# RESPONSE TO PRODUCTIVITY COMMISSIONS' INQUIRY INTO: *DATA AVAILABILITY AND USE*

## FROM

## THE *HEALTH MARKET QUALITY*
## RESEARCH & DEVELOPMENT PROGRAM
## OF THE
## CAPITAL MARKETS COOPERATIVE RESEARCH CENTRE

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## 1.  Introduction

The **Capital Markets Cooperative Research Centre (CMCRC)** provides thought leadership and break-through technology solutions for health and financial markets. We are Australia's leading research and development organisation in this field.

Our submission to the Productivity Commission's *Inquiry into Data Availability and Use* provides a set of recommendations to increase the availability and improve the use of health data for the benefit of consumers, health services providers, researchers and the system's funders, planners and managers.  It addresses some of the specific questions set out in the Productivity Commission's *Issues Paper of April 2016*. Our focus in this document is exclusively on **health data** wherever it exists in Australia.

The submission is divided into four sections:

1. *Introduction*
2. *About the CMCRC's Health Market Quality research and development program*
3. *Our key recommendations*
4. *Our response to specific questions set-out in the Commission's issues paper*

## 2.  About CMCRC's Health Market Quality R & D Program

The *Health Market Quality* (HMQ) R&D program of the Capital Markets Cooperative Research Centre (CMCRC) covers the application of advanced data sciences to all public and private healthcare settings.  The program encompasses a collaboration between CMCRC, ten major Australian universities and a group of over 30 private and public health organisations that collectively engage with over 60% of Australia's $150bn+ annual health spend.

The HMQ program is focused on the delivery of a wide range of data analytics-driven solutions for funders, providers and consumers, robust and challenging research to positively reform Australia's inefficient health system, and training, through our PhD program, of Australia's next generation of Health Data Scientists to support the rapidly emerging Digital Health environment.

The HMQ R&D program has three key streams:

- *Overcoming data fragmentation across the Health Market.*
- *Reducing fraud, abuse, waste and errors from a clinical and financial perspective thereby delivering improved market efficiency and integrity as well as improved health outcomes for consumers.*
- *Empowering all Australian consumers to play an active, fully-informed role in the choice, cost and quality of their healthcare.*

Our R&D program recognises that the quality and completeness of health data is essential to:

(a) *Enable health management and funding organisations to plan, assess and provide high quality, cost effective healthcare services and facilities;*

(b) *Empower consumers to participate in managing their health and understand healthcare options ranging from choice of interventions through to understanding the quality and cost of medical services, pharmaceuticals, etc; and*

(c) *Support the vital requirement for future-focused medical and health services research.*

We will shortly publish a foundational component of our work on 'overcoming data fragmentation'. This will encompass what we believe is the most comprehensive stock take of health data assets ever undertaken in Australia. The study covers all areas of health: public and private, state and federal. The work will be published as a series of reports supported by a web site that is intended to serve as a vital resource for the Australian health sector. This recognises that the sector needs to take far greater advantage of sharing available data resources in a secure way in order to enable a fair and efficient *Health Market*.

The joining-up of data from both public and private health data silos is essential to enable evidence-driven policy to plan, manage and deliver targeted and efficient healthcare services. Health data silos exist across the public and private sectors, as well as within university and research institutes. Often the silos are a consequence of fragmented health service funding and delivery across primary and tertiary, private and government healthcare settings. The problem is compounded by a multiplicity of laws and regulations which, while well-intentioned, pose significant, and, in some cases, insuperable obstacles to providing continuity of health care to each Australian.

## 3. Key Recommendations

In order to increase the availability and improve the use of data, the following actions are essential:

- ***Enable the expanded use of existing data sets to deliver fully informed healthcare for individual consumers.***

  This requires new approaches that allow for the joining-up of health data traditionally stored in local IT systems of services providers including GPs, specialists, public and private hospitals, imaging and pathology, pharmacy and allied health providers.

