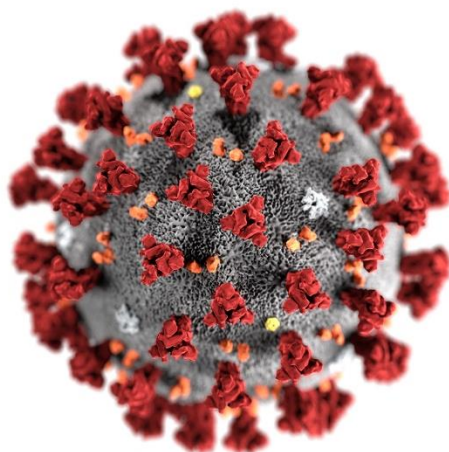


LESSONS FROM THE PANDEMIC

WHY DATA ACCESS IS CRITICAL

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EXECUTIVE SUMMARY

The global COVID-19 pandemic places policy makers at the epicentre of the vital issue of health data sharing to improve the lives of patients, clinical practice and provide best Government for the people. This report is being released as the Federal Government climbs out of the first stages of its health response to the crisis and as it addresses the nation's major economic challenges.

The pandemic has brought into sharp focus how timely access to linked datasets can better support more efficient decision making at Federal and State level. Australia has been lauded for its management of the global health challenge with so few lives lost due in large parts to decisive border control, the lockdown of residential aged care facilities and the strict enforcement of social distancing.

The fact that Federal and State Governments were dragged into public issues of COVID-19 infection relating to a cruise ship, aged care facilities and State Hospitals begs the question: will politicians and health sector leaders maintain an appetite for data sharing gained in these challenging times when things have calmed and the healthcare system returns to a safe harbour?

Parliamentarians are called on to display political courage when it comes to data sharing to deliver best health outcomes for Australians. This report identifies three recommendations for decision makers:

- 1. Parliamentarians need to understand the crucial importance of sharing data in a timely manner for the benefit of patients, clinicians and epidemiologists***
- 2. The need for political action to promote and persuade the public and community leaders of the value and importance timely data plays in quality health outcomes***
- 3. Policy action supporting the vital role timely health data plays in developing a robust and responsive healthcare system in good times to rapidly respond and perform in crises.***

Linking data – the process of matching different pieces of data that are thought to relate to the same person, family, place or event – will provide crucial information for patients in a timely manner to extend and save lives. Australia is internationally recognised for holding high quality digital health data of health, economic and social value, yet there are governance and legislative barriers in accessing it, particularly datasets from the Pharmaceutical Benefits Scheme (PBS) and the Medical Benefit Scheme (MBS).

Linkage would enhance PBS data by enabling better understanding of patients using medical services and costs, as this report highlights. To maintain the momentum of sharing digital health data as the country emerges from the pandemic, it is crucial that Government builds trust with the Australian people by ensuring it maintains strict data management technology and privacy techniques.

Throughout the COVID-19 crisis, health and other forms of public data have been critical in understanding and mitigating the impact of COVID-19, including transmission, identifying risk factors, progression and identifying management strategies. This report shows that linked data has been helpful in forecasting and decision-making and is an essential and powerful tool to improve healthcare supply chains.

COVID-19 has exposed vulnerabilities within Australia's medicines supply chain and production capability. It is only with comprehensive, patient level linked data that decision makers can fully understand the impact of delays or breaks in health service provision on different diseases as a consequence of a decrease in standard monitoring, screening and non-essential surgery.

Telehealth has had a relatively slow uptake since 2011 but the COVID-19 outbreak has seen the expansion of Telehealth with Medicare-subsidised telehealth now part of universal telehealth delivery. In future, data could manage emergency department loads as seniors prefer to consult doctors from home, providing savings at the Federal and State levels.

The acceptance of the benefits of data sharing by policy holders will enable the adoption of new technologies, including artificial intelligence, providing patient benefit and cost effectiveness. This report highlights the way data sharing lessons and advances during the COVID-19 pandemic should not be lost. Rather, policy makers should see it as a pathway to progress, enabling better preparation and planning to cope with significant health challenges in the months and years ahead by designing a more efficient and capable fit-for-purpose health system of the future.

INTRODUCTION

The value of data has never been more critical to patients, Governments, the healthcare sector and the wider public in light of the COVID-19 pandemic. In response to this unprecedented health emergency, we have seen a greater level of bipartisan cooperation, including the establishment of a National Cabinet to coordinate the Federal and State level response.

