Newcastle University

ePrints

Garrety K, McLoughlin I, Dalley A, Wilson R, Yu P.

National Electronic Health Record Systems as 'Wicked Projects': The Australian Experience.

***Information Polity* 2015**

DOI: http://dx.doi.org/10.3233/IP-160389

Copyright:

This is the authors' accepted manuscript of an article that is published in its final definitive form by IOS Press, 2016. The final publication is available at IOS Press through http://dx.doi.org/10.3233/IP-160389

Date deposited:

28/07/2016

This work is licensed under a Creative Commons Attribution-NonCommercial 3.0 Unported License

Newcastle University ePrints - eprint.ncl.ac.uk

National Electronic Health Record Systems as 'Wicked Projects': The Australian Experience

Karin Garrety (corresponding author)
School of Management, Operations and Marketing
University of Wollongong
Northfields Ave
Wollongong, NSW 2522
Tel: +61 2 4229 2161
karin@uow.edu.au

Ian McLoughlin
Monash Business School
Monash University
Caulfield Campus
Melbourne, Victoria 3145
Ian.McLoughlin@monash.edu

Andrew Dalley
Illawarra Health and Medical Research Institute
University of Wollongong
Northfields Ave
Wollongong, NSW 2522
andrewdalley@exemail.com.au

Rob Wilson
Newcastle University Business School
Newcastle University
Newcastle upon Tyne, UK NE1 4JH
Rob.Wilson@ncl.ac.uk

Ping Yu
School of Information Systems and Technology
University of Wollongong
Northfields Ave
Wollongong, NSW 2522
ping@uow.edu.au

National Electronic Health Record Systems as 'Wicked Projects': The Australian Experience

Abstract

Governments around the world are investing in large scale information and communication technology projects that are intended to modernize and streamline healthcare through the provision of nationally accessible electronic health records. In this way, they hope to 'tame' the complex 'wicked' problems facing healthcare, such as rising costs and fragmented delivery. However, these projects often encounter difficulties. Using a case study of Australia's 20-year journey towards a national electronic health record system, we show how these projects can ironically take on the characteristics of the 'wicked problems' they are intended to solve, and how a failure to recognize and cope with these 'wicked' characteristics can lead to waste, conflict and frustration among potential users. We suggest some alternative approaches to the management of large-scale ICT projects in healthcare and other public service sectors that deal with complex, sensitive data.

Key words: information technology; electronic health records; wicked problems; Australia.

1. Introduction

Attempts by governments to procure and implement nationwide electronic health record systems (NEHRSs) – which policymakers argue are essential for improving service delivery and consumers' experiences – have instead emerged as paradigm cases of public policy failure [1-4]. NEHRS projects frequently run into trouble, as diverse groups and individuals raise concerns about privacy, security and safety, and system implementers and users encounter the sheer technical difficulty of collating and exchanging data across multiple technology platforms [5-7]. In a sector with many different stakeholders, it has proved extraordinarily difficult to design technologies that satisfy a diverse range of clinical requirements in ways that are also cost effective, standardized and patient-centric. At the same time the policymaking and project management processes which initiate such investments and are meant to ensure that they deliver in a timely and cost effective way have been found to be seriously wanting [e.g. 8, 9]. In this article we argue that a significant source of difficulty lies in the propensity of politicians and policymakers to reduce the complex problems facing healthcare to matters involving the collection and exchange of information, a reduction that begs its own ultimately problematic 'solution' in the form of NEHRSs.

We use the experience of Australia's long journey towards a NEHRS as an example of how attempts to 'streamline' healthcare through information and communication technology (ICT) can, if poorly managed, ironically exhibit the characteristics of the 'wicked problems' they were intended to solve. We begin by summarizing some salient features of wicked problems relevant

to our argument, and the attraction of ICT as an apparent 'solution' to the difficulties facing healthcare. After outlining our sources of data and methods, we use the Australian experience to illustrate the ways in which a failure to recognize the inherently wicked nature of large-scale ICT design and implementation has contributed to waste, delay and widespread dissatisfaction among intended users. We conclude by offering some suggestions for alternative approaches that may help to avoid some of the pitfalls experienced by nations that have attempted to implement large scale NEHRSs. Whilst our observations are based on the experience of healthcare ICT in one country, we believe they are relevant to other jurisdictions and to the governance and management of complex e-government projects in general.

2. The wicked problems of healthcare and the leap to NEHRSs as a 'solution'

The concept of wicked problems has its origins in a critique developed by Horst Rittel and Melvin Webber of rational 'engineering' approaches to urban and social planning [10]. The concept has proved attractive to public policy scholars and practitioners struggling to understand why so many social problems are difficult or impossible to solve, despite our capacity to devise seemingly sensible projects and programs to address them [11-13]. Rittel and Webber argue that policymakers confront two types of problems in their work – the 'tame' and the 'wicked'. Tame problems are relatively well defined and their causes are understood well enough to provide reliable suggestions for possible solutions. The information required to reach those solutions, along with procedures for doing so, are readily accessible. Those working on or interested in tame problems generally agree about problem definitions, causes and solutions. Wicked problems and their causes, on the other hand, are much more difficult to define and identify.

They emerge in complex environments in which many interacting and interdependent elements – human, social, cultural, technical and political – combine to create intractable dilemmas that can endure without resolution for decades. As the causes of wicked problems such as poverty, crime, and rising healthcare costs are multiple, unclear and contested, proposed 'solutions' often rely on a propensity to define 'the problem' in particular, circumscribed terms. For example, NEHRSs can plausibly 'solve' problems in healthcare, as long as those problems are attributed to deficiencies in the availability of and means of sharing information. Another characteristic of wicked problems is that when 'solutions' are implemented, they often have unintended consequences, thereby generating further problems of their own [10,13].

The health policy arena is of course rife with wicked problems [12,14]. Rising costs can be attributed to multiple interacting causes – ageing populations, unhealthy lifestyles, chronic diseases and co-morbidities, and inefficiencies and fragmentation in the delivery of care, to name just some. These 'causes' are themselves multidimensional with many possible 'solutions' that straddle the remit of multiple organizations and professional groups. Moreover, the health sector exemplifies the circularity and interdependence of wicked problems and solutions. Phenomena currently identified as 'problems', such as ageing populations and chronic ailments, are the consequences of earlier 'solutions' that reduced the rate of infectious disease and prolonged life. Likewise, while specialization in healthcare delivery has improved treatment, it has also led to rising costs and fragmentation in services [14]. Policymakers in many nations have initiated repeated cycles of reform, in attempts to reduce costs while improving outcomes [15,16]. As is typical of wicked problems, however, it is difficult to discern with any certainty what 'works' and what doesn't, and recurrent rounds of reform seem to be a feature of health policy in many

nations, as successive governments seek to remedy the negative consequences of previous changes [17].

