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Healthcare Identifiers Framework Project

AMA submission to the Department of Health and Aged Care consultation

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The AMA is supportive of projects that will improve information sharing within the health system and provide healthcare providers with seamless access to a patient's relevant healthcare information at the point of care.

The AMA vision for an interoperable health system is outlined in our 2022 position statement.¹

Australia must start moving toward a genuinely interoperable healthcare system that will facilitate the elimination of the current silos and reduce inefficiencies. The AMA strongly supports interoperability across the intersecting health and human services sectors, including acute care, primary care, allied health, community care, as well as aged care and disability services. Accordingly, the AMA welcomes this consultation.

However, the AMA is concerned that this Project is too ambitious and poses significant risks relation to the proposals around:

- replacing other identifiers (particularly Centrelink Customer Reference Numbers - CRNs, Medicare numbers, DVA numbers, provider numbers and Ahpra numbers) with Individual Healthcare Identifiers (IHIs) and Healthcare Provider Identifiers (HPI-Is);
- expanding the types of organisations that can access IHIs;
- expanding the purposes for which IHIs can be used; and
- expanding the circumstances where an individual can “consent” to their IHI being used to link their health and other personal information.

These changes:

- have substantial privacy implications;
- would impose substantial implementation costs on doctors (particularly any move away from Medicare numbers and provider numbers); and
- have the potential to delay or derail achievement of the project's core objectives.

¹ <https://www.ama.com.au/articles/ama-position-statement-system-interoperability-healthcare-2022>

The AMA's preferred path forward is to continue building and using the infrastructure we already have, with the healthcare provider and HI definitions that already apply. Once interoperability is achieved, there will be scope (and time) to consider expanding definitions and including other professionals in the provider registers, noting that the AMA is not supportive of this idea.

Currently, the primary role of IHIs is to help healthcare providers accurately communicate information with each other and identify and access patient records in the My Health Record system. In short, IHIs are designed to be used by healthcare providers for the provision of healthcare to an individual. Anyone using IHIs outside of this context must be authorised to do so under the HI Act. The AMA is satisfied with these provisions.

In the future, when full healthcare system interoperability is achieved, the risk for exposure and inappropriate use of IHIs will only increase. When considering that an IHI brings together substantial personal information on an individual (their name, gender, date of birth, their Medicare or DVA number), the AMA has serious concerns around the proposed expansion of providers and services that will be able to access and use IHIs.

Furthermore, as the Department of Health would be aware, the review of the Privacy Act 1988 has not been completed yet. It is highly likely that the changes to the Privacy Act will impact other relevant legislation, including the HI Act. The Attorney General's Department has flagged that the Government was considering modelling the reviewed Act on the GDPR model of EU and UK.² The AMA suggests that these two processes should be happening concurrently.

Below we provide further commentary to the specific questions asked under individual problem statements.

1. HI use in key programs, services, and systems

The AMA was supportive of the draft National Healthcare Interoperability Plan: Connecting Australian Health Care when it was released in 2021.³

The Healthcare Identifiers Framework Project (the Project) recognises the potential barriers and asks for feedback on strategies that may lead to better adoption of HIs across the health system. These include direct government initiatives and support, using HIs in Australian Government health programs and services, including regulatory frameworks, and linking the use of HIs to funding and accreditation.

Successful implementation of interoperability of clinical information systems will require buy in from stakeholders at all levels of the Australian health system. Healthcare providers will adopt the use of HIs if they are easy to use and do not result in increased workload. One of the reasons for the relatively low uptake of My Health Record among some medical professional groups is that My Health Record often does not communicate with the doctors' medical software, and in

² <https://www.ag.gov.au/rights-and-protections/publications/privacy-act-review-report>

³ <https://www.ama.com.au/articles/ama-submission-national-healthcare-interoperability-plan>

order to access My Health Record, doctors are commonly required to log out of their usual clinical software.

The AMA does not support linking HIs to funding and accreditation as proposed on page 13 of the Consultation paper. We have concerns with how this may impact public hospitals or community health providers that are already underfunded or struggling to achieve their performance targets. Instead, the AMA supports the introduction of incentives and legislation to encourage the implementation of standards and conformance arrangements, and the national cross jurisdictional implementation of infrastructure to support discoverability and information exchange. The AMA also recommends adding provisions to the National Health Reform Agreement that outline the roles of the Federal and State governments in this process.

