



Consumers Health
Forum **OF** Australia

**Office of the National Data
Commissioner Data Availability
and Transparency Bill:
Exposure Draft Consultation**

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Consumers Health Forum of Australia (2020) *Submission to the Office of the National Data Commissioner Data Availability and Transparency Bill exposure draft consultation*. Canberra, Australia

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Overview

The Australian Government is committed to modernising how we use public sector data. Improving how we share and use this data, with safety, integrity and appropriate consumer protection measures, will benefit Australians through more effective government policies, programs, and service delivery, and through improved research outcomes.

The Exposure Draft of the Data Availability and Transparency Bill 2020 (the Bill) is a step towards modernising the use of data held by the Australian Government. The data reforms presented in the draft Bill are an opportunity to establish a new framework that can proactively assist in designing better services and policies. The reforms encourage our academics and the research community to innovate and find new insights from public sector data without having to go through stifling and vague bureaucratic processes when working with data custodians.

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs, including health-based research. We have over 250 members reflecting a broad spectrum of organisations including state-based consumer peaks, condition-specific groups, volunteer patient groups, professional associations, Primary Health Networks (PHNs) and the research community.

We work in collaboration with our members, national partners and research collaborators to influence policy, programs and services to ensure they are in the consumer and community interest. In developing our submission we provided our members the opportunity to input into our responses and consulted with our 'Research and Data Special Interest Group', a group of nearly two-dozen everyday consumers with an interest in health research and data.

CHF is pleased to make this submission in response to the Office of the National Data Commissioner (NDC) Data Availability and Transparency Bill (DATB) exposure draft consultation.

CHF Submission

1. Response to the Consultation Paper

CHF agree with the importance of sharing and using data in a safe and consistent way for the public good to enhance services, design policy and increase knowledge while ensuring that individual consumers are protected. We strongly support the embedding “Privacy by Design” thinking into the DATB to protect individual consumers

We also agree with data sharing specifically being optional, Data Custodians not being required to share data through this scheme or at all, and allowing for Data Custodians to use alternative arrangements to share their data if they exist.

CHF broadly agrees that both the permitted purposes of data sharing (delivery government services, informing government policy and programs, and research and development) and precluded purposes (law enforcement, compliance and assurance, national security) have been specified appropriately.

However we would advocate for a strengthening on the caveat of all permitted purposes, most likely ‘research and development’ in a practical sense, the requirement for the purpose to meet public good not be a private/commercial profit generating purposes. We have some concerns about the example provided of potentially sharing data with private sector for a benefit of ‘increased jobs’ (page 21 consultation paper). This does not seem an appropriate definition of ‘the public good’.

We note that members of the public would likely have concerns about permitting the possibility of private/commercial profit driven sharing of government collected data about the Australian public, such as the example given of creating new pharmaceutical treatments for researcher profit. We would advocate for any such private profit generating purpose to be outright prohibited unless there is a clear and direct “public good” outcome that is the primary purpose of the project e.g. developing a new vaccine. In addition where a project does lead to the generation of income or profit, there should be an accreditation requirement of sharing a significant proportion of any income generated back with the data custodian

We agree with the concept of entities “Accrediting” to participate in sharing and using data. The ability for an organisation to accredit once, be put into the system and then be able to quickly and easily access data in a safe way will have positive effects on data usage and linkage.

We presume the one entity can be accredited as both a “User” and a sharer (“ADSP”) e.g. Government agencies can be both accredited to share data collected they have collected to other Government agencies as required and access data others have used/

We support the five principles approach (Projects, People, Setting, Data and Outputs) in the DATB and believe it to be appropriate and comprehensive. Although we query about how broad ‘Project’ principle will interpreted. It is not clear if it will need to be specific or if it can be

more general e.g. if a consumer updates their address details with one Government department that is shared to all departments (with their consent)

The scope of regulatory enforcement options seems potentially appropriate and comprehensive, but we feel further details on what the range of listed penalties are and the different circumstances that would lead to them being actioned is necessary. It is also unclear to us what, if any, public reporting of penalties being issued and explanation for those penalties is required under the proposed Bill.

We have some concerns whether as a regulator the NDC will be appropriately funded and resourced to effectively monitor and enforce the regulations, given the chronic underfunding issues in other Government regulatory agencies. Whilst the Bill does not explicitly discuss resourcing, we think there should be some mention of the need for this to be adequate to allow the NDC to fulfill this function.

We strongly support a Public Register of accredited users, accredited providers and data sharing agreements. Although we would like some clarify about the timeframes with which this information is required to be added to the Public Register and how quickly changes in detail will be reflected. In addition clarity around whether the Public Register will contain 'records of intention', for example, the intention for a new entity to accredit or the intention for a new data sharing agreement to be created between entities, to allow for the community to express support or opposition for the proposed new item before any data sharing commences.

