

Data Linkage Branch WA

Submission for Productivity Commission Inquiry into Data Availability and Use

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Contact: Janine Alan
Program Manager
Data Linkage Branch
Department of Health WA
1C, 189 Royal Street
East Perth WA 6004

This Submission:

In June 2016, the Western Australian (WA) Department of Health (DoH) provided a submission to the WA Department of Premier and Cabinet (DPC) Review of Data Linkage Capabilities in WA. This WA DoH submission is also of relevance to the Productivity Commission Inquiry into Data Availability and Use. Hence, the same submission (including layout) is supplied for the Productivity Commission's consideration.

SECTION 1: STRENGTHS, CAPABILITIES AND CAPACITIES

DoH builds and operates a data linkage infrastructure (the WA Data Linkage System, WADLS) that is capable of securely linking data collections from a wide range of sources to enable approved activities including policy, planning and research. The Data Linkage Branch (DLB) manages the WADLS. The WADLS is one of only two well-established and enduring data linkage systems in Australia, the other being the Centre for Health Record Linkage (CHeReL) in New South Wales. The rapid and promising progress of data linkage centres elsewhere in Australia has and will continue to benefit from the lessons learnt and shared by DLB and CHeReL.

1: Data and linkage infrastructure

From its modest beginnings in 1995, the WADLS is now one of the most comprehensive, high quality and enduring linkage systems worldwide. It currently comprises a linkage infrastructure spanning over 400 data collections (both infrastructure and ad-hoc)¹, representing 88⁺million links (~ 4.1 million people) dating back to 1945. Health linkages form over half of the WADLS (Attachment 1). This focus is largely attributable to DoH's established track record of collecting high quality electronic administrative data, driven by regulatory requirements and DoH's need to support a wide range of medical and health-care functions (e.g. patient safety and quality, disease surveillance, population health management, clinical decision support, cost effectiveness). Recurrent funding from DoH has made these achievements possible and ensured continued stability of the WADLS. External sources of funding (e.g. LotteryWest), while time-limited and purpose-specific, have also contributed to the success of the WADLS and demonstrated the value of past partnerships with the academic sector.

2: Expertise

The process of linking data is a highly specialised field. Over the past 20 years, DLB has developed and refined a diverse range of high quality products and services based on specialist knowledge and facilities. The scale and sophistication of the WADLS relative to the size of DLB's workforce and budget is testament to this expertise and agility.

DoH fosters a culture of continuous improvement and innovation. Notable examples of DLB's pioneering work include establishing: (1) a Client Services Team to assist data applicants; (2) genealogical links over multiple generations; (3) the Custodian Administered Research Extract Server (CARES, Attachment 2); (4) DLB derived Indigenous Status Flag (Attachment 3); (5) DoH Data Steward and Custodian Group; (6) transparent activity metrics²; (7) software developments to improve linkage, value-adds, workflow management and performance reporting (e.g. a new data linkage system called DLS3, enhanced geocoding capabilities, and a new Client Services task management system); and (8) researcher training course (commenced 2016).

DLB's linkage activities represent another level of intellectual input that refines and/or adds value to the original data sources and requires significant expertise and accumulated knowledge. DLB receives frequent communication from other data linkage centres regarding these unique features, which demonstrate peer recognition of these strengths. DLB also collaborates regularly with other recognised experts in data linkage (Centre for Data Linkage at Curtin University and CHeReL) regarding linkage quality, privacy preserving record linkage methods, technological advancements, and WA's data linkage position in the changing national linkage landscape (including the Population Health Research Network).

¹ <http://www.datalinkage-wa.org.au/data-linkage/glossary>

² <http://www.datalinkage-wa.org.au/data-linkage-branch-dashboards>

Another unique strength is DoH's Human Research Ethics Committee (HREC), established in 2008 and registered with the National Health and Medical Research Council (NHMRC). This HREC is a highly specialised group that arguably has the strongest understanding of data linkage of any WA ethics committee. It plays a vital role in the responsible and ethical use of sensitive DoH data, while protecting individuals' welfare, rights and dignity. DoH's HREC fosters confidence in all data providers who contribute to the WADLS. All DoH processes are currently undergoing review in light of the Health Services Act 2016 and related health reform work. It is too early to comment what effect this will have on the HREC ToR and data linkage activities.

