DATA AVAILABILITY AND USE

RESPONSE TO THE DRAFT REPORT

December 2016

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ABOUT RESEARCH AUSTRALIA

Research Australia is an alliance of 160 members and supporters advocating for health and medical research in Australia. Research Australia's activities are funded by its members, donors and supporters from leading research organisations, academic institutions, philanthropy, community special interest groups, peak industry bodies, biotechnology and pharmaceutical companies, small businesses and corporate Australia. It reflects the views of its diverse membership and represents the interests of the broader community.

Research Australia's mission is to make health and medical research a higher priority for the nation. We have four goals that support this mission:

- A society that is well informed and values the benefits of health and medical research.
- Greater investment in health and medical research from all sources.
- Ensure Australia captures the benefits of health and medical research.
- Promote Australia's global position in health and medical research.

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DATA AVAILABILITY AND USE

RESPONSE TO THE DRAFT REPORT

Summary of Recommendations

Research Australia supports many of the Draft Reports recommendations. Where we have provided substantive comments these are summarised in the table.

Recommendation	Research Australia response
Draft Recommendation 3.2 *Publicly funded entities, including the Australian Research Council, should publish up-to-date registers of data holdings, including metadata, that they fund or hold.* *Publication of summary descriptions of datasets held by funded researchers but not released, and an explanation of why these datasets are not available, are also essential and would provide far greater transparency about what is being funded by taxpayers but withheld*.	Research Australia supports this recommendation, and welcomes the Productivity Commission's recognition that the presumption in favour of the release of data needs to be balanced against several other factors including the initiating researcher's priority in publishing research findings, commercialisation considerations, restrictions imposed by legislation and ethics approval, privacy and confidentiality, and the capacity to provide access through secure sharing environments. Research Australia submits rules and protocols will need to be developed by funding bodies, e.g. the NHMRC and ARC, in conjunction with researchers to ensure a balance is struck between the interests of the instigating researchers, the research subjects and the broader research and public communities.
Draft Recommendation 5.2 *The Privacy Act 1988 (Cth) exceptions that allow access to identifiable information for the purposes of HMR without seeking individuals' agreement, should be expanded to apply to all research that is determined to be in the public interest.* *The Office of the Australian Information Commissioner should develop and publish guidance on the inputs required to establish a public interest case.*	In relation to establishing a public interest case, Research Australia submits that if the research has been funded by the ARC or NHMRC and/or has received approval from an approved Human Research Ethics Committee, this should be sufficient to establish that the research is in the public interest.

Draft Recommendation 5.4 *To streamline approval processes for data access, the Australian Government should:* - *issue clear guidance to data custodians on their rights and responsibilities, ensuring that requests for data access are dealt with in a timely and efficient manner;* - *require that data custodians report annually on their handling of requests for data access;* - *prioritise funding to academic institutions that implement mutual recognition of approvals issued by accredited human research ethics committees.*	In relation to prioritising funding applications to academic institutions that implement mutual recognition of HREC approvals, existing funding processes are directed to funding the best research based on research excellence, track record and capability, need etc. The processes are already time consuming and complex and the subject of concerted efforts to reduce the time and effort involved in both making and assessing applications. **Research Australia submits this process should not be further burdened with another assessment criterion, particularly one which is not aligned to the merits of the research proposal.**
Draft Recommendation 7.2 *The pricing of public sector datasets to the research community for public interest purposes should be the subject of an independent review.*	Research Australia supports this recommendation. In the case of publicly funded research, broadly the alternatives are that the cost of preparing and providing public datasets is borne by the research sector or the agencies. In either case, the cost will need to be recognised and will ultimately be funded by the Australian, state or territory governments. As with all pricing structures, there is the scope for incentives, disincentives and inefficiencies. Research Austrlaia submits that while allowing agencies to charge for access to data may provide an incentive for data custodians to do so, the simpler and more efficient model is for the agency to carry the cost. Research Australia submits that where there is a cost to researchers for access to data this cost needs to be transparent and known in advance so that the cost can be included in funding applications.
Draft Recommendation 7.3 *Minimally processed public sector datasets should be made freely available or priced at marginal cost of release.* *Where there is a demand and public interest rationale for value-added datasets, agencies should adopt a cost recovery pricing approach. Further, they should experiment with lower prices to gauge the price sensitivity of demand, with a view to sustaining lower*	Research Australia supports this recommendation. In particular, where datasets are created once but subsequently re-used, making the dataset available to the initial and subsequent researchers free of charge addresses issues of equity and the sense of 'ownership' a researcher might have over a dataset. Some of the questions this avoids include: If researcher A paid for the creation of the dataset, why should researcher B have free access? Should

