Converging outcomes in nationally shareable electronic health records (NEHRs): An historical institutionalist explanation of similar NEHR outcomes in Australia, England and the United States of America

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Declaration

Except where indicated in footnotes, quotations and the bibliography, I certify that I am the sole author of the thesis submitted today entitled:

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in terms of the Statement of Requirements for a Thesis issued by the University Higher Degrees Committee.

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Abstract

The adoption of nationally shareable electronic health records (NEHRs) in Australia, England and the United States became major policy and political issues between c1998 and 2015. They continue to be so. As a policy issue, the benefits of ehealth, and subsequently NEHRs as mechanisms for institutional change, were rhetorically popular. Politically however, the development, implementation and regulation of NEHRs proved to be difficult and fraught with criticism from nearly all ehealth stakeholders. The NEHR programs each country pursued at the national level were exceptionally expensive and complex infrastructure undertakings. They involved institutional change management that produced tension amongst stakeholders, required the state to decide on trade-offs that produced winners and losers, and resulted in unintended consequences. Initially, each country approached these policy and political issues differently. Examining why they then had substantially similar outcomes is the substantive puzzle that lies at the centre of this research.

This thesis adopts an historical institutionalist approach to explain why state efforts to pursue the development, implementation and regulation of NEHRs at the national level in Australia, England and the United States resulted in substantially similar outcomes despite adopting initially different approaches. The thesis first compares why each case study country pursued ehealth, embarked on organisational change in order to achieve its ehealth and NEHR goals, and adopted NEHRs, noting similarities and major differences. The thesis then compares the state's role in the development of NEHRs at the national level in each country, again noting similarities and differences. A comparative evaluation of the cases is then undertaken in order to explain why each state continued to pursue NEHRs, despite the significant barriers to institutional change they faced. Here, the theoretical concepts of path dependency, critical junctures and incremental change are used to enhance the explanation. The thesis will then explain why the outcomes, as assessed through the lens of public policy evaluation, were substantially similar in each country. Finally, the thesis details the findings of the research through the lens of historical institutionalism and states the significance and implications of the research.

The research found that while each case study country approached the policy and political issues of ehealth and NEHRs differently, the outcomes were substantially the same because their goals, and the barriers they faced in trying to achieve them, were very similar. Australia started with a decentralised national health information network (NHIN) then changed to a centralised NEHR. England started with, and continued to pursue, a centralised NEHR. The United States eschewed government development and implementation of an NEHR and took the path of incentivising and regulating electronic health records (EHRs) in an effort to make them nationally shareable. Similar goals across the three countries included moving from a paper to an EHR system; giving patients more control over their health information; making EHRs interoperable; increasing EHR usability and the meaningful use of patient health information; and improving the efficiency and effectiveness of care. Similar barriers included: cost, privacy, trust, stakeholder preferences, and the state attempting to drive change too quickly producing stakeholder resistance and negative outcomes. The thesis findings also provide support for theoretical explanations of institutional stasis and change within the context of path dependency, critical junctures and incremental institutional change.

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Glossary

General Terms

API	Application Programming Interface.
Clinician-centred care	Clinician-centred care put the patient at the centre of a process of care where clinicians were the experts who had most of the power in the clinical decision-making process and thus over patient outcomes.
Critical Junctures	In the historical institutionalist literature, critical junctures are moments in time when change to the *status quo* is possible and policy makers have feasible alternative policy options. A critical juncture results in a new path or *status quo*.
eHealth	The institutional framework within which health information is recorded, stored and accessed in digital form. Commonly written as e-health, E-health and e-Health.
EHR	The term Electronic Health Record (EHR) is used to describe the concept of a longitudinal record of a patient's health and healthcare – from cradle to grave. It combines both the information about patient contacts with primary healthcare as well as subsets of information associated with the outcomes of periodic care held in EHRs of other healthcare providers
EMR	Electronic Medical Record.
GFC	Great Financial Crisis (2008–09). This term is commonly used in the US. Global Financial Crisis is commonly used in Australia and England.
GP	General Practitioner.
Health Informatics	The term informatics has been used to cover information, technology, processes, analytical tools and techniques, governance and the skills needed to use all of these to improve healthcare.[1] It is part of the broader ehealth institutional landscape impacting NEHR technical interoperability, standards, the usability of health information by both clinicians and patients, and governance issues such as privacy and the use of patient data.
Historical Institutionalism (HI)	One of a number of new institutionalist frameworks. HI examines how the institutional design of government systems influence stakeholder decision making and policy outcomes over time.
Interoperability	In the context of this thesis, interoperability means that that relevant, reliable and useful patient health information in the form of a nationwide EHR is always available at the point of care. This requires intra and inter organisational digital connectivity (as opposed to a manual paper-based system). For example, discharge summaries, specialist referrals, prescriptions and medication management. Key components of interoperability include the structural alignment of institutional systems with desired outcomes (systems integration, standards, information at the

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[1] Department of Health, "Health Informatics Review," 2008, 7.

	point of care, system efficiencies) and information governance (control, privacy, constrained choice, data management).
Meaningful Use	In the context of this thesis, meaningful use has two major components. Firstly, that the EHR will be used by service providers in the normal process of providing care with the expectation that meaningful use compliance will improve patient outcomes, enhance efficiency and improve the public good. Secondly, that the EHR will support a patient-centred healthcare system where optimal health outcomes reflect patient choices regarding their quality of life, as opposed to clinician or other healthcare stakeholders.
NEHR	Nationally Shareable Electronic Health Record.
NRPPs	Norms, rules, practices and procedures.
Opt-in	A specific NEHR process that gave patients the right, but not the obligation, to have an NEHR, such as the PCEHR.
Opt-out	A specific NEHR process that gave patients the right to exit from, or not take up, an NEHR, such as the SCR.
Path Dependency	In the historical institutionalist literature, path dependency refers to choices made at critical junctures establishing a *status quo* which tend to restrict future policy choices due to increasing returns, lock-in, sunk costs, positive feedback, and self-reinforcement – thus providing an explanation of institutional stability over time.
Patient-centred care	Patient-centred care was an informed patient at the centre of the clinical decision-making process with clinicians as one among many sources of expertise. This view was predicated on patient choice and control over outcomes, which could vary considerably, and which might or might not follow clinical expertise of doctor knows best or one way for all. The *status quo* was clinician-centred care and in practice this proved very difficult to change.
Patient Centricity	“A partnership among practitioners, patients, and their families to ensure that decisions respect patients’ wants, needs and preferences and solicit patients’ input on the education and support they need to make decisions and participate in their own care.”[2] The reality in the US was somewhat different. Clinicians, healthcare providers and insurance companies – the producers and controllers of patient health information – were powerful actors that saw the system in terms of the patient being at the centre of connected, and somewhat coordinated, care. Consequently, patients were often part of a system where outcomes were driven by these powerful actors rather than by patients.
PHR	Personal Health Record.
PIPs	Practice Incentive Payments.

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[2] Lior Miller, cited in NEXA, “The Path to Patient Centricity,” *NEXA Blog*, 2017.

Plausible	The term plausible explanation is used in this thesis as opposed to the term falsifiable and are not intended to be used in the context of being opposed to an implausible explanation.
Stakeholders	The major NEHR stakeholders this research identified as influencing NEHR public policy were the state (including the government/bureaucracy and departments/agencies); healthcare providers (GPs, clinicians, healthcare provider organisations); privacy and healthcare consumer advocates; EHR vendors; and patients (often called consumers by politicians).
Usability	In the context of this thesis, usability means that patient health information at the point of care is in a format that can be easily actioned by both clinicians and patients in a way that enhances meaningful use. What information is deemed useful, and in what format, varies by stakeholder and has led to significant contestation over the design of EHRs subsequently affecting power relationship ratios. Key components of usability include constrained choice, trust (provenance, accuracy and completeness of information), standards, and the time it takes to see and action relevant information.

Australia

ADHA	Australian Digital Health Agency – the institutional successor to NEHTA.
AMA	Australian Medical Association.
COAG	Council of Australian Governments.
DoH	Department of Health (from 2013).
DoHA	Department of Health and Ageing (2001 to 2013).
HealthConnect	The Australian Government's attempt to build a national health information network (NHIN).
IHI	Individual Healthcare Identifier.
MyHR (MHR)	My Health Record – the successor to the PCEHR based on an opt-out model of consent.
NEHRT	National Electronic Health Records Taskforce.
NEHTA	National eHealth Transition Authority – the institutional successor to HealthConnect tasked with developing a national EHR.
NHIMAC	National Health Information Management Advisory Council established in July 1998 as the peak national body that advises the Australian Health Ministers on issues related to fostering a national approach to using information and communication technologies to change the way healthcare is delivered. In November 1999 NHIMAC commissioned the National Electronic Health Records Taskforce to advise the

	Australian Health Ministers on the development of a national approach to electronic health record systems.[3]
NHIN	National Health Information Network.
PBS	Pharmaceutical Benefits Schedule
PCEHR	Personally Controlled Electronic Health Record – the Australian Government's attempt to implement a nationally shareable EHR based on an opt-in model of consent.
RACGP	Royal Australian College of General Practitioners.

England

BMA	British Medical Association.
CfH	NHS Connecting for Health, responsible for delivering the SCR.
CPRD	Clinical Practice Research Data Agency.
DoH	Department of Health.
NAO	National Audit Office.
NCRS	National Care Records Service.
NHS	National Health Service.
NPfIT	National Programme for Information Technology.
SCR	Summary Care Record – NHS England's attempt to implement a nationally shareable EHR.

United States

CDC	Centers for Disease Control and Prevention.
CEHRT	Certified electronic health record technology.
CMS	Centers for Medicare and Medicaid Services.
CPO	ONC's Chief Privacy Officer.
Eligible Professional	Medicare and Medicaid incentive payments could be made to an "eligible professional" (or to an employer or facility) who was not classified as a hospital eligible professional. An eligible professional for Medicare purposes only included physicians. There were five types of eligible professional for Medicaid purposes: physicians, dentists,

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[3] Vera Dimitropoulos and Joanne Callen, "National Health Online Summit," *Health Information Management Journal* 30, no. 1 (2001).

	certified nurse midwives, nurse practitioners and physician assistants who are not hospital based.
Eligible Provider	An eligible provider, for the purposes of Medicare and Medicaid incentive payments, was defined as a hospital, employer or facility that met the provision of professional services requirements of the HITECH Act 2009. Examples included a children's hospital, an acute-care hospital, a Medicare Advantage organisation and critical access hospitals. Payments were based on a formula using data on inpatient bed-days or discharges and the meaningful use of CEHRT over a specified reporting period.
HIE	Health Information Exchange.
HIPAA	*Health Insurance Portability and Accountability Act 1996.*
HITECH	*Health Information Technology for Economic and Clinical Health Act 2009.*
HHS	US Department of Health and Human Services.
ICD	The International Classification of Diseases. Owned, developed and published by the World Health Organization (WHO) and adopted by national governments and other regulating bodies. Editions are categorised by -10 (Tenth Edition). In the U.S. ICD-10 went into effect on 1 October 2015, with US-specific adaptions that split into two systems: ICD-10-CM (Clinical Modification) for diagnostic coding and ICD-10-PCS (Procedure Coding System) for inpatient hospital procedure coding.
OCR	Office for Civil Rights.
ONC	Office of the National Coordinator for Health Information Technology.
PHR	Personal Health Record. The PHR may be either electronic (EPHR) or paper-based collections of health or wellness data about an individual's health from multiple sources, including healthcare providers of all types and patients themselves. The term is more widely used in the United States than in Australia or England and is closely related to similar terms used, often interchangeably, in the literature, such as patient internet portal, patient portal, patient-shared/held/carried record, patient accessible records, personal medical record.[4]
PHI	An individuals protected health information as per the national standards established by the HIPPA Privacy Rule.
VA	US Department of Veteran Affairs.

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[4] N. Archer et al., "Personal Health Records: A Scoping Review," *Journal of the American Medical Informatics Association* 18, no. 4 (2011): 515.

Conventions used in this thesis

I have used the Chicago Manual of Style 17th edition footnote referencing style in order to avoid unnecessarily repetitive, and space consuming, intext referencing. For the same reasons, I have also used the following conventions in the thesis:

1. When more than one reference from the same source or author is used consecutively, and the nature/name of the source/author is subsequently clear, the reference number or attribution is placed:

    a. After the first use of the name of the source or author if identified before one or more quotations or paraphrases.

    b. After the name of the source or author if identified before any list whose content is primarily from the identified source.

    c. After the last quote in a sentence where all quotes in the sentence are from the same source or author.

2. Punctuation in referencing follows the following format: punctuation then quotation marks (as in ,”).

Note: Use of Boxes

Boxes are used throughout the thesis to explain concepts, provide abbreviations, summarise relevant information and provide supporting evidence for the arguments made in the main text so as not to unnecessarily interrupt the flow of the text.

The Author's Perspective

I come to this research on electronic health records (EHRs) with a desire to bring about effective change. That desire partly stems from having taught history and government (among many other subjects) at the high school level in both Australia and the United States for over two decades. It also comes from my natural inclination to look at institutional norms, rules and procedures, and work out how they could better achieve desired outcomes based on best practice and the concepts of Rawlsian fairness and individual capability. This is a practical normative approach to what "should" happen. I therefore found the rhetoric of ehealth alluring but the outcomes somewhat unsatisfying. Lower health costs and improved patient outcomes brought about by transforming healthcare service delivery make sense on a logical "if we do X then Y will follow" level. That formula held enough promise for governments in Australia, England and the US to collectively spend tens of billions of dollars directly on, or as incentives to build, extensive and often massive eHealth systems. By now I expected ehealth to work as advertised over a decade ago. After all, it seemed so simple: spend a bunch of money on health-specific information communication technology (ICTs) systems, link these systems together, train health professionals in how to use the ehealth system, plug in the patient and voila - lower costs and improved patient outcomes. It did not happen. eHealth became yet another example of big "top down" expensive government failures or partial successes. I wanted to know why.

I wanted to know why ehealth was not living up to its promise for two reasons. First, and personally most important, were the annoyingly repetitive experiences my mother was having with health systems in Australia. Having been hospitalised five times over six months, including three trips to the ER via ambulance, she had some insight to offer on the different systems each emergency service and hospital used. So did I, as I accompanied her to the ER on two occasions. However, my initial interest in EHRs was piqued by her experience in a car accident three years earlier. When I found out she had spent the first 20 minutes after the ambulance had arrived sitting on the kerb answering questions about her medical history before being whisked away to the ER it suddenly hit me that ehealth solutions had yet to make it into the real world in a fully integrated and seamless manner as advertised by the rhetoric for nearly two decades. I wanted to know why.

My mother's health system experiences are illustrative in that they provide insights into the process of care, the quality of care and the barriers to optimal care and patient outcomes that result from all three. These insights come from first-hand experience with, and observation of, the information exchange process between points of care in multiple healthcare settings. Insights also indicate where cost savings may be made, though saving in one area may simply free up funds to be used in another.

A typical information exchange experience for mum, in settings where ICT systems lacked interoperability and/or paper records were still relied upon, began with verbally giving the ambulance paramedic all her details while being hooked up to various diagnostic tools in the ambulance. The paramedic typed all the verbal data into a laptop which took up to 20 minutes. The laptop automatically recorded the electronic diagnostic data. Upon arriving at the hospital the nurse who received mum wrote down all this information as the paramedic read it from the laptop's screen. The first time this happened mum was amazed and in her own words found it:

> a bit ridiculous, because surely she [the nurse] could have got a USB stick and put it in his [the paramedics] computer and downloaded it all and stuck that into her computer and it all comes up … it must be very disappointing for them [the paramedics] to go into the hospital with their computer, with all this data on it, and then see pencil on paper stuff going on.[5]

I asked the paramedic why they had to go through such a manual exchange process and was told: "Their computers don't talk to ours – it's a different government department."[6] On another occasion all mum's information popped up on the paramedic's laptop, as she had been picked up by ambulance in that location twice before. However, upon arrival at the hospital the paramedic still read out the information to the receiving nurse who typed it into her computer. Someone then retrieved mum's paper file which was about 3cm thick and everyone who saw her from then on had that large file in their

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[5] Diana Roper, Interview 1, 2015.

[6] Confidential source.

hands. More and more paper was added to the file – both hand written notes and computer printouts from monitoring machines. When the ER doctors first saw mum they asked the same type of questions as the paramedics.