Furthermore, ongoing investment in digital healthcare technologies is required to achieve the efficiencies expected of a modern Australian health system. Funding is required to ensure equity of access – that mainstream developments and technologies are accessible to all those needing health care, not just those who can afford them. The AMA would like to see an investment plan attached to the interoperability plan. E-health must be an area of significant investment into the future if we are to achieve the efficiencies that are required for a modern health system. While this may require significant initial investment, we expect this would be offset by great cost savings into the future.

With regards to the situations and systems or areas of healthcare where HIs should not be used by default, the AMA has some concerns around the growing market of instant telehealth and online script providers and how they use the patient data. Stronger data governance arrangements and enforceable rules are required, as well as stronger privacy protections in the legislation to protect the patients from any data misuse. Legislative reform to address these concerns would make the AMA position on whether or not these organisations should be able to have access to HIs redundant. The AMA's recommendations are outlined in our Data Governance position statement.⁴

Finally, one critical element for the successful implementation of HIs will be the ability of medical software vendors to achieve conformance in a timely manner. This is a major factor that is not discussed in the Consultation paper. The AMA has consistently observed that by the inability of software vendors to achieve conformance has caused delays in implementation of past significant digital health initiatives, including those referenced in the Project such as electronic prescribing and secure messaging.

The AMA has previously called for establishment of standards for clinical software providers requiring software coding compliance. The AMA also supports the adoption of consistent national interoperability requirements in government ICT procurement processes. While putting standards in place will go some way to ensure unification of information across the health sector, there should also be more stringent requirements put on vendors to comply and implement the standards linked to specific timelines. This important area of healthcare cannot be left up to the market to regulate itself.

⁴ AMA Position Statement on Data Governance and Patient Privacy 2022 <https://www.ama.com.au/articles/ama-position-statement-data-governance-and-patient-privacy>

2. Scope of healthcare and provider eligibility

The Consultation paper proposes broadening the definition of ‘health services’ to include organisations (such as schools and home care services) that provide services and functions that impact on the health, care and wellbeing of individuals. The AMA acknowledges the note in the paper that authorising a program, organisation or individual to use a HI does not automatically give them access to any further health information of an individual. However, the AMA still has some concerns around the proposal to expand health service definition, particularly given that these services may require individuals to “consent” to use of their health information in order to utilise the service.

The AMA continues to support the existing privacy and security controls in the My Health Record. A significant element of that security is the requirement for the conformant clinical software to assign unique staff member identification codes and records each time a health service staff member accesses the My Health Record system. A log is automatically generated to record each time the My Health Record is accessed by a health provider. These logs mean Record owners can see which organisations have accessed their Record in real time and the System Operator can drill down to identify which staff member Individual Healthcare Identifier was used to sign into the Record.

The AMA expects that any expanded access to HIs will ensure the same level of privacy protections for both patients and doctors, including NOT allowing private sector and for-profit entities (such as insurers or for pre-employment checks) to have access to the patients’ health records.

We are also concerned about how the proposed expansion of definition of ‘health service’ – in particular the inclusion of ‘healthcare support provider organisations or services’ – will interact with the proposal to replace other identifiers, such as CRNs, Medicare numbers and DVA numbers, with IHIs. The use of Medicare numbers and other government related identifiers (such as passport numbers and drivers’ licence numbers) is tightly regulated. This is so that they do not become a unique identifier for an individual (i.e., a de facto Australia card) that is used by the private sector as a primary database key or to link multiple data sets. IHIs are unique, ubiquitous, government issued numbers that bring together substantial personal information on an individual, such as their name, gender, date of birth, their Medicare or DVA number. Accordingly, they should be afforded – at minimum – the same level of protection as Medicare cards.

While schools and other educational institutions for example play an important role in ensuring wellbeing of children and young people, the AMA does not see how these institutions accessing and using IHIs would improve individual health of those enrolled. Schools can, and already do, implement health and wellbeing programs, to support their students, and the Consultation paper does not explain how those programs could be improved if schools could access IHIs.