Australia has been internationally recognised and commended for its response to the crisis. Despite this, the short and long-term impacts to our health sector have brought into sharp focus the ways in which timely access to linked datasets can support better and more efficient decision making, avoiding/managing disruption to health care and mitigating risks to patient health outcomes. Linking de-identified data, including the Pharmaceutical Benefit Scheme (PBS) and Medicare Benefit Schedule (MBS) could greatly inform government policy, enhance understanding of how patients interact with the health system and more broadly improve healthcare quality and service delivery with greater cost-efficiency.¹

Australia currently captures a wealth of real-world data and its appropriate use can make a significant difference to our society.² Real-world data relates to patient health status and/or the delivery of health care which is routinely collected throughout the patient journey.

As we move beyond the short-term crisis response and towards recovery, we have a unique and critical opportunity to observe and implement lessons from COVID-19 to shape a more informed, sustainable, decisive and responsive health sector using data as its foundation.

Recommendation 1.1: To provide a holistic understanding of the patient health journey, including access – and at a population level – understand national trends and the effectiveness, outcomes and relationships and analysis of health policy, it is essential to link this information together and use it in a timely fashion.¹

AUSTRALIAN HEALTH SPENDING

Health spending in Australia as a proportion of GDP has grown consistently over the past 20 years. In 2017-18 the total health spending was \$185.4 billion, which accounts for 10 percent of overall economic activity.³ A range of factors contribute to these increasing costs and the significant challenges faced by the health sector, including an ageing population, increased costs of medical interventions and higher incidence of chronic diseases.

At the time of producing this paper, the Australian Government has provided \$2.4 billion towards healthcare in an effort to combat COVID-19.⁴ This includes \$1.5 million allocated to develop the COVIDSafe app, which utilises public data to monitor community transmission.⁵ However, the long-term costs (many yet to be realised) will require significant resourcing.

Recommendation 1.2: Access to more comprehensive data is essential in building a cost-effective, efficient healthcare response, particularly as we seek to strengthen our broad economic outlook post COVID.

HEALTH DATA ACCESSIBILITY IN AUSTRALIA

Australia is domestically and internationally recognised for holding high quality digital health data that has significant health, economic and social value.⁶ Despite this, there are significant governance and legislative barriers in accessing readily available, linked data including the Pharmaceutical Benefit Scheme (PBS) and Medicare Benefit Scheme (MBS) linked datasets. Despite Australia's technical readiness: "Australia stands out among other developed countries as one where health information is poorly used."⁷

Beyond benefits to the health sector and patient outcomes there is real economic value in more effectively utilising health data. In a 2014 report, Lateral Economics suggested health-specific data could contribute as much as \$5.9 billion into the economy each year.⁸ Linking data refers to a process of matching different pieces of data that are thought to relate to the same person, family, place or event to form 'a new, richer dataset.'¹

Currently, trusted government partners including Prospection have access to restricted datasets, including the PBS which give insights into prescriptions, benefit and patient contributions for all prescriptions supplied by approved suppliers. At this time, however, significant delays in the timeliness of the data mean that analysis of medicine usage can be delayed by 4-7 months. Monthly data would help ensure more responsive and accurate research, with only 2-3 months lag at any one time. As such, there is an argument a reluctance to share data between the Government and the public will leave the nation stagnant in its ability to better prepare for pandemics of the future.

Despite its value, PBS data only provides part of the picture. Without more sophisticated linkage to datasets like the MBS, we are unable to understand the holistic patient health journey, including medical services and costs, hospital visits and the interrelation of conditions and medical interventions. At a population level linking PBS and MBS data will greatly improve the evidence base for research and policy planning.

According to Australia's Population Health and Research Network, 'no single data collection' is sufficient to 'allow an understanding of the complex pathways that result in health or disease' or to determine 'whether Australia's health and social systems work in optimal ways.'⁹ The more datasets that researchers are able to link together, the greater our depth of understanding and analysis become. As such, it is possible to use these datasets to understand trends, patterns and correlations at a patient and population level. "Data linking has the capacity to maximise that resource and to create new opportunities for more complex and expanded evidence-based policy and research."¹⁰

Even prior the outbreak of COVID-19 there have been significant calls from government and the health sector to allow accessibility to linked PBS and MBS data. There is 'an "untapped potential" to utilise data generated by the healthcare system.'¹ Linked MBS and PBS data is the fourth most requested data from the Australian Government. However, presently there are legislative restrictions and binding privacy guidelines that strictly constrain the linkage of de-identified MBS and PBS data.

