

**Feedback in response to Australia’s Primary Health Care 10 Year Plan,**

**Primary Health Reform Steering Group.**

**Australian Privacy Foundation**

**17 July 2021**

**About the Australian Privacy Foundation and this feedback**

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. Information about the APF appears at the end of this submission. We welcome this opportunity to provide a response to the Primary Health Reform Steering Group’s proposed 10 Year Plan (the Plan).

**Aim**

The aim of this response is to support the Primary Health Reform Steering Group success in devising a useful 10 year plan; which is in everyone’s best interests. So we offer this enhanced, nuanced understanding of comprehensive information about the impact of poor patient/client consent mechanisms to linked health data collections. Our critique of the Plan is designed to be constructive, supporting patient trust in digital health implementations into the future.

**The APF also wants to foster community awareness of the real life risks people face when the data collections are poorly managed, as increasingly seems to be the present case. Trust is the foundation of useful community and individual healthcare but seems increasingly overlooked in health authorities’ search for cost containment, perceived efficiencies, convenience and access to health research information, a risky approach. The risks might not often play out in public life, but when they do, these risks can prove really damaging to people and to the future of Australian digital health care more generally.**

**Synopsis of APF feedback to the Plan**

1. The Quadruple Aim must embody independently audited practice consent mechanisms so that they are explicitly transparent to new and existing patients, with a particular focus on exponential changes to practice information handling measures.
2. Recommendation 2 must respect and adhere to the consumer and human rights enshrined by the Australian legal system.
3. Recommendation 2 must embody explicit consent mechanisms, as per the APF comment on Quadruple aim 1 and remain an “opt in” rather than ever evolving into an “opt out” system over time.
4. Recommendation 15 must include support from a professionally recognised, independent, privacy or security expert that can apply Privacy Enhanced Technologies to digital healthcare

systems so as to increase community trust in the systems.

5. Recommendation 15 reads in a way that emphasizes cost and convenience, rather than a fundamental respect for people. The APF maintains the Recommendation needs to be meaningfully re-phrased to respect human rights, advancing consumer trust in digital health readiness.
6. The APF maintains that the Plan must test and guarantee claims of 'secure' messaging and digital infrastructure that is publicly available to support ongoing, even growing, consumer and patient confidence in digital health implementations into the future.
7. The APF maintains that achieving Recommendation 18 action outcomes depends upon the Plan's capacity to satisfactorily address questions of governance and consent shortcomings that are directly relevant to service delivery in localised and general practice contexts.
8. The Action Plan must be refreshed to take heed of the important APF feedback contained in this response. APF experts would be happy to assist the Primary Health Reform Steering Group with the implementation of a revised and workable Plan that fosters growing community trust in digital health implementations.

#### [APF approach to feedback](#)

The APF has made previous submissions on primary and other health-related issues to authorities from universal human rights epistemologies, combined with the findings of the Australian Law Reform Commission (ALRC) report of 2008.<sup>2-3</sup> That is, our work is guided by the core principles of knowledge, truth, philosophical scepticism and upholding the scientific method. Thus privacy must be recognised as a fundamental human right that “should take precedence over a range of countervailing interests, such as cost and convenience” .<sup>3</sup> Our epistemologies inform this submission and are also consistent with a range of detailed official and civil society analyses over many years.<sup>4</sup>

The APF supports this review of the Plan because it may help to address what we have noted, a significant lack of engagement from authorities when asked to respond to civil society enquiries on important and significant matters relating to personal information protection and health. These authorities include, but are not limited to, the Australian Digital Health Agency (ADHA), the Department of Health (DoH), the Australian Institute of Health and Welfare (AIHW) and the Therapeutic Goods Administration (TGA).<sup>4</sup>

This APF feedback responds to specific recommendations listed in the Summary of Findings reported in the Paper unless otherwise noted.