prices if demand proves to be reasonably price sensitive.	researcher B contribute to help A recoup their initial outlay?
Draft Recommendation 9.1 *…The definition of 'consumer data' should be provided as part of a new Act regarding data sharing and release (Draft Recommendation 9.11). Given the need for this definition to have broad applicability, it should also be included within the Acts Interpretation Act 1901 (Cth). Consequential amendments to other Commonwealth legislation would ensure harmonisation across federal laws.*	Notwithstanding the reference in the recommendation to 'personal information as defined in the *Privacy Act 1988 (Cth)*' it is not clear if the Commission intends the definition of 'consumer' to apply in all the circumstances in which health information (and other data relevant to HMR) is provided. In some contexts, particularly where a health service is provided by a private sector health provider, the individual may readily be characterised as a 'consumer'. In other contexts e.g. admission to an emergency department following a motor accident or as the subject of a notifiable disease notification, characterisation as a consumer seems less intuitive. Nonetheless, the same principle that an individual should not have control over information to which they can no longer be linked remains relevant. Research Australia submits that the same principle applied to 'consumer data' should extend to health information collected from individuals, and to data collected by other government departments and agencies.

Introduction

Research Australia welcomes the opportunity to respond to the *Data Availability and Use* Draft Report. This submission supplements the submission made by Research Australia in response to the Issues Paper in July.

Many public-sector datasets are an underutilised national resource, and that the failure to make these datasets available to researchers prevents the full economic value of these datasets from being realised. In the case of health and medical research (HMR), the economic benefits from the better use of datasets are threefold:

- more efficient and cost effective research (much of which is funded by the Commonwealth, state and territory governments)
- greater efficiencies in the delivery of health care (again, much of which is funded by the Commonwealth, state and territory governments)
- the development of new and profitable health products and services.

Research Australia agrees with the Commission that the entire regulatory framework relating to the collection and use of data needs to be reformed and supports the active management of the risks associated with the release of data as an alternative to the default position of not allowing access. Such a risk management approach requires not only an understanding of the risks but an appreciation of the benefits that can be realised from the greater use of data for individuals and the broader community.

The Commission's conclusion that trust and transparency are critical is also supported. In the case of HMR, researchers are often asking people to share their information for research purposes where it seems there is no direct benefit to the individual, relying on their willingness to support the greater good. Thus, trust that the researchers will use their data responsibly and ethically, is essential to this social contract.

Research Australia acknowledges that giving individuals greater access to, and control over their data can be important to trust and transparency. The question of who owns and controls data is important, but the greater rights of individuals should not extend to deidentified data. There needs to be a recognition that when data ceases to identify an individual or can be traced back to an identifiable individual, it ceases to be about them or to be 'their' data. The Commission has effectively reflected this view in the discussion of the concept of consumer data and its recommendations.

Research Australia also recognises that many existing databases and platforms may be ill suited to the new framework envisaged by this report. Extracting information from them in the most useful and cost efficient way must of course be the priority, however attempting to rebuild or rescope some systems to fit the future, often at great cost, should be avoided. The approach should be to build for the future, identifying and defining the requirements of what best practice, should look like with a long term national plan to support this key infrastructure.

In the following pages we have responded to many of the Commission's recommendations. Overall we are supportive of the approach taken by the Commission.

Response to the Report's Recommendations

Draft Recommendation 3.1

All Australian Government agencies should create comprehensive, easy to access data registers (listing both data that is available and that which is not) by 1 October 2017 and publish these registers on data.gov.au.

States and territories should create an equivalent model where one does not exist and in all cases should make registers comprehensive. These should in turn be linked to data.gov.au.

The central agencies responsible for data should:

- *set measurable objectives, consistent with best practice, for ensuring that available data and metadata are catalogued and searchable, in a machine-readable format*
- *improve accessibility of data for potential data users.*

Limited exceptions for high sensitivity datasets should apply. Where they do, a notice indicating certain unspecified datasets that have been assessed as Not Available should be published by the responsible department of state, on the relevant registry.

