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# UNLOCKING THE POSSIBILITIES: The Productivity Commission's Inquiry into 'Data Availability and Use' and the Implications for Injury and Disability Schemes

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# UNLOCKING THE POSSIBILITIES: The Productivity Commission's Inquiry into 'Data Availability and Use' and the Implications for Injury and Disability Schemes

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### **Abstract**

The Productivity Commission released its final report on 'Data Availability and Use' in March 2017. This report considers the benefits and costs of increasing the availability and use of data in Australia across the private and public sectors. The report documents a number of findings and recommendations that revolutionise the collection, storage, use and sharing of public and private sector data. Unlocking the insights from these data sources can have potentially significant implications for injury and disability schemes.

This paper will start by giving some background on the current landscape of data that is used by injury/disability schemes. It will then outline the relevant findings and recommendations from the report. We will explore the opportunities that can be generated as a result of the implementation of the new data framework, focusing on:

- safety and risk prevention;
- injury management, treatment/recovery, retraining, return to work pathways, reintegration into the community; as well as
- coverage, product design, benefit design, pricing and costs.

Increasing the availability of data may also introduce a number of challenges. The paper will discuss various considerations relating to privacy, security and discrimination and how these challenges may be overcome.

Keywords: data; privacy; productivity; commission; disclosure; sharing; deidentify; custodian; dataset; access; consumer; rights; release; linkage; NDC; ARA; NID.

### 1. Introduction

The recommendations within the Productivity Commission's report are important as they represent a dramatic shift in government thinking with data now recognised as a shared asset to be widely leveraged for the common good. Increasingly, governments across Australia see the value and potential in making better use of the data it collects and many jurisdictions are already

taking steps to build data sharing regimes that allow government to make better use of the vast amounts of data and information they hold.

Growth in data has rapidly escalated over the last 15 years with the amount of digital data generated in 2002 now generated every two days. There are currently 2.7 zettabytes of data in the digital universe and it is estimated that by 2020, 35 zettabytes (or 35 trillion gigabytes) of data will be generated annually.

The diversity of data is also growing rapidly – historically, data related primarily to information collected and stored on paper and this has now transformed to include information collected through internet activity, transactions and through the growth of the internet of things such as cameras, mobile devices and industrial equipment and the sensors embedded within these devices. Data available includes both structured and unstructured data including video, audio, text, sensor data and log files.

Rapid technological advances and unprecedented computing power increases the scope to leverage the growing volume of data in innovative ways to deliver greater insights and knowledge and to aid more effective and better-informed decision making. There are many real examples of innovative uses of data that have fundamentally transformed everyday life such as apps that suggest the quickest route to your destination taking into account traffic conditions in real time. There are also examples of the use of data to develop solutions in business and government, for example, in the United Kingdom, data linked between administrative health records and cancer screening registries has been used to improve the diagnosis of cancer, leading to earlier detection and improved survival rates.<sup>II</sup>

Australia's provision of open access to public sector data is well behind countries with similar governance structures. For example, in the UK, the midata program, a government initiative, encourages voluntary data sharing within the private sector. Midata brings together business, consumer and privacy groups in a scheme to give consumers access to portable and electronic formats of data held about them by companies. Consumers are able to see what data organisations have collected about them and can access this data to try and find the most appropriate products and services for them.

In New Zealand, the Integrated Data Infrastructure was introduced to bring together tax, health, justice, education and Accident Compensation Corporation data to provide insights to government to inform decision making related to the delivery of better services to the public and to improve social and economic outcomes for New Zealand.

In Australia, there is limited intra-governmental sharing of data between public sector agencies or between agencies and researchers. Much of the overall

growth in data collection and analysis occurs within the private sector where data is collected on customers, including personal details and data relating to transactions. Platforms for the sharing of data within the private sector do exist and one example of this in Australia is Data Republic which offers a platform that allows companies and government to exchange data in a secure environment. Within the public sector, the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) are accredited data integrators for Australian government data.

Against this landscape of rapidly growing data volumes that, to date, have not been fully utilised within Australia, the Productivity Commission was requested to:

- Consider the benefits and costs of options for increasing availability of, and improving the use of data (both public and private sector) by individuals and organisations;
- Examine the options for collection, sharing and release of data;
- Identify ways consumers can use and benefit from access to data, in particular, their own personal data; and
- Investigate avenues to preserve privacy and control over data use for individuals.

The Commission recommends comprehensive reform to Australia's frameworks (related to regulation and protection) for the collection and use of data to leverage the value of the wealth of data available in today's digitised world. The transformation of Australia's data infrastructure is aimed at building society's confidence and trust in data use and to promote the idea that data is in fact an asset and can be used to drive commercial value and potential innovations.

If the Commission's recommendations are adopted in full, significant legal and structural support will be required. The recommended framework for open and transparent data sharing and management includes the following reforms:

- a new Data Sharing and Release Act to govern data access, sharing and release and to establish the Office of the National Data Custodian to guide and monitor the new data system. The Act is intended to complement the existing Commonwealth Privacy Act, State-based legislation and community consultations.
- Creation of a 'Comprehensive Right' giving consumers greater control over their own data. This will be a matter for Parliament to legislate and would cover both public and private sector data.
- Creation of a regime for data sharing and release that recognises the different risks and benefits of different datasets which involves the establishment of Accredited Release Authorities within particular sectors.

The implementation of the recommended framework within an already complex regulatory regime will be a challenge. It remains to be seen whether and to what extent the proposed framework will be adopted.