## APF Feedback

### The Quadruple aim 1.

A purpose of Quadruple Aim 1, that is to *Improve the patient experience of care (including quality of care and satisfaction)*, needs to refer to respect for individuals and their human rights in the context of consent processes. This includes issuing:

1. Explicit consent mechanisms to supersede the present opaque information and consent paperwork currently issued to new patients, and
2. Refreshed and explicit consent forms for existing patients as general practice information handling protocols change. This process does not occur at present, relying instead on one of 'blind' implied consent, where the patient continues to consult practitioners at the same general practice, apparently consenting to changes they know nothing about.

Appendix 1 illustrates APF samples of the opaque and patronising paperwork for new patients and the experience of one patient trying to update their consent arrangements with their regular primary carers, while attempting to access security policies from the same general practice, as discussed above.

1. **The Aim must embody audited practice consent mechanisms so that they are explicitly transparent to new and existing patients, with a particular focus on exponential and ongoing changes to practice information handling measures.**

### Recommendation 2 (Single primary health care destination):

*Formalise and strengthen the relationship of individuals, families and carers with their chosen primary health care provider and practice.*

Moves to formalise relationships between people with a single, chosen primary health care provider and practice must not tether individuals to a given practice for the purpose of Medicare, Health Insurance refunds or related services. Freedom of choice and meaningfully informed choice are basic tenets of our economy and legal system.

The APF has been troubled to note an overall wicked problem with health service and health product consumer protections, that is regulation's spread over a range of government and quasi-government bodies (such as the TGA, Australian Competition and Consumer Commission, the Medical Board of Australia, tribunals and several Health Commissions), some of which are more active than others; a few bodies are more transparent and responsive than their counterparts, while several health authorities seem more 'captured' than others. Freedom of choice with chosen health care providers cannot prove notional rather than substantive in the Aim because of apparent deception or because one party wasn't fully informed of the range of consequences linked to relationships with a single,

chosen health provider.

**2. Recommendation 2 must respect and adhere to the consumer and human rights enshrined by the Australian legal system.**

*Recommendation 2 (Voluntary Patient Registration):*

The Voluntary Patient Registration (VPR) implementation, a building block for achieving the Plan's intended outcomes, such as a single health-care reference point for clinical teams to enable or coordinate patient care, can only strengthen the relationships between people and their chosen primary health care provider and practice if individuals are authorised to seek information from and update their own VPR. Trust underpins this authorisation as the foundation of individual and community healthcare. The current My Health Record (MHR) system, for example, is unsatisfactory on this matter because the community does not trust in it.<sup>5-6</sup> Patients may not update or amend clinical information stored in their MHR information and the system remains largely empty across Australia.<sup>5,7</sup> The challenge of empty MHRs is exacerbated by the fact that people are automatically enrolled into the system without their consent or even knowledge, which is considered voluntary because individuals can "opt-out" of it, with many achieving this by not populating their record at all. The MHR often proves irrelevant to the decisions people make about their own healthcare and that of their loved ones.<sup>7</sup> Further, people's MHR information can actually prove unhelpful for medical care, jeopardising an individual's health and wellbeing.<sup>8</sup> The MHR system patronises people in real life, so many do not trust it. The APF is concerned to ensure the real life voluntariness of the proposed VPR is built in and **never** amended to an "opt out" system so people can trust in it. Without patient and community trust, the VPR will prove unhelpful for patients in the context of their medical care.

**3. Recommendation 2, VPR implementation, must embody explicit consent mechanisms, as per the APF comment on Quadruple Aim 1 and remain an "opt in" rather than ever evolving into an "opt out" system over time.**

*Recommendation 15 (Digital Infrastructure):*

*Develop digital infrastructure and clinical systems to better support providers to deliver safe and effective care.*

The APF supports the notion of best practice digital infrastructure for health care, which necessarily excludes the MHR system, where quality of information can never be relied upon. With respect, we question the professional bona fides of digital health technicians designing or reverse engineering the digital health systems currently in use by all health authorities; we question the certified and best practice, qualified privacy and security professional support requirements of enabling Recommendation 15. For example, the Australian National Audit Office (ANAO) published an

assessment of the DoH using data from 2018-19 and reporting in March 2020. The ANAO reported the lowest possible maturity rating for DoH cybersecurity practice and strategies.<sup>9-10</sup> The evidence suggests Australian health authorities are ranked very low in this domain.