> It doesn't give you much confidence when you've answered the same questions all the time. If they came to you and said, "we've looked at all your results and your heart rate is back to normal, the blood tests show your potassium and magnesium levels are okay now" etc. they confirm to you that you're coming on, that you're doing well. But when they're asking you the same questions that have been asked before, well you really wonder which lunatic's running the asylum because nobody seems to be confident about what they know.[7]

About 12 hours after arriving in ER the following process got underway:

> Another nurse came around, and she had a whole pile of files and mine was on the top, and she opened it up and she said: "I'm just checking through to make sure I've got all the boxes ticked" and she sat with me for about 20 minutes, just going over all the things and turning the papers over and ticking boxes ... and filling in all the details – all different kinds of things: what kind of illnesses you had before, what surgeries you had before. Now all that was on records somewhere in that file because each time I had been to the hospital I had told them. It's all so slow and everyone does double work – it's a terrible waste. Then she went to the next cubicle and did the same with the next lady, and the same with the next cubicle. That was just her job. So, that's very time consuming.[8]

Someone then transferred some of that information into a computer. By the time all this information made it onto a printed discharge summary there were some mistakes. Nothing major, but previous before and after events in the medical history (episode followed by operation) were mixed up in the timeline which may lead clinicians who deal with the same episode of care to misread causality.

Mum's laughing response to this process was:

> It's absolute madness, and we go into that situation expecting them to cure what we've got![9]

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[7] Roper, Interview 1.

[8] Roper.

[9] Roper.

And yet, she was quite happy with the quality of care. The staff were always very polite, helpful and very kind. However, the noise in the ER made it very difficult to sleep and the lack of privacy was disconcerting at times.

Mum was then able to compare this repetitive, time consuming semi-manual process with her experience in St Stephen's, Hervey Bay's new digital hospital.

> In Hervey Bay Accident and Emergency they do seem to spend a lot of time putting stuff into the computer. But when they come to see you they've got a file in their hand and they're doing paper stuff. When I was in the new e-hospital, the digital hospital, they didn't carry any files around with them at all. They had a trolley, and when they came to take your blood pressure, or your temperature or anything like that, they just put this thing over my wrist band, which had some kind of barcode, then they put the thing in my ear for my temperature and put the blood pressure thing on and then just walked out. Not a pen in sight, not a file in sight. When my doctor came around he said "I've read everything all about you and you're doing fine." He can read it from home. He didn't pick up a file and read through it, he already knew it before he came to visit me. I thought it was marvellous. He said: "if you've got any problems when you get home, let me know, I've got everything on my computer about it."[10]

When comparing the different hospital systems she thought the digital hospital "beat everybody hands down."[11]

Lack of ICT interoperability and the reliance on legacy paper systems obviously seemed to be barriers to optimal care when compared with the integrated, paperless system adopted by St Stephen's digital hospital. The process of care in traditional settings was slower, repetitive and sometimes frustrating for the patient. From the patient's perspective the quality of care improved in the digital setting and cost savings garnered by improving the process of care seemed obvious. Mum also thought her outcomes (satisfaction, warmth, quiet, less stress, confidence in the care being provided, service delivery through patient centric ICT) were better in the digital environment.

My mother's experiences and insights were reinforced in a very personal way when my wife, Suzy, was diagnosed with leukemia in mid 2015 and subsequently died three

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[10] Roper.

[11] Roper.

months later. We both experienced first-hand amazing and dedicated care navigating and participating in a health system that had yet to master interoperability, usability and the meaningful use of health information. One example will suffice to make this point. Suzy was initially placed in a hospital ward that ran on paper health records. Clinical staff, while willing to share information with both of us, found continuity of care difficult at times and over a number of shifts would ask us the same questions about Suzy's condition and the care she had received up to that point. The lack of interoperability was rammed home when Suzy was moved from the ward to the ICU which operated an electronic medical record system. A paper file well over one inch thick accompanied Suzy in her transfer and I watched as a team of clinicians pored over the material. Eventually the senior clinician told me that the most important piece of paper detailing her condition and treatment to date was missing and asked if I could fill them in on what Suzy had been through. Luckily I had the relevant information, but only because I was with Suzy during her diagnosis and treatments, had asked plenty of questions and had read many of her clinical reports. ICU was able to proceed on the information I gave them and subsequently confirmed that information by bringing Suzy's entire care team from her previous ward to the ICU in an effort to improve the continuity of care she was receiving. Writing this thesis I am keenly aware of how gaps in interoperability and the usability of information may impact patients and their families who are unable to master information in complex medical environments, even to the limited extent I was able to, and thus affect their health outcomes.

Second, my own, admittedly unrealistic, expectations that by now public policy solutions would be efficient and effective having not been fulfilled led to what I initially thought was a novel form of cognitive dissonance. I had somehow believed the rhetoric that rapid advances in information technology would lead to a revolution of greater import and disruptive impact than the industrial revolution, would happen at a phenomenal rate that would dramatically change the way we lived for the better in our own life times, and would usher in a new age of efficient, effective and, above all, citizen centric governance. Part of that promise was the transformation of healthcare - not just through amazing new drugs, but through the wonders of ehealth. I have since learned that what I thought was cognitive dissonance particular to me, was a rather common experience of those taking a ride on the Gartner Hype Cycle, particularly when they are mired in the trough of disillusionment and struggling to climb the slope of enlightenment. I blame Star Trek – science fiction should be a reality by now! Obviously, implementing ehealth as a viable solution to increasing healthcare costs and ageing populations with chronic long-term conditions such as diabetes, was far more complex than '"build system infrastructure X, get service delivery outcome Y."

What seemed to be missing from both my mother's, and subsequently my wife's, experiences and my unrealised expectations, were patient capability rights through which healthcare service delivery might truly be transformed. Patient outcomes were central to ehealth rhetoric, particularly the rhetoric around the shift from a clinician-centred to a patient-centred system.[12] However, the patient seemed to be missing in actuality and had been replaced by ehealth information systems architectures. The focus was on technology hardware and software and paid only incidental attention to the capability of patients to effectively access and use their health information and make individual decisions about their health outcomes. I wanted to find out why NEHR programs had not delivered on all their claims of better patient outcomes.

I feel that this thesis, in part, provides a plausible explanation for why better patient outcomes have been so hard to achieve.

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[12] Terms used include: "patient-centred care, consumer engagement, patient participation and citizen engagement." Australian Commission on Safety and Quality in Health Care, "National Standards and Accreditation Patient and Consumer Centred Care National Safety and Quality Health Service," 2015.The patient-centred focus is particularly apparent in the AHMC's National E-Health Strategy Summary, in the section 'National Vision for E-Health.' AHMC, "National E-Health Strategy Summary," 2008, 5. Consumer access, control, privacy, and the interoperability of the ICT infrastructure were all focused on improving patient outcomes. Newman and Frank see the National E-health Strategy as having a threefold approach: "to improve … quality and safety … system accessibility, equity, processing and cost efficiency … by empowering consumers to better manage their own health." Lareen Newman and Oliver Frank, "The Rhetoric and Reality of E-Health: A Critical Assessment of the Benefits of e-Health in Primary Health Care," *Australian Journal of Primary Health,* 19 (2013): 265–66. Doing so requires improving consumers health literacy which is one component of patient rights capabilities.

Chapter 1 Introduction

> *Michael Wooldridge, who was health minister in the Howard government, argued at a recent industry event that in 2000 Australia led the world in health IT but today it was a "disgrace." "We still don't have a functioning e-health system and hundreds of millions of dollars have been put into that debacle," he said.* [13]

This thesis examines a critical issue in the health systems in advanced nations – successfully replacing paper health records with nationally shareable electronic health records (NEHRs). Efforts to do this have been widespread but have seen limited success and the development, implementation and regulation of NEHRs has been heavily criticised. This research examines the efforts of Australia, England and the United States to implement NEHR programs from the late 1990s to 2015. Each country initially adopted a different approach. However, over time all countries centralised their efforts (to varying degrees) to improve the interoperability, usability, meaningful use and patient control of health information. Why, and how, they did this is the central focus of this thesis.

This research looking at the move from paper to nationally shareable electronic health records was not about simple policy changes but a massive systemic shift for very complex and large health systems with hundreds of thousands of stakeholders. It also impacted tens of millions of patients. These health systems have billions of transactions each year and trying to shift from one system to something completely different based on technology caused immense systemic disruption, conflict between stakeholders and stakeholder pushback, and resulted in significant systemic change. This was an effort to change the system entirely rather than merely barnacle on another component.

Box 1-1 contains several short vignettes that capture the dilemmas of healthcare that are at the crux of this thesis. They are not a definitive representation of current progress in ehealth for each of the three case study countries.

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[13] Sarah-Jane Tasker, "Funding 'Debacle' Hurts e-Health Innovation," *The Australian*, 2017.

Box 1-1: Vignettes on ehealth

Australia: Who is This Patient?

> Having worked in an emergency department for over thirty years it would be fantastic to know the patients that come in because many people come in ill or injured with no identification on them, or little identification or the incorrect identification sometimes. Well a good example we had a patient who came into North Shore when I was there, maybe from a crash, who died. He lived a long way away in the country and a decision was made to call the family to let them know that their son had been killed in a car crash. Because normally the police go but the circumstances of this were such that I actually rang. I asked to speak to the next of kin who was the mother, then the mother answered the phone and I said "Are you Mrs. So and So," and I confirmed that "you've got a son So and So." She said yes, so I said "Well we've got a young male who has just been brought in from a car crash and unfortunately didn't survive." And she said "What!" She said "He's here with me." And I said "Is this So and So, date of birth?" She said "Yes. He's here and I'll get him." She put him on the phone and I'm talking to him. Anyway, to cut a long story short, this fellow in the car crash had stolen his wallet and because he came in with this fellow's wallet and because you take the wallet out of the pocket and you know, this is the ID. And I've seen many circumstances where people had other people's identification or had multiple sets of identification on them. Surprising enough, frequently, people have several, two or three aliases or more sometimes. There is a group in our community who often have multiple licences from every state in Australia in different names sometimes, and when they come in, they've been injured in a car crash for example or they collapse in the street, nurses go through their pockets and they've got four licences. One for Victoria, one for NSW, one for the Northern Territory and one for Tasmania. Sometimes in different names. So patient identification is one of the most important things we do in hospitals. We need to identify the patient so we can access the PCEHR.

Dr John Vinen, Medical Director, Calvary Health Care

England: From Paper to Information Available from Anywhere

> I think there are a few anecdotal examples that I could give that have transformed the way patients interact with their doctors in beneficial ways. We had one lady who had, was on holiday in Florida and broke her leg and ended up being treated in an emergency room there and based on those doctors being able to access and to view her previous history changed the approach they took, and certain drugs and things that she had, not a full allergy but an adverse reaction to it in the past that they were then able to make the decision not to use that rather than the patient's interpretation of that history. And then on a more sort of social and care level, there was a lady who had a mother who was in a nursing home in the UK and the daughter had emigrated to Australia and was therefore very worried about being so far away from her mother, but equally her family and her children and her job were in Australia. So she was struggling to be able to balance both and struggling to get in touch with the nursing home and the doctor at the right point in the day to discuss how her mother's care was going. So by the mother and the daughter sharing a password to the online record the daughter was able to log in from Australia and see each time that the doctor or nurse visited her mum and see how her care was progressing.

Dr Fraser Booth, Director, Patient Access To Electronic Records Systems (PAERS)

> The patient looks like an idiot when they go to the doctor. They're discharged. They go to their GP and say, "I've just been discharged from hospital and they told me to come and see you and I had some blue pills and they did something to my stomach." What the hell is that about, and somebody somewhere has written a pointless discharge letter which is stuck in the mail somewhere, so the doctor has to sort of work from first principles. I think we do start to have systems to cure it but there's that kind of flow.

Dr Tony Cornford, Associate Professor in Information Systems, LSE

United States: Connected Health – Frustration to Engagement

> Michael is 51 years old and is a type 2 diabetic from a family where anyone who ever turned 40 became type 2 diabetic. “People think I’m fat, that I’m lazy but the reality is I eat healthy, I exercise five days a week, I track my glucose reading – I just haven’t been able to control my A1C[14].” Michael had been going to an endocrinologist for a number of years and was always frustrated because he would go in every six months for his visit and the endocrinologist would adjust his diabetes medication based on an A1C lab value that was rear looking. His frustration was: “why are you prescribing me medication that is based on a lab value rather than adjusting things and helping me to monitor my behaviour in real time?” So Michael took to downloading his glucose levels every month, putting them in a PDF and faxing them to his endocrinologist who discarded it as he did not know how to interpret the data in an actionable way. Through frustration Michael left his endocrinologist and found a new care provider who had signed on to ONC’s pilot program to demonstrate how patient generated health data could improve the quality of care for patients. Validic, in partnership with the care provider, developed a type 2 diabetes monitoring program that tracked glucose values, blood pressure readings, weight readings, nutrition data and activity data through a wearable tracker that integrated with the EHR and the care manager’s workflow. Michael’s response was: “I was ecstatic. That’s all I needed to be an engaged patient because my data, that I was already tracking, was going exactly where I wanted it to go on a daily basis which was right in front of my clinician and my care management team.” Two weeks into the program the diabetic nutritionist noticed that Michael’s glucose level spiked between 7pm and 9pm each night, even though no food was logged. It turned out that Michael was a snacker and would eat a handful of chips or pop-corn while watching TV which was enough to cause the spike in glucose levels. So he cut out the snacking and within 30 days Michael’s A1C dropped by half a point from 8 to 7.5. That was the first time Michael was able to actually control his A1C through behavior change. He said: “it was the first time I ever felt I could control my diabetes, that I could control my health through my own actions” and that was really empowering for him.

Drew Schiller, CEO of Validic, FierceMarkets Webinar, 9 November 2017.

Context

It is important to start this thesis with a brief explanatory note that orientates the reader within the policy space of nationally shareable electronic health records (NEHRs) which is in turn embedded within the vast, complex and terminology specific institution of ehealth. The term eHealth represents the institutional framework within which health information is recorded, stored and accessed in digital form. The primary form of recording, storing and accessing patient health information across multiple providers is the electronic health record (EHR). For patient health information to be accessed by more than one healthcare provider that information has to be interoperable – available at each point of care. The purpose of shared electronic health records is to “exchange various types of data including medication, allergies, medical history, laboratory reports,

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[14] An A1C test is a measure of glycated hemoglobin (blood sugar).

referral letters, and discharge summaries."[15] This research has been conducted at the national level, therefore each case study country's shared electronic health record unit of comparison will be referred to as a nationally shareable electronic health record (NEHR)[16] because each case study country pursued "nationally integrated electronic records as part of a wider political vision."[17]

The introduction structures the thesis in the following way. First, it states the research question I will be adopting and outlines the topic of research. Second, there is a brief note on important terminology used in the thesis in order to enhance readability. Third, it explains the rationale for doing the research, briefly looks at the state of the literature and highlights the significance of the research. Fourth, it outlines the methodology to be used in the research. Fifth, it provides an overview of the case studies and outlines how the evidence collected will be evaluated. Sixth, it states what I expected to find from an initial survey of the field in 2012. Seventh, it summarises my contribution to knowledge, and states the limitations of the research. Lastly, the introduction outlines the structure of the thesis to follow.

This research seeks to provide a plausible[18] explanation in answer to the thesis question: *Why did state efforts to pursue the development, implementation and regulation of nationally shareable electronic health records at the national level in Australia, England and the United States result in substantially similar outcomes despite adopting initially different approaches?*

Historically all patient health records were paper or card based and stored in the place patients received their health care. For the vast majority of people this was their general practitioner's (GP's) office. Other healthcare providers – such as hospitals and specialists – would create their own paper-based records. The sharing of information[19] was limited

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[15] Trisha Greenhalgh, S. Hinder, K. Stramer, T. Bratan, and J. Russell, "Adoption and Non-Adoption of a Shared Electronic Summary Record in England: A Mixed-Method Case Study," *British Medical Journal* 341, no. 1 (2010): 1.

[16] For a definition of the term NEHR as used in this thesis see the Glossary and Introduction.

[17] Greenhalgh et al., "Adoption and Non-Adoption of a Shared Electronic Summary Record in England," 1.

[18] As opposed to falsifiable, not as opposed to implausible.

