RACGP response to the Australian Digital Health Agency consultation on the draft Health Information Exchange (HIE) Architecture and Roadmap

December 2024

RACGP

1.Introduction

Every year, almost nine in 10 Australians visit a general practitioner (GP) for their essential healthcare, making an average of 7.6 visits. In 2023, more than 22 million Australians chose to see a General Practitioner (GP), with most choosing to attend a usual GP or usual general practice (Health of the Nation 2024) – making GPs the most accessed health professional in our health system. It is therefore essential any new national digital health technologies integrate seamlessly with existing general practice systems and support GP workflow. GPs must be involved in the design, development, testing and implantation of digital technologies that will be used in general practices.

To that end, the Royal Australian College of General Practitioners (RACGP) is pleased to provide a response to the Australian Digital Health Agency (the Agency) consultation on the draft Health Information Exchange (HIE) Architecture and Roadmap. Our response has been structured to align with the consultation survey, and we thank you for the opportunity to provide a response outside of the original character limit for each question.

This submission supplements feedback given at the online meeting on the draft HIE Architecture and Roadmap held with the RACGP on 3 December 2024 and at the consultation webinar on 4 December 2024.

We acknowledge this is the first of many consultations on the future HIE and the RACGP looks forward to continued consultation through our ongoing relationship with the Agency.

2.About the RACGP

The RACGP is the voice of GPs in our growing cities and throughout rural and remote Australia. For more than 60 years, we have supported the backbone of Australia's health system by setting the standards for education and practice and advocating for better health and wellbeing for all Australians.

As a national peak body representing over 50,000 members working in or towards a career in general practice, our core commitment is to support GPs from across the entirety of general practice address the primary healthcare needs of the Australian population. We cultivate a stronger profession by helping the GPs of today and tomorrow continue their professional development throughout their careers, from medical students and GPs in training to experienced GPs.

We develop resources and guidelines to support GPs in providing their patients with world-class healthcare and help with the unique issues affecting their practices. We are a point of connection for GPs serving communities in every corner of the country.

Australia's GPs see more than two million patients each week, and support Australians through every stage of life. The scope of general practice is unmatched among medical professionals. Patient-centred care is at the heart of every Australian general practice, and at the core of everything we do.

3.Consultation response

3.1 What are the major barriers or challenges to adoption of the outcome of Health Information Exchange and interoperability?

The RACGP considers key barriers to be:

Lack of standards and levers to drive their implementation

- There is a lack of data and interoperability standards. These are needed to drive consistency in the way data is captured and to ensure it can be presented in a standardised way across all healthcare systems. The RACGP acknowledges the work currently underway to develop interoperability standards as part to the CISRO led Sparked collaboration
- Legislation mandating implementation of standards and data sharing is also required. We acknowledge the "Share by default" legislation, if passed, will go some way to addressing this issue
- Variation in regulations and digital infrastructure across jurisdictions is problematic.

Financial

- Anything that increases cost to general practice will struggle with widescale adoption. General practices are small business and margins are extremely thin
- There is a historical lack of adequate investment in change and adoption programs for both healthcare providers and consumers.

Education

- There is a general lack of clinical informatics or digital health education through all stages of medical education, from undergraduate, through hospital and into specialty training
- There is also a lack of education and awareness raising about new digital technologies and this has contributed to poor adoption, especially in non-GP settings.

Consent and security

- Consent requirements for data sharing and use, for both patients and providers, can seem complex and burdensome
- Diverse and non-interoperable trust frameworks between and within organisations, jurisdictions and disciplines
- A lack of trust, amongst some consumers and health professionals, in digital systems and government institutions.

Additional comments

Measures must be taken to ensure increased adoption of digital health does not impact equity of access for those populations with poor digital literacy or access. For example, older Australians, people from culturally and linguistically diverse (CALD) communities , people with disabilities that do not allow easy use of digital tools (for example, people who are blind or vision impaired), people in rural and remote areas who may not have the appropriate infrastructure to support access to digital solutions and people who can't afford access to technology. Supportive measures must be in place to ensure all Australians can receive high quality care. This includes digital services that are inclusive of CALD communities and are culturally safe for Aboriginal and Torres Strait Islander people (for example, there is consultation with communities to understand their needs and ensure these are met).

3.2 Are there any aspects of the Health Information Exchange that you would like to highlight as a positive step/improvement?

The RACGP highlights the following areas of the HIE:

Strengthening stakeholder engagement, as articulated in the following statements from the HIE:

- *working in close concert with current and planned jurisdictional digital health investments, to enable a new level of interoperability across the health sector and modernise existing systems and processes (Executive summary on page 10)*
- *the recognition of the need for genuine partnerships, and engagement with stakeholders, consumers, and delivery partners to listen, and maximise opportunities as part of the change process* (Appendix D – Change enablement principles).

