

# Citizens, patients and policy: a challenge for Australia's national electronic health record

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## Abstract

Australia will implement a personally controlled electronic health record (PCEHR) over the next three to five years. Development of an e-health policy framework to support this initiative has involved healthcare providers and patients, but the discussion appears to have bypassed non-patient citizens. There is a risk that this omission may result in difficulties with implementation and uptake of the new system.

**Keywords (MeSH):** *Policy; Policy Development; Health Policy; e-Health; Electronic Health Records; Privacy; Informed Consent.*

## Introduction

Australia, like many other developed countries, is in the process of implementing a national shared electronic health record (EHR) system. This implementation has raised a number of interesting policy issues, including those concerning patient privacy, patient identification, and the management of patient consent for participation and for primary and secondary use of information. Achieving effective citizen participation in the development of public policy is an important part of a participatory democracy. Although the use of interest groups as proxies may be convenient, it may not provide a reliable substitute for direct citizen engagement. Patient organisations have been actively consulted about Australia's EHR, and involved in discussions about relevant policy issues. However, the development of the underlying policy framework does not appear to have involved citizens directly, other than in their role as patients.

While this paper provides a commentary on Australia's approach to the development of national e-health policy, it does not attempt to provide a comprehensive summation or analysis of the policy itself, or to examine EHR developments within individual states and territories.

## Citizen, patient or consumer?

Some tensions exist between the differing roles and terminologies of citizen, patient and consumer. Talcott Parsons (1951) first formulated the notion of a 'sick role' which exempted patients from responsibility for their incapacity, and from the obligations of their normal social roles, while imposing an obligation to try to get well, and to seek competent professional help to do so. Subsequent analyses of the sociology of healthcare, and of the role of the patient, have moved on from Parsons' view. Patients are now reframed as 'consumers', with an assumption that they have a consumer's right to select and choose in the health marketplace. However, this viewpoint is not universally accepted. Keaney (1999) suggests that patients ought to be considered as partners

in a continuing process of inquiry, rather than as passive consumers of pre-packed healthcare. Although Parsons' notion of the patient's role in society may now seem somewhat dated, the transition from citizen to patient still provides a valid conceptual framework. Church et al. (2002) cite Tuohy and Evans' observation (1986) that in healthcare citizens assume two major roles. They are on the one hand collective taxpayers, and on the other, individual users of services. A citizen's view of a policy debate may reveal a dichotomous position, with views as a funder distinct from those as a recipient. In the context of the discussion presented here, the separate roles of patients and of non-patient citizens are considered to offer differentiated viewpoints on matters of health policy. Not all citizens are patients, but (almost) all patients are citizens.

## Engaging citizens in health policy

A brief review of the relevant literature shows a body of work dealing with the challenges and benefits of engaging citizens in public policy, and more specifically in health policy. One of the earliest considerations of the issues associated with citizen engagement came from the discipline of urban planning. Sherry Arnstein (1969) described a 'ladder of participation', with eight levels or 'rungs' of citizen participation, in three stages. Arnstein's first stage is Nonparticipation, which can involve Manipulation – an attempt to 'educate' participants to an acceptable viewpoint - or Therapy, which sets out to 'cure' their deviant perceptions. The second stage encompasses Degrees of Tokenism: Informing; Consultation (which may include what Arnstein refers to as 'window-dressing participation'); and Placation, when participants hear and are heard, but are not necessarily heeded. The third stage involves Degrees of Citizen Power: Partnership, Delegated Power, and finally Citizen Control, which can provide citizens with opportunities for trade-offs, decision making seats, and possibly managerial control.

There have been increasing trends towards the direct engagement of citizens in the development and implementation of health policy. A discussion paper on citizen

participation (CP) prepared for the Commission on the Future of Health Care in Canada identifies that:

*... reported advantages to CP in health planning include a system that addresses the specific needs, values, culture and attitudes of the community. Furthermore, it provides the opportunity for greater support of resulting decisions and services, a more efficient use of scarce resources, an enhancement of community awareness of health issues, a mechanism for public feedback and increased networking, access to local resources and skills of community members, and an enhanced sense of control and empowerment within the community. (Pivik 2002: v)*

Curtain (2003) uses the OECD's three-stage model of citizen relations (similar to the three stages of Arnstein's ladder) to review the extent to which Australian governments are engaged with citizens. He identifies three roles for citizens in this process: as taxpayers, as users of services, and as members of the local and national community, and notes that:

*By bringing three perspectives to bear on an issue, citizens as citizens are often better placed than politicians or public servants to identify policy priorities, reconcile conflicting values and work out what choices are more consistent with their community's values (p.35).*