The example use cases provided on pages 14, 18 and 22 of the Consultation paper pertain to providers and health professionals that can already access and use My Health Record and HIs. For

example, there is already provision to allow access to care recipients' My Health Record (and thereby their IHIs) for aged care providers. An aged care worker can help coordinate the transfer of an older person to an Emergency Department under the current settings, but that aged care worker must be a registered health practitioner, such as a Registered Nurse or an Enrolled Nurse. The AMA does not see how allowing personal care workers (who may not have sufficient qualifications), access to an older person's My Health Record or their IHI would improve the care of that older person, particularly in light of the recent legislative changes and the requirement for aged care homes to have a registered nurse on site 24/7.

The Consultation paper also does not detail who would maintain the register of organisations and individuals who would be allowed to access and use HIs. Currently, this register is maintained by Services Australia. To get an HPI-I, a person needs to provide healthcare services and be registered with Ahpra. If they are not registered with Ahpra, they must be a member of a professional organisation that consists of members who practise the same healthcare profession.⁵ If the definition is expanded, would Services Australia be expected to set up a register of childcare workers, teachers, social workers and similar for members of these professions to be able to access and use HIs? This would be a long process that may slow down other projects to improve interoperability.

The AMA sees merit in allowing mental health counselling organisations that employ registered health workers such as mental health nurses or GPs, like the ones providing counselling or group counselling for youth, to use HIs to identify individuals who access their services. This would be useful for governments and health policy planners as it would allow them to monitor individual patient journeys through the health system. For example, an evaluation of youth counselling service headspace commissioned by the Department of Health and Aged Care published in October 2022 found that the longer-term impacts of headspace were not adequately measured and that improvement in data collection is required.⁶ It recommended linking the relevant data sets such as self-harm hospitalisations, substance abuse hospitalisations, suicide deaths, MBS mental health services accessed, among other. Linking these data sets would be simplified using HIs, but the AMA insists relevant privacy protections must be in place.

3. Clarity around healthcare administration entities and uses

Page 19 of the Consultation paper states that currently there is doubt on whether the current legislation allows healthcare administration entities to use HIs for the purposes of payments and claims, workforce management and research and evaluation.

It proposes two amendments:

- (a) clarifying that HIs can be used in all parts of delivering and managing "healthcare services".
- (b) Allowing "healthcare administration entities" to use HIs.

⁵ <https://www.servicesaustralia.gov.au/characteristics-professional-associations-for-hi-service?context=22876>

⁶ KPMG 2022. Evaluation of the National headspace Program – Final Report <https://www.health.gov.au/sites/default/files/documents/2022/10/evaluation-of-the-national-headspace-program.pdf>

In considering the first amendment, it is important to consider the proposed expansion to the definition of “healthcare services”, to include wellbeing services.

In considering the second amendment, it is important to note that the proposed definition is not limited to government entities. It would also include: any organisation that “provides administrative, planning, research and policy functions related to healthcare”. This may include PHIs, billing agencies, workers compensation insurers, software providers, Google, recruiters, Seek, consultants, venture capitalists etc.

The AMA does not support the proposal for employer HR systems to use doctors’ HPI-I instead of their name or Ahpra registration number, as outlined in example use case 2 under this problem statement (page 20). Using an HPI-I of a healthcare provider for workforce management purposes, including in an HR system, which may or may not have adequate data governance and privacy protections in place, but will hold the private data of healthcare providers, cannot be supported by the AMA. Furthermore, we fail to see what improvement use of HPI-Is in an HR system would bring both to the employee and the employer, that cannot be achieved with the current system.

The AMA sees great merit in utilising the de-identified data that would become available through genuine, functional interoperability and HIs to improve workforce planning, as well as for research and evaluation. The AMA is supportive of the proposed list of healthcare administration entities that should be allowed to use HIs. The AMA expects that with the increased uptake of HIs and greater use of HIs generated data for policy and health system planning, appropriate data governance structures will be put in place to ensure health data is not compromised.

The AMA calls for appropriate data governance structures to be put in place to enable and ensure protection of the integrity of data, preventing unauthorised access to data, data loss, data modification or deletion. Data governance frameworks applied by relevant entities in the healthcare space must demonstrate that patient data is handled in a transparent and accountable manner, with relevant privacy protections in place, with clearly identified and stated data governance roles. Frameworks should define who can access data, the specific circumstances in which they can access the data, the purposes they can access and use data for, and how the data can be accessed.

