	Native Title Corporations
VII	Medicare Australia Voluntary Indigenous Identifier

Overview

Approximately 30 people attended The Lowitja Institute and Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) roundtable **Aboriginal and Torres Strait Islander Health Data Linkage**, in Melbourne on 31 October 2013. The roundtable was attended by a diverse range of organisations from across the country with an interest in data and data linkage, including the Aboriginal community controlled sector, government agencies, health service providers/clinics, research institutes and non-government organisations.

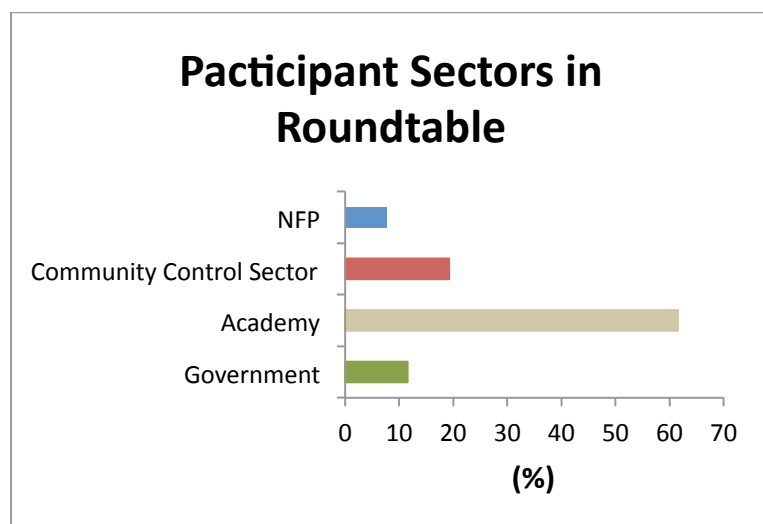


Fig. 1 Participant sectors at the data linkage roundtable

The purpose of the roundtable was to:

- bring together researchers, community controlled services and government agencies involved in data collection, analysis and usage, data management and data integration and linkage
- provide an overview of data gaps and barriers to good health data and linkage concerning Aboriginal and Torres Strait people
- identify opportunities for closing data gaps through data linkage strategies, including the linking of registry and administrative databases across jurisdictions
- improve data linkages at the regional level
- establish better communication/collaboration across the different health systems to improve data linkage capacity
- identify potential interventions based on the sharing of ideas on data and data linkages
- share information about current data linkage initiatives in different States around Aboriginal and Torres Strait Islander health data
- discuss ownership and use of data and their linkages.

Organising Committee

Ray Lovett (AIATSIS), Lisa Jackson Pulver (University of New South Wales), Gail Garvey, Tara Dempster-Clark and Liz Izquierdo from the Lowitja Institute.

Roundtable Themes

Roundtable themes were informed by the following process:

- Selection of and participation by key players across the data linkage and Indigenous health sectors
- Before the roundtable event, three documents distributed to roundtable participants
 - Public support for data-based research to improve health: A discussion paper based on the proceedings of a Menzies Foundation Workshop, Menzies Foundation, 16 August 2013
 - The Lowitja Institute Data Linkage Roundtable: Background document, Ray Lovett, n.d., and
 - Australian Bureau of Statistics Data Linkage Program, ABS, n.d.
- Presentations by key experts in data, data linkage and Indigenous health
- Discussions of themes, issues and priorities by roundtable participants, including presenters.

The key themes and accompanying research topics identified were:

- current data linkage initiatives
- data ownership and use
- data linkage capacity and integration.

Opening Address

Dr Ray Lovett outlined a conceptual framework for the roundtable. His address defined data and data linkage, outlined their relevance and importance to Aboriginal and Torres Strait Islander health and wellbeing, and identified the main custodians and stakeholders in Indigenous data management. His key message was that the gathering of information and its subsequent use requires collaborations of all key players (including data custodians, stakeholders and users) throughout the life cycle of research programs and projects, from research design, collating of data, analysis, interpretation and reporting.

