



Consumers Health
Forum OF Australia

SUBMISSION

Draft National Interoperability Plan

December 2021

Consumers Health Forum of Australia (2021)
Draft National Interoperability Plan.
Canberra, Australia

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*Consumers Health Forum of Australia is funded
by the Australian Government as the peak
healthcare consumer organisation under the
Health Peak and Advisory Bodies Program*

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Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interest of Australian healthcare consumers and those with an interest in healthcare consumer affairs. CHF works to achieve safe, quality, and timely health care for all Australians, supported by accessible health information systems.

At the heart of CHF's policy agenda is consumer centred care with access to and delivery of clinically safe and high-quality health care as key areas of focus. The sharing and use of consumers' health data in a safe and consistent way is an important component of making the system work for consumers in a seamless way that means they can have confidence that they are getting the appropriate care based on their identified needs. CHF has been a strong advocate for key measures like My Health Record and has consistently called for the digital systems being used in different parts of the health system to be able to communicate with each other to facilitate that seamless approach. We welcome the opportunity to comment on this draft Interoperability Plan as it sets the groundwork to achieve that vision.

Consumer attitudes to sharing health information

CHF has been involved in and undertaken extensive consumer consultations on digital health issues, including on consumer attitudes and experience with telehealth and in relation to the review of the National Digital Health Strategy. Importantly the latter consultation, involving 150 consumers, included questions on attitudes to sharing of health information. Overall, these consultations and other related research indicates the key message, with caveats on privacy and security, is that consumers are generally happy with sharing their health information with their health providers. However, as an interoperable system, there is a significant level of disappointment at levels of use by providers and access to their health information that My Health Record (MHR) promised. They want providers to input their health information in a central place and want them to use it as they move across the health system where they encounter multiple health providers. As they see the expansion of digital health their increasing frustration at consistently having to repeat their medical history to numerous providers is obvious.

In terms of the Interoperability Plan CHF feels confident that consumers would welcome significant improvements within the health system that gave them access to their health information and allowed their health information to be shared with their health providers in a safe and secure manner.

Interoperability principles

Question 1: Do you support the interoperability principles in Section 3.1, or should some principles be amended, added or removed?

Principles

CHF supports the Interoperability principles. However, we wish to highlight key issues related to the Actions linked to the principles. Overall, for many Actions, also linked to an assumed Future State, additional elements need to be included. As discussed below, in numerous areas of the Plan, Actions must be based on a clear assessment of barriers. We understand that such an assessment is likely to come within the remit of other areas of the Australian Digital Health Agency, such as that related to the National Digital Health Strategy. It is our view, however, that many areas of the Plan require baseline data including identification of barriers be linked to Actions to ensure benefits from improved interoperability can be realised. Actions should include a statement on the type of base line data/assessment required to achieve the desired outcomes from Actions.

Interoperability principles

Question 2: Are there any key actions missing to promote the objectives of this Plan?

Priority areas

Recognising the difficulties created by the federated health funding system CHF agrees that a major focus of the plan for national interoperability must be on achieving consistency across States, Territories, and the Commonwealth. However, while the pursuit of national technical interoperability consistency is necessarily in the tertiary sector and their Emergency Departments the Plan does not adequately identify other key areas of the health system.

CHF is of the view that for a national interoperable system to be achieved the interface between the tertiary health system and primary health care is critical. However, success in achieving the benefits of interoperability, to the health system and consumers requires an equal priority focus on the interface between General Practice and all other parts of the primary health care system. General Practice is central in that it represents the link to all other parts of the primary health care system (Allied Health, diagnostic and pathology services, Secondary Health Care (Specialist care outside the hospital system) and aged care.

An interoperable health system must deliver a seamless experience for consumers as they move across all its parts such that the consumer feels it is one system.

Action 9.3

The Plan refers to the US 21st Century Cures Legislation related to driving interoperability. While somewhat unsuitable in its detail to the Australian system it does provide fruit for consideration in terms of driving interoperability. This is particularly the case in identifying drivers for those areas of the health system which have been the slowest in uptake and for which more successful drivers implemented in other parts of the health system, do not work. Practice incentives for example.

While at this stage the Interoperability Plan is not identifying solutions CHF is of the view that it should include a section on identifying options for driving uptake either in terms of legislation and/or links to accreditation in the health system. It seems logical that the increasing importance of digital health and interoperability in delivering quality care and the consequent economic benefits be built into aspects of accreditation linked to timelines for implementation in the Interoperability Plan. **At its present stage the Plan should include an Action related to the assessment of potential options in this regard.**

Driving interoperability for hospitals will be based on State/Territory investment issues and or the need to address a variety of barriers. Regardless the implications are that **investments must be made to drive use.**

For General Practice strategies for driving interoperability sit with the Commonwealth. Beside technical barriers in General Practice (acknowledged in the plan) an important issue in terms of their investment in aspects of digital health has been the freeze on GP Medicare Rebates and the impact in an environment of increasing practice costs (as well as access to healthcare by consumers). While the Plan proposes to assess levels of interoperability it is important to consider the many and varied underlying issues that represent barriers to uptake.