The development and implementation of standards as articulated in the following statements from the HIE:

- *a move to address current legislative barriers nationally, and legislative and policy settings that enable standardised and secure information sharing across Australian jurisdictions* (section 2.1.2 on page 19)
- *regulating national health information standards including mandating of Fast Healthcare Interoperability Resources (FHIR) to support interoperability (section 3.4.3 (4) on page 37)*
- *a single health services provider directory and authentication framework (section 7.2 from page 63)* which aligns with the Directory outlined in the HIE roadmap. From a GP perspective, updates and changes to any such directory must not be administratively burdensome and must rely on the principle of entering data once for use multiple times.

Legislative reforms, as articulated in the following statements in the HIE:

- *a robust HIE policy and legislative framework, using the existing frameworks that underpin and support health information sharing when needed to ensure appropriate care provision* (page 10)
- Healthcare Identifiers (HI) reform (outlined in section 3.4.3 (4) on page 36) which would enable appropriate health professionals such as paramedics to access My Health Record – the RACGP is supportive of a move more broadly for the use of HIs, even as replacement to the use of Medicare numbers, as a way to consolidate and standardise the way participants in the healthcare system are identified.

3.3 Are there any specific areas that the document does not address that should be considered?

The RACGP believes the following areas should be addressed:

Consent

- The HIE needs to address how forms requiring authorisation will be accommodated, for example:
  - The need for patients to sign preoperative admission and consent forms for hospitals
  - Doctors being required to sign driver license medical or disability car parking forms
  - Signing of medical certificates (for both private employers and workers compensation purposes).

Standards

- Section 5.1.2 ‘Architectural implications’ which includes “Standards driven (but not mandated)” appears to be counter to other sections of the document, including “development of the legislative and policy framework will consider options for mandating national health information sharing standards and will consider how best to implement, audit and govern the mandate (section 3.4.2, 2. Interoperability standards) – As per our response to question 2, the RACGP supports regulating national health information standards including the mandating of Fast Healthcare Interoperability Resources (FHIR) to support interoperability.

Governance

- The quality of records is highly variable across both GP and non-GP organisations. Current data sharing largely relies on deliberately-curated reports and summaries for high-quality information, whereas automatic sharing will result in an overwhelming amount of

information which may be low quality, low relevance or both – the roadmap must demonstrate how this will be addressed
- The roadmap needs to ensure there is no additional administrative burden placed onto general practice as has occurred previously with the uploading of Shared Health Summaries and registration for MyMedicare
- There is inadequate recognition in the draft of the need for personal point-to-point communication between healthcare providers without sharing with the broader health community (for example, a GP and psychiatrist communicating about a patient's progress)
- Whilst acknowledging "that the governance and funding approaches will evolve with time given policy and legislative considerations and developments" (7.1.1, page 62), the inclusion of health professionals and consumers in the governance of the HIE is important
- While accepting My Health Record as the primary exchange platform for consumers, the roadmap overemphasises My Health Record as a significant part of the solution for data sharing with healthcare providers. This is problematic given individuals can opt out of My Health Record (with around 9% the population not having one) and is a consumer record and not designed as a clinical record, and should never be considered a complete medical record as patients can control what is visible and who can access information. However, it can be a useful tool for sharing information with those consumers who have one.

Change and adoption

- The proposed investment in change and adoption programs for both healthcare consumers and providers should be further articulated
- The HIE, as described in the draft, assumes system adoption by private (non-GP) medical specialists and allied health professionals who, for the most part, have not been engaged in My Health Record and or with the secure communication tools that are currently available. The roadmap must address how these providers will be supported and incentivised to engage in these digital advancements
- Ut would be beneficial to map and address the pain points for both consumers and healthcare providers in detail as has been done for jurisdictions in Appendix 4, D,4 'Jurisdiction pain points'.

Health equity

- In its current state the myGov platform, which hosts services including My Health Record and Medicare, is not multilingual. While it has some translated information, the main interface and the medical information within it are primarily in English, therefore limiting its usefulness in improving access to healthcare information for consumers whom English is not their primary language. This must be addressed by the HIE to ensure healthcare equity.

Financial investment

- The system will be built on the technology available at the time of building, but as with most technology, this will also quickly date and ongoing long-term funding will be required to maintain and upgrade this system.

