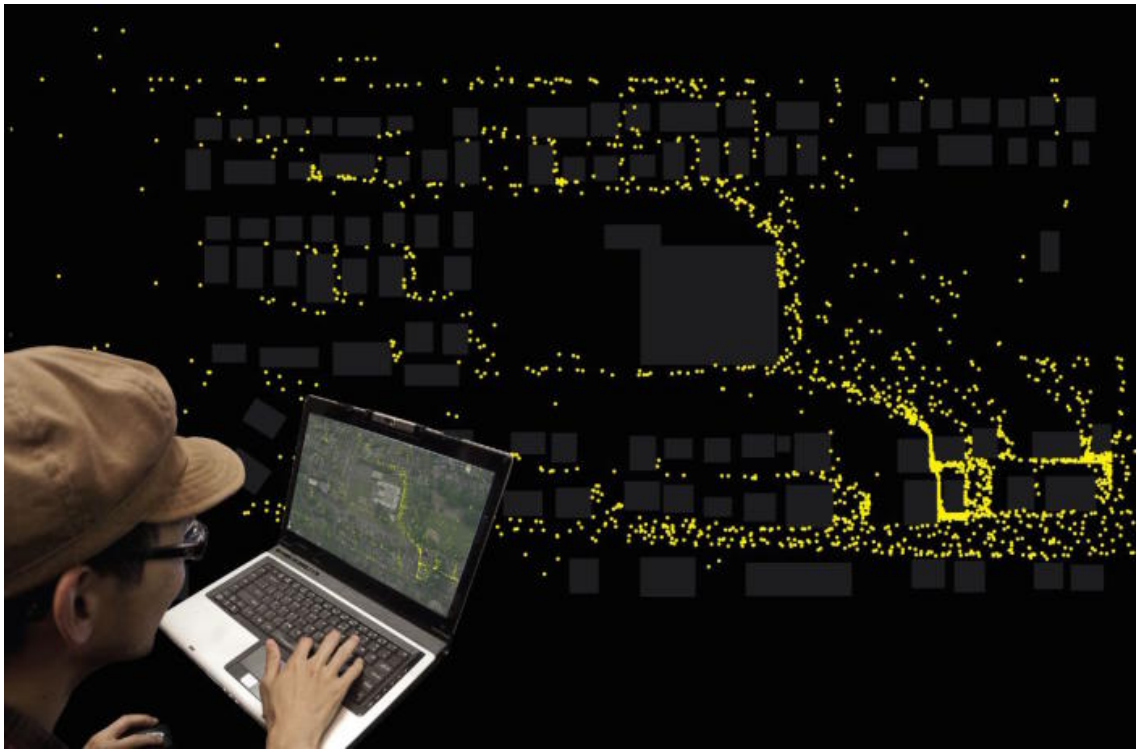
THE UNIVERSITY OF MELBOURNE

RESPONSE TO THE PRODUCTIVITY COMMISSION'S DRAFT REPORT ON DATA AVAILABILITY AND USE

16 DECEMBER 2016



Data visualisation of urban pollen distribution. *Picture: Intel Free Press/flickr*

Introduction

The University of Melbourne congratulates the Productivity Commission on its Draft Report on the inquiry into Data Availability and Use. The University submitted to the Issues Paper earlier in 2016, following a detailed consultation process with over thirty academics from many disciplines across the University. We welcome this opportunity to provide a response to the Draft Report.

As noted by the University's initial submission, and throughout consultations with the Commission, a successful reform agenda to make better use of data will be integral to Australia's future economic productivity, research outcomes, policy development and social wellbeing. Whilst the complexity of the task was widely observed by submitters to the inquiry, the Draft Report proposes a comprehensive and potentially transformative new Framework for Australia's data future.

The reforms proposed in the Draft Report strike a practical balance between opportunity and risk management, with appropriate consideration of the public good, future national capabilities, and citizens' rights and protections. Structured and unstructured information being collected by public agencies and other entities represents a valuable asset to Australia. The Draft Report's framework for ensuring better use and management of these assets will prove a significant step forward.

The Draft Report covers many aspects of Australia's data access challenges and provides accurate context for legislative and regulatory action. We are particularly pleased to see that the Commission has used the example of health and research data in Appendix D to articulate some of the problems and opportunities associated with the use of data.

In particular, the University also welcomes the following Draft Recommendations including the reform concepts of National Interest Datasets, National Data Custodian, Accredited Release Authorities (ARAs) and trusted users:

- A new *Data Sharing and Release Act* and other amended legislation to provide certainty and a strong foundation for the national reforms to digital data (**Draft Recommendation 9.11**). In the University's view an additional benefit of a new Act will be the opportunity for parliamentary examination and a national conversation about data access and use.
- Establish an Office of National Data Custodian and ARAs to be funded to assist data custodians with quality data curation and release (**Draft Recommendations 9.5 and 9.6**).
- Establish new processes for trusted users to access identifiable and de-identified datasets for agreed uses (**Draft Recommendation 9.7**).
- Rights-based measures to increase individuals' control and access to their personal information and data preferences (**Draft Recommendation 9.2**).
- Identification of National Interest Datasets to enable trusted users' access to data with high-value and a public interest element, including identifiable data and linked datasets in some circumstances (**Draft Recommendation 9.4**).
- Measures to assist key sectors to shift towards an open access default practice, rather than a risk-averse practice (**Draft Recommendation 2.1**).