Research Australia supports this recommendation. Research Australia recognises the importance of including datasets held by states and territories in the Productivity Commission's findings and recommendations; the linking of Commonwealth, state and territory datasets has the greatest potential to support new discoveries in HMR and to improve the safety, quality and efficiency of health care.

Draft Recommendation 3.2

Publicly funded entities, including the Australian Research Council, should publish up-to-date registers of data holdings, including metadata, that they fund or hold.

Publication of summary descriptions of datasets held by funded researchers but not released, and an explanation of why these datasets are not available, are also essential and would provide far greater transparency about what is being funded by taxpayers but withheld.

Research Australia supports this recommendation, and welcomes the Productivity Commission's recognition that the presumption in favour of the release of data needs to be balanced against several other factors including the initiating researcher's priority in publishing research findings, commercialisation considerations, restrictions imposed by legislation and ethics approval, privacy and confidentiality, and the capacity to provide access through secure sharing environments.

Research Australia submits rules and protocols will need to be developed by funding bodies, e.g. the NHMRC and ARC, in conjunction with researchers to ensure a balance is struck between the interests of the instigating researchers, the research subjects and the broader research and public communities.

Draft Recommendation 4.1

The Australian Government should adopt a minimum target for voluntary participation in Comprehensive Credit Reporting of 40% of accounts. If this target is not achieved by 30 June 2017, the Government should circulate draft legislation to impose mandatory reporting by 31 December 2017.

Research Australia makes no comment on this recommendation.

Draft Recommendation 4.2

All Australian governments entering into contracts with the private sector, which involve the creation of datasets in the course of delivering public services, should assess the strategic significance and public interest value of the data prior to contracting. Where data is assessed to be valuable, governments should retain the right to access or purchase that data in machine readable form and apply any analysis that is within the public interest.

Research Australia makes no comment on this recommendation.

Draft Recommendation 5.1

In conjunction with the Australian Bureau of Statistics and other agencies with data de-identification expertise, the Office of the Australian Information Commissioner should develop and publish practical guidance on best practice de-identification processes.

To increase confidence in data de-identification, the Office of the Australian Information Commissioner should be afforded the power to certify, at its discretion, when entities are using best practice de-identification processes.

Research Australia supports this recommendation. Research Australia agrees with the Commission's conclusion that many data custodians are reluctant to exercise the discretion provided to them to release de-identified data for fear of data being re-identified at some later stage or an error occurring which could lead to the release of identified data. Providing guidance on best practice de-identification processes which agencies could use (and also rely on as evidence of due diligence in the event of a disclosure) should help encourage data custodians to provide de-identified datasets for research purposes.

This is also part of a broader cultural change within the system at all levels to normalise and encourage the sharing of data.

Draft Recommendation 5.2

The Privacy Act 1988 (Cth) exceptions that allow access to identifiable information for the purposes of HMR without seeking individuals' agreement, should be expanded to apply to all research that is determined to be in the public interest.

The Office of the Australian Information Commissioner should develop and publish guidance on the inputs required to establish a public interest case.

Research Australia supports this recommendation. The understanding of what is important to health and wellbeing is constantly expanding; the impact of gender, income, physical location, social support and cultural background are all now recognised. Disciplines in the social sciences are important contributors to this research and expanding access to identifiable information to all research can help eliminate potential arguments about what is, and is not, research for HMR.

In relation to establishing a public interest case, **Research Australia submits that if the research has been funded by the ARC or NHMRC and/or has received approval from an approved Human Research Ethics Committee, this should be sufficient to establish that the research is in the public interest.** The National Statement on the Ethical Conduct of Human Research, which guides human research and the assessment of research proposals by Human Research Ethics Committees, has a as its first requirement that the research has merit.

> *'Research that has merit is: justifiable by its potential benefit, which may include its contribution to knowledge and understanding, to improved social welfare and individual wellbeing, and to the skill and expertise of researchers…'*[1]

Research Australia would be pleased to work with the Commission further on developing the public interest definition for the final report.

Draft Recommendation 5.3

The Australian Government should abolish its requirement to destroy linked datasets and statistical linkage keys at the completion of researchers' data integration projects.

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[1] National Statement on Ethical Conduct in Human Research 2007 (Updated May 2013). The National HMR Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. Commonwealth of Australia, Canberra. P.12

Data custodians should use a risk-based approach to determine how to enable ongoing use of linked datasets. The value added to original datasets by researchers should be retained and available to other dataset users.