Advocates of NEHRSs frequently depict healthcare as a ‘information intensive’ industry, with many of its problems attributed to deficits in data collection, storage and exchange [e.g. 18,19]. Proponents claim that NEHRSs will provide more accurate, legible and accessible information than their paper-based counterparts. Errors will be more readily detected and corrected. Tests will not have to be repeated because paper results have been lost or are stored elsewhere. At the same time, ‘clinicians will have at their fingertips all of the information needed to provide the best care' [20, p. iii] whilst people will ‘be spared the ritual of repeating their name, address, previous and recent medical history to every [provider] they have to deal with’ [21, p. 24]. Furthermore, citizens who have access to their own electronic records will become empowered ‘consumers’, more able to engage in their own care, thereby reducing their reliance on the healthcare system [22].

However, the sharing of health data on a national scale across complex organizational and other boundaries is still a novel concept and its impacts on the quality, safety and efficiency of care remain an active and contested area of debate and investigation [23,24]. As a result, policymakers seeking advice on the potential benefits of NEHRSs often rely on models and extrapolations from pilot trials which generally predict considerable savings from the implementation of the technology. For example, an Australian study claimed that the increased productivity and reduction in adverse events resulting from the introduction of a NEHRS would save the nation up to $AU7.9 billion over 10 years [25].

Given the intuitive appeal of NEHRSs as a means of taming wicked healthcare problems and the predicted savings that could follow, it is not surprising that many governments have invested in the technology. The risks associated with implementation have often been underestimated, and assumed to be detectable and controllable through popular software engineering tools. These tools frame system development as a linear process whose interface with the contexts in which the systems are supposed to work is limited to requirements gathering, and sporadic opportunities for end users to comment on evolving specifications and architectures [26,27]. Below, we illustrate some of the ways in which NEHRS projects and their contexts frustrate attempts to manage them according to these linear processes. First, however, we provide some background on the research design, data sources and methods that have informed this article.

3. **Research design, data sources and methods**

The following case is drawn from a broader retrospective and comparative study of attempts since the 1990s to build regional and national systems for sharing electronic health data in Australia and England [4,28-30]. In this article we seek to understand why attempts to implement EHRSs at a national scale so frequently run into trouble and why the lessons learnt seemingly do not inform efforts to rescue existing projects or subsequent initiatives. In order to explore these issues, we draw on a nearly two decades long series of policy initiatives and projects that aimed to develop a NEHRS in Australia. We believe the Australian example is relevant because of the longevity of the experience and the opportunities that this could be assumed to have offered policymakers to learn from past developments and mistakes. At the same time, Australia has

been independently evaluated as a leader in the development of some e-enabled public services on a national scale, for example in the taxation system, and to have accomplished this in the context of a federal government structure [31]. In healthcare such development faces particular challenges given the complexity of the funding models in a federated structure and the sometimes confused responsibilities of the commonwealth and states in relation to different aspects of care delivery [32].

Our data consist primarily of publicly available documents, supplemented with interviews with key informants involved with the two most significant NEHRS projects attempted since 2000. Documents included reports from government enquiries, ministerial and policy statements, submissions to governments by individuals and interest groups, system architectures, blog posts, position statements by professional bodies and lobby groups interested in NEHRSs, newspaper articles and articles published in specialist journals and magazines. The documents were organized for analysis using Zotero software, which enables sorting and searching of the data. A chronology of significant events was constructed, and key areas of tension and difficulty identified for further analysis.

We interviewed 13 individuals who were close to or personally involved in NEHRS development in Australia. Some of these informants held high ranking positions in the organizations tasked with design and implementation. Interviews were used to clarify details about the processes that were undertaken, and to provide feedback on our developing ideas. Subjects were also invited to reflect on the overall trajectories of the projects – what, in their view, had worked reasonably well, and what could have been done differently.

Our overall methodological approach involved ‘heuristic’ as opposed to statistical generalization and was aimed at ‘refining our analytical understanding’ of the phenomena of interest. Such generalization emerges from a dialogue between theoretical perspectives and empirical data, with ‘the empirical as a precondition for the development of the theoretical, and the theoretical as an indispensable tool for the exploration of the empirical’ [33, p. 295, see also 34]. From the broad range of perspectives and theoretical frameworks available to us as a research team – which is comprised of academics and practitioners with backgrounds in medicine, health informatics, management and the social sciences – the concept of wicked problems seemed to hold promise as a conceptual focus that could help explain the difficulties that have been encountered during attempts to build NEHRSs in Australia and elsewhere. Developing ideas were circulated among the team to produce the narrative and argument below.

4. **Becoming the ‘wicked problem’ instead of solving it - NEHRSs in Australia.**

According to Head [13, p. 103], wicked problems are characterized by (a) a complexity of elements, subsystems and interdependencies; (b) uncertainty in relation to risks, consequences of actions, and changing patterns of funding, priorities and expectations; and (c) a divergence in viewpoints and values. We now show how attempts to design and implement a NEHRS in Australia exhibit many of these features. In our view, the dissatisfaction expressed by providers and recipients of care regarding what they see as suboptimal outcomes from these attempts can be attributed to a failure on the part of policymakers and project managers to adequately recognize and address these wickedly problematic aspects of NEHRS projects.

We suggest that there are three aspects to this failure that help explain the disappointing results of investments in two large-scale NEHRS initiatives – a project called Health*Connect* which was abandoned after an estimated expenditure of $AU5 billion [35][1] and a second attempt which, three years after being launched in 2012, was used by only a small proportion of citizens and care providers [36]. First, politicians and policymakers failed to recognize the complexity and risk inherent in NEHRS projects, succumbing instead to a 'dangerous enthusiasm' for electronic 'solutions' to the problems facing healthcare. This first failure generated a second shortcoming, namely, the use of conventional project management approaches which, although effective for 'tame' situations, are highly challenged in multi-stakeholder environments and projects with porous boundaries [37]. Finally, there was an unwillingness to learn from these failed approaches. Divergent priorities and values were not viewed as integral aspects of the projects, presenting opportunities for productive negotiation and development, but rather as troublesome 'barriers' to be ignored or overcome.

4.1 Failure to recognize and understand complexity

The history of NEHRSs in Australia is peppered with policy statements that exhibit enthusiastic support for the technology These can be found in the earliest pronouncements, for example a joint ministerial statement in 1992 that called for a 'health communications network' that would provide 'more efficient, effective and continuous patient care across health sector boundaries'

[1] The Department of Health has removed the Health*Connect* documents from its website. However, they can be accessed by entering http://www.health.gov.au/internet/hconnect/publishing.nsf/Content/home into the Internet Archive Wayback Machine at web.archive.org

[38] through to recent times, when the Federal Health Minister claimed that a 'rebooted personalised My Health Record' would give 'instant access to the information needed to treat patients safely and efficiently without having to gamble on unknowns in their medical history' [39]. (See Table 1 for a chronology of key events).