There are understandable concerns around the privacy and security of health data, particularly in ensuring the de-identification of individual health records, however, modern advances in data management technology and privacy preserving techniques have made re-identification difficult, and data security protocols provide an additional layer of protection.¹¹

In addition, evidence shows the community is more willing to share health data to support research. We have seen "significant cultural shift in the way data is regarded."¹² Surveys conducted by Research Australia consistently show that consumers are increasingly ready to share their data for research.³ The high uptake of the Australian Government COVID-19 app (over 5.1 Million at time of paper) is further evidence of support for data sharing if transparency and net community benefit are maintained.

Prospection recognises the need to constantly balance data privacy with the overwhelming public benefits from readily available linked datasets, such as PBS, MBS and hospital and state government health data.¹⁴

Recommendation 2.1: There is a strong argument for the need to value the role of more timely use of targeted data outside times of disruption. Considered and coordinated data sharing between Government and the community is not an insurmountable challenge given the advances made during the COVID-19 pandemic.

DATA AND THE IMPACTS OF COVID-19

MANAGING THE OUTBREAK

Health and other forms of public data have been critical in understanding and mitigating the impact of COVID-19, including transmission, identifying risk factors, progression and identifying management strategies.

Effective modelling for government and health strategies which seek to eliminate or control COVID-19 has necessitated unprecedented data collection, analysis, and sharing to reduce transmission¹⁴ and effectively adapt to the long-term impacts of the crisis. These effects, however, have been too reactive. To more effectively plan for the current and future crisis, Australia needs to build and extend electronic health records. Data linkage is the key to comprehensive COVID-19 surveillance as well as managing non-COVID-19 health challenges.¹⁴

The Australian government's public demonstration of effective data-driven emergency health response was largely reflected by a willingness of the Australian public to support data harnessing to manage transmission. Over five million Australians downloaded the COVIDsafe app in a collective effort to reduce community transmissions. This presents an opportunity to capitalise on the wide recognition real-time and comprehensive data as critical in effective policy and decision making.

More readily available, linked data can much better prepare our response to future Coronavirus' outbreaks and enable us to identify and monitor patient level trends during the early stages. Further, policy makers and the healthcare system can better understand the possible interplay between COVID-19 and non-COVID conditions which influence transmission.¹⁴ For example, social determinants, existing conditions or cultural factors could be included and assist to more effectively plan for future outbreaks.

Beyond the crisis management, commissioning a coordinated stream of modelling, data collection and analysis in multiple sectors to help optimise the adaptation function of the Controlled Adaptation strategy, make the data transparent, and use it in the medium to long-term for decision making on COVID-19¹⁴.

Recommendation 2.2: We call on the Government to establish a national real-time health data repository starting with COVID-19 related data that links primary, secondary and acute care that can be extended to other areas of healthcare.

MEDICINE SUPPLY CHAIN

Timely and linked data sources are paramount in medical/health supply chain management, creating better demand planning strategies and decision making by collecting and analysing data in real-time. COVID-19 has exposed many vulnerabilities within Australia's medicines supply chain and production capability.

To effectively manage the current crisis and the flow on effects there is a need for a more robust data platform enabling the monitoring of changes in purchasing behaviours, stock shortages, supply disruption and impacts of government intervention which can then be analysed. Shortages in domestic capacity was revealed by the lack of access to personal protective equipment and there were also risks in patient access to critical medical supplies.

For example, the Rural Pharmacy Network Australia expressed concerns about rural access to prescription and non-prescription medicines, primarily due to concerns around patient stockpiling and large pharmacy mass-ordering.¹⁵ The Federal Government was forced to implement a series of strategies to manage the impact of the COVID-19 pandemic with regards to usage, dispensing and supply of medicines, especially those manufactured overseas where there was risk of supply interruption.¹⁶

Strategies included, limits on patient scripts per month to prevent stockpiling, boosting domestic production, ongoing work with pharmacists, GPs and the States and Territories to allow medicine substitution by the pharmacist in the event of a shortage. Beyond crisis supply chain management, there is likely to be emerging pressures in medicine supply where real-time data will be critical.