[19] See the definition of interoperability in the Glossary.

or non-existent and healthcare service providers and patients would not normally have access to GP records or records from other healthcare providers beyond those provided by a paper letter or the fax machine. Some healthcare providers actively resisted sharing health information believing the records were their intellectual property. EHR vendors developed proprietary EHRs that lacked interoperability in order to maintain market share. Siloed storage of health information therefore had two major drawbacks. Firstly, the lack of interoperability limited the usability[20] of health information to those providers and patients who had immediate access to it. Secondly, siloed health information was a significant barrier to the meaningful use[21] of all patient health information to improve healthcare service delivery. This situation was particularly acute for a patient arriving unconscious at hospital. How would emergency clinicians know what medications the patient was on, what allergies they had, or what their recent medical history was?

Governments began to see this as a systemically dysfunctional problem to be addressed by policy intervention. Therefore, the goal of many nations in recent times has been to commission a system to provide relevant, reliable and useful patient health information available at the point of care.[22] Improving healthcare service delivery outcomes has been the driver of NEHR programs for at least two decades and positive political rhetoric has supported a combined total of over 50 billion dollars being spent in Australia, England and the US on EHRs by these respective national governments.

A different approach to NEHRs was initially adopted by each state due to differences in the development of institutional pressures and tensions that led to respective NEHR programs. Australia initially adopted a decentralised national health information network (NHIN) and when that failed to achieve its goals switched to a centralised NEHR in the form of the personally controlled electronic health record (PCEHR). England adopted a centralised NEHR in the form of the summary care record (SCR) which was the core component of the very large National Programme for Information

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[20] See the definition of usability in the Glossary.

[21] See the definition of meaningful use in the Glossary.

[22] This is evidenced by numerous scholars, including: Greenhalgh, Morris, Wyatt, Thomas, & Gunning, 2013; Jolly, 2011; and Thune, Alexander, Roberts, Burr, & Enzi, 2015

Technology (NPfIT) that was part of the Blair government's modernisation agenda. The state in the US initially adopted a leadership and guidance role in an effort to encourage healthcare providers to move from paper health records to EHRs. With the passage of the *Health Information Technology for Economic and Clinical Health Act of 2009*, the state adopted a centralised regulatory approach, consisting of incentives and penalties, in an effort to make EHRs nationally shareable. The US left the development and implementation of NEHRs to EHR vendors and healthcare providers, whereas Australia and England adopted state-based programs. All countries had a goal of increasing patients' control of their health information through privacy regimes and by providing patients with access, transfer and use rights.

A robust rhetoric, the enabling narrative, touted the benefits of NEHR programs and persisted throughout the period of research. A typical example of supporting rhetoric for ehealth was this statement from the Australian National E-Health Strategy in 2008:

> E-Health will enable a safer, higher quality, more equitable and sustainable health system for all Australians by transforming the way information is used to plan, manage and deliver health care services.[23]

Similar claims have been made in England and the United States, as seen in Chapter 4.

Nevertheless, what is apparent after decades of mixed results on ehealth and major NEHR programs is that in Australia, England and the United States the claims of transforming the health system through the application of new information communication technology (ICT) have been rather optimistic. It became apparent in the research that outcomes would not just be determined by technology but by the policy pathways policymakers adopted, or were forced to adopt, as a result of critical junctures and incremental institutional change.

Rationale for Undertaking the Research

There were four main reasons for this research. First, NEHRs were, and continue to be, an important public policy issue with extensive claims that they will improve the

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[23] Australian Health Ministers Advisory Council, "National E-Health Strategy: Summary," 2008, 26.

efficiency and effectiveness of healthcare and benefit patients. This claim is premised on NEHRs being interoperable and containing usable patient information which is meaningfully used to improve patient health outcomes. Interoperability means sharing patient health information across organisational and jurisdictional boundaries and in an NEHR is ideally available at all points of care. Usability means that the information in the NEHR is relevant, reliable and timely and can be used by both clinicians and patients in the pursuit of better health outcomes. The meaningful use of information means using NEHRs to improve the efficiency and effectiveness of healthcare. This research tests whether NEHR assertions and claims are valid. This topic has not been conclusively studied although there is ongoing research, and some controversy, as to why some ehealth projects succeed, at least partially, and why many fail. There is, currently, a move to towards the notion that policy success in this area is not just a matter of building functional information technology systems. Managing NEHR institutional change, effectively engaging stakeholders, implementing a healthcare model that is truly patient-centred, developing interoperable digital health records, the usability and meaningful use of health information are all are areas of study to which this research contributes.

Second, considerable funding has been allocated by states to NEHR programs in pursuit of these claims. It is important to examine these claims and how states attempted to reap the potential benefits of NEHR programs. Therefore, there is a need for some comparative analysis of e-health institutions and the NEHRs they have created in an effort to improve the delivery of healthcare services and thus improve health outcomes. The development of NEHR programs is a common public policy problem in numerous countries and important lessons can be learnt by analysing the development and implementation of e-health institutions and the outcomes different NEHR policies produce. Similarities and differences can be identified in order to explain why partial success is perhaps the best outcome that can be reasonably expected over the medium term. In addition, ideational change and the legitimation of new institutions can be mapped; structural processes including changing patterns of behaviour and the technological possibilities envisioned can be analysed; agency in the form of actors and interests at the individual and organisational level can be explored; and service delivery outcomes can be assessed. Each dimension can inform explanations of what changed and why.

Third, the literature gap identified in Chapter 2 shows there is little comparative case study research that adopts an historical institutionalist framework comparing NEHRs across Australia, England and the United States. Historical institutionalism assesses the temporal aspects of NEHR programs with a focus on the institutions and historical trajectories of NEHR development, implementation and regulation. This research therefore has the opportunity to make a contribution to empirically based theoretical concepts of path development such as path dependence, critical junctures and incremental institutional change.

Fourth, this research also contributes to comparative public policy evaluation theory including adding the component of normative justification. In policy terms, a deeper understanding of what happened, why it happened and what the outcomes were may be useful for future NEHR policy development. The thesis also asks the question: should NEHR policy have been pursued in the manner it was in each country? Therefore, this research helps conceptualise NEHR systems turning into reality in a public policy context. Developing NEHR systems is a very complex policy area where significant state support and/or coercion may be crucial for success or alternatively may be difficult to impose, be of limited value or simply counter-productive in achieving the service delivery improvements desired. At times policy makers may feel that they are “herding cats” in their efforts to persuade people and organisations to adopt new institutional norms, rules and practices and to actually use NEHRs to obtain the benefits policy makers seek. State-sanctioned attempts at producing interoperable e-health systems and the meaningful use of health information in a patient centric fashion are worthy of study as they give key insights into why public policy initiatives can fail, be only partially successful or achieve the success envisioned by their advocates. This study will test policy makers’ assertions and claims against the information I obtained by conducting interviews with proximate actors and against evidence presented in the literature.

Core Research Questions

Thesis question:

Why did state efforts to pursue the development, implementation and regulation of nationally shareable electronic health records at the national level in Australia, England and the United States result in substantially similar outcomes despite adopting initially different approaches?

A number of key sub-questions were asked in the research process. They were:

1. Why did each country initially adopt a different approach to NEHRs? This will form the basis of analysis in Chapter 8.
2. How did the initial policy approach change over time and why?
3. Why did each country's NEHR program result in substantially similar policy outcomes in the categories of interoperability, usability, meaningful use and patient control of information?
4. How do governments, through their policy engagement, recalibrate a system to best suit their policy needs?

These research questions look at change over time, focusing on what, if anything, changed and why that change took place. Answers to these questions inform the comparative analysis and public policy evaluation completed in chapters 8 and 9. The answers to the above questions are also assessed within the theoretical framework of historical institutionalism as presented in Chapter 10.

Research Framework

Methodology

NEHRs are a significant public policy topic as evidenced by the time (decades), effort (organisational and institutional creation and development) and money ($50 billion plus) dedicated to the implementation of NEHR systems. Consequently, there were a variety of different public policy research approaches in the discipline of political science that were considered in developing the research framework for this thesis. After conducting a survey of the literature (see Chapter 2) an institutionalist approach was chosen. The major lens of the research framework is historical institutionalism (HI). This thesis is a comparative study that emphasises path dependency and critical junctures, ideational change and the legitimation of new institutions, structural processes, agency, co-production, and the comparative and public policy evaluation of service delivery outcomes developed out of the theory and literature review in Chapter 2 and the research design in Chapter 3.

Historical institutionalism (HI) was chosen as the lens through which I constructed my research framework for several reasons. HI enabled me to provide a plausible, as opposed to falsifiable, explanation of what changed and why and to assess the historical dimensions that influenced the outcomes of the research, including a longitudinal analysis of social, medical professional, technical and fiscal trends. HI is also concerned with the power relationships between stakeholders and providers, and NEHR programs are a public policy issue with winners and losers. Also, critical junctures have resulted in shifts in the directions systemic policies have taken.

Case Studies

I have used a national comparative case study approach, exploring the different NEHR options implemented or planned in Australia, England, and the United States. The criteria used to select these case study countries focused on their similarities and differences at the macro, ehealth system, organisational and NEHR institutional levels in the domain of ehealth. Of particular importance were the influence of key social, fiscal, medical professional and technological trends that influenced NEHR institutional design and therefore healthcare service delivery outcomes.

The case study countries were similar in many ways, including that they were all pursuing national EHR strategies with national governments as significant healthcare funders. Converging social, medical professional, technical and fiscal trends were also broadly similar. They also had many similar expected service delivery outcomes in the areas of patient-centred healthcare, system efficiencies, the effectiveness of treatment, co-production and patient engagement, and improving the public good. The role of the state in legislating and rule-making to improve the interoperability, usability and meaningful use of EHRs was significant in all three case study countries.

However, the countries had differences in who provided healthcare and how it was funded. These differences stem in part from social trends: healthcare as a social good to which citizens have a right in Australia and England; and, in the US until ObamaCare, healthcare as a personal good where you earn a right to healthcare by working.[24] Rights regimes were a significant issue in all three case study countries, however the rights regimes adopted were different. For example: Australia's Personally Controlled Electronic Health Record (PCEHR) asked patients to personally opt-in (choose to have a PCEHR) to the system and adopted significant patient control and privacy mechanisms but the result was clinician opposition and low uptake. This initial phase was later changed to a requirement for patients to opt-out (make a deliberate choice not to have a PCEHR) of a universalist system. England's Summary Care Record (SCR) adopted an opt-out requirement. In the US, healthcare providers decided what EHR model they would implement. The institutional composition of NEHRs was also different in each country and to some extent led to different service delivery outcomes in the short and medium terms.

In Australia and England, centralised EHR models were driven by the public bureaucracy, strongly supported by supplier rhetoric about positive service delivery outcomes. In the US, national government funding for EHRs has been statute driven and remains primarily directed towards areas where the government funds healthcare (Medicare, Medicaid) and is significantly influenced by the issue of personal privacy. This shows a more pronounced division between the private and the public sector than in Australia or England. In Australia, for example, Practice Incentive Payments (PIPs) to digitise the records process went to all GPs, whereas in the US there were Medicare and Medicaid percentages to achieve (as explained in Chapter 7).

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[24] Brian Richards (The Australian National University), Interview, 2014.

Case study data was gathered from 90 semi-structured elite interviews with proximate players involved in the rollout of NEHR programs and from document analysis. Documents included official government policies/reports, funding information, media analysis, academic and provider evidence of service delivery outcomes, ehealth blogs, and stakeholder submissions to NEHR reviews.

Analytical Frameworks and the Evaluation of the Evidence

Within the framework of historical institutionalism I am largely adopting a state centric approach: how do governments, through their policy engagement, recalibrate a system to best suit their policy needs? This approach analyses the ability of governments to initiate and promote change that affects the broad context in which various stakeholders operate. Governments have this ability because state power rests on such things as elections, significant resources, and the command authority to regulate, which makes or significantly influences NEHR values, norms and rules. The concepts of state and bureaucratic autonomy will be investigated. Therefore, the research adopts an HI framework that analyses the main research question through the lenses of path dependency, critical junctures and incremental institutional change. It also analyses the question through the lens of public policy evaluation. The key questions that arise from this approach are:

1. To what extent were the main NEHR institutional outcomes in Australia, England and the United States path dependent?
2. To what extent were the main NEHR institutional outcomes a result of critical junctures?
3. To what extent were the main NEHR institutional outcomes a result of incremental institutional change?
4. To what extent were NEHR policies successful?

Question 4 will be evaluated over six categories. These categories are: (1) processes used to affect policy change; (2) goal attainment (interoperability, usability, meaningful use and patient control of health information); (3) programmatic and operational dilemmas; (4) distributional outcomes (benefits and limitations); (5) evaluating the political consequences and fallout; and (6) normative justification. These categories, and how they emerged from the literature, are discussed further in chapters 2 and 3.

Questions 1 to 3 will involve analysis of institutional change using frameworks adopted from the literature on path dependency and critical junctures. These frameworks will "drill down" from a macro level of analysis (e.g. paper to digital), through the ehealth system chosen, then an organisational level of analysis (e.g. HealthConnect[25] to NEHTA[26] to the ADHA[27]) to an NEHR institutional level of analysis focusing on the unit of comparison (e.g. HealthConnect[28]/PCEHR[29]/MyHR[30]). These levels of path dependence and critical juncture analysis will be presented in Chapter 3 (Research Design) and the analysis fleshed out in Chapter 10 (Historical Institutional Analysis and Key Findings).

The comparative evaluation of the cases to explain what changed and why will be concluded by asking key questions that integrate the scholarship of Theda Skocpol, in particular her 1979 work found in *States and Social Revolutions*,[31] and path dependency and critical juncture theory. This section will explore common patterns of change, structural transformations, changes in privilege and institutional power bases, barriers to change and challenges to emerging institutions, building new state organisations to consolidate change, power relationship ratios, winners and losers, and important variations in outcomes between case studies.

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[25] HealthConnect was the Australian Government's attempt to build a national health information network.

[26] National eHealth Transition Authority – the institutional successor to HealthConnect tasked with developing a national EHR.

[27] Australian Digital Health Agency – the institutional successor to NEHTA.

[28] National Health Information Network.

[29] Personally Controlled Electronic Health Record – the Australian Government's attempt to implement a national EHR based on an opt-in model of consent.

[30] My Health Record – the successor to the PCEHR based on an opt-out model of consent.

[31] Theda Skocpol, *States and Social Revolutions: A Comparative Analysis of France, Russia, and China* (London: Cam, 1979).

Projected or Likely Findings

Based on my initial survey of the field in 2012, I expected to make the following findings which will be compared with the empirical evidence established in this research as part of my explanation of institutional stability and change over time.

1. Path dependency by itself would indicate that it would be more likely than not that different policy approaches to the digitisation of health records would lead to substantially different outcomes.

2. For similar NEHR outcomes to occur critical junctures would need to change the *status quo*.

3. Theories of incremental institutional change would test assumptions embedded in both path dependency and critical juncture theory and highlight the role of endogenous factors in producing institutional change.

4. The different NEHR starting points for each country would be explained through the analysis of developing institutional pressures and tensions over time prior to the first critical juncture.

5. NEHR programs would have both benefit and dis-benefit implications for stakeholders. For instance, benefits might include strong privacy controls increasing trust in, and subsequent patient use of, the NEHR. However, on the disbenefit side, strong privacy may restrict the ability of medical researchers to access clinically relevant data limiting potential improvements to population health outcomes.

6. If NEHRs adopt structural processes that limit or direct stakeholder agency (such as opt-in, opt-out, mandatory EHRs) then path dependencies will be created that affect service delivery outcomes.

7. For individual agents, choices (individual agency) will be constrained by the rules, regulations and standard operating procedures (formal and informal) of ehealth institutions and NEHRs.

Contribution to Knowledge

My thesis makes a contribution to knowledge by developing a theoretically informed plausible, as opposed to falsifiable, explanation of why each country had substantially similar NEHR outcomes in the areas of interoperability, usability, meaningful use and patient control of information despite adopting initially different approaches to NEHRs. This plausible explanation was supported by research that developed a significant body of knowledge and original contributions to public policy evaluation. Implications for theory generated by the research included historical institution generally and critical junctures in particular, public administration theory and methodology. Implications for policy and practice included digital governance, and program and project management. Specifically, the research made the following contributions:

1. Produced an historical account of the development of EHRs in Australia, England and the United States from the late 1990s to June 2015.
2. Used an historical institutional framework to:
    a. explain the development of, and change within, e-health systems and NEHR programs in the three case study countries
    b. create NEHR path dependency models for each case study country.
3. Enhanced public policy evaluation by adding the categories of programmatic and operational dilemmas, and normative justification, to the established model.
4. Linked health system and NEHR complexity to the eventual adoption of a centralised approach in all three countries.
5. Identified the key similar categories that drove each country's NEHR goals. These were interoperability, usability, meaningful use and patient control of health information.
6. Identified the characteristics that influenced the outcomes for these categories in the analysis in chapters 8, 9 and 10.

