# Flying Blind

**Australian Consumers and Digital Health** Australian Health Data Series: Volume 1

October 2016



CMCRC
ASSURING MARKET QUALITY

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This work has been produced by the ***Health Market Quality* Research Program** of CMCRC, as part of the *Health Data Series*. **Volume 1 of the Australian Health Data Series** is a key component of our research to inform and enable health managers and service providers to provide appropriate and effective healthcare, and empower *consumers to play an active, fully informed role in assessing the appropriateness, cost and quality of their healthcare choices.*

Electronic copies of the report can be downloaded from the Flying Blind Web site at: https://flyingblind.cmcrc.com

**Authors:** Uma Srinivasan, Suresh Rao, Divya Ramachandran and David Jonas

**Art Work and Graphics**: Sofia Carvajal, Chris Taylor

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**Contact:**
David Jonas
CMCRC Health Market Quality Research Program
Email: djonas@cmcrc.com

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## Australian Consumers and Digital Health
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# EXECUTIVE SUMMARY

The Australian health system records sufficient high quality data in digital form to support consistent and targeted, real-time, personalised healthcare for each Australian. While, at a whole-of-population level, Australians enjoy high quality healthcare, our study shows that the acute level of data fragmentation creates an environment in which individual consumers, their next of kin and their service providers are ***flying*** partially or completely ***blind***. The problem then extends to those charged with policy, resourcing, management and funding decisions in the public, private and non-government organisation (NGO) sectors, as well as health and medical researchers whose work is vital to the future health of consumers and the financial health of the country.

The fragmentation is the result of a number of key factors. Health services are delivered across a myriad of primary, secondary, hospital and allied healthcare settings, by a combination of private, public and NGO providers, many of which are regarded as independent businesses. These are, in turn, funded and paid in many different ways and through different channels by consumers, state, territory and federal governments, and a wide range of insurers and related schemes. That each key player may use one or more of a diversity of consumer identifiers and, in some cases, different health information coding schemes for their records, adds a ***lost in translation*** twist that further exacerbates effective use of data, even where this is brought together. Of equal significance are the multiplicity of state and federal laws and regulations that deal directly or indirectly with health data governance. While undoubtedly well intentioned, many present, or are interpreted as presenting, significant, and, in some cases, insuperable obstacles to rational combinations of health data. When viewing health as a market we have a clear case of ***market failure***, a point that is made directly and indirectly in recent submissions to the Productivity Commission's inquiry into ***data availability and use***.

The current situation does not result from a lack of goodwill or investment. Governments, universities and research bodies and service provider collectives (for example, doctors, hospitals, insurers) have made significant investments in improving health data collection and linkage over the past two decades. However, these efforts have been largely focused around assembling ***fit-for-certain-purposes*** datasets that are generally de-identified, geographically bounded and do not contain complete health data even for the populations they are seeking to study. Indeed, much cost and effort is often incurred in attempting to detour around the many barriers and data weaknesses that are described in more detail in our report.

In relation to consumer-centric health data initiatives, most effort has been directed towards what is now termed ***My Health Record***. This initiative has been underway in various guises for almost two decades, but has yet to gain significant traction amongst consumers and health service providers. Commentators have noted that tapping into complete, current and 'fast flowing' datasets of healthcare providers is an alternative model that delivers more comprehensive and 'real-time' benefits to consumers and their carers as well as providing the richest possible environment to support system planning and management, and research.

We are effectively in the fifth decade of the digital era. Today, the power of data-and-evidence-driven product and service delivery is taken for granted across many aspects of our lives. It is therefore ironic, that the most intrinsic and important aspect for each of us, namely our healthcare, remains such a significant outlier.

The perceived wisdom that continues to mitigate against joining up personal data to improve health is today significantly out of step with consumers increasing demand for instantaneous, personalised service delivery and their understanding of the social-contract necessary to achieve this. Generally, consumers have confidence that secure information processing regimes can deliver the benefits while mitigating the risks.

It is important to note that a range of other countries have tackled this situation boldly and have environments that leverage the power of health data for both preventive and curative healthcare.

This report is intended as an urgent ***call to action*** for the nation. While the notion of ***data*** may well be unexciting, the power of complete, quality data to dramatically improve the fortunes of all health market stakeholders, particularly consumers, is assured. The knock-on benefits to burgeoning health budgets is an important by-product.

The time for piecemeal data initiatives is long since passed. The nation must embrace an initiative that is truly transformative. This requires that we start from the perspective that data recorded at the point-of-service is the richest, most accurate and most current resource we have and that we should seek to ***capture once and use many times***. It goes without saying that using state-of-the-art techniques to assure security and privacy are intrinsic to any solutions approach, but we must not let these issues deflect, hamper and ultimately defeat the initiative as has happened too often in the past.

To succeed, such an initiative must be representative of key stakeholders, with consumers, clinicians and other health services providers determining the health outcomes required and policy makers, funders and researchers driving the what, when and how. Whilst acknowledging that government is a key stakeholder, this initiative should be driven as much by non-government stakeholders. The mission and funding of the initiative must be independent of electoral and government funding cycles. It must also be freed from the constant changes in stakeholder and management groups that are the characteristic of many national initiatives. We should adopt an iterative, lightly engineered approach that will deliver immediate benefits and avoid costly mistakes and dead-ends.

At a detail level, we will need to adopt persistent identifiers for consumers and providers, and consistent health information coding schemes as well as addressing legislative and regulatory barriers that unnecessarily hamper consumer and community sanctioned collection and use of health data.

We are confident from our extensive interactions with stakeholders across the health market that there is broadly based support for such an initiative. As one stakeholder put it: "At the end of the day, our health is all we have".

# 1 INTRODUCTION

## 1.1 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 HMQ program delivers data analytics based solutions for healthcare funders, providers and consumers, robust and challenging research to drive improvements in Australia's health market, and, through our PhD program, training of Australia's next generation of Health Data Scientists. In short, the program aims to catalyse innovation from the rapidly emerging Digital Health environment.

The HMQ R&D program has three key themes:

1. Overcoming data fragmentation across the Health Market.
2. Reducing fraud, abuse, waste and errors thereby delivering improved health outcomes for consumers alongside greater market integrity and efficiency.
3. Empowering all Australian consumers to play an active, fully informed role in the choice, cost and quality of their healthcare.

Our program recognises that completeness and quality of health data is essential to:

(a) Empower consumers to participate in managing their health and their interaction with the healthcare system, in a fully informed manner covering appropriateness of treatments as well as the cost and quality of service providers and healthcare products;

(b) Enable health policy management and funding organisations to plan, assess and operate high quality, cost effective healthcare services and facilities; and

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

## 1.2 Australian Health Data series of reports

Our ***Australian Health Data Series*** of reports derive from our work on Theme 1: ***Overcoming data fragmentation across the Health Market.*** A key objective of this foundational research is to enable us to address the following questions:

(1) Are health consumers fully informed about the status of their health, their healthcare choices and the cost and quality of services and products in the health market?

(2) Are healthcare service providers sufficiently informed to provide appropriate and continuous care to each consumer?

(3) Do policy makers have a complete picture of consumers' health data, the cost and quality of healthcare, and probable future health market demand patterns to make informed decisions?

(4) Do healthcare funders in the public and private sectors have the right information to make evidence-based funding and payment decisions?

(5) Do researchers have access to appropriate levels of healthcare data to enable the research that will inform the nature, cost and quality of treatments as well as healthcare planning and service delivery?

Our research encompasses a comprehensive stock take of health data assets in Australia, possibly the most complete undertaken to date. The findings will be published as a series of three reports, supported by a web site (www.flyingblind.cmcrc.com) that is intended to serve as an important resource for the Australian health sector.

## 1.3 The Aims and Objectives of Volume 1

Volume 1 of our series focuses on the consumer health journey as it unfolds through interactions with health service providers. Volumes 2 and 3, to be published over the coming months, extend to encompass a view of data from the perspective of funders, policy and regulatory agencies, and research organisations.

The report focuses on the health data that is routinely collected or created at all points in which Australian consumers interact with healthcare service providers – we term this ***point of service*** (POS) data. Whilst other sources of health data are becoming increasingly important in assessing and maintaining individual wellbeing – such as genomic data, tele-medical data and lifestyle data sourced from the rapidly expanding world of wearable technology, smartphone apps, and direct consumer feedback – our contention is that the POS data is the most severely underutilised in the Australian healthcare context.

POS data is the most commonly collected and generated healthcare data; it is also the most fragmented and has significant variations in depth and quality. At present, researchers do not have extensive access to POS data. Neither do government planning, policy, regulatory and compliance agencies, and nor do the private and public funders that need to make informed decisions on the most equitable and efficient allocation of health funding.

Yet, perhaps most importantly, neither consumers nor their health service providers have comprehensive access to POS data, thanks to the endemic fragmentation of service provision and data collection existing in Australia. Indeed, this fragmentation and lack of access is currently inhibiting the provision of effective, fully-informed healthcare in Australia. Without access to POS data, consumers have no way of comparing the merits of different health providers or deciding whether a specific healthcare intervention is in their best interests; these information asymmetries are a prime contributor of the market failure currently afflicting Australian healthcare. Likewise, healthcare providers do not have access to an integrated, 'big-picture' record encompassing the entirety of a patient's medical history – something that is not simply wasteful, but potentially dangerous.

Before we proceed, the use of the term ***consumer*** calls for some clarification. By consumer, we mean every individual who interacts with the healthcare system in both its preventive and curative aspects. This could be someone who purchases over-the-counter medicine from a pharmacy, sees a specialist or participates in a preventive health campaign. ***Patients*** are a subcategory of healthcare consumers. We define patients as individuals who have entered the health system for diagnostic, preventive and curative interventions: for example, someone seeing their GP, attending an imaging or pathology lab for investigations, or undergoing surgery in a hospital. Thus, ***patient*** is used in the report when referring to individuals who are undergoing some form of healthcare diagnosis or treatment.

Either way, both the preventive and curative aspects of healthcare require effective data collection, linkage and usage. Our key objective then is to determine how and why current approaches fall short of what should be the fundamental goal of Australian health: that consumers receive appropriate, timely and fully informed healthcare.

## 1.4 Our Approach

In order to achieve the objectives of the study our approach has been to:

1. Map the health journey of a consumer across the spectrum of healthcare service providers including primary care, secondary care (provided by specialists upon referrals by primary care physicians), public hospital and private hospital care, ancillary and allied services, community health, aged care, and other services. We have sought to capture consumer interactions with the health market irrespective of their nature, thereby including routine, emergency and elective admissions, as well as those related to work and traffic accidents;
2. Review primary transactional data sources created by service providers;
3. Map the corresponding journey of the consumer's health data;
4. Identify gaps in the flow of information that inhibit continuity of care across the sector;
5. Identify areas that need to be addressed to empower consumers with access to cost effective continuity of care across the healthcare continuum;
6. Identify inefficiencies caused by fragmented data across public and private health sectors, that represent obstacles to funders and policy makers making evidence-based decisions and to medical and health services researchers; and
7. Identify regulatory and other related policies that restrict the accessibility and usage of datasets by researchers to improve personal health alongside the integrity, efficiency and effectiveness of the health market.

In this report, the focus is on empowering the consumer and therefore we address items 1 to 5. Subsequent reports will cover Items 6 and 7 in detail.

# 2 CONSUMERS (NOT) AT THE CENTRE OF THE AUSTRALIAN HEALTHCARE ENVIRONMENT

This section commences by touching upon the complexity of the Australian health system and its impact on consumers' health data, a subject that is then analysed in greater depth in section 3. We then examine the journey that patients take through the health system and reflect upon how this creates point-of-service data silos that impact upon how adequately informed both healthcare providers and consumers are. Finally, we highlight some recent consumer views regarding the use of their health data.

## 2.1 The Complexity of Australian Healthcare

When viewed from the perspective of 'connected care', the Australian healthcare sector is severely fragmented, something that stems from a series of historical decisions that have left the market with numerous disconnects and 'rail gauge' problems. The current set up is a labyrinthine mix of:

- Private and public health services.
- Different levels of (non-integrated) primary, secondary, in-hospital, ancillary and allied healthcare.
- Multiple sources of funding and payment from public and private sources and consumers themselves. (1, 2)
- Multiple legislative and contractual frameworks across the jurisdictions and funding/payer environments. (3–7)
- Numerous policy, administrative and compliance bodies and agencies operating at state, territory and Commonwealth government levels.
- Multiple reporting regimes and data collection requirements.

This complexity, as visualised in *Figure 1 below*, frustrates the possibility of data sharing that is essential for fully informed healthcare.