In the late 1990s, such sentiments legitimized public investments in Australia's first attempt to build a NEHRS [40]. This system, called Health*Connect*, would provide a 'health information network' for all Australians by 2010 [41]. The initial plan was to spend two years on research, development and pilot trials, followed by an incremental rollout that would update and connect existing ICT systems. The plan was abruptly disrupted in 2004 when, even before the pilot trials had ended, Federal Health Minister (and later Prime Minister) Tony Abbott announced that rollouts of Health*Connect* would soon commence.

This unexpected announcement reportedly 'stunned stakeholders' as system architectures, standards and governance arrangements were far from complete [42]. Abbott was apparently frustrated by the slow pace of ICT in health, comparing it to the finance sector which was making rapid progress in developing e-commerce. If financial institutions could connect electronically, he claimed, the health sector's failure to do so must be due to incompetence and outdated attitudes [43]. A senior figure in the Health*Connect* project team told us in interview that Abbott and 'some of the State ministers … completely misunderstood how hard and complicated it would be'. For them 'it's just a matter of building a great big computer'.

When Abbott tried to expedite the roll out, preparations for implementation revealed the complexity of the task at hand. The legal firm Clayton Utz was contracted to examine the medico-legal issues associated with the system. One of the firm's partners summarized the situation neatly in a newspaper report:

> There's a whole bunch of questions. How do you determine liability in a shared record? How do you determine the extent of the consent given? Who owns the information? How do you authorise documents that currently require a signature? What are the security requirements? It's vast [44].

There were also tensions among the federal, State and territory jurisdictions regarding the roll out. Responsibilities for healthcare in Australia are split among these jurisdictions, as well as private and community sector organizations. Most notably for the development of a NEHRS in Australia, primary care is funded largely through a national insurance scheme, while state and territory governments are responsible for the management of public hospitals, including their ICT systems [32]. Building a NEHRS thus requires cooperation among jurisdictions and their advisory bodies, as well as Standards Australia, the medical software industry and potential users. Health*Connect* was administered out of a federal department, and encountered problems, even 'deep mistrust' according to some [45, p. 7], in its relationships with state health departments. According to one of our interview informants, a senior health administrator who has been involved in multiple state and federal ICT projects, a lack of involvement by the states was 'the main reason' that Health*Connect* failed: 'the states didn't understand it, didn't buy in, didn't invest, didn't support'. Another of our informants told us that although the states 'were all sold on the concept', the project still 'caused them considerable anxiety'. By the middle of 2005,

in the face of such realities Health*Connect* was downgraded by the federal government from a ‘national health information network’ to a ‘change management strategy’ [46].

In 2009, enthusiasm for digital solutions to problems in healthcare were rekindled, this time in the context of a sweeping reform initiative instituted by the Rudd Labor government. According to the expert body convened to drive this reform,

> The introduction of a person-controlled electronic health record for each Australian is one of the most important systemic opportunities to improve the quality and safety of health care, reduce waste and inefficiency, and improve continuity and health outcomes for patients [25, p. 8].

In the following year, federal funds of $AU467 million were allocated to build a nation-wide person-controlled electronic health record (PCEHR). Federal health minister Nicola Roxon adopted the reform commission’s recommendation to set ‘a definite start date’ of July 2012 for the system as this would help to end the protracted ‘talkfest’ which, in its view, had inhibited progress to date [25, p. 131].

Again policymakers, this time with the help of a National e-Health Transition Authority (NEHTA), rushed towards a ‘solution’. Soon after the funding announcement, NEHTA and the Department of Health and Ageing drafted a *Concept of Operations* document that outlined how the PCEHR would work. The system would be organized around a ‘shared health summary’ that could be supplemented with additional clinical documents and patients’ own private notes. Although the shared health summary would be curated by ‘nominated

providers' it would be 'owned' and controlled by citizens, who could choose to withhold information if they wished. It would be a parallel system, that is, doctors would be required to keep their own records as well. Significantly, participation was to be optional for both providers and healthcare recipients [47].

Equally significant was the target date set by Federal health minister Nicola Roxon for the system to go 'on-line'. This was to be 1 July 2012, a date she insisted upon in the face of persistent claims that the system and its associated standards and governance arrangements would not be ready by then [48, 49]. Inevitably, the system that 'went live' in July 2012 was indeed very basic. Citizens could register an interest in obtaining a PCEHR on www.ehealthinfo.gov.au, but the creation of records was delayed until GP software was rolled out later in the year [50]. By February 2013, seven months after the launch, fewer than one percent of the nation's healthcare providers were registered to access the PCEHR [51]. In the first year, only 2.7 percent of a population of around 22 million people had registered for a PCEHR, and 4,585 shared health summaries had been uploaded [52]. There were reports of faulty data appearing in people's records [53] and patient information being 'garbled and confused' when presented to doctors [54]. When it appeared that the government would miss its target of 500,000 patient registrations in the first year, 'sign up squads' were sent into hospitals and nursing homes [55]. The pursuit of what were perceived by clinicians in particular as superficial measures of progress such as the number of citizen registrations, bred further cynicism and disengagement, as they failed to acknowledge deeper systemic problems [56]. Although government agencies declared the PCEHR a 'success' [57], several of NEHTA's key clinical advisors resigned 'in frustration' as their concerns went unheeded. Their leader later described the PCEHR as 'shambolic' [56].

4.2 The weaknesses of a conventional approach to managing uncertainty and risk

Both of Australia's significant NEHRS projects used what could be described as conventional approaches to system design. That is, they were guided by an assumption that user requirements could be 'captured' early in the design process and inscribed into abstract plans and architectures. Uncertainties and risks could be managed by consulting stakeholders, devising appropriate governance arrangements and educating potential users [58]. The Health*Connect* project team followed what it saw as 'best practice' in public sector ICT system design at the time – a 'Federal Enterprise Architecture Framework' that was developed in the Unites States [59]. Within this framework, entities and processes were conceptualized in idealized terms, 'independent of any system or implementation considerations and organizational constraints' [26, p. 53]. The Health*Connect* architecture defined the functions of the system, such as registration, identification and authentication of users, collection, storage and exchange of data.

The first version was produced by bureaucrats in the Department of Health and Ageing, none of hom had expertise in the day-to-day delivery of care in the public or private sector. The draft was reviewed by a specially convened working group comprised of clinicians, health bureaucrats, academics, a consumer representative and health informaticians. This group's task was to 'socialize' it (interview, policy advisor) and 'get it to a point where it is acceptable for public consumption' (interview, health informatician and member of architecture working group). The working party was disbanded after giving its advice and took no further part in architecture development. According to a person who was involved in Health*Connect* in an advisory

capacity, ‘the business architecture was being run by people who did not understand the business of health care delivery’.

