



Queensland University of Technology
Response to Data Sharing and Release Legislative Reforms
Discussion Paper

QUT welcomes the proposed data sharing and release legislative reforms. The provision of access to public sector data will be a valuable resource for research and innovation. The proposed legislative reforms are aligned with other initiatives for research outputs such as, the [FAIR](#) data principles of Findable, Accessible, Interoperable and Reusable which provide a useful framework for thinking about sharing data in a way that will enable maximum use and reuse. There is also a new set of global principles that have just been released in regard to Indigenous Data Governance. The principles of CARE (Collective Benefit, Authority to Control, Responsibility, Ethics) are being put forward by [Global Indigenous Data Alliance](https://www.gida-global.org/) <https://www.gida-global.org/>.

QUT aims to work with researchers and their collaborators, in public and private partnerships, to understand their needs, devise the most efficient and effective strategies and develop uniquely tailored solutions to create impact. We have recently established the QUT Centre for Data Science to bring together the expertise of statisticians, machine learners, computer scientists and domain-specific researchers to extract powerful information from data to help solve real-world challenges in health, industry, society and the environment.

Appropriate data sharing and release legislation may facilitate a step change in improving researchers' experiences when dealing with government through the better use and sharing of public data across government to deliver tangible solutions to challenging problems affecting the broader Australian community, to inform policy, improve services and enhance trust with the Australian community.

QUT wishes to provide comment on the Discussion Paper under the following headings.

- Accreditation requirements
- Governance
- Data management
- Case study for data sharing
- Ongoing concerns

Accreditation requirements

The discussion paper looks at an accreditation framework for organisations that access data (accredited users) and for data service providers (data custodians). Accreditation is at two levels – organisation or individual. At the organisational level, accreditation will require standards for facilities, processes and governance for data and at the individual level, training and skill requirements. As a potential accredited data user, QUT is interested to learn more about what will be required from Institutions and researchers to achieve accreditation. QUT acknowledges that this will be further developed as part of this consultation and would like to raise the following points for consideration to inform and assist the development of the proposed accreditation framework:

- Human Research Ethics Committees (HRECs) are required to review and approve research about people or their data according to the principles of the NHMRC National Statement on

Ethical Conduct in Human Research, 2007 ([updated 2018](#)). Therefore, access to information about people (in individually identifiable, re-identifiable or non-identifiable form) as part of an existing published or unpublished source or database will require review by an HREC and this will need to be recognised in accreditation rules/standards. Generally, where research involves large datasets or data collections, the National Statement requires HRECs to consider a waiver of consent where it is impractical to obtain an individual's explicit consent to the use of their information. As part of this consideration the University HREC must comply with Privacy Guidelines (s95 Guidelines and s95A Guidelines) of the *Privacy Act 1988* to avoid legislative breaches.

Furthermore, the National Statement recognises that research involving the use of datasets may be used in ways that risks identifying individuals. Research involving predictive analytics, machine learning capabilities, increased commercial accessibility and the growing proliferation and sharing of data sets may risk data and privacy breaches (degradation of privacy protections). Therefore, the University strongly supports additional guidance as part of the proposed accreditation system to assist researchers, HRECs and Institutions to navigate this complex environment to avoid privacy breaches.

Governance

- The discussion paper supports effective governance to manage and use data. QUT supports the research data management practices as outlined in the recently released NHMRC [Management of Data and Information in Research](#) guide to support the revised NHMRC [Australian Code for the Responsible Conduct of Research](#), 2018.
- A number of specific points noted below require appropriate governance consideration.

Data management

Data categories:

- The discussion paper defines three categories of data: **closed data**, **shared data** and **open data release**. QUT recommends that consideration be given to how the legislation will handle the dynamic nature of these data categories. From QUT's experience, data defined within any of these three categories can change to another category over time. For instance, at a point in time, data may be **closed**, however, at another time point the same data might become **shared** or **open**. Similarly, data that was **open** might become **closed** for instance, as a result of the withdrawal of consent.

Access and purpose:

- With many funding agencies and journal policies encouraging or requiring researchers to share their research data/research outputs and/or requiring researchers to deposit data on publicly available data repositories, the legislation reforms will need to consider how these datasets will be used in future research and any governance arrangements for possible future uses such as, access permissions, ownership arrangements, intellectual property and appropriate security.
- The legislative proposal and accreditation framework should further consider how the proposed legislation will facilitate access to datasets for research that may involve collaborations with international partners, commercial industry partners or other organisations that may not be accredited users but may still require access to the information to facilitate the research. These considerations should also include appropriate access and governance arrangements in such collaborations, such as ownership, Intellectual Property, future use and storage.
- Whilst the discussion paper notes that there are *"a number of complex issues that the legislation still needs to address. These include: commercial purposes, consent, building towards a national system,"* the reuse of data is a further point of complexity. From QUT's experience, beyond the FAIR principles of data, analysis of data will invariably lead to use of

data for purposes not originally intended. We suggest consideration is given to developing guiding principles as to the ‘purposeful application of data’. For instance, to mitigate potential misuse of data, a guiding principle might be introduced along the lines that **data can only be reused if it is of ‘public good’, or of ‘value’ to particular sectors of the Australian community.**

- Of potential relevance to addressing these complex issues faced by the legislation, QUT has developed an exemplar-driven approach to inform institutional research data management policies. This approach, termed, ERDMAS outlines a conceptual framework that defines ‘classes’ of data¹, including commercial uses of data.
- QUT agrees that it is important to identify the ‘purposes’ to be supported by the community for data sharing. Similar issues are faced with patient data: identified, codified and deidentified. A conceptual framework has been developed that might be reviewed to inform the legislation development². As part of this, QUT has developed a **dynamic consent module** that caters for managing patient data. This dynamic consent module is fully customisable and could be reviewed as a model for broader legislation.

Case study for data sharing

QUT’s Director of eResearch chairs the APEC Rare Disease Network and, in December 2018, the governments of the 21 member economies endorsed the APEC Rare Disease Action Plan³. One of the pillars of the Action Plan is to “Manage pooling and usage of patient data securely and effectively” for the estimated 200 million individuals living with one of 7000 rare diseases. The tripartite government/industry/academic partnership requires alignment with patient groups, specialised clinics, industry, and electronic health records across Australian jurisdictions. This requires addressing the same issues of safeguards, privacy and security protections for sharing health data that can dramatically and rapidly improve patient outcomes.

Ongoing concerns

The Data Sharing Legislation Roundtable in Brisbane, on 9 October 2019 highlighted a number of key issues that QUT agrees need to be resolved to successfully deliver the legislation. These include:

1. Competing view on consent
2. Concerns about the legislation overriding existing data secrecy provisions and privacy protections
3. Competing views on the benefits and risks of the legislation.

QUT welcomes the opportunity to contribute comments to assist further discussion and developments for this important legislative reform. We look forward to working with the Australian government and other stakeholders to progress these reforms.

¹ Bellgard, M, ERDMAS: An exemplar-driven institutional research data management and analysis strategy, *International Journal of Information Management*, 50 (2020), 337-340, <https://www.journals.elsevier.com/international-journal-of-information-management/open-access-articles>

² Bellgard et al., RD-RAP: beyond rare disease patient registries, devising a comprehensive data and analytic framework, *Orphanet J Rare Dis.* 2019 Jul 12;14(1):176, <https://www.ncbi.nlm.nih.gov/pubmed/31300021>

³ APEC Rare Disease Action Plan: <https://www.apec.org/rarediseases/Action-Plan>