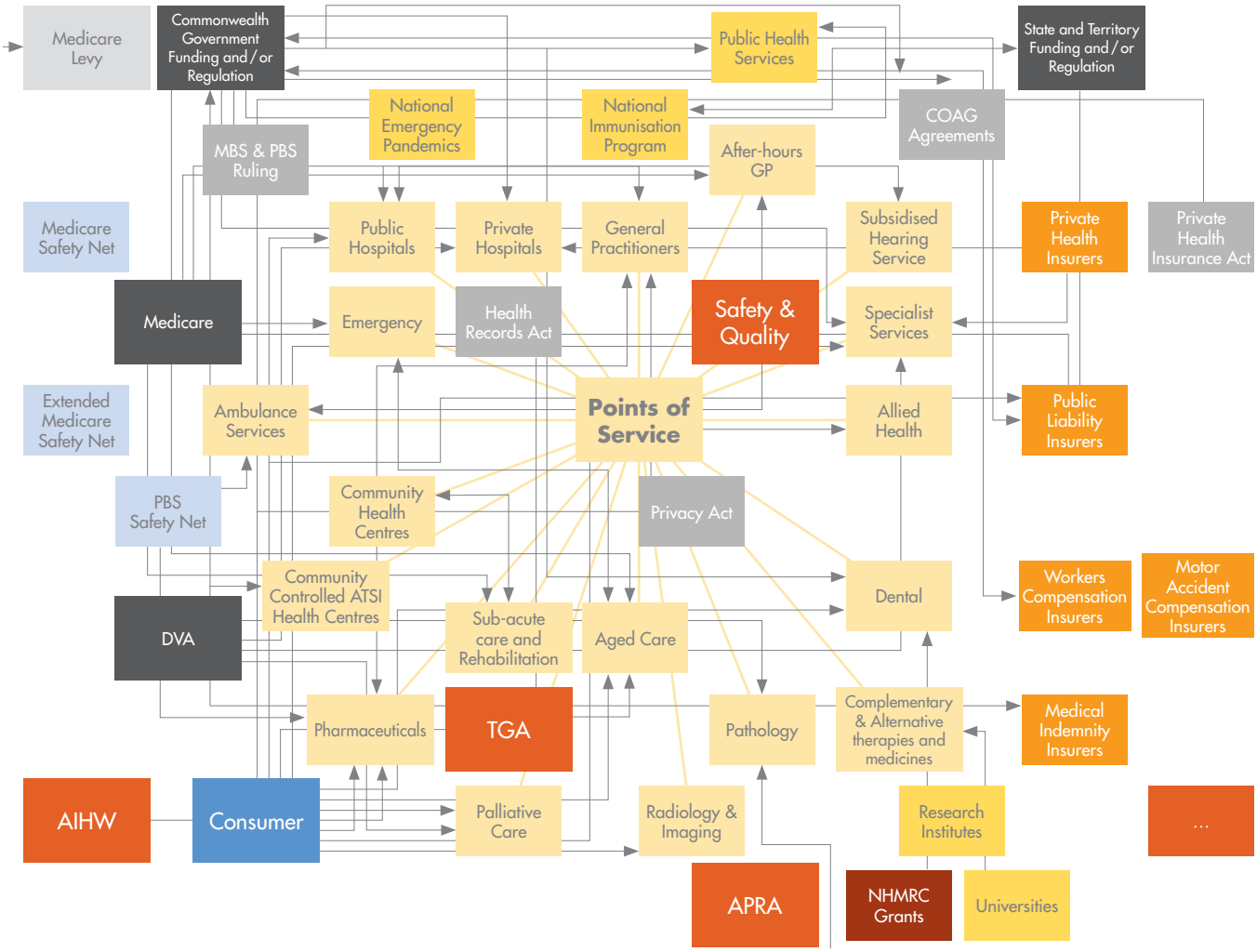



*Figure 1: The Australian Healthcare Environment*

## 2.2 The Consumer Healthcare Journey

Consumers have to navigate a range of alleyways and detours throughout their healthcare journey often without the appropriate information to allow them to decide who would be best to service them and what interventions may or may not be in their best interests. At the same time, their health data, which is essential to fully informed care, will often not follow them as they move between different service providers. *Figure 2* illustrates a stereotypical journey through the health system. Each bubble represents a service provider offering a specific type of service.

While the diagram shows the different stages of the healthcare journey, not all patients will experience all stages of this journey and some journeys will be continuously iterative. The extent to which each consumer interacts with the health system will be determined by the level of care they require and the coordination – or lack thereof – of healthcare providers.

The analysis below provides a brief examination of the key points of service at which data is generated. This is not intended to be exhaustive and excludes for example, allied healthcare and community and aged-care services.

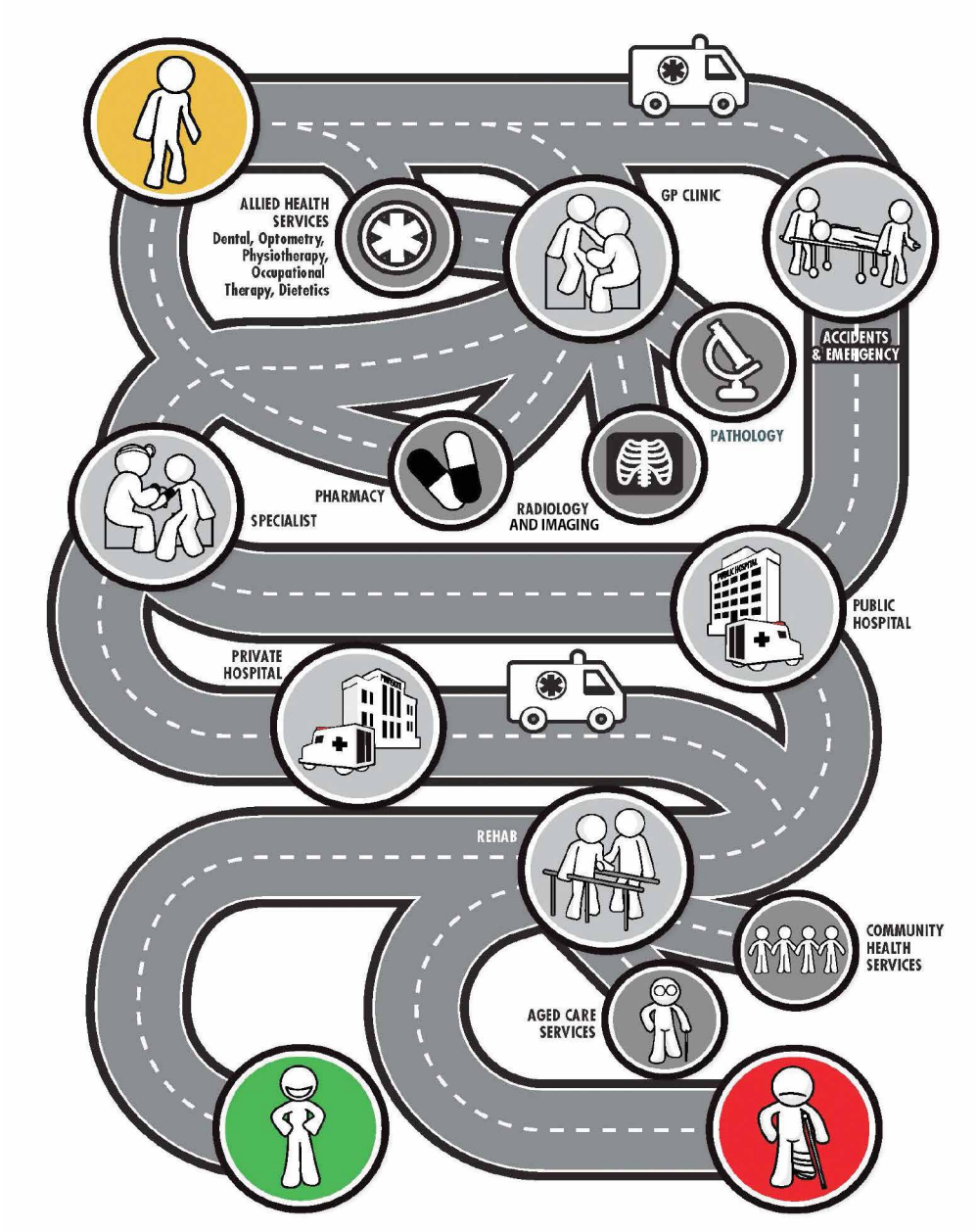



*Figure 2: The Consumer Healthcare Journey*

### Entry into the Health System

General Practitioners (GPs) usually serve as a first point of contact for consumers. As such, they represent the primary entry point into the health system, but other entry points exist such as the out-patient and emergency facilities in hospitals and clinics, and community health services particularly in rural and remote communities.

Depending upon the nature of the presenting problem, GPs usually pursue one or more of the following actions:

(i) issue a script that may later be dispensed by a pharmacy (although the GP has no confirmation that this has happened);

(ii) refer the patient for pathology investigations;

(iii) refer the patient for radiology and imaging services;

(iv) refer the patient to one or more specialists or allied health professionals;

(v) send the patient directly to a private or public hospital in case of an emergency.

### Specialist Services

Specialists attending to patients may pursue one or more of the same paths of action as GPs. This may or may not, be undertaken in consultation with the referring GP, and the ongoing level of communication and coordination of care between the two is not assured through full data exchanges.

### Hospitalisation

If a patient requires investigative or therapeutic procedures, their GP or specialist will usually refer them for a hospital admission. At this point the nature of their journey will be dependent upon whether they are public patients or covered by private health insurance(4) or the DVA benefits scheme(8) or accident compensation insurance.

### Public Patients

Public patients, not covered by alternative funding mechanisms, will seek to attend a public hospital outpatient clinic for specialist services, and, if required, seek admission as inpatients in a public hospital. Once a patient enters a public hospital for treatment, the public hospital system becomes the POS and a source and repository of all data related to the treatment of the patient. Outpatient services performed in a public hospital for non-admitted patients attract Medicare funding(9) and data related to these outpatient services become a differential data category. It is important to note that within each jurisdiction's public hospital system (and related ambulance services) continuity and connectedness of patient data is not necessarily assured across different hospitals nor between ambulance and emergency. This has important implications for consumers and their providers.

### Private Patients

Patients covered by some form of insurance or by the DVA benefits scheme usually have three options: seeking admission at a private hospital, or as a private patient in a public hospital, or as a public patient in a public hospital. The former is usually favoured as generally this means shorter waiting times for surgical procedures.

As with public hospitals, the continuity and connectedness of patient data is not assured across different private hospitals, even those within the same private hospital group. It is certainly not assured where a patient, having had an original treatment in a private hospital, may have to be admitted, in an emergency, to a private hospital in a different group or to a public hospital.

### Post Hospital Care

Depending on the nature of the diagnosis and treatment, the patient may be discharged with no further clinical care required, or they may be referred for rehabilitation and sub-acute care and/or community care before finally being cleared to return home. Once again, neither the completeness nor timeliness of data exchanged between the hospital, attending clinician/s, the rehabilitation provider/s and the primary healthcare clinician is assured.

## 2.3 Point of Service creating rich data silos

Significant volumes of data are recorded throughout the consumer health journey. In fact, at every point of service (POS), data is collected or created by every health service provider that a consumer interacts with from birth to death. As illustrated in ***Figure 3***, this may include any or all of the following classes of service provider: GPs, specialist clinicians, pathology service providers, radiology and imaging facilities, pharmacies, community healthcare centres, ambulances, public hospital emergency departments, public hospital admissions, private hospital admissions, aged care facilities, allied health service providers such as physiotherapists and dieticians, dentists, optometrists and so on.

Data collected and stored at points of service include:

(i) patient details,

(ii) details of service(s) provided,

(iii) clinical notes regarding the health status of the patient and the provider's 'diagnosis',

(iv) diagnostic test (pathology, imaging) information, and

(v) the nature and costs of services and other associated diagnosis and treatment costs.

*The major points of service, their role, the type of data recorded, and the mandatory stakeholders with whom the data is shared are shown in Appendix 6.1.*

The nature of the data recorded varies depending on the primary purpose for which the data is required and the role of the specific POS provider. Furthermore, the level of detail varies significantly across providers. For example, data recorded during a hospital admission episode is far deeper and wider than that related to an outpatient encounter with a GP, a specialist or an ancillary provider. Likewise, the data recorded may be influenced by the particular IT system used by the provider (10-12), its interoperability capability, and the mandatory and regulatory guidelines stipulated by the regulators and public and private health funders.

In general, irrespective of the type of IT system used by the provider, a form of indexing mechanism, usually based upon a patient identifier, will be used within that system to link a patient's multiple ***consultations*** (within a GP or specialist's practice management system) or ***admission episodes*** (within a hospital, via the patient administration system). However, very little data linkage occurs between different providers.

Alongside the direct care services mentioned above, there are many different varieties of indirect public health services that also collect important consumer level health services (13) data. These are implemented at a population level, e.g. immunization (14) and screening programs (15), or targeted at specific population groups (e.g. Indigenous Australians, children, people with disabilities, culturally and linguistically diverse Australians) or implemented in specific settings (e.g. schools, religious or social institutions, local communities). In many situations, these add to the number of silos across which a single consumer's data is scattered.