- Mechanisms for data custodians to apply for accreditation for data linkage, and abolishment of linkage key destruction requirements (**Draft Recommendations 5.3 and 5.5**).
- The creation and publication of easy-access data registers for data held by all Australian, State and Territory Government agencies (**Draft Recommendations 3.1 and 3.2**).
- The pricing of public sector datasets to the research community for public interest purposes to be subject of an independent review (**Draft Recommendation 7.2**).
- Pursuant to principles of open access and open government, release of all non-sensitive public sector data (**Draft Recommendation 9.10**).
- Expansion of the *Privacy Act* 1988 (Cth) exceptions that allow access to identifiable information for the purposes of health and medical research without seeking individuals' agreement to also apply to all research that is determined to be in the public interest (**Draft Recommendation 5.2**).

The University, in welcoming the Draft Report, notes there are important areas which require further clarity or consultation on implementation or impact. This includes those recommendations which are likely to impose significant administrative or resourcing burdens on public research institutions in the short-medium term. The areas of the Draft Report on which the University makes detailed comment are:

- National Interest Datasets and trusted access;
- Research funding and research data;
- Streamlining ethics committees;
- Measures to encourage and protect innovation;
- Infrastructure for sharing health data.

The University thanks the Productivity Commission for its sustained engagement and consultation with our academics and experts throughout the inquiry, including through a roundtable and public hearings. We believe it is important that academics and universities continue to be engaged on policy and practice development related to data creation, data transformation, data access, and data analysis. The research sector has expertise on both technological and analytical fronts, including:

- practical know-how for building technology for housing, cleaning, and analysing data;
- developing techniques to assess the risk of identification of individuals in a single or in linked datasets;
- development of techniques for analysing data housed in different locations; and
- conducting the analysis and portrayal of data that may underpin policy and productivity.

As researchers, data generators, data custodians and data users, the University supports ongoing efforts to make data accessible and secure, especially at a unit level as this is important for policy analysis and academic research.

For further information or to discuss our submission, Professor James McCluskey, Deputy Vice Chancellor (Research) can be contacted on dvc-research@unimelb.edu.au or (03) 8344 3238.

University of Melbourne recommendations on the Draft Report

- The University recommends that the final Report should emphasise **a wider array of potential National Interest Datasets (NIDs)** as possible contenders for designation as NIDs and access by trusted users, such as national health, clinical, economic, social and population data.
- The University recommends the Framework should include **a National Data Advisory and Consultative Forum** comprised of non-government data experts to advise the National Data Custodian, relevant departments and Accredited Release Authorities on public interest data needs, technological aspects, data governance and data release priorities.
- Regarding accreditation of trusted users in the research sector, the University recommends that the **process for gaining approval be light-touch** and streamlined, utilising existing academic quality, governance and accreditation processes within the research sector where possible.
- The University recommends that, where possible, the Framework for making decisions about **releasing data should have checks and balances**, decision review components, appeal procedures and/or introduction of non-government expert evidence or information about potential data release.
- The University supports the concept of incentives to enable greater re-use of researchers' data, but **does not support the proposal to prioritise research funding by performance in data openness**.
- With regard to public registries of publicly funded datasets, the University recommends a phased approach, including detailed consultation.
- The University recommends the Commission's final report should emphasise **streamlining and harmonising research ethics legislation and committee protocols** on research ethics approvals across State and Territory jurisdictions, as well as between sectors and institutions.
- The University recommends **strengthening safe-harbouring legislative protections**, to facilitate data-centric innovation and ensure research-purposed experimentation may be undertaken lawfully.
- The *Privacy Act* 1988's proposed research exception should extend to conduct covered by the *Privacy Amendment (Re-identification Offence) Bill* 2016, in particular so that **'white hat' efforts at testing and improving information security will not be at risk**.
- A streamlined and accessible ecosystem for health data is required to keep Australia in a world-leading position in biomedical research. The University would welcome a clear recommendation from the Commission for Commonwealth and State Governments to work jointly on **planning and procuring a long-term and nationwide Electronic Medical Records network** and integrated e-health data for the benefit of enhanced medical research and improved health outcomes.

National Interest Datasets and trusted users

The University strongly supports **Draft Recommendations 9.4, 9.5 and 9.6**, which outline proposals for parliamentary designation of National Interest Datasets (NIDs), establishment of an Office of the National Data Custodian and establishment of Commonwealth and State/Territory public agencies as Accredited Release Authorities. These reforms would enable significant improvements in access to data, especially to public sector datasets.

We also strongly endorse the comments on page 24 of the Overview that continued consultation and a national conversation is critically required on implementation aspects and staging of reforms, in order to build public support for the changes across the Australian community and jurisdictions.