3: Relationships

DoH has over 20 years' experience building quality relationships with a wide range of stakeholder groups to inform the development and refinement of DLB products and services. Some of these groups include: intra- and inter-government departments, non-government organisations, legal and legislative experts, data providers, consumer groups, users of linked data, external funding agencies, HRECs and other data linkage centres. Programs of inter-agency work that have benefited from these collaborative relationships include the DoH Renal Demand Modelling Program, the Road Safety Infrastructure Project, and the Developmental Pathways Project. DoH recognises that many successful data linkage developments in WA have been the result of effective inter-sectoral partnerships.

4: Value/Impact

The impact of WA data linkage capabilities is inarguable, although no recognised metric exists that fully describes its value to all stakeholders. Academic enthusiasts of linked data often describe its value in terms of grants, awards, fellowships, publications, conference presentations, and postgraduate recruitment (and completion). DoH both supports and actively participates in these worthy metrics. Additionally, DoH routinely demonstrates the value of linked data as a vital health system management tool that promotes rapid business intelligence and practical solutions to immediate questions and challenges. Examples include analysis of: disease patterns, disease outbreaks, patient safety and quality, program evaluation, affordability, accessibility, clinical decision making, purchasing, planning, activity and performance reporting, and data quality improvement (Attachment 4). These DoH activities currently represent at least 50% (and growing) of DLB's business. DoH has grown these capabilities through: (1) dedicated recurrent funding for data linkage; (2) significant investment in information management strategies, workforce and technological platforms; and (3) development of a mature, transdisciplinary and agile in-house data analytics workforce who know how to analyse and interpret linked health data and meet DoH's time critical and multifaceted information needs. Similar investment is needed from other government departments before other agencies can realise comparable business intelligence benefits.

SECTION 2: BARRIERS AND IMPEDIMENTS TO DATA LINKAGE

Concerns about the barriers and impediments to data linkage are neither new nor unique to WA. There are five chief factors, described below.

1: Perceptions

Attachment 5 shows a range of perceptions about data linkage in WA. In-depth analysis is needed to improve understanding and problem solving. Importantly, care is needed to avoid oversimplification and a blame culture from unfairly damaging WA's data linkage reputation.

2: Roles and responsibilities

Linked data products and services are a complex endeavour involving many stakeholders. To date, the enthusiasm for linked data has often outpaced agreed and formalised understanding of roles and responsibilities, which includes the management of timelines, costs, quality, scope, risks, escalation processes and benefits. Usually, stakeholders turn to DLB to trouble-shoot issues. Lasting solutions require improved partnership, leadership, ownership, education and resourcing to ensure progress in the right direction.

3: Resourcing

It costs to have a linkage system the size and complexity of the WADLS, and 'big data' more generally. Workforce, equipment, software, and secure facilities, etc are not cost-trivial considerations. DLB receives ~\$1.2M in recurrent funding from DoH (2015/16), which is small compared with DoH's annual research investment (\$14⁺M). The lack of other sources of recurrent funding negatively affects WA's capacity to invest in data linkage infrastructure. Additionally, original funding from the National Collaborative Research Infrastructure Strategy (NCRIS) was principally geared toward enabling jurisdictions with no linkage infrastructure, which disadvantaged data linkage centres such as DLB and CHeReL. NCRIS funding also shares many limitations of other external funding sources: time-limited; confined to specific expenses and activities; and focussed on short-term goals. DoH continues to mitigate the risks of: (1) funding shortfalls and (2) cost shifting from other stakeholders, by charging partial cost recovery for linked data products and services (DLB recovered 13% of its total budget in 2015). Cost recovery is also common practice at national and international data linkage centres (e.g. CHeReL and Population Data British Columbia). A valid comparison of these charges requires a comprehensive understanding of how different data linkage centres operate (including budget, workforce, expenses, scale of the data linkage system, and range of linked data products and services).

4: Legislative barriers and informed consent

WA data linkage, and DoH data release more generally, operates within a legislatively and policy dense environment (Attachment 6) that is currently ungoverned by specific Western Australian privacy law and frequently occurs without informed consent. This gives rise to complex governance structures that seek to balance personal privacy with potential public benefit through secondary data use (e.g. research). This can cause considerable impediments to data linkage, as evidenced with cross-jurisdictional data linkage projects (Attachment 7). Changes in the legislative landscape, such as the Health Services Bill 2016, may bring some improvement, but it is currently too early to assess its impact. Establishment of a WA Privacy Act, and/or a nationally consistent privacy protection system, would be welcome enablers.

