



Health Issues Centre
Consumer voices for better healthcare

Submission to National Digital Health Strategy consultation

November 2021

Executive Summary

The Health Issues Centre (HIC) welcomes the additional opportunity to contribute to the development of the National Digital Health Strategy ('the Strategy').

The Strategy is a critical piece of Australia's evolving healthcare infrastructure. This importance has been amplified by the rapid acceleration of digital health adoption during the pandemic.

HIC has identified three themes for the Australian Digital Health Agency's (ADHA) consideration as it finalises the new Strategy:

- Theme 1: Embed the principle of consumer-driven healthcare into the Strategy
- Theme 2: Equity and digital inclusion
- Theme 3: Protecting consumer rights

Ensuring consumer centricity in Australia's digital health architecture should be paramount. Consumers have a personal stake in healthcare and consumer involvement is critical to effective digital healthcare policy development, participation and uptake.

The new Strategy should reflect the need to address the digital divide. Digital health provides opportunities for improved, person-centred consumer healthcare, but many vulnerable Australian are missing out and risk being left behind.

Rapid digital health uptake has also outpaced the evidence and understanding of best practice, including consumer privacy and access rights.

The Health Issues Centre recommends:

1. That the importance of consumer needs should be elevated in the new Strategy (compared to the previous strategy), by including 'partnering with consumers' as a strategic priority for ADHA.
2. That the Strategy should explicitly commit ADHA to working with a range of consumer health groups so that diverse consumers voices are heard.
3. That the new Strategy explicitly addresses barriers to digital access, and includes specific actions for reducing the 'digital divide,' broadly defined
4. That ADHA explicitly addresses consumer healthcare rights in the Strategy by establishing national principles to guide the introduction of digital initiatives that embed rights regarding participation, access, security and redaction.

Who we are

HIC is a registered charity recognised by the Victorian Government as the state's peak consumer health advocacy body. Operating for over 35 years, we:

- listen to the voices and experiences of everyday people to help shape policy decisions and service delivery in the health system
- use cutting edge social listening research to provide real insights into consumer experiences at a grassroots level
- are a recognised leader in consumer and community engagement training
- advocate on behalf of health consumers and provide a conduit for discussion between government, health service providers and consumers, particularly those often marginalised from decision making
- operate a social enterprise arm which provides fee-for-service consultancy services

Introduction

Digitisation of health is inexorable and will deliver significant benefits, but this should not be at the expense of civil rights and/or those consumers who are not digitally engaged.

We commend the Government for the introduction of Telehealth MBS items during the COVID-19 pandemic and its commitment to updating the National Digital Health Strategy.

A challenge now for Government is ensuring this digital healthcare innovation is driven primarily by evidence-based policy rather than emerging technology capability. A failure to do so may mean embedding unintended consequences system-wide, including the erosion of basic consumer rights.

System architecture should be subject to Privacy Impact Assessment in the planning stage. More broadly, there is a need for a set of principles to inform all systems development and to prevent the unconscious erosion of consumer rights.

Raising health literacy, upgrading internet access, and subsidising the costs of devices and data plans are all important but will still not be enough to bridge the digital divide for many consumers. There will need to be a period where parallel processes are in place so that those who are digitally challenged will not be disenfranchised.

HIC would welcome further opportunities to contribute to the design and implementation of the Strategy, and to work with Government on how best to meet consumer expectations as Australia's digital health policy framework and infrastructure develops and matures.

Key themes

Theme 1: Embed the principle of consumer-driven healthcare into the Strategy

"The systems we put in place are supposed to serve people – not the other way around"
– Participant, HIC consumer forum¹

HIC believes consumer-defined goals and ongoing consumer input should underpin Australia's new National Digital Health Strategy. However, the initial emerging themes from the online survey as articulated by ADHA do not currently recognise this imperative.