7. Identified the similarities across countries in the enabling narrative and the claims made for the potential benefits of NEHRs.
8. Found that common policy issues forced a level of conformity on all three NEHR programs.
9. Produced seven generalisations about public policymaking that have the potential for prediction and for drawing lessons across countries as presented in Chapter 10.
10. Identified a number of areas for further research.

Thesis Structure

This introduction is Chapter 1 of the thesis. The rest of the thesis will be structured as follows:

Chapter 2 presents the theory and key bodies of literature that informed my research. Here I discuss the literature on historical institutionalism (HI), path dependency, critical junctures, incremental institutional change and public policy evaluation. The literature on comparative health policy, electronic health records and nationally shareable electronic health records is discussed. These concepts are addressed in further detail in Chapter 3 on research design which explains the rationale for the research, describes the methods I used to conduct the research, and explains how I applied theory to the examination and evaluation of NEHR programs. Chapter 4 presents the aspirational narrative contextualising claims made about ehealth and NEHRs. Claims of potential benefits became the enabling narrative that justified NEHR programs and their funding. Chapters 5, 6 and 7 present the case studies on Australia, England and the United States respectively. Here I explain the development, implementation and regulation of NEHRs at the national level. Chapter 8 focuses on a comparative evaluation of the three cases outlining the similarities and differences in the comparison criteria used to explain how and why institutional pressures and tensions led to policy problems and issues that resulted in each country's NEHR program. This is followed, in Chapter 9, by a comparative public policy evaluation of the extent to which each country's NEHR program was a success. The thesis concludes in Chapter 10 with an HI analysis that plausibly explains why state efforts to pursue NEHRs had broadly similar outcomes. This chapter also includes a detailed discussion on the originality of the thesis and its contribution to knowledge, some comments regarding generalisations about public policy making and presents areas for further research.

Chapter 2 Theory and Literature Review

The objective of Chapter 2 is to outline the theoretical framework used to examine the topic of NEHR institutional change over time. Specifically, why did different initial approaches to NEHRs in each of the three case study countries end up with substantially similar outcomes in the categories of interoperability, usability, meaningful use and patient control of health information? I have combined three approaches to deal with the research question and this chapter presents the key bodies of literature that inform my research.

Part 1 will examine historical institutionalism (HI) and will review the literature I am drawing on: path dependency, critical junctures and incremental institutional change. Some of the debates in HI, and how they inform my approach to this research are outlined. The reason for my choice of HI over other strains of new institutionalism, is explained. Part 1 also includes a discussion on defining institutions, why they matter and how they are related to NEHR research. The questions that emerge from this literature evaluate the extent to which NEHR institutional outcomes in Australia, England and the United States were path dependent, a result of critical junctures and/or a result of incremental institutional change. This approach informs an answer to the research question by explaining why initial variation led to substantial similarity in outcomes (as noted above).

Part 2 will build on the HI framework in Part 1 by examining the literature on comparative public policy evaluation. It looks at types of public policy and public instruments and addresses the concept of normative justification. The focus is on evaluating success and failure and identifying the characteristics that influenced initial variation in NEHR programs and those characteristics that then led to substantially similar outcomes. Success, partial success and failure outcomes will be linked in the analysis that emerges from Chapter 9 (Comparative Public Policy Evaluation) and in the analysis of path dependency, critical junctures and incremental institutional change presented in Chapter 10.

Part 3 will examine the literature on comparative health policy, comparative case studies of electronic health records (EHRs), the nomenclature of EHRs and the apparent lack of cross-national comparative research comparing the categories of interoperability, usability, meaningful use and patient control of health information in NEHRs. Different theoretical perspectives will be presented, such as moral orders, as these proved useful in developing my approach to answering the research question. This literature provides some supporting information for the arguments I make in the evaluation chapters on NEHR complexity and centralisation, particularly regarding programmatic processes and some of the dilemmas NEHR programs faced in trying to achieve their goals. This extensive literature therefore has links to the theory presented in Parts 1 and 2. However, there is a lack of comparative case studies that compare the categories I have specified above across the three case study countries as an explanation for NEHR institutional outcomes. This thesis addresses this gap in the literature.

I address the concepts of path dependency, critical junctures, incremental institutional change and public policy evaluation in further detail in my research design chapter (Chapter 3) and the analysis chapters (chapters 8, 9 and 10). I have done this to show more clearly how I move from theory to method through specific questions that emerge from the literature (Chapter 2) and to inform my findings regarding the research question.

Part 1

Historical Institutionalism

Historical institutionalism emerged as one of the major strands of new institutionalism and attempted to explain both institutional stasis and change. Lowndes argued that the theory and methods of the old – or traditional - institutionalist approach dominated political science until the 1950s.[32] Contemporary theories explaining institutional

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[32] Vivien Lowndes, "The Institutionalist Approach," in David Marsh and Gerry Stoker, eds., *Theory and Methods in Political Science*, 3rd ed. (Basingstoke: Palgrave Macmillan, 2010), 60. Lowndes stated that "institutionalism *was* political science."

change developed as a reaction to the constricting structuralist focus of the old institutionalist school on “formal rules, organisations … [and] official structures of government”[33] and behavouralism’s dismissal of “institutions as no more than the simple aggregation of individual preferences.”[34] The most prominent theoretical approaches within this broad framework include historical institutionalism (HI), rational choice institutionalism, sociological institutionalism, and more recently, discursive and constructivist institutionalisms.[35] These new approaches challenged the assumptions and limitations of the old institutionalist approach broadening the focus to include informal conventions, broader networks and their constraints on governance outside and within the state, ideas and political agency. New institutionalism was a recognition that multiple catalysts could influence policy development and trigger policy change and identifying those that were decisive in any particular context could benefit from a broader set of theoretical tools and an expansion of traditional research methods. In particular, new institutionalism stressed “the role that strategic interaction between actors plays in the determination of political outcomes.”[36]

There were therefore a number of institutional theoretical frameworks within which to situate my research. I chose HI because it allowed for a comparative framework that could integrate contributions and insights from different perspectives to provide a richer explanation of institutional stasis and change. Steinmo argued that “historical institutionalism grew out of an interest in explaining variation,”[37] especially in terms of how institutions structured politics and produced differences in policy “across nations and over time.”[38] This approach is particularly relevant to cross-national comparative research that focuses on understanding key institutional characteristics that influence policy development and implementation over time. Exemplary studies within the HI

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[33] Gerry Stoker, "Introduction," in Marsh and Stoker, 15.

[34] Vivien Lowndes, "The Institutional Approach," 61.

[35] Lowndes described nine strains of new institutionalism adding normative, empirical, international, network and feminist institutionalisms. Lowndes, 65.

[36] Peter A. Hall and Rosemary C. R. Taylor, “Political Science and the Three New Institutionalisms,” *MPIFG Discussion Paper*, vol. 96, 1996, 18.

[37] Sven Steinmo, “Historical Institutionalism and Experimental Methods,” in *The Oxford Handbook of Historical Institutionalism*, ed. Orfeo Fioretos, Tulia G. Falleti, and Adam Sheingate (Oxford: Oxford University Press, 2016), 107.

[38] Steinmo, 107.

literature framework that influenced my choice of adopting HI include those of Theda Skocpol, James Mahoney and Kathleen Thelen, Paul Pierson[39] and Adam Sheingate among many others. The strength of these studies is that they analyse the complexity of circumstances and try to bring all the factors together to explain outcomes, which is the approach I am taking by using HI in this research.

Pierson argued that "many perceive the clash between those advocating rational choice theory and their critics to be the dominant cleavage in contemporary political science."[40] One of the arguments for HI was that it accommodated of a variety of institutional factors in explaining policy development and outcomes, and posits "a world that is more complex that the world of tastes and institutions often postulated by rational choice institutionalists" [41] particularly when HI is "attentive to the relationship between institutions and ideas or beliefs."[42] This was an appealing framework for this research as it enabled me to address more complicated and complex issues in developing the explanation I am trying to make, including trying to understand the particular effects of path dependency and critical junctures on technological investment. Rational choice assumptions of fixed sets of preferences and actors behaving entirely instrumentally in a strategically calculated way to "maximize the attainment of those preferences"[43] as part of a choice agenda, focuses on a deductive "calculus approach to the problem of explaining how institutions affect individual action."[44] While this approach lends itself to "systematic theory building"[45] critics argue that it is a relatively simplistic account of human motivation whose predictions are "sensitive to small changes in assumptions

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[39] On the sources of path dependence and their relation to technology, see Paul Pierson, "Not Just What, but When: Timing and Sequence in Political Processes," *Studies in American Political Development* 14, no. 1 (2000): 72–92; Paul Pierson, "Increasing Returns, Path Dependence, and the Study of Politics," *American Political Science Review* 94, no. 2 (2000).

[40] Pierson, "Not Just What, but When," 72.

[41] Hall and Taylor, "Political Science and the Three New Institutionalisms," 96:10.

[42] Hall and Taylor, 10.

[43] Hall and Taylor, 10.

[44] Hall and Taylor, 10.

[45] Hall and Taylor, 18.

about pay-off matrices, preference structures and the like, which are frequently arbitrary or unsupported by data."[46]

Over time, HI has faced a number of challenges. The most prominent is the critique that while HI presents "a compelling account of stability"[47] its main weakness is that it "is incapable of coping with change."[48] This is, in part, due to explanations of institutional stability being described as path dependent Stability endures "despite substantial changes in politics" due to increasing returns, lock-in, sunk costs, positive feedback, and self-reinforcement. These factors make institutions resistant to change and make particular courses of action "virtually impossible to reverse."[49] It is true that small initial decisions can have long-lasting effects (the persistence of NEHR patient control regulations despite their impact on desired program goals is an example). Enrico Coiera argued that it is "a deep source of frustration that health systems seem so resistant to change" and that "this inertia to change may be a more fundamental property of the health system."[50] He goes on to say that "healthcare has come to be constructed so that it is resistant to new policies and practices, even across apparently dissimilar national systems."[51] This is caused by complexity and competing demands that result in clinical and system inertia. This is particularly the case in hierarchical organisations where "configurations known as sticking points can lock the organisation into behaviours that are not even locally optimal."[52] Coiera argued that "for innovation to succeed in the

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[46] Hall and Taylor, 18. While rational choice institutionalism has elegantly explained institutional origins and why existing institutions continue to exist, Hall and Taylor argue that the rational choice approach is severely limited because it is "often highly functionalist … intentionalist … [and] voluntarist" and its explanations probably only apply well to "a limited number of settings." Hall and Taylor, 19–20.

[47] Edward Anthony Koning, "The Three Institutionalisms and Institutional Dynamics: Understanding Endogenous and Exogenous Change," *Journal of Public Policy* 36, no. 4 (2016): 639. I address the issue of tautology in Chapter 3.

[48] B. Guy Peters, Jon Pierre, and Desmond S. King, "The Politics of Path Dependency: Political Conflict in Historical Institutionalism," *Journal of Politics* 67, no. 4 (2005): 1275.

[49] See Paul Pierson, "Increasing Returns, Path Dependence, and the Study of Politics," *American Political Science Review* 94, no. 2 (2000): 251; Scott E. Page, "Path Dependence," *Quarterly Journal of Political Science*, no. 1 (2006): 88; Henry Farrell, "The Shared Challenges of Institutional Theories: Rational Choice, Historical Institutionalism, and Sociological Institutionalism," in *Knowledge and Institutions*, ed. Johannes Glückler, Roy Suddaby, and Regina Lenz (Springer Open, 2013).

[50] Enrico Coiera, "Why System Inertia Makes Health Reform so Difficult.," *BMJ (Clinical Research Ed.)* 342 (2011): 1.

[51] Coiera, 1.

[52] Coiera, 2.

presence of system inertia there must first be reduction in system complexity."[53] He went on to say that this can be achieved through system apoptosis that both builds and destroys processes creating a bundle approach that is coherent and self-reinforcing. Systemic bundling would simplify clinical actions to a series of steps that has "limited opportunity to avoid individual steps because of competing demands."[54]

Despite evidence of institutional stability it is clear that political and policy change does occur, in turn producing institutional change. To explain institutional change and to effectively deal with the criticism that path dependency is "overly deterministic,"[55] HI initially adopted the concept of punctuated equilibrium whereby change is contingent upon an exogenous crisis disrupting path dependent processes. These critical junctures can clearly be seen in NEHR programs. Hall and Taylor defined critical junctures as "moments when substantial institutional change takes place thereby creating a 'branching point' from which historical development moves onto a new path."[56] Hannigan's research in health and social care suggests that "critical junctures initiate (or take place within) longer trajectories of care, and the decisions that are made during them can propel people and processes in directions which may be hard to reverse."[57] However, the critical junctures approach was criticised as being too narrow and focusing on formal institutions undergoing formal change due to exogenous events, thus missing "institutional dynamics that take place behind the surface."[58] Hall and Taylor added the argument that the principle problem with critical junctures is to explain what precipitates a critical juncture and that even though "historical institutionalists

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[53] Coiera, 3.
[54] Coiera, 3.
[55] Stephen Bell, "Do We Really Need a New 'Constructivist Institutionalism' to Explain Institutional Change?" *British Journal of Political Science* 41, no. 4 (2011): 884.
[56] Hall and Taylor, "Political Science and the Three New Institutionalisms," 10.
[57] Ben Hannigan, "Crossing Disciplinary Boundaries and Sharing Unrelated Datasets Led to 'Critical Junctures' in Practitioner Outreach," *LSE Impact of Social Sciences Blog*, 2013.
[58] Koning, "The Three Institutionalisms and Institutional Dynamics: Understanding Endogenous and Exogenous Change," 644.

generally stress the impact of economic crisis and military conflict, many do not have a well-developed response to this question."[59]

In answer to the common problem of a focus on stability and exogenous shocks[60] brought forth by path dependence and critical junctures, explanations of incremental institutional change posit that "a majority of institutional change may in fact occur through gradual change processes which may nonetheless be transformative over time."[61] This approach stresses endogenous change that is constrained and adaptive, and where change can happen due to shifts in power between institutional stakeholders and the variable enforcement of rule compliance. Mahoney and Thelen argued convincingly that incremental modes of change such as displacement, layering, drift and conversion can occur due to both exogenous and endogenous pressures and tensions,[62] which was observed in this research. Change agents did affect the rules of the NEHR institution, particularly over privacy and patient control of information, which was relevant to the research question by helping to explain incremental change over time. "Displacement occurs when existing rules are replaced by new ones"[63] and can be a slow-moving process such as when a new organisation is introduced and competes with an old one. This was seen with the creation of NEHTA and the fading away of HealthConnect in Australia, and meaningful use rules slowly forcing change in EHRs in the US. "Layering occurs when new rules are attached to existing ones, thereby changing the ways in which the original rules structure behaviour."[64] This process was seen with NEHR privacy regulations. "Drift occurs when rules remain formally the same but their impact changes

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[59] Hall and Taylor, "Political Science and the Three New Institutionalisms," 10. Garud et al. explain that path dependence has been used to "explain both the persistence of existing institutions as well as the creation of new ones" and see this as "a problem only to the extent that continuity and change cannot be understood as processes driven by similar dynamics." A good example is paper health records persisting but their increasing inefficiencies being a key catalyst for the creation of a new EHR path. Raghu Garud, Arun Kumaraswamy, and Peter Karnøe, "Path Dependence or Path Creation?," *Journal of Management Studies* 47, no. 4 (2010): 762.

[60] For more depth on the challenge of explaining change see James Mahoney and Kathleen Thelen, "A Theory of Gradual Institutional Change," in *Explaining Institutional Change: Ambiguity, Agency, and Power*, ed. James Mahoney and Kathleen Thelen (Cambridge University Press, 2009).

[61] Andre Sorensen, "Taking Path Dependence Seriously: An Historical Institutionalist Research Agenda in Planning History," *Planning Perspectives* 30, no. 1 (2015): 28.

[62] Mahoney and Thelen, "A Theory of Gradual Institutional Change," 2009.