Presentations

Six presentations by experts in their field, covered the roundtable themes were delivered:

1. **Australian Bureau of Statistics: Current data linkage activities – What the future might hold** by Julie Nankervis, Director, National Centre for Aboriginal and Torres Strait Islander Statistics
2. **Data ownership and use – Research perspective** by Associate Professor Margaret Kelaher, The University of Melbourne
3. **Data ownership and use – Community control sector perspective** by Professor Ngiari Brown, National Aboriginal Community Controlled Health Organisation (NACCHO)
4. ***Couplage des données sans frontier* or Data linkage without borders** by Associate Professor Jane Freemantle, The University of Melbourne
5. **Access to data for enhanced mortality database project: Issues and problems** by Dr Fadwa Al-Yaman (Australian Institute of Health and Welfare, AIHW), Dr Len Smith (The Australian National University, ANU), and Tetteh Dugbaza (AIHW)
6. **Opportunities for large scale collaborative research in Aboriginal health through improved data linkage capacity and integration** by Professor Emily Banks, National Centre for Epidemiology and Population Health, ANU.

Presentations are available at <www.lowitja.org.au/data-linkage-roundtable>.

Panel, Group and Whole-of-Roundtable Discussions

Following the presentations, all presenters joined in a panel and answered questions from roundtable participants. Participants were then split in three groups and were asked to propose a list of potential collaborative research projects in data and data linkage for the benefit of Aboriginal and Torres Strait peoples and their communities.

In proposing their ideas and projects, all groups were asked to develop suggested strategies and/or recommendations around such activities, as well as identifying who would be best placed to implement the recommendations (taking account of the gaps and critical issues identified in their discussion). Each group reported their discussion of themes and priorities were then reported to whole roundtable.

Finally participants in each group were asked to identify and consider one key project for further development, identifying the key research question, aims, methodology, and impact of developing of the project.

Presentations and discussions aimed to inform/improve policies, programs and practices among stakeholders represented at the roundtable. The list of priorities developed from this reflective exercise will form the basis of a briefing paper for relevant stakeholders and politicians.

The next two sections summarise the priorities and project ideas discussed at the roundtable, the rationale behind each of them and the potential actions to address them.

Priorities Identified

Data stakeholders

Engagement of relevant stakeholders at early stages of projects/initiatives is paramount. This will promote more collaborative initiatives and data sharing and ensure project continuity and sustainability on data linkage. Data stakeholders include users, custodians, owners, collectors and consumers.

Data management

This involves collection, use, reuse, access, ownership, custody, governance, sharing. Data collection is the starting point, and strategies should be in place to ensure good methods are used, as bad data is worse than no data.

It is critical that custodians of data develop a framework, information/guidelines around data management, to enable decisions around data use, access and administration. Documented protocols should be user-friendly.

Short-term goal/actions

1. Establish a reference group/advisory board arising from this forum to:
 - advocate and communicate the messages, key finding and recommendations of this roundtable to key stakeholders, custodians, users and beneficiaries of data and data linkages, for example, AIHW, ABS)
 - develop a statement on the importance of data linkage, covering successful examples, proposals for concrete solutions in data management and use, and how-to strategies to promote data linkage projects such as the identification and quantification of risks versus benefits of releasing and using data and the health cost in dollars of not doing so
 - design and plan actions and initiatives based on this statement
 - serve as channel to work with custodians to release data, specifically ABS
2. Produce a literature review to:
 - list and map all existing data linkage initiatives and data sets across the country, their level of access, custodians, governance arrangements, and the cost of data release and access. This review will also allow data linkage stakeholders to identify the barriers to accessing data by recognising the role of data custodians and having quality discussions with them
 - map the ideal journey of population data, from when it is collected, analysed, interpreted and used, so as to deliver better health to Aboriginal and Torres Strait Islander peoples, and to overlap the data with actual experiences and life stories of patients. The review will look at successful programs in South Australia, West Australia and Victoria, and internationally in New Zealand and Canada (www.uaps.ca/). Using existing data linkage work in Western Australia (www.datalinkage-wa.org.au/projects/indigenous-identification-project) and Victoria (www.vacms.net.au) make the journey back of those initiatives and evaluate how was done; to map similarities and differences. Establish the gaps and plan the necessary initiatives to fill them. Plan the road to success, using innovative, modular ways and discrete initiatives, stages/projects so they are more achievable,

easier monitored and funded. NACCHO and their primary health care centres network, and/or other umbrella Indigenous health organisations, should be incorporated in this planning