The Australian Government and related entities have already overwhelmingly identified the need for consumer centricity in health care. For example:

- The second of the National Safety and Quality Health Service Standards – 'Partnering with Consumers' – explicitly requires health services to partner with consumers²
- CSIRO has identified empowering consumers and addressing health inequality as essential to Australia's health transition³
- The MBS Review Taskforce recommended that Government⁴:
 - 'Ensure all future reviews require consumer input and use a consumer framework to enable a consistent and consumer-focused approach' (Recommendation 1)
 - 'Introduce standardised health outcome and patient reported outcome measures' (Recommendation 8)

This need for consumer centricity in Australia’s digital health architecture has been separately validated by the WHO’s Global Digital Health Partnership (a collaboration of governments and the WHO):

- “Moving forward, Australia should concentrate national efforts on developing a more comprehensive understanding of the consumer or citizen’s perspectives about digital health”⁵

While ‘Putting users at the centre’ is one of the seven ‘Guiding Principles’ underpinning the current Strategy, consumer wants and needs do not feature in the seven ‘Strategic Priorities’ which describe the actual focus areas for the ADHA.⁶

Consumers have a personal stake in healthcare and consumer involvement is critical to effective digital healthcare policy, participation and uptake. HIC’s ongoing program of consumer forums and engagement^{7,8,9} show consumers’ strong interest in digital health’s evolution and in the delivery of the next strategy.

Recommendation:

- The importance of consumer needs should be elevated in the new Strategy (compared to the previous strategy), by including ‘partnering with consumers’ as a strategic priority for ADHA.
- The Strategy should explicitly commit ADHA to working with a range of consumer health groups so that diverse consumers voices are heard.

Theme 2: Equity and digital inclusion

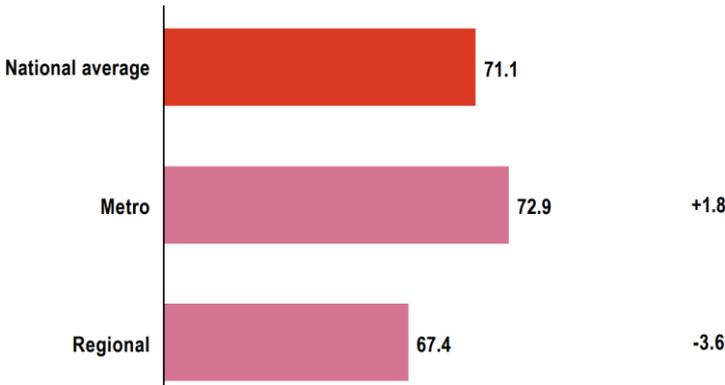
‘Weak governance of digital technologies is causing health inequities and compromising human rights’¹⁰ (The Lancet)

Digital health provides opportunities for improved, person-centred consumer healthcare. Most consumers agree that sharing clinical information could potentially improve health treatment.¹¹

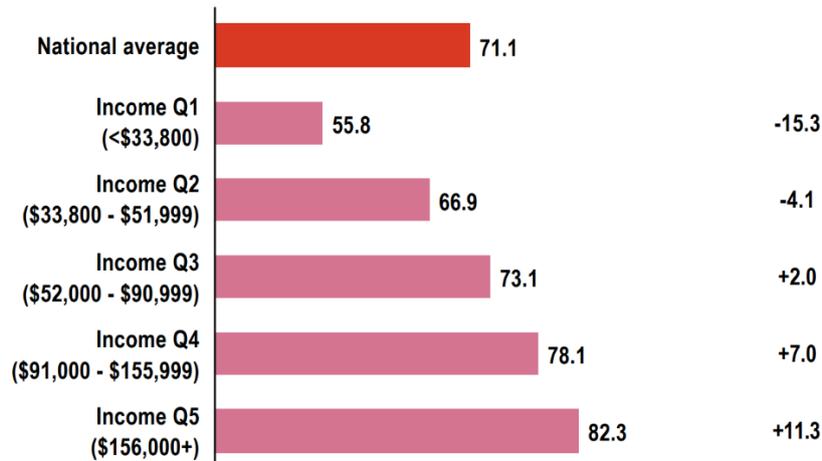
Yet vulnerable Australian are missing out and risk being left behind. The Australian Digital Inclusion Index (2021) shows that:

- Digital inclusion increases with education, employment, and income
- There is a marked divide between metropolitan and regional areas
- 11% of Australians are ‘highly excluded’ and 17% are ‘excluded’
- Digital inclusion remains closely tied to age¹²

For example, the Index scores demonstrate the rural/regional and metro divide...