Regarding the Commission's information request for further views on datasets that are of national interest and that could feasibly be designated as such under the process proposed, it is the University's view that the final Report should emphasise a wider array of potential NIDs as contenders for designation as NIDs. The Draft Report flags 'key registries of businesses, services or assets, and data on activity and usage in areas of substantial public expenditure' as possible examples of NIDs. The Draft Report also comments that other NIDs 'may be less immediately obvious but will become clear candidates over time' and the framework is intended to extend beyond the 'low-hanging fruit' to include access to de-identified datasets that are integral to service delivery and decision making, as well as key privately held datasets'.

To effectively enable public interest research and policy development, the University recommends the Commission's final report should similarly flag national health, clinical, economic and population data – including some datasets that might be more micro-level than the macro-level datasets mentioned by the Commission in the Melbourne public hearing – as core examples of datasets that are fundamental to research and discovery in the national interest. We note recent discussions and proposed legislative amendments to the *Privacy Act* 1988, and related disclosures by University of Melbourne researchers about de-identification challenges and potential re-identification of public datasets. De-identification challenges may prove less of a barrier to data access and risk to personal privacy if sensitive datasets with identifiable data are only accessible in controlled circumstances by trusted users.

In support of a more expansive approach to NIDs, and given that some NIDs may include sensitive and identifiable information, we acknowledge and affirm with the Commission's suggestion that not all NIDs should be immediately made public.

Recommendation: The University recommends that the final Report should emphasise a wider array of potential National Interest Datasets as possible contenders for designation as NIDs and access by trusted users, such as national health, clinical, economic, social and population data.

We also note the Commission's draft proposal under **Draft Recommendation 9.4** for a 'deliberative forum, such as a parliamentary committee, to take community input and review nominations made, and to make proposals for future designations'. The decision-making authority over the designation

of NIDs, the degree of public availability and the decision about access for trusted user groups will crucially impact the adoption and demonstrable success of this data reform over years.

A deliberative forum with open public record is a commendable proposal. The Commission has noted the transparency of a parliamentary committee as a benefit of that forum. However, the University has concerns that a parliamentary committee, in isolation, may lack the expertise in data applications and broad professional representation necessary to make the significant decisions about NIDs designation. Additionally, the University recommends an independent advisory committee with participation from leading research, scientific, industry, legal, political, departmental and community representatives, to provide advice on NIDs designation. The University outlines below the suggestion of a National Data Consultation and Advisory Forum that may be a useful addition to a parliamentary committee's oversight functions.

The University recommends that an expert-led mechanism or process for making decisions of this kind about data access will have the benefit of being flexible and able to evolve with time. Many of the current processes are outdated because they reflect guidance and decisions that were made at a time when most data was not easily machine-readable. While guidance is needed for today's issues and the structure of data as it stands, we strongly recommend ensuring this guidance can be updated regularly as needs change and as innovation brings forward new techniques and processes unknown today. An advisory forum comprising expert data users along with policy experts would be an appropriate model for achieving this.

The advisory forum could be statutorily or non-statutorily established; it could potentially publish its advice and assist with conduct of community or sector consultations; it could provide direct input into the Parliamentary Committee's oversight processes; it could advise on data release issues and priorities with the relevant Commonwealth department and decision-maker, such as the Office of National Data Custodian or Attorney-General's Department. Such a Forum has similar but not identical precedents in other areas of policy including: the Information Advisory Committee to the Office of the Information Commissioner; the Immigration Detention Advisory Group; the Illicit Tobacco Industry Advisory Group; or the Expert Panel on Constitutional Recognition of Aboriginal and Torres Strait Islanders.

Recommendation: The University recommends the Framework should include a National Data Advisory and Consultative Forum comprised of non-government data experts to advise the National Data Custodian, relevant departments and Accredited Release Authorities on public interest data needs, technological aspects, data governance and data release priorities.

Regarding the establishment of ARAs, which will 'largely be existing public sector agencies' (page 16 Overview), the University recommends (from a data requester and data user perspective) that the timelines and resourcing for public sector ARAs be sufficient to meet the responsibilities attributed to them under the new Framework. The increased demand for data access envisaged under the new Framework would necessitate a corresponding increase in resourcing to public sector ARAs to ensure the necessary expertise and capacity to process data requests efficiently.

Trusted users and higher-risk data access

The University strongly supports **Draft Recommendations 9.7 and 9.8**, which cover access arrangements for trusted users, and access management roles for the proposed Office of the National Data Custodian. The University concurs that with proper governance and consideration it is possible to achieve appropriate management of data and access, from perspectives of risk, privacy, and cost, to permit quality analysis of issues affecting Australians. We agree with the need to develop a credible trust framework for enabling access to sensitive data by individual researchers and also maintaining community confidence.

As highlighted in our initial submission to the Commission, the University strongly supports the concepts of pre-approved trusted users and the secure sharing of identifiable and sensitive information. The 'default approval for access', as flagged by the Commission in the Draft Report, is an important feature and seems likely to enable researchers and institutes housed in universities to readily obtain trusted user access. Further clarity on the definition of trusted users likely to be accredited through employment or study within a university, such as research personnel (rather than professional staff), would be welcomed by the University.