### 2. Data currently used in Injury and Disability schemes

A wide variety of data is collected by injury and disability schemes but often only a subset of it is used in a meaningful way. The types of data used by actuaries for reserving, pricing and monitoring typically include:

- Exposure information (e.g. wages by industry code for workers compensation, numbers of vehicles by vehicle class for Compulsory Third Party (CTP));
- Driver profile and vehicle details (for CTP);
- Demographic data (e.g. age, gender, indigeneity);
- Claim status (e.g. active, finalised, reopened, litigation indicator);
- Details about the incident (e.g. cause of accident/injury);
- Details about the injury/disability (e.g. nature of injury, injury severity, primary disability);
- Transactional information (e.g. payments by payment type);
- Details about scheme participant outcomes;
- Case estimates.

Schemes can use both data collected by the scheme itself and also data collected externally. Examples of external data sources that might be used include industry data related to occupational diseases, motor collision data and meteorological data.

Scheme managers rely on data to estimate the cost of risk and to set prices for their insurance policies. Schemes are generally able to adopt a number of rating factors if there is a proven statistical basis to do so (and if they meet legislative requirements) and they rely on data to identify these factors and the relativities between them. However, compulsory classes such as CTP and Workers' Compensation have some restrictions on how data may be used to set prices to ensure premiums remain affordable for all policyholders. Nevertheless, in order to accurately estimate and project total scheme costs that allow for a changing mix of profiles, it would be desirable to capture all factors that have an influence, regardless of whether they can be used for rating purposes.

In addition to the typical data used for reserving, pricing and monitoring purposes, other data items may be used for analyses such as fraud investigations, where users may drill down to a much more granular level to investigate the activity of specific service providers. In conducting expense analyses, data from a time and motion study may be analysed to understand the effort and resources needed to perform various claims handling activities. Where a scheme has been rebranded, it may be of interest to understand the success of this rebranding, through analysing data on the number of times the new brand has been searched on internet search engines, or the number of times it has been referenced in social media posts.

The nature of data potentially available to schemes has also expanded, for example, to include improved availability of personal medical information (through wearable technology such as Fitbits which provide information on exercise, activity, sleep patterns etc.) and real time motor information such as

location, driver behaviour and engine information provided through the use of telematics.

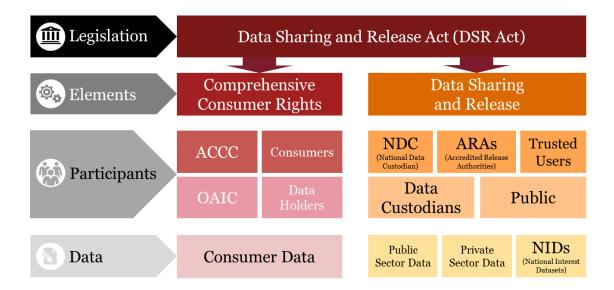
In our view, whilst a variety of data is currently being used by schemes to provide insights (whether these are used by actuaries or non-actuaries), this only constitutes a small subset of the large universe of data potentially available to schemes to support decision making. Furthermore, this universe could be expanded through the collection of other types of data that could be used to supplement existing data for meaningful analyses.

### 3. Key Recommendations

The Productivity Commission has made forty-one recommendations in its report. In this paper, we have documented the key recommendations, and those that are expected to have implications for injury and disability schemes.

The following diagram summarises the new data framework recommended by the Inquiry.

Figure 1: New Data Framework



### Data Sharing and Release Act

New legislative reform through the Data Sharing and Release Act (DSR Act) will be introduced to implement a new data framework. The new framework will consist of two elements. The first element involves the creation of a new right for active data use by consumers through reform to competition policy, with the objective of increasing competition and consumer choice. The second element involves the establishment of a structure for data sharing and release, with the aim of authorising better sharing and release of data that is in the public interest, overriding outdated secrecy provisions. These two elements are further explained below.

### A New Comprehensive Right for Consumers

The DSR Act will introduce a new comprehensive right for consumers, giving them greater control over the use of their own data. For the purposes of this element, consumers will include both individuals and small and medium sized businesses (SMEs). The Act will give both the data holder and the consumer 'joint rights' to access and use the consumer's data, as opposed to the current situation where consumers generally have limited access to their own data. In particular, the new right will allow:

- consumers to receive copies of their own data;
- consumers to request edits/corrections to their data;
- consumers to be informed when their data has been traded or disclosed to third parties; and
- consumers to instruct data holders to transfer data in machine readable format to a third party (who may be a competitor).

This right applies to both public and private sector data. Although there are some similar provisions, it is separate from the Privacy Act, which regulates the handling and use of personal information about individuals. Note that in Australia, no one 'owns' data, although copyright law may give possible claim to ownership over a processed dataset. Privacy law only regulates how personal information is collected, used and disclosed. It does not specify any 'ownership' of data.

With respect to this reform, consumer data is defined as digital data held by a product/service provider that is identified with a consumer and associated with a product or service provided to that consumer. In its broadest definition, consumer data includes:

- all personal information as defined by the Privacy Act;
- all files posted online by the consumer;
- all data from consumer online transactions or internet activity;
- data purchased by the product/service provider, or obtained from a third party; and
- other data on transactions/activity in digital form relevant to transferring data to a nominated third party.