Abelson et al. (2003) reviewed the use of deliberative methods for public participation in healthcare. They identified a need for approaches which strengthen two-way interaction between decision makers and the public, and noted that deliberative democracy involves a collective 'problem solving' discussion, with persuasion and altering of participants' views. Power relationships are not necessarily excluded from this process. They identify four broad approaches to deliberative participation:

- *Citizen juries* (known as 'planning cells' in Germany) which involve 20 or so participants, and have been in use since the 1970s
  - *Citizens' panels* which are similar to juries, but have more permanency, providing a resource to consider different issues over time
  - *Consensus conferences* which typically involve small sub-group meetings with experts, followed by a larger meeting to present main observations and conclusions
  - *Deliberative polls* which incorporate a deliberative component within a conventional opinion poll.
- Citizen participation can have its drawbacks.

A number of challenges have been identified, including:

*... time constraints, lack of representation, difficulty reaching marginalized populations and a lack of education and training specific to CP ... a lack of resources, perceived status differentials, processes that are not fully accessible, poor communication, differing definitions of participation, conflicting vested interests, incongruence between stated purpose and practice, tokenism and role strain. (Pivik 2002: v)*

There have been few evaluations of the effectiveness of deliberative methods in health policy. Church at

al. (2002) reviewed the use of citizen participation in Canada, and offer two perspectives on the interest of provincial governments in citizen participation in health-care. The first perspective embraces the assumptions that citizens want to participate, and that their participation results in better decision-making. They found little evidence for either assumption. Their second perspective was that governments use participation as a means of co-opting citizens to a larger political agenda.

Arnstein's conception of citizen participation has been criticised as being overly simplistic, and its transferability to the more complex domain of health service planning questioned:

*A linear, hierarchical model of involvement – Arnstein's ladder – fails to capture the dynamic and evolutionary nature of user involvement. Nor does it recognise the agency of users who may seek different methods of involvement in relation to different issues and at different times. (Tritter & McCallum 2006: 165).*

Despite these concerns, Arnstein's ladder remains a useful tool with which to gauge the extent of citizen involvement in matters of public policy.

### Australia's national EHR

The last decade has seen significant progress towards the implementation of national EHR systems in many developed countries. In Australia, work on a national EHR system was initiated following the House of Representatives 'Health On-Line' report (Slipper & Forrest 1997). Australia's health ministers established the National Health Information Management Advisory Committee (NHIMAC) in 1998, and The National Electronic Health Records Taskforce was established as a subcommittee of NHIMAC in 1999. The Taskforce produced 'A Health Information Network for Australia' (2000), which included a recommendation for a national approach to the implementation of EHRs. This national implementation was initially pursued through the HealthConnect program (Australian Government Department of Health and Ageing [DoHA] 2010), but in 2005 HealthConnect was recast as a 'change management strategy' (Abbott 2005). Responsibility for the development of the national EHR was transferred to the National e-Health Transition Authority (NEHTA), which had been established by Australian Federal, State and Territory governments to develop essential foundations for e-health.

In 2009, Commonwealth, state and territory health ministers announced the introduction of an individual health identifier for all Australians (*Healthcare Identifiers Act 2010* (Cth)), and the 2010 Federal Budget included an allocation of \$446.7 million over two years as initial funding for the introduction of a personally controlled electronic health record (PCEHR), which is to include a patient summary. A draft Concept of Operations for the PCEHR was released in April 2011 (DoHA & NEHTA 2011).

## Policy issues

Policy issues related to electronic health records and e-health have proved challenging and divisive. Sound policy for e-health necessitates a fine balance between security and privacy for individuals and groups, and improved sharing of health information to support better care. Australia's e-health policy debate has many of the characteristics of a 'wicked problem', which are:

*...social system problems which are ill-formulated, where the information is confusing, where there are many clients and decision makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing (Churchman 1967: B-141).*

Wicked problems usually have no 'right answer', and any compromise solution risks leaving most stakeholders dissatisfied. Westbrook et al. (2007) note that information systems have been identified as a way of improving health service delivery, but caution that the 'wicked' nature of the task presents challenges for both implementation and evaluation.

Broadly, the policy debate has involved: those with an interest in the design and implementation of an EHR system to improve care through better information sharing; those with expertise in legal and privacy matters, who generally advocate for a cautious approach; health-care providers (particularly medical practitioners) who understand the need for caution, but also see significant future benefits in a functioning EHR system; and to a lesser extent those who will make use of aggregated health data. The views of patients have been represented in the debate by health consumer organisations, notably the Consumers Health Forum of Australia (CHF), whose successive e-health projects have been effective in eliciting patient views on e-health (Bresnan 2004).