Regarding trusted user accreditation, the University recommends the Commission advise in its final report that any process for gaining approval be light-touch and streamlined as far as possible, in order to reduce new administrative burdens and delays on researchers embarking on projects. For potential trusted users formally associated with research institutions, a simplified or fine-tuned process within existing research accreditation would be a preferred model. The University also notes the likely need for ongoing monitoring and invigilation of standards for trusted user status throughout the introduction of this model nationally and within institutions. Monitoring and fine-tuning of trusted user accreditation and processes are therefore likely to carry an ongoing resourcing cost to research institutions.

The University also observes that key definitions and implementation details are yet to be determined, such as the meaning of 'project' (end of Draft Recommendation 9.7) insofar as the application of penalties or cessation of access for large organisations in cases of individual breach. The legislative process establishing NIDs and trusted user access will enable further clarity and practical discussions across relevant sectors on these aspects.

Recommendation: Regarding accreditation of trusted users in the research sector, the University recommends that the process for gaining approval be light-touch and streamlined, utilising existing academic quality, governance and accreditation processes within the research sector where possible.

Streamlined access to identifiable and de-identifiable data

Draft Recommendation 9.8 also recommends mechanisms and draft parameters for streamlining access to identifiable data by trusted users, flagging universities amongst the likely entities from which trusted users may be drawn, depending on conditions in place such as 'the necessary governance structures and processes to address the risk of inappropriate data use…including access to secure computing infrastructure'. From the quantitative research perspective, personal data is often crucial for analysis but the reporting of results is usually aggregated to obscure identification of subjects used in the analysis. Figure 3 in the Draft Report represents an effective and workable depiction of the various ways in which data of varying levels of sensitivity might be used under the new Framework.

The University endorses the approach taken by the Commission to sharing identifiable data in managed and secure circumstances. We agree with the Commission's remarks on page 11 of the Overview that risks of data misuse tend to relate more to poor storage or management of data, rather than public release of data that is either used securely or robustly de-identified.

As noted by the Draft Report, any university researcher would be bound by data use agreements and would be educated about the consequences of misusing or releasing personal information. Access to identifiable data would place trusted researchers in the same category as public servants who need to access identified data. In circumstances of criminal misuse, the University would support legal penalties for unauthorised access or disclosures by researchers working within institutions.

Decision-making on data release

The University endorses the Commission's preferred approach of identifying a comprehensive, coordinated and cooperative solution to data holdings and integrated release across Australian jurisdictions, in order to avoid the outcome of ad hoc and fragmented (and thus lower-value) data release around the country.

The Commission has sought views on alternative models for achieving this, emphasising in the Draft Report a model in which data is curated by the original data custodian (federated model) but the release authority has the ability to release the data (aggregated model). In **Draft Recommendation 9.6**, selected government agencies are proposed to be Accredited Release Authorities (ARAs) with responsibilities for 'deciding whether a dataset is available for public release' and curating and delivering NIDs.

The University recognises the Commission's reasoning for the above model. We nevertheless observe there may be future challenges with vesting decision-making power about data release with too few public service departments. We discourage the adoption of a centralised or heavily aggregated model for data accumulation and/or release. Vesting the decision making power entirely in the public sector or across too few departments would risk inefficiency and higher costs. Utilising a small group of government agencies in a particular data area could also negatively promote a concentration of skills when Australia needs skill development broadly across government agencies.

Moreover, data access is more than a technological issue. Whether a given dataset or set of measures is relevant from a societal perspective requires an understanding of the needs and interests of society which is often found in a range of organisations from specific government departments to outside groups. For this reason, the University applauds the Australian Government's inaugural Data Fellowship Programme launched in late 2016, which provides coaching and seconding of public sector data users into diverse policy areas in order to advance the public sector's data skills, policy development and service provision.

Regarding they key decision-making parts of the Framework, such as the ARAs and the creation of the National Data Custodian, the University recommends the Commission should consider building in additional checks and balances for review of decisions about data management and release, including introduction of non-government expert evidence and advice. We encourage the Commission to consider a national governance structure that includes leading government agencies as well as non-government experts. In other parts of this submission, we have proposed a National Data Consultation and Advisory Forum that could serve this purpose.

Recommendation: The University recommends that, where possible, the Framework for making decisions about releasing data should have checks and balances, decision review components, appeal procedures and/or introduction of non-government expert evidence or information about potential data release.

The Commission's Draft Report proposes that selected Australian and State/Territory government agencies would be accredited as ARAs by the National Data Custodian. However, in considering accreditation arrangements it will be useful to learn from other sectoral organisations with experience that might have utility for ARA models. As an example, the University hosts AURIN, an e-infrastructure project with visibility across multiple sectors, which has developed considerable expertise relating to data access challenges and solutions.

AURIN has been on the frontline as a principal organisation and practice-leader in facilitating expert and community access to data, translating research data and supporting the development of implementable policies. AURIN's model is effective because it streamlines the permissions process by providing access to data that has already been cleared for release. It also acts as a go-to point for datasets that may require additional negotiation or permission for more granular access and as such plays a valuable intermediary role, rather than being a release authority per se.