Research Australia supports this recommendation. The destruction of linked datasets is a very blunt tool to ensure privacy and security, and one which comes with a high price in terms of the cost, time and inconvenience associated with recreating datasets in response to subsequent requests for access to the same data.

There is an expectation that the investment of tax payer funds would ensure a maximum return of the investment. The destruction of information that has potential for re-use is an anathema to this expectation.

Draft Recommendation 5.4

To streamline approval processes for data access, the Australian Government should:

- *issue clear guidance to data custodians on their rights and responsibilities, ensuring that requests for data access are dealt with in a timely and efficient manner;*
- *require that data custodians report annually on their handling of requests for data access;*
- *prioritise funding to academic institutions that implement mutual recognition of approvals issued by accredited human research ethics committees.*

State and territory governments should mirror these approaches to enable use of data for jurisdictional comparisons and cross-jurisdiction research.

Research Australia supports this recommendation in relation to issuing guidance to data custodians and requiring that they report annually on their handling of requests for data access.

In relation to prioritising funding applications to academic institutions that implement mutual recognition of HREC approvals, existing funding processes are directed to funding the best research based on research excellence, track record and capability, need etc. The processes are already time consuming and complex and the subject of concerted efforts to reduce the time and effort involved in both making and assessing applications. **Research Australia submits this process should not be further burdened with another assessment criterion, particularly one which is not aligned to the merits of the research proposal.**

This recommendation could have unintended consequences, including further complicating data access requests and grant approval processes, and discouraging collaboration between researchers from different institutions (with different mutual acceptance arrangements) and with health providers (which may not be party to mutual acceptance arrangements). Research Australia submits that institutions' mutual recognition of HREC approvals should not be a criterion for government funding of research applications at this time. The Commission notes in its report that there is already significant work underway in relation to mutual recognition of HREC approvals (although progress has been slow). While supportive of mutual recognition, Research Australia submits that the NHMRC should be allowed to continue to progress this issue.

Draft Recommendation 5.5

In light of the Australian Government's commitment to open data, additional qualified entities should be accredited to undertake data linkage.

State-based data linkage units should be able to apply for accreditation by the National Data Custodian (Draft Recommendation 9.5) to allow them to link Australian Government data, and the intention of 'open by default' should apply to these exchanges.

Research Australia supports this recommendation. More agencies authorised to link Commonwealth, state and territory based datasets would be a significant benefit; ideally any accredited Commonwealth, state or territory agency should be able to undertake data linkage across multiple jurisdictions.

Draft Recommendation 6.1

Government agencies should adopt and implement data management standards to support increased data availability and use as part of their implementation of the Australian Government's Public Data Policy Statement.

These standards should:

- *be published on agency websites*
- *be adopted in consultation with data users and draw on existing standards where feasible*
- *recognise sector-specific differences in data collection and use*
- *support the sharing of data across Australian governments and agencies*
- *enable all digitally collected data and metadata to be available in commonly used machine readable formats (that are relevant to the function or field in which the data was collected or will likely be most commonly used), including where relevant and authorised, for machine to machine interaction.*

Policy documents outlining the standards and how they will be implemented should be available in draft form for consultation by the end of 2017, with standards implemented by the end of 2020.

Agencies that do not adopt agreed sector-specific standards would be noted as not fully implementing the Australian Government's Public Data Policy and would be required to work under a nominated Accredited Release Authority (Draft Recommendation 9.6) to improve the quality of their data holdings.

Research Australia supports this recommendation.

Draft Recommendation 6.2

The private sector is likely to be best placed to determine sector-specific standards for its data sharing between firms, where required by reforms proposed under the new data Framework.

In the event that voluntary approaches to determining standards and data quality do not emerge or adequately enable data access and transfer (including where sought by consumers), governments should facilitate this, when deemed to be in the public interest to do so.

Research Australia makes no comment on this recommendation.

Draft Recommendation 2.1

In determining datasets for public release, a central government agency with policy responsibility for data should maintain a system whereby all Australian governments' agencies, researchers and the private sector can, on an ongoing basis, nominate datasets or combinations of datasets for public release, with the initial priority being the release of high value, in-demand datasets.