A number of e-health policy issues have generated significant public discussion and debate including: concerns about patient privacy; the introduction and management of health identifiers; whether consumers will opt-in to the national EHR system, or be included by default with an opportunity to opt-out; and mechanisms for direct and the secondary use of health information.

## Consultation and engagement

Both the introduction of health identifiers legislation and the design and planning of the PCEHR have been accompanied by well-managed consultation processes.

DoHA released a discussion paper on the identifiers legislation in July 2009, with a consultation period that ran for just over a month. Two stakeholder forums were held to discuss the draft, and public submissions were invited. Over 90 submissions were received, 21 in confidence. Of the 72 submissions available for review, eight were from individuals (in a population of 22 million). Further consultations were conducted for the exposure draft legislation (between 20 November 2009 and 7 January 2010), the exposure draft regulations (between 12 March 2010 and 9 April 2010) and NEHTA's draft HI Service Implementation Approach and draft HI Service

Communications Plan (between 1 June and 28 June 2010).

NEHTA has undertaken a comprehensive and thorough approach to consultation about the planned national EHR. Draft descriptions of the proposed system have been published, and public comment invited. During 2008 NEHTA conducted workshops involving a wide range of stakeholder groups in Alice Springs and in Brisbane, with the outcomes presented to a 'peak body' summit in Canberra. The Privacy Blueprint was discussed at roundtable sessions specifically considering privacy and secondary use of data. Two workshops (in Alice Springs and Brisbane) included 142 participants, with one person attending both workshops. Of these, 71 represented health provider organisations (46 medical, 12 nursing, 13 allied health). In total there were 11 representatives of a disease interest group (such as the Heart Foundation and the Cancer Council), and seven health consumer representatives, three of those from CHF. The extent of consumer involvement in the roundtable discussions of privacy and the secondary use of data were also limited. In addition, NEHTA commissioned a quantitative survey of 2,700 participants (UMR Research 2008), using a public opinion poll.

Given the background knowledge required for effective participation, the involvement of representatives of patient organisations rather than individual patients is understandable. And in light of the significant efforts of CHF over a number of years to broadly canvas patient views about e-health, this approach was entirely appropriate. However, there is little evidence of direct citizen involvement in the discourse about the EHR, or about health identifiers. Neither is there much visible evidence of widespread public discussion or debate about the policy issues, or evidence that the general public has any working knowledge of the proposed EHR system, and how it will operate in practice.

## EHR policy framework

Like many areas of emerging public policy, there are few clear published statements of the policy. The shape of policy emerges from successive iterations of documents which describe the proposed system. Much of Australia's policy for implementation and use of Health Identifiers (HIs) becomes apparent from legislation passed in June 2010, while the most comprehensive description of what is intended for the PCEHR is in the Draft Concept of Operations (DoHA & NEHTA 2011), released as a discussion document, which provides details of the policy direction for the development and implementation of Australia's national PCEHR. However, there remains some doubt that newly elected governments, particularly those in Victoria and New South Wales, will consider that they are rigidly bound by their predecessors' e-health policy commitments.

The current policy framework for the PCEHR is described in some detail in the DoHA/NEHTA Draft Concept of Operations (DoHA & NEHTA 2011). Extensive

safeguards are provided for patient privacy. Patients can control the addition of information to the record, and selectively allow or deny access by healthcare providers and provider organisations. A healthcare provider may access records in an emergency, except those flagged as 'no access' (DoHA & NEHTA 2011: 59).

Patient records in the PCEHR are to be identified using an Individual Health Identifier (IHI) assigned by Medicare as IHI service provider. IHIs are assigned automatically, based on existing records for Medicare cards and Department of Veteran Affairs healthcare cards, and activated at the request of the individual. There does not appear to be an option for an individual to prevent the assignment of an IHI.

The PCEHR system operates on an opt-in model; an individual's participation is entirely voluntary. Individuals who decide not to have a PCEHR will not be disadvantaged in terms of their access to healthcare services. An individual may choose to withdraw from the PCEHR at any time. Their record is then de-activated; information will still be stored, and available to the PCEHR operator for maintenance, audit and other approved purposes, but not to health care providers or individuals.