The following box elaborates on applicable learnings from AURIN's function as a cross-disciplinary and cross-sectoral data portal.

Australian Urban Research Infrastructure Network

Background to AURIN's data access capability

The University of Melbourne is lead agent for the Australian Urban Research Infrastructure Network (AURIN). AURIN provides researchers, policy-makers and decision-makers with access to high-value datasets, analytical tools and services that enable better decisions about Australia's urban areas. Since its inception in 2010 AURIN has coordinated the release of around 1500 datasets for access and use by the research community. AURIN coordinates the collection of data from a variety of authoritative data sources (archival and dynamic), and provides access to this information through the AURIN Portal and associated platforms.

Since the formal launch of the AURIN Portal just over two years ago, it has registered 5000+ users nationally and this number continues to grow. Whilst the primary audience for AURIN has been academics and students from Australian research institutions, the infrastructure developed has been increasingly adopted by federal, state and local government policy-makers for the source of data and tools to guide their activities, including regional productivity and planning.

AURIN is an initiative funded by the Australian Government under the National Collaborative Research Infrastructure Strategy (NCRIS) with strong links to other NCRIS projects such as NECTAR and the Australian National Data Service (ANDS).

AURIN's experience and applicability to possible ARA models

AURIN provides a complete data release and delivery service, negotiates access to high-quality data for end users and also provides a purpose built platform (the AURIN Portal) through which to access the data. The results of the research can then also be released back to the AURIN end-user community through the AURIN Portal and other AURIN platforms such as AURINMap. AURIN has extensive experience in the following capabilities relevant to potential ARA functions:

- Managing the release of nationally significant or high-value datasets including managing access to restricted or sensitive datasets to approved end-user groups. Examples in AURIN's current practice include the Australian Business Register data (geocoded business addresses) and the National Health Services Directory data (locations of GPs) and Australia Property Monitors sales data;
- Developing metadata, including the current collaboration with ANDS, to develop a metadata tool and expand metadata available about datasets;
- Building relationships with data custodians in Government and the private sector;
- Developing and advising on data standards including approaches to licensing;
- Responding to demand from end-user researcher community to carry out national research.

Research funding and research data

Prioritised research funding

The Draft Report at **Draft Recommendation 9.9** recommends that 'research funding should be prioritised on the basis of progress made by research institutions in making their researchers' data widely available to other trusted researchers at the conclusion of research projects'.

The University notes the positive intent of this draft recommendation, on the basis that the public benefit will be increased if there is greater re-use of researchers' data. Cultural change and transformed research practices may be more likely to emerge if research groups who add value to public datasets are recognised for this. However there are many factors important in the determination of priorities for access to future public funding, and incorporating such a measure does not seem to be the appropriate incentive to achieve the public policy outcome sought.

We also highlight a number of implementation and contextual considerations that surround this proposal. The consequences of this Draft Recommendation on the distribution of research funding – competitive or otherwise – would be significant and far-reaching, thus requiring further review and specific consultation with the research sector.

First, there is already a wide array of sector-applied criteria and quality thresholds for the granting of public funds for research, which should continue to apply with any future criterion of data release performance.

Second, the costs of de-identifying and permanently hosting an accumulating library of large and complex datasets will be extensive and would therefore be a factor in future research funding. In this regard, existing collaborative platforms for hosting research data could potentially be targeted for national investment as a starting point. For instance, the University currently works with the Australian National Data Service (ANDS), which is supporting the development of the 'Australian Research Data Commons', a cohesive collection of research data resources from all Australian research institutions, supported by NCRIS, to make better use of Australia's research data outputs. However, even with existing infrastructure such as these, current data-sharing arrangements and infrastructure is unlikely to be sufficient to cope with vastly higher volumes of data made available for access under the new Framework, meaning the costs of implementing this proposal would remain very high.

Third, the University observes the unequal starting point for research institutions across the nation in terms of capability and processes for sharing research datasets, which could become entrenched disadvantage as a result of the implementation of the proposed funding prioritisation.

Fourth, we note that the consequences of this Draft Recommendation (along with others, such as **Draft Recommendations 3.2** and **5.4**) would stretch to cover a very wide range of organisations and institutions, including Publicly Funded Research Agencies. While 'Academic Institutions' are listed and discussed with reference to **Draft Recommendations 9.9, 3.2 and 5.4** on page 379 of the Draft

Report, in practice, there are other major publicly funded research institutes, such as the CSIRO, Bureau of Meteorology and Australian Nuclear Science and Technology Organisation, that would appear to be similarly impacted by this proposed research funding incentive. As noted in the Draft Report on page 330, there is 'about $8.6 billion [government funding to research] each year, of which about $2.9 billion goes to universities, and another $1.8 billion is provided to publicly funded research agencies'. In the University's view, the diverse characteristics, mandates and operating environments of publicly-funded research organisations would likely bring complexity and potentially risk and unintended consequences if this Draft Recommendation was adopted.