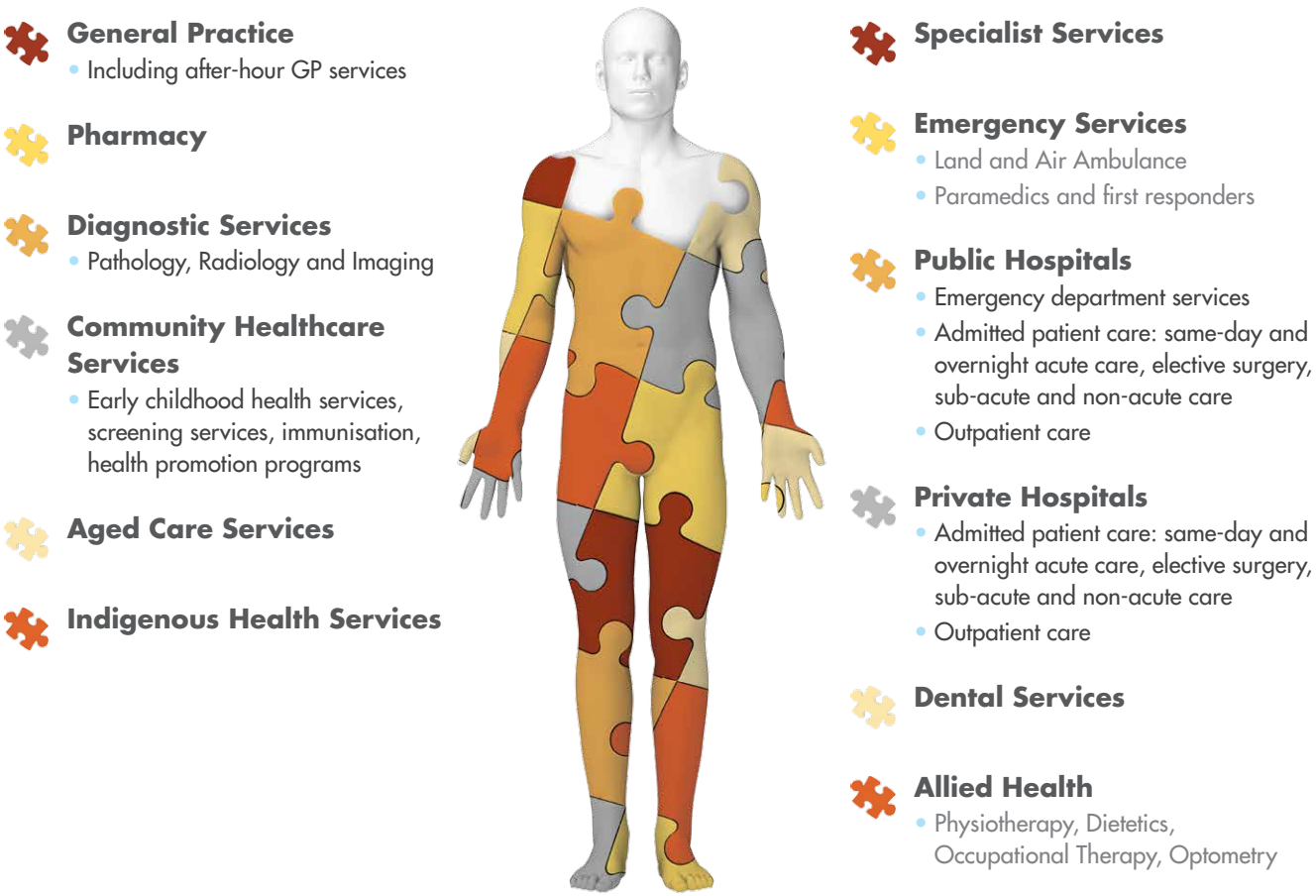



*Figure 3: The puzzle of fragmented healthcare*

## 2.4 Fragmented data and the Australian consumer

A primary consequence of fragmented data for Australian consumers is that they cannot be completely confident about receiving fully informed healthcare from providers. The opaqueness of the system means that consumers are often not aware that the system that is primarily in place to serve them is deficient. Furthermore, the absence of consumers' access to their own healthcare data as well as the lack of intelligence regarding the appropriateness of treatments for their condition, and the quality and cost of potential service providers means that they cannot be confident about making fully informed choices. These issues are examined in further detail below.

### Fully Informed Providers

In a clinical sense, the lack of effective data sharing or data integration between different healthcare providers means that, in many cases, they are not in a position to deliver fully informed healthcare at an episodic level nor provide effective continuity-of-care to consumers. It is common practice for a patient to have to 'carry' medical history information (usually provided in a printed form by the referring clinician) and physical diagnostic records (e.g. x-rays, pathology results) to each new service provider. The extent to which this information is captured into the receiving provider's system and then passed on in turn to further service providers is not assured.

On the one hand, this represents a considerable waste of time and effort resulting in ongoing data quality issues. At a deeper level, it means that providers do not have access to a fully integrated patient history, with the potential for unnecessary duplication of services, particularly pathology and radiology services. This inability to see the 'big picture' of a patient's health is potentially dangerous, especially in an emergency setting.

Effectively linked data sets enable healthcare providers to view and digest the full scope of a patient's health journey; this can be bolstered by the huge power provided by data-science based analytics to call out important markers and trends in the data. This facilitates care that is timely, better targeted, and properly informed. For example, by viewing a fully integrated health record a clinician may be able to recognise certain warning signs or patterns in a patient's health that might have otherwise been unnoticed, allowing them to make an effective preventive intervention.

Completeness of data is also essential to enable consumers to benefit from the increasingly exponential power of sophisticated software systems to effectively 'intersect' their health data with ***computable evidence and facts***, thereby increasing the accuracy and timeliness of both diagnostic and treatment decisions.

### Fully Informed Consumers

Consumers' lack of access to their own healthcare data and intelligence regarding the appropriateness of treatments for their condition, and the quality and cost of service providers means that they cannot be confident about making fully informed choices. As we shall see in Section 4 below, this issue is not merely a matter of receiving the best and most appropriate healthcare but also a matter of personal cost or value for money.

Improved data sharing will go a long way to reducing the information asymmetry that currently characterises healthcare in Australia and allow consumers to exercise better and more fully informed choice at all stages of their journey. This theme will be more fully explored in Section 4.1.

## 2.5 Consumer attitudes to their healthcare data

While some Australians continue to express apprehension over the privacy and security of their personal health data, recent research shows that most Australians are increasingly willing to share their own health and medical data, at least for research purposes.

For instance, Research Australia's 2016 polling showed that **91**% of Australians are willing for their data to be used for research purposes in particular to support:

- 79% to advance health and medical research
- 74% so healthcare providers can improve patient care
- 68% so public health officials can better track disease, disability and their causes

Furthermore, Australians are articulating a growing desire to access their own health records. Recent research by Accenture(16) shows that the number of consumers who believe they should have full access to their electronic health records has increased significantly over the past two years, from 78% in 2014 to 88% today. The study also reveals how the divide between consumers and clinicians on this issue has widened considerably in the same time. The number of clinicians who believe that consumers should be able to access their health records ***dropped*** from 18% in 2014 to just 11% today. This disconnect is symptomatic of why progress in joining up consumer health data has been so poor to date.

The multiple complexities of the Australian health system result in a market with numerous disconnects and 'rail gauge' problems.

Fragmented service delivery is the direct cause of fragmented consumer health data.

Neither consumers nor their service providers can be assured of the completeness of health data required to provide fully informed healthcare. This further denies consumers many of the benefits that can be delivered by computer assisted diagnostics and healthcare advice.

Recent surveys reveal consumers' broadly based support for the use of their data to drive improved care by their providers, health and medical research and to enable improved management of the health system. Consumers also require access to their full health histories, a view starkly at odds with their clinicians.

# 3 THE HEALTH DATA MAZE

As we have noted earlier, the provision of consumer-centric healthcare is dependent on bringing together relevant, complete and current data for each consumer. This rich data when intersected with the knowledge of healthcare professionals, and ***computable evidence and facts*** provides the foundation for ***personalised precision healthcare*** in Australia.

The previous section focused on the service points at which health data is captured, and the absence of consistent approaches to exchanging or linking this data. This section unpacks the 'problem' by examining the range of causes for data fragmentation, the 'rail gauge' issues associated with identifiers and health information coding, and the lack of effective action in addressing these. We also examine how the varying requirements for reporting of health data and the significant siloing of this data once received, further frustrate attempts to provide a longitudinal, joined-up view of a consumer's health.

## 3.1 Causes of Data Fragmentation

A number of factors have caused the fragmentation of consumer health data, and inhibited the free flow and/or linkage of this data in Australia. These can be broadly categorised as: structural factors, administrative fragmentation, and legal and regulatory policies. These issues are vexed in their nature, but nonetheless are solvable. Doing so will enable consumers to enjoy fully informed healthcare.

### Structural Factors

The first and most obvious obstacle is the structure of the Australian healthcare system that may be regarded as an 'accident of history'. Here the separation between privately and publicly funded, primary, secondary hospital and allied healthcare is rendered problematic, by the almost complete autonomy of each provider and the lack of mandates and mechanisms to enforce and support sharing of data, even though consumers often need to use a range of healthcare services.

This leads to the creation of ***health data silos***: independent data repositories full of useful, often critical, information with no links to other datasets. This compromises individual episodes of care as well as effective continuity of care.

### Fragmentation of Administration, Funding & Payment

The impacts of structural factors are then amplified by the high degree of administrative fragmentation characterising Australian health. A range of different Commonwealth, state and territory government agencies are responsible for regulating, funding and administering health. Public and private health insurers and government-backed accident compensation insurance schemes expand the complexity at a claiming and payment level. The impacts of the National Disability Insurance Scheme (NDIS) are yet to be determined given its nascent state, but will probably exacerbate the fragmentation.

Any primary care that takes place outside of the hospital system is managed and paid for through the federally funded Medicare (or DVA) and PBS systems, but public hospital admissions are managed and paid for by individual states and territories (supported by federal funding). In the same vein, private hospital admissions are managed by private or NGO organisations and are paid (partially or completely) by one of many health or accident compensation insurers. Consumers are often required to meet additional out-of-pocket costs in relation to much of the above.

In this situation, there is no easy way to ensure effective data linkage and sharing between different sections of the healthcare system, between federal and state/territory health arms, or across private and public settings.

### Legal and Regulatory Policies

Adding to this situation are the legislative and regulatory frameworks(17-22) that are not fully harmonised across federal and state levels, and are often marked by complexity, and a lack of clarity regarding appropriate data sharing/release protocols. This legislative/regulatory environment has been a key reason or, at least, the excuse for the inertia that has dogged the vital issue of health data linkage for decades.

One knock-on effect is that crucial health information from Australia's vast data collections such as the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Schedule (PBS) remain largely untapped.

As noted in section 2.5 above, the current health data regime is patently out of step with the evolving views of consumers regarding the use of their own data for the improvement of their health, healthcare service provision, and the support of research.

## 3.2 Many Points of Service Data – few connections

As we have seen in section 2 above, every health service provider collects or generates data related to a patient's health condition, medical history, treatment details, and so on. This results in the many data silos illustrated in *Figure 5 below*.

For example, in the case of a GP, patient clinical data is held within their specific practice management IT systems. (10, 11). Similarly, in the case of hospitals, large amounts of clinical data related to an admission or episode-of-care are held in a hospital's electronic medical record system or other patient administration and hospital management systems.(12). Even within a ***single hospital*** it is not unusual for different service delivery points(23) (e.g. ambulance/emergency) to have their own independent systems, which as noted earlier, are not necessarily linked. That some of this information is unstructured form (e.g. clinical notes and observations) complicates some aspects of effective data sharing particularly that rely upon 'intelligent' computer processing.

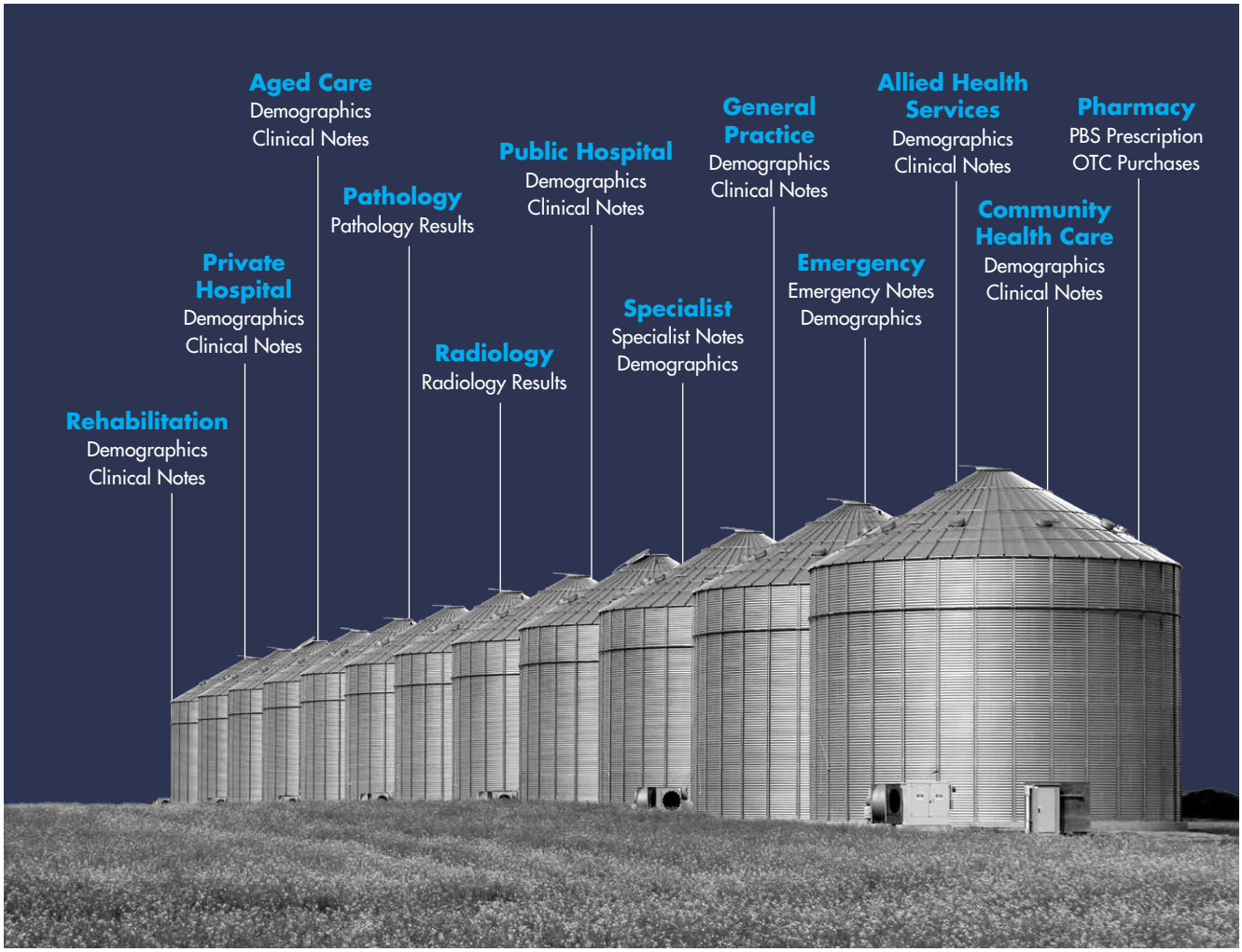



*Figure 5: Health data silos*

## 3.3 Proliferation of health consumer identifiers – entrenching Data Silos

As noted above, data for each patient are held in a multiplicity of unconnected healthcare provider systems.