An individual may choose to make their information available to all health care providers who are providing their care, or only to those who have been given the individual's Provider Access Code. The individual can also establish an 'include list' (providers who have access) and an 'exclude list' (providers who are denied access) (DoHA & NEHTA 2011: 54). It should be noted that some stakeholders have raised concerns about the complexity inherent in the limited access features. Access to an individual's PCEHR record may involve transfer of information to a local system, for which PCEHR access controls no longer apply.

The PCEHR system includes a reporting service which can analyse information from multiple records, audit trails and activity logs to produce operational reports, and details of system uptake and usage. Most reports will contain de-identified data, and those with identified data will be restricted to authorised users. The types of reports are expected to evolve over time, and may be extended to support additional approved uses. Reports will be available to users evaluating the PCEHR system, and those with permission to use the PCEHR for approved uses. In the first release, the reporting portal will only be used for operational reporting and evaluation. It appears that patient consent for secondary use of their information is either taken for granted, or to be obtained only at the time of record activation.

### **Does policy match expectations?**

Although most research into health system preferences is focused on patients (and often on patients receiving many health services), it is possible to elicit and codify the policy expectations of citizens (who may or may not currently be patients or carers) about aspects of the

healthcare system, while also taking note of the concerns of interested commentators.

Although the issues they raise are not directly related to the proposed PCEHR, Handelsman, Turner and Conway (2011) have recently expressed concerns about what they see as legislated breaches of privacy and trust in areas of healthcare such as infertility treatment and genetic testing. Their concerns raise a question about the potential for future legislation to retrospectively change the policy under which the PCEHR operates, effectively creating a structural privacy breach for data which is held within it. The custodian of PCEHR data would be bound to provide the data to a third party, even if that action was against the express wishes of healthcare provider and patient.

Greenleaf (2010) reviewed a number of unresolved privacy issues which emerged from the legislation intended to introduce individual health identifiers. These concerns included: the iterative introduction of the IHI - subsequent stages of implementation were not clearly elaborated at the time the legislation was presented; the capacity of organisations to assign and use an identifier without the subject being aware; and the lack of effective controls over subsequent use of data identified with an IHI (including potential for use by other agencies, including police and social services).

In Australia, the Menzies Centre for Health Policy and The Nous Group (2008) conducted a survey of the attitudes of 1,200 Australians to the health system. The vast majority (90%) preferred the option of health providers having direct access to their health information, while 65% believed that confidential access to the record without specific consent was acceptable. A vast majority believed that the health record should be available to the treating doctor (99%), to other health professionals providing care (97%) and to the patient (95%). The policy as described appears to match these expectations.

In New Zealand, Parkin and Paul (2011) used a citizens' jury to explore public views about the use of identified data for the evaluation of medication safety. Over the course of its deliberations, the jury came to a unanimous view that researchers contracted by a public body should have access to identified data, provided relevant legal and ethical considerations were met. In Ireland, Buckley, Murphy and MacFarlane (2011) used a questionnaire to evaluate the attitudes of Irish citizens to the use of health records held by their general practitioner (GP) for research. A majority (83.7%) were willing to let their GP decide when to provide anonymous data without informing them; 71.9% said they would like to be asked before the GP provided identified data. The means by which any future use of PCEHR information would ensure that legal and ethical considerations would be addressed, and that clinician approval might be sought, remain open questions.

## Conclusion

In the context of Australia's PCEHR, there is little discernible evidence that the views of citizens have been considered. As a community, Australians will have had little prior exposure to policy issues of privacy, consent and secondary use, and may feel that they have not been adequately consulted. Mistrust, scepticism and caution may lead to resistance to the introduction and uptake of the EHR system, and result in a reiteration of adverse views which may already have been addressed effectively. It is possible that the policy framework which has been established for Australia's PCEHR meets the wishes and expectations of the majority of citizens whose health information it may hold, and whose taxes will fund it. However, if that proves to be the case, it will be by accident, and not by design or deliberation. Arnstein (1969) would identify patient consultation as her fourth rung of citizen involvement, among the Degrees of Tokenism; the engagement of non-patient citizens would struggle to reach the first rung.

There have been significant tensions in the Australian e-health policy debate between legal and privacy advocates, healthcare providers, and health informatics professionals involved in the design and implementation of e-health systems. It is almost inevitable that policy is, in the end, politically enacted.

There has been little apparent concern in these deliberations for the views of the citizens whose taxes will pay for the system, and whose health details will be recorded in it. That omission could result unnecessary challenges to implementation and uptake.

There may well emerge in the community at large a sense that the policies governing the PCEHR have been framed by politicians, bureaucrats and technocrats, with scant regard to the attitudes and expectations of patients (through organisations as their proxies), and none to those of non-patient citizens.

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