Last, we observe that the intellectual property right of data creation (whether it is primary or secondary) is a significant asset for researchers. Some data is proprietary (e.g. business data) which will require exceptions for disclosure under the new framework of publication, which may ultimately act as a new barrier to accessing the data. There are many projects that require the use of propriety and/or confidential data from organisations that arguably should not be released into the public domain. In those instances, it would not be a benefit to place those researchers at future disadvantage in seeking public funds.

Recommendation: The University supports the concept of incentives to enable greater re-use of researchers' data, but does not support the proposal to prioritise research funding by performance in data openness as outlined in Draft Recommendation 9.9.

Releasing research datasets and registers of summary descriptions of data

The University acknowledges the positive intentions behind **Draft Recommendation 3.2**, which proposes that publicly-funded entities, including the Australian Research Council (ARC), should publish up-to-date registers of data holdings, including metadata, which they hold, or publication of a summary description if the dataset is not made available.

This would be an important, but challenging, reform and could potentially add great public benefit to research by enhancing discoverability of data. A primary challenge to this draft recommendation is the significant costs and administrative impact on publicly-funded data custodians, and the currently limited, and rapidly evolving and maturing, standards and tools for metadata management.

A second challenge is the proposed implementation timeline applied to this recommendation, observing that the transition to new practices and data platforms within an institution will require requisite time for developing the capability, testing practices, training people and implementing the process. There is also the importance of avoiding duplication of efforts; registry databases of research datasets may exist through alternate avenues to the institutional point of access, such as disciplinary registers including the biodiversity-focused Atlas of Living Australia, or the cross-disciplinary ANDS (as discussed above).

Again, the University notes that careful consideration will be required about the type of information contained in a dataset to be released publicly if a dataset has proprietary or confidential data. The proposed publication incentive and standard requirement for information about publicly funded

research data could have an unintentional poor result of stalling research progress, if an organisation decides not to work with a research team because of the requirement that their data could be released into the public domain. We appreciate that if research is funded through public revenues, products of that research should be accessible to others. But there are many factors that should be considered including the innovation of the individual researcher, the level of sensitivity of the data being used, and the source of the data.

Recommendation: With regard to public registries of publicly funded datasets, the University recommends a phased approach, including detailed consultation, in further consideration of Recommendation 3.2.

The University agrees with the Commission at **Draft Recommendation 5.3** that requiring destruction of data at the end of a research project can be a waste of resources - it prevents testing of the results as well as the creation of new projects that build on existing work. Application of a structured risk assessment tool may assist the process of deciding whether to keep or destroy a dataset. Access to previously linked datasets should continue to require ethical approval for each new project.

Standards for data curation and release

The University supports **Draft Recommendation 6.1** to develop uniform data management standards across government agencies to make data fit for release. Drawing on the experience of AURIN (see above), the University recommends that obtaining consent or a licence to use and share data is an important element in assessing whether data is fit for release. As a consequence of the research sector-specific challenges outlined by the Commission in the Draft Report (pages 140-141), negotiating the consent of the person or institution that created the data to share it with others is a significant part of the release checklist. Ideally, research data could be shared through an open data licence, or if sensitive, released to a specific group for further research. The experience of data curators and release managers at the University is that these issues need to be addressed in parallel with data standards around access and usability.

Streamlining ethics committees

Draft Recommendation 5.4 regarding guidelines, reporting and funding prioritisation for ethics committees is a commendable approach in concept. Implementation details, yet to be determined, will influence the degree to which these changes have a positive impact on data access and availability. As outlined in our earlier submission, research institutions, including the University of Melbourne and associated biomedical research precincts, are already advancing a program of streamlining ethics approvals and mutual recognition of ethics approvals where appropriate. A key disjuncture in ethics approval for clinical trials often occurs over State/Territory jurisdictional boundaries. In addition to recommending that States/Territories should take actions to mirror the federal approaches in Draft Recommendation 5.4, the University recommends the Commission emphasise the importance of streamlining and harmonising research ethics legislation and committee protocols on research ethics approvals across jurisdictions.

Recommendation: The University recommends the Commission's final Report should emphasise streamlining and harmonising research ethics legislation and committee protocols on research ethics approvals across State and Territory jurisdictions, as well as between sectors and institutions.

We are concerned that additional administration will arise from a new reporting requirement for data custodians to report on their handling of requests for data access. Ethics committees at the University seek to process approvals in as timely and efficient manner as possible. The reporting requirement should be developed in such a way so as to limit a new administrative burden on institutions and avoid adding further time delays to ethics committee governance and processes.

The current suggestion in the Draft Report is that 'funders using Commonwealth money should monitor and annually publish tables showing the availability of data following the completion of research projects'. The University observes that this is a relatively resource intensive addition to current institutional reporting arrangements. As earlier discussed, we also observe that this change to regulatory practice would impact a wide array of Publicly Funded Research Agencies beyond universities. The implications and costs of this recommendation to provide incentives for performance will have a scaled-up impact when applied, as appears to be, to the entire publicly-funded research system in Australia.

Related to ethics committee functions under the future Framework, the University endorses the Commission's proposal in Chapter 9 of the Draft Report that ethics committees, along with new ARAs, would be appropriate bodies to provide final authority on approvals for use and access for data handed over by data custodians for inclusion as a NID. This is consistent with existing sector practices and expertise; at present, some exemptions (such as access to data without individual consent) are granted by an ethics committee. In the University's view, it will be important to retain these processes of ethical review, but perhaps to streamline them by codifying some of the circumstances in which exemptions can or should be granted.