4. Applications and structures of HPI-Os and HPI-Is

Healthcare Provider Identifiers – Individual (HPI-Is) and Healthcare Provider Identifiers – Organisation (HPI-O) require individual healthcare providers and provider organisations to register to obtain HPI-Is and HPI-Os.

The key objectives for implementation of HPI-O and HPI-I structures must be that they are simple and easy to use, that registration happens once and that they result in reduced administrative burden, both for healthcare organisations and the individual providers, in particular medical professionals. In the AMA’s view, the goal of health system interoperability achieved through

implementation of HIs should be to reduce administrative burden for healthcare workers, improve healthcare worker satisfaction and create system efficiencies, in addition to improving health outcomes.⁷ Therefore, the AMA is supportive of policies that are aimed at achieving these goals.

The AMA does not see the current policy around which employees of a healthcare provider organisation can manage HPI-O information as a barrier to their use. There were objective reasons the system was set up the way it was, so that unauthorised access to data and patient information could be prevented.

Under the current legislation, a healthcare provider organisation, in registering with the HI Service, can choose to adopt a single Seed HPI-O structure (commonly used for a small medical practice) or a combined Seed and Network HPI-O structure (more suited to a hospital with multiple departments). Even with the current protections in place, Professor McMillan's review of the My Health Record Act found that

“this intention can be undermined if a large organisation adopts a single (Seed) HPI-O structure or if separate organisations that have grouped together for IT efficiency are covered by a single HPI-O. The audit log will record access to a person's MHR at the HPI-O level, making it difficult to identify the organisation within the group that accessed the record. This runs counter to consumer expectations of transparency in the access history”.⁸

In the current system, this could mean that, with the rollout of My Health Record in aged care facilities for example, one single provider of aged care services that operates multiple aged care facilities, could have a single HPI-O. With the proposal of expanding access to HIs for workers in aged care, other than healthcare workers, this could mean that private health information could be accessed by workers who do not provide direct care to the resident, without the resident/their family ever being aware of this. This is just one example.

As such, the AMA recommends that changes to the *Healthcare Identifiers Act 2010* ensure HPI-Os are used to identify both locations and services. The key policy, program, and operational objectives and benefits that HPI-O structures must support is consumer confidence in the security and transparency of the system, balanced with reducing the administrative burden for healthcare providers.

The AMA is cognisant of the fact that successful implementation of interoperability of clinical information systems will require buy in from stakeholders at all levels of the Australian health system. That buy-in can be achieved through multiple policy levers, including financial incentives, changes in legislation and clinical standards.

One of the levers that the AMA considers beneficial would be the adoption of consistent national interoperability requirements in government (Commonwealth or State) ICT procurement processes. One of the causes of the current difficulties in achieving communication between

⁷ <https://www.ama.com.au/articles/ama-position-statement-system-interoperability-healthcare-2022>

⁸ <https://www.health.gov.au/resources/publications/review-of-the-my-health-records-legislation-final-report?language=en>

different healthcare providers even within the same State/Territory health system is the fact that there are no restrictions on what medical software, mobile application or IT system they can purchase and use. This results in health system inefficiencies and puts extra burden on patients to navigate when managing their healthcare journey. An illustrative example is the requirement for patients to use mobile applications to schedule appointments in public hospitals. When the patient needs to see specialists in different public hospitals, they are often required to download and manage separate applications to do this. This can be extremely difficult for some patients, particularly older patients who are not well versed in using mobile applications, for whom English is a second language or for those from disadvantaged backgrounds. For this reason, the AMA supports co-design of technologies that enable system interoperability, developed in close consultation with medical practitioners and patients.

Furthermore, the AMA supports stringent standards and national conformance arrangements for digital infrastructure to ensure unification of information across the healthcare sector. Standards and conformance arrangements create challenges for software vendors but are necessary to optimise efficiency and effectiveness of the Australian healthcare system.