Importantly in all parts of the health system actions must focus on ensuring the technical solutions reflect an understanding of, and link to standardised workflows.

Actions designed to promote and incentivise interoperability must be based on a clear understanding of these many barriers.

Interaction with non-digital health reform strategies

In terms of actions there appears to be little acknowledgement of broader health system reform and its impact on how the Interoperability plan relates to such strategies. For example, the Primary Health Care Plan creates greater interactions between providers. CHF believes it is important that a statement regarding how Interoperability will take into account non-digital Government health policy reforms be incorporated into the Plan.

Section 6: Information sharing

Consumer trust and confidence in digital health systems and sharing of their health information is growing but maintaining this momentum in consumer attitudes is critical. Research consistently illustrates that consumers see tangible benefits to themselves and those they care for in sharing the health information with their providers. While consumers rate their health data as one of their highest concerns when it comes to privacy, health providers are those most trusted by consumers in terms of maintaining the privacy and confidentiality of their health information.

In recent significant consultations with consumers, all groups while identifying the advantages of sharing health information, included qualifiers in relation to control, privacy, and safety in relation to the use of the health information. Consumers raised the need for a national data protection standard, with heavy penalties and strong safeguards to avoid unauthorised use of their health data. This reflects a support consumer for proposals in the plan for a consistent approach across all jurisdictions.

An Office of the Information Commissioner 2020 survey on consumer attitudes to data privacy demonstrated that 83% of Australians want government to provide more protection of the privacy of their data. This and other research illustrate a consistent tension between the consumers' privacy concerns and a general willingness to share data for the public good in terms of health service delivery, policy development and identification of health priorities.

In this context the Interoperability Plan must set out in more detail what the clear aim is in terms of consent in terms of a national approach. It is unclear, for example whether legislative change at State/Territory level will be required or legislative amendments or other options to amend the problems associated with current national privacy legislation which are not well translated to the health sector.

In terms of the outline of the future state CHF wishes to see a statement that consumers will have access to clear, plain language information detailing how their privacy and confidentiality will be protected and separately how they can control with whom their health information is shared in an interoperable environment.

Section 6.1.2

The above section identifies the need for a "digital consent service that supports all health information". Clarification and further detail on what a "digital consent service" will entail is necessary. Further how this links to "common access policies" that will "enable health system wide access to health information".

Section 8: Benefits, evaluation and measuring maturity

There is a concern that the approach in this section focuses on monitoring maturity of interoperability without reference to current barriers to uptake. A precursor to measuring benefits and maturity should include the use of base-line data that identifies current barriers in different parts of the health system to uptake of interoperable systems. While such a role is perhaps outside the remit of the Plan it seems essential that the success of drivers/solutions to overcome barriers will be linked to the benefits and maturity outcomes. In the absence of this baseline data, particularly in terms of the overall objective of Interoperability, what is in fact being measured? In this regard CHF is of the view that a clear statement in the Plan is required to indicate that identifying the current state of interoperability will be associated with data on current barriers which will allow not only assessment of benefits and maturity but will identify the success or otherwise of strategies to reduce current barriers to interoperability uptake.

Further, CHF is of the view that baseline surveys of interoperability of GPs, hospitals and pharmacies should incorporate, where relevant, assessment of consumer experiences in relation to digital health, considering existing, ongoing, and future research. In this context digital literacy of both providers and consumers will be critical in determining progress in levels of interoperability. However, impact assessment should not be narrowed to improved health outcomes but ensure the ability to be linked to improvements in consumer access to healthcare and the impact of strategies such as digital literacy.

Overall, the issue of benefits must include an assessment of benefits to consumers. These include enhanced patient experience, improved safety (page 61) and improved access to healthcare

Section 9: Governance and incentives to promote interoperability

The Plan in some areas appears to take a “build it and they will come” approach that ignores the complexity of driving uptake by providers in different parts of the health system. This is perhaps reflected in Section 3.3 on accomplishments to date in which MHR is noted. While a good example of a technical interoperability achievement where it has been “built”, use by providers in all parts of the health system remains low.

The real benefits of interoperability can only be realised through “use” and driving or promoting use must be approached based on identified barriers which vary across the different parts of the health system.

Question 3: Would you like to see any changes to the scope or timeframe of the proposed actions?

The Plan's statements on "consent" seem to be inconsistent. The Plan on a Page states a medium-term milestone under Information Sharing as "Investigate options for supporting a national approach to individual consent".

At Section 6.4 Implementation Actions. Action 6.4 it is described as investigating options to enable consumers to grant consent to access all their health information. Contrary to The Plan on a Page, here the timeframe is listed as "short".

The Plan seems to separate these two issues in that Action 6.4 does not reflect the statement in the Plan on a Page which does not appear in the Actions.