- ***Enable the expanded use of existing data sets to improve policy and resource allocation decisions.***

The current minimum data set used for policy is a small subset of highly filtered public sector datasets. Both the types of data sets used and the number of variables from each data set needs to be expanded to enable development of evidence-based policies.

This requires new approaches that enable wider access to joined-up health data sets stored across AIHW and multiple federal and state government agencies that plan, fund and pay for health services and those that assure quality and safety. Over time this data needs to be enriched with more detailed diagnosis and treatment data from the systems of health services providers.

- ***Review, and where required amend legislations across all jurisdictions in Australia governing the collection of and access to healthcare data and its use. This is essential to enable linkage of health data sets for the same individual independent of service delivery setting, jurisdiction and geography.***

  Legislation and regulatory policies are not uniform across federal, state and local levels. Crucial health information from Australia's vast data collections such as MBS and PBS, remain untapped, because of the current legislative environment. It is important to note that the current restrictive regime, much of which was imposed decades ago, is patently out of step with the evolving views of consumers regarding use of their own data for the improvement of their own health and healthcare, and to support research.

- ***Implement consistent, clearly articulated policy, specification and process for de-identification of individual records to facilitate data access and sharing for research and planning purposes without violating the privacy of individuals.***

  Lack of uniform approaches to de-identification of health data, driven by the requirement to address the risk of privacy violation, are wasteful and limit the use of data sets collected at great cost. Robust technological solutions to address this challenge exist today and should be used uniformly across jurisdictions to create a climate of confidence in sharing data for research and systems planning, assessment and management purposes.

- ***Research datasets: Create a regulatory and funding environment and a corresponding infrastructure that maximizes the longevity of research data sets and their reuse after the initial study has been completed.***

  Policies on ethics, longevity, and reuse of data need to be reviewed to ensure that data sets collected by universities and research centres, at great cost, are used to their full potential. Current restrictive policies on reuse of research data impede this.

- ***Subject to ethics and other approvals, health data sets should be made available at affordable costs for researchers and repurposed for use by other researchers to make the process of data access more efficient and cost-effective.***

  As a general principle, the funding and use for research data sets should not be restricted by time and use.  Acquiring data sets currently consume a substantial portion of both the time and funding of research projects.  Research grants should consider the long term value of assembled data assets. Implementing some of the above recommendations will assist in the continuity of custodianship of research data assets after a project concludes or the original researcher or custodian decides to leave a project.

- ***Mandate the use of uniform health information coding schemes across all health care services delivery channels, both private and public.***

  Currently a variety of health information coding schemes and standards are used across private and public, primary and tertiary health care. Consistency of coding is essential to (a) provide continuity of care to the individual, (b) understand the health trajectory of populations, and (c) allocate appropriate resources for targeted service delivery.

# 4. RESPONSE TO QUESTIONS SET OUT IN THE INQUIRY

## 4.1 DATA SETS OF HIGH VALUE

Data sets that deal with healthcare service delivery contain episode level clinical data – e.g. MBS, PBS and systems used by GPs, specialists, hospitals, imaging and pathology providers, pharmacists and allied health. This data, collected and stored continuously at all points of service (both public and private sector), are valuable data assets that should be used to:

- *enhance the precision of healthcare delivery to each individual;*
- *drive informed policies by governments;*
- *offer insights on costs and service utilisation to both public and private sector funding bodies;*
- *provide evidence-based service delivery for consumers; and*
- *enable researchers to provide evidence-based insights to all stakeholders in the healthcare environment.*

When collected over a period of time, in a uniform standardised structure, these data sets can also become important assets for longitudinal studies to support efficient and effective healthcare services.

> *The current approach of using minimum data sets that trickle down from jurisdictions to policy makers and funders is of much lower value than the original transaction data collected routinely by every service provider. Having the complete transaction data in near real time, rather than the mandated minimum dataset can offer invaluable insights for effective health management.*

In the public sector, healthcare is administered and managed by federal and state governments, all of whom play a part in policy formulation, managing the health budget, and managing service delivery.