This broad definition of consumer data will apply until each industry registers data specification agreements with the Australian Competition and Consumer Commission (ACCC), which may specify definitions that are narrower than this. The ACCC will be responsible for educating consumers on the new right, assessing levies charged by data holders for applying the new right, and handling complaints. The Office of the Australian Information Commissioner (OAIC) will continue to have responsibility for compliance with the Privacy Act.

### Structure for Data Sharing and Release

Currently, data is already being collected, stored, integrated, shared and released on a business as usual basis by existing data custodians. For example:

- Samples of census data that are collected by the ABS are de-identified and released for public use on request, under specified conditions of use.
- The AIHW holds and grants access to data on a range of health and welfare topics. Some of this data is publicly released whilst others are shared subject to approval.
- Data.gov.au is a platform that allows the public and researchers to find and access datasets published by the government. Information on unpublished data is also available.

The DSR Act will introduce a new structure for data sharing and release that promotes greater use of nationally significant datasets by applying a risk based approach to data sharing and release. Instead of the current mindset of releasing non-confidential data on request only, the new structure strives to create a culture of actively pushing out data in a coordinated way. Note that data 'sharing' refers to the sharing of sensitive data with 'trusted users' that meet certain required standards. Data 'release' refers to the open release of non-sensitive data to the public.

This element of the Act will be achieved through the establishment of various new entities/participants, as discussed below. In addition to this, a special classification will be assigned to datasets of particular significance, known as National Interest Datasets, to enable the prioritisation and focus of data sharing and release.

### The National Data Custodian

The DSR Act will establish the National Data Custodian (NDC), which is a statutory office that will oversee the operation of the DSR Act. Some of its key responsibilities include:

- the management of the national data system;
- the designation of National Interest Datasets;
- the accreditation of Accredited Release Authorities and determining which key datasets each ARA is responsible for;
- the provision of guidance to ARAs and data custodians on risk management, such as data curation, data security, deidentification methods etc;
- the management of ethical considerations of data use; and
- the streamlining of the approval process for data access and use.

### **Accredited Release Authorities**

Accredited Release Authorities (ARAs) will be accredited by the NDC. ARAs are national or state/territory based public sector agencies that are 'sectoral hubs of expertise'. Their key responsibilities include:

 the coordination of State and Federal Government agencies and data custodians to integrate datasets across a sector (and between sectors);

- perform data linkage activities for their jurisdiction or sector and perform ongoing work to ensure the continued accuracy of data and usability over time;
- the approval of trusted users and the provision of data to trusted users;
- the determination of whether a dataset should be shared or released; and
- the provision of assistance to data custodians on curation, deidentification, encrypting, data linkage (of National Interest Datasets and other datasets) and risk management.

### **Trusted Users**

Trusted users are individuals, personnel in government agencies or research bodies who meet certain governance standards and requirements, such that they can be given access to 'sensitive' data that is not suitable for open release. They will be responsible for the appropriate use of this data.

Trusted users must sign a legal undertaking that sets out the safeguards for data use. They can only access data in a secure computing environment. ARAs grant access to trusted users on a program (rather than a project) basis. A trusted user status ceases when a program is completed or the individual leaves the agency.

### **National Interest Datasets**

As mentioned previously, a special classification will be assigned to datasets of particular significance, known as National Interest Datasets (NIDs), to enable the prioritisation and focus of data sharing and release. It is expected that once these NIDs are shared/released, that they can be used to generate additional benefits to the nation.

NIDs are a subset of high value datasets meeting the following criteria:

- offer clearly described public interest benefits (broad economic and social benefit) beyond benefits to initial data holders;
- focus on nationally significant subject matter;
- form the basis for performance evaluation and comparison between programs and investments by the government.

Only a relatively few number of datasets will meet the criteria to be classified as NIDs. They will need to have a high degree of coverage of the population and are likely to be datasets created as a result of linkage, integration or transformation. Acquisition of private sector datasets may be made for the purposes of creating NIDs. These will mainly include data collected in the private sector due to services funded or legislatively authorised by public policy, such as education, health, utilities, water, telecommunication etc.

Datasets will be designated as NIDs by the NDC and ARAs will support the preparation, maintenance and curation of NIDs. Initially, the designation will

focus on Commonwealth datasets and their State/Territory counterparts. Funding will be provided for curation, linkage and aggregation across jurisdictions and sectors. Once designated as an NID, the classification would last for 10 years. ARAs will provide broad access to NIDs via open release to the public if appropriate, or by initially trialling through sharing with trusted users to demonstrate that individual identification is not compromised. Data custodians who contributed to the creation of NIDs should be given access to the final, linked, de-identified dataset.

### Other Recommendations

Other notable recommendations from the Inquiry are as follows:

- Government agencies are to release non-personal and nonconfidential data for widespread use, including information that identifies individuals that is already in the public domain.
- Non-sensitive NIDs are to be released immediately.
- A central government agency in each jurisdiction is to be given responsibility to maintain a system whereby government agencies, researchers and the private sector can nominate datasets for public release with priority given to high value, in-demand datasets.
- Australian government agencies entering into contracts with private sector providers that involve the creation of datasets should ensure that they have the right to access or purchase data in machine readable form.
- The private sector is to determine their own sector-specific standards for data sharing.
- Allow access to identifiable individual information without consent, for all public interest research.