While consistent patient and provider identifiers could play a vital role in enabling the reliable and efficient linkage of data across discrete data stores, the nature of healthcare delivery in Australia means that patients have a range of different identifiers across the health system. This phenomenon further entrenches the data silos illustrated in *Figure 5 above*. For instance, public health services often have several layers of identifiers used at a hospital, local health district, and state level. Indeed, NSW Health use Medical Record Number (MRN) at hospital level, AUID at Local Health District (LHD) level, and EUID at state level. Most of these are unknown to the consumer themselves.

*Table 1* provides a survey of the many consumer/patient identifiers that are typically in use across the health sector[24-27]. Public health services use some of these identifiers (e.g. AUID) internally for administrative reporting.

| # | Identifier | Colour/ Symbol | Known/Unknown (to consumer) | Description |
|---|---|---|---|---|
| 1 | V-IHI | | Unknown | Practice software vendor generated consumer identifier (internal to software): specific to the practice software in use at the Point of Service and likely to be different at each practice. |
| 2 | IHI | | Known | Individual Healthcare Identifier (allocated to all individuals enrolled in Medicare, or who hold a Department of Veterans' Affairs (DVA) treatment card and others who seek healthcare in Australia) |
| 3 | MRN | | Unknown | Medical Record Number (One per consumer in public hospital – as in hospital's Patient Administration System) |
| | Additional MRN | | Unknown | Additional Medical Record Numbers – For ***each*** State/Jurisdiction/LHN (different) MRN used to identify patient; there may be multiple used across states/Jurisdictions/LHNs |
| 4 | AUID | | Unknown | Area Unique ID – one generated for each consumer/patient in hospital within Local Health District |
| 5 | EUID | | Unknown | State health identifier for a patient generated by Enterprise Patient Registry System (e.g. in NSW) – used to link patient records in the public health system |
| 6 | Medicare Number | | Known | Medicare provided consumer identifier |
| 7 | PHI Member No. | | Known | Private Health Insurance provided consumer identifier (member number) |
| 8 | PH Group Id | | Unknown | Private hospital group identifier |
| 9 | PH MRN | | Unknown | Private hospital Medical Record Number (One per consumer in hospital) |
| | Additional PH MRN | | Unknown | Additional Private hospital Medical Record Number (there may be more than one assigned to a patient in different private hospitals across the country, or even within a PH group) |
| 10 | DVA File No. | | Known | Department of Veterans' Affairs File number – issued to each individual eligible for DVA benefits. |

*Table 1: A snapshot of Health Identifiers used across the Australian Health Sector*

The 'autonomy' of healthcare provider systems combined with multiple reporting requirements also results in the usage of multiple identifiers within the same consumer health record, as illustrated below in *Table 2*.

| Purpose of ID → / Point of Service ↓ | ID summary | Clinical Care Record | My Health Record | Medicare billing | Private health insurance billing | Department of Veteran Affairs benefits claims | Jurisdiction/ LHN level linkage | Private hospital group linkage |
|---|---|---|---|---|---|---|---|---|
| General Practitioner | | V-IHI | IHI | Medicare Number | | DVA File No. | | |
| Medical Specialist | | V-IHI | IHI | Medicare Number | | DVA File No. | | |
| Pathology Laboratory | | V-IHI | IHI | Medicare Number | | DVA File No. | | |
| Radiology Service | | V-IHI | IHI | Medicare Number | | DVA File No. | | |
| Pharmacy | | V-IHI | IHI | Medicare Number | | DVA File No. | | |
| Public Hospital | | MRN & Additional MRNs | IHI | Medicare Number | PHI Member Number | DVA File No. | MRN<br>IHI<br>AUID<br>EUID | |
| Private Hospital | | PH MRN & Additional PH MRNs | IHI | Medicare Number | PHI Member Number | DVA File No. | | PH MRN<br>PH Group Id |
| Allied Health Service | | V-IHI | | | PHI Member Number | DVA File No. | | |
| Community Health Centre | | V-IHI | | Medicare Number | PHI Member Number | DVA File No. | | |
| Aboriginal Medical Service | | V-IHI | | Medicare Number | PHI Member Number | DVA File No. | | |
| Aged Care Service | | V-IHI | IHI | Medicare Number | PHI Member Number | DVA File No. | | |

*Table 2: Multiple Identifiers (per POS) for one Consumer*

While many provider systems contain a consumer's Medicare number this is by no means universal. Furthermore, legislation prohibits the effective use of this identifier for data-linkage purposes.

The IHI (individual health identifier) created for the national *My Health Record* initiative has potential, but is not yet widely deployed and once again has legislative restrictions on its usage. Complexities associated with this identifier also limit its reliability. In the current implementation there are three "types" of the IHI (verified, unverified, provisional) and five "status indicators" (active, deceased, retired, expired, resolved). The "types"(28) are transitional indicators for the IHI and are stored within each PAS (Patient Admin System). If the IHI "moves" from system to system, or provider to provider there is a real risk that the "type" may not transition across due to timing.

## 3.4 Health information coding schemes

The fact that patients have multiple identifiers is not the only data-specific issue compromising the integrity of care in Australia. Substantially compounding this problem is the use of a variety of different codes to represent diagnosis, treatment and billing/funding information across Australian health. Again, this is largely due to the heterogeneous health service environment, as well as the varied needs of regulators, policy makers, funders and providers.

Health information coding schemes(29) are vital to assure:

(a) consistent classification of symptoms, diseases, treatments and events that occurred during primary care, secondary care and hospital episodes. (e.g. ICD-10, DRG, SNOMED) (29, 30)

(b) uniform billing for treatments and services provided by primary care physicians, specialists, hospitals, pathology and imaging and allied health services, (e.g. CMBS)(31)

(c) the recording of information relevant to their specific priorities and purposes, such as emergency and ambulance services, (e.g. ambulance, emergency status categories). (32-37)

(d) consistent classification of treatments provided by other provider groups such as dentists(38) or pathologists.(39).

(e) classification of adverse events information (e.g. CHADX).(40)

Unfortunately, there is significant heterogeneity in relation to the use of alternative health information coding schemes, and, in some cases, even in the way in which coding schemes are used across primary, secondary and tertiary healthcare in public and private healthcare settings.

### Primary Care Clinical Codes

Put simply, the coding schemes used by primary care providers to record diagnoses and treatments are quite arbitrary. The clinical coding scheme utilised is often determined by the IT vendor that supplies the GP's practice management software. An international coding scheme called ICPC-2,(41) is gaining prevalence in the international community to codify clinical information resulting from a consumer visit to a primary care provider. However, in Australia vendors use their own variations of ICPC-2 as there is no regulatory mandate for GPs to code clinical data in a national or international standard format. Data provided to Medicare merely uses the MBS billing code that usually conveys little or no information about the patient's diagnosis and treatment.

### Hospital Clinical Codes

The public and private hospital systems have far more consistency and use the Australian modified version of international ICD-10 (AM)(42) codes to record diagnoses and treatments in the hospital admission and discharge data (also referred to as administrative or HCP data(43)). Hospitals also routinely use the Australian Refined Diagnosis Related Group (AR-DRG)(44) classification system to group admitted acute episodes of care into cost or activity buckets. The AR-DRG classification system is a patient classification system that provides a clinically meaningful way of relating the types of patients treated in a hospital to the resources it requires. AR-DRGs consists of approximately 800 patient classes with classification based upon the patient's diagnoses, interventions and other routinely collected data.

In addition to the above, ambulances and hospital emergency services use a number of other coding schemes depending on the purpose of coding and the nature of services provided. For example, hospital emergency departments use the Australian Triage Scale (ATS) (33) to record triage categories. Ambulance services use the Emergency Response Grid (36) to allocate an emergency response code – although these are different to the codes assigned by the Emergency department.

### SNOMED-CT

An emerging standard gaining traction is SNOMED-CT (Clinical Terms) (30). SNOMED codes are based on clinical terminology that links terms, synonyms and definitions used in clinical documentation and reporting. The primary purpose of SNOMED-CT is to encode the meanings that are used in health information and to support the effective clinical recording of data with the aim of improving patient care. While SNOMED is the preferred standard of the Australian Digital Health Agency and has the potential to enhance the accuracy of coded health data, it is not in widespread general use.

## Other Codes

MBS codes (31) are used for billing in-hospital and outpatient services provided by GPs, specialists, anaesthetists and other clinical service providers, but as noted above these codes provide little if any clinical information, especially in relation to GP consultations. PBS codes (45, 46) are used for billing pharmaceutical products that are subsidised by the Australian government through the Pharmaceutical Benefits Scheme. Accident compensation insurance schemes use their own coding scheme (e.g. TOOCS (47)) to record workers' compensation claims that include information related to the type of occurrence, nature of injury and other points of interest.

Other codes used within the healthcare system include AUSTPATH (39) and LOINC (48) codes to identify laboratory observations. Dental services have their own set of codes and glossary of terms. The Therapeutic Goods Administration (49) uses the Global Medical Device Nomenclature (GMDN) (50), an international coding system, to identify and classify medical devices. The TGA uses the GMDN system as one of the criteria to distinguish one kind of medical device from another.

This terminology "Tower of Babel" has the potential to compromise the understanding of health diagnoses and treatment summarised in a consumer's health record. The knock-on effect is also to weaken the data analytics that support health and medical research as well as the planning and management of the health system.

*Table 3* summarises the major health information codes used for diagnoses, treatments and billing purposes in Australia (29-39, 41, 42, 44-48, 50-55).

### Health Information Codes

| Causes, Diagnosis, Treatment | Billing, Compensation | Urgency, Priority | Other* |
|---|---|---|---|
| ICD-9 | MBS Item Code | The ATS | The Australian Schedule of Dental Services and Glossary |
| ICD-10 | PBS Item Code | Emergency Status Codes | AUSTPATH |
| ICD-10AM | PBS Prescriber Code | Ambulance Priority Codes | LOINC* |
| TOOCS | TOOCS | | GMDN |
| ACHI | HICAPS | | |
| AR-DRG | | | |
| ICPC-2 | | | |
| ICPC-2 PLUS | | | |
| ICEI | | | |
| SNOMED CT | | | |

*Table 3: Health Information Codes used across the Australian health sector*

*Combined with multitude of identifiers, coding schemes, and reporting requirements health management has indeed become onerous.*

## 3.5 Health Planning and Management – Data Collection and Management Approaches

While the datasets necessary to support health system planning and management do not require individually identifiable health data, they are rendered far more useful and reliable where long term health trajectories for consumer 'categories' can be accurately studied.

The requirements of public and private sector bodies concerned with regulation, planning and funding influence what kinds of data are collected, linked and exchanged, as well as how data is codified. These bodies include the Australian Government Department of Health (and its many agencies), state health departments, private and public health insurers and accident compensation insurance schemes. Each stipulates the mandatory minimum data set requirements that health service providers are required to collect and report to them. The reporting mechanisms and details (56) vary between public and private medical and hospital service providers. This diversity combines to weaken the basis upon which funders, policies agencies and compliance agencies make significant decisions related to policy, planning, safety and quality, which in turn directly and indirectly compromises consumers' health.

The Commonwealth Department of Health specifies national reporting arrangements and mandates (57) the periods for which data are collected and collated. It also specifies the national minimum data set collection that is to be provided to the Australian Institute of Health and Welfare (AIHW). Hospitals forward patient administrative and clinical data via their local health district to the relevant state or territory health authorities on a periodic basis. In turn, state and territory health authorities provide the data to the AIHW for national collation on an annual basis. This 'cascading' approach filters and fillets health data down to minimum data sets as illustrated in *Figure 6*.