For example, various potential treatments and vaccines are currently being trialled on patients with COVID-19 and if successful, monitoring and responding rapidly to patient uptake will be critical. Development and uptake of COVID-19 treatment bridge medicines or future vaccines. Linked data will be critical to understand how these treatments may influence or be influenced by other health factors. We will learn more about the vulnerabilities of the health system caused by the pandemic due to lack of access to relevant datasets in the months ahead.

Using data to create an early alert system for risks to supply chains and medicine stocks which have been impacted by a sudden change to purchasing behaviours is critical in managing future epidemics, but will also allow us to evaluate the impact of government intervention.

Recommendation 1.3: Providing access to more granular, real-time geographic data in future will enable effective monitoring of medicine consumptions and trends in medical interventions across regions. Real time data will enhance the ability to manage supply chains during and beyond pandemic periods, which is particularly critical when international supply chains are impacted.

DISRUPTION TO NON-COVID-19 CONDITIONS

In response to the COVID-19 outbreak, the Federal Government-imposed restrictions on non-essential and non-emergency surgeries and the closure of out-patients to relieve pressure on the hospital system and to reduce the likelihood of transmission. This dramatic change to patient healthcare access, combined with public fear of contraction and efforts to socially isolate is predicted to have significant disruption of management and potential exacerbation of non-COVID health conditions.

For example, a marked reduction in pathology testing and clinical presentations for non COVID-19 problems indicate a possible delay in the management of existing conditions and lack of attention for new health challenges.¹⁷ It was noted that there is concern that following the pandemic: “There will be the adverse effects of neglecting other health issues...and there will be difficult trade-offs being made by patients to defer important diagnoses or treatments in favour of minimising exposure to coronavirus.”

In addition, some clinicians fear a potential spike of severe non-coronavirus illnesses as patients with early symptoms of cardiovascular or other serious conditions may avoid presenting to emergency departments.¹⁸ Failing to seek treatment for mild to moderate health issues can lead to more serious health problems for the individual and place greater burden on hospitals.¹⁹ A survey of 175 GPs conducted by specialist health publication *The Medical Republic* found about half had lost more than 30 percent of their revenue. Roughly one-third reported losses of less than 30 percent.

Only with comprehensive, patient level linked data can we fully understand the impact on different diseases as a result of delays or breaks in health service provision as a consequence of a decrease in standard monitoring, screening and non-essential surgery. The acute and chronic stress due to the unprecedented societal disruption caused by COVID-19 risks exacerbating existing conditions or may see patients develop previously undiagnosed conditions such as heart attacks, strokes and compromised mental health.²⁰

In March, Australia's national crisis support service Lifeline answered almost 90,000 calls, an increase of 25 per cent over the same time last year.²¹ In addition, it is likely that thousands of Australians, particularly those who work in front-line services, will suffer from post-traumatic stress disorder.

The health system is likely to experience a significant backlog of non-elective surgeries and delayed diagnosis or treatment of non-COVID conditions. The Alfred Emergency and Trauma Centre academic director Professor Peter Cameron identified concerns that fewer attendances for other conditions may result in some major health complications in the coming weeks and months.

Similarly, The Royal Australian and New Zealand College of Radiologists (RANZCR) has also raised concerns about patients with cancer delaying or discontinuing treatment based on safety concerns or capacity of clinical services.¹⁹ Even with the limited PBS data available we won't be able to assess impacts on changing patterns for many months, with potentially life-threatening consequences.

Linking PBS and MBS data sets could enable linking with other datasets in the future, which can greatly increase the range of and responsiveness of health data analysis. For example, linking emergency hospital visitation data with MBS and PBS datasets would increase understanding of individual patient pathway and the way Australians use the health system as a whole.²²

Recommendation 2.3: Rapidly accessible linked data will be critical for broader preparedness continuing to manage the yet unknown impacts of this crisis and those of the future, including all aspects of response, governance, supply chain, and stockpiles. This could also extend to fully understanding the reasons for and nature of transmission and what actions could better mitigate these in future.

TELEHEALTH

Digital technologies have been crucial in managing the spread and transmission of COVID-19 and has enabled patients, particularly those in the high-risk categories, to receive essential care and support whilst social distancing. Since 2011, Telehealth has had a relatively slow uptake despite various incentives and technological improvements.