- produce a catalogue listing (summary table) of existing data collections across government and other organisations in the country
 - develop strategies to find out when and where data is becoming available and by whom.
3. Plan a summit sponsored by a government agency with champions from diverse sectors, including media, land councils, ethics committee groups, data stakeholders, community, politicians and others, to facilitate data release from custodians.
 4. Explore the possibility to access Native Title Corporations (NTCorp) database.
 5. Develop a communication strategy that informs and demonstrates:
 - the value of good-quality data and its linkage to improve health for Aboriginal and Torres Strait Islander peoples
 - relevance of strategies to improve the collection and storage of data, such as continuous quality improvement
 - population data as a national asset for health, welfare, education, housing and the like
 - how data linkage could help to monitor more effectively the closing the gap strategy's impact on health and wellbeing of Indigenous people
 - how the combination of diverse data sets offer advantages in the design of health policies
 - how a holistic approach of linked and integrated data can tackle health issues using evidence-based research.

Long-term goal/actions

1. Establish a national data repository for Aboriginal and Torres Strait Islander health data with endorsement/agreement from all state jurisdictions. The model used by birth registration could be transferred to data linkage agreements
2. Work towards a bureaucratic reform on the way data access is managed
3. Develop knowledge around budgets for data release
4. Build a data health-informed workforce
5. Build community (Aboriginal and Torres Strait Islander) governance and authority in data linkage delivery and access. This might be achieved through NACCHO and affiliates, Central Australian Aboriginal Congress, and/or National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data. Alternatively, any or all of these Indigenous organisations could provide advice to the custodians of data, such as ABS, and could act as a reference group
6. Use existing systems, for example, taxation and Medicare numbers to develop opportunities for linking data
7. Link Medicare, e-health, health surveys, primary health care centres, community-controlled health sector data for Aboriginal and Torres Strait Islander people

8. Link Census, hospital data and other data sets, to understand relationships by incorporating longitudinal studies
9. Recommend that NACCHO builds capacity in data linkage space by providing reference group to data custodians and by analysing and making available their own high-quality data (collected through their primary health care centre's network), for use by project researchers (subject to ethics considerations)
10. Establish a gold standard linkage, using data and data linkages from Aboriginal land councils, Census, Medicare Australia Voluntary Indigenous Identifier (VII), NTCorp and Aboriginal community controlled health organisations
11. Use e-health as a potential opportunity to get Aboriginal and Torres Strait Islander identifiers to facilitate identification and use of that data
12. Provide e-health access and uptake to improve vaccination rates
13. Develop methodologies to treat data (research and development initiatives)
14. Evaluate health outcomes by identifying and documenting patient journey gaps in services using Medicare Australia Voluntary Indigenous Identifier, or VII
15. Encourage ABS to maximise use of census data for data linkage projects (according to the ABS, 10% de-identified data is available to researchers)
16. Improve service delivery through e-health or patient controlled health research
17. Initiate renewal of cervical screening by monitoring and mapping the disease in Aboriginal people with data linkages.

Project Ideas

Project 1: Improving timeliness of vaccination delivery

Question

Does an improved system of vaccination reminders improve timeliness of vaccination uptake among Aboriginal people?

Aim: To reduce the incidence of vaccination-preventable diseases.

Methods

- Amalgamate all data sets of individual Aboriginal medical services (AMS).
- Link AMS data on individual clients with the modifiable diseases register, child immunisation register, national hospital morbidity, and the National health index.