Also, the evolution of digital health tools has been accompanied by a surge in peer-reviewed, individual, community group and academic fostered policy suggestions about ethical and privacy-enhancing ways to use the tools, which seem to be overlooked by Australian general practices and health authorities. Emerging Privacy Enhancing Technologies (PETs) support moves by health authorities to enable relevant data sharing while protecting privacy and confidentiality. The Plan does not explore available and future tools in support of PETs. For instance, homomorphic encryption is a PET that encrypts information such that it does not need a secret key for computation, but requires the secret key for other uses by the information owner.<sup>12-13</sup> We think it is critical to 'future-proof' the Plan (and more comprehensive successors) by taking advantage of and promoting the use of emerging PETs, building in community trust, rather than embedding a continued focus on spurious and outmoded de-identification processes, supported by an unsophisticated, old-fashioned digital health toolset and patronising consent mechanisms as the accepted way to link health and medical information.

- 4. Recommendation 15 must include support from an independent, professionally recognised privacy or security expert that can apply PETs to digital healthcare systems for success and to ensure growth in community trust.**

[Recommendation 15 \(Action Plan\):](#)

All of the actions required to cover Recommendation 15, such as interoperable infrastructure across primary and tertiary health care, integrated clinical systems (ad hoc - integrated with what?), multidisciplinary communications, workforce digital readiness and consumer digital readiness are well-worthwhile but present wicked problems beyond the scope of the Australian government to respect people seeking healthcare across private and public sector practices. A threshold issue, arguably the most critical of the actions outlined, consumer digital readiness, will only occur when information systems are transparent and respectful of human agency.

- 5. Recommendation 15 reads in a way that emphasises cost and convenience, rather than a fundamental respect for people. The APF maintains the Recommendation needs to be meaningfully re-phrased to respect human rights, advancing consumer trust in Australian digital health readiness.**

[Recommendation 17 \(Data\):](#)

*Support a culture of continuous quality improvement with primary health care data collection, use and linkage.*

The APF agrees with Recommendation 17 that a culture of continuous quality improvement with primary health care data collection, use and linkage is a crucial part of the Plan. Sadly this is not the case at present because PETs are not embedded in the Plan or Australian health systems.<sup>10-11</sup> The opaque and complex matrix of responsibilities outlined in the Plan about digital healthcare on the one hand, accompanied by the lack of consequence for misuse or misinterpretation by end-users, in addition to limited or ineffective transparent and available remedies for those affected by these flaws, on the other hand, is a persistent APF discomfort that is reflected in people’s mistrust of digital health systems.

For instance, the Australian Primary Health Insights (PHI) project maintains a knowledge system which holds both MBS and PBS records in the same database, where information is collected by data extraction applications fitted to general practice Computerised Information Systems (CISs) after ostensible de-identification. De-identified data can, increasingly, be re-identified (or have traits useful for re-identification revealed) by appropriately equipped foreign and domestic actors, researchers and miscreants.<sup>11-15</sup> The MBS and PBS information collected by the PHI system completely and precisely identify who the information collected concerns, regardless of aggregation for public research purposes. The co-location of MBS and PBS information in a single database is enabled via a lawful loophole in Australian legal structures.

Also, there is no public record of PHI digital information system decision-making processes so that civil society can engage meaningfully with these.

Despite consent mechanisms ostensibly covering PHI information databases, these do not occur at a real-life level. No-one is made sufficiently aware of the PHI processes designed to obtain and record their consent to the data extraction of identifiable, detailed medical records from general practice information systems, as is illustrated in Appendix 1.<sup>15</sup> While there are multiple references to ‘secure’ messaging and digital infrastructure throughout the Plan, especially in Recommendation 17, there is no reference to PETS, active consent mechanisms or public records of decision-making; it is much easier to use these terms in a report than to implement, test and guarantee their efficacy to the community.