[63] Mahoney and Thelen, 16.

[64] Mahoney and Thelen, 16.

as a result in external conditions."[65] Lastly, "conversion occurs when rules remain formally the same but are interpreted and enacted in new ways."[66]

There is also a thriving debate between the "importance of institutions compared with the role of ideas in the policymaking process … [and the lack of any] clearly identified sources of agency."[67] This is an issue for state-centred theorists such as Skocpol. However, Skocpol recognised the importance of "bringing the state and state-society relationships to the fore in the definition of important, substantive problems for research … [in order to highlight] the interconnections of institutions and organisations that [may identify] comparatively conceptualized patterns of some sort."[68] This included understanding group identity formation and the "goals and capacities of social groups that become involved in politics."[69] Here, ideas matter and inform the development of "state-building and the changing capacities of states to achieve particular goals."[70] While the focus is on states as both actors and institutional social structures that shape social and political processes, Evans et al. argue that "there is a recognised need to improve conceptualizations of the structures and capacities of states, to … explore in many settings how states affect societies through their interventions – or abstentions – and through their relationships with social groups."[71] This approach is particularly relevant to this research as it identifies an area of the literature that is currently lacking in depth.

For example, while there are numerous works on ehealth describing what the state has done, how it has done it, and what the outcomes are, there is little literature on the framework of the state as an actor, its capabilities and capacities to influence change in institutional social structures, and the impact this has on NEHRs. In Australia, without state intervention EHRs would have been left to the private market

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[65] Mahoney and Thelen, 17.

[66] Mahoney and Thelen, 17.

[67] Peters, Pierre, and King, "The Politics of Path Dependency: Political Conflict in Historical Institutionalism," 1284.

[68] Theda Skocpol, "Why I Am an Historical Institutionalist," *Polity* 28, no. 1 (1995): 103–4.

[69] Skocpol, 105.

[70] Theda Skocpol, "Bringing the State Back In: Retrospect and Prospect," *Scandinavian Political Studies* 31, no. 2 (2008): 109.

[71] Peter B. Evans, Dietrich Rueschemeyer, and Theda Skocpol, eds., *Bringing the State Back In* (Cambridge University Press, 1985), vii.

and state-level EMR systems with little likelihood of national interoperability given that the states still do not have interoperable systems. The national government's abstention from NEHRs saw little progress in the years between HealthConnect and the PCEHR. The state's relationships with social groups (called stakeholders in this thesis), and its incorporation of their ideas into policy, made a significant impact on the development, implementation, regulation, uptake and use of the PCEHR. Trade-offs were important here and reflected that "socioeconomic relations influence[d] and limit[ed] state structures and activities."[72] Only the state at the national level had the capacity to bring about an NEHR, though capability was lacking for some time. In England and the US the role of the state was also of fundamental importance in pursuing an NEHR. The value in this analytical approach is that it allows exploration of different/similar state strategies in achieving a common goal of an NEHR while at the same examining how those "states influence[d] political cleavages and collective action."[73] It is also an attempt to "mediate between general theoretical debates (path dependency and critical junctures) and the specific evidence that in-depth case studies and comparisons can provide about *variations* in state organisations, public policies, and their roots and consequences."[74]

It is important as part of the HI framework to explain how I approach institutions. While the term "institution" is widely used, Hodgson argues that "there is no unanimity in the definition of this concept."[75] However, there has been an increasing acknowledgement that "the role of institutions in social life involves the recognition that much of human interaction and activity is structured in terms of overt or implicit rules."[76] Hall and Taylor argue that historical institutionalists define institutions as "the formal or informal procedures, routines, norms and conventions embedded in the organizational structure of the polity or political economy."[77] They went on to argue that institutions are relatively persistent and that they mediate policy outcomes by influencing the current

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[72] Evans, Rueschemeyer, and Skocpol, viii.
[73] Evans, Rueschemeyer, and Skocpol, viii.
[74] Evans, Rueschemeyer, and Skocpol, viii.
[75] Geoffrey M. Hodgson, "What Are Institutions?" *Journal of Economic Issues* 40, no. 1 (2006): 1.
[76] Hodgson, 2.
[77] Hall and Taylor, "Political Science and the Three New Institutionalisms," 6.

situation through contextual features inherited from the past.[78] These characteristics were evident in this research, particularly in the persistence of NEHR programs, and I therefore agree with Stephen Bell's statement that "institutions matter because they shape the choices, behaviour and even the interests and identities of agents."[79]

Hall and Taylor saw HI as posing "three seminal questions: how do actors behave, what do institutions do, and why do institutions persist over time?"[80] In answering these questions Hall and Taylor argued that HI scholars look through a relatively distinctive lens that adopts either a calculus or cultural approach that focuses on how institutions effect the behaviour of individuals and thus affect political outcomes.

> First, historical institutionalists tend to conceptualize the relationship between institutions and individual behaviour in relatively broad terms. Second, they emphasize the asymmetries of power associated with the operation and development of institutions. Third, they tend to have a view of institutional development that emphasizes path dependence and unintended consequences. Fourth, they are especially concerned to integrate institutional analysis with the contribution that other factors, such as ideas, can make to political outcomes.[81]

This research adopts a broad definition of institutions as decision delivery systems which give operational meaning to customs, practices, relationships, behavioural patterns and organisational objectives through the development of norms, rules and procedures. This approach is particularly suited to empirical examination within an historical institutionalism framework that focuses on comparative analysis, path dependency, critical junctures and patterns of institutional change over time. A central theme encountered in comparative studies of states as actors and institutions embedded in political and economic relations has been the concern with how states acquire capacities to act and how the process of constructing such capacities is affected by various phenomena relevant to the particular study at hand. With NEHRs, those phenomena

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[78] Hall and Taylor, 9.

[79] Bell, "Do We Really Need a New 'Constructivist Institutionalism' to Explain Institutional Change?" 883.

[80] Hall and Taylor, "Political Science and the Three New Institutionalisms," 7.

[81] Hall and Taylor, 7. The calculus approach focuses on the strategic calculation of individual preferences and the cultural approach focuses on the role of individual choice bounded by established routines or familiar patterns of behaviour. Hall and Taylor, 7–8.

may include powerful social actors at home and abroad; transnational flows of ideas, practices, technology, values and norms; antecedent structural conditions; and other exogenous and/or endogenous pressures and tensions. It is the interaction of various phenomena with the political process that is of interest in explaining the emergence of particular kinds of organisational structures and substructures within state apparatuses and the influence these have on the subsequent capacities of states to implement NEHR policy that is a key component of this thesis.

The institutional approach adopted in this thesis also allows for the integration of normative ideas into the analysis of the policy process. In this regard, Pierson and Skocpol argue that:

> the work of historical institutionalists also bridges divides within political science, including the gulf that sometimes separates normative theorists from empirical researchers. Normative dilemmas are frequently apparent in the phenomena explored by historical institutionalists, whose studies thus give substance to debates raging among political theorists.[82]

A broad interpretation of institutions allowed the research to develop normative understandings of the origins, variety and dynamics of national systems of shareable electronic health records. Doing this establishes the normative consensus on what should happen with NEHR programs in each case study society contributing to the analysis of path dependent decision making and critical junctures. This approach relied on inductive reasoning, supporting Hall and Taylor's argument that HI often depends on induction, which allows HI scholars to "discriminate among competing explanations" but which has led to a slower process of aggregating "their findings into systematic theories about the general processes involved in institutional creation and change."[83]

The core concern of this thesis is the institutional characteristics of NEHRs operating within, and potentially between, states. I draw upon Finer[84] in defining Australia, England and the United States as nation states (hereafter referred to as states) where

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[82] Paul Pierson and Theda Skocpol, "Historical Institutionalism in Contemporary Political Science," in *Political Science: State of the Discipline*, ed. Ira Katznelson and Helen V. Milner (New York, 2002), 5.

[83] Hall and Taylor, "Political Science and the Three New Institutionalisms," 21.

[84] Samuel E. Finer, *The History of Government from the Earliest Times. Volume 1: Ancient Monarchies and Empires* (Oxford: Oxford University Press, 1997), 2–4.

sovereignty resides in, and is democratically exercised by, the nation – that is, the politically significant members of its population. Institutionally, sovereignty is exercised through legislative and regulatory processes by democratically elected representatives and sanctioned regulatory bodies. These regulatory processes are influenced by numerous stakeholders, prevailing ideological factors and converging trends (social, medical professional, fiscal and technical). The interaction of these influencing characteristics produces a complex institutional array of values, norms, rules, practices and procedures that define NEHRs within each state. The ehealth institutional outcome unit of comparison, or "complex object of explanation"[85] for each state is state sponsored, nationally shareable electronic health records (NEHRs): the journey from HealthConnect through the PCEHR and onto the MyHR in Australia; the SCR in England; and systemic NEHR development as a direct result of the HITECH Act of 2009 in the United States.

I will work within HI and test the applicability of the HI theoretical literature to my cases by drawing on path dependency to explain NEHR institutional stability and critical junctures to explain NEHR institutional change. I will also incorporate incremental institutional change in order to show that institutional change is the result of the development of both exogenous and endogenous pressures and tensions and that small changes can have long-lasting effects. By combining these approaches I am following the advice of Thelen,[86] Van Der Heijden and Kuhlmann[87] and others that it will produce a richer and more informative explanation in answer to my thesis question. In this way I will contribute to the literature on institutional stasis and change with a specific contribution to an area that lacks depth – comparative analysis of NEHR public policy across Australia, England and the US.

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[85] Skocpol, *States and Social Revolutions,* 4.

[86] Kathleen Thelen, "The Explanatory Power of Historical Institutionalism," in *Zur Theoriefahigkeit Makro-Sozialer Analysen*, ed. Renate Mayntz (Frankfurt, 2002).

[87] Jeroen Van Der Heijden and Johanna Kuhlmann, "Institutional Layering: A Review of the Use of the Concept," *Politics* 31, no. 1 (2011): 9–18.

Part 2

Comparative Public Policy Evaluation

There is an enormous literature on public policy in a variety of policy areas. However, McConnell states that there is surprisingly little written on claims of policy success especially in terms of detailed key criteria used to systematically measure policy success or failure.[88]

What is a Public Policy?

Kerr argues that any definition of policy must include specific criteria that clearly differentiate the term from "related notions such as plan, promise and principle."[89] Kerr's definition relies on an agent intending to act, or acting on, a conditional imperative – that is, when conditions exist more than once – that can be revised through substitution by policy makers at any time.[90] While this is a useful starting point for causally mapping a policy process, it does not address the case of policy makers allowing change to occur by choosing not to act. De Percy illustrated this point in his description of the co-evolution of communications technology and institutions, arguing that the adoption of a new technology can occur when governments enable, or do not prevent, its adoption and that both enablement and non-prevention are policy choices that change the *status quo*.[91]

Broadly, policy is "whatever governments choose to do or not to do".[92] When examining public policy it is "necessary to discuss relationships between institutions, values, interests and resources."[93] For this research, the question was whether NEHRs were a public policy that could be comparatively evaluated across cases? By adopting

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[88] Allan McConnell, *Understanding Policy Success: Rethinking Public Policy* (Basingstoke: Palgrave Macmillan, 2010), 11, 14.

[89] Donna H. Kerr, "The Logic of 'Policy' and Successful Policies," *Policy Sciences* 7, no. 3 (1976): 352.

[90] Kerr, 352–53.

[91] Michael de Percy, "Connecting the Nation: An Historical Institutionalist Explanation for Divergent Communications Technology Outcomes in Canada and Australia" (The Australian National University, 2012), 233.

[92] Dye, cited in Paul Cairney, *Understanding Public Policy: Theories and Issues* (London: Palgrave Macmillan, 2012), 25.

[93] Glyn Davis, John Wanna, John Warhurst and Peter Weller, *Public Policy in Australia*, 2nd ed., (1993).

Cairney's[94] types of public policy and the instruments used by policy makers (see Table 2-1 below) it is clear that the answer to this question is yes.

Table 2-1: A Comparative Evaluation of Types of Public Policy / Policy Instruments Between Australia, England and the United States

Types of Public Policy / Policy Instruments	Australia	England	United States
Was there public expenditure?	**Yes** AUD$2.5 billion +	**Yes** £15 billion +	**Yes** USD$30 billion +
Were economic penalties used?	**No**	**No**	**Yes** Failure to achieve meaningful use goals
Were economic incentives used?	**Yes** PIP payments	**Yes** Data quality initiatives	**Yes** Adoption and use incentive payments
Were government-controlled benefits linked to behaviour?	**No**	**No**	**Yes** Reduction in Medicare/Medicaid payments to providers
Were formal regulations or legislation used to control behaviour?	**Yes** Particularly for privacy and data sharing	**Yes** Particularly for privacy	**Yes** Particularly for privacy and data sharing
Were there voluntary regulations such as agreements between governments and other actors?	**No**	**No**	**No**
Were there legal penalties for non-compliance?	**Yes** Particularly for privacy and data breaches	**Yes** Particularly for privacy and data breaches	**Yes** Particularly for privacy and data breaches
Was there public education and advertising to highlight the benefits and risks of certain behaviours?	**Yes** Benefits of privacy, uptake and use of the PCEHR widely advertised	**Yes** Benefits of privacy and use of the SCR widely advertised. Public awareness campaign with the BMA. Summary Care Record Public Information Programme.	**Yes** Privacy regulations and the benefits of the meaningful use of health information advertised

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[94] Cairney, *Understanding Public Policy*.

Were services and resources provided to help change behaviour?	**Yes** Sign-up campaigns, support for clinicians to actively use the PCEHR	**Yes** Support for clinicians to actively use the SCR	**Yes** Numerous programs resourced to foster interoperability and the meaningful use of health information
Were resources provided to tackle illegal behaviour?	**Yes** Funding of compliance monitoring and prosecution of regulatory non-compliance	**Yes** Funding of compliance monitoring and prosecution of regulatory non-compliance	**Yes** Funding of compliance monitoring and prosecution of regulatory non-compliance
Were organisations funded to influence public and media attitudes?	**Yes** NEHTA funded numerous advocacy organisations	**Yes** Mainly government organisations	**Yes** ONC, CPO, CMS
Was funding provided for scientific or advisory committee work?	**Yes** NEHTA funded numerous advisory committees	**Yes** Particularly reports and assessments of progress towards goals	**Yes** Intra-departmental and stakeholder interactions
Did organisational change occur?	**Yes** Significant change from HealthConnect to NEHTA to the ADHA + the growth of the ehealth unit in the DoH	**Yes** Establishment of the NPfIT followed by the establishment, incremental change and disbanding of numerous organisations	**Yes** Establishment of ONC, layering for CMS and CPO
Were services provided directly or via non-government organisations?	**Both** Mostly government	**Both** Mostly government	**Both** NEHR mostly private providers
Did the government provide a single service or set up quasi-markets?	**Single service**	**Single service**	**Quasi-markets** Regulation, incentives and penalties BUT market providers of NEHRs

Note: a "no" in the table indicates nothing of any significance in relation to the particular policy element was present. Definitions of abbreviations used in the table can be found in the Glossary.

The similarities and differences in the types of public policy and policy instruments relevant to each country is further explored in the case study and analysis chapters and informs my answer to the research questions.

Literature on Evaluating Public Policy Success or Failure

The evaluation of public policy has ultimately rested on whether or not policy is seen as a success, failure or something in between. Newman argued that "it is frequently acknowledged that success and failure are inherently subjective concepts"[95] and that "no agreement has emerged on what constitutes a 'successful' policy … because a particular program that is declared a success by one evaluator may just as easily be viewed as a failure by observers from a competing social group or ideological camp."[96] Newman saw this as hampering the evaluation of public policy and proposed a framework that conceptualises policy success by dividing aspects of policy into four separate areas: process, goal attainment, distributional outcomes and political consequences. This framework builds on the work of a number of scholars who have approached the topic from the perspective of policy success and, more recently, policy failure.