Recommendation: The University strongly recommends that the proposal to prioritise research funding by performance on ethics committee processes as outlined in Draft Recommendation 5.4 requires detailed review and consultation with the publicly funded research sector.

Measures to encourage and protect innovation

We are in the midst of a transition to a more digital society. People today are hyper connected and demonstrably willing to take advantage of increasing power of automation based on insights generated from data. This is why data availability must be a crucial focus for policy reformers. The Draft Report provides a potentially fruitful pathway for Australia to achieve a proactive data-focused regime that balances privacy protection and public good.

Researchers often study issues and policies by looking back through accumulated data to uncover links and patterns; this is evident in the many case studies included in the Draft Report. One of the potential powers of data, however, is to use real-time or current information to identify emerging issues and to think dynamically about the potential effects of proposed actions or policies.

Research collaborations between university and publicly funded researchers, private sector, government business and industry are increasingly prominent as avenues to resolving issues of national importance and in contributing to economic growth. Strengthened privacy requirements should not hamper such collaborations, whose success often relies on access to publicly funded data by various participants in those partnerships.

Therefore, it is also important to recognise that as the new Australian data governance framework proposed by the Commission is implemented over time, we can expect to witness unprecedented growth in data technologies – machine learning, data analytics and automation and integration over the next decade. This high rate of innovation and transformation is the basis for the following feedback recommendations from the University.

National Data Consultative and Advisory Forum

Recommendation: To support the Office of the National Data Custodian proposed in **Draft Recommendation 9.5**, as a mechanism to de-risk and build trust in the data governance framework there should also be established a National Data Consultative and Advisory Forum.

The intent behind this recommendation is to ensure the Framework is informed by relevant expert communities drawn from key data practitioners, data experts and government, evolves and is updated as new technologies and capabilities are developed and as community or regulatory expectations change, and which is informed by international practices.

This entity could also be effective in other regards, such as advising on, nominating or assisting with decisions about NIDs (as discussed above) and working collaboratively across Commonwealth and State/Territory public agencies to ensure all layers of government and administration in Australia are harmonised in achieving the data access outcomes. The risk-averse approach to data openness in government and bureaucracy observed in the Draft Report will take time to change and may, in some politically sensitive areas of policy, such as evaluation of government policies, remain challenging. For these reasons, as outlined earlier in this submission, the University views great benefit in an independent source of advice and potentially decision-making contribution on important threshold issues such as National Interest Databases, data governance and data linkage.

Safe harbouring framework to encourage innovation

Opening data to entrepreneurial activity and innovation processes will bring substantial benefits. This has been noted by the Commission's comments on page 292 on outcomes sought from these reforms, including 'boosting Australia's competitive advantage and business opportunities through innovation and a world-leading data environment'.

In the University's view it is necessary to strengthen the safe-harbouring legislative protections as part of the proposed data Framework. This is necessary in order to facilitate data-centric innovation in specified secure circumstances so new ideas can be tested and experimentation in data-driven products and services may be undertaken within the bounds of the law.

A mechanism or legal amendments along these lines would be crucial for researchers, entrepreneurs and industry partners to be cutting-edge and innovative in developing new ideas and solutions without being exposed to legal risk. Again, the National Data Consultative Forum we propose could become proactive in responding to emerging issues and will have the expertise and sector confidence to respond with early warning of changing technological challenges, consult widely on appropriate best practice, advise on regulatory guidelines and make recommendations on legislative changes.

Recommendation: The University recommends strengthening safe-harbouring legislative protections, to facilitate data-centric innovation and ensure experimentation may be undertaken lawfully.

Privacy, research defence and exceptions

The University supports **Draft Recommendation 5.2** that states existing exceptions in privacy legislation (sections 95 and 95A of the *Privacy Act*) should be extended to cover public interest research more generally. This allows sharing of personal information for health and medical research purposes without obtaining the consent of individuals.

We submit that it should extend to conduct covered by the *Privacy Amendment (Re-identification Offence) Bill* 2016, in particular so that 'white hat' efforts at testing and improving information security will not be at risk. We also recommend that the Commission should examine the application of relevant intellectual property statutes and doctrines, such as breach of confidence.

The University appreciates the need for criminal and other penalties for the misuse and distribution of re-identified data. However, criminal laws relating to the act of re-identification would require a research defence to protect 'white hat innovators' who work on the frontier of data to test its limits and weaknesses. In this regard, the University acknowledges parallel policy considerations underway in Australia about strengthening legislative penalties for the act of re-identifying de-identified data.

We recommend the Commission make a more precise statement of an exemption to cover pioneering research activity into data security and other aspects of data use, so that researchers can continue to conduct their research with confidence. Such an exemption statement would prevent the unwanted result of researchers not engaging in research activity for fear of legal repercussions. For instance, this situation could arise through linkage of government datasets with university-held datasets, which inadvertently resulted in re-identification of data. Or, there have been instances where researchers are conducting responsible re-identification for public interest purposes to test database re-identification security for the purpose of improving database privacy.