**6. The APF maintains that the Plan must test and guarantee claims of ‘secure’ messaging and digital infrastructure in the public domain to support ongoing, even growing, consumer and patient confidence in a digital health future.**

**Recommendation 18 (Research):**

*Empower and enable contextually relevant, translational and rapid research and evaluation in primary health care, addressing questions directly relevant to service delivery in localised contexts.*

The action plan supporting Recommendation 18 includes the establishment of an Australian National Institute for Primary Health Care Research Translation (ANIPHCR), building primary health research capacities, reinstating a research governance framework based largely on the Australian Primary Health Care Research Education and Development Strategy (APHREDS) that operated from 2000 to 2014, in support of translation collaborations, and finally, Public Health Networks (PHNs), who own and operate the PHI information collection project, and Aboriginal Community Controlled Health Organisation (ACCHO) facilitation.

The establishment of the ANIPHCR, re-establishment of an APHREDS-style research framework and collaboration with PHNs and their PHI information holdings must address APF discomfort with:

1. The co-location of PBS and MBS records in PHN information holdings and
2. Unsatisfactory consent mechanisms.

Research translation and innovation can only be achieved when people consent to a trusted system, such as APHREDS-style bodies, if overseen by a trusted governance framework acting in accordance with the Australian Privacy Act and the National Health and Medical Research Council (NHMRC) guidance.<sup>16-17</sup> The operation of the Plan will also need to balance necessary and existing mechanisms for ethical oversight, while managing the risk of further contributing to the duplication in governance and ethical responsibilities between Human Research Ethics Committees (HRECs) and data custodians. HRECs must always provide approval for the disclosure of claims for medical research purposes and their role must be clearly delineated from government and PHN data custodian decision-making, including the implementation of alternative regulations – such as those implied throughout the Plan. Indeed the security rules about storing patient health information are growing more fragmented over time, adding complexity to the ongoing ‘wicked problem’ of achieving functional and trust-worthy digital health technology development and usability.

- 7. The APF maintains that achieving Recommendation 18 action outcomes depend upon the Plan’s capacity to satisfactorily address questions of governance and consent shortcomings that are directly relevant to service delivery in localised contexts.**

**Recommendation 20 (Implementation):**

*Ensure there is an Implementation Action Plan developed over the short, medium and long-term horizons*

- *Ensure consumers, communities, service providers and peak organisations are engaged throughout implementation, evaluation and refinement of primary health care reform.*

The Plan constructs an edifice of digital health benefit, which if only partly crumbles and fails, risks a large adverse and cascading impact on community trust. The impact of a loss of community trust, combined with disappointed community expectations, is demonstrable by science and by people “

voting with their feet”, that is, the 10% of Australian’s that have actively opted out of the MHR, and usage shortcomings within the same system.<sup>18</sup>

8. **The Action Plan must be refreshed to take heed of the important APF feedback contained in this response. APF experts would be happy to assist the Primary Health Reform Steering Group with the implementation of a revised and workable Plan that fosters growing community trust in digital health implementations.**

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## Australian Privacy Foundation

### Background Information

The Australian Privacy Foundation (APF) is the primary national association dedicated to protecting the privacy rights of Australians. The Foundation aims to focus public attention on emerging issues that pose a threat to the freedom and privacy of Australians. The Foundation has led the fight to defend the right of individuals to control their personal information and to be free of excessive intrusions.

The APF's primary activity is analysis of the privacy impact of systems and proposals for new systems. It makes frequent submissions to parliamentary committees and government agencies. It publishes information on privacy laws and privacy issues. It provides continual background briefings to the media on privacy-related matters.

Where possible, the APF cooperates with and supports privacy oversight agencies, but it is entirely independent of the agencies that administer privacy legislation, and regrettably often finds it necessary to be critical of their performance.

When necessary, the APF conducts campaigns for or against specific proposals. It works with civil liberties councils, consumer organisations, professional associations and other community groups as appropriate to the circumstances. The Privacy Foundation is also an active participant in Privacy International, the world-wide privacy protection network.

The APF is open to membership by individuals and organisations who support the APF's Objects. Funding that is provided by members and donors is used to run the Foundation and to support its activities including research, campaigns and awards events.