We are equally supportive of the NDC producing an Annual Report about what data has been shared, what purposes has been shared for, systematic issues that have arisen, providing further guidance etc. Although we would advocate expanding the annual report to also include detailing the outputs that result from DATB sharing as well as breaches that occurred and penalties that were issued.

We believe the proposed National Data Advisory Council (NDAC) to provide advice to NDC is well designed, with a good range of views to be accounted for. Although we would like further clarity at how public the actions, advice, meeting minutes etc of the NDAC will be.

We agree that a three-year review after commencement of the DATB seem appropriate, however would argue that 10 years periodically after that is too long of a gap given expected speed of data usage and changes. We would suggest 5-year intervals commencing after the initial three-year review.

We also note some confusion about the function of a report 'tabled in parliament' every 10 years by the Minister and what avenues of review that provides in addition to the NDC Annual Reports. Can Parliament debate or reject these reports if they are unsatisfied with the contents? Additional clarity in this area would be appreciated.

We agree with the position article on page 21 of the Consultation Paper that "the public interest is served by good public policy developed by effective institutions in line with community expectation and norms".

We also agree with the requirement for formal ethical consideration processes to occur before data sharing for a project commences, with clear links to both NHMRC Guidance and to be developed ONDC Guidance ideal. Noting that does not mean a formal HREC must be involved but that ethical considerations being factored into DATB project must be clearly factored in.

We note that getting consumer consent for the sharing of this data is key to this system being successful and accepted by the community. We would recommend that consumers should be given the maximum flexibility of options to consent to “pre-consent” to sharing some or all of their data, for some or all purposes, by some or all users at the time of collection (i.e. by the Data Custodian/Providers). Additionally, they should be given the ability to consent to share historical data, current data and prospective data. They should also be given the ability to review and change their consent arrangements in a timeframe/cycle nominated by themselves. We generally disagree with the notion that it is not feasible to get consent in some situations or that in some circumstances consent should not be sought as it may risk consumers denying consent and thus lowering the quality/value of the data and outputs.

Interested to learn how the DATB will interact with the Consumer Data Right

A consumer/public awareness campaign is good idea, but we note the need to not only produce material in plain-English but also in other languages given the multicultural background of the Australian population. As well as a broad range of health literacy levels and communication formats e.g. written, visual, audio, online, physical etc

We are pleased to note the ODNC agreeing or agreeing-in-principle to all of the PIA Recommendations provided in Appendix A.

2. Data Availability and Transparency Bill 2020 Feedback

CHF notes that we are not an expert on legal matters and as such some of our queries and suggestions may stem from a lack of technical expertise.

We note that legislation is difficult to parse by its nature and some plain language guidance to provide clarity on what the compliance/regulatory acts and penalties are and who they apply to and why would be beneficial.

For example, Chapter 2 paragraph 14 refers to penalties to a ‘person’, rather than an ‘entity’ as expressed in other sections of the draft Bill. It is unclear to us why the penalties discussed in this paragraph would only apply to individuals and not potentially levied against organisations or other groups captured in the definition of “entity”.

In regards to the specific penalties noted both in Chapter 2 and elsewhere, Civil penalties of 300 units (~\$66,000) and criminal penalties of either 12 months or 2 years imprisonment (if ‘reckless’), it is not clear how these penalties were determined and how they compare to other comparable penalties for appropriateness. Or how ‘reckless’ is determined.

Additionally, it is unclear if these penalties are exact amounts, maximum amounts or minimum amounts. Given the nature of data that will be covered by the DATB there are

possible breaches were such penalties may potentially be grossly excessive but equally there are possible breaches where they are grossly inadequate. It is also unclear how these penalties may compound in the event of multiple breaches of similar or differing types- if an entity for example inappropriately accessed data multiple times and inappropriately shared data multiple times would they receive 1 penalty overall, one access penalty and one sharing penalty or a penalty for each individual offense committed.

By our reading of the legislation we note with some concern there appears to be no requirement for consumers to be notified about breaches that occur and penalties that occur, both in regards to general public awareness but specifically for those consumers whose data was involved or potentially in breaches.

We would advocate for Part 4.3, Paragraph 60 to include 'community expectations' inserted as an explicit criteria and function of the NSAC advisory areas.

We have some concerns that as written Part 5.2 Paragraph 73(5) may imply an accredited entity can still function as if accredited i.e. collect and use data, even while accreditation has been suspended, which would be in conflict with paragraph 13(3)b

We would advocate for Part 6.5 paragraph 124 to be modified to include in the annual report information about any accreditation suspension, cancellations, data breaches and regulatory actions/penalties that occurred in the 12-month period of the report.

3. Data Availability and Transparency Bill (Consequential Amendments) 2020 Feedback

We have no specific feedback/response as, the amendments to other legislation are minor and appropriate

CHF has no specific feedback or response to note in regards the DATB (Consequential Amendments) 2020. The details of the proposed amendments appear to be appropriate.

