Australian
Privacy
Foundation

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National E-Health Transition Authority
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RE: APF SUBMISSION

1. HI SERVICE IMPLEMENTATION APPROACH

2. HI SERVICE COMMUNICATION PLANS

3. HEALTHCARE IDENTIFIER REGULATIONS

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. I am writing in my capacity as Chair of the Health Sub Committee of the APF.

SECTION 1

As you are no doubt aware, we published the APF policy position on eHealth Data and Health Identifiers in 2009. The policy is attached to this submission and is publicly available at http://www.privacy.org.au/Papers/eHealth-Policy-090828.pdf. My core comments about the HI Service Implementation Approach and the HI Service Communication Plans documents reiterate these general principles (see the Section 3 of this submission).

1.1 THE HI SERVICE IMPLEMENTATION APPROACH

The HI Service Implementation Approach document refers to the International experience, claiming the US model is inferior to that used by the NHS in the UK. Yet recent evidence suggests a debacle over the UK creation of summary care record without the knowledge or consent of citizens (https://www.ucl.ac.uk/news/scriefullreport.pdf). Moreover recent evidence suggests the HI poses difficulties in accident and emergency hospital because the pace and culture of emergency care make conditions for accessing electronic records difficult to achieve (1). " ... numerous examples of "dissonance" between what policy makers and IT experts expected and the actual experience of patients and clinicians "so that care for many patients with chronic illnesses could not be informed by the summary record bridged by an HI (1). Indeed some commentators argued the summary care record has the potential to do more harm than good (2). No evidence suggests an HI Service is directly linked to any patient care benefit.

1.2 HI SERVICE COMMUNICATION PLANS

The Service Communications document outlines strategies to misinform the public or euphemise the effect of the HI Service on their everyday medical care. Motherhood statements allude to strategies and marketing plans, publishing stories about the proposed service without informing patients these service will not be trialled before roll out, that patients will be treated as guinea pigs over the next decade or so while health authorities address shortcomings as they occur (as occurred with the NHS (1)) and that the vision outlined in the document is just that- a vision, not actuality. The Communication document seems to misrepresent truth and risks to the public rather advise citizens of ways they can be fully informed partners in the EHealth process. Hard evidence, research data, finds little evidence that the eHealth record, and so associated HIs, achieve any of the benefits outlined in the Communication Plan (1).

1.3 THE REGULATIONS

The deadline for public consultation about the regulations supporting the Health Identifier Bill and Health Identifier Amendment Bill was on the 16th April 2010. Prior to notification of email alert from the Department of Health and Ageing's Healthcare Identifiers Service page (http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-ehealth-consultation) of the passage of the HI Bill Parliament on June 25th 2010, the most recent communication received from the list was on 12th March 2010. Yet anecdotal evidence indicates that negotiations and consultations about amendments to the draft regulations supporting the HI Bill that continued after April 16th. Why did no communication to privacy and other advocacy stakeholders occur? Are some Australians more worthy of consultation than others? People want eHealth systems to be trustworthy, transparent and respectful of their needs and values. We are very disappointed by the lack of transparency that has characterised the entire HI process.

SECTION 2

The table below compares the HI Service Implementation and the HI Service Communication documents with APF Policy.

APF POLICY	HI SERVICE IMPLEMENTATION	HI SERVICE COMMUNICATION
Health care must be universally accessible	Access to health care must not be conditional on access to health care data or on demonstration of the person's status (such as residency rights or level of insurance). The implementation document makes access to healthcare impossible	The HI Service aims to be consistent, while it really ensures access to healthcare is conditional on access to health care data or on demonstration of the person's status.