Universities, research centres and not-for profit organisations collect and manage specific data sets, often sponsored by government grants (example NHMRC). These data sets, though collected for specific projects, often contain valuable information that can inform and influence health policy.

> *Research data sets should be made available for longer periods of time for use by multiple agencies to inform research and policy, even after the original project concludes.*

## 4.2 COLLECTION AND RELEASE OF PUBLIC SECTOR HEALTH DATA

*Q. What are the main factors currently stopping government agencies from making their data available?*

Despite the Council of Australian Governments affirming its support for data sharing arrangements between jurisdictions (as expressed in the 2009 *National Government Information Sharing* strategy), when it comes to health data, this policy has been effectively stillborn.  The capacity to effectively use data resources continues to be frustrated by fragmented approaches to health services policy, funding and management, service delivery, ownership and custodianship protocols and legislative restrictions.  This is despite changing consumer attitudes and preferences and the increased capacity for technology-based solutions to protect security and privacy.

Australia has comprehensive health data collections, systematically collected by various agencies at both state and federal government levels. *But their potential has yet to be realised.*

> *In general, there is no effective sharing of data between the private and public sectors in health even though consumers use both for their healthcare services.  The separation between primary and tertiary care, further amplified by the split in delivery across public and private sector settings, results in health data silos and does little to ensure efficiency of healthcare delivery or continuity of healthcare for the individual consumer.*

Some factors that contribute to data silos are listed below.

- *A fragmented approach to data ownership influenced by healthcare funding split between state and federal governments and the provision of healthcare across private and public settings.*
- *The administrative policy that primary care is managed through the federally funded Medicare system, and public hospital services are managed by individual states, complicates sharing due to divided custodianship of data.  Even within states, data is often fragmented across hospitals and health districts.*
- *Fragmented service delivery across primary healthcare and tertiary hospitals – inhibits free flow of consumer health data. As a result, no one has access to consumer's complete health record, nor is it possible to take a system wide view of the quality, cost and appropriateness of healthcare interventions.*
- *Many regulatory policies do not take into account state-of-the-art technologies on preserving security and privacy.*
- *Restrictive policies on data access and use prevents effective data sharing even within public sector organisations. For example, planners and funders within state or federal departments of health are often not able to access comprehensive, joined-up data sets in their own jurisdiction.*

- *Several agencies at the state and federal levels (for example IHPA - Independent Hospital Pricing Authority, Safety and Quality Commission, and AIHW) work with the same source to manage different aspects of healthcare often drawing different components of information from the same data source (such as hospital administrative data) for different aspects of service planning.*

The main factors currently stopping government agencies from making their data available are:

- *A view that data may be misused to identify individuals especially when linked with other data sets;*

- *A view that consumers do not want their data (even if de-identified) to be shared/used for research etc. Recent surveys by e.g. Research Australia[1] and studies by Deloitte[2] suggest that this is unfounded;*

- *A lack of understanding of secure technology infrastructure (such as SURE[3]) that are primarily designed with the purpose of preserving privacy/confidentiality; and*

- *A reluctance to "relinquish" ownership of the data and share it, despite it being obtained through public sector mechanisms and through public funding.*

### Q. Should the collection, sharing and release of public sector data be standardised? What would be the benefits and costs of standardising? What would standards that are 'fit for purpose' look like?

When it comes to the issue of health data the answer is a resounding 'yes' for the reasons outlined at length in earlier and later parts of this paper.