### 4. Unlocking the Possibilities for Injury and Disability Schemes

### **Unlocking the Possibilities**

The recommendations made by the Inquiry, if implemented effectively, are expected to revolutionise the way data is managed and shared. The change in the playing field could establish a culture (in both public and private sectors) that improves all aspects relating to data, beyond the direct impacts of the specific reforms themselves. In general, this would lead to:

- the collection of more data:
- improvements in the quality of data (completeness, accuracy, consistency);
- improvements in data storage and risk management;
- greater trust and comfort in data sharing; and
- an overall increase in the 'usefulness' of data.

When data becomes 'more useful', it will encourage more analyses and improved analyses to be conducted to solve different problems or to solve problems in different ways. This in turn may reveal the need for an expansion in the data being collected. The resulting 'eco-system' will bring increased

insights that fosters innovation to bring greater benefits to the community. Injury and disability schemes will also share in these benefits.

It is obvious that unlocking the insights from data to reduce risks of injury and improve outcomes for those with injuries or disabilities is in the public interest. This implies that data that can be used for the purposes of improving injury prevention, injury management and/or any aspects of injury/disability schemes could qualify as NIDs.

There are specific provisions in the Inquiry's recommendations that focus on public interest datasets. However, rather than restricting our discussion to these specific provisions, we have taken a broader view of how 'more data' and 'more useful data' can be used to influence outcomes in an injury/disability scheme setting. We have focused on 'what might be possible', rather than the specifics of how the 'possibilities' might be achieved, for the purpose of generating ideas and discussion.

In general, the additional available data can be used in two ways:

- for real-time, tactical purposes (where behaviour, decisions and outcomes can be influenced immediately); and
- for research and strategic purposes (where data is analysed to inform longer term improvements in the structure and operations of the scheme).

The following sections discuss how improvements to data availability can lead to analyses to achieve better outcomes from both an injury prevention perspective (pre-event) and from an injury/disability management perspective (post-event). Both real-time and strategic examples have been included. The learnings and insights from these would then flow through to impact design, pricing and costs for schemes.

### **Opportunities for Injury Prevention**

Sensors, Wearable Devices and Health Apps

A number of research studies have shown that a person's health can be closely associated with risks of injury. For example, people who are obese may have an increased risk of falls, trips and slips. Sleep apnoea, which is strongly associated with obesity, can increase the risk of injuries from road accidents. There is also a body of evidence that suggests a linkage between physical wellbeing and mental health. Therefore, it follows that people's behaviour with respect to their health and well-being can be good predictors of injuries and accidents (be it physical or psychological). People who look after themselves, e.g. eat healthy foods, exercise regularly etc. may be less likely to have or cause an injury. The opportunity for injury schemes would then be to collect data on this, analyse the strength of the relationships, which would then inform policy changes to incentivise the desired behaviour. We know that data on health behaviours is already being generated and captured through sensors, wearable devices and health apps on smart phones. The challenge would be for injury schemes to harness this data and make use of it. An example where

a similar principle has already been adopted is the Qantas Assure Wellness Program which awards 'points' for exercising (walking, running, swimming and cycling). These activities are monitored using wearable technology through the Qantas Assure App. Consumers can use the points earned towards paying premiums for health, life and travel insurance policies purchased with Qantas.

In a workers compensation context, an approach that could be taken to encourage 'healthy behaviour' would be for employers to offer health and well-being programs/benefits to employees (programs that have been proven to reduce risks) and for injury schemes to offer premium discounts to these employers (subject to the rate of take-up of the programs by employees). We could expect the frequency and/or severity of injuries to fall as a result of the favourable change in behaviour.

Alternatively, in a compulsory third party (CTP) insurance context in the absence of pricing regulations, policyholders could present evidence of healthy behaviour in return for premium discounts. QBE already offers discounts on comprehensive motor insurance premiums to reward good 'driving behaviour' as measured through their insurance box technology.

### **Employee Satisfaction**

Various studies have demonstrated strong relationships between employee satisfaction/engagement and workers compensation injuries. The linkages between employee engagement and psychological injuries are not so difficult to understand. Employees who are unhappy in the workplace or suffering from stress on the job are more likely to make psychological claims. Viii In our experience, this is particularly evident in the public sector. Interestingly, some studies have also shown an association between employee satisfaction and physical injuries. In particular, mental stress can be a cause of back pain and musculoskeletal disordersix. If data on employee engagement was made available (e.g. employee satisfaction survey results), it could be analysed to understand the strength of the relationship present and used for rating purposes. Employers with favourable results could receive a premium discount. This would incentivise a greater effort for employers to understand the sources of stress and/or develop better relationships with employees. Where appropriate, training programs can be implemented that discourage bullying, discrimination and harassment behaviours, which are common causes of stress claims in the workplace.

### **GPS** and Cameras

With advances in technology and changes in workplace culture, a greater proportion of the workforce is working flexibly. In particular, there has been a trend for employees to work away from the office environment, made easy by remote access to the office network. They could be working from home, or working from the local café. This means that the working environment is no longer under the control of the employer, making occupational health and safety difficult to manage. How can employees be made aware of the risks to

injury and help reduce these risks? There is an opportunity to use GPS data and data from cameras to help identify risks.

GPS data could be used to identify instances when employees are working away from the office. Cameras on smart devices could be used to capture information about the environment, with apps used to process this information and highlight areas of risk, such as insufficient lighting; non-ergonomic set up of the home office; tripping hazards etc. Some technology that enables this already exists. Interior designers use structure sensors that attach to smart devices to scan and measure objects and an app called 'Canvas' can be used to capture 3D scans of rooms and spaces, enabling accurate measurements to be made within the scan.\* This data would enable better risk assessments and prevention strategies to be made, even if it just involves alerting the worker via a pop up message in real time about the risk areas, such that they can take their own precautions.