5: Complexity

Complexity is unavoidable in providing a multi-faceted data linkage service that meets the needs of many stakeholders, especially when these needs are shaped by varied agendas, competing priorities and (at times) rivalries. Data linkage involves a web of technical experts, data providers, data users, legislation, ethical considerations and organisational structures carried out under stringent conditions to protect privacy, maximise public good, and ensure public trust. Navigating this web can be difficult for the reasons mentioned in Themes 1-4 above. Complex projects, which are on the increase (Attachment 8), add further challenges and highlight there is no one-size-fits-all solution to managing complexity in this field. It also highlights the importance of having a dedicated Client Services Team with expertise to manage linked data delivery processes (Attachment 9).

SECTION 3: DATA LINKAGE SYSTEMS, INFRASTRUCTURE AND PROCESSES

1: Systems and Infrastructure

DLB systems comply with DoH's Information Management Strategy and operate alongside the IT infrastructure of the Health Support Services (HSS). Briefly, these systems (bespoke and proprietary) include the WADLS (Attachment 10), Linkage Application (DLS3), Geocoding Application, Family Connections System, CARES and Task Management System (TMS) as well as WA Health data exchange systems (e.g. MyFT). See also Section 1, Theme 1.

2: Processes

The governance, coordination and regulation of WA's health data and data linkage infrastructure is a big job. Behind the scenes is a network of policies, rules, relationships, decision-making, tools, administrative and support processes. DoH coordinates these processes effectively (within existing constraints) to benefit all stakeholders while protecting confidentiality. This may become the joint responsibility of multiple stakeholders if other WA data linkage models develop outside DoH.

In brief, DoH governance of its data, including the WADLS 'Master Links File', is consistent with the collection, access and disclosure requirements embodied in a variety of legislation, policy frameworks

and regulations (Attachment 6). The Director General of DoH delegates these data responsibilities to Data Stewards, who are assisted by Data Custodians, noting the latter are unparalleled subject matter experts in the collection, management and interpretation of Health data. All data release must be authorised by the Data Steward and/or Custodian in line with Director General approved policies. Where personal health data is used for research, it requires approval from the NHMRC accredited DoH HREC. Research conducted using DoH data must also have DoH research governance approval. Use of DLB products and services, including links from the WADLS, require authorisation by the DLB Program Manager. Data Custodians and DLB are jointly responsible for ensuring linked data requests are technically and logistically feasible, which at times includes escalation to relevant DoH Data Steward(s). DLB coordinates this activity using a draft application review process³, formerly referred to as the Expression of Interest (EOI) phase. DLB also coordinates the draft application review process on behalf of non-DOH data providers to the WADLS (upon request). Importantly, DoH respects these data providers have their own independent processes that DoH has no authority to change, prescribe, override or hasten.

SECTION 4: RECOMMENDATIONS

This submission concludes with 15 recommendations to further enhance WA data linkage capabilities.

1. Build on the considerable body of work (past, present and future) aimed at improving data linkage capabilities locally, nationally and internationally.
2. Increase and sustain investment from other government departments in inter-sectoral data linkage (including data providers, technical and analytic workforce, hardware software, secure facilities, education and training).
3. Agree on stakeholder roles and responsibilities.
4. Enact legislative enablers of data linkage (WA and nationally).
5. Understand and target barriers and impediments to effective data linkage and clarify perceptions via an agreed WA Data Linkage Communication Strategy.
6. Create an agreed strategy to inform the rate and direction of growth of WA's data linkage capabilities.
7. Establish criteria for assessing the linkage 'readiness' of data providers.
8. Via an agreed WA Data Linkage Communication Strategy, improve understanding of the similarities and differences between data linkage centres, (nationally and internationally) to inform meaningful comparisons (i.e. infrastructure, funding, workforce, quality & productivity, legislation, etc).
9. Improve public consultation and reporting on the use and impact of linked data, including views on informed consent and measurement of tangible value/benefit.
10. Improve streamlining of application and approval processes across sectors and jurisdictions.
11. Pursue innovation in linked data technologies, privacy preserving record linkage methods, anonymisation techniques, and linkage quality.
12. Investigate innovative models that expand WA's linkage infrastructure to: (i) include non-health linkages; and (ii) complement the WADLS and other Australian linkage centres.
13. Investigate secure data access environments (including governance, users, purpose and content).
14. Investigate WA and national open data access initiatives as they relate to linked personal data, with appropriate attention to public views, time, cost, quality, scope, risk and benefits.
15. Seek collaboration with other data linkage centres to achieve nationally agreed definitions for terms such as 'personal', 'sensitive' and 'health' information.

³ <http://www.datalinkage-wa.org/access-and-application/application-process/custodian-engagement-draft-application>