Many of the stakeholders who were consulted on the architecture iterations, including doctors, nurses and consumer representatives, found it difficult to engage with an abstract document that deliberately eschewed any consideration of the contexts in which healthcare encounters took place. During one consultation session, a ‘response form’ was handed out that included the question ‘Is the proposed structure for Health*Connect* appropriate? According to a consultant’s report that analyzed the feedback, ‘The views of several respondents are summarized by the words of one: “The information is so general that no useful comment can be made”’ [60, p. 25]. Healthcare provider organizations called on the Health*Connect* team to pay more attention to the contextual richness and variability of their working environments, and to build on and support, rather than replace, their existing technologies and routines [61-63]. The General Practice Computing Group pointed out that

> General practice is a ‘people service’ and as such successful implementation will require consideration of human factors: how do general practitioners enter data currently, what is the attitude of the general practitioner to workflow issues, how do general practitioners want to receive radiology and pathology (i.e. as a summary or the full report) etc. [63, p. 9].

Such calls were overtaken by events as outlined above and the project was scaled back before ‘human factors’ could be given their due consideration.

Many of the problems that plagued Health*Connect* stem from an assumption that the system could be centrally planned by bureaucrats, and sporadic consultation with potential users would help refine the details. Post-implementation 'change management' and 'benefits realization' would ensure ready adoption [64,65]. Instead, the technology-driven approach to managing the project was overwhelmed by the complexity presented by the diversity of interests and expectations of doctors, nurses, administrators and recipients of care, the concerns of privacy and consumer advocates, the capacities of ICT vendors and legacy systems already in place, the availability of funds, the priorities of federal and state jurisdictions, medico-legal uncertainties, and patchy and inconsistent privacy laws [66]. Amidst this tangle of interacting elements were some enduring tensions, a prime example being a conflict between those who seek to enhance the widespread availability of individual health information, and those who see such availability as a threat to privacy.

4.3 Inability to reach compromise and learn from divergent viewpoints and values

The abstract and rigid Health*Connect* architectures did not facilitate the sort of productive engagement that would enable workable compromises among stakeholders with different priorities and preferences to be negotiated. Nevertheless, when interest in a NEHRS re-emerged several years after Health*Connect*'s demise, policymakers once again issued a predesigned blueprint for the system's operations, this time in the guise of a *Concept of Operations* document. Given the short time frame (less than 18 months) consultation was swift and changes in response to feedback were minimal. As the push towards

implementation intensified, risks, uncertainties and differences of opinion came ever more forcefully to the surface. One of the most enduring conflicts affecting the revised attempt to develop a NEHRS in Australia has revolved around the desirability and consequences of 'personal control', that is, the capacity of citizens to selectively withhold information from the electronic record that appears in the national system.

Doctors, as represented by the Australian Medical Association (AMA) and the Royal Australian College of General Practitioners (RACGP) have consistently argued that the clinical utility and therefore professional uptake of a NEHRS depends on the reliable availability of 'core clinical data' such as current medications, allergies, adverse events and recent diagnostic results [e, g, 67, 68]. The capacity of 'personal control' to render the data incomplete would, according to the AMA 'de-medicalize' the system [69]. In its view, a 'disproportionate emphasis given to the concerns of an extreme minority who wish to mask details of their health record' would lead to a system that was hampered by 'unacceptable complexities' [70, p. 2].

The Consumers Health Forum (CHF) on the other hand, has consistently lobbied for citizen control over the contents of, and access to, their records. According to CHF CEO Carol Bennet, 'Consumers won't engage if there is an attitude that comes from the dark ages that doctor knows best' [quoted in 71]. When the AMA refused to back down, the CHF 'slammed' the association for a perceived 'refusal to accept that the world has moved on from the "secret doctors' business" of paper-based records that patients rarely see' [72]. The Australian Privacy Foundation (APF) also favoured personal control but argued that because the documents in the PCEHR were accessible to the government bureaucrats who administer the system, the 'personal control' features trumpeted by its supporters were largely illusory.

According to the APF, the data consolidation enabled by a NEHRS was 'inherently risky' because it created a 'honey pot' of personal information that would attract those who sought to access private information for ulterior purposes. In its view, while ICT can help improve care, the focus should be on facilitating a federated infrastructure that would allow providers to communicate with each other on an as-needed basis without a centralized repository of data [73].

During the federal election year of 2013, the opposition conservative parties exploited the PCEHR's difficulties, claiming that the '$1 billion e-health debacle … speaks volumes about Labor's incompetence' [74]. Critics claimed that the PCEHR was difficult to use, contained mistakes, had little clinical utility and was not accessible in most hospitals [56]. After being elected, the new conservative coalition initiated a review of the system [75].

Some of the submissions to the review were highly critical. For example, the RACGP claimed that:

> The development program has been driven politically and by a desire for volume rather than high-quality, useful clinical information. The clinical community has not been effectively engaged in product development, especially with the current release program. This has resulted in a system that fails to meet clinical requirements, is not acceptable nor sustainable [76, p. 3].

The review panel identified 14 'key and repeating concerns' in the feedback [75, p. 14-15]. The most frequently raised of these was:

> The divide between clinicians who are concerned with data accuracy under a patient controlled model and consumers and others who identify the personally controlled nature of the electronic record as fundamental.

Despite widespread criticisms, the panel recommended that 'it is worth the effort to find a way through the many challenges, conflicting requirements and varying but valid opinions to continue with the build of this important national asset' [75, p. 4]. It noted, however, that the 'value proposition for users' would need to be improved through better design, switching to an opt-out model and facilitating the inclusion of pathology results and diagnostic images, neither of which was available due to arguments over the timing and authorization of uploads [75, 77]. The panel also proposed a name change, and a reconfiguration of governance arrangements. Under an opt-out model, all citizens would receive a MyHR unless they took steps to be excluded. The personal control feature should be retained, but there should be a 'flag' added to 'hidden' data that would allow the 'clinical author' of the data to discuss the impact of such 'control' with the relevant patient [75, p. 17].

Doctors' groups and the CHF welcomed the shift to opt-out, though doctors remained cautious. The RACGP supported the 'further development' of the PCEHR, but noted that there was 'ongoing confusion' about its purpose [78, p. 3]. The AMA also expressed support for 'a properly built and governed PCEHR system' and continued to lobby for the removal of personal control over key health details [79, pp 1-2]. Privacy advocates, on the other hand, opposed the move [80]. A parliamentary committee on human rights argued that the reasons for shifting to opt-out were not 'pressing and substantial enough' to warrant limiting citizens' right to privacy

[81]. The dissenting voices were overruled, however. Legislation to enable changes to the PCEHR was passed in 2015 and trials of an opt-out system are scheduled for 2016 [82].

5. **Managing wickedly problematic projects**

Given the waste and frustration that typically attend large scale health ICT projects it is important to continue searching for 'better' ways of managing them. When it comes to wicked problems, however, it would be foolish to offer a step-wise process or model as a route to 'success' as such techniques are designed for situations that are tame. Nevertheless, Head's criteria above are not only useful for highlighting the shortcomings of the Australian approach but also for exploring ways in which some of the problematic aspects of wicked ICT projects might be rendered more tractable.