Some of the issues around standardised coding are:

- *There are several health information coding systems used across healthcare in primary and tertiary healthcare in public and private healthcare sectors.*

- *Even within primary healthcare systems, the clinical coding is determined by local IT vendors. An international coding scheme such as ICPC-2 should be made a mandatory standard for recording patient encounters.*

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[1] See http://crm.researchaustralia.org/documents/item/536 - "overwhelming majority of Australians are supportive of their medical records and information being used for research"

[2] http://www2.deloitte.com/content/dam/Deloitte/global/Documents/Life-Sciences-Health-Care/gx-lshc-healthcare-and-life-sciences-predictions-2020.pdf

[3] See http://www.saxinstitute.org.au/our-work/sure/

> *Standardised coding across public and private sector data would be of great benefit to the entire health sector.*
>
> *Standard set of identifiers used uniformly across primary and tertiary care, public and private sector health would be of enormous benefit for continuity-of-care;*
>
> *Standard set of identifiers used uniformly across primary and tertiary care, public and private sector will enable consumer-centric healthcare, measurement of quality of care across all clinicians irrespective of the multiple settings within which they work, as well as helping researchers deliver maximum value. This is also likely to reduce costs in the long term.*

### Q. How could governments use their own data collections more efficiently and effectively?

While much public sector health data resides with Australian Institute of Health and Welfare, Medicare and PBS, it is reported that many functions within federal health planning, funding and monitoring bodies do not have full access to this data, nor to routinely-collected transactional level health data to perform data analysis that can inform evidence-based policy.

Governments must develop governance strategies to link / collate/aggregate the full set of routinely collected clinical and administrative health data from multiple jurisdictions (in near real time) to proactively plan and manage health services.

> *Current government reports are, in general, high level statistical summaries that are of limited value to consumers, providers, planners and researchers.*
>
> *Australian governments should publish reports that enable consumers to have fully informed participation in their own healthcare.*
>
> *Countries like USA and UK release data that summarise the utilisation and payments for procedures, services, and prescription drugs provided to Medicare beneficiaries by specific inpatient and outpatient hospitals, physicians, and other suppliers. These data include information for common inpatient and outpatient services, all physician and other supplier procedures and services. As an example of US Medicare Reports on Service utilisation by provider can be seen at*:https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/Part-D-Prescriber.html

***Q. What specific government initiatives (whether Australian Government, state, territory or local government, or overseas jurisdictions) have been particularly effective in improving data access and use?***

There are several initiatives both in Australia and overseas that have been established to improve data access and use of healthcare data. A few examples are provided here:

## Australian examples

### Population Health Research Network (PHRN)

Established with the backing of the Australian Government (as part of the National Collaborative Research Infrastructure Strategy) and supported by all Australian states and territories, the PHRN has built a network that enables some existing health data from across Australia to be brought together and made available for health and health-related research purposes.

### SURE Infrastructure

*SURE*, the Secure Unified Research Environment, established and operated by the SAX Institute (with PHRN funding) provides data custodians at state/federal/public/private sector levels with a safe/secure mechanism for providing health data collections to researchers under appropriate approval processes.

http://www.saxinstitute.org.au/our-work/sure/

> *Despite existing secure environments that promote collaboration across organisations, individuals and departments within state and federal governments do not get easy access to their own jurisdiction data, let alone linked data collections.*

### Australian Digital Health Agency

The Australian Digital Health Agency[4] established on 1 July 2016 is a statutory authority established by the Australian Government to lead and provide direction in digital health. One aspect of its vision is to "provide secure storage and appropriate access to standards based health information in accordance with individuals consent in order to improve health outcomes for all Australians".

The web site serves as portal to enable Australian health service providers to transition to a digital health environment.

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[4] https://www.digitalhealth.gov.au/

### My Health Record

The Australian Digital Health Agency is responsible for establishing and implementing the My Health Record[5] initiative (earlier known as the PCeHR) which is a secure online summary of individual health information. This initiative, which has been underway in various guises for well over a decade, has yet to gain much traction amongst consumers and health service providers. Currently there are two trials underway with an opt-out model for creating the individual health record for consumers. An opt-out model is expected to significantly increase participation rates.