The APF does not claim any right to formally represent the public as a whole, nor to formally represent any particular population segment, and it accordingly makes no public declarations about its membership-base. The APF's contributions to policy are based on the expertise of the members of its Board, Committees and Reference Groups, and its impact reflects the quality of the evidence, analysis and arguments that its contributions contain.

The APF's Board, Committees and Reference Groups comprise professionals who bring to their work deep experience in privacy, information technology and the law.

The Board is supported by Patrons The Hon Michael Kirby AC CMG and The Hon Elizabeth Evatt AC, and an Advisory Panel of eminent citizens, including former judges, former Ministers of the Crown, and a former Prime Minister.

The following pages provide access to information about the APF:

- Policies <https://privacy.org.au/publications/by-date/>
- Media <https://privacy.org.au/home/updates/>
- Current Board Members <https://privacy.org.au/about/contacts/>
- Patron and Advisory Panel <https://privacy.org.au/about/contacts/advisorypanel/>

The following pages provide outlines of some of the campaigns that the APF has conducted:

- The Australia Card (1985-87) <https://privacy.org.au/About/Formation.html>
- Credit Reporting (1988-90) <https://privacy.org.au/campaigns/consumer-credit-reporting/>
- The Census (2006) <https://privacy.org.au/campaigns/census2006/>
- The Access Card (2006-07) <https://privacy.org.au/campaigns/id-cards/hsac/>
- The Media (2007-) <https://privacy.org.au/campaigns/privacy-media/>
- The MyHR (2012-) <https://privacy.org.au/campaigns/myhr/>
- The Census (2016) <https://privacy.org.au/campaigns/census2016/>

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**Appendix 1**

Medical  
Centre

CONSENT FORM

We require your consent to collect personal information about you. Please read this consent form carefully and sign where indicated below.

This medical practice collects information from you for the primary purpose of providing quality health care. We require you to provide us with your personal details and a full medical history so that we may properly assess, diagnose, treat and be pro-active in your health care needs. This means we will use the information you provide us in the following ways.

- o Administrative purposes in running our medical practice.
- o Billing purposes including compliance with Medicare and Health Insurance Commission requirements.
- Disclosure to others involved in your healthcare including treating doctors and specialists outside this medical practice. This may occur through the referral to other doctors, or for medical tests and in the reports or results returned to us following referrals.
- o Disclosure to other doctors in the practice, locums etc. attached to the practice for the purpose of patient care and teaching. Please let us know if you do not want your records accessed for these purposes and we note in your record accordingly.
- o Disclosure for research and quality assurance activities to improve individual and community health care and practice management, all information in these instances is un-identified. These activities are ongoing within the practice. I have read the information above and understand the reasons why any information must be collected. I am also aware that this practice has a privacy policy on handling information.

/ understand that / am not obliged to provide any information requested of me, but failure to do so may compromise the quality of healthcare and treatment given to me. I understand that if any information is to be used for any other purpose other than set out above, my further consent will be obtained.

/ consent to the handling of my information by the practice for the purposes set out above, subject to any limitations on access or disclosure that I notify this practice of.

(Please tick if agree) / am happy to receive Appointment and/or Recall SMS text reminder messages.

Signed.....

Name..... Date.....

Signed as Guardian of child.....

Name.....

Figure 1: Sample Medical Practice Consent Form

## PATIENT REGISTRATION FORM

### CLINIC PRIVACY STATEMENT

Please read this carefully. You may also view this statement at our website.

collects information from you for the primary purpose of providing quality health care. We require you to provide us with your personal details and a full medical history so that we may properly assess, diagnose and treat illnesses and medical conditions, ensuring we are proactive in your health care. To enable ongoing care, and in keeping with the Privacy Act 1988 – Australian Privacy Principles, we wish to provide you with sufficient information on how your personal information may be used or disclosed and record your consent or restrictions to this consent.

Your personal information will only be used for the purposes for which it was collected or as otherwise permitted by law. We respect your right to determine how your information is used or disclosed.

The information we collect may be collected by a number of different methods. Information may include test results, consultation records, Medicare details, data collected from observations and conversations with you, and details obtained from other health care providers (e.g., specialist correspondence).