First, given the complexity of interdependent elements, the diversity of viewpoints and the uncertain risks and consequences, developing 'solutions' in the form of documents such as the Heath*Connect* architectures and later the PCEHR *Concepts of Operations* is counterproductive. Moreover, in the Australian case, these solutions were developed by bureaucrats and ICT specialists, not by people with a deep understanding of the ways in which information is created and used in healthcare. Feedback was sought from people with such knowledge, but within the context of the already-existing blueprints. Furthermore, these blueprints were too abstract and generic to enable the identification and management of the many diverse and interlocking subsystems that would have to be mutually adjusted to support each other, such as work routines, legacy systems, funding streams and regulatory practices. By launching the projects with grand

overarching designs, the Department of Health and Ageing and its advisory bodies closed off any possibilities for alternative approaches such as, for example, an incremental provider-led process that explored different ways that ICT could be used to improve information flows across the healthcare sector. Any alternative mode of proceeding would of course also have to cope with a complexity of interconnecting elements, uncertainties and diverse viewpoints. However, there is evidence that these challenges can to some extent be managed at local and regional scales. Face-to-face collaboration enabled data sharing to occur during the Health*Connect* regional pilot trials [83], and international experience shows that high levels of clinical engagement in the development of digital networks that build on existing tacit and/or explicit consent arrangements which allow data sharing in the interests of care, can prove acceptable and useful. Examples of such systems can be found in Denmark, New Zealand and the Netherlands, nations that are frequently acknowledged as leaders in health ICT development and use ([84-86]. It is significant, however, that none of these nations has succeeded in building the sort of nationally accessible and static repositories of individual health data that have been so attractive to policymakers in Australia. Attempts to build such systems have run into familiar difficulties – concerns about privacy, consent, data quality and clinical utility. Instead, where success has been achieved, it has been in the timely exchange of relevant health data for particular circumstances, rather than the compilation of static repositories [6, 87, 88]. As we have seen, the latter raise thorny issues of information ownership, liability and responsibility for data quality, aspects of NEHRSs that have proved particularly intractable.

Building workable regional health ICT systems through close collaboration among providers, patients, developers and regulators, and then federating them into larger networks, may provide a

means of escaping the worst pitfalls of large-scale pre-designed NEHRS implementations. However, given the wicked nature of the problems they confront, any system is likely to be a temporary settlement carved out of ongoing debates and uncertainty. Perhaps the most deeply problematic aspect of healthcare ICT, especially when it comes to large scale systems accessible to and/or managed by governments, concerns the privacy of citizens whose information they contain. One reason that privacy is so contentious is that it is rooted in paradox. The properties of ICT that make it so attractive to citizens and policymakers also render it risky and threatening. As Tsoukas has succinctly noted, 'The information society spawns paradoxes that prevent it from satisfying the temptations it creates' [89, p. 828].

The possibilities of widespread easy access to health information that tempt the proponents of NEHRS are frustrated by a mirror image of intrusive surveillance and an irretrievable loss of privacy. Callen and Austin suggest that digital technologies such as NEHRS test the limits of a modernist world view that is based on ‘assumptions of essentially linear, teleological lines of progress, ontological stability, epistemological certainty, and the promise of enlightened human agency’ [90, p. 21]. Such assumptions hold reasonably well when dealing with tame problems but have little purchase on the wickeder aspects of digital technologies, such as those concerning privacy. In relation to the issue of privacy in the digital age Callen and Austin claim that ‘neither retreat [to a pre-digital age] nor regulation is possible’. Instead, we are being forced to consider ‘in what form or even *whether* [privacy] can exist in ways we recognize’ [90, p. 33]. Current debates and tensions around privacy, purpose and risk in relation to NEHRSs are manifestations of a struggle to come to terms with the implications of a technology that offers so many possibilities, while generating new risks, challenges and uncertainties.

6. Conclusion

The story of NEHRSs in Australia is far from over and new enthusiasms for the use of ‘big’ and ‘open’ data to drive innovation in the healthcare sector suggest that the digital health record is a thin end of a much larger digitalization ‘wedge’. It remains to be seen whether the proposed shift to an opt-out model and financial incentives for use by GPs [91] will help to evolve the Australian MyHR system into a more useful tool that is valued by those delivering and receiving healthcare. Regardless of what happens in the future, we now have 15 years of experience of attempts to build a workable NEHRS. It is timely to reflect on the consequences of the decisions that have been made and the processes that have been undertaken, in order to ascertain what might be learned about the development and implementation of ICT in the healthcare sector. Examining major policy ‘blunders’ in the UK, including the ill-fated attempt to introduce NEHRS in the English NHS, King and Crewe suggest that the inherent complexity of these often ‘hyper-ambitious’ endeavours is beyond the competence of the politicians who initiate them and the civil servants who advise them. Moreover, the projects typically progress in the absence of appropriate means of tracking progress and allocating accountability, with the consequence that the scale and gravity of the ‘blunder’ usually emerges slowly and only after most of the damage has been done [9, loc]. As they go on to suggest, one set of lessons revolves around getting the ‘right people in the room’ when decisions to initiate large-scale projects are made and seeking ways to ensure that an ‘operational disconnect’ does not emerge between the realities of the problems facing healthcare and what might assist in tackling them, and the ‘magical’ properties all too often associated with ICT by politicians [9. loc. 4916-4946].

Acknowledgements: This work was assisted by an Australian Research Council Discovery Grant titled **'***Generating Insights for the Future: A Retrospective, Comparative Study of Attempts to Implement Large Scale Electronic Health Record Systems***'** (DP 10100084). We are also indebted to the people who agreed to be interviewed.

References

[1] Dunleavy P, Margetts H, Bastow S, Tinkler J. Digital era governance: IT corporations, the state, and e-government. Oxford University Press; 2006.

[2] Gauld R, Goldfinch S. Dangerous Enthusiasms: E-Government, Computer Failure and Information Systems Development. New Zealand: University of Otago Press; 2006.

[3] McLoughlin I, Wilson RG. Digital Government at Work: A Social Informatics Perspective. Oxford: Oxford University Press; 2013.

[4] McLoughlin I, Garrety K, Wilson R. The Digitalization of Health Care: Electronic Health records and the Disruption of Moral Orders. Oxford University Press; Forthcoming.

[5] Stafford N. Germany set to introduce electronic patient cards despite doctors' opposition. British Medical Journal. 2008; 336:689. doi: http://dx.doi.org.ezproxy.uow.edu.au/10.1136

[6] Zwaanswijk M, Ploem MC, Wiesman FJ, Verheij RA, Friele RD, Gevers JK. Understanding health care providers' reluctance to adopt a national electronic patient record: an empirical and legal analysis. Medicine and Law. 2013;32(1):13–31.