Without extension of legal protections for serendipitous discoveries or protections for public interest testing of data/identity security, the University remains concerned about potential risk of adverse, unwanted and possibly unforeseen impacts on researchers under the current or future versions of the *Privacy Act 1988* or other data related legislation.

Recommendation: The *Privacy Act* 1988's proposed research exception should extend to conduct covered by the *Privacy Amendment (Re-identification Offence) Bill* 2016, in particular so that 'white hat' efforts at testing and improving information security will not be at risk.

Regarding **Draft Recommendations 9.2 and 9.3**, covering individuals' Comprehensive Right to access digitally held data about themselves and oversight and complaints handling functions for individuals, the University supports the draft recommendations. We recommend further discussion in the final Report about the protections already available to consumers under the Australian Consumer Law including under s18 (misleading or deceptive conduct in trade), which may also be relevant.

The University also strongly supports the Commission's findings at various points in the Draft Report, including at Finding 8.1, about the importance of maintaining a social licence for the collection and use of people's data through enhancement of consumer rights, genuine safeguards, transparency, and effective management of risk. As part of building trust and confidence in the new system, the University recognises the need for appropriate penalties for breaches of data use, to ensure the long-term functioning of the future Framework and the broadest benefit to society.

The University looks forward to working with governments, sectors, stakeholder and communities to establish a trust-based environment for data custodians and reformed processes based on genuine risk assessments, reflecting expectations and developing increased trust in data security across the wider community, thereby enabling more people to benefit from enhanced access to data.

Infrastructure for sharing health data

Appendix D in the Draft Report provides an extensive discussion on nationwide health data management and barriers to data access in that sector, including the progress of My Health Record and how IT interoperability can present issues in both public and private healthcare and research.

The University welcomes the deep consideration given by the Commission to this area of data access. The critical importance of a more streamlined and accessible ecosystem for health data to keep Australia in a world-leading position in biomedical research was a key point in the University's initial submission to the inquiry.

However, we recommend that the Commission's final Report should include a stronger focus on the substantial risks that face Australia's health system due to the lack of an integrated data foundation and the impediments this creates to better clinical, research and patient practise. This current status has a direct social and economic impact – international cooperation in medical research can only been continued if recruited participants for research can be easily identified and data can be exchanged on a real time basis through big data techniques and integrated digital record systems. New developments in genomics, precision medicine and systems biology all require a more sophisticated integrated data infrastructure than is currently available in Australia. No single nation has resolved all of these issues, but in many cases in the United States and Europe the trajectory for achieving these goals began over a decade ago. Australia's data infrastructure will need to keep pace with international leaders to ensure the benefits are fully captured.

As outlined in the University's earlier submission, when compared to OECD equivalents, Australian hospitals have a very low uptake of electronic medical record systems (or Electronic Health Record system as used in the Draft Report) and the idea of transferring data from one level of the sector to another is almost impossible. The federally-led My Health Record is under-used with around 4 million Australians signed up and the barrier of a highly-complex governing legislation, as noted by the Commission in the Draft Report. While Australia has commendable pockets of activity in data collection and management, on a national scale there is limited real use of data for enhancing patient care, and no overall integrated data foundation to draw all parts of the sector together.

The productivity risks of this situation are high. The health and medical research sector is already seeing the effects of these restrictions. Lack of comprehensive data integration has been traced to sub-optimal health outcomes in medical research, and beyond in clinical outcomes.

In addition to the discussion included in the Draft Report in Appendix D, the University would welcome stronger, centrally placed recommendations by the Productivity Commission on measures to put Australia on the right track to remain internationally competitive in health and health research. The Draft Report comments on page 501 that 'there is little evidence in Australia of government efforts to address the need for interoperability through procurement processes'. The Draft Report also remarks on page 513 that 'there are many and varied operating systems observed across jurisdictions currently in Australia, and a diversity of procurement policies and practices…[and] separate purchasing decisions, with little coordination'.

Appendix D outlines the many benefits of Electronic Health Records and provides an update on slow-advancing eHealth policy in Australia, including the recent efforts to improve MyHealth Record opt-out trials in parts of Australia. The University's view is that this Inquiry is a suitable opportunity to strongly encourage strategic investment in critical digital technologies and infrastructure to enable health record interoperability and data collection, sharing and access, including escalated investment in interoperable electronic medical records in all health institutions and clinical settings.

The University would welcome a clear recommendation from the Commission for Commonwealth and State Governments to work jointly on planning and procuring a long-term and nationwide Electronic Medical Records network and integrated e-health data for the benefit of enhanced medical research and improved health outcomes, and with the appropriate privacy protections.

Recommendation: A streamlined and accessible ecosystem for health data is required to keep Australia in a world-leading position in biomedical research. The University would welcome a clear recommendation from the Commission for Commonwealth and State Governments to work jointly on planning and procuring a long-term and nationwide Electronic Medical Records network and integrated e-health data for the benefit of enhanced medical research and improved health outcomes.

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