Consequences of doing it (positive impact)

Positive consequences include improved systems and improved health.

Consequences of not doing it (negative impact)

This includes poor timeliness of vaccination, and continued high levels of vaccination preventable diseases.

Project 2: 4-year old health check

Question

What is the impact of a 4-year old health check?

Aim

To assess whether health checks have positive impacts on early childhood learning. For example, the study assesses the role that healthy ears have on language abilities at school, which in turn can also impact on school attendance and early learning.

Methods

Compare a variety of health indicator results arising from health checks against school attendance and NAPLAN test results over time.

Consequences of doing it (positive impact)

Health screening policies for 4-year olds could positively impact school attendance and learning improvements.

Consequences of not doing it (negative impact)

Not carrying out the project could be costly to Aboriginal children as they get older.

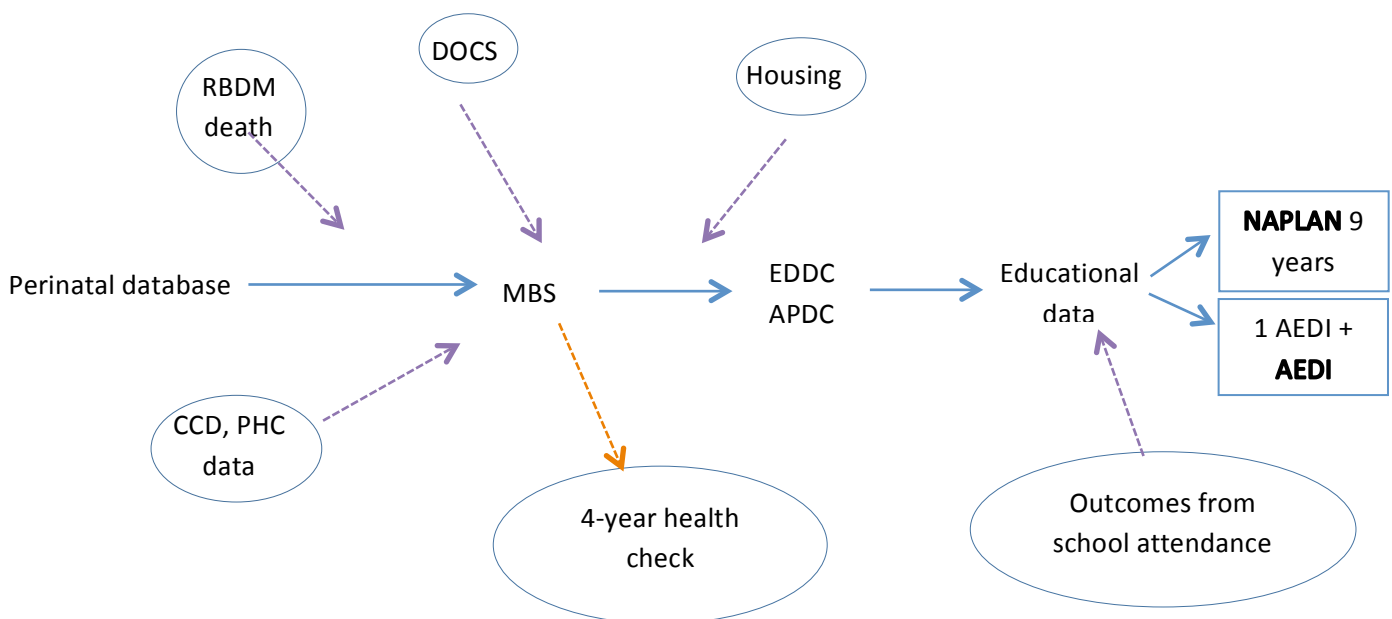


Fig. 2. Flow diagram showing data require to assess factors impacting on a 4-year old learning. RBDM: Registry of Births, Deaths and Marriages; DOCS: Department of Community Services; MBS: Medicare Benefits Schedule; EDDC: Emergency Department data collection; APDC: Admitted Patient data collection; NAPLAN: National Assessment Program – Literacy and Numeracy; AEDI: Australian Early Development Index; CCD: Community cultural development; PHC: Primary health care

Project 3: Linking VII with the patient journey

Question

What is the best way of linking data to close the gap in Indigenous health?