[7] Currie WL. Health IT Policy in the UK: The Case of Electronic Health Records. In: Michell V, Rosenorn-Lanng D, Gulliver S, Currie W, editors. Handbook of Research on Patient Safety and Quality Care Through Health Informatics. Hershey, PA: IGI Global; 2013. p. 363–81.

[8] Bacon R, Hope C. Conundrum: Why Every Government Gets Things Wrong - And What We Can Do About It. London: Biteback Publishing; 2013.

[9] King A, Crewe I. The blunders of our governments. London: Oneworld Publications; 2014.

[10] Rittel HW, Webber MM. Dilemmas in a general theory of planning. Policy sciences. 1973;4(2):155–69.

[11] Australian Public Service Commission. Tackling Wicked Problems: A Public Policy Perspective. Canberra: Commonwealth of Australia; 2007.

[12] Ferlie E, Fitzgerald L, McGivern G, Dopson S, Bennett C. Making Wicked Problems Governable?: The Case of Managed Networks in Health Care. Oxford University Press; 2013.

[13] Head BW. Wicked problems in public policy. Public Policy. 2008;3(2):101–18.

[14] Shaw SE, Rosen R. Fragmentation: a wicked problem with an integrated solution? Journal of health services research & policy. 2013;18(1):61–4. DOI: 10.1258/jhsrp.2012.012002

[15] Flood C. International health care reform: a legal, economic and political analysis. London: Routledge; 2000.

[16] Twaddle AC, editor. Health care reform around the world. Westport, Connecticut; 2002.

[17] Paton C. Garbage-can Policy-making Meets Neo-liberal Ideology: Twenty Five Years of Redundant Reform of the English National Health Service. Social Policy & Administration. 2014;48(3):319–42. DOI: 10.1111/spol.12044

[18] Canada Health Infoway. Electronic Health Records: Canada's next generation of healthcare at a glance [Internet]. 2006. Available from: https://www2.infoway-inforoute.ca/Documents/Vision_Summary_EN.pdf

[19] Commission of the European Communities. e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area [Internet]. Brussels; 2004. Available from: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2004:0356:FIN:EN:PDF

[20] Department of Health and Human Services (HHS). Using the Power of Information Technology to Transform Health and Care [Internet]. 2008. Available from: http://www.healthit.gov/sites/default/files/hit-strategic-plan-summary-508-2.pdf

[21] Burns F. Information for health: an information strategy for the modern NHS 1998-2005 [Internet]. London: NHS Executive; 1998.

[22] Ball MJ, Carla Smith N, Bakalar RS. Personal health records: empowering consumers. Journal of Healthcare Information Management. 2007;21(1):77–86.

[23] Brenner SK, Kaushal R, Grinspan Z, Joyce C, Kim I, Allard RJ, et al. Effects of health information technology on patient outcomes: a systematic review. Journal of the

American Medical Informatics Association [Internet]. 2015 [cited 2016 Jan 8]; Available from: http://jamia.oxfordjournals.org/cgi/doi/10.1093/jamia/ocv138

[24] RAND Corporation. Health Information Technology: An Updated Systematic Review with a Focus on Meaningful Use Functionalities [Internet]. Santa Monica, CA; 2014. Available from: http://www.healthit.gov/sites/default/files/systematic_review_final_report_508_compliant.pdf

[25] National Health and Hospitals Reform Commission. A Healthier Future for all Australians: Final Report [Internet]. Canberra: Australian Government; 2009 Jun [cited 2011 Mar 15]. Available from: http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report

[26] HealthConnect. HealthConnect Business Architecture version 1.0. Canberra: Commonwealth of Australia; 2003.

[27] National Audit Office. National Programme for IT in the NHS. London: Stationery Office; 2006

[28] Garrety K, Dalley A, McLoughlin I, Wilson R, Yu P. Managing collaboration across boundaries in health information technology projects. In: Maeder AJ, Martin-Sanchez FJ, editors. Health Informatics: Building a Healthcare Future Through Trusted Information. Amsterdam: Ios PressInc; 2012. p. 58–63.

[29] Garrety K, McLoughlin I, Wilson R, Zelle G, Martin M. National electronic health records and the digital disruption of moral orders. Social Science & Medicine. 2013;101(0):70–7.DOI: 10.1016/j.socscimed.2013.11.029

[30] Garrety K, McLoughlin I, Zelle G. Disruptive Innovation in Health Care: Business Models, Moral Orders and Electronic Records. Social Policy and Society. 2014 Oct;13(4):579–92.DOI: 10.1017/S1474746413000560

[31] Dunleavy P, Margetts H, Bastow S, Tinkler J. Australian e-Government in comparative perspective. Australian Journal of Political Science. 2008;43(1):13–26. DOI: 10.1080/10361140701842540

[32] Dugdale P, Healy J. The Australian Health Care System, 2014. In: International Profiles of Health Care Systems. Washington DC: The Commonwealth Fund; 2015. p. 11–20.

[33] Tsoukas H. Craving for generality and small-N studies: a Wittgensteinian approach towards the epistemology of the particular in organization and management studies. In: Buchanan DA, Bryman A, editors. The SAGE handbook of organizational research methods. Los Angeles, London: Sage; 2009. p. 285–301.

[34] Greenhalgh T, Russell J, Ashcroft R, Parsons W. Why National eHealth Programs Need Dead Philosophers: Wittgensteinian Reflections on Policymakers' Reluctance to Learn from History. Milbank Quarterly. 2011;89(4):533–63.DOI: 10.1111/j.1468-0009.2011.00642.x

[35] LeMay R. E-Health: Australia's $5bn black hole. ZDNet Australia [Internet]. 2008 Dec 15 [cited 2010 Jun 24]; Available from: http://www.zdnet.com.au/e-health-australia-s-5bn-black-hole-339293816.htm

[36] Pearce R. 2.5m Australians sign up for eHealth records. Computerworld [Internet]. 2015 Oct 27 [cited 2016 Jan 8]; Available from: http://www.computerworld.com.au/article/587547/2-5m-australians-sign-up-ehealth-records/

[37] Flyvbjerg B, Bruzelius N, Rothengatter W. Megaprojects and risk: An anatomy of ambition. Cambridge University Press; 2003.

[38] Australian Health Ministers' Conference Working Party. A National Health Information Systems and Technology Strategy. Canberra: Australian Health Ministers' Advisory Council; 1992.

[39] Ley S. Media release: Patients to get new myHealth Record [Internet]. 2015 [cited 2015 Jun 7]. Available from: http://www.health.gov.au/internet/ministers/publishing.nsf/Content/DCF48150452A3F8FCA257E4100088F92/$File/SL050.pdf

[40] National Electronic Health Records Taskforce. A Health Information Network for Australia. Canberra: Commonwealth of Australia; 2000.