There was a total of 820,429 consultations nationally between 2011-19. Following the COVID outbreak the federal government drastically overhauled telehealth arrangements, expanding Medicare-subsidised telehealth services to create a system of "universal telehealth." This was widely supported move, including by the RACGP.²³ The expanded utilisation and increased Federal government investment and expansion has been vital in minimising transmission and providing non-COVID related healthcare.²⁴

The Federal Minister for Health Greg Hunt released a statement on 21 May 2020 that in the two months since 13 March, 10.39 million services were delivered to 5.71 million patients, with 69,647 providers using Telehealth services. The \$536 million in benefits paid is a significant investment aiding access and continuity of care and allowing health care providers to continue their services.

Effectively, Telehealth was universally introduced to mitigate the reduction in GP visits so care was still available to patients who could not visit GP practices for health concerns. Using MBS data makes it possible to see if overall, patients are still accessing required primary care at the same rate, whether it has been reduced and what are the health impacts? Given the dramatic reduction in face-to-face patients seeing their doctor across the country, there is a strong argument to provide early access to the MBS for better planning and preparation to provide continuity to deliver patient care.

The uptake of telehealth could have positive effects for health sector capacity, potentially reducing emergency department patient loads in the future. Tele or video consultations can reduce the visits required for cancer patients or older/less mobile patients.

Telehealth is helping to replace the drop in face-to-face consultations with early evidence suggesting a broad community embracing of telehealth since the COVID-19 expansion according to Australian Medical Association President Dr Tony Bartone. Without clear, real-time data it is difficult to assess if overall patient engagement with primary care will be affected in the wake of COVID-19 and whether Telehealth is having the desired effect.

However, effective management of this service hinges on the availability of readily accessible data. For example, will Telehealth uptake directly correlate with reductions in face-to-face visits at individual or population levels? Will standards and patterns of care decrease and what are the impacts and costs of telemedicine across different diseases?

Telehealth will forever change how patients interact with the health system. This is certainly for the better, however only timely, integrated data can ensure we understand, manage and mitigate against the unintended consequences of such a dramatic shift.

Meaningful and timely analysis will be essential to identify bottlenecks or risks within the new healthcare journey as a result of telemedicine, allow analysis of the costs of telemedicine versus traditional consultation and identify opportunities for cost savings or improved patient journeys post COVID-19.

Recommendation 3.1: Readily accessible data is essential in the understanding and monitoring of the rapidly evolving patient interactions with primary care post COVID-19 and Telehealth expansion. It is critical to understand the impact of the rapid expansion of the delivery of quality healthcare, as well as short and long-term patient health outcomes.

TECHNOLOGY AND INNOVATION

The COVID-19 pandemic has shown the Government, healthcare sector and the public there is the appetite to share data through cutting edge technology and innovation to achieve quality healthcare outcomes. And, in extraordinary circumstances, to be the envy of many nations. Will Australia pull up stumps or continue the journey?

The Government's utilisation of the highest level of data privacy and security technology will foster public trust and further strengthen community support for health data sharing for better patient and health system outcomes. The widespread response to COVID-19 has highlighted cross-sector capacity and an unprecedented willingness for collaboration to innovate, which requires being able to harness complex data to support ever-growing technological capability.

Existing data sources such as the PBS dataset have enabled health partners to innovate and scale capability and capacity, however there is an imperative to fully utilise the rich data technologically available to us. To support this, it is critical that the government support community messaging to seek medical care in managing existing conditions and diagnosis and treatment of both COVID-19 and non-COVID-19 conditions.¹⁴ Harnessing and communicating the extensive benefit of data in evidence-based decision making will be critical in government narrative.

At the same time, policy makers are challenged with maintaining the course to harness data from e-health (e.g. video/telehealth and apps) as an important part of routine health care, supported by nationally agreed standards and quality indicators. The COVID-19 pandemic has provided the perfect pivot for Telehealth to become a viable part of patient care if the data can be shared to demonstrate patient benefit and cost effectiveness in the wake of the take up boost.

As new technologies emerge and are adopted, including Artificial Intelligence (AI), more sophisticated data analysis and harnessing of digital capabilities can help in understanding the benefits to create health choices and options for patients and clinicians.

Recommendation 3.2: Policy makers of all persuasions are at a crossroads when it comes to optimal patient care where one road is linked data and technology and the other is a pre-COVID-19 road of de-linked, untimely and distrustful stakeholders leading to nowhere.

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