...and the income divide¹³:



HIC and Safer Care Victoria convened a public forum in June 2021 with 158 registrants to examine the extent and impact of the “digital divide.”¹⁴ Key findings included that our system has been extensively digitised and numerous cohorts are facing barriers to digital health access, including those with specific conditions.

The new Strategy should reflect the need to address the digital divide, including internet access, social disadvantage, health literacy and other barriers to digital health use. This is supported by the recent (November 2021) report by the House Select Committee on Mental Health and Suicide Prevention, which recommended:

- “that the Australian Government ensures the next National Digital Health Strategy (2022-27) explicitly addresses barriers to digital access, and includes specific actions for reducing the ‘digital divide.’”¹⁵

In framing and reaching this conclusion, the Committee notes that ‘it is critical that services continue to be supported and operate offline and in physical locations, to ensure that the delivery of digital services does not reduce access.’

HIC supports the Committee’s recommendation.

Recommendation:

- That the new Strategy explicitly addresses barriers to digital access, and includes specific actions for reducing the ‘digital divide,’ broadly defined

Theme 3: Protecting consumer rights

"I feel there is great benefit in data sharing, but consent and safety are essential. Having had my ATO hacked recently, I also feel having all that comprehensive data online and connected puts consumers at risk in a myriad of ways."

– Participant, HIC consumer forum¹⁶

Rapid digital health uptake has outpaced the evidence and understanding of best practice, including consumer privacy and access rights.

Health Issues Centre works continuously with consumers to understand and advocate for their healthcare needs. During 2020-21, we consulted on digital health with over 350 consumers in online forums alone. Consumers clearly told us:

- **security of data** is important. Consumers want to feel confident that data is stored securely, in the right jurisdiction within Australia and to know their access rights – it is not sufficient to simply dial-up punitive measures for breaches¹⁷
- they do not want digital health gains to be at **the expense of basic consumer rights**¹⁸
- they are **concerned they could lose control** of their personal health data, e.g. the right to opt in or out, the right to withhold consent to access
- they want to retain the **right to curate what information the records should hold** and the accuracy of that information:
 - While there is no 'one' consumer view on privacy, it is particularly important for people with blood-borne diseases, mental health diagnosis, and/or a history of being a victim of domestic violence
 - Curating information is not just about unauthorised access – consumers gave numerous examples of "unconscious bias" where stigma over previous experiences affected the quality of care they received.¹⁹

Other studies have also found consumer reticence on security and trust:

- The Academy of Technology, Science and Engineering found consumers will accept new technologies, but there are **concerns surrounding data privacy, cybersecurity, data ownership, trust, and access and equity**²⁰
- The Office of the Australian Information Commissioner found 83% of Australians want government to provide more protection of the privacy of their data²¹

Data security is critical to consumer safety. Further, it builds trust, and uptake of new technologies is heavily influenced by consumer trust.²²

The new Strategy is an opportunity to take further positive action that protects consumers' rights and personal data. National principles embedding consumer rights would be a welcome initiative.

Recommendations:

- That ADHA explicitly addresses consumer healthcare rights in the Strategy by establishing national principles to guide the introduction of digital initiatives that embed rights regarding participation, access, security and redaction.