5. Healthcare consumer and provider choice

It is the AMA's position that patients who are empowered to access and control their health information are transformed from passive recipients of care to active participants in their healthcare. The AMA is supportive of policies that are aimed towards this goal, including utilisation of HIs for that purpose, but only when such policies result in better health outcomes for the patient.

The AMA does not accept that private health insurers should be considered separately from insurers in general, as suggested on page 25 of the Consultation paper. The AMA is satisfied with the current provisions of the Healthcare Identifier Act that state that HIs cannot be used by the insurer for the purpose of underwriting health insurance or determining eligibility for or coverage level of health insurance. These provisions are consistent with the community rating scheme under the *Private Health Insurance Act 2007*, which prohibits discrimination against individuals based on their health, age or some other characteristic likely to result in the need for increased healthcare.⁹ They are also consistent with the My Health Record legislation.

While it is true that private health insurers already manage large amounts of health data about their customers, the AMA does not support sharing health information with private health funds outside the existing statutory schemes.¹⁰ Patients' medical information must be protected to maintain the clinical independence of their healthcare pathway. The AMA therefore insists that the current prohibitions around the use of HIs for insurance and employment purposes must continue.

⁹ <https://www.legislation.gov.au/Details/C2020C00026>

¹⁰ AMA Position Statement on Data Governance and Patient Privacy 2022
<https://www.ama.com.au/sites/default/files/2023-01/Data%20Governance%20Position%20Statement%20-%20FINAL.pdf>

The AMA understands the proposals in the Consultation paper as aiming to replace (or provide an alternative to) the patient's Medicare card. Considering the example use case provided on page 24, the consumer is expected to be able to quote their IHI when booking a health service online. Currently, patients generally do not know their IHIs and the Office of the Australian Information Commissioner has raised concerns about them being used on immunisation statements.¹¹ A healthcare provider can establish an IHI from the patient's name, gender, date of birth and Medicare/DVA number. The requirement for multiple data points reduces the risk of a person deliberately or inadvertently providing an incorrect Medicare/DVA number. The Consultation paper does not set out how this risk would be addressed if patients quote IHIs and IHIs are used in a variety of contexts that only have a loose connection to providing healthcare. The AMA has concerns around this and calls for a broader discussion around this proposal, one that will involve consultations with the broad cross section of consumers.

6. Support for Healthcare Technology Services

The AMA is supportive of the provisions in the current legislation that only allow software vendors that are contracted directly by a healthcare provider to access the HI service directly, and collect, use, adopt and disclose HIs. This is consistent with the restrictions (in Australian Privacy Principle 9) on non-government bodies collecting, using, adopting and disclosing government related identifiers. These restrictions exist so that these identifiers do not become universal identifiers. In other words, there are public policy reasons why organisations such as Google and Apple are not permitted to use Medicare numbers or CRNs to identify and link customer records. These public policy reasons apply equally to HIs.

The consultation and discussion papers released as part of the review of the Privacy Act¹² highlight the expansion of big tech companies into the healthcare space. They also query whether consumers, particularly consumers under 18, are providing genuine consent to use of their data. For example, consumers often "consent" to data from health apps (such as appointment bookings, period trackers and wearable technology) being sold to third parties. This may not be in the patient's best interest. For example, Facebook has been criticised for allowing advertisements about extreme weight loss to be targeted at teenaged girls.¹³ In an environment where privacy regulations are below the standard of other developed nations – EU and UK for example – the AMA is concerned that the data collected by the intermediaries, unless properly regulated, may find its way into the hands of those from whom private, personal, individual health data should be protected from.

In addition to the existing conformance requirements and statutory prohibitions on misuse of HIs, the requirement that the software vendor has a direct contract with a healthcare provider acts as a control on further use of HIs by software vendors. By contrast, consumers are less likely to know who they are contracting with or the terms of that contract. The Consultation paper

¹¹ <https://www.oaic.gov.au/privacy/guidance-and-advice/privacy-guidance-regarding-individual-healthcare-identifiers-ihis-on-covid-19-digital-vaccination-certificates>

¹² <https://consultations.ag.gov.au/rights-and-protections/privacy-act-review-discussion-paper/>

¹³ <https://www.sbs.com.au/news/the-feed/article/facebook-approves-ad-targeting-teens-interested-in-extreme-weight-loss/htqzci573>

does not propose any minimum contract terms or any restrictions on what kinds of entities could become intermediaries. For example, a company with no connection to Australia may offer a fitness app to Australian consumers. It is unclear from the Consultation paper what restrictions would apply to this company using a patient's IHI (with their "consent") to develop a valuable database about other products or services they may be interested in buying. For example, would the intermediary be permitted to collect information about "preferences" (see use case study on page 14).