A list of requested datasets should be published. Decisions regarding dataset release or otherwise, and access arrangements, should be transparent. Agencies should provide explanations where priority datasets are not subsequently released on legitimate grounds. Where there are not legitimate reasons for withholding requested data, remedial action should be undertaken by the Australian Government's central data agency to assist agencies to satisfy data requests.

Existing government data initiatives, such as data.gov.au, should be leveraged as part of this system.

Research Australia supports this recommendation.

Draft Recommendation 7.1

Beyond achieving a 'fit for release' standard (Draft Recommendation 6.1), government agencies should only value add to data if there is an identified public interest purpose for the agency to undertake additional value adding, or:

- *the agency can perform the value adding more efficiently than either any private sector entities or end users of the data; and*
- *users have a demonstrable willingness to pay for the value added product; and*
- *the agency has the capability and capacity in-house or under existing contract; and*
- *the information technology upgrade risk is assessed and found to be small.*

Research Australia supports this recommendation.

Draft Recommendation 7.2

The pricing of public sector datasets to the research community for public interest purposes should be the subject of an independent review.

Research Australia supports this recommendation. In the case of publicly funded research, broadly the alternatives are that the cost of preparing and providing public datasets is borne by the research sector or the agencies. In either case, the cost will need to be recognised and will ultimately be funded by the Australian, state or territory governments. As with all pricing structures, there is the scope for incentives, disincentives and inefficiencies. Research Australia submits that while allowing agencies to charge for access to data may provide an incentive for data custodians to do so, the simpler and more efficient model is for the agency to carry the cost.

Research Australia submits where there is a cost to researchers for access to data this cost needs to be transparent and known in advance so that the cost can be included in funding applications.

Draft Recommendation 7.3

Minimally processed public sector datasets should be made freely available or priced at marginal cost of release.

Where there is a demand and public interest rationale for value-added datasets, agencies should adopt a cost recovery pricing approach. Further, they should experiment with lower prices to gauge the price sensitivity of demand, with a view to sustaining lower prices if demand proves to be reasonably price sensitive.

Research Australia supports this recommendation. In particular, where datasets are created once but subsequently re-used, making the dataset available to the initial and subsequent researchers free of charge addresses issues of equity and the sense of ‘ownership’ a researcher might have over a dataset. Some of the questions this avoids include:

If researcher A paid for the creation of the dataset, why should researcher B have free access? Should researcher B contribute to help A recoup their initial outlay?

Draft Recommendation 7.4

For datasets determined through the central data agency’s public request process (Draft Recommendation 2.1) to be of high value and have a strong public interest case for their release, agencies should be funded for this purpose. Funding should be limited and supplemental in nature, payable only in the event that agencies make the datasets available through release or sharing.

Aside from this additional funding, normal budgetary processes should apply for all agencies’ activities related to their data holdings.

Research Australia supports this recommendation. The provision of data for research purposes by agencies should be part of their core business, and a reflection of the obligation they have to the individuals whose data has been collected and to the broader public to ensure that the community receives the greatest possible return on the investment it makes in the collection and storage of this data.

Draft Recommendation 9.1

The Australian Government should introduce a definition of consumer data that includes:

- *personal information, as defined in the Privacy Act 1988 (Cth)*
- *all files posted online by the consumer*
- *all data derived from consumers' online transactions or Internet-connected activity*
- *other data associated with transactions or activity that is relevant to the transfer of data to a nominated third party.*

Data that is transformed to a significant extent, such that it is demonstrably not able to be re-identified as being related to an individual, should not, for the purposes of defining and implementing any Comprehensive Right, be defined as consumer data.

The definition of 'consumer data' should be provided as part of a new Act regarding data sharing and release (Draft Recommendation 9.11). Given the need for this definition to have broad applicability, it should also be included within the Acts Interpretation Act 1901 (Cth). Consequential amendments to other Commonwealth legislation would ensure harmonisation across federal laws.

Research Australia acknowledges that giving individuals greater access to and control over their data can be important to trust and transparency. The question of who owns and controls data is important, but the greater rights of individuals should not extend to deidentified data. There needs to be a recognition that when data ceases to identify an individual or be traced back to an identifiable individual,it ceases to be about them or to be 'their' data. The Commission has captured this in the above recommendation and expanded on this in the Draft Report's discussion of the concept of consumer data.