[41] Brook S. Health data on network. The Australian. 2000 Jul 28;

[42] Dearne K. Abbott forces pace on e-health. The Australian. 2004 Mar 16;

[43] King A. Abbott Puts His Foot down on EHR Delivery. The Age [Internet]. 2005 Sep 30 [cited 2008 Sep 17]; Available from: http://www.theage.com.au/articles/2005/10/03/1128191644067.html

[44] Richards D. Your life history, online. Sydney Morning Herald [Internet]. 2005 Jun 16 [cited 2010 Apr 29]; Available from: http://www.smh.com.au/news/Health/Your-life-history-online/2005/06/16/1118869018806.html?from=moreStories

[45] Boston Consulting Group. NEHTA Review [Internet]. 2007 Oct [cited 2009 Jun 22]. Available from: http://www.docstoc.com/docs/69750313/NEHTA-Reviewhttp://www.docstoc.com/docs/69750313/NEHTA-Review

[46] Dearne K. A simple message from hospital to GP will launch a new era in e-health. The Australian. 2005 Oct 11;

[47] Department of Health and Ageing. Draft Concept of Operations: Relating to the introduction of a personally controlled electronic health record (PCEHR) system. Canberra: Australian Government; 2011 Apr.

[48] Coiera E, Kidd M, Haikerwal M. A call for national e-health clinical safety governance. Medical Journal of Australia. 2012 Apr 16;196(7):430–1. DOI: 10.5694/mja12.1047

[49] Senate Community Affairs Legislation Committee. Report of the Senate Inquiry into Personally Controlled Electronic Health Records Bill 2011 [Provisions] Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011 [Provisions] [Internet]. Canberra: Commonwealth of Australia; 2012 Mar. Available from: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/pers_cont_elect_health_rec_11/index.htm

[50] Foo F. More bumps in e-health road. Australian IT [Internet]. 2012 Nov 27 [cited 2013 Jan 7]; Available from: http://www.theaustralian.com.au/australian-it/government/more-bumps-in-e-health-road/story-fn4htb9o-1226524459540

[51] Dunlevy S. Doctors shun e-health records scheme [Internet]. news.com.au. 2013 [cited 2013 Feb 28]. Available from: http://www.news.com.au/national-news/doctors-shun-e-health-records-scheme/story-fncynjr2-1226578254203

[52] National e-Health Transition Authority. NEHTA Scorecard August 2013 [Internet]. 2013. Available from: http://www.nehta.gov.au/component/docman/doc_download/1777-nehta-scorecard-august-2013?Itemid=

[53] McDonald K. PCEHR exposes more examples of PBS errors. Pulse+IT [Internet]. 2013 Aug 26 [cited 2013 Dec 4]; Available from: http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=1565:pcehr-exposes-more-examples-of-pbs-errors&catid=16:australian-ehealth&Itemid=327

[54] Bracey A. “Garbled and confused”: trust in e-health dives. Medical Observer [Internet]. 2014 Feb 18 [cited 2014 May 27]; Available from: http://www.medicalobserver.com.au/news/garbled-and-confused-trust-in-ehealth-dives

[55] Dunlevy S. Outrage as eHealth record sign-up squads hit Australian hospital patients in bid to boost numbers. Herald Sun [Internet]. 2013 Apr 14 [cited 2013 Jul 22]; Available from: http://www.heraldsun.com.au/news/national/outrage-as-ehealth-record-sign-up-

squads-hit-australian-hospital-patients-in-bid-to-boost-numbers/story-fncynkc6-1226619874616

[56] Dunlevy S. $1 billion e-health system rejected by doctors as “shambolic” [Internet]. News.com.au. 2013 [cited 2013 Oct 2]. Available from: http://www.news.com.au/lifestyle/health/billion-ehealth-system-rejected-by-doctors-as-8216shambolic8217/story-fneuz9ev-1226722256752

[57] Heath J. More money for eHealth scheme. 2013 Jul 18 [cited 2013 Oct 1]; Available from: http://www.afr.com/p/australia2-0/more_money_for_ehealth_scheme_51OBlYOalDkyQQhdLaxlFJ

[58] Stewart J, Williams R. The wrong trousers? Beyond the design fallacy: Social learning and the user. In: Howcroft D, Trauth EM, editors. Handbook of critical information systems research: theory and application. Edward Elgar Publishing; 2005. p. 195–221.

[59] Chief Information Officers Council. Federal Enterprise Architecture Framework Version 1.1 [Internet]. 1999. Available from: http://www.enterprise-architecture.info/Images/Documents/Federal%20EA%20Framework.pdf

[60] DH4 Pty Ltd. Public Consultation on Development of Systems Architecture. Report on Analysis of Responses. Version 2.0. 2004.

[61] Australian Nursing Federation. Draft HealthConnect Business Architecture Consultation Submission #31. 2002.

[62] Royal College of Nursing Australia. Submission re Draft HealthConnect Business Architecture. 2002

[63] General Practice Computing Group. Submission to HealthConnect Business Architecture 1.9 2005

[64] HealthConnect. Implementation Strategy. Canberra: Commonwealth of Australia; 2003.

[65] Fujitsu Consulting, Australian Department of Health and Ageing. The HealthConnect Benefits Realisation Framework V1.0. Canberra: Commonwealth of Australia; 2004

[66] Paterson M. HealthConnect and privacy: A policy conundrum. Journal of Law and Medicine. 2004;12(1):80–91.

[67] Australian Medical Association. AMA submission: PCEHR/HI Legislation Discussion Paper [Internet]. 2015 [cited 2016 Mar 30]. Available from: https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/consultation-submissions/$FILE/105%20-%20AMA.PDF

[68] Royal Australian College of General Practitioners. Position Statement: GP e-health summary [Internet]. 2011 [cited 2011 Mar 14]. Available from: http://www.medicalnewstoday.com/articles/215669.php

[69] Australian Medical Association. Media release: Medical advice missing from e-health records plan [Internet]. 2011 [cited 2011 Sep 27]. Available from: http://ama.com.au/node/7163

[70] Australian Medical Association. AMA submission to the Department of Health and Ageing on the Draft Concept of Operations Relating to the introduction of a Personally Controlled Electronic Health Record System [Internet]. 2011 [cited 2011 Jun 15]. Available from: http://ama.com.au/node/6777

[71] Dunlevy S. AMA attacks e-health record plan. The Australian [Internet]. 2010 Dec 1 [cited 2011 Feb 7]; Available from: http://www.theaustralian.com.au/national-affairs/ama-attacks-e-health-record-plan/story-fn59niix-1225963522922

[72] Foo F. Forum slams doctor PCEHR e-health record control. The Australian [Internet]. 2013 Nov 27 [cited 2014 Jan 23]; Available from: http://www.theaustralian.com.au/technology/forum-slams-doctor-pcehr-e-health-record-control/story-e6frgakx-1226769779430

[73] Australian Privacy Foundation. APF feedback about the exposure draft PCEHR Bill 2011 (PCEHR Draft Bill) and exposure draft PCEHR (Consequential Amendments) Bill 2011 [Internet]. 2011 [cited 2012 Mar 10]. Available from: https://www.privacy.org.au/Papers/DoHA-PCEHRBills-111027.pdf

[74] Dutton P. Media release: Labor's $1 billion E-Health Debacle [Internet]. 2013 [cited 2013 Oct 1]. Available from: http://www.peterdutton.com.au/MediaHub/MediaReleases/tabid/75/articleType/ArticleView/articleId/403/Labors-1-billion-E-Health-Debacle.aspx

[75] Royle R, Hambleton S, Walduck A. Review of the PCEHR [Internet]. 2013 [cited 2014 May 29]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/46FEA5D1ED0660F2CA257CE40017FF7B/$File/FINAL-Review-of-PCEHR-December-2013.pdf.