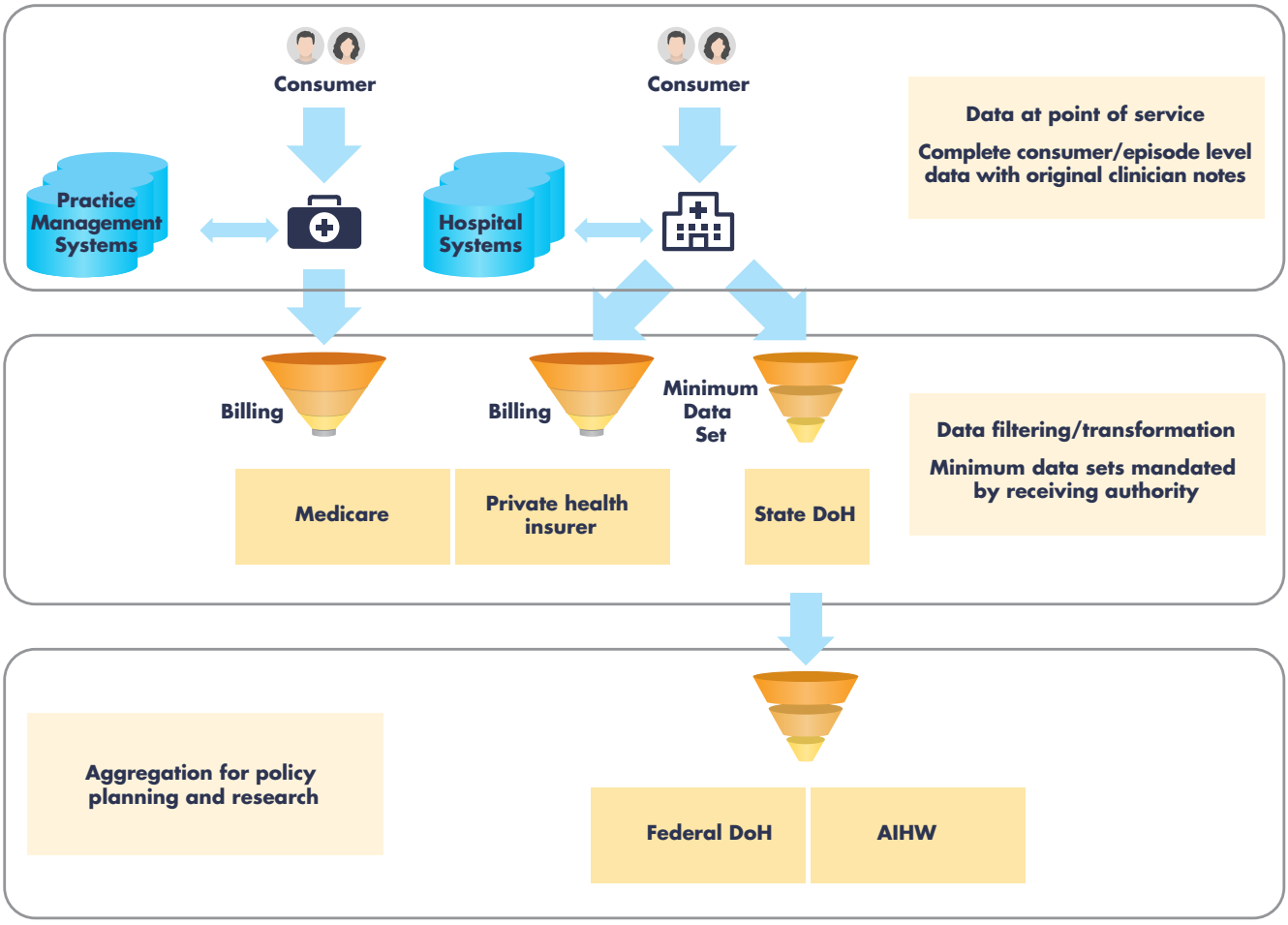



*Figure 6: Data filtering*

## 3.6 Health Research – Data Collection and Management Approaches

The data fragmentation and coding issues do not simply have implications for healthcare planning and funding. They also present substantial challenges to those conducting medical and health-related research. Research is vital to all aspects of consumer health. Research drives improvements in diagnosis and treatments, identifies the effectiveness and safety or lack thereof of treatment regimes, and provides vital insights into the effectiveness and efficiency of how health is organised, funded and what future skills and facilities the sector requires.

Research Australia(58) reports that approximately $6bn is expended by the public and private sectors on health and medical research each year. Much of this is funded by consumers through their direct and indirect taxes. However, in spite of the significant efforts of the Population Health Research Network (PHRN), Australian researchers continue to suffer from the lack of readily usable, comprehensive, longitudinal, linked data sets. This seriously compromises the efficacy of this research and the value that it represents for each consumer dollar expended.

In general, Australian health services providers collect and compile mostly complete and codified digital administrative health data sets. As we have noted above, there is not necessarily consistency in identifiers and health information coding systems, nor is there any established requirement or mechanism to link or consolidate all of a consumer's health data.

A range of government agencies, private organisations, universities and research centres analyse, aggregate and synthesise health data for different (1, 59-64) purposes. Research centres and not-for profit organisations manage specific data sets, often sponsored by funding (65) grants. These data sets are used for research that inform and influence health policy, for purposes including translational research, epidemiological research as well as to compute performance indicators and metrics to inform healthcare funding policies.

Research data sets are often painstakingly assembled from multiple transactional systems and/or existing data stores (e.g. AIHW). This absorbs a disproportionate amount of time and funding for most research studies. Significant amounts of time and resources are spent in seeking ethics approvals, identifying the data collections, joining up data with appropriate procedures to protect privacy and confidentiality, setting up secure IT infrastructure, and so on. Depending on the research question, data are also often gathered through targeted surveys that are designed to gather additional data (66) unavailable in transaction systems

In spite of this effort and cost, the data sets upon which research is based are often incomplete or less than fully reliable for the reasons outlined throughout this report. This requires that researchers make assumptions and/or qualify their research findings, compromising research effectiveness and outcomes for Australians as a whole. In addition to the intrinsic factors that bedevil the connectedness of health data in Australia, there are other, further factors that contribute to frustrating the effectiveness of health research:

- short term funding for research projects resulting in isolated compilation of single purpose-driven datasets;
- multi-jurisdiction administration;
- current regulatory policies on data linkage and sharing;
- privacy laws;
- prohibitions and/or restrictions on the use of Medicare and IHI identifiers coupled with the multiplicity of other identifiers used in their place; and
- lack of continuity in funding that limits collection and analysis of longitudinal data to monitor the efficacy and impact of intervention and translational studies.

A further important factor to note is that in spite of the significant cost and effort required to create research data collections, many become inaccessible data islands once the initial research is completed.

The root causes of data fragmentation are structural factors, administrative fragmentation, and legal and regulatory policies, or the interpretation of these.

The linkage of datasets is rendered more difficult or impossible by inconsistent healthcare consumer identifiers and the use of multiple health information coding systems.

Administrative data collections contain incomplete filtered and filleted data that limit their usefulness for planning and managing precision population health and monitoring the efficiency and quality of health services.

Health and medical research requires the continuous assembly and linkage of limited fit-for-purpose datasets. In spite of the significant effort and cost involved the reliability and representativeness of these datasets is often in question.

# 4 HEALTH FUNDING AND MARKET FAILURE

Earlier we examined how the fragmented structure of health services delivery, the lack of consistent identifiers and varying health information coding systems create a disconnected and dysfunctional data universe with the knock-on potential to compromise a consumer's health outcome. This situation is exacerbated by two additional factors. Firstly, the lack of transparency in the health market regarding the pricing and quality of healthcare service providers and the associated issue of the appropriateness of proposed treatments. Secondly, the multiple funding and payment structures that have emerged historically as a by-product of the divide between public and private healthcare funding and delivery.

## 4.1 Consumer Choice and Health Market Failure

The issues we have examined throughout the report do not simply affect treatment outcomes: they also have substantial implications for the cost and efficiency of healthcare in Australia. Here it is useful to conceptualise healthcare as a market. Like any market, healthcare has buyers, sellers and regulators; like any market, it is prone to failure – stemming from information asymmetries, inefficiencies and other problems. Indeed, the extent to which all market participants have access to accurate, complete and timely information will determine the fairness and efficiency of a market, meaning that these are compromised where information asymmetries exist.

This framework allows us to deduce that the health system in Australia has clear instances of market failure. These failures stem primarily from the information asymmetries that exist between providers and consumers, but significant asymmetries also exist between funders and providers. The latter fragmentation is most starkly illustrated by the significant differences in prices that healthcare service and product providers charge for identical goods and services to different funders and payers.

Australian consumers have little to no access to transparent data and evidence-based intelligence that could allow them to assess the appropriateness of prescribed treatments, or compare the costs and quality of care provided by healthcare professionals. Although as a percentage of GDP Australia sits at the OECD mean(67) healthcare costs in Australia are some of the highest in the world, and out-of-pocket costs charged by providers have been increasing rapidly over the past ten years *(see Figure 7 right)*. In the same period, the fees commanded by most clinicians (other than GPs) have soared. (68).

In many cases, consumers are in the dark regarding the nature and scale of costs and out-of-pocket expenses their treatment will incur, nor can they easily test the market to see if equivalent care is available at a lower cost. This is particularly true for procedures conducted in a private health setting. Most providers do not 'publish' fee data, meaning that consumers will only be made aware of prices charged during a consultation or shortly before an in-hospital admission. 'Shopping around' for different providers is a difficult and time-consuming exercise that few consumers willingly undertake. Even referring GPs are unaware of these price variations. It is well established that prices vary quite considerably for the same procedures, which reflects how effectively many providers are using the current information asymmetry to their best advantage. In the following section we will show how price-related information asymmetry problems are amplified by the fragmented nature of healthcare funding and claiming/payment approaches in Australia. The provision of greater access to data will do much to redress these information asymmetries.

Aside from and possibly more important than transparency of cost information is the fact that consumers have no dependable basis for determining the relative quality of providers, nor the appropriateness or otherwise of a recommended treatment. The latter can lead to a situation where perverse incentives are at play as consumers may rely almost entirely on their provider when making decisions as to whether they should have a particular intervention. The high incidence of low value care (meaning care that delivers little or even negative changes in quality of life) in Australia and other fee-for-service based countries (e.g. US) is indicative of this problem. For example, a number of studies have shown that a substantial proportion of knee arthroscopies – surgeries that cost on average between $4-5,000 – are no better than placebos (69) and carry a risk of side effects. Despite this, thousands of Australians continue to have them every year.

Reducing the fragmentation of POS data and improving consumer access to metrics such as provider cost and quality represents a critical step forward in promoting the efficient functioning of the health market by making it fairer and more transparent. In addition, consumers deserve far greater capacity to determine the appropriateness or advisability of recommended treatments that is possible if policy and regulatory authorities, backed by researchers, are able to make full use of all significant longitudinal health datasets.

**Health Data Series – Volume 1: Australian Consumers & Digital Health**

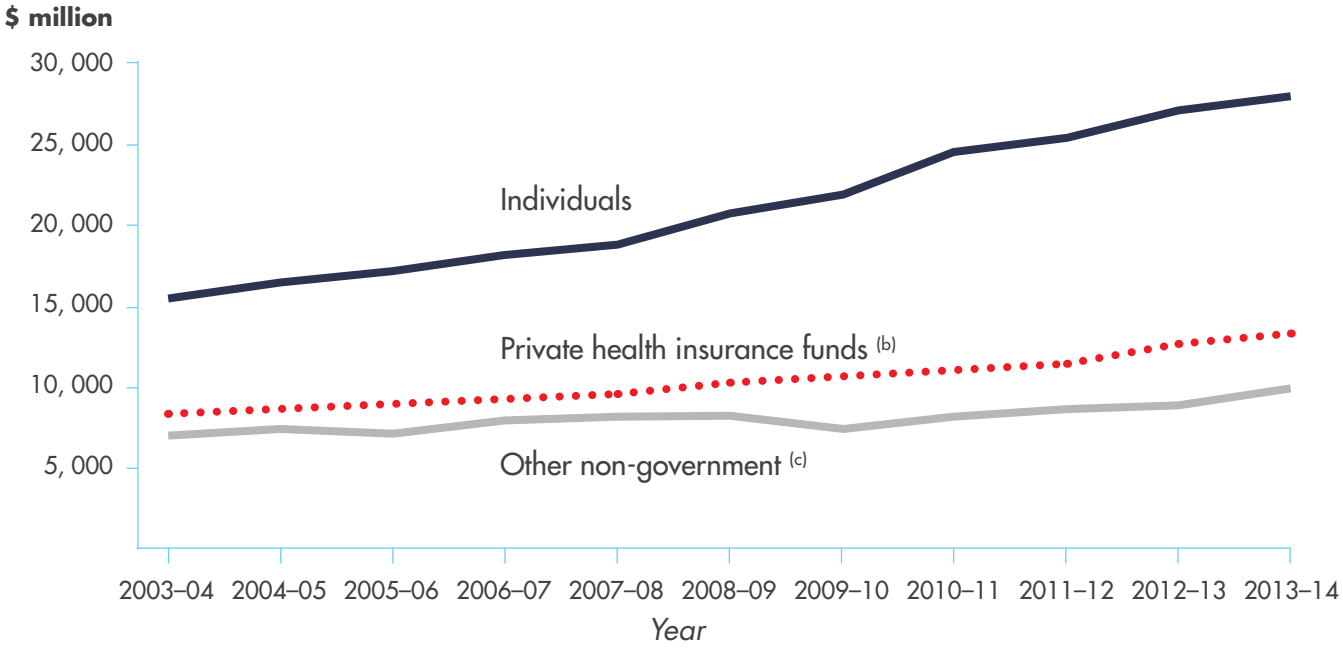



*Figure 7: Increasing out-of-pocket expenses*

(a) Constant price health expenditure for 2003–04 to 2013–14 is expressed in terms of 2013–14 prices. Refer to Appendix C for further details.