> *'The desired outcome from defining consumer data should be that if the data point was received from an individual and subsequently remains substantially unaltered such that it is able to be linked within the systems of the firm back to that individual then it is consumer data. This approach would nevertheless allow entities who transform data and hold it in a way that does not identify or link back to an individual to continue to do so without impeding innovations that may flow from that. To apply more broadly than the Privacy Act, any new concept would need to be defined in existing legislation that has a broad coverage, as well as any new data-specific legislation.' P. 303*

This approach of allowing entities to continue to hold data when it has been transformed in such a way that it can no longer be linked back to an individual, is equally applicable to individuals' health information. Notwithstanding the reference in the recommendation to 'personal information as defined in the *Privacy Act 1988 (Cth)*' it is not clear if the Commission intends the definition of 'consumer' to apply in all the circumstances in which health information (and other data relevant to HMR) is provided. In some contexts, particularly where a health service is provided by a private sector health provider, the individual may readily be characterised as a 'consumer'. In other contexts e.g. admission to an emergency department following a motor accident or as the subject of a notifiable disease notification, characterisation as a consumer seems less intuitive. Nonetheless, the same principle that an individual should not have control over information to which they can no longer be linked remains relevant.

Research Australia submits that the same principle applied to 'consumer data' should extend to health information collected from individuals, and to data collected by other government departments and agencies.

Draft Recommendation 9.2

Individuals should have a Comprehensive Right to access digitally held data about themselves. This access right would give the individual a right to:

- *continuing shared access with the data holder*

- *access the data provided directly by the individual, collected in the course of other actions (and including administrative datasets), or created by others, for example through re-identification*
- *request edits or corrections for reasons of accuracy*
- *be informed about the intention to disclose or sell data about them to third parties*
- *appeal automated decisions*
- *direct data holders to copy data in machine-readable form, either to the individual or to a nominated third party.*

Individuals should also have the right, at any time, to opt out of a data collection process, subject to a number of exceptions. Exceptions would include data collected or used as:

- *a condition of continued delivery of a product or service to the individual*
- *necessary to satisfy legal obligations or legal claims*
- *necessary for a specific public interest purpose (including archival)*
- *part of a National Interest Dataset (as defined in Draft Recommendation 9.4).*

The right to cease collection would not give individuals the capacity to prevent use of data collected on the individual up to the point of such cessation.

Research Australia supports this recommendation.

Draft Recommendation 9.3

The Australian Government should provide for broad oversight and complaints handling functions within a reformed framework for individual data access. Key roles should be accorded to the Australian Competition and Consumer Commission (ACCC) the Office of the Australian Information Commissioner (OAIC), and to existing industry ombudsmen.

Any charging regimes, policies or practices introduced to address costs associated with data access, editing or transferability should be transparent and reasonable. The ACCC should be responsible for monitoring and assessing the reasonableness of charges applied. The ACCC, supported by state and territory Fair Trading Offices, should also educate and advise consumers on their new rights in regard to data access and collection.

For specified datasets (such as in banking) the relevant ombudsman scheme would need to be expanded to deal with disputes.

Research Australia makes no comment on this recommendation.

Draft Recommendation 9.4

The Australian Government, in consultation with state and territory governments, should establish a process whereby public and private datasets are able to be nominated and designated as National Interest Datasets (NIDs).

Datasets (across the public and private sector) designated as NIDs would satisfy an underlying public interest test and their release would be likely to generate significant community-wide net benefits. Designation would occur via a disallowable instrument on the recommendation of the National Data Custodian.

NIDs that contain non-sensitive data should be immediately released. Those NIDs that include data on individuals would be available initially only to trusted users and in a manner that retains the privacy of individuals and/or the confidentiality of individual businesses. The in-principle aim should be for these de-identified datasets to be publicly released in time.

The process to designate datasets as being of national interest should be open to the states and territories in order to cover linked datasets, with negotiations undertaken to achieve this.

For community confidence, consideration should be given to use of a deliberative forum, such as a parliamentary committee, to take community input on and review nominations made, and to make proposals for future designations.

Research Australia supports this recommendation in relation to the identification of National Interest Datasets.

INFORMATION REQUEST

The Commission seeks further views on datasets that are of national interest and that could feasibly be designated as such under the process proposed.

In response to the request from the Commission for input on the identification of NIDs, Research Australia refers to the characteristics identified in our earlier submission to the Inquiry and our response in relation to high value public sector data, which is effectively the same as NIDs:

High value data for the research sector is held in datasets that contain information about individuals' health and other characteristics.

