

23 November 2020

Consultation response: Health information sharing legislative reform

About the Victorian Healthcare Association

The Victorian Healthcare Association is the not-for-profit peak body supporting Victoria's public health and community services to deliver high quality care. The VHA represents Victorian public hospitals, registered community health services, multi-purpose services, and bush nursing services.

On behalf of its members the VHA delivers vision, value and voice for the Victorian health sector by shaping policy, advocating on key issues and supporting members to respond to system reform. Our role is to contribute insight and expertise to promote collaboration and transformation of the Victorian healthcare system.

We welcome the opportunity to provide a submission on the proposed health information sharing legislative reform. The recommendations in this submission are based on feedback received in consultation with our members.

Recommendations

Assessment of needs and existing solutions

The VHA acknowledges that the ability for treating practitioners to securely share health information constitutes best practice for patient care by providing a more substantial picture of a person's treatment history. However, the proposed clinical information sharing (CIS) solution may not be the most appropriate mechanism to achieve the intended aim for patients to move between services and receive treatment over an extended period in a safe and coordinated way.

Consumer-controlled information sharing capability already exists within the health system through the national framework provided by My Health Record. Establishing a CIS solution that is state based allows for potential duplication, while including only the public sector does not reflect Victorian consumer needs and typical engagement with the health system. Some consumers access a combination of private and public services, at times simultaneously such as in the maternity context, and they are mobile, relocating interstate for a time and dipping in and out of the Victorian health system.

Further, a CIS solution that does not incorporate all elements of the patient journey through the health system including public, private, registered community health and ambulance services will not be fit for purpose. For regional and rural communities in particular, the inclusion of health information collated by ambulance services in a CIS solution is vital to prevent delays and mitigate risks during patient transfer from ambulance to emergency departments and urgent care centres.

While outside the scope of this discussion paper, we encourage the Department of Health and Human Services (the Department) to consider the practical implementation of the legislative reform in a pilot trial of the proposed CIS solution. A commitment to review the legislation two years after its introduction would also be prudent and allow unintended consequences to be addressed beyond any pilot trial period or implementation. To identify pilot sites and ensure the CIS solution is fit for purpose, we would encourage broad consultation across the health sector and with consumers. This is necessary to ensure that all stakeholders support the initiative, that foreseeable issues can be addressed prior to implementation, and for full consultation and education to occur.

Recommendation: That the Department consult broadly with the health sector and consumers to conduct a pilot trial of the proposed CIS solution and commit to reviewing the legislation two years after introduction of the reform to ensure the solution is fit for purpose.

Recommendation: Ensure all Victorians benefit from the reform by expanding the proposed CIS solution to facilitate information and data sharing with all parts of the health system including the private sector, primary and community health and ambulance services.

Investment in an equal implementation baseline

The pandemic context has demonstrated the benefits of a Victorian health system that is collaborative and consistent, allowing for rapid and coordinated system-wide responses. The increased consumer demand for telemedicine and digital health solutions during this time has also exposed the longstanding variability and incompatibility of public health service digital health infrastructure.

The VHA supports the strengthening of a coordinated digitised approach to address the everyday health care needs of Victorians throughout the COVID-normal period and beyond. However, healthcare IT systems often operate as legacy systems and require significant investment in order to ensure inter-operability between the multiple existing systems to avoid costly inefficiencies.

The development of a more substantial and, ideally, complete picture of a person's treatment history cannot be achieved without significant continued investment in IT infrastructure to support services to digitise health information. Without additional funding for the implementation of a CIS solution, the full suite of benefits associated with its uptake may not be realised or else health services may have to redirect funds for clinical services to these activities. State-wide consistency and distribution of this resourcing to achieve an equal baseline of digital competency and support is critical to address the variable digital health capabilities of services and result in mutual benefits for the health system and Victorian communities.

As well as capital investment, human resources will be needed to update existing IT, and to provide training to relevant staff in relation to the CIS solution and any updates required to link internal IT systems. Health services that have implemented EMRs and localised information sharing partnership arrangements also report that systemic transformation of this scale requires the investment of considerable time and expertise. This includes digital health expertise to develop specific policies and strategies around governance, change management, privacy and confidentiality, operations and risk mitigation.

Recommendation: That the State Government provide substantial investment to support implementation of the CIS solution to achieve an equal baseline of digital competency across Victorian health services. This includes the establishment and improvement of compatible electronic medical records systems (EMRs), patient information systems and client management systems to support a smooth and rapid transition to health information digitisation.

Recommendation: That the State Government design and deliver standardised information sharing strategies, policies and protocols for all services across the health system participating in the proposed reform to ensure a consistent state-wide approach to compliance and implementation.

Secure sharing and robust safeguards to promote access to care

This is a tenuous time for health services and consumers as people cautiously begin to reengage with their health providers. The unique lockdown period in Victoria has led to a backlog of deferred and delayed health care such as vital disease and mental health prevention, detection, intervention and support. It is imperative that the proposed reform does not affect consumer confidence in the health system, particularly as services begin to address the backlog of patient care while encouraging people to continue to access COVID-19 testing and treatment.