By signing below, you (as a patient/parent/guardian) are consenting to the collection of your personal information, and that it may be used or disclosed by the practice for the following purposes:

- Administrative purposes in the operation of ;
- Billing purposes, including compliance with Medicare requirements;
- Follow-up reminder/recall notices for treatment and preventative healthcare, frequently issued by text messaging or via HotDoc;
- Disclosure to others involved in your health care, including treating doctors and specialists outside this medical practice. This may occur through referral to other doctors, or for medical tests and in the reports or results returned to us following the referrals;
- Accreditation and quality assurance activities to improve individual and community health care and practice management;
- For legal related disclosure as required by a court of law; \*
- ~~For the purposes of research only where de-identified information is used.~~ \*
- ~~To allow medical students and staff to participate in medical training/teaching using only de-identified information.~~ \*
- To comply with any legislative or regulatory requirements, e.g., notifiable diseases; and
- For use when seeking treatment by other doctors at

At all times we are required to ensure your details are treated with the utmost confidentiality. Your records are very important, and we will take all steps necessary to ensure they remain confidential.

### PRIVACY CONSENT

Please fill in the spaces below if you understand and agree to the following statements in relation to our use, collection, privacy and disclosure of your patient information.

1. I have read *Clinic Privacy Statement* and understand the reasons why my information must be collected, and the purposes for which my information may be used or disclosed. I understand that if my information is to be used for any purpose other than that set out above, my further consent will be obtained.
2. I give permission for my personal information to be collected, used and disclosed as described above, including contact via text messaging to my mobile phone number. I understand only my relevant personal information will be provided to allow the above actions to be undertaken and I am free to withdraw, alter or restrict my consent at any time by notifying this practice in writing. *\* Except for deleted terms.*

Patient name		If signing on behalf of, state your name	
Signature		Your relationship to the patient	
Date		Date	

Official use only

Received by: \_\_\_\_\_

Via email: \_\_\_\_\_

*\* Please exclude my data from any extraction or sharing not explicitly connected to my individual medical care.*

*Please exclude my data from sharing with PHN in de-identified or identified form.*

Figure 2: Practice consent form populated to withdraw from all secondary health data collection

<p><u>Tue, 23 Feb 2021 at 17:25</u>  <u>&gt;snip&lt;</u>  <u>On another matter, would you please remove me from the PHN data collection application using PenCAT or POLAR, again as soon as convenient as I do not consent to the process.</u>  <u>Thank you</u></p>
<p><u>On Fri, 26 Feb 2021 14:24,</u>  <u>wrote:</u>  <u>Hi there</u>  <u>Please confirm that you have removed me from the PHN data collection application using PenCAT or POLAR, for the PHN and PIP - QI data collection process/es as soon as possible as I do not consent to the process. See email below for my initial request last week. Any data you collect about me must only be shared for the purpose of primary health care; I do not consent to any secondary data collection.</u>  <u>Thanks</u></p>
<p><u>On Fri, 5 Mar 2021 at 11:19, wrote:</u>  <u>Dear Practice Manager,</u>  <u>Please confirm that you have removed me from the PHN data collection application using PenCAT or POLAR, for the PHN and PIP - QI data collection process/es as soon as possible because I do not consent to the process. See emails below for my initial requests - over 2 weeks. Any data you collect about me must only be shared for the purpose of primary health care; I do not consent to any secondary data collection.</u>  <u>On a related note, please email me a copy of the practice privacy policy.</u>  <u>Yours sincerely</u></p>
<p><u>09/03/2021</u>  <u>Dear Practice Manager</u>  <u>In hopes of speeding my enquiry re the practice privacy policy and my withdrawal of consent for my health information to be shared with PHN data collection and PIP-QI links, I went to your web site to download your new patient information sheet and consent paperwork but the link is dead, no file opens when I select that option.</u>  <u>Further, have you progressed my withdrawal of consent and would you confirm this. This discussion has continued for some time and I do not wish to take it to the Health Services Commission. Please respond to me.</u>  <u>Thank you</u></p>

Figure 3: Individual's attempt to withdraw implied consent from a GP