In an effort to justify claims of policy success by political actors in a systemic way, David Marsh and Allan McConnell moved "beyond the assumption that success equates with meeting policy objectives or producing 'better' policy" [97] by "focusing on three dimensions: process success; programmatic success; and political success."[98] In doing so they acknowledged the importance of Bovens et al. and their argument that "assessments of success or failure in government are therefore dependent on temporal, spatial, cultural and political factors."[99] The indicators of process success include the legitimacy in the formation of choices, the passage of legislation, political sustainability, and policy innovation and influence. The indicators of programmatic success focus on operational implementation, achievement of intended outcomes, the efficient use of resources and the benefits of policy to different actors. Indicators of political success focus on the political popularity of the policy. McConnell built on this heuristic by defining "policy success on the basis that it is a matter of fact as well as of interpretation" [100] and went on to detail "a spectrum of outcomes from success to

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[95] Joshua Newman, "Measuring Policy Success: Case Studies from Canada and Australia," *Australian Journal of Public Administration* 73, no. 2 (2014): 192.
[96] Newman, 192-193.
[97] David Marsh and Allan McConnell, "Towards a Framework for Establishing Policy Success," *Public Administration* 88, no. 2 (2010): 565.
[98] Marsh and McConnell, 564. Indicators of success are listed on page 571.
[99] Bovens et al. (2001, p.20) in Marsh and McConnell, 576.
[100] Allan McConnell, "Policy Success, Policy Failure and Grey Areas in-Between," *Journal of Public Policy* 30, no. 3 (2010): 346.

failure"[101] which is particularly useful when assessing complex policy environments such as NEHRs. This approach is based on his definition of policy success.

> A policy is successful insofar as it achieves the goals that proponents set out to achieve. However, only those supportive of the original goals are liable to perceive, with satisfaction, an outcome of policy success. Opponents are likely to perceive failure, regardless of outcomes, because they did not support the original goals.[102]

This perspective is evident in ehealth and NEHR policy in all three case study countries, particularly in the areas of privacy and patients' control over their health information as will be discussed in later in the thesis.

Howlett built on the work of Marsh and McConnell by examining the lessons of failure "such as policy accidents, errors, mistakes and anomalies,"[103] linking them with the three dimensions – process, programme and political – discussed above, in an attempt to integrate policy learning and policy success and failure. McConnell acknowledged Howlett's contribution, adding that while "policy failures seem pervasive"[104] there is no universal agreement on defining failure given differing benchmarks and "the propensity of policy opponents to emphasise those aspects that have failed to be achieved, and for policy supporters to emphasise those that have."[105] This reveals the "realpolitik of types and degrees of failure"[106] and the ambiguities and conflicting tensions between stakeholders and their perceptions of policy implementation and outcomes. McConnell addressed these issues by applying three degrees of failure (tolerable, conflicted and

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[101] McConnell, 346. For an in-depth discussion on the spectrum from success to failure, the issue of complexity and the problems of identifying, measuring and framing success see McConnell, *Understanding Policy Success*.

[102] McConnell, *Understanding Policy Success*, 40–41.

[103] Michael Howlett, "The Lessons of Failure: Learning and Blame Avoidance in Public Policy-Making," *International Political Science Review* 33, no. 5 (2012): 539.

[104] Allan McConnell, "What Is Policy Failure? A Primer to Help Navigate the Maze," *Public Policy and Administration* 30, no. 3–4 (2015): 221.

[105] McConnell, 227. This lack of agreement on what constitutes public policy failure is supported by Kay and Boxall who argue that no scientific objective standards exist for measuring public policy failure. For an in depth analysis on what constitutes public policy failure and their argument on socially constructed failure emerging from inquiries undertaken by experts and those emerging from public politics see Adrian Kay and Anne Marie Boxall, "Success and Failure in Public Policy: Twin Imposters or Avenues for Reform? Selected Evidence from 40 Years of Health-Care Reform in Australia," *Australian Journal of Public Administration* 74, no. 1 (2015): 33–41, https://doi.org/10.1111/1467-8500.12135.

[106] McConnell, "What Is Policy Failure? A Primer to Help Navigate the Maze," 221.

outright failure) to the process, programme and political dimensions in an effort to ascertain which failures are survivable, which are not and which failures "may actually be a consequence of success in other"[107] [realms]. For example, success in imposing a rigid privacy regime in Australia led to a failure of clinical use of the PCEHR. Therefore, the result is tensions between failures that are readily apparent in my research on NEHRs and which reveal surprising patterns of policy success and failure across the three case study countries. The three patterns identified by McConnell will be used in the analysis presented in Chapter 9. They are as follows:

> *Process success vs. programme/political failure.* Government succeeds in the policy making phase of the policy cycle by getting authoritative approval for the decision or decisions it sought, but the very means of doing so (such as rushing a bill through a legislature, ignoring consultation feedback about potential implementation problems, marshalling evidence to legitimise the proposed policy) can create risks – which may come to fruition – that the programme fails in the implementation stage to achieve its goals, resulting in political backlash which proves unmanageable.[108]
>
> *Political success vs. programme failure.* Colloquially, this would refer to "good politics but bad policy." For example, government may succeed in perpetuating its governance ideas by initiating policy with a high placebo content, demonstrating that a policy is in place to tackle a particular "wicked problem," but which fails to actually deliver on programme goals because of the complexity and intractability of problems with multiple individual, institutional and societal causes.[109]
>
> *Programme success vs. political failure.* Government succeeds in implementing unpopular programme measures, but leads to political failure. [Here the programme is] implemented with efficiency but producing damage to governments' key political success aspirations, e.g. reputational protection, control of policy agendas and promotion of governance ideas.[110]

McConnell argued that the framework he presents was a useful way to map the characteristics of policy outcomes across multiple cases, which will be done in Chapter 8 of this thesis. He also provided a working definition of policy failure.

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[107] McConnell, 237.
[108] McConnell, 238.
[109] McConnell, 238.
[110] McConnell, 238.

> A policy fails, even if it is successful in some minimal respects, if it does not fundamentally achieve the goals that proponents set out to achieve, and opposition is great and/or support is virtually non-existent.[111]

Kay and Boxall's analysis of success and failure in public policy emphasised endogenous institutional change, particularly that of layering and conversion. They identified two mechanisms that "connect assessments of policy failure and subsequent reform."[112] First, political actors may learn from policy failure (though learning may be "incomplete and asymmetrically distributed"[113]) and second, policy failure may act as a catalyst for deinstitutionalisation and institutional change. Both mechanisms were observed in this research when formal rules on privacy in Australia negatively impacted clinical workflows resulting in informal institutional practices, including workarounds to get or maintain access to health records, subverted formal rules and undermined the formal institution of NEHRs contributing to an endogenous process of policy change.

Newman acknowledged the improved frameworks developed by Bovens et al., Marsh and McConnell, and McConnell as useful building blocks in the quest for analysing policy success and failure. However, he criticised the approach taken by Bovens et al. as having unclear dividing lines between process and outcome, arguing that "the point of creating a framework is to separate aspects of public policy that can then be treated separately (in as much as they can be) in order to facilitate evaluation."[114] He claimed that "the bulk of the policy evaluation literature deals only with goals or outcomes and not with their connection" and thus saw Marsh and McConnell's division of policy making into the three categories of process, program and politics as "the most complete framework for the establishment of policy success to date."[115] However, Newman criticised Marsh and McConnell's framework as not addressing "the distributional implications of policy as a separate component"[116] which he saw as a distinctive indicator of success that should be evaluated separately "so that contested interpretations of

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[111] McConnell, 221.
[112] Kay and Boxall, "Success and Failure in Public Policy: Twin Imposters or Avenues for Reform? Selected Evidence from 40 Years of Health-Care Reform in Australia," 34.
[113] Kay and Boxall, 36.
[114] Newman, "Measuring Policy Success," 195.
[115] Newman, 196–97.
[116] Newman, 196.

policy outcomes can be accounted for in evaluations of success."[117] Newman therefore expanded Marsh and McConnell's framework to four categories of policy evaluation, set out in Table 2-2 below.

Table 2-2: Newman's Four Categories of Public Policy Evaluation[118]

	Process	Goal Attainment	Distributional Outcomes	Political Consequences
Indicator of success	Public policy is converted into substantive legislation or public programming.	Stated policy objectives are achieved.	Some groups benefit from a particular policy, in specific ways, to a certain degree.	Governments or other political actors benefit from the public reaction to, or perception of, a policy.
Significance	Connects policy inputs to policy outputs.	Addresses the "top-down" aspect of policy formulation and implementation.	Addresses the "bottom-up" aspect of policy implementation.	Accounts for the cyclical nature of the policy process.
Limitations	Inputs and outputs may not be evaluated to the same criteria.	Objectives may be unclear, unstated, or falsely represented. Long-term objectives may be different from short-term objectives.	How groups benefit can be subjective, so "success" must be defined in terms of "success for whom".	There may be a significant time dimension to political consequences, which could obscure evaluation in the short term.

Newman acknowledged that this framework has some limitations, which can be seen in this research on NEHRs and will be discussed in Chapter 9.

> For one, the effects of time may change the conclusions of a particular analysis, as norms and circumstances change and new evidence appears. Second, inputs to the policy process, which include social and political goals, may be measured differently than outcomes, which are often evaluated in monetary terms. Third, policy objectives can be unclear, misunderstood or misrepresented, or intentionally kept secret. Evaluations of policy success will need to be sensitive to these considerations.[119]

I add a fifth category (presented as the third category between goals and distributional outcomes in chapters 3 and 9) of programmatic and operational dilemmas in order to

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[117] Newman, 196.
[118] Newman, 197.
[119] Newman, 197.

address Newman's concern that past research has not separated components as more distinct indicators of program success, partial success and failure.

Normative Justification

Following Newman's framework of separating aspects of public policy so they can be treated separately I have added a sixth category of "normative justification" to Newman's four categories of public policy evaluation. Stewart has made the criticism that "political scientists wonder about what governments actually do, as distinct from what they ought to do, or even what they say they do."[120] The theoretical building blocks for adding a normative justification category to public policy evaluation emerge from sociological institutionalism through the study of "the way in which institutions create meaning for individuals" [121] and normative institutionalism which studies "how the norms and values embodied in political institutions shape the behaviour of individuals."[122]

Normative justification in public policy evaluation has its roots, in part, in Kerr's assertion that "the purpose for the policy is normatively justifiable to the relevant public"[123] and in Boyne's[124] competing values and multiple constituency models of public service improvement. Kerr argued that:

> for any policy which has a relevant public to count as normatively justifiable or "good," then that policy's goal or purpose must be justifiable by appeal to some norm, principle or value which the relevant public shares with the agent and which the relevant public sees as applicable in this particular case.[125]

This appeal to the relevant public can clearly be seen in the claims policy makers (the agent in Kerr's argument) made as to the benefits of NEHRs as presented in Chapter 4 and the empirical case study chapters. Newman criticised Kerr's approach as focusing on absolutes that cannot handle differing political perspectives. However, it provided a base upon which Boyne's dimensions of control and power, and Stewart's and Bozeman's

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[120] Jenny Stewart, *Public Policy Values* (Basingstoke: Palgrave Macmillan, 2009), 1.
[121] Lowndes, "The Institutionalist Approach," 65.
[122] Lowndes, 65.
[123] Kerr, "The Logic of 'Policy' and Successful Policies," 361.
[124] George A. Boyne, "What Is Public Service Improvement?," *Public Administration* 81, no. 2 (2003): 211–27.
[125] Kerr, "The Logic of 'Policy' and Successful Policies," 361.

values arguments, can build towards a clear category of normative justification that would include an indicator of success, its significance and its limitations.

By mapping the dimensions of control and power Boyne illustrated that:

> contradictions between different interpretations of effectiveness become explicit. The competing values framework highlights that it is impossible for organizations to emphasize simultaneously control and flexibility, or to be responsive primarily to both internal and external stakeholders. The multiple constituency model assumes internal and external groups use different criteria to judge effectiveness.[126]

Boyne's contention that "ideas about effectiveness are contested and that such contestations, in part, reflect power relations" reflects the political struggle various stakeholders engage in to "impose their preferred criteria"[127] and is clearly seen in the development and implementation of NEHR policy. However, there is a gap in the literature on NEHR interoperability, usability, meaningful use and control of patient health information centred on different stakeholder values. Stewart argued that values are "under-acknowledged when public policy is dissected or explained"[128] and that the concept of values "has not previously been accorded explicit attention by policy analysts."[129] Doing so helps explain how values lead to norms, rules, practices and procedures (NRPPs), as explained in Chapter 4, and supports Stewart's argument that "when governments made their policy choosing, it was overwhelmingly value choices that they made."[130]

Stewart defined values as "principled goals"[131] and argued that what governments choose to do or not do is "enormously important"[132] and implied that there is a moral component to policy outcomes that can be seen as good or bad. Institutional values can

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[126] Boyne, "What Is Public Service Improvement?," 219–20.

[127] Boyne, 221.

[128] Stewart, *Public Policy Values*, 15. McLoughlin et al. address values in the EHR space using the framework of moral orders which seeks to "rethink the nature of 'the record' and the moral orders upon which the rights, relationships, and responsibilities that enable it to function are based." Ian P. McLoughlin, Karin Garrety, and Rob Wilson, *The Digitalization of Healthcare*, 1st ed. (New York: Oxford University Press, 2017), 12.

[129] Stewart, *Public Policy Values*, 1.

[130] Stewart, 3.

[131] Stewart, 1.

[132] Stewart, 1.

be seen in the development and implementation of NEHRs in the clash over patient-centred and clinician-centred care, privacy and control of patient health information. The constrained choices imposed by NEHR rules, issues of public value and the public good, and power relationship ratios also demonstrate institutional values. Essentially, normative justification aligns public policy evaluation with a society's public values and thus addresses a gap in the policy evaluation literature in which concepts such as the public good, rights, values and power relationship ratios are subsumed by other categories without a clear indication of normative consensus.

Moore argued that "public value rests on three tests being met: (i) production of things of value to clients and stakeholders (ii) legitimacy in being able to attract resources and authority from the political authorising environment and (iii) being operationally and administratively feasible."[133] McConnell argued that "subsequent case studies and debate show that public value is something of a slippery concept (see Rhodes and Wanna 2007, 2008, 2009) [and that] Moore doesn't define public value and it is as contested as the term public interest."[134] However, Bozeman did make a clear statement regarding a society's public values that will be used in this thesis to structure an argument regarding policy success or failure along normative lines:

> A society's public values are those providing normative consensus about (a) the rights, benefits, and prerogatives to which citizens should (and should not) be entitled; (b) the obligations of citizens to society, the state and one another; and (c) the principles on which government and policies should be based.[135]

In policy terms, the normative issues that structure a society's public values imply a "chosen balance of rights versus utility"[136] that reflects institutional conflicts and tensions whose outcome is defined by stakeholder power relationship ratios. In ehealth, and for NEHRs, stakeholder conflict and tension was present over many interoperability,

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[133] Moore, 1995, p.71, cited in McConnell, "Policy Success, Policy Failure and Grey Areas in-Between," 347.
[134] McConnell, 347.
[135] Barry Bozeman, *Public Values and Public Interest: Counterbalancing Economic Individualism* (Washington, DC: Georgetown University Press, 2007), 13.
[136] Stephen Darlington, "Balancing Rights and Utility in Determining Power Relationship Ratios in E-Health Systems," in *Proceedings of the European Conference on E-Government, ECEG* (Kilmore End: Academic Conferences International Limited, 2013), 587.

usability and meaningful use issues. Patient control of health information, clinician-centred versus patient-centred healthcare, opt-in versus opt-out of the NEHR, and privacy were some of the most prominent of these. Trade-offs on these issues decided by the state indicate stakeholder power relationship ratios. The analysis in this thesis extends out of Newman's distributional outcomes to examine issues of power and how they influence values, norms and the rules that govern processes, practices and procedures.

My contribution to this literature is outlined in Chapter 9 and will contribute a new perspective on public policy evaluation by following Newman's advice to "divide out aspects of public policy that can be evaluated separately, so as to specify exactly what has failed or succeeded, in what way, and for whom."[137] I did this by creating six categories of evaluation, as compared to those proposed by Bovens et al. (2), Marsh and McConnell (3) and Newman (4). The addition of categories that allowed for the more nuanced evaluation of dilemmas and normative justification proved useful in the subsequent analysis. The questions that emerge from the literature on public policy evaluation will be presented in Chapter 3's discussion on research design.

Part 3

Comparative Health Policy

The literature on comparative health policy attempts to explain change in health systems by identifying the factors that are the determinants of change in a system and in health. Of particular interest to this thesis is the effort to differentiate between those institutional "problems that have common roots" and those "which spring from specific national circumstances."[138] This is helpful for "both an understanding of policy alternatives and a description and partial explanation of policy impacts and long-run

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[137] Joshua Newman, "Measuring Policy Success," 192–93.