All health and community health services in Victoria care for people with complex and sensitive care needs, and a one-size-fits-all approach to clinical information sharing will fail to address the nuance required to safeguard consumers'

rights to privacy and confidentiality and in some cases, their personal safety. The voice of consumers appears absent in the design and delivery of this reform. As the 'end user' of the proposed CIS solution, it is imperative that consumers be included in its ongoing design and delivery to determine whether its purpose and approach justifies the lack of consumer consent and control, and identify any unintended consequences of its application.

In addition to the data security identity and access management capabilities outlined in the consultation paper, health services have identified several sensitive care episodes in which additional safeguards for privacy and confidentiality are essential for consumer protection and ongoing accessibility of the health system. These include clinical and non-clinical information related to family violence, custody and legal guardianship, child protection, elder abuse, complex mental health conditions, paediatric health, and sexual and reproductive health including abortion. It is vital that the CIS solution includes specific provisions that allow hospitals to be permitted to withhold certain sensitive information, with patient consent or where requested, without penalties including information related to the above sensitive care episodes.

With respect to consumer control of health information, the New South Wales model of patient consent and access does not provide the sufficient level of security required to protect patients and consumers. This reform should provide protections to allow patients to opt out, the right to apply for access to their records and request that information is not disclosed.

Recommendation: That a consumer-controlled CIS solution be considered to safeguard privacy and confidentiality by allowing patients to opt-out, apply for access to their records and request that information is not disclosed.

Recommendation: It is imperative that rigorous consumer consultation and prompt response to key concerns about the proposed CIS solution be addressed transparently and early in the reform design and implementation process. This would enable the CIS solution to reflect nuances in complex and sensitive care episodes and may address the risk of consumers withdrawing from services and failing to receive essential care and treatment.

Recommendation: Privacy safeguard mechanisms such as governance processes, risk controls, 'break-glass authority', determination of clinical and non-clinical 'authorised persons' to access, release and redact highly sensitive information must be considered and developed in close consultation with clinical and non-clinical experts including mental health professionals and social workers. Additionally, the design and delivery of these mechanisms should incorporate learnings from other sectors including existing family violence information sharing principles and protections.

Recommendation: That the Department provide a comprehensive and targeted suite of communications for specific audiences including health and community health services, clinicians and communities to support services implement the reform and assist to ensure that consumer access to care is uncompromised by its introduction.

Delegation of responsibilities and penalties for breach

We support the proposed regular audits by departmental data stewards to ensure information is accurate and up to date, and that risk of adverse consequences and errors is minimised. However, we strongly oppose the application of onerous auditing processes requiring substantial time and resource investment from health services and appropriating resources allocated to essential everyday care delivery.

Additionally, the proposed operational guidelines make no mention of delegated responsibility for implementation of protocols in the event of a privacy or data breach. This includes investigation, tracing, containment, resolution, timely communication with affected consumers and procedures for redress. Clarification of this processes and responsible authorities should be shared with participating services for input as part of the consultation process.

The proposed civil penalties for unlawfully requesting or obtaining access to health information under the Health Records Act (2001) are \$49,600 for a body corporate and \$9,900 in other cases, such as individuals. This is less punitive than the penalties in New South Wales and Queensland related to misuse of clinical information sharing systems, and drastically below those associated with My Health Record which have increased to a maximum of

\$315,000 with criminal penalties including up to 5 years' imprisonment. As a result, the proposed penalties outlined in the consultation paper do not provide sufficient deterrence for misuse of data and information. Additionally, because the civil penalty is far lower than its national My Health Record counterpart, the proposed penalties and sanctions give an impression of leniency that does not reflect overall assurances of the reform to safeguard data security and protect confidentiality.

According to the consultation paper, liability implications for the Department apply only to a breach 'that could alter or delete patients' personal data'. This is a lesser threshold for appropriate use of data and information than that placed on others users of the CIS solution. The misuse and unauthorised sharing of data by the Department should have attached penalties, regardless of whether it has the potential to, or does, result in the specific consequences outlined in the consultation paper. To promote consistency, fairness and compliance, the liability implications for all who use and access shared information through the CIS solution should be equal.

Recommendation: That any auditing processes be streamlined and aim to reduce the administrative burden on individual health services to comply and protect resources allocated to essential everyday care delivery.

Recommendation: That comprehensive consultation be held with participating services to determine details of the operational guidelines and delegated responsibilities for implementation of protocols in the event of a privacy or data breach. This includes investigation, tracing, containment, resolution, timely communication with affected consumers and procedures for redress, as well as determination of liability where multiple services are involved in a breach.

Recommendation: That consistent, equal and increased penalties be applied to any breaches related to the use of the CIS solution to safeguard consumer privacy and confidentiality aligned with penalties associated with My Health Record.



For further information contact

Hannah Neven Gorr
Lead, Health Sector Advocacy

hnevangorr@vha.org.au

0407 845 711