The AMA believes that consumer facing and intermediary software should have the same or higher HI conformance requirements and safeguards as software used by healthcare providers.

It is also important to ensure that organisations (such as medical software providers) who already have access to HIs do not use patient information obtained from My Health Record and other regulated channels for other unpermitted purposes. Australian software providers are already exploring opportunities to monetise patient data made available to them under the current scheme.

The AMA would consider any action by software providers to collect, use and disclose HIs that has not been explicitly consented to by the data owner (the patient) to be unauthorised use of HIs.

Furthermore, page 25 of the Consultation paper notes that an increasing number of 'consumer facing' health apps inform consumers' decisions and behaviours, including wearable devices for tracking or monitoring health. The AMA believes there should be rules and strong protections put in place when and where IHIs can be linked. Firstly, the devices and software would have to be assessed by the Therapeutic Goods Administration under the framework for regulation of software based medical devices. The AMA also proposes that only the devices that are prescribed by doctors for health monitoring/management purposes be allowed to have access to consumer IHIs. More detail is available in the AMA submission to the ADHA consultation on the mHealth applications Assessment Framework.¹⁴

7. Clarity around permitted uses and concerns about penalties

While the AMA is supportive of providing more clarity to healthcare providers around the use of IHIs, and alleviating their concerns, this does not mean that they should be given free reign around how they use and manage IHIs.

The AMA is concerned with the proposal on page 27 of the Consultation paper that "HIs (IHI, HPI-I and HPI-O) by themselves are not considered personal information". HIs are government related identifiers and, like a numberplate, may be "personal information" (as defined in section 6 of the *Privacy Act 1988*) depending upon what other information is held by the recipient.¹⁵ As noted above, the current review of the *Privacy Act 1988* has not been completed. The outcome

¹⁴ <https://www.ama.com.au/articles/ama-submission-australian-digital-health-agency-adha-consultation-mhealth-applications>

¹⁵ <https://www.oaic.gov.au/privacy/guidance-and-advice/what-is-personal-information>

of that review will have direct impact on what is and is not considered personal information under the legislation in Australia. For example, the EU GDPR definition of personal information includes “any information relating to an identified or identifiable natural person”.¹⁶ This would include the person’s IHI.

8. Flexibility and agility to support evolving use cases

Page 27 of the Consultation paper states that the Department has “received feedback that the Act should be less specific about how the entities relate to each other, and how services are delivered”. No further details about this feedback are provided, by whom and in what context.

In response to perceived problems, the Department proposes amending the Act to give more power to the Minister for Health and Aged Care. The Minister can already make rules for the purpose of healthcare administration, including under the HI Act and the My Health Record Act. For example, the McMillan Review of the My Health Records Legislation in 2020 proposed that “the Minister for Health make a Rule under the My Health Record Act s 109(7A) to prescribe a framework to guide the collection, use and disclosure of MHR patient health information for research or public health purposes.”¹⁷ In spite of this, to date the MHR data has not been made available to researchers and public health experts. The delay is due to the health governance arrangements not yet being developed.¹⁸

Accordingly, it does not appear to us that the Department has demonstrated a need for the Minister to have additional powers.

Conclusion

The AMA thanks the Department of Health for the opportunity to comment on the proposed changes. While we support an interoperable health system and the increased uptake of HIIs to achieve that interoperability, we have concerns around some of the proposed instruments, as outlined. We hope that the Department will give these concerns due consideration. We remain open to working with the Department and the broader Government so that this important policy reform is achieved in a considered manner.

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¹⁶ <https://gdpr-info.eu/>

¹⁷ <https://www.health.gov.au/resources/collections/review-of-the-my-health-records-legislation>

¹⁸ <https://www.health.gov.au/topics/health-technologies-and-digital-health/what-we-do/use-of-my-health-record-data>