(b) Funding by private health insurance funds excludes the Australian Government private health insurance rebate.

(c) Includes funding by injury compensation insurers. All non-government sector capital expenditure is also included here, as the sources of funding of non-government capital expenditure are not known, this capital expenditure would be spread across all funding columns.

**Non-government sector funding of total health expenditure, by source of funds, constant price, constant prices(a), 2003–04 to 2013–14**

Source: Australian Institute of Health and Welfare 2015. Health Expenditure Australia 2013–14. Health and welfare expenditure series no. S4. Cat. no. HWE 63. Canberra: AIHW.

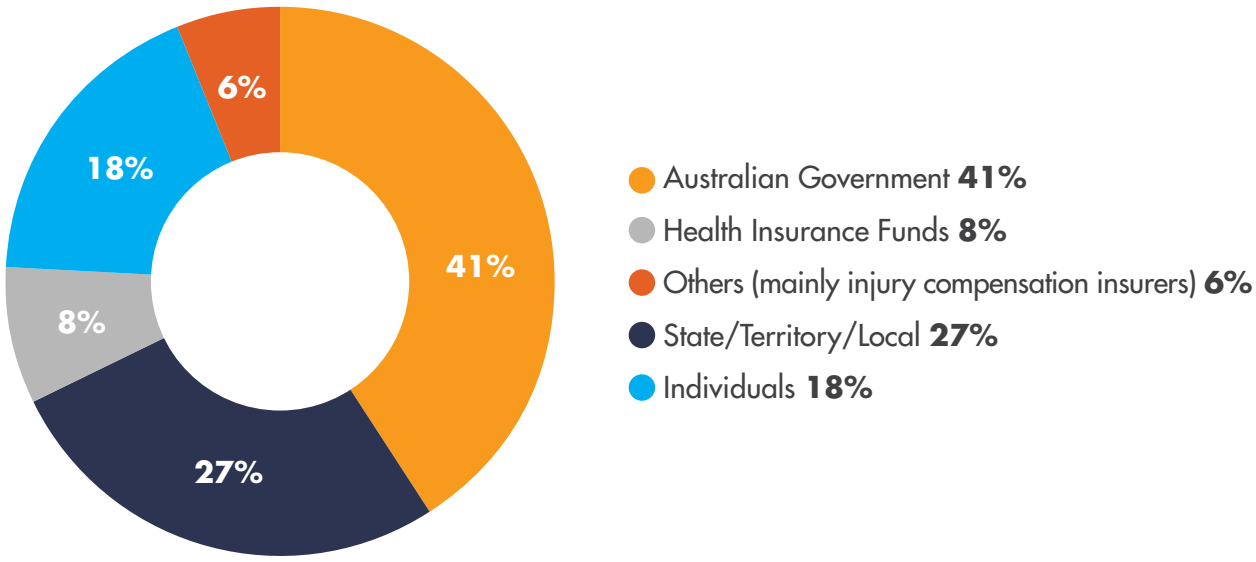
## 4.2 Healthcare Funding in Australia

The artificial compartmentalisation that characterises funding for primary, secondary, in-hospital and allied healthcare and accident and disability related care contributes heavily to the information asymmetry and consequent lack of transparency in the healthcare sector. However, it also imposes significant administrative costs on providers, funders and administrators – and most importantly, on consumers themselves. This does not simply lead to a lack of consumer choice: it also makes it difficult for the market to accurately measure the cost-benefit of healthcare at a national level and leads to a significant degree of wastage in the health system. The McKeon Review report(70) (the Strategic Review of Health and Medical Research in Australia established by the Australian Government in late 2011 and reported early in 2013) estimated waste (unnecessary procedures and adverse events) to be as high as 20-30% of total health costs.

All Australian citizens and permanent residents are entitled to a level of government funded public healthcare. Services, medications and devices are provided through a mixture of Commonwealth and State/Territory funded public hospital and clinic services alongside Medicare, the Commonwealth funded health insurance scheme and the Pharmaceutical Benefits Scheme (9, 71, 72).

Australian healthcare funding is sourced from the public sector, private insurers, and consumers themselves. The broad-brush breakdown of Australia's health funding of $150billion for 2013-14 is illustrated in *Figure 8 below*.

**Total funding for health expenditure as a proportion of total health expenditure, current prices, by source of funds 2013–14 (per cent)**




Source: Australian institute of Health and Welfare 2015. Health expenditure Australia 2013–14. Health and welfare expenditure series no. 54 Cat. no. HWE 63. Canberra: AIHW.

*Figure 8: Health expenditure funding*

**Public sector** healthcare funding comes from both federal and state (3) budgets. Consequently, there are shared responsibilities for cost, effectiveness and the quality of care across several jurisdictions and across several different federal and state health departments and agencies.

Government funding at Commonwealth, State and Territory levels covers:

- free or, more typically, subsidised treatment by health professionals such as doctors, specialists, optometrists, and in specific circumstances, dentists, and other allied health practitioners;
- free treatment and accommodation for public patients in a public hospital;
- 75% of the Medicare Benefits Schedule fee for services and procedures for a private patient in a public or private hospital – this does not include hospital accommodation and items such as theatre fees, medicines and implantable devices;(73) and
- free or subsidised access to pathology and radiology services.

**Medicare** is funded by the Commonwealth through a mix of general revenue and the Medicare levy(74) which is currently 2% of taxable income with an additional surcharge of 1% for high-income earners without private health insurance cover.

In addition to Medicare, the Department of Veterans Affairs (DVA) (8) manages the funding and services provided to veterans and their families.

The Medicare Benefits Schedule (MBS) (9) lists services that are subsidised by the Australian Government under Medicare.

The Pharmaceutical Benefits Scheme (PBS)(75) provides some medicines at a lower cost to Australian residents.

**Private health insurers** and **accident compensation insurers** represent the next largest group of healthcare funders. About 47% of Australians (5) have hospital treatment cover from private health insurance (PHI). This enables appropriately insured PHI members to bypass waiting lists and receive treatment through their preferred clinician in a private (or public) hospital. Private Health Insurers also provide 'ancillary' coverage for allied health services (4, 5) which are not covered by Medicare or the public hospital system, such as dental treatment and physiotherapy.

**Accident compensation insurers** pay for care where the cause of a health episode is a work or transport related accident. Each jurisdiction has its own set of workers' compensation and transport accident schemes, that are often managed by multiple insurance agents.

Finally, we cannot forget that it is **consumers** who are the major funders of all healthcare costs through direct and indirect taxes (at both state and federal levels), insurance premiums, direct payments for healthcare goods and services, and, finally, through out-of-pocket contributions when public and private insurance schemes (6, 7) do not meet the full costs of care.

As noted above, the complexity of the funding and payment approaches are significant contributors to the fragmentation of consumer data as illustrated in *Figure 9*.




*Figure 9: Funding & payment models that increase data fragmentation*

The individual consumer contributes a portion of the total cost at almost all POS. The figure also illustrates the additional expenses borne entirely by consumers in the areas of over-the-counter medicines, alternative medicines and health and lifestyle products. These have increasingly become a key area of direct cost for consumers.(6, 7).

As we saw in ***Figure 7 above***, direct funding of health services by individuals is the fastest growing segment of healthcare funding over the past ten years. A recent parliamentary paper on out-of-pocket expenses(6) has highlighted the dramatic increase in 'other medicines' which account for over-the-counter medicines.

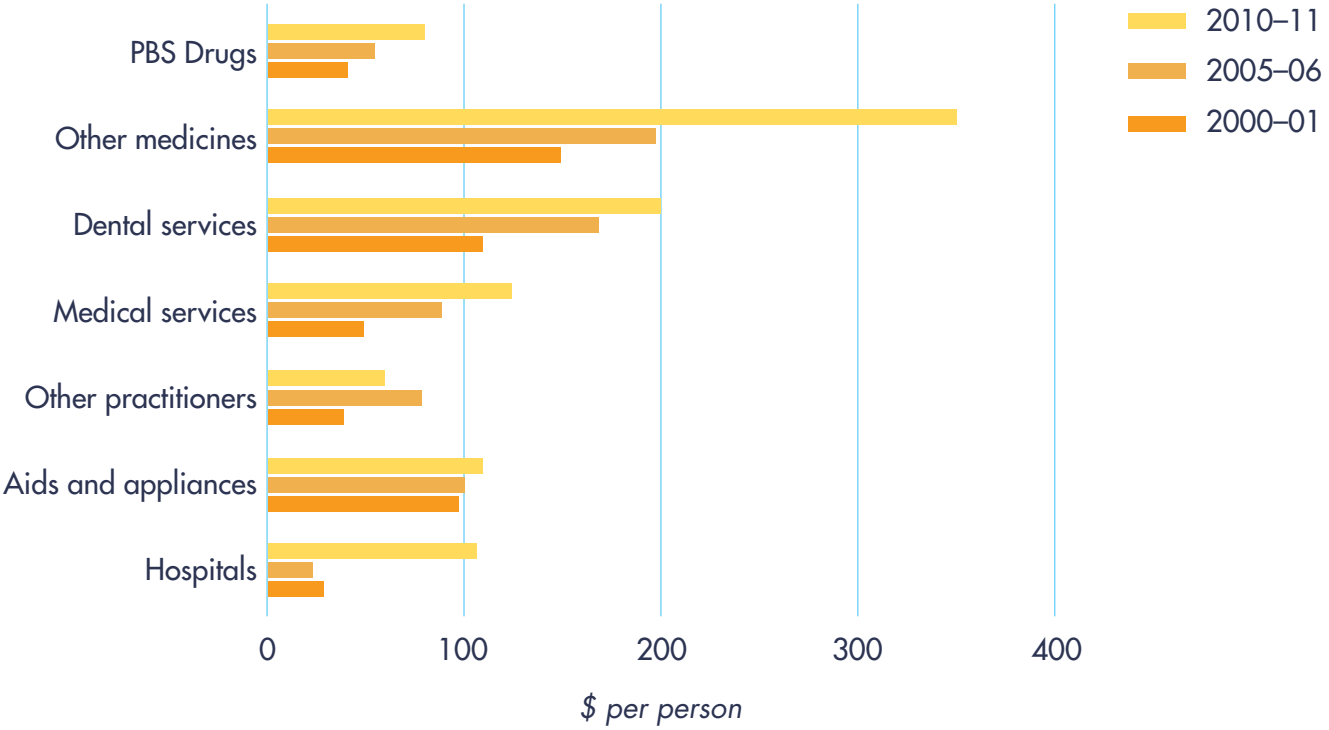



*Figure 10: Consumer Expenditure on other medicines**

An examination of the Australian health system reveals classic symptoms of market failure.

Consumers have no access to transparent evidence-based information to assess the appropriateness of care, nor compare costs or quality of care provided by services providers.

The complex and compartmentalised federal versus state, and public versus private funding, coupled with fragmented billing and payment systems, are a key contributor to the fragmentation of consumer health data. In addition these generate significant administrative inefficiency and cost.

Out-of-pocket expenses for consumers have increased significantly. Consumers are most often in the dark regarding their healthcare choices, options, costs and out-of-pocket expenses.

*Source: Out-of-pocket payments for healthcare—finding a way forward – Parliament of Australia. [online] Available at: http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook44p/OutOfPocketPayments [Accessed 25 Aug. 2016].

# 5 CONCLUSIONS AND CALL TO ACTION

## 5.1 Conclusions

A multiplicity of historical decisions have resulted in a health market that is acutely fragmented. We have fragmentation across policy, regulatory and health management settings. We have fragmentation across Commonwealth and state/territory legislation and regulation that directly or indirectly governs health data. We have fragmentation across many funding regimes. We have fragmentation at the level of who provides care and in what setting, and which party or parties pay for this.

Within the many pieces of this fragmented universe, historical decisions have largely determined what data is collected, what identifiers are applied, what health diagnoses and treatment coding schemes are used, who collects and uses the data, who 'owns' this data, who it has to be shared with or reported to and in what circumstances, and how long it has to be held.

The end-result may be described as ***market failure*** in that consumers and their carers are denied reasonable access to their data to manage their health and healthcare. Consumers are also denied the benefits that would flow from having their comprehensive, joined-up data available, in a variety of de-identified and/or aggregated forms to those charged with the planning and management of the health system as well to advance health and medical research.