[76] Royal Australian College of General Practitioners. RACGP Submission: Review of the Personally Controlled Electronic Health Record (PCEHR) [Internet]. 2013 [cited 2013 Dec 4]. Available from: http://www.pulseitmagazine.com.au/images/stories/pulse/pcehr/racgp.pdf

[77] McDonald K. DoH aims for pathology and imaging on PCEHR by December. Pulse+IT [Internet]. 2014 Jul 21 [cited 2014 Aug 12]; Available from: http://www.pulseitmagazine.com.au/australian-ehealth/1978-doh-aims-for-pathology-and-imaging-on-pcehr-by-december

[78] RACGP. Submission to the Department of Health on the Electronic Health Records and Healthcare Identifiers Legislation Discussion Paper [Internet]. 2015 [cited 2015 Jul 9]. Available from: http://www.racgp.org.au/download/Documents/Reports/RACGP-Submission-to-the-Department-of-Health-on-the-Electronic-Health-Records-and-Healthcare-Identifiers-Legislation-Discussion-Paper.pdf

[79] Australian Medical Association. AMA submission: PCEHR/HI Legislation Discussion Paper [Internet]. 2015 [cited 2016 Mar 30]. Available from: https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/consultation-submissions/$FILE/105%20-%20AMA.PDF

[80] Australian Privacy Foundation. Feedback on the PCEHR/IHI Legislation Discussion Paper [Internet]. 2015 [cited 2015 Jul 9]. Available from: https://www.privacy.org.au/Papers/DoH-PCEHR-150624.pdf

[81] Parliamentary Joint Committee on Human Rights. Twenty-ninth Report of the 44th Parliament [Internet]. Canberra: Commonwealth of Australia; 2015 Oct [cited 2016 Jan 8]. Available from: http://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/Completed_inquiries/2015/Twenty-ninth_Report_of_the_44th_Parliament/c01

[82] Pearce R. Inquiry backs legislation for "opt-out" eHealth record. Computerworld [Internet]. 2015 Nov 10 [cited 2016 Jan 8]; Available from: http://www.computerworld.com.au/article/588570/inquiry-backs-legislation-opt-out-ehealth-record/

[83] Department of Health and Ageing. HealthConnect Evaluation. Canberra: Commonwealth of Australia; 2009.

[84] Schoen C, Osborn R, Squires D, Doty M, Rasmussen P, Pierson R, et al. A survey of primary care doctors in ten countries shows progress in use of health information technology, less in other areas. Health Affairs. 2012;31(12):2805–16. DOI: 10.1377/hlthaff.2012.0884

[85] Codagnone C, Lupiañez-Villanueva F. Benchmarking deployment of eHealth among general practitioners [Internet]. Luxembourg: European Union; 2013 [cited 2015 Jul 5]. Available from: http://dx.publications.europa.eu/10.2759/24556

[86] Currie WL, Seddon JJM. A cross-national analysis of eHealth in the European Union: Some policy and research directions. Information & Management. 2014 Sep;51(6):783–97. DOI: 10.1016/j.im.2014.04.004.

[87] Health Information Strategy Steering Committee. Health information strategy for New Zealand. Wellington: Ministry of Health; 2005.

[88] Kierkegaard P. Interoperability after deployment: persistent challenges and regional strategies in Denmark. International Journal for Quality in Health Care. 2015;27(2):147–153. DOI: 10.1093/intqhc/mzv009.

[89] Tsoukas H. The tyranny of light: the temptations and the paradoxes of the information society. Futures. 1997;29(9):827–43.

[90] Callen JC, Austin EK. Deterritorializing Utopia: The Possibility of Techno-Utopias in Societies of Control. Administrative Theory & Praxis. 2016;38(1):19–36. DOI: 10.1080/10841806.2015.1128220

[91] Rowley D. New ePIP rules ripe for gaming RACGP.pdf. Medical Observer [Internet]. 2016 Jan 15 [cited 2016 Feb 3]; Available from: http://www.healthandlife.com.au/wp-content/uploads/2016/01/New-ePIP-rules-ripe-for-gaming-RACGP.pdf

TABLE 1: The Development of NEHRSs in Australia

Date	Key Events
1991-92	Australian health ministers propose a 'Health Communication Network'
2000	Launch of Health*Connect* , a 5-10 year project to build a 'national health information network for all Australians'.
2004	Health minister Abbott announces expedited national roll out of Health*Connect.*
2005	Health*Connect* reconfigured to a modest 'change management strategy'.
	National e-Health Transition Authority (NEHTA) established to 'identify and develop the necessary foundations for e-health'.
2009	National Hospital and Health Reform Commission recommends a 'personally controlled' electronic health record (PCEHR) to the Labor Federal Government
2010	*May:* Federal Labor Government commits $467 million in its Budget to implementation of PCHER by July 2012
	28th June: Health Identifiers Act passed paving way for all Australians to be issued with a unique health identification number.
2011	*April:* Draft *Concept of Operations: Relating to the introduction of a PCEHR system* released. Consultation until June.
	September: Federal Minister for Health and Ageing Roxon, releases revised version of *Concept of Operations: Relating to the introduction of a PCEHR system* along with draft legislation for a *Personally Controlled Electronic Health Records (PCEHR) Bill*.
2012	*26th June: Personally Controlled Electronic Health Records (PCEHR) Act* passed.
	1st July: PCEHR goes 'live' and citizens able to register on-line amidst press reports of technical problems and little interest by healthcare providers and consumers
2013	*August*: 2.7% of population had registered for a PCEHR and little functionality available to users.
	November: New Federal Coalition Government Announces Review of PCEHR chaired by Richard Royle, Executive Director of a private hospital.
2014	*January:* Royle Review reports to Government but findings not published for five months until successful Freedom of Information request.

2015 *May*: Federal government finally responds to review and confirms new funding in Budget to ‘restructure’ the PCHER and indicates intention to make the system ‘opt-out’.

2016 *July*: Proposed date for eHealth Commission to replace NEHTA and administer renamed ‘My Health Record’.