### Employer claims track record

In deciding whether to join a particular organisation, employees may want to take into consideration the past workers compensation claims track record of the employer. This might be especially relevant for high risk, labour intensive industries, where the frequency of physical workplace injuries is likely to be higher. A good track record may indicate good occupational health and safety and injury risk prevention practices of the employer. If this type of data was made available for benchmarking the frequency of injuries across employers by industry, organisations with good performance may be more able to attract talent. This would encourage all employers in the industry to improve their performance in injury prevention.

### Social media data

Various techniques have been developed to monitor social media data, including the content of tweets and posts, as well as searches made on search engines. Apps have been developed that scrape the web for this data and data mining techniques can be used to interpret word choices/phrases used in tweets and searches to identify instances of psychological diseases and depression. For example, 'We feel' is an online web tool developed by the CSIRO for the Black Dog Institute that analyses tweets to look for emotions, the strength of the emotions, and linkages with social, economic, environmental factors, with the aim of identifying depression.xi The 'Mindstrong' health app uses digital phenotyping to understand mental health through the way people use their smartphones.xii Word choice, typos, voice patterns and physical movements are analysed to reveal mental, psychological diseases and depression, with the hope of reducing suicide risk.

If this data could be collected at an individual level and analysed, it could be used for early identification of these conditions such that intervention can be used to prevent development into more serious psychological conditions. This would not only benefit those with the conditions to reduce the possibility of self-

harm, but also the people around them, as sometimes those who suffer from psychological conditions may inflict harm and injury to others.

### Opportunities for Injury Management and Early Intervention

### Service Provider Benchmarking

Most schemes currently engage service providers via contracts with specified terms. Such providers can include claims managers, occupational rehabilitation, medical and legal providers. The quality of service for different service providers may differ significantly, and it may be difficult to identify a standard of quality/outcome. The collection and publication of data on outcomes for service providers may assist in decision making. For example, it may be useful to understand the expected recovery times for scheme participants for different types of injuries. This would allow:

- providers to understand their performance relative to benchmark performance;
- in the workers compensation context, claimants and employers to better plan for return to work;
- scheme participants to benchmark the progress of their recovery and seek alternate support if it is not progressing as expected;
- schemes to more accurately project costs; and
- development of a performance based remuneration structure for service providers that could encourage improved performance and therefore better outcomes for scheme participants and/or the scheme itself.

### Service Provider Market Place and Service Reviews

The availability of data and the ability to assess it in real time can lead to greater efficiency in case management. For example, if an online and mobile marketplace similar to 'airtasker' was made available, this could provide a platform whereby:

- The scheme manager can upload claims or cases that need to be managed (including some de-identified details regarding the participant).
- Service providers can bid to manage the claim/case or treat the
  participant for a fee, with a specified outcome such as return to work
  within a certain number of days or an improvement in functional
  capacity. Service providers bear the risk of not achieving specified
  outcomes.
- Ratings and reviews can be used to incentivise the service provider to manage the claim/case appropriately, with insurers/schemes opting to only deal with service providers with proven track records as evidenced by their ratings.

The establishment of a market place could aid access for new entrants and promote competition. It may also result in a more efficient allocation of

resources, for example by identifying locations or types of injuries that require specialist treatments, where demand for services exceeds supply.

### Accessing data from other organisations

Schemes may be able to access and share information with other sectors to support data driven decision making. For example, data from the wider health sector could be used to identify the most successful treatments (most responsive, durable and cost effective) applied to particular types of injuries. In this way the data accessed for the management of a workers compensation scheme is not just limited to information on work related injuries. Data collected by Roads authorities relating to driving infringements could allow for more accurate risk rating of individual drivers for CTP.

Some disability schemes collect information on non-financial outcomes e.g. the National Disability Insurance Agency (NDIA) collects information on the impact that the operation of the scheme has on the quality of life of scheme participants. This outcomes framework involves questionnaires that collect information about various domains of life of participants. We are aware that not all disability schemes have mechanisms in place to collect this type of information as a measure of success of the scheme. In our view, it would be in the public interest for schemes to share their knowledge of and experience in collecting and analysing this data for the purposes of improving their operations. In addition to the sharing of information between schemes, there may be benefits for schemes to access other sources of data collected in relation to scheme participants. For example, GPS data and Opal card data provide information regarding movements and consumer data can provide information about expenditure. This type of data may give an indication of the level of social and community participation achieved by scheme participants. Alternatively, if scheme data was linked to taxation and welfare data, it would be possible to track whether scheme participants have been able to return to work (because they would earn an income and pay tax), or whether they are in receipt of welfare payments. The sharing of data in this way should also allow for a more seamless transition of participants between systems (e.g. as a workers compensation claim becomes finalised, the welfare system would already have this claimant's details.)

### Transferability of consumer data

Where scheme participants are able to select their own service providers or where they receive services or treatment from multiple service providers, transferability of data will aid the process of switching providers and/or sharing information between providers, promoting competition and efficiency. All the information about their care needs, condition or treatment history can be easily transferred from one provider to another rather than the scheme participant themselves having to act as a conduit of information between service providers.