Future state

In relation to the *High Level Current and Future State Comparison Journey* (page 26) and the scenarios outlined in Appendix F (from page 92):

- The Future State assumes a level of digital literacy for the consumer and other providers in the health care team (example "the Specialist") to make this a reality, which the HIE alone will not achieve
- There is an assumption in these scenarios that there is a funding structure in place to facilitate access to ongoing allied health care
- Many of the examples suggest non-GP specialists can view (and will have the capacity to search within) a GP's records, which is both unrealistic and concerning from a privacy and consent perspective, and will result in pushback from both GPs and consumers around this concept
- Scenario 4 (page 94) dismisses the unique skill set and established relationships GPs have with their patients, which make them adept at supporting diagnosis and management of mental ill health. It is also an unrealistic scenario given the significant lack of bulk-billing psychiatric services, particularly in regional locations. Making the scenarios more realistic may improve buy-in by healthcare providers
- The Future State, as described by the HIE, does not align with current GP workflows – for example, the onus on the GP to arrange review following an emergency department presentation.

Suggested changes to wording within the draft

The RACGP provides the below editorial suggestions to ensure the document and the scenarios within it align with real world practice, thus building confidence amongst GPs and other clinicians of the value the HIE will provide.

Section	Current wording	Suggested wording	Rationale
2.2.2, page 20 and other references to "acute"	"a national solution that connects across primary, acute, and allied health sectors"	"a national solution that connects primary care, hospitals and other types of health care facilities"	"Acute" in this context refers to "hospitals", which is the word that we suggest be used. GPs also provide care of their patients' acute (meaning 'short term' and not 'severe') conditions such as infections, injuries and emotional and psychological crises. Allied health professionals also

			provide care of patient's acute conditions as well as care of their chronic conditions. The use of acute in this context dismisses that work
3.1.1, page 22	"The HIE will deliver a set of national capabilities using a consistent approach, based on agreed standards, to facilitate the sharing of health information across existing systems such as My Health Record and other health information sources"	"The HIE will deliver a set of national capabilities using a consistent approach, based on agreed standards, to facilitate the sharing of health information across existing systems such as GPs' systems, other health professionals' and organisations' systems and My Health Record"	The change supports a more holistic vison for the HIE and removes the overemphasis of My Health Record as a significant part of the solution for data sharing with clinicians
Table 5, goal 3, page 23	"Consumers gain control of their health care journey"	"Consumers can appropriately participate in and influence their health care journey"	Healthcare consumers gain greater control of their health care
Table 6, page 24	"Information is leveraged"	"Information is used for multiple purposes"	If this is the intent of the sentence, it is unclear to readers
3.3.3, page 30	"Consumers' health information will follow them through their health journey, supporting continuity of care."	"With their health information accessible through a connected system"	This suggestion follows a recent discussion as part of the CISRO led Sparked collaboration where it was agreed that the use of "follow them" elicited imagery of stalking. This is important given that some consumers will not want certain

			health information following them
7.2.1.1, Table 21, page 63	“There is no single approach on which health information is collected for providers.”	“There is no single approach on which contact and professional information is collected for providers”?	There is confusion on reading this that it relates to the personal health information of healthcare providers rather than their details as providers
Scenario 4, page 96	“The Psychiatrist receives an eReferral notification for a new patient, and uses this to authorise her access to Maxine’s record which the GP associated with the eReferral token…”	“The Psychiatrist receives an eReferral notification for a new patient and uses this to authorise access to the referral generated by Maxine’s GP. The referral contains a concise statement of the reason(s) for the referral and Maxine’s Mental Health Treatment Plan”	The original wording suggests the Psychiatrist (and extrapolating to other scenarios, other non-GP specialists) can view and will have the capacity to search within the GP’s record. The token should provide access to the referral information curated by the referring GP only, such as with an eScript which does not open access to a patient's prescribing record within the GPs record

4.Conclusion

GPs have led the way amongst health professionals in computerisation and early adoption of new digital technologies for many years. While some, many or most health professionals are eager to adopt and implement new systems and processes that are likely to improve the safety, quality and efficiency of care, others are happy using technology they are familiar with. To ensure uptake of technological advancements, its value must be clearly demonstrated, be easier to use, provide better information exchange, align with or improve workflow and be supported by strong change and adoption strategy. GPs must be involved in the design, development, testing and implantation of technologies that will be used in general practices.

Mandating standards for interoperability will be a significant step towards improving record quality and accuracy of information exchange.

We thank you for the opportunity to provide input into the review of the draft HIE architecture and roadmap and look forward to contributing to further discussions and consultation on this topic.

Should you have any questions or comments regarding the RACGP's submission, please contact Ms Joanne Hereward, Program Manager Practice Technology and Management at joanne.hereward@racgp.org.au.