	on the basis of residency status and/or income.	
The health care sector is by its nature dispersed.	Health care is provided by thousands of organisations and individual professionals, each with a considerable degree of self-responsibility. The sector is far too large, and far too complex to be centrally planned. This document does not address the public/private sector challenge. Only public sector organisations must use the HI, not private and many health services across the country will not be registered for the services for several years. The confusion that ensures when the service commences operation is likely to trigger embarrassment at best and adverse health effects at worst.	
Personal health care data is inherently sensitive.	Many individuals have serious concerns about the handling of at least some categories of health care data about themselves. The Service ensures potential data linkage to health information to hundreds of thousands of people on a routine basis.	The document pretends that consumers will be able to directly access HI services that have not been planned or enabled yet –i.e. "If you want to, you can look your number up through Medicare's online services (p10)."
The primary purpose of personal health care data is personal health care.	The protection of the individual person is the primary function of personal health care data and systems that process it. The key users of that data have been health care professionals. Key users will now include government agencies and researchers that do not need patient consent for the routine use and linkage of patient information.	The HI Service targets include Healthcare providers, organisations, related research and better practice organisations; Australian, State and Territory governments, including Ministers and regulatory agencies; Health information technology industry and vendors- tertiary purposes of personal health care.
Other purposes of personal health care data are secondary, or tertiary.	Public health is important, but is a secondary purpose. Administration,	The document acknowledges the HI Service has been established to serve the

	insurance, accounting, research, etc. are neither primary nor secondary but tertiary uses. The HI Service allows the tail of health and public health administration and research to wag the dog of personal health care	needs of an enormous number of Healthcare stakeholders who are NOT patients.
Patients must be recognised as the key stakeholder.	Government agencies and corporations must directly involve people, at least through representatives of and advocates for their interests, in the analysis, design, construction, integration, testing and implementation of health information systems. This has not occurred with the implementation plan; instead patients are assigned a compulsory number and told what to do.	The document refers to a series of public stakeholder meetings and forums, suggesting that feedback was positive “overall” when contemporaneous notes from meeting participants suggest the reverse. Health authorities closed these meetings before participants were able to put all of their questions.
Health information systems are vital to personal health care	People want systems to deliver quality of service, but also to be trustworthy, transparent and respectful of their needs and values. Yet people will have no direct access to information stored about them in the HI Service for several years and will need to work through an intermediary when information stored about them is incorrect.	The Service Communication promises “Only authorised people will be able to access your IHI number” (p.10). Given that authorisation will take several years to enable and audit processes are erroneously claimed to be able to identify individuals (they can’t, only a machine name), people will not be able to trust the HI service. Sometimes withholding information they perceive as embarrassing

		or damaging from clinicians.
Health carers make limited and focussed use of patient data.	Health carers require effective but controlled interoperability among health care data systems, and effective but controlled communications among health care professionals. The HI Service is for the benefit of tertiary users (administration, insurance, accounting, research, etc.), not for the benefit of personal health care	
Data consolidation is inherently risky	Physically and even virtually centralised records create serious and unjustified risks. Services can be undermined by single points of failure. Yet the document pretends this will not be the case with regard to the HI service. It distinguished between the terms ‘centralised’ and ‘distributed’ database when these are essentially the same thing. Report authors create new understandings of existing dictionary-based words to define the HI Service.	N/A
Privacy impact assessment (PIA) is essential	The Implementation document overlooks the findings from 3 PIAs- 1 from Mallesons, Stephen Jaques, 1 from Clayton Utz and the last from Gallexia. The strategy rides roughshod over these, outlining a road map to privatise their Electronic Health Records [EHRs] (Google. HealthVault) and so cut national spending on an EHR;	The 3 PIAs are referred to, while their content and the fact that their findings have been overlooked are not. Is this mischievous?

	thereby ensuring access effective health care may not be universal[3].	

The Service Implementation and the HI Service Communication documents, as with recent secret consultations to update the Regulations, do not comply with APF policy. We are disappointed by the lack of transparency and hard evidence the documents embody. The implication of the concerns listed above is to ask again whether the APF is wasting our time with this and other HI or eHealth submissions to authorities.

Yours sincerely

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Contact Details for the APF and its Board Members are at:

http://www.privacy.org.au/About/Contacts.html

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3. Cross, M. The perils of privatised health records. http://www.guardian.co.uk/commentisfree/libertycentral/2010/jun/22/dangers-privatisation-online-health-records