[138] Robert H. Blank, Viola Burau, and Ellen Kuhlmann, *Comparative Health Policy*, Fifth edit (Basingstoke: Palgrave Macmillan, 2017), xiii.

outcomes."[139] Scholars working within the framework of historical institutionalism have often focused on patterns of healthcare provision, funding and governance and the courses of action taken by governments in pursuit of various desired healthcare policy outcomes. Blank and Burau argue that, "despite diverse approaches, common trends are apparent."[140] Common trends describing diversity across systems and sub-systems, priority setting, the allocation and rationing of resources, the organisation of power within health systems, the complexity and interdependence of health and other care systems inform explanations that answer key questions posed in this thesis.

The over-arching theme in the literature on comparative health policy is that "major policy initiatives altering the fundamental institutional mix and structural balance in health care decision-making systems are episodic and rare."[141] Steinmo and Watts go so far as to argue that institutional structural barriers can make large scale health reform impossible providing a salient example in national health insurance reform in the US. They argue that the reason the US, alone amongst developed democracies, "does not have a comprehensive national health insurance system (NHI) [is] because American political institutions are structurally biased against this kind of comprehensive reform."[142] This structural bias has persisted despite the public in post-war industrial democracies, including the US, having a basic preference for comprehensive public health programs due to their frustration with "the costs and inaccessibility of health care."[143] Despite finding culture and interest arguments for the failure of reform flawed and unsatisfying unless centred "within the institutional context in which they were formed,"[144] the central argument Steinmo and Watts put forward supports entrenched

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[139] G. Thomas Tayler, "Castles, Francis G. The Comparative History of Public Policy: Patterns of Post-War Transformation, 1989, (Book Review).," *Perspectives on Political Science* 20, no. 1 (1991): 298.
[140] Blank, Burau, and Kuhlmann, *Comparative Health Policy*, xiv.
[141] Carolyn Hughes Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.* (Oxford University Press, 1999), 11.
[142] Sven Steinmo and Jon Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," *Journal of Health Politics, Policy and Law* 20, no. 2 (1995): 330.
[143] Steinmo and Watts, 331–33.
[144] Steinmo and Watts, 336. They identify Jacobs culturalist analysis counter-argument that Britain and America created radically different health care systems due to the differences in basic public preferences as their main competition. Jacobs basic public-preference argument has more validity if applied to post-system consolidation as public preferences for national healthcare grew then stabilised in England and Australia and, with the exception of Medicare, remained mostly pro-market in the US.

oppositional interests with enormous political power as a defining barrier to successfully implementing healthcare policy reform.[145] However, the question remains: if American political institutions are structurally biased against comprehensive health reform why was the Affordable Care Act and the HITECH Act passed creating an ehealth institutional environment that gave the US federal government significant regulatory powers and incentive funding to pursue NEHRs?

Tuohy supports Steinmo's and Watts' contention that structural bias can determine institutional paths with distinctive logics that are "products of the eras of their birth, when broad political forces created windows of opportunity for policy change."[146] While it is broadly accepted in historical institutionalism that "institutions give priority to some interests and ideas rather than to others,"[147] scholarly explanations of how and why they do so, and the factors they identify as determinants of change vary. However, the focus on the balance of influence between competing factors that mix differently over time is common. For example, "political values, elite and public attitudes, and interest group behaviour" [148] are central to Steinmo's and Watts' analysis. Similarly, yet identifying different specific factors of interest, Tuohy's main concern "is with the dynamics of change in the decision-making systems of the health care arena – that is, the systems through which day-to-day decisions are made about the production and consumption of health care services." Those dimensions are: firstly, the mix of "hierarchical, market-oriented, and collegial elements that characterize the decision-making system"[149] which is an adaption in the context of the health arena of control mechanisms identified by Fuchs (1993), Boulding (1968) and Lindblom (1977)[150]; and secondly, the balance of influence within that system of "three broad categories of actors

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[145] Supported by Immergut and others in Steinmo and Watts, 341.

[146] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, vii.

[147] Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," 336.

[148] Steinmo and Watts, 336.

[149] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, 9.

[150] Tuohy, 10.

– the state, health care professionals [authority, skill, and wealth[151]] (and particularly the medical profession), and private financial interests."[152]

For Tuohy, it is the intersection between instruments (among various types of actors – state, private finance and health care professionals) and influence (of social control – hierarchy, market and collegiality)[153] that is most analytically revealing in policy terms and is used to identify and explain the relevance of competing bases of power. By throwing into relief key features of policy making in the healthcare arena, Tuohy argues that cross-country comparative learnings emerge as competing bases of power attempt to influence the "relationship of technological development to policy change"[154] such as with NEHRs. This enables an explanation of the "capacity of the policy process to deal with matters central to the human condition"[155] such as privacy and the use of patient health information within ehealth systems. Blank and Burau identify the regulatory, distributive and redistribution policies that governments adopt as determinants of change in healthcare systems. They argue that "all of these policies create winners and losers"[156], often as the result of trade-offs. Therefore, for government policy to be successful it needs to avoid imposing undue constraints on key stakeholders and at least obtain their tacit support as one powerful player's dissent can fracture support for an initiative even if it does not constitute a veto.

Rejecting explanations that focus solely on a single factor such as institutions, Blake and Adolino argue that a confluence of factors explains adoption or veto of health policy reform. Their argument has three main pillars. First, the structure of the political system matters. A unitary political system with a dominant executive faces fewer veto points than a federal political system. Therefore, parliamentary systems that combine "executive and legislative power in one body offer fewer veto points than presidential systems, which disperse power across different branches of government, limiting that of

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[151] Tuohy, 10.
[152] Tuohy, 10.
[153] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*
[154] Tuohy, ix.
[155] Tuohy, ix.
[156] Blank, Burau, and Kuhlmann, *Comparative Health Policy*, 3.

the executive."[157] This pillar supports the arguments made by Steinmo and Watts, and Tuohy, reflecting the difficulty of instituting major healthcare reform in the US. Second, the nature of party rule matters in that parties on the left of the political spectrum are more likely than those on the right to support a stronger role for the state in addressing social-welfare concerns. Third, the features of civil society matter in that societies that value social solidarity with a corporatist pattern of interest group activity are more likely to support a central role for the state "in ensuring health care access and provision"[158] than those that emphasise individual responsibility. This was particularly the case in England despite the attempt to institute private-market reforms in the healthcare sector in the 1970s and 1980s.

The role of the state is of central importance to historical institutionalist cross-national comparisons of healthcare policy. To some extent this is because as the healthcare policy environment becomes more complex "the state appears to be ineluctably drawn to even more interventions"[159] offering new opportunities for fundamental change. Steinmo and Watts argue that once there is an extension of the state into a policy area it changes "public attitudes about the proper realm of public authority" [160] and effectively legitimises state intervention. Tuohy's argument that policy "episodes occur only when a coincidence of external forces is strong enough to overcome the resistance of interests within the arena"[161] to change is an important one. Essentially, the ability and willingness of those who command the key levers of the state authority to act in concert and thus provide the political system with a consolidated base of authority for policy action is crucial. As a matter of comparison, the role of the state therefore asks researchers to consider which problems have common roots, which spring from specific national

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[157] Jeremy Shiffman, "Political Context and Health Financing Reform," *Health Systems and Reform* 5, no. 3, 2019, 258.
[158] Shiffman, 258.
[159] Morone and Dunham 1985; Morone 1990 in Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," 363.
[160] Steinmo and Watts, 339.
[161] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, 11.

circumstances and is health policy in developed countries converging – possibly, as some commentators argue, due to globalisation.[162]

The impact of information technology on the access to, use of, and purpose of patient health information has impacted the dynamics of change in each of the case study countries. Resulting shifts in power have benefited the state and corporate actors over medical professionals. This development was foreshadowed by Tuohy who argued that accommodations and alliances the state (in Australia and England) and finance (in the US) had previously made with the medical profession, giving the profession a dominant position, were shifting as information technology altered the "dynamics of structural change in the health care field."[163] As large databases of patient records were assembled both the state and corporate healthcare providers saw potential benefits in accessing this information for healthcare needs, outcomes and cost control. Tuohy argues that "medical practitioners had no comparative advantage in this regard" and that the advantage belonged to "large corporate entities whose operations gave them the opportunity to compile such databases and whose resources were substantial enough to bear the costs of investment in information technology."[164] How and why these developments had the "potential to fundamentally shift the balance of influence among state actors, health care providers and private financial interests in the health care decision-making system"[165] is one of the focuses of this thesis. In particular, the thesis identifies major institutional and structural policy interventions that produced these changes. While the distinctive logic of each particular system may have been different between each country, and progress lacking uniformity, the attempts by states to impose and regulate the concept of NEHRs that developed out of EHR information technology transformations led to converging outcomes and an increase in state power in the healthcare arena.

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[162] Blank, Burau, and Kuhlmann, *Comparative Health Policy*, xiii.

[163] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, 252.

[164] Tuohy, 252.

[165] Tuohy, 252.

Comparative Electronic Health Record Literature

There is a vast literature on electronic health records (EHRs) that focuses on health informatics,[166] challenges and solutions in the use of EHRs, practice experience in using EHRs, and the benefits of using EHRs both broadly and for specific systems. This body of literature also includes government reports as well as academic analysis that focuses on the implementation of EHR programs. Theoretical approaches include strong structuration theory, actor-network theory, complexity theory in health systems and orders of worth amongst many others; these cover a range of quantitative and qualitative studies. However, there is little comparative case study work in historical institutionalism using a qualitative method that compares interoperability, usability, meaningful use and patient control of information in NEHRs across Australia, England and the US.

The key studies that have informed this research are comparative studies of EHRs across more than one country. Of note is the work of Greenhalgh et al. and McLoughlin et. al. Greenhalgh et al.'s case study comparison of a nationally shared electronic patient record in Scotland, England, Wales and Northern Ireland reflected some of the findings of this thesis. [167] Different strategies with similar visions encountered complex development and implementation environments that led Greenhalgh and her team to conclude that "when designing and implementing complex technologies with pervasive implications, policymakers must consider not only technical issues but also the personal, social and organisational aspects of the programme."[168] McLoughlin et al.'s comparative case study on digital healthcare's disruption of moral orders was a very useful source of information on the drivers of policy interest in digital health and aspects of the development and implementation of NEHRs in Australia and England. McLoughlin et al.'s research was conducted from the theoretical perspective of moral orders and made the argument that "the digitalization of health records not only potentially disrupts the

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[166] One of the most prominent scholars on ehealth systems is Enrico Coiera whose has written widely on health informatics.

[167] Trisha Greenhalgh et al., "Introducing a Nationally Shared Electronic Patient Record: Case Study Comparison of Scotland, England, Wales and Northern Ireland," *International Journal of Medical Informatics* 82, no. 5, 2013.

[168] Greenhalgh et al., e125.

systems, processes, and the business models which form the basis of the way healthcare gets done, but also challenged the normative dimensions through which different stakeholders construct their identities and public positions around competing distributions of risks, rights, and responsibilities." [169] This argument tangentially supports the argument I make regarding power relationship ratios later in the thesis. There is also some interesting comparative literature on the ways in which ideas interact with policy and practice in healthcare settings, and Tenbensel et al. argue that these interactions are "strongly mediated by policy settings and institutional legacies of particular jurisdictions."[170] Such mediation was found in this research.

Timmermans' and Berg's examination of sociological scholarship on medical technologies divided the literature into three theoretical perspectives: technological determinism, social essentialism, and technology-in-practice. [171] An assumption in technological determinism is that technology's effect has mostly been harmful and that in the health arena it "enforces medical social control"[172] is relevant to this thesis, especially from the perspective of privacy and control of patient health information. EHRs and NEHRs are "controversial, innovative technologies threatening to disturb the social order."[173] However, the reductionism embedded in the theory of technological determinism does not always hold up in the empirical analysis of NEHRs as quality, safety, patient control over their health information and some cost benefits do emerge. How EHRs and NEHRs affect patient care as sociological catalysts is the domain of social essentialism. Here, EHR and NEHR technology "represent choices between sets of freedoms and constraints" that are "treated differently in a different culture or at another historical juncture."[174] While not the primary focus, this thesis examines to some extent

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[169] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*.

[170] Tim Tenbensel et al., "How Do Policy and Institutional Settings Shape Opportunities for Community-Based Primary Health Care? A Comparison of Ontario, Québec and New Zealand," *International Journal of Integrated Care* 17, no. 2 (2017): 1.

[171] Stefan Timmermans and Marc Berg, "The Practice of Medical Technology," *Sociology of Health and Illness* 25, no. SPEC. ISS. (2003): 99.

[172] Timmermans and Berg, 99.

[173] Timmermans and Berg, 100.

[174] Timmermans and Berg, 102.

the empirical accuracy of this perspective through the application of the comparative method of examining cases that have different conditions but similar outcomes.

While all three strands of the literature can be seen to have some relevance to the development, implementation and regulation of EHRs and NEHRs it is Timmermans and Berg's argument regarding the logical next step for social scientists critiquing technology-in-practice to "move beyond criticism and influence the creation and implementation of medical technologies"[175] that has the most saliency for this thesis. Scholarly influence in the NEHR arena can be seen in the rearrangement of power between the state, providers of care, and patients; mediating policy maker and stakeholder expectations regarding the benefits of NEHRs and whether or not they will work for them or have little effect; and the active mediation of the clinical encounter by transforming the clinicians note-taking and medical record reading.[176] It is the empirical examination of infrastructural technologies such as records and information systems that only become effective after standardisation that "requires much in-depth investigation and elaboration."[177] Notable examples of recent scholarship include that of Wyatt et al.[178] who investigate the uses of routine general practice data in England, EHRs and the delivery of healthcare's triple aim, and standards issues within health information systems. Further, Mesko et al. explore physician empowerment in the digital health era and argue that patient empowerment and the spread of digital health have allowed "the job of being a medical professional to become more rewarding and creative,"[179] an area of tension that is exposed in the case study research of this thesis.

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[175] Timmermans and Berg, 97.

[176] Timmermans and Berg, 106.

[177] Timmermans and Berg, 104,108.

[178] David Wyatt, Jenny Cook, and Christopher McKevitt, "Perceptions of the Uses of Routine General Practice Data beyond Individual Care in England: A Qualitative Study," *BMJ Open* 8, no. 1 (2018): 1–8; David Wyatt, Scott Lampon, and Christopher McKevitt, "Delivering Healthcare's 'Triple Aim': Electronic Health Records and the Health Research Participant in the UK National Health Service," *Sociology of Health and Illness* 42, no. 6 (2020): 1312–27; Carl J. Reynolds and Jeremy C. Wyatt, "Open Source, Open Standards, and Health Care Information Systems," *Journal of Medical Internet Research*, 2011.

[179] Bertalan Mesko and Zsuzsa Győrffy, "The Rise of the Empowered Physician in the Digital Health Era: Viewpoint," *Journal of Medical Internet Research* 21, no. 3, 2019, 1.

Comparative Nationally Shareable Electronic Health Record Literature

While there are a number of single country studies on EHR policy and programs, and some studies that compare aspects of the development and implementation of EHRs across two or more countries, there appears to be no cross-country comparative research that compares the interoperability, usability, meaningful use and patient control of health information in nationally shareable electronic health records as the factors that are the determinants of change in health systems. There is also some debate about the nomenclature of EHRs, as the term is often used interchangeably with electronic medical records (EMRs), personal health records (PHRs), personally controlled electronic health records (PCEHRs), summary care records (SCRs) and nationally shareable electronic health records (NEHRs).

The most common comparisons early in the development of ehealth systems were between paper records and the potential and actual benefits of specific features of electronic records. As the number of countries implementing EHRs as part of large scale ehealth systems increased, the focus of research changed to the impact such systems and their component parts such as EHRs had on the quality, safety and cost of healthcare. Black et al. identify a number of problems with the literature on ehealth technologies such as EHRs. Their main concern was that the quantity, quality and consistency was weak and repeatedly of poor quality and the number of evaluations in relation to the number of ehealth implementations is comparatively small.[180] They also identify a significant evidentiary gap between "postulated and empirically demonstrated benefits of ehealth technologies"[181] particularly in relation to improvements in patient outcomes and cost effectiveness. They note that the repeated claims of potentially transformative eHealth technologies remain uncritically accepted and their scientific basis remains to

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[180] Ashly D. Black et al., "The Impact of Ehealth on the Quality and Safety of Health Care: A Systematic Overview," *PLoS Medicine* 8, no. 1, 2011, 1–16.