At the Commonwealth Government level this includes: Pharmaceutical Benefits Scheme (PBS), Medical Benefits Scheme (MBS), Social Security and Veterans Affairs records, and more specific registers such as the Australian Childhood Immunisation Register. With the move to an opt-out model the My Health Record will also become an increasingly valuable dataset.

Within the jurisdiction of the Australian states and territories relevant datasets includes hospital admission records, Maternal and Child Health records, registers of births & deaths, primary care records where delivered by state agencies, educational attainment and school data, child protection, criminal convictions, and prison population data.

The private sector (both not for profit and for profit) also play a significant role in the delivery of healthcare in Australia. Relevant datasets from this sector include primary care data, hospital admission records, and data on childcare and aged care.

What characteristics define high-value datasets?

High value datasets are generally characterised by large volumes of reliable data on a large or complete population collected over an extended period. Sufficient and appropriate information to support reliable linkage with other datasets either through deterministic or probabilistic methods is also of value.

High value datasets should be collected and stored in a manner which enables the use and linkage of de-identified data for research purposes. Research should be recognised in the enabling legislation and other governing documents as a legitimate purpose for which information can be collected, used and disclosed; and access to data for appropriate research purposes should be facilitated by the owners/operators of data sets.

Draft Recommendation 9.5

The Australian Government should establish an Office of the National Data Custodian, as a new function within the Government to have overall responsibility for the implementation of data management policy.

Specifically, the National Data Custodian (NDC) would have responsibility for broad oversight and monitoring of Australia's data system, recommending the designation of National Interest Datasets, and accrediting Release Authorities and trusted users within the reformed data system.

Research Australia supports this recommendation but only if the Natioanl Data Ciustodian is properly resourced and has the authority and power to effect the changes required to collect, use and retain data and make it available as a vauled national resource. A body that exists in name only will have little effect on the status quo.

Draft Recommendation 9.6

Selected Australian and state/territory government agencies should be accredited as Release Authorities by the National Data Custodian. In considering applications for accreditation, the National Data Custodian should consult a wide range of parties and ensure Accredited Release Authorities (ARAs) have sectoral expertise. The current model used by the National Statistical Service for appointing data linkage authorities should be considered in developing a model upon which to base this process.

ARAs will be responsible for:

- *deciding (in consultation with initial data custodians) whether a dataset is available for public release or limited sharing with trusted users*
- *collating, curating and ensuring the timely updating of National Interest Datasets.*

ARAs will also perform an important advisory role in regard to technical matters, both to government, and to the broader community of data custodians and data users.

Research Australia supports this recommendation.

Draft Recommendation 9.7

Trusted users should be accredited by the National Data Custodian for access to those National Interest Datasets (NIDs) that are not publicly released. Trusted users should be drawn from a wide range of potential entities, including: all Australian Government and state and territory government agencies; all Australian universities; and other entities (be they corporations, not-for-profit organisations or research bodies) that are covered by privacy legislation.

The default position should be that someone from one of these organisations would be approved for access unless the National Data Custodian transparently specifies a reason, on consideration, of why this should not occur.

For trusted users of NIDs, trusted user status should provide an ongoing access arrangement, with few restrictions on what could be done with the data. Trusted user status for NIDs should cease when the user leaves the approved organisation or be suspended if a breach occurs by any other trusted user in that same organisation and/or working on the same project.

Research Australia supports this recommendation.

Draft Recommendation 9.8

Arrangements for access by trusted users to identifiable data held in the public sector and by publicly funded research bodies should be streamlined and expanded by the Australian Government. The National Data Custodian should be given responsibility to:

- *develop, in consultation with data custodians, a list of pre-approved uses for a dataset, and make decisions on access to data for projects not consistent with the pre-approved uses list*
- *grant, on an approved project-specific basis, trusted user access to personnel from a range of potential entities, including: all Australian Government and state and territory government agencies; all Australian universities; and other entities (be they corporations, not-for-profit organisations or research bodies) that:*

- *are covered by privacy legislation*
- *have the necessary governance structures and processes in place to address the risks of inappropriate data use associated with particular datasets, including access to secure computing infrastructure.*

Access would be granted for the life of the specific approved project. Trusted user status for use of identifiable data would cease when the user leaves the approved organisation; a project is completed; or if a breach occurs in that same organisation and/or project.