Sharing experience and information

Over the last decade or so, there has been a dramatic increase in the use of the internet to seek health advice and share health experiences. Sources of advice range from officially accredited services to unmoderated consumerled chat rooms and forums, e.g. steadyhealth.com. These forums facilitate exchange and sharing of experiences and knowledge. This concept could be expanded to an injuries/disabilities context and can lead to a number of benefits:

- Chatrooms may provide a network for scheme participants where individuals can support each other emotionally, through the sharing of experiences with those having similar hardships.
- Best practice approaches to treatment may emerge from collecting and distilling data from conversations on what has worked well and what hasn't.

An example of the use of this data mining approach is the Sickweather app that searches Twitter and Facebook for public comments on respiratory and gastrointestinal illnesses as well as allergies and plots them on a map.xiii When passing through a 'sick' zone, users can view the illness report and see their proximity to the area.

This knowledge sharing can extend beyond local jurisdictions to international learnings.

Data available from new technologies

New technologies such as the 'Internet of Things' and sensors provide new and innovative ways to connect with scheme participants and achieve efficiencies. For example, the data collected from wearable devices can be used by workers' compensation claims professionals to:

- provide a real-time view of the capabilities, the health status and progress of the recovery of an injured worker;
- track injury recovery which may assist in ensuring painkillers are not overprescribed;xiv and
- design recovery plans and long term prevention strategies for injuries or re-injuries e.g. workers suffering from severe burns may need to stay out of the sun and a wearable device can be used to monitor their exposure to sunlight.

### Opportunities for improving Benefit Design

Benefit structure designed to improve outcomes

An increase in the availability of data will allow analyses to support changes in benefit structure that may lead to better outcomes for scheme participants. Data currently collected by schemes can be quite limited and specifically relates to scheme participants only. However, the quality of outcomes for scheme participants will likely depend on a myriad of factors arising from their individual circumstances. A better understanding of the full picture for them

and those affected by their condition (e.g. family members) may lead to changes in benefit design to better meet their needs.

For example, family members are often relied upon to provide informal (unpaid) care for scheme participants. This can be quite stressful for family members and reduce their capacity to work to earn the income they could have otherwise earned. Some may end up relying on welfare payments as a result.

The ability to link data from different sources for the scheme participant as well as for those around them who are affected will give a more comprehensive picture of their needs. Analysis may reveal that participants have better outcomes when they are cared for by family members, in which case it may be desirable to change the benefit structure to provide compensation for family carers to encourage this practice. Conversely, analyses may indicate that full-time care provided by family members is too taxing, and results in a net negative societal/economic impact. In this case, the benefit design may be modified in a way that provides better support for part-time family care.

### Applying a Lens of Realism

Much of the discussion above has been generated assuming a status of 'utopia', where the application of the recommended framework produces an environment that encourages the collection, sharing and usage of data freely. However this may not be realistic. In fact, some of the examples that we have cited do not need the implementation of the framework for their application. Greater sharing of data across injury and disability schemes; across similar schemes in different jurisdictions; or across schemes and other sectors (e.g. the Health sector) can occur now. However, we are only aware of limited instances of sharing, and there could be various reasons for this. Schemes may be too focused on managing their own issues e.g. rolling out new reforms, to consider the logistics and benefits of sharing data with other schemes. Alternatively, a scheme may have made a significant investment in a particular area to improve its operations and is not prepared to share its intellectual property. There could also be privacy concerns with respect to data on individuals, although it should be possible for schemes to share de-identified data. Ultimately, there needs to be a balanced consideration of scheme interests against public interests and privacy concerns. How the new framework can influence these considerations in practice remains to be seen.

We believe that the following specific provisions of the new framework could have a tangible impact on schemes:

- the new consumer right;
- the designation and creation of NIDs; and
- the use of identifiable data on individuals without consent for public interest research.

The new consumer right should make it much more seamless for scheme participants to transition between service providers, encouraging competition and ultimately leading to better (more efficient and effective) service delivery.

The designation of NIDs could mean the compulsory sharing of data between schemes and/or jurisdictions to create a unified dataset, if it is deemed to be in the public interest. However, the application of this provision could be subject to different interpretation, with the level of sharing and the type of data to be included in the NIDs subject to significant debate. For example, whilst it may be in the public interest to improve employee satisfaction for the purposes of reducing the incidence of workers compensation injuries, it may not be realistic to require employers to submit employee satisfaction data for inclusion in the NID even though the framework provisions allow for the acquisition of private sector data where necessary. Similarly, employers are unlikely to agree to the publication of their workers compensation track records to allow prospective employees to benchmark between employers, even if this is in the public interest. Employers have their reputations to protect in these respects and poor performing employers may not be willing to share.

Another instance where the application of the provisions for the creation of NIDs may be difficult is in the access and sharing of data on individuals (even if the resulting dataset is de-identified). For example, we have suggested that GPS data, Opal data and consumer expenditure data (from retailers) may be useful in giving an indication of community participation and quality of life of scheme participants. Again, whilst it would be in the public interest to assess participant outcomes for the purposes of improving scheme operations, participants may object to this 'big brother' approach to monitoring their outcomes. The practical implementation of the framework will need to balance the considerations of privacy concerns against public interest needs. Similarly, where the framework allows for the use of identifiable data without consent for public interest research purposes, the actual application of this provision may still face challenges from privacy advocates.

### 5. Challenges and Risk Management

In addition to the practical challenges of implementing the proposed framework discussed above, additional challenges will emerge as the availability of data increases over time. The sections below discuss these challenges and how the new data framework seeks to overcome them, as recommended by the Commission's report.