Aim

Assess whether the development of Indigenous infrastructure for the analysis and storage of data sets, and governance arrangements for data linkages, can strengthen Indigenous capacity in and integration of data sets

Methods

Link qualitative experiences and life stories of Indigenous patients as collected and analysed by community organisations to patient health histories through VII.

Consequences of doing it (positive impact)

Such data linkages and sharing will focus the delivery and access of more comprehensive health services to communities.

Consequences of not doing it (negative impact)

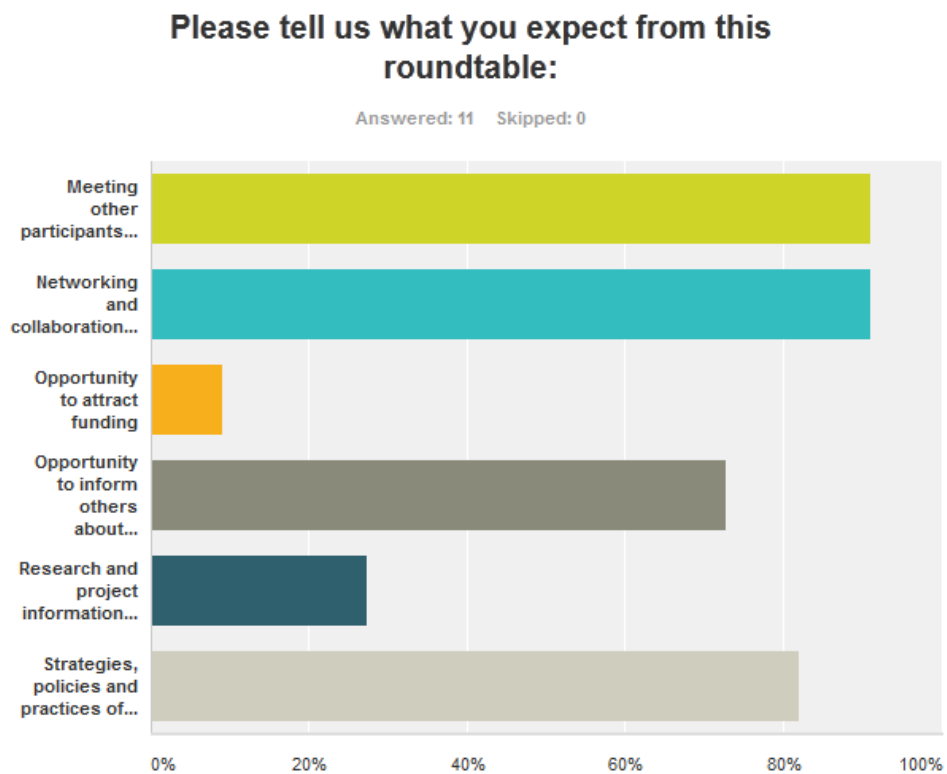
Indigenous capacity and data integration is not realised.

Appendix 1: Roundtable Agenda

The Lowitja Institute and AIATSIS Aboriginal and Torres Strait Health Data Linkage Roundtable