It is CHF's view that investigating options for supporting a national approach to individual consent should take into consideration outcomes of essential consumer consultation on Action 6.4

CHF considers that Action 6.4 should also include "Investigate options for supporting a national approach to individual consent". Both components will require extensive consumer consultation in terms of a national approach and the "enablement" mechanisms for consumers to grant consent to access health information

In this context we suggest the timeframe be set at "medium".

Question 4: Are there any actions that your organisation would like to be involved in progressing, and what would that involve?

CHF works to achieve safe, quality, and timely health care for all Australians, supported by accessible health information systems. It has undertaken extensive and highly successful consumer consultations in relation to Digital Health with funding from both the Commonwealth Department of Health and the Australian Digital Health Agency.

CHF recommends and expects an explicit role for consumers in all implementation activities where consumers encounter the health system, but particularly in relation to Information Sharing, Innovation and Benefits.

Interoperability initiatives

Question 5: Which, if any, of the implementation initiatives in Section 7.4 would you like prioritised for delivery and why?

CHF supports the following initiatives as priorities

- Electronic Requesting - reduction in paper-based errors and ease of access to diagnostic images and reports and reduction in duplication of imaging requests will all contribute to improved quality and safety in the delivery of healthcare to consumers.
- Care Management support network – represents patient centred care and an important issue in terms of Australia’s ageing population.
- Information discoverability – critical for continuity of care and quality and safety. Particularly important in terms delivering a seamless experience for consumers and relieving many of the current burden of having to repeat their stories at every encounter or maintain their own, often paper records of past treatment.

Question 6: Is your organisation leading any activities that should be identified in the final plan?

CHF works to achieve safe, quality, and timely health care for all Australians, supported by accessible health information systems. At the heart of CHF’s policy agenda is consumer centred care with access to and delivery of clinically safe and high-quality health care as key areas of focus.

In this context CHF would wish to see a greater emphasis on the involvement of consumers in a range of Actions in the Plan, particularly regarding consumer consultations.

Statements on The Future State under sections of the plan largely relate to expected technological outcomes. The Future State sections should also highlight key expected outcomes for consumers many of which are not specifically digital, but which potentially deliver improvements in their encounters with the health system and access to healthcare.

General feedback

Question 7: Do you have any additional feedback on the plan?

State/territory adoption issues

In consultation for a ADHA has advised that states and territories have committed to what is at this stage is a draft Interoperability Plan. We would thus assume formal commitment will be sought on the final version of the Plan given that it is likely consultations will recommend some changes to Actions.

There is some concern as to how the Commonwealth Government proposes to gain commitment from States and Territories beyond that of the Plan. Given variations in their health systems in terms of existing interoperable maturity, gaining commitment and consistency in delivering Actions, including within the milestone timeframes, is not likely to be possible.

CHF understands that some States do not have state-wide digital health systems and in such cases the investment in meeting the Plan's objectives will be more problematic. The reality is that costs of meeting actions in a coordinated and consistent manner will vary between States and Territories and commitment to budget allocations can change depending on future political leadership.

CHF is of the view that the Plan needs further detail in relation to how it will work with states and territories and the risks and dependencies in them being able to deliver within the proposed milestone time frames. Additionally, whether the Commonwealth is committed to investing in support for those states or territories that are likely to find the budget costs challenging.

State/territory regulatory issues

Within states and territories, the tertiary health care sector represents the largest area of impact in terms of their investment and overall change to meet the Plan's objectives. It is not clear whether states and territories apply the same regulatory requirements on private hospitals as those for public hospitals. CHF believes that the Plan should make clear that regulatory changes required to implement the Plan will apply equally to public and private hospitals, and indeed for any other private health providers where regulatory change is required for national consistency.

Overall comment on the interoperability plan

CHF is disappointed the draft Interoperability Plan does not have more detail given the current National Digital Strategy highlighted the need to progress interoperability over three years ago. Whilst acknowledging the need to bring the many different moving parts into alignment was always going to take time it appears we still have some way to go, and the Plan is lacking in some of the specifics on how this will be achieved.

For consumers the questions that are and will continue to arise relate to how interoperability will be delivered. With the expansion of digital health and increased uptake, interest and support, consumers are demanding improvements linked to interoperability and fail to understand the lack of progress.

Consumers have had a “taste” of a range of benefits from recently introduced digital health innovations, and despite a range of issues, they want more but better.

While CHF understands the demands surrounding delivery of national interoperability largely consumers do not. The Plan will be incomprehensible to most consumers without high level digital health knowledge combined with an understanding of how the Australian health system works and is funded.

CHF understand very clearly that consumers need a plain language document that outlines the complexity of delivering national interoperability and in that context the benefits they will realise from its ultimate achievement.

While there is a long and challenging road ahead in delivering national interoperability, giving consumers access to information that allows them to understand the benefits to them and those they care for, is a strategy for support and acceptance.