## International Examples

### Europe *epSOS (Smart Open Services for European Patients)*

A pilot project aimed to design, build and evaluate a service infrastructure that demonstrates cross-border interoperability between electronic health record systems in Europe. Both a methodological process and durable implementations (termed building blocks) which form the basis for a longer term, Pan-European approach to building interoperable solutions were delivered during the course of the project.

http://www.epsos.eu/home/about-epsos.html

### Norway

A large amount of health data on Norwegian citizens are already available electronically. Advocacy and support for health data linkage is prominent among health experts, as seen in the article titles "Unethical to restrict linkage of health data" according to Camilla Stoltenberg, Director-General of the Norwegian Institute of Public Health" in the Science Nordic.

http://sciencenordic.com/unethical-restrict-linkage-health-data

### Sweden *Swedish eHealth Agency (eHälsomyndigheten)*

The Swedish eHealth Agency aims to contribute to improved health care, care and the nation's health by pursuing development of a national e-health infrastructure. The activities focus on promoting public involvement and providing support for professionals and decision-makers. 90% of all prescriptions are e-prescriptions.

http://www.government.se/government-agencies/swedish-ehealth-agency-ehalsomyndigheten/

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[5] https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/content/home

### *United Kingdom* *NHS England*

The NHS has a vision to improve health outcomes and the quality of patient care through digital technology and innovation. "Patients will only have to tell their story once. With consent, care records will be available electronically across the health system by 2018 for urgent care services and 2020 for all services – dramatically improving coordination of care, particularly for those with complex conditions."

https://www.england.nhs.uk/2014/11/leaders-transform/

### *USA* *Kaiser Permanente*

"Even if patients need to be hospitalized, care delivery is seamless because all physicians and other health professionals have access to KP HealthConnect, our electronic medical record database." Hal Wolf, senior vice president and chief operating officer of the Permanente Federation.

http://www.mckinsey.com/industries/healthcare-systems-and-services/our-insights/what-health-systems-can-learn-from-kaiser-permanente-an-interview-with-hal-wolf

"Access to complete, integrated health information improves care through better informed decisions," Jamie Ferguson, vice president, Health IT Strategy and Policy at Kaiser Permanente (Calif.), one of the Care Connectivity Consortium's five founding organizations.

https://share.kaiserpermanente.org/article/care-connectivity-consortium-and-healtheway-announce-collaboration-to-advance-national-patient-data-sharing/

### *USA* *Medicare*

The US Centre for Medicare and Medicaid services publish very valuable data that enables transparent access to valuable health data.

For example, US Medicare publishes provider utilisation data: you just download them from their web at:

https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/index.html

The hospital data from the HCUP project is the most impressive: The National Inpatient Sample has 7 million admissions each year and one can buy this data for about $350 per year.

http://www.ahrq.gov/research/data/hcup/index.html

## 4.3    DATA LINKAGE

**Q. Which datasets, if linked or coordinated across public sector agencies, would be of high value to the community, and how would they be used?**

Linking consumer healthcare data collected by primary and allied healthcare providers, laboratories and pharmacies, with public and private hospital emergency and admissions data would present a complete and holistic picture of the service utilisation patterns of different demographic and population segments, and in turn help in planning efficient and high quality healthcare services.  Such linkage can also improve efficiencies, avoid duplication and assure high-quality, cost-effective healthcare.

Linking primary health data, pharmacy data (both PBS and over the counter purchases) with social life style behaviour data from ABS – could offer valuable insights to understand health and life style patterns of specific communities, which can help in proactive planning of appropriate health services that are targeted to the needs of specific sections of community or address gaps in services in specific geographical communities.

Continuity of care regardless of which public hospital the consumer goes to within state or across jurisdictions is essential. This requires all public hospital data, regardless of jurisdiction to be linked.

**Q. Which rules, regulations or policies create unnecessary or excessive barriers to linking datasets?**

*Legislation and Regulatory Policies*

Federal legislation surrounding schemes such as Medicare and PBS require urgent examination, particularly in the light of contemporary consumer attitudes to their own healthcare and health data, in order to maximise the use of these invaluable data sources for driving evidence-based personal and public healthcare.

Changes to regulatory policies governing health data should be mandated, as in other sectors such as the finance and energy sector.

For example, AHPRA have established a framework and governance arrangements for Data access and research policy[6].  Notwithstanding the proposed policy, AHPRA will not release protected information that identifies individual practitioners.  This policy limits a fully informed public examination of pricing and safety issues.

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[6] See https://www.ahpra.gov.au/About-AHPRA/What-We-Do/Data-access-and-research.aspx

*Research Ethics Approvals*

The processes surrounding ethics approvals by researchers are fraught with obstructions and delays. Ethics applications require a detailed specification of the data sets to be used for a research project. Data custodians, however, do not wish to share the data specifications till the ethics application is approved. This type of *Catch-22* situation leads to endless delays in obtaining ethics approvals even for funded researchers.

In addition, researchers who have obtained ethics approvals have to incur significant expense to access public sector data such as that housed in CHeReL[7].

Getting access to de-identified public sector data sets from Medicare are prohibitively expensive for most research institutions.

***Q. How can Australia's government agencies improve their sharing and linking of public sector data? What lessons or examples from overseas should be considered?***

We believe data sharing and linking can be improved by the following:

- *Catalogue the collections that are held and publish information about them (e.g. data dictionaries) through a web site.*
- *Ensure that the published information on data collections is updated regularly.*
- *Make the data collections available to all federal and state government departments and accredited research bodies for research and policy formulation on the basis of appropriate and efficient approval processes.*
- *Shift the onus of justifying "denial" to the data custodian i.e. de-identified data should be made available under appropriate protocols of access unless there is a good reason not to.*

Examples of overseas exemplar environments have been provided in response to earlier questions.

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[7] See http://www.cherel.org.au/pricing

## 4.4 HIGH VALUE PRIVATE SECTOR HEALTH DATA

**Q. What private sector datasets should be considered high-value data to: public policy; researchers and academics; other private sector entities; or the broader community?**

The following are examples of the high-value datasets that exist outside of the public (federal and state) health settings:

- *Medical and Hospital claims data held in practice management systems and private hospital admission and discharge data (HCP Discharge data).*
- *Ancillary / Allied health data of providers and consumers in practice management systems and payment systems (e.g. those of private health insurers and payment platforms such as HICAPs.*
- *Health data (related to clinical diagnosis, laboratory and radiology results) of individuals held by clinician practices in practice systems (e.g. GPs/ specialists/ radiologists).*
- *Data held by community health centres – very little (if any) information is available on this.*
- *Prescriptions data captured by GP practices and transferred to pharmacies through the private eRx Script Exchange. This exchange currently has more than 1 billion scripts[8] (and growing). This would be a very valuable source of data for research projects – no such dataset exists outside this private repository.*

**Q. In each case cited, what characteristics define such datasets?**

All above data stores are characterised by the following:

- *They are transactional and have the comprehensive (often clinical) data required to provide fully informed patient care: i.e. patient/episode level data;*
- *They are held in private data stores: often within proprietary software systems; and*
- *They are not shared across private/public sector domains or even within the private sector across practices or service providers.*

**Q. What would be the public policy rationale for any associated government intervention?**

Government needs to create totally clarity around the issue of data ownership and access.

Traditionally, ownership of *data sets* is claimed by service providers, and, in some cases, their software system/solutions providers

Of fundamental importance should be the legal recognition that individual personal health information belongs to the consumer/patient or, where equitable, is jointly owned by the

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[8] See http://www.erx.com.au/one-billion-scripts/

practitioner and patient with the patient having easy low or no-cost access.  This is an issue that needs to be clearly articulated and debated at the public policy level.

Consumer access to health data, directly and via their trusted advisers such as clinicians is equitable as consumers fund all private healthcare services both as direct payers and tax payers.

***Q. What benefits would the community derive from increasing the availability and use of private sector data?***

It is not possible to provide fully informed, evidence driven, precision personal and public healthcare without completeness of access to necessary data-sets.

Opening up access (under strict privacy/confidentiality principles/guidelines) could provide very valuable data for research, health policy, and development of systems/processes that contribute to continuity of care for the consumer.

Use of private sector data could also be used to prevent abuse and waste from over-servicing and drive efficiencies.  The products and services offered by LORICA Health, a CMCRC company, is based on private sector health data. LORICA Health's submission to the Productivity Commission highlights the innovation possibilities of using private and public sector health data.

## 4.5    ACCESS TO PRIVATE SECTOR HEALTH DATA

***Q. Are there any legislative or other impediments that may be unnecessarily restricting the availability and use of private sector data? Should these impediments be reduced or removed?***

The issue of ownership of data and datasets needs to be resolved. Private service providers are concerned about:

- *Privacy concerns of consumers;*
- *Their own commercial interests; and*
- *Concern that release of personal clinical information to an individual (who has the right to it) could lead to clinical misuse or litigation.*

We have referred above to the inconsistency and/or lack of clarity regarding the application of the various privacy and health records and other legislative and regulatory environments across Australian jurisdictions.  A reasonable, clear and consistent legislative/regulatory regime must be established that is heavily informed by the views of all Australians.

Another major impediment is the lack of a consistent use of individual health identifier across all health systems whether public or private.

Government should mandate the use of the IHI (now assigned to an individual by Medicare) in all health systems/software and mandate that commercial software developers change their systems to reflect this.

## 4.6    CONSUMER ACCESS TO, AND CONTROL OVER HEALTH DATA

*Q. What impediments currently restrict consumers' access to and use of public and private sector data about themselves? Is there scope to streamline individuals' access to such data and, if there is, how should this be achieved?*

We have referred to a range of these above.  Key causes are extreme data fragmentation across service and payment providers, a myriad of legal and regulatory regimes that either do restrict access or are used as an excuse to deny access, and a general 'can't do' rather than 'can do' attitude across many data custodians.

More broadly, there are a number of issues related to consumer access to their own health information:

- *Consumers do not know that they own their personal health information and can ask for it from their provider.*
- *Health services providers (e.g. GPs) 'copyright' is unclear: what information related to the consumer does the doctor "own"?*
- *The guidelines[9] on what providers can charge consumers for providing individual health information are complex.  The guideline suggests "reasonable" costs may be charged. However, this could vary depending on what the provider believes is reasonable.*
- *Given the fragmented nature of services, fees and charges paid for by public and private funders, it is practically impossible for the naïve consumer to access their information even though they have a right to it.*

Consumers need access to complete information to prevent the development of chronic health conditions, or to manage these effectively.  They need trusted information to assess whether clinical interventions are necessary and appropriate.  They also need information about quality, cost and availability of providers so that they can exercise fully informed choice in relation to this crucial aspect of their lives.  This requirement is acute for consumer's advisers and carers.

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[9] See https://www.oaic.gov.au/engage-with-us/consultations/health-privacy-guidance/business-resource-access-to-health-information-by-health-service-providers

***Q. Are regulatory solutions of value in giving consumers more access to and control over their own data?***

Regulatory solutions are an essential but not sufficient solution to overcoming the current impasse. These need to be supported by approaches to funding/payment within the system and repositioning the consumer at the heart of the health system rather than at the periphery.

There is a clear and present need for a comprehensive initiative to increase use of Australia's healthcare data in a secure environment that should be spear-headed by core groups such as the Council of Australian Governments and the Australian Health Ministers' Advisory Council – with key representation from the research community, funders, and most important, the consumers.

***Q. To what extent can voluntary data sharing arrangements — between businesses / between businesses and consumers / involving third party intermediaries — improve outcomes for the availability and use of private data? How could participation levels be increased?***

Relying on piecemeal voluntary data sharing arrangements will not work to the level required to make an effective difference. We need key public and private funders, clinicians, researchers and consumer advocates to work collaboratively to bring health data together, as robust technologies already exist to protect security and privacy of every individual's data.

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