[181] Black et al., 1. Supported by Granja et al. who conclude that a vast amount of eHealth interventions failed during clinical implementation when assessed against access, quality and cost containment. Factors determining success or failure common to my thesis included: workload, workflow disruption, alignment with clinical processes, undefined and changed roles, undetermined face-to-face communication and staff turnover. Conceição Granja, Wouter Janssen, and Monika Alise Johansen. "Factors Determining the Success and Failure of Ehealth Interventions: Systematic Review of the Literature," *Journal of Medical Internet Research* 20, no. 5, 2018, 2, 5–7.

be established despite large scale expenditure on ehealth investment in the UK (£12.8 billion) and the US ($38 billion),[182] an issue explored in Chapter 4 and the case study chapters of this thesis. Identifying socio-technical factors as determinants of change, Black et al. argue that if these factors are given insufficient attention, then challenges ensue that create significant difficulties for implementation of EHRs such as the NHS, for example, experienced with the Connecting for Health initiative in hospitals in England.[183]

Non-standard usage of terminology poses challenges in accurately identifying what type of record is being compared. In particular, throughout the literature and in general practice within healthcare the terms EHR and EMR have been used interchangeably. However, there is a growing consensus regarding terminology that has emerged from the regulatory authorities, such as the Office of the National Coordinator for Health Information Technology (ONC) in the US, Connecting for Health in England, and the National eHealth Transition Authority in Australia. All three authorities broadly see EMRs as the digital version of the paper records held within a healthcare provider organisation, whether a small clinical practice or large corporate provider, that "contains the medical and treatment history of the patients in one practice."[184] The defining factor is that "the information in EMRs doesn't travel easily out of the practice"[185] and that in terms of transferring a patient's health information to specialists and other members of the care team "EMRs are not much better than a paper record."[186] EHRs, by contrast, are built to share information beyond the organisation that originally created, collected and compiled it. They include a broader view of a patient's care including patient contacts with primary care, secondary care and subsets of information associated with the outcomes of periodic care held in the EHRs of other healthcare providers. An NEHR extends that definition to the national level. An NEHR is a state regulated mechanism that aims to share patient health information seamlessly at all points of care within a

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[182] Black et al., "The Impact of Ehealth on the Quality and Safety of Health Care: A Systematic Overview," 2.

[183] Black et al., 12.

[184] Peter Garrett and Joshua Seidman, "EMR vs EHR – What Is the Difference?," *Health IT Buzz*, 2011.

[185] Garrett and Seidman.

[186] Garrett and Seidman.

nation through interoperability standards in a way that the information is usable to achieve meaningful beneficial health outcomes. In policy terms, NEHRs – such as the SCR in England and the PCEHR in Australia – aimed to improve the safety, quality and patient outcomes of healthcare and lower costs within the healthcare system through the meaningful use of patient health information. A personal health record (PHR) is primarily for the patient's personal use and may include information from an EHR as well as information that the patient adds themselves such as health information that comes from wearable devices, blood sugar tests and heart rate monitors. This information is unlikely to find its way into an EMR or EHR but is increasingly part of the NEHR concept.

Research Gap

The literature focuses on broad factors that are seen as the determinants of change in health systems, the intersection between instruments and influence that identify and explain competing bases of power, and ehealth technologies, including component parts of EHRS, that impact quality, safety and patient outcomes. However, there is little comparative literature on NEHRs that explores interoperability, usability, meaningful and patient control of health information across my three case study countries. In particular, there seems to be little on NEHRs as a mechanism for achieving desired policy outcomes. In part, this is because, as Black et al. found, research into ehealth and EHRs is a "poorly ordered discipline"[187] that needs more critical review in the light of empirical evidence. They argue this is because evaluations to date have largely favoured simplistic approaches, which have provided little insight into why a particular outcome has occurred."[188] Therefore, this thesis will go some way towards correcting a persistent gap in the literature which, though while specific in this instance to NEHRs, does directly address Steinmo and Watts earlier finding that "there are few genuinely comparative political histories of the politics of health care reform."[189]

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[187] Black et al., "The Impact of Ehealth on the Quality and Safety of Health Care: A Systematic Overview," 9.

[188] Black et al., 11.

[189] Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," 334.

This thesis aims to fill the gap identified above using detailed empirical evidence to answer key questions that emerged from the literature and from the use of an historical institutionalist qualitative framework approach to the research. Some of the major questions are:

1. Do the NEHR interoperability, usability, meaningful use and control of patient health information policies that governments adopt make a difference in healthcare, and if so, to what extent has NEHR policy been designed to resolve or manage the myriad dilemmas evident in complex health systems?
2. Are there common trends and challenges in the healthcare policy arena on NEHRs that can be tested and emulated or are “national systems … so idiosyncratic that only home-grown solutions are possible[?]”[190]
3. Do the particular characteristics of a particular national arena continue to channel policy development along distinctive paths?

This chapter has outlined the theoretical framework of historical institutionalism and public policy evaluation used to examine NEHR institutional change over time. Path dependency, critical junctures, incremental institutional change were reviewed. These concepts, and the questions that emerge from them and the comparative health policy and NEHR literature that inform an answer to the research question, will be addressed further in following chapter on research design.

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[190] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, vii.

Chapter 3 Research Design

Introduction – Purpose of the Research

This research seeks to provide a plausible, as opposed to falsifiable, explanation in answer to the thesis question: *Why did state efforts to pursue the development, implementation and regulation of nationally shareable electronic health records (NEHRs) at the national level in Australia, England and the United States result in substantially similar outcomes despite adopting initially different approaches?* There were four main reasons for this research. First, NEHRs were, and continue to be, an important public policy issue with extensive claims that they will improve the efficiency and effectiveness of healthcare and benefit patients. This claim is premised on NEHRs being interoperable and containing usable patient information which is meaningfully used to improve patient health outcomes. Second, considerable funding has been allocated by states to NEHR programs in pursuit of these claims. It is important to examine these claims and how states attempted to reap the potential benefits. Third, the literature gap identified in Chapter 2 shows there is little comparative case study research that adopts an historical institutionalist framework comparing NEHRs across Australia, England and the United States. The research therefore makes a contribution to empirically based theoretical concepts of path development such as temporal sequencing, path dependence, critical junctures and incremental institutional change by establishing whether or not, or to what degree, these phenomena were present in each case. Fourth, the research also contributes new knowledge to comparative public policy evaluation theory including adding the component of normative justification. In policy terms, this deeper understanding of what happened, why it happened and what the outcomes were may be useful for future NEHR policy development.

Part 1 of this chapter will outline the research method used to conduct the research. The thesis is an interpretive study that employs a qualitative methodology of examining cases that have different initial conditions yet similar outcomes. It is characterised by an explanatory empirical approach based on comparative case studies emphasising key patterns of similarity and difference over time. First, the strengths and weaknesses of adopting a case study approach will be discussed, as will the author's reflexivity. Second, the process for gathering and analysing the data will be covered. This process includes case selection, data collection (ethics approval, semi-structured interviews, examination of primary and secondary sources, theory and literature), data analysis, generalisability, and the empirical limitations and boundaries of the research.

Part 2 of the chapter explains how the comparative evaluation of the cases will be undertaken and the development of two theoretical frameworks to structure the research. A number of sub-questions emerge from the theoretical framework and the comparative method used in the thesis, the answers to which inform the overall argument presented in answer to the thesis question. These questions will be stated in the Part 2 of this chapter. These theoretical frameworks are: 1) comparative public policy evaluation and 2) historical institutionalism (both foreshadowed in Chapter 2). The explanatory strength of historical institutionalism will be enhanced by first analysing the policy outcomes of institutional development in ehealth and NEHRs using comparative public policy evaluation (CPPE). Using Newman's[191] four categories of policy evaluation – process, goal attainment, distributional outcomes, political consequences – and contributing a fifth category of normative justification a richer and more nuanced explanation of why initially different institutional approaches resulted in substantially similar outcomes will be provided. The combination of historical institutionalism and CPPE therefore contributes to theory development. It also informs the research questions to be asked which attempt to unravel the complexities at the nexus of ehealth institutional policy development and subsequent creation of state sponsored EHRs, as well as to assess institutional outcomes.

An historical institutionalist approach (HI) is adopted to examine three modes of institutional stasis and change which are unified in their attention to explanations rooted in time. The three modes are path dependency, critical junctures and incremental institutional change. This framework will be used to map the historical development of ehealth institutions, identify the nationally shareable electronic health record (NEHR)

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[191] Newman's approach is based on David Marsh and Allan McConnell's (2010) earlier contribution.

options available to policy makers and the NEHR adoption choices made, and explain what changed and why. The examination of each mode will result in a series of questions, as previously indicated, that will be used to analyse the empirical evidence found in chapters 5, 6 and 7. The path dependency and critical juncture modes will inform heuristic frameworks and diagrammatic models used to frame the empirical evidence to explain similarities and differences.

The discussion in Chapter 10 will present a high-level explanatory HI framework based on the scholarship of Theda Skocpol, in particular her 1979 work found in *States and Social Revolutions*. Therefore, questions that emanate from Skocpol's theoretical perspective inform the discussion in Chapter 10 and will be outlined in Part 2 of this chapter.

Part 1

Research Method

The method chosen to conduct the research for this thesis is a qualitative comparative case study. Specifically, it embeds the theoretical framework of historical institutionalism and comparative public policy evaluation in the comparative method using cases that present a 'different conditions but similar outcomes' approach. Different conditions are identified through examining the specifics of each country's ehealth system's institutions. Similar outcomes are explained in terms of policy convergence across case study countries. This method is appropriate for comparing institutional change over time as it has benefited from the long and productive history in the social sciences of comparative analysis linked to historical investigation with thinkers such as Adam Smith, Karl Marx, Max Weber and, more recently, Carolyn Hughes Tuohy and Theda Skocpol figuring prominently.[192] Comparative case studies involve a certain degree of unpredictability and may result in an adjustment or change

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[192] James Mahoney and Dietrich Rueschemeyer, *Comparative Historical Analysis in the Social Sciences*, Cambridge Studies in Comparative Politics (Cambridge: Cambridge University Press, 2003), 3.

of focus[193] as empirical evidence gathered over time guides the researcher to a more complete understanding of the research topic. Meloy notes that this flexible approach to "conducting and writing up qualitative research is an evolutionary and inductive process."[194] The research journey this thesis has undertaken reflects this evolving approach in that it changed from researching patient rights to the portability of their health information to explaining converging outcomes in NEHRs – a much bigger institutional change story.

When conducting comparative research, the researcher must address three important questions: why do we compare, how do we compare and what is it our comparative studies are finding?[195] Adopting this approach, this research aims to explain, as opposed to prescribing the adoption of, particular ehealth and NEHR policies. The research mostly undertakes inductive pattern recognition, rather than deductive model-testing, identifying **IF** path dependency, critical junctures and incremental institutional change occur and influence policy outcomes. I use the words 'mostly' and 'rather than' deliberately because, as Tuohy notes, scholarship in comparative health policy is characterised by a rich mix of considerations rather than answering questions in either/or terms.[196] The complexity of this type of research is borne out in this thesis where explanation and pattern recognition do to some extent test models of path dependency, critical junctures and incremental institutional change that result in some policy convergence across case study countries.

Qualitative Comparative Case Study

Author's Reflexivity Over Time

At the conceptualisation of the research stage the initial thesis question focused on patient rights to the portability of their health information. This was based on my interest in health information rights and my original assumptions regarding the utility

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[193] Judith M. Meloy, *Writing the Qualitative Dissertation: Understanding by Doing*, 2nd ed. (Mahwah: Lawrence Erlbaum Associates, 2002), 1.

[194] Meloy, 1.

[195] Carolyn H. Tuohy, "Shall We Dance? The Intricate Project of Comparison in the Study of Health Policy," *Health Economics, Policy and Law* 7, no. 1 (2012): 21.

[196] Tuohy, 21.

of EHRs in that space. As the research progressed, it became clear that there was a bigger institutional story that demanded investigation and explanation and that health information rights were only one part of a much bigger institutional change picture – one where NEHR policy choices structured health information outcomes. The method of data collection applied in the research, mainly semi-structured interviews, was particularly useful in adapting the thesis as it developed. Broad ranging interviews provided the data needed to answer the different conditions yet similar outcomes question that emerged from the research. This proved to be a far more interesting and complex institutional story than originally envisioned, particularly when examining stasis and change at different levels within the ehealth institutional framework.

Strengths of the Case Study Approach

The value of case studies is well known in political science.[197] Further, comparative case studies broaden "our understanding of the political world, leading to improved classifications and giving potential for explanation and even prediction."[198] Tuohy argues that "comparisons across *time within* nations can marry well with cross-national comparison"[199] which is the approach taken in this thesis. Doing so leads to a "more nuanced understanding of the scope and limits of the possible in particular nations, in ways that can inform policy debate."[200] By comparing cases, the research will also attempt to find out if NEHR regulation-based governance frameworks were sustained

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[197] Marsh and Stoker, *Theory and Methods in Political Science*; Mark Exworthy et al., eds., *Shaping Health Policy: Case Study Methods and Analysis* (The Policy Press, 2012). Exworthy and Powell argue that health policy has not been immune to the trend of case studies arguably becoming "the predominant method by which much of social science is conducted," 3.

[198] Rod Hague and Martin Harrop, *Comparative Government and Politics: An Introduction*, 8th ed. (Basingstoke: Palgrave Macmillan, 2010), 46. Gerring argues that "much of what we know about the empirical world is drawn from case studies," which is supported by Yin who sees case studies as "the building blocks from which we construct our understanding of the political world." John Gerring, "What Is a Case Study and What Is It Good For?" *American Political Science Review*, (2004), 341; Yin, 2003, in Hague and Harrop, *Comparative Government and Politics*, 46.

[199] Tuohy, "Shall We Dance? The Intricate Project of Comparison in the Study of Health Policy," 22, emphasis in original.

[200] Tuohy, 22.

and refined over a long time period and to what extent consensual institutions and processes were required to make this happen.[201]

This research compares the development, implementation and regulation of NEHRs at the national level in Australia, England and the United States in order to establish a plausible explanation of NEHR institutional stasis and change over time, contributing to the literature on institutional evolution. It is a longitudinal study that extends beyond a key moment in time and "establish[es] sequences of events"[202] which are useful for "detecting developments or changes in the characteristics"[203] of the object of interest. Capoccia argues that longitudinal studies of critical junctures have enabled scholars to successfully offer "systematic analyses of institutional origins … generat[ing] key theoretical insights on the origins of important institutions and … guid[ing] research on other, comparable cases."[204] Theory therefore informs the method used to analyse the data collected by focusing on comparing the development of institutional pressures and tensions; institutional values and norms, rules, practices and procedures (NRPPs); and the barriers to, and enablers of, institutional change. The thesis does so by examining NEHR path dependency, critical junctures and incremental institutional change in order to plausibly explain why the initial adoption of different approaches to NEHRs resulted in substantially similar interoperability, usability, meaningful use and control of patient health information outcomes. The case study technique adopted in this thesis allows for the establishment of "a more variegated set of tools to capture the complexity of social behaviour"[205] that preserves "the texture and detail of individual cases, features that are often lost in large-N cross-case analysis."[206]

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[201] Tuohy argues that consensual political institutions and processes are less typical in the American context which is supported by Steinmo and Watts. Examining how politics and process came together to produce significant healthcare reform and establish an NEHR project in the US is one of the more interesting aspects of this thesis. Tuohy, 22.

[202] Toronto Institute for Work & Health, "What Researchers Mean by Cross-Sectional vs. Longitudinal Studies," At Work, accessed April 26, 2017.

[203] Toronto Institute for Work & Health.

[204] Giovanni Capoccia, "When Do Institutions 'Bite'? Historical Institutionalism and the Politics of Institutional Change," *Comparative Political Studies* 49, no. 8 (2016): 101.

[205] John Gerring, *The Case Study: What It Is and What It Does*, *The Oxford Handbook of Comparative Politics*, 2013, 2.

[206] Gerring, 3.

Weaknesses of the Case Study Approach

Tuohy's observation that comparative studies are a "dance – between explanation and prescription, between inductive and deductive analysis, and between attention to converging elements and attention to the continuing distinctiveness of each nation"[207] is apt. For some research traditions this approach may seem to lack rigour with the methodological status of the case study seen as "suspect." [208] