November 6, 2020

Office of the National Data Commissioner

Data Availability and Transparency Bill 2020: Exposure Draft Accreditation Framework: Discussion Paper

Feedback from the Linked Data Committee at the Telethon Kids Institute

This is a submission from the Telethon Kids Institute 'Linked Data Committee' which brings together professional staff and researchers from across the Institute involved in linked data projects including those representing data management, community engagement and communications. Many Committee members have extensive experience with projects involving both State and Commonwealth administrative data. The purpose of the Linked Data Committee is to provide advice, leadership, fidelity and harmonisation of Institute relationships among the many sectors engaged in creating and using administrative and linked data.

Some members of the Committee have been engaged with the ONDC process from the start including contribution to a submission for the original Productivity Commission Inquiry on Data Availability and Use. We commend the ONDC for the exceptional effort that has been put into the development of the Data Availability and Transparency Bill and its associated documents as well as the extensive consultation processes.

Overall, we would like to see that the legislation is written in a way that promotes and enables data sharing (with all the appropriate protections in place) rather than being still somewhat prohibitive in its tone. Consider the SA Public Sector (Data Sharing) Act 2016 which starts with the following: "The Act: is a law that applies to all public sector agencies, promotes the use of public sector data as a public asset, enables data-driven government to make evidence-based decisions and evaluate policy, programs and services" https://www.dpc.sa.gov.au/responsibilities/data-sharing/information-sharing-in-south-australia/sharing-public-sector-data

The following points relate broadly to the draft Bill & Explanatory Memorandum, the Accreditation Framework and the guidelines that will support and guide data sharing under the Scheme. We understand that some of these issues raised will be made clearer in guidelines to come. Whilst the accreditation process will allow data custodians to make quicker judgements about an organisation's data capability, it will not necessarily speed up a data application process and data access, especially if this involves multiple agencies. We strongly advocate for a reduction of bureaucracy around the data approval processes, where practical to do so. From our experience, data custodian concerns tend to focus on project

methodology and data items rather than broader issues of governance and data security where the credentials of the data applicants and their organisation are well known. However, this is in the context of administrative data linkage systems that are supported by strong independent ethics processes that accompany each application for data. Where these ethics processes are weaker, or non-existent, it can place more responsibility on data custodians to make decisions for which they may not be qualified or best placed to adjudicate. Please accept the following points for consideration.

1. **Accreditation focus on users**. Streamlining data sharing requires a system-wide improvement across all entities involved in the Scheme – Accredited users, Accredited data service providers (ADSPs) and data custodians. The proposed Accreditation Framework revolves around those accessing public data and not those providing it (i.e. the data custodians) unless they are wishing to access data from other Commonwealth agencies and their role shifts to that of a user. Data custodians (*Commonwealth bodies that control public service data, and have the right to deal with the data*) are automatically an entity in the scheme. At present, there is no acknowledgement of the different capabilities of Commonwealth agencies in terms of the data quality, capacity and technical expertise required for data sharing. Some are far more advanced than others. Therefore, we question whether all Commonwealth agencies who will automatically be part of the scheme as holders of public data under current definitions should also be accredited and required to meet certain standards? Otherwise, what will compel agencies to improve data quality and internal data handling and curation standards? In short, data custodians should be accredited for skills and practice in the same way data users are, so that equal standards are observed on both sides of the agreement.

   This same principle can be extended to a need for standards around decision-making about data sharing. This should not be left in the hands of individual data custodians to decide at their discretion, as this leads to inconsistent data supply and biased outcomes for data applicants. A consistent and publicly available standards framework for data custodian approval should be part of the process for all data requests. Formal and independent ethics processes (with appropriately trained panel members) can also be helpful in guiding decisions around data sharing.

2. **Community involvement and public awareness**. There is very little mention of the community in the Accreditation Framework - given this data collected is about the lives of Australian community members, this seems like an oversight that needs to be addressed. Other government agencies that have accreditation programs such as the Australian Commission on Quality and Safety in Healthcare who have developed Standards may provide some points to be considered. Ultimately it's about openness and transparency of the processes undertaken to protect people's data and privacy: https://www.safetyandquality.gov.au/standards/national-safety-and-quality-health-service-nsqhs-standards/assessment-nsqhs-standards/consumers-and-accreditation.

   The public has a right to know where their data are being kept, how it is being used and by whom. Whilst there will be publicly available registers that are accessible to the public, aiming at transparency of the scheme, we think that there is a gap in terms of stating how the public will be made aware, and the need to detail a public engagement strategy.

3. **Data sharing purposes.** The Data Sharing Agreement will require a project/program to specify data sharing purposes, and that sharing may occur for one or more of three main purposes. Data sharing purposes (subclauses (b) & (c)) may overlap if involving a partnership between a Commonwealth agency and a research organisation. This may need clarification. Clause 8. Point 25. "*Subclause (b) covers sharing for the purpose of informing policy, programs, or service delivery where those activities are conducted by, or involve, the Commonwealth government. This could support sharing between Commonwealth entities. It could also support sharing where the Commonwealth government is 'involved'*…" It is not clear if this includes research and whether universities and other academic institutions would be included here.

4. **Greater clarity around application of ethics processes**. There is a lack of clarity around when ethics processes would apply and when they would not. It is implied in some parts that this decision, including whether it would be impracticable to obtain consent may be left in the hands of data custodians. Furthermore, data integration can create datasets that are more sensitive than the individual data sources and it is usually the role of a Human Research Ethics Committee to make decisions about the sensitivity of the combined data set – this should not be the responsibility of one data custodian contributing data. Is it expected that the application of ethics would only apply if the data is shared externally but not if data is shared between Commonwealth agencies?

   Consultation Paper. 3.2 Projects must observe applicable ethics processes. *"The applicable form of ethics review will depend on the kind of project. Some projects may be reviewed by data custodians themselves, while others may require formal review by a Human Research Ethics Committee (HREC) registered with the National Health and Medical Research Council (NHMRC)."* This statement also obscures the fact that an ethics committee will not consider a project unless it has approval from the relevant data custodians – these processes go hand in hand (unless the project can be judged as being of negligible risk).

   Consultation Paper. 3.3. Consent is necessary unless it is unreasonable or impracticable to obtain. It is not clear who makes this decision. Would this be different if the sharing is for purpose (a) e.g. sharing information for pre-filling forms – where does this sit in respect to consent?

   Clause 16 Data sharing principles**.** Subclause (1)(b) Should it not be that *the question of whether it is unreasonable or impracticable to seek their consent* is always subject to ethics review i.e. subclause (1)(a)? This is more than just saying that "parties must still consider implementing other controls to protect privacy.." as stated in the explanatory memorandum (point 125).

5. **Monitoring of Requests to Data Custodians by the ONDC**. The expectation should be that data sharing will take place and that custodians need to have a good reason to deny access. It is not clear how data sharing requests to data custodians and consequent decisions will be identified, reported and monitored (especially if the decision is to reject the request). If a request is refused, is it possible that this does not fall under the Scheme because a Data Sharing Agreement was never entered into? At what point does a request for data fall under the Scheme and the regulatory remit of the Commissioner? Will there be an avenue for data requestors to go in the event that they are restricted or denied access to data?

Explanatory Memorandum. Page 10. Point 52. **Avenues for redress**. "*Data sharing decisions by data custodians will not be reviewable on their merits under this scheme. Such decisions are best made by data custodians as they have a full understanding of the risks and public interest in sharing their data*". We advocate for all such decisions to be documented and not come down to one individual. The ability to make these judgements will vary across agencies and individuals will have different capabilities in this regard, especially for a complex project involving integrated data.

Explanatory Memorandum. Page 32. Point 203. **Clause 23. No duty to share.** "This clause ensures that custodians follow due process to consider requests that appear appropriate and made in good faith, before accepting or rejecting those requests, without committing custodians to waste resources on frivolous or vexatious requests". What mechanism is there to address barriers to data sharing as perceived/experienced by custodians? We note that Clause 24 requires the Commissioner to report annually on *the number of requests received by data custodians of public sector data for sharing of data under this Act and information about the reasons for requests being agreed to or refused* – what will be the mechanism for Data Custodians to report to the Commissioner?