4. Data Availability and Transparency Regulations 2020 Feedback

CHF has no specific feedback or response to note in regards the DATB Regulations 2020. The details of the proposed Regulations appear to be appropriate.

5. Response to the Privacy Impact Assessment (PIA)

Broadly we agree with all 13 recommendations provided in the PIA and are pleased that the ONDC Agrees to 11 and Agrees-in-Principle to the remaining 2.

We agree with the discussed idea (page 28) that the DATB Objects should have some explicit mention of privacy protections, such as “ensuring privacy is protected when data is shared”. We have some concerns excluding privacy protections at this level and relying on other mechanisms may result in a non-holistic approach.

We also agree that current legislative framework around ensuring Data Minimisation happens is not sufficient (page 33-34) and explicit efforts must be taken by the ONDC to making data minimisation occurs.

We agree with the noted discussion around nuance of deidentification of data and limitations of deidentification process (page 48-49). Though deidentifying data is an essential part of protecting consumers information and privacy, it is not by itself a sufficient protection for consumers so additional safeguards are required. We would note that of the three permitted purposes, only the first (“delivery of government services”) should likely have a need for deidentified data to not be the default data type shared. While the other two purposes would need exceptionally strong project specific reasoning to share non-deidentified data.

On the Outputs Principle (page 49-50), we would recommend the adding of requirement that any outputs emerging from DATB shared data must contribute to the public good and remain in public hands through either ownership (or co-ownership) by public agencies, be released into the public domain or both. For example, the publication of an output in a non-open access academic journal should not be permitted.

We agree with the noted concern that positioning the NDC within PM&C rather than as an independent entity will affect the perception of it as an independent entity and possibly its actual independence (page 61). Especially in the context of recent scandals such as “Sports Rorts”, “Water Buybacks” and the Western Sydney Airport land purchase. We equally agree that there are potential risks around adequate resourcing due to not being independent that could impact the ability of the NDC to function independently and effectively.

CHF also agrees with the need to run a public awareness campaign but notes that providing plain-English materials while critical is not sufficient by itself to ensuring that the broad multicultural population of Australia is able to be effectively engaged. Producing materials in other languages spoken in Australia is essential, as is producing materials that target different levels of health literacy and use different formats of communication.

6. Accreditation Framework Discussion Paper Comments and Responses

CHF has no specific overall feedback or response to note in regards the Accreditation Framework. The details of the proposed accreditation system appear to be appropriate and comprehensive in principle, but we note that pending release of the various Instruments (Rules, Guidelines etc) set by the Minister and NDC that view may change depending on the details.

In response to the specific questions posed in the Discussion Paper:

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

We would recommend to be eligible for accreditation the organisation would not need to be owned by Australians but would need to be legally based, incorporated and operated within Australia.

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

We agree that Individuals should be accredited in relation to an organisation, whether an ADSP or a Data Custodian or Accredited User, but also recognise that having the capacity to capture and record individual accreditation to ease the transfer of individuals between different accredited organisations would be beneficial.

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

No comment.

4. What would those circumstances be?

Whenever an organisations wishes to access and use Government collected data, provided the Agency does not have its own arrangements for data sharing (e.g. the ABS MADIP) then we presume going via the DATB process would be mandatory and thus require using an ADSP. We are unsure what alternative pathways exist that would require mandating the use of an ADSP.

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

Potentially but CHF is not ideally positioned to assess the relative value of the proposed data capability elements. One element that does not appear to be included but we would advocate should be is the history of the organisation and key individuals within the organisation in regard to issues of appropriate use and handling of data.

As a non-data capability element that should be considered, the capacity structures and processes with the organisation to effectively engage with the public and ensure their intended/potential uses of the data are aligned with community expectations and meet public good criteria.

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

No comment

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?

We are not aware of specific frameworks, standards or processes that the Accreditation process should recognise but agree in principle aligning with any appropriate ones that exist would be worth considering.

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?

30 calendar days for the initial assessment, with additional time allocated based on any further information the NDC requires from the applicant.

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

No comment

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, presuming there is capacity for the NDC to call for earlier accreditation if they believe circumstances require it.

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

Yes. We would expect it is not only appropriate but should be required.

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

No. None of the information listed as being required to provide for accreditation would be inappropriate for provision in a public register. Conversely all of the listed information should be made public in the registers to allow for community assurance that all parties are acting appropriately.

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

No additional information beyond items noted in response to Q4.

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

We would in-principle argue against any accreditation fees and believe that the system should be appropriately funded and resourced by the Government. This could be especially in the early stages of adopting the system where additional fees may prove a barrier for necessary and interested parties to engage in the process and reduce the success of the system, in particular potential ADSPs.