Research Australia submits that all NHMRC Administering Institutions (i.e. organisations authorised to administer NHMRC grants) should be accorded the same status as universities. In addition to universities, this would extend trusted user status to medical research institutes and some hospitals and health networks. NHMRC Administering institutions should then be automatically treated as trusted users, without requiring any further vetting or approval process. In addition to employees, these research organisations should then be able to make data available to researchers involved with the organisation but not employed e.g. visiting professors and fellows, adjunct professors.

Research Australia questions why, in the case of NHMRC Administering Institutions, the National Data Custodian should be required to provide project-specific approval for specific personnel. Research Australia's understanding from the Draft Report is that these arrangements relate to deidentified datasets. Responsibility for the governance, management and approval of individuals should rest with the relevant organisation, not the Data Custodian, and should be managed as part of the normal research governance processes. In the case of Administering Institutions, there is no evident justification for the additional application process and overheads associated with the Data Custodian providing project-specific and personnel-specific approvals. In addition to increased cost and inconvenience, separating responsibility for approving access to data from the normal research governance processes could lead to less effective oversight.

Consideration also needs to be given to situations where a researcher transfers from one trustee user organisation to another and the research goes with the individual. In this case the user access must transfer as seamlessly as possible with the person (at most it should be a notification rather than a re-approval process).

Draft Recommendation 9.9

Public research funding should be prioritised based on progress made by research institutions in making their researchers' data widely available to other trusted researchers on conclusion of research projects.

While Research Australia is supportive of the principle of making researchers' data widely available, we do not support making this a consideration in the funding application and approval process.

As noted in response to recommendation 5.4, existing funding processes are directed to funding the best research based on research excellence, track record and capability, need etc. The processes are already time consuming and complex and the subject of concerted efforts to reduce the time and effort involved in both making and assessing applications. This process should not be further burdened with another assessment criterion, particularly one which is not aligned to the merits of the research proposal.

Research Australia submits that there are other less disruptive mechanisms which can be used to encourage/mandate publication of data, including public reporting of institutions' record in releasing data. Research Australia submits that the Commission should instead recommend that the NHMRC and ARC examine what measures they can take to encourage/mandate researchers making their data available.

Draft Recommendation 9.10

All non-sensitive public sector data should be released, consistent with release priorities and as resources allow, with curation, provision of metadata and adherence to agreed standards resourced as specified in Draft Recommendation 7.4. A realistic assessment of the risks associated with public release of identifiable information that is already public in a less accessible form, should be undertaken by all governments.

Data that could be used for program or agency performance management purposes should not be withheld from release.

Research Australia supports this recommendation.

Draft Recommendation 9.11

The Australian Government should introduce a Data Sharing and Release Act which includes the following:

- *Provisions requiring government agencies to share and release data with other government agencies and requiring sharing between government agencies and other sectors.*
  - *These provisions would operate regardless of all restrictions on data sharing or release contained in other legislation, policies or guidelines.*
  - *The provisions may be waived in limited exceptional circumstances, and the Act should specify what these circumstances are.*
- *Strengthened provisions on access to data by individuals, including rights to access and edit data about them, a right to have data copied and transferred, and a right to request that collection cease.*

Provisions establishing the Framework for the governance of Comprehensive Rights of consumers, access to National Interest Datasets, approval of trusted users, and accreditation processes for Release Authorities.

Research Australia supports this recommendation.

Conclusion

As the quantities of data collected about all of us grows, so does our capacity to utilise this data for the benefit of all. As the Draft Report has identified, there is evidence that community attitudes to data and questions of privacy and security are changing, and legislation and government practices need to change to both reflect this change and enable us to harness this data as a valuable resource. Now is the time to act if we are to make the most of the opportunities public data provides to improve the delivery of government services and the health of our community, and to create the new economic opportunities and jobs of tomorrow. The Commission's Draft Report is a very important step in what Research Australia acknowledges will be a long but fruitful journey in harnessing the transformative power of data in contemporary society.

While we are overwhelmingly supportive of the Commission's recommendations and direction, there are a few areas in which we have proposed alternative approaches. We would be pleased to discuss these proposals and any other aspect of our submission or the Draft Report further and the opportunity to continue to work with you on this significant opportunity to effect strong policy change for public good.

Research Australia looks forward to the Commission's Final Report.

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