-
- ¹ Health Issues Centre, *Forum Report – HIC/Safer Care Victoria Forum Series on involving Consumer Leaders in Healthcare Reform – Telehealth*, <https://hic.org.au/wp-content/uploads/2020/12/SCV-HIC-Telehealth-Forum-Report-For-Website.pdf>.
- ² National Safety and Quality Health Service Standards (Second Edition), <https://www.safetyandquality.gov.au/sites/default/files/migrated/Fact-sheet-1-Intro-to-the-National-Safety-and-Quality-in-Health-Service-Standards-2nd-ed.pdf>
- ³ Future of health: shifting Australia’s focus from illness treatment to health and wellbeing management. Commonwealth Scientific and Industrial Research Organisation. Retrieved from <https://www.csiro.au/en/Showcase/futureofhealth> September 2019
- ⁴ Medicare Benefits Schedule Review Taskforce, *An MBS for the 21st Century: Recommendations, Learnings and Ideas for the Future - Final Report to the Minister for Health*, December 2020: <https://www.health.gov.au/sites/default/files/documents/2020/12/medicare-benefits-schedule-review-taskforce-final-report-an-mbs-for-the-21st-century-recommendations-learnings-and-ideas-for-the-future.pdf>
- ⁵ WHO, Citizen access to health data – An International Review, 2020: <https://www.gdhp.org/59380/widgets/301901/documents/174780>
- ⁶ *Safe, seamless and secure: evolving health and care to meet the needs of modern Australia – Australia’s National Digital Health Strategy*, <https://www.digitalhealth.gov.au/sites/default/files/2020-11/Australia%27s%20National%20Digital%20Health%20Strategy%20-%20Safe%2C%20seamless%20and%20secure.pdf>
- ⁷ *The Digital World of Healthcare Forum*, June 2021.
- ⁸ Health Issues Centre, *Forum Report – HIC/Safer Care Victoria Forum Series on involving Consumer Leaders in Healthcare Reform – Telehealth*, <https://hic.org.au/wp-content/uploads/2020/12/SCV-HIC-Telehealth-Forum-Report-For-Website.pdf>.
- ⁹ Health Issues Centre, ‘Report from Public Consultations - Will sharing improve caring? A Clinical Information Sharing System’, August 2020.
- ¹⁰ The Lancet Digital Health (editorial), Digital technologies: a new determinant of health, *The Lancet Digital Health*, 2021;3(11):e684: [https://doi.org/10.1016/S2589-7500\(21\)00238-7](https://doi.org/10.1016/S2589-7500(21)00238-7).
- ¹¹ Health Issues Centre, ‘Report from Public Consultations - Will sharing improve caring? A Clinical Information Sharing System’, August 2020.
- ¹² Thomas, J., Barraket, J., Parkinson, S., Wilson, C., Holcombe-James, I., Brydon, A., Kennedy, J. (2021). Australian Digital Inclusion Index: 2021, Dashboard Dataset Release 1. Melbourne: RMIT and Swinburne University of Technology, and Telstra.
- ¹³ Thomas, J., Barraket, J., Parkinson, S., Wilson, C., Holcombe-James, I., Brydon, A., Kennedy, J. (2021). Australian Digital Inclusion Index: 2021, Dashboard Dataset Release 1. Melbourne: RMIT and Swinburne University of Technology, and Telstra. <https://www.digitalinclusionindex.org.au/>
- ¹⁴ *The Digital World of Healthcare Forum*, June 2021.
- ¹⁵ House of Representatives Select Committee on Mental Health and Suicide Prevention, *Mental Health and Suicide Prevention - Final Report*, Parliament of Australia, November 2021. https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/024705/toc_pdf/MentalHealthandSuicidePrevention-FinalReport.pdf;fileType=application%2Fpdf
- ¹⁶ Health Issues Centre, ‘Report from Public Consultations - Will sharing improve caring? A Clinical Information Sharing System’, November 2020
- ¹⁷ Health Issues Centre, ‘Forum Report – HIC/Safer Care Victoria Forum Series on involving Consumer Leaders in Healthcare Reform – Telehealth,’ <https://hic.org.au/wp-content/uploads/2020/12/SCV-HIC-Telehealth-Forum-Report-For-Website.pdf>.
- ¹⁸ Health Issues Centre, ‘Report from Public Consultations - Will sharing improve caring? A Clinical Information Sharing System’, November 2020.
- ¹⁹ Health Issues Centre, ‘Report from Public Consultations - Will sharing improve caring? A Clinical Information Sharing System’, November 2020.
- ²⁰ Academy for Technology, Science and Engineering, *A New Prescription — preparing for a healthcare transformation Australian Academy of Technology and Engineering*.
- ²¹ Office of the Australian Information Commissioner, *Australian Community Attitudes to Privacy Survey 2020* <https://www.oaic.gov.au/engage-with-us/research/australian-community-attitudes-to-privacy-survey-2020-landing-page/2020-australian-community-attitudes-to-privacy-survey>
- ²² Australian Academy of Technology and Engineering, ‘A New Prescription — preparing for a healthcare transformation,’ 2019.