### **Challenges from Data Availability**

As data becomes more available, there will be challenges from three fronts – concerns from individuals/the community, concerns from data holders/providers and concerns from data users. These challenges also explain why data release, sharing and use have been so limited to date.

### Concerns from Individuals/the Community

The main concerns that individuals/the community have in giving access to their data are as follows:

- fear of an invasion of privacy;
- fear of being targeted/discriminated against;
- identity theft/fraud;
- fear of being tracked/monitored, resulting in a loss of freedom;
- dissatisfaction that their data will be used for commercial purposes.

These concerns are exacerbated by the fact that consent is currently given, often without individuals genuinely understanding how the data will be stored or used by the data holder, or how the data may be shared with third parties.

### Concerns from Data Holders/Providers

The main challenges that limit data holders/providers from making data more readily available are as follows:

- a dense web of legislative requirements governing data sharing;
- an entrenched culture of risk aversion in the public sector, primarily caused by a misinterpretation of privacy legislation requirements and the penalties from confidentiality breaches;
- the lack of a whole of government approach, with significant jurisdictional barriers to data sharing;
- intellectual property rights that impose a limit on the sharing of data;
- legal limitations on the linkage of datasets;
- legacy IT systems, hindering the automation of data provision;
- the requirement for datasets to be destroyed after research projects have been completed.

### Concerns from Data Users

The main barriers that limit data users from accessing and making better use of data are as follows:

- lack of discoverability of data, with users unaware of what data is actually collected by data holders;
- lack of data standards, resulting in inconsistent definitions of data fields and formats being used across different datasets;
- lack of skills and resources from data holders to maintain/maximise the usability of datasets;
- fragmented collection and release of data by data holders, resulting in difficulties in repeating the analyses over time;
- lengthy approval processes to access data, including lengthy processes for approvals by ethics committees for research.

Whilst the concerns of the various participants are legitimate, the Productivity Commission report suggests that risk aversion is not the answer. The following section discusses some of the risk management solutions and approaches to

managing data identified by the Commission that will help overcome these challenges.

### **Data/Risk Management**

One of the main concerns from individuals/the community about giving access to their data revolves around the security in how their data will be stored and uncertainty in how their data will be used. Data holders/providers are also concerned about the penalties and reputational damage that data breaches would bring. Even with data that has been de-identified, there have been cases where re-identification techniques have been applied to data without authority. For example, in 2016, the Department of Health had to withdraw its publication of a de-identified open dataset on Medicare and PBS claims once it was revealed that it could be decrypted to identify practitioner details.\*

The Inquiry suggests that the approach to addressing the community's concerns is to build trust. If individuals feel that they have a sense of control over their own data and they are able to share in the benefit from the use of their data (or can see potential benefits to the community), they would be more open to sharing their data. For example, around 84% of Australians are enrolled in at least one customer loyalty program, where information about the customer is collected in exchange for certain benefits to the customer.xvi Further, surveys conducted suggest that over 90% of Australians are willing to share de-identified health data about themselves to advance medical research and improve patient care.xvii The new right to consumer data introduced as part of the new framework goes towards building trust.

With respect to the security of data storage and use, history has shown that in most cases, data breaches occur due to malicious/criminal activity rather than human error/systems failure. If the community has a sound basis for believing in the integrity and accountability of entities handling data, they would be more willing to share their data.

The Inquiry has suggested the following risk management approaches to building trust in the community:

- Recent amendments to the Privacy Act require mandatory notification of data breaches.
- Proposed amendments to the Privacy Act introduce criminal and civil penalties if de-identified data published by the Commonwealth Government is re-identified and disclosed.
- The NDC will publish better guidance for de-identifying data and ARAs will provide assistance to data custodians with de-identifying data.
- ARAs will publish formal risk management processes to effectively assess and manage the risks associated with the sharing and release of data under their control, including data security and accountability of data holders and data users.
- ARAs will implement the trusted user model, where only accredited users are able to access data in a secure environment, with controls on how data can be used.

- The trusted user model will be governed by data sharing agreements that specify permitted uses and disclosures of data; who may use or receive data; safeguards to prevent unauthorised use; the binding of subcontractors to the same rules; and prohibiting the re-identification and contacting of individuals.
- Secure computing environments will be used e.g. the SURE system, which is an environment disconnected with external servers, subject to rigorous vetting and usage monitoring.
- Risk management processes will be regularly reviewed and revised to account for new and emerging risks.

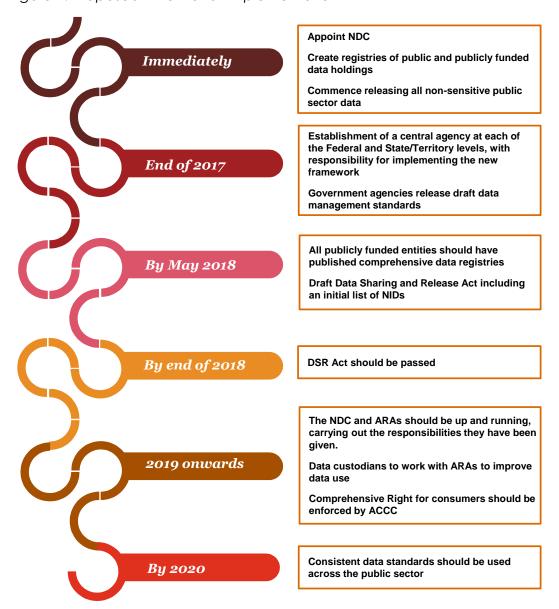
With respect to overcoming the concerns of data users, the following aspects of the Inquiry's recommendations address these:

- Government agencies and publicly funded entities must create comprehensive data registries and publish them to aid data discovery.
- Government agencies should adopt and implement consistent data standards to facilitate the comparison, aggregation and linkage of data, including the creation of longitudinal datasets.
- Additional qualified entities should be accredited to undertake data linkage. Currently, only six accredited state-based 'nodes' can link state data, and three accredited integrating authorities - the ABS, the AIHW, and the Australian Institute of Family Studies (AIFS), can link Commonwealth data.
- Approval processes to access data and approvals by ethics committees should be streamlined.
- The existing exceptions in the Privacy Act that allow access to identifiable individual information without consent for health and medical research should be extended to all public interest research.
- Publicly funded research must openly publish research data and metadata, to facilitate use by other researchers.
- The requirement for linked datasets and linkage keys to be destroyed at the end of research projects should be abolished to ensure that value added by researchers is retained and available to other users.
- ARAs will curate datasets and ensure the timely update and maintenance of datasets.

### 6. Timeline for Implementation

The Commission has recommended comprehensive reform to Australia's data regulatory and protection frameworks which will require significant support from a legal and structural perspective. An ambitious timeline to reform has been proposed and the key recommended milestones and timeline for the implementation of the new framework and the Inquiry's recommendations are described in the figure below.

Figure 2: Proposed timeline for implementation



We are aware that a taskforce has been established within the Department of the Prime Minister and Cabinet to advise the Government on its response to the recommendations made by the Productivity Commission. However, no responses have been made thus far.

The release of this report signposts a shift in the government's attitude towards data use. Many jurisdictions are already responding to the challenge of making better use of the data they collect and are well into planning for whole-of-government data sharing.xviii

In Western Australia, the government has been advised to construct a whole-of-government data linkage system which builds on the State's existing strengths in population health data linkage and research. The success of the health data linkage has prompted a growing demand to link non-health data including data related to the justice and corrections system, disability services and education and training.

South Australia's whole-of-government data sharing legislation came into effect in May 2017. This legislation aims to extend the reach of data sharing by enabling the government to work with the Commonwealth, other states and territories, local councils and the non-Government sector. A new data analytics office has been formed with the responsibility of coordinating data storage, sharing and analysis.

The Victorian Government has established the Victorian Centre for Data Insights (VCDI) to improve the way they share and use data. The VCDI will lead projects which showcase the benefits of sharing data across government to make better decisions. They are also developing new legislation that sets out how data can be responsibly shared across government while protecting privacy and data security.

NSW has had a data sharing act since 2015. This act aims to remove the barriers that impede the sharing of government sector data and to implement measures to facilitate the sharing of government sector data between other agencies. In 2015, the state government also established the Data Analytics Centre (DAC) to facilitate data sharing between agencies to provide data driven insights to support evidence based decision making and policy setting. More recently, the NSW Government has contracted Data Republic to deliver a secure open data marketplace to allow the state government to provide controlled access to a range of government datasets.

In addition to the state initiatives outlined above, the Commonwealth Government announced as part of the budget in May 2017 that it will invest \$131 million over three years in the Data Integration Partnership for Australia (DIPA).xix The functions of DIPA include:

- creating high-value national data assets to build longitudinal data about populations, businesses, the environment and government. This will involve data integration (i.e. the linking of datasets); and
- establishing data analytics teams to maximise the use of these datasets to enable cost effective and timely insights.

This will result in improved, evidence-based government programs and policies that focus on areas like social and economic welfare, and government

efficiency. In particular, the government has expressed an interest in using the insights to identify and prevent risks of disability in the workplace, and to support ongoing workforce participation for those with a disability.

DIPA will preserve the privacy of individuals and the confidentiality of businesses by analysing de-identified data. The ABS and the AIHW are two accredited authorities that will carry out data integration for DIPA. Other organisations, including non-government organisations, may also apply for accreditation. The new datasets created for the DIPA will only be accessible by trusted users within secure environments.

There are many parallels that can be drawn between DIPA and the new data framework, although the new framework is obviously much broader, covering both private and public sector data. Time will tell as to whether the two initiatives will interact.

### 7. Conclusion

The new data framework recommended by the Productivity Commission as documented in its report on 'Data Availability and Use' introduces a risk managed approach to data sharing and release. We believe that this is an important first step to changing the culture in the Australian environment, and if implemented effectively, will result in greater availability of data across both the public and private sectors. The potential for innovation and increases in efficiency as a result of the insights gained from analyses of this data could bring wide-ranging benefits to the community, including injury and disability schemes. The possible impacts of the new data framework on the prevention of injuries and improvement of outcomes for scheme participants outlined in this paper represent only some of the opportunities made possible if the recommendations within the framework are adopted.

With the report recommendations currently being considered by the government taskforce, Schemes should be working to understand and quantify what could be gained if the proposed changes were to be adopted. This will require a consideration of what is currently possible in the absence of the recommended framework and what the barriers are to creating value using existing data. Schemes also need to form a view as to what could be possible if the recommended framework were to be implemented, and may determine that there are benefits to be gained from the implementation and therefore that it may be worthwhile to lobby for this. Regardless, Schemes should be considering how best to set themselves up for success should the recommendations be implemented.

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