Furthermore, as we have noted, consumers have little to no access to transparent, data and evidence-based intelligence to allow them to assess the appropriateness of prescribed treatments, or compare the costs and quality of care provided by healthcare professionals. One of the consequences that flow from this is that healthcare costs in Australia are amongst the highest in the world, and out-of-pocket costs borne by consumers have increased rapidly over the past decade.

The perceived wisdom that continues to mitigate against joining up personal data to improve individuals' health is significantly out of step with consumers' increasing demand for instantaneous, personalised service delivery and their understanding of the social-contract necessary to achieve this. Generally, consumers have confidence that secure information processing regimes can deliver the benefits while mitigating the risks.

The current situation does not result from a lack of goodwill or investment. Governments, universities and research bodies, and service provider collectives have made significant investments in improving health data collection and linkage over the past two decades. However these efforts have been largely focused around assembling ***fit-for-certain-purposes*** datasets that are generally de-identified, geographically bounded and do not contain complete primary, secondary, in-hospital and allied health data even for the populations they are seeking to study. Who may use these data-sets and under what conditions are generally so highly restrictive as to limit access to all but the brave or well-funded.

In relation to consumer-centric health data usage, we have noted that most attention is focused around the ***My Health Record*** initiative. This initiative, now under the stewardship of the recently formed Digital Health Agency, has yet to gain significant traction amongst consumers and health service providers in spite of being underway for almost two decades and incurring very high levels of expenditure. While national EHR initiatives are seen as a robust approach to supporting consumer-centric healthcare, the Australian solution has had to be engineered around the health service fragmentation, identifier and coding issues as well as actual and perceived legislative and regulatory issues. The end-result is one that imposes significant overheads on providers and requires a level of active 'management' by each consumer. Commentators have noted that tapping into complete, current and 'fast flowing' datasets of healthcare providers is an alternative model that delivers more comprehensive and 'real-time' benefits to consumers, as well as reducing time, effort and costs for clinicians. This is not to say that best aspects of both could not be brought together.

In Appendix 6.2 we have provided brief snapshots of how other countries and/or major healthcare entities have created environments that effectively leverage the power of consumer health data for the many purposes outlined in this report. These case studies should give us confidence in moving forward to resolving the current impasse.

## 5.2 Call to Action

Resolving this situation rapidly and effectively will be dependent upon recognising the following:

- This is an urgent, national ***personal*** and ***population*** health issue requiring an appropriate and urgent national response.
- The positioning of consumers as owners of their health data must be entrenched. This is essential to unlock data from silos and empower consumers to determine how their health data will be used. In this vein we must recognise that consumers' views regarding the collection and use of their health data are 'ahead' of the views of many at the political, health planning and service provision levels, and even 'ahead' of those portrayed by some advocacy bodies.
- A solution does not require reengineering the health market even though we have called out its complex, fragmented and, in part, dysfunctional structure. What is required is that data is 'freed up' for use by all key stakeholders. The resultant 'transparency' will drive the transformation of the market over time.
- Resolving this issue transcends governments. A resolution must embrace consumers, clinicians and other service providers, governments, funders and managers of health, and researchers.
- Success will be dependent upon persistence and focus and cannot be subject to the vagaries of electoral and government funding cycles and the accompanying changes in policy, priorities and governance and management arrangements that usually accompany these.
- Point-of-service datasets provide the best base for moving forward. We should leverage this data in as efficient and timely manner as possible to deliver.
- An iterative, lightly engineered approach will deliver immediate benefits and avoid costly mistakes and dead-ends.
- Gaining early, wide-spread support from consumers and clinicians directly and through community and advocacy bodies will be essential for success. Demonstrating that data security and privacy preservation can be assured will be important.

The initiative should be driven by the desired end-goal and not be skewed at the outset by actual or perceived legacy situations. This requires the following sequence of early actions:

- An important first step will be to articulate and gain broad agreement as to what the end outcome or ***light on the hill*** is. We have articulated this as: ***consistent and targeted, real-time, personalised healthcare for all Australians, as well as improved evidence-based systems planning and management and research***.
- This should be followed by an assessment of possible 'solutions' recognising that a range of iterative short, medium and long term approaches is entirely appropriate. Here international case studies will be most helpful.
- Thereafter the status-quo should be studied and transitional pathways identified. It is entirely possible for the old and new worlds to co-exist for extended periods of time.

We propose that the mandate to drive the implementation and ongoing management of this initiative be given to an appropriate national body. The Australian Digital Health Agency may well be the best candidate to commence this process, but its mandate, governance and funding arrangements will have to be modified over time to enable it to genuinely represent the coalition of vitally interested stakeholders referred to above, and for its mission to continue uninterrupted by the vagaries of political and budgetary cycles.

It will be vital to recognise that rapid and successful implementation will have to be 'outsourced' across existing public and private sector health market organisations. This will not necessarily translate into the eye-watering budgets usually required for national initiatives provided that appropriate, lightly engineered, iterative approaches are adopted.

At a detailed implementation level some of the actions that will be required are as follows:

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

  This requires new approaches that allow for the joining-up of health data recorded at all points of service.

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

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

  This requires new approaches that enable wider access to joined-up health datasets 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.

- **Mandate the use of consistent health information coding schemes across all healthcare service delivery channels, both private and public.**

  As noted earlier a variety of health information coding schemes and standards are used across private and public, primary and tertiary healthcare. 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.

- **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 datasets 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 relatively 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 processes 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 datasets 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 is the basis to empower the consumer and inform policy.**

  In relation to research data sets it is important to create a regulatory and funding environment and a corresponding infrastructure that maximises the longevity of these data sets and their reuse after the initial study has been completed.

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

  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 across jurisdictional boundaries. This requires a simplification of ethics approval processes to replace the current restrictive policies on reuse of research data.

  As a general principle, the funding and use for research datasets should not be restricted by time and use. Acquiring datasets 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.

Note: Some of these recommendations are incorporated within our submission(76) to the Productivity Commission's 2016 inquiry *into Data Availability and Use*.

*The CMCRC is not alone in this regard. In fact, a range of responses to a recent Productivity Commission Issues Paper have emphasised the transformative effects that improved data sharing and linkage can have on Australia's healthcare system. See Appendix 6.3 for a brief summary of comments from stakeholders to Productivity Commission.*

# 6 APPENDICES

## 6.1 Data collected and shared by service providers

### General Practitioner

| | |
|---|---|
| **Role:** | To provide primary care outside hospital settings |
| **Data Collected:** | Patient demographics, Clinical data, Medicare number, Service provided |
| **Data shared with:** | ***Medicare*** (MBS), Billing data;<br>***PHN*** Mandatory minimum dataset for clinical audit and specific population studies. |
| **Type of data shared:** | Medicare number and MBS item number with MBS<br>Provider-id, Medicare Number, with Pharmacy (via e-RX script exchange)<br>Provider-id, Medicare Number with Lab/Radiology<br>Referral letter to specialists/hospitals |

### Specialist

| | |
|---|---|
| **Role:** | To provide specialist medical care usually on referral from a General Practitioner |
| **Data Collected:** | Patient demographics, Clinical data, Medicare number, Service provided |
| **Data shared with:** | ***Medicare***, MBS Billing data;<br>***PHI*** – Member number, MBS Data, Billing (Fees) for privately insured patients |
| **Type of data shared:** | Medicare number and MBS item number with MBS<br>Provider-id, Medicare Number, with Pharmacy (via e-RX script exchange)<br>Provider-id, Medicare Number with Lab/Radiology<br>Referral letter to specialists/hospitals |

### Radiologists

| | |
|---|---|
| **Role:** | To provide specialist service related to diagnostic imaging tests and interventional procedures or treatments that involve the use of X-ray, ultrasound, and magnetic resonance imaging equipment. |
| **Data Collected:** | Patient demographics, Clinical data, Medicare number, Service provided |
| **Data shared with:** | ***Medicare***, Billing data;<br>***Hospitals and referring GP***/specialist, test results |
| **Type of data shared:** | Medicare – Medicare number, MBS item number;<br>Referring GP/specialist – clinical findings<br>Hospitals – clinical findings |

### Pathologists

| | |
|---|---|
| **Role:** | To provide pathology services privately or as part of a public or private hospital. Service involves identification of the cause and processes of disease and illness by examining/testing samples of tissues, blood and body secretions. |
| **Data Collected:** | Patient demographics, Clinical data, Medicare number, Service provided |
| **Data shared with:** | ***Medicare***, Billing data;<br>***Hospitals and referring GP***/specialist, test results |
| **Type of data shared:** | Medicare – Medicare number, MBS item number;<br>Hospitals/GPs – Clinical data including test results |

## Pharmacies

| | |
|---|---|
| **Role:** | To dispense prescription drugs as well as supply over-the-counter (OTC) medicines and supplements. |
| **Data Collected:** | Patient demographics, Medicare number,<br>Provider-Id, Prescription script details,<br>Prescription data – Non PBS<br>Other OTC medication purchased by consumer |
| **Data shared with:** | ***Medicare PBS***, Billing data; |
| **Type of data shared:** | ***Medicare – Medicare number***, Provider-id and PBS prescription data |

## Public hospitals

| | |
|---|---|
| **Role:** | To provide a range of non-admitted (e.g. emergency and outpatient clinics) and admitted patient health services including emergency, elective care, medical and surgical services, maternity services. Publicly funded. |
| **Data Collected:** | Medicare number, Patient demographics, Clinical data,<br>Services provided including accommodation, theatre, pharmacy, laboratory and radiology services, other allied health services,<br>MBS procedures and Diagnosis codes, DRGs<br>Optional – Member number for private patients. |
| **Data shared with:** | ***Medicare***, (MBS) Billing data; PBS<br>***LHN*** (Local Health Networks) a common governing structure for a group of hospitals within each state<br>***State Department of Health*** (minimum dataset – administrative and clinical data) – via LHNs<br>***AIHW*** – via SDOH (as per minimum dataset specified by AIHW)<br>***PHI*** – Privately insured patients, all hospital services billed<br>***Accident compensation insurance schemes*** – Patient clinical data, for patients whose claims are due to traffic accidents or workers' compensation.<br>***DVA*** – Billing and Clinical data for people who are eligible under the Veterans affairs cases. |
| **Type of data shared:** | Medicare – Medicare number, MBS item number;<br>LHN – Complete patient admission records of hospitals within the governance framework)<br>State DOH – Patient data Minimum data set specified via LHNs |

## Private hospitals

| | |
|---|---|
| **Role:** | To provide a range of non-admitted (e.g. outpatient clinics) and admitted patient health services including elective care, medical and surgical services, maternity services. Privately funded. |
| **Data Collected:** | Medicare number, Patient demographics, Clinical data,<br>Member number for privately insured patients, Date of admission and discharge<br>All Services provided and costs of services – including accommodation, theatre, pharmacy, laboratory and radiology services, other allied health services,<br>Clinical data including diagnosis and procedure codes and DRGs for the episode of care. |
| **Data shared with:** | ***PHI*** – Privately insured patients, all hospital services billed, including accommodation, prosthetics, laboratory and radiology services, other allied health services<br>***PHI*** – Hospital Discharge Data (includes patient demographics, Date of admission and discharge, diagnosis, procedures, DRG codes)<br>***Medicare*** MBS and PBS<br>***AIHW*** – via (minimum dataset specified by AIHW on behalf of FDOH)<br>***Accident compensation insurance schemes*** – Patient clinical data, for patients whose claims are due to traffic accidents or workers' compensation.<br>***DVA*** – Billing and Clinical data for people who are eligible under the Veterans affairs cases. |
| **Type of data shared:** | PHI – Claims – list of services and associated costs for all services including accommodation, theatre charges, prosthetics, lab and radiology services<br>PHI – Hospital Discharge Data (includes patient demographics, Date of admission and discharge, diagnosis, procedures, DRG codes)<br>Medicare – Medicare number, MBS item number; State health dept. – Minimum Dataset; PHIs – Health Insurance identifier, item no. |

## Allied health services

| | |
|---|---|
| **Role:** | To provide a range of health services not including medical, nursing or dental; Includes services such as dieticians, chiropractors, occupational therapists, physiotherapists etc. |
| **Data Collected:** | Patient demographics, Clinical data, Medicare number, Health Insurance number, Service provided. |
| **Data shared with:** | ***Medicare*** (Dental and Optometrist services)<br>***PHI*** for billing – all allowed ancillary services<br>***DVA*** for claims related to eligible veterans<br>***Accident compensation insurance schemes*** – Billing for claims that fall under the preview of Workers Compensation and traffic accident |
| **Type of data shared:** | Medicare – Medicare number,<br>Member Number – type of service, cost of service |

## Community Health Centres

| | |
|---|---|
| **Role:** | To provide community based health promotion and disease prevention services such as advocacy, education, early intervention, mental health rehabilitation, immunisation, screening services etc. to local populations. |
| **Data Collected:** | Patient demographics, Clinical data |
| **Data shared with:** | LHNs (LHDs); DVA |
| **Type of data shared:** | Community Health Minimum Dataset – aggregate numbers (patient contacts, hours spent, number of sessions by service); DVA data – patient demographics, service type, entitlement. |

## Aboriginal Medical Services/Aboriginal Community Controlled Health Services

| | |
|---|---|
| **Role:** | To deliver holistic and culturally appropriate health services to the community that controls it. Each state has its own set of local health clinics and community centres for delivering healthcare services across geographical regions within their state. |
| **Data Collected:** | Not known |
| **Data shared with:** | Not known |
| **Type of data shared:** | Not known |

## Aged care services (Aged care homes and home based services)

| | |
|---|---|
| **Role:** | *Home based services*: To provide entry-level support services for older people who need some assistance with daily living in order to live independently at home. This is delivered via the Commonwealth home support program (CHSP)<br>*Aged care homes*: Owned and run by Australian government approved private operators. |
| **Data Collected:** | Not known |
| **Data shared with:** | Not known |
| **Type of data shared:** | Not known |

Other primary care services include:

- After hours GP Services
- Flying doctor services
- Ambulance and paramedic services

## 6.2 A sample of Australian and Overseas Case Studies

This section provides short vignettes to showcase primarily international initiatives that represent either best practice or certainly better practice than Australia when it comes to the recording and use of consumer health data to achieve improved personal care as well as enhanced systems planning, management and research.