6. **Data sharing agreements**.
   Consultation Paper. 2.2.4 Data Sharing Agreements should be necessarily broad to include data repositories and programs of work using the same data sets as well as projects. There should also be scope to amend or extend time for an existing Agreement as is a common occurrence in research projects that are tied to funding and delayed delivery times for data.

Accreditation Framework Discussion Paper September 2020
Response to Discussion Questions:

1. **What is considered to be an appropriate level of Australian ownership for an organisation to be eligible for accreditation?**

   Don't know about Accredited Users. Perhaps ADSPs should be 100% Australian given heightened sensitivity as associated with combining data sets. From a public relations perspective this could also be a strong position.

2. **Should individuals acting on behalf of an Accredited Data Service Provider be accredited individually? If so, what might be appropriate arrangements?**

   Yes. All individuals whether in an Accredited User or an ADSP should be accredited and prove their ability to handle the data appropriately. Standards should be the same for shared accountability. This will also flow through into penalties and liability issues if there is a breach considered to be the responsibility of an individual.

3. **Are there circumstances when it should be mandatory to use an Accredited Data Service Provider for a data sharing project?**

   Yes.

4. **What would those circumstances be?**

Where data integration is required involving more than one data custodian for a project that requires de-identified data. This doesn't necessarily have to be 'complex' which is difficult to define and relative to the skills within an organisation. Accredited Users should not have access to identified data if the data is created by another agency (provided by another Data Custodian) under the Scheme, and by default, all integration should be undertaken by an ADSP? The selection of study cohorts involving more than one agency should also be undertaken by an ADSP.

5. **Are there elements of data capability that should be given more or less weight in the accreditation process, i.e. making elements mandatory or optional?**

    Yes. Major elements that serve to protect security should be mandatory (physical security and ICT controls including database management, storage and transfer protocols and protections from cyber-attacks).

6. **What elements would be most useful to Data Custodians to support their decision-making process when considering sharing and access to data?**

    The Accreditation Framework has three broad categories of accreditation criteria, none of which speak to the relationship of an organisation's relationship with the community and we think that this should be addressed. As referenced above, the Australian Commission on Quality and Safety in Healthcare have developed eight Standards of which Partnering with Consumers is one of those Standards. The ONDC might like to consider a similar approach.

7. **Should the accreditation process recognise other frameworks, standards or processes that have assessed an element of data capability? If so what standards/processes might be appropriate to recognise?**

    Yes. Recognition that an organisation has received approval from a governance office to conduct research using State-based government administrative data (e.g. the WA Department of Health Research Governance Office). Such approval is contingent on having received approval from a Human Research Ethics Committee. For individuals, having completion of ABS Datalab training should be acknowledged.

    Where the accredited users are sub-units within a large organisation such as a research institute or university department, we propose that the accreditation process recognise the common elements associated with working in the larger organisation (e.g. the governance and administrative arrangements, and organisation-wide data security), separate to the data capabilities specific to the team or sub-unit as identified. This should assist with streamlining the accreditation process as Universities and research institutes should already have the appropriate mechanisms in place to protect data storage, transfers and use.

8. **Are there any elements of data capability that should be captured in order to understand an accredited entity's ability to keep data safe?**

    No comment.

9. **What is a reasonable period of time to assess an application?**

4-6 weeks.

10. Are there further ways we can streamline the accreditation process?

As per response to Q7 which would recognise the capabilities of an organisation with sub-units.

11. Do the timeframes to renew accreditation, every 5 years for Accredited Data Service Providers and every 3 years for Accredited Users, seem reasonable?

Yes.

12. Is it appropriate to notify parties to Data Sharing Agreements of an accredited entity's suspension?

Yes.

13. Is there any information that must, or must not, be made publicly available through the registers of accredited entities?

If an accredited user is part of a larger organisation (sub-unit) then the larger organisation should be named.

14. Is there any information that should be made available to Data Custodians through the registers of accredited entities?

It may be useful for Data Custodians to have a list of current Data Sharing Agreements that the accredited entity is involved in (or make this a searchable field in the Agreements).

15. Is charging a fee for accreditation, such as a renewal fee, reasonable?

No, as ultimately sharing data is for the public good.

We hope this feedback is helpful to the ONDC.

Sincerely,

Francis Mitrou

Chair, Linked Data Committee
Telethon Kids Institute