Time	Topic
8:30am	Registration Tea/Coffee
9:00am	Welcome (Gail Garvey) Outline of the day (Lisa Jackson Pulver) Participants' introduction (name, organisation, expectations)
9:20–9:30am	An overview: Data Linkage concerning Aboriginal and Torres Strait Islander people (Ray Lovett, AIATSIS)
9:30–10:30am	Presentations (5–7 minutes) <ol style="list-style-type: none"> 1. ABS: Current data linkage activities, what the future might hold (Julie Nankervis) 2. Data ownership and use <ol style="list-style-type: none"> a. Research perspective (Margaret Kelaher) b. Community controlled sector perspective (Ngiare Brown) 3. Potential interventions and data sharing to improve data linkage at national and regional levels (Jane Fremantle) 4. Opportunities for large scale collaborative research in Aboriginal Health through improved data linkage capacity and integration' (Emily Banks)
10:30–10:50am	Morning tea
10:50–11:20am	Open Panel discussion and question time
11:20am–12:00noon	Group Work –Table discussions on research priorities on nominated topics. Groups to generate a written summary of priorities (dot point format)
12:00noon–12:45pm	Lunch
12:45–1:30pm	Group Work continued Groups reporting back to workshop participants
1:30–2:30pm	Open discussion. Conclusions and strategies to approach to where to from here?'
2:30–3:00pm	Closing remarks

Appendix 2: Analysis of pre-Roundtable Survey

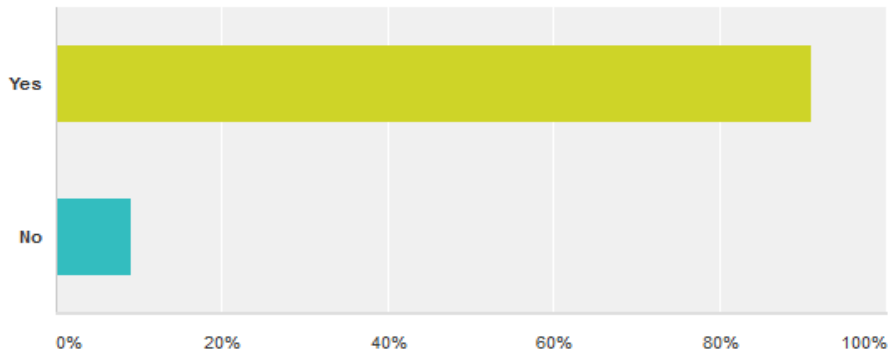


Q1 comments

- discussing ways forward to obtain the nationally held data sets including claims data for MBS and PBS to be linked with state-based data sets
- Learning about what is happening in other jurisdictions with data linkage and its use in Indigenous health.

Is there a need to establish a national data linkage network?

Answered: 11 Skipped: 0

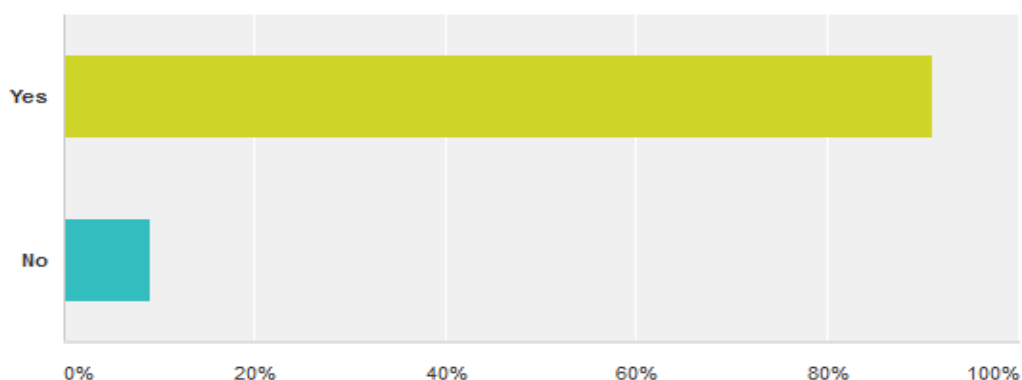


Q2 comments

- There is potential for data linkage to play a larger role in informing on Aboriginal and Torres Strait Islander peoples health outcomes
- We need to work together to gain access to the nationally held data sets
- To some extent the PHRN should fulfil the technical role and there are state-based interest groups for researchers, but a national interest group would be good.
- A network would be helpful regarding guidance of appropriate methods to measure Indigenous status
- Australia already has a national data linkage network, the PHRN (www.phrn.org.au) and there has been significant investment in the Network by the Commonwealth, State and Territory Governments and also by a range of academic institutions across Australia in the last 4 years
- learning more about the prospects, challenges and opportunities for combining Indigenous population-level data across jurisdictions and collaborations to investigate important policy questions such as the developmental pathways increasing and decreasing risks for involvement with the justice system, etc.

Is there a need to establish a national data linkage network?

Answered: 11 Skipped: 0

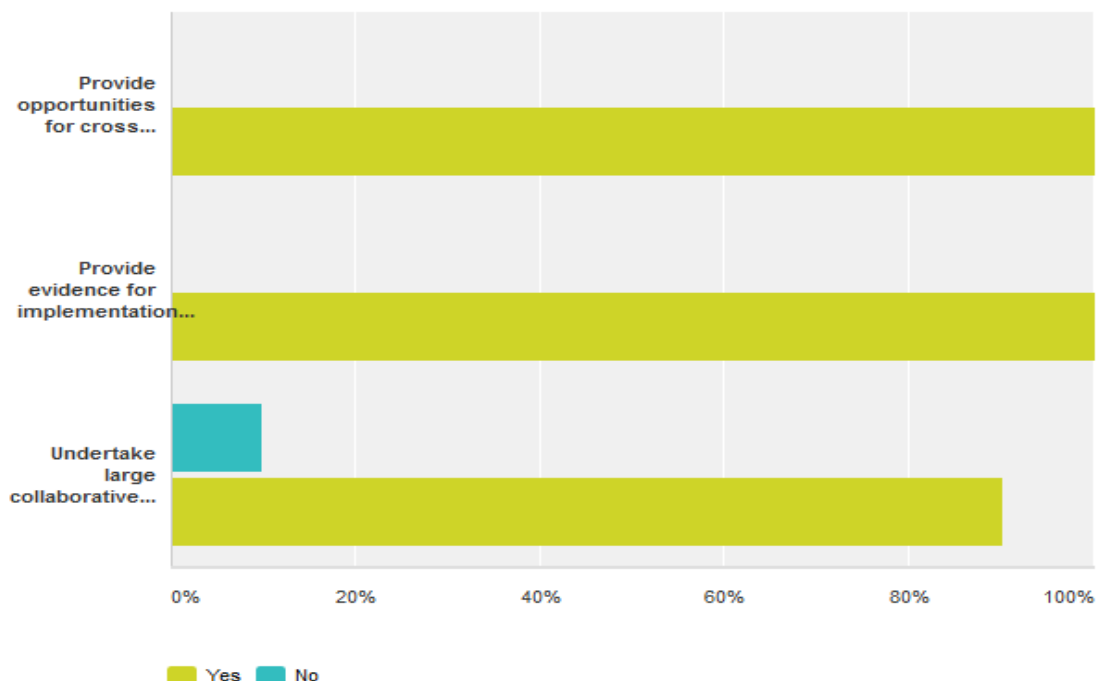


Q3 Comments

- ABS would be interested in participating
- I believe the PHRN may be an example of a national data linkage network. Data linkers may have to liaise with the PHRN a lot more
- I currently work for Australia's national data linkage network, the PHRN
- I am the convenor of the NSW data linkage interest group.

Which of the following activities could be included in such a network?

Answered: 11 Skipped: 0



Q5. National network or partnership might explore to influence positive change around data linkage opportunities? Comment

- Developing common ethics approval processes 2. Developing common protocols for obtaining access to data from States and Territories (e.g. a coordinator of all S/T administrative data: possible, one coordinator for health data, birth and death registration data, housing data etc.)
- Shared methodologies that maximise valid analytic opportunities from the data
- Advocacy for nationally held data sets
- Consulting with Indigenous communities and organisations about the benefits of data linkage, the privacy and confidentiality safeguards it requires, and how this can be used to make better use of already collected data
- The PHRN is building data linkage infrastructure at both the State/Territory and national level to enable the activities described in question 4
- support the creation of shared data linkage infrastructure advise on strategies for Aboriginal community engagement in data linkage.