### 6.2.1 Australian initiatives

We commence by acknowledging the work underway by the Australian Digital Health Agency, but note that as this is a federal agency, its capacity to influence and reshape health data recording and use in Australia is currently limited.

#### Australian Digital Health Agency
***My Health Record***

The Australian Digital Health Agency 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 individual's consent in order to improve health outcomes for all Australians".

The Agency is responsible for implementing the My Health Record[2] initiative (formerly known as the PCeHR) which is a secure online summary of (some) individual health information. This initiative, which has been underway in various guises for almost two decades, has yet to gain significant 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.

While a national EHR can rightly claim to be an important part of addressing the current data fragmentation, many national and international commentators have noted that tapping into the complete, current and 'fast flowing' datasets of healthcare providers is an alternative model that delivers more comprehensive benefits to both consumers and the regulators and funders of health.

### 6.2.2 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. For instance, see the article titled "Unethical to restrict linkage of health data" by 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 healthcare 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/

## 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*

While Kaiser Permanete may not be a preferred model for Australia, the American model of private healthcare has enabled organisations such as Kaiser Permanente to have complete health records of all their members, which includes data about every aspect of care including all hospital admissions and outpatient encounters including visits to GPs, specialists, pharmacies, laboratories, allied health services.

The following is a quote from Hal Wolf, senior vice president and chief operating officer of the Permanente Federation:

"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."

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 organisations.

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:

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

## 6.3 A Brief summary of comments from stakeholders to Productivity Commission

A recent Productivity Commission Issues Paper invited submissions from a wide range of stakeholders – including industry bodies and companies, universities and research institutes, and government agencies – to comment on data access issues in Australia. Stakeholders were asked to:[1]

(a) Discuss the benefits and costs associated with making public and private datasets more available

(b) Examine the options for collection, sharing and release of data

(c) Identify the ways consumers can use and benefit from access to data

(d) Consider how to preserve individual privacy and control over data use.

Out of 211 submissions, nearly one ***third*** chose to spend time addressing the way in which data sharing and linkage could revolutionise Australia's healthcare system. A great many of the respondents believed that the current data environment is inhibiting the potential for superior healthcare in Australia, and as such, the list of proposed healthcare benefits that could come from facilitating greater linkage between both public and private sector data holders was nearly limitless. Multiple submissions pointed to the ways in which research could be transformed, treatment outcomes enhanced and policy improved; a number also referred to the possibilities that data linkage offered to enrich consumer choice across all aspects of the health system. Indeed for one submission, the list of potential opportunities and benefits stemming from data linkage were 'constrained only by the imagination'.[2]

In the same vein, there was broad consensus regarding the factors that are limiting data sharing and linkage. Whilst the disjointed nature of Australian healthcare was only rarely explicitly referred to, it is clear that the majority of impediments to data sharing identified by the submissions are deeply related to the fragmentation affecting all levels of the health system. Technological capacity was not often seen as a problem. Instead, the most prominent issues were the current legal and regulatory framework surrounding data access, the unwillingness of data custodians to release data, and the multiplicity of different ethics committee approvals required for researchers and other interested parties to access health data. It is of no surprise then that the harmonisation, standardisation and streamlining of both privacy laws and ethics approval processes was frequently called for. Although most of the submissions noted that a balance needed to be struck between data sharing and individual privacy, many were also quick to point out that effective tools – for example de-identification and data anonymisation – already existed to ensure that privacy would not be heavily compromised by greater data availability.

Similarly, how data is locked-up in silos and proprietary vendor systems and the lack of data standardisation were seen to be considerable obstacles to overcome. However, many submissions pointed out that these issues, as well as other potential roadblocks associated with increased data usage – such as varying levels of data quality, confusion over-reporting requirements and the costs associated with facilitating data interoperability – could be surmounted by effective leadership, diligent investment and the adoption of standardised approaches surrounding the use and collection of health data at both a provider and agency level. At the same time, the issues surrounding private sector health data, such as how to deal with commercial-in-confidence data, were seen as more challenging but no less important. Without the linkage of private health insurer and private hospital datasets and other forms of private sector health data to publicly held data there would be a substantial gap in Australia's healthcare picture.

Above all, the key message which emerged is that radical improvement to Australian healthcare is well within our grasp. Those submissions expressing scepticism regarding the benefits of data linkage were firmly in the minority – and only one of these explicitly concerned itself with health sector data.

[1] Productivity Commission Issues Paper, Data Availability and Use, April 2016.

[2] Submission 77 QIMR Berghofer

## 6.4 Glossary of Terms and Abbreviations

| Term | Description |
|---|---|
| **AIHW** | Australian Institute of Health and Welfare. |
| **Allied Health Services** | Allied health includes services provided by health professionals, other than doctors, nurses, and dental professionals. Allied Health Professionals include physiotherapists, occupational therapists, dietitians etc. |
| **Ancillary Health Services** | Health services provided by health professionals, but which are not classed as Medical or Hospital, and are not covered by Medicare. Ancillary services include physiotherapy, dental services, speech therapy, ambulance travel, home nursing and spectacles. May also include some medicines that are not on the Pharmaceutical Benefits Scheme (PBS). Also known as General Treatment. (PrivateHealth.gov). The term "Ancillary" is typically used by Private Health Insurers. |
| **AR – DRG** | Australian Refined Diagnosis Related Groups (AR-DRGs)<br>AR-DRGs were developed to reflect Australian clinical practice and use of hospital resources into clinically meaningful categories of similar levels of complexity (outputs) that consume similar amounts of resources (inputs).<br>The AR-DRGs are now used by private health insurers, state and federal health authorities to manage, measure and pay for healthcare services performed by hospitals. |
| **AUSTPATH** | Australian Pathology Code Set – Sets of Pathology request and result codes/coded terms recommended by Standards Australia for electronic HL7-based messaging within Australia, per AS4700.2. The report codes are a constrained set of LOINC codes. |
| **Australian health system** | Australia's health system is a 'web': a web of services, providers, recipients and organisational structures. (AIHW). It is a complex maze of private and public health services, funded by the public sector, private funders, and the consumers. |
| **CHC** | Community Healthcare. |
| **CHSP** | Commonwealth Home Support Programme. |
| **CMCRC** | Capital Markets Cooperative Research Centre. |
| **DHA** | Australian Digital Health Agency. |
| **DoH** | Department of Health. |
| **DRG** | Same as AR – DRG. |
| **DTO** | Digital Transformation Office. |
| **DVA** | Department of Veteran Affairs. |
| **GMDN** | Global Medical Device Nomenclature: an international system used to identify and classify medical devices. The codes and terms allow medical devices with similar features to be identified. |
| **GP** | General Practice/General Practitioner. |
| **HCP** | Hospital Casemix Protocol. |
| **HMQ** | Health Market Quality research & development program. |
| **ICD – 10** | International Statistical; Classification of Diseases and Health Problems (10th version) standardised by World Health Organisation. |
| **ICD – 10 – AM** | Australian Modification of the International Statistical; Classification of Diseases and Health Problems (10th version) standardised by World Health Organisation. |
| **ICD – 9** | International Classification of Diseases version 9. |
| **ICEI** | International Classification of External Causes of Injury. |
| **ICF** | International Classification of Functioning, Disability, and Health. |
| **ICPC – 2** | The International Classification of Primary Care Version 2. |
| **ICPC – 2 PLUS** | (also known as the BEACH coding system) is a clinical terminology classified to the International Classification of Primary Care, Version 2. |
| **LHN (Also LHD, LHHS)** | Local Health Network – an administrative grouping of public health services (mainly public hospitals) within a state; States may have different names for this entity e.g. in NSW they are called LHDs (Local Health District), in Queensland they are known as LHHS (Local Hospital and Health Services) etc. |
| **LOINC®** | Logical Observation Identifiers Names and Codes. LOINC® is a common language (set of identifiers, names, and codes) for clinical and laboratory observations.<br>It is a catalogue of measurements, including laboratory tests, clinical measures like vital signs and anthropomorphic measures, standardised survey instruments, and more. |

| Term | Description |
|---|---|
| **MBS** | Medicare Billing Schedule. |
| **MBS item code** | MBS Item numbers (also referred to as MBS Codes) are used by Australian healthcare practitioners to bill Medicare for medical services performed. |
| **Medicare** | Federal health insurance that provides Australian residents access to healthcare. Medicare aims to ensure that all Australians have access to free or low-cost medical, optometry, midwifery and hospital care and in special circumstances, allied health. (DoH) |
| **Medicare Levy** | Taxpayers pay a levy of 2% of their taxable income, which partly funds Medicare. |
| **OTC medication** | Over-the-counter medication. |
| **PBS** | Pharmaceutical Benefits Schedule. |
| **PBS Item Code** | Pharmaceutical Benefits Schedule (PBS) codes are administrative codes to assist in claims processing. |
| **PBS Prescriber Code** | The Prescriber Codes are used to indicate who is approved to prescribe PBS medicines. |
| **PhD** | Doctor of Philosophy. |
| **PHI** | Private Health Insurance. |
| **PHN** | Primary Health Networks. |
| **POS** | Point of Service. Any point where healthcare services are provided to the consumer. E.g. GP, Hospitals, CHC, Dental, Allied Health Service etc. |
| **POSD** | Point of Service Data. |
| **Primary Care** | In Australia, primary healthcare is typically a person's first point of contact with the health system. No referral is required for this level of care, but is a gateway to the wider healthcare system. Primary care services are delivered via general medical and dental practitioners, nurses, Indigenous health workers, pharmacists and other allied health professionals such as physiotherapists, dietitians and chiropractors.<br>Primary healthcare is delivered in a variety of settings, including general practices, Aboriginal and Community Controlled Health Services, community health centres and allied health services, as well as within the community, and may incorporate activities such as public health promotion and prevention. (AIHW) |
| **Private Hospital** | Private hospitals are mainly owned and managed by private organisations; either for-profit companies, or not-for-profit non-government organisations. They include day hospitals that provide services on a day-only basis, and hospitals that provide overnight care. |
| **Procedure (Australian Classification of Health Interventions(ACHI). Based on ICD-10 Procedure Codes** | A procedure is defined as a clinical intervention that is surgical in nature, carries a procedural risk, carries an anaesthetic risk, requires specialised training, and/or requires special facilities or equipment only available in an acute care setting. Procedures therefore encompass surgical procedures and also non-surgical investigative and therapeutic procedures such as X-rays and chemotherapy. Client support interventions that are neither investigative nor therapeutic (such as anaesthesia) are also included. |
| **Public Hospital** | Hospitals mainly owned and managed by the state and territory governments. Public acute hospitals mainly provide 'acute care' for short periods, although some provide longer-term care, such as for rehabilitation. Public psychiatric hospitals specialise in the care of people with mental health problems, sometimes for long periods. |
| **Secondary Care** | Secondary care is medical care provided by a specialist or facility upon referral by a primary care physician (Nicholson 2012). It includes services provided by hospitals and specialist medical practices. Secondary healthcare can also refer to ongoing services not necessarily provided in the hospital, such as psychiatrists, physiotherapists and occupational therapists. (Health Issues Centre) |
| **SNOMED or SNOMED CT** | Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT) SNOMED CT is a standardised healthcare terminology including comprehensive coverage of diseases, clinical findings, therapies, procedures and outcomes. It provides the core general terminology for the electronic health record (EHR) and contains more than 357,000 concepts with unique meanings and formal logic-based definitions organised into hierarchies. |
| **State DoH** | State Department of Health. |
| **The ATS** | The Australasian Triage Scale – A triage system is the basic structure in which all incoming patients are categorised into groups using a standard urgency rating scale or structure. |
| **The Australian Schedule of Dental Services and Glossary** | This is a coding system of dental treatment, where three-digit code numbers are assigned to items or clinical procedures that are part of current dental practice. |
| **TOOCS** | Type of Occurrence Classification System. TOOCS3.0 is designed primarily for use in the coding of workers' compensation claims, but it can also be used by employers in the workplace. It continues to allow for the addition of more detailed and specific codes where so desired by the use of an additional digit to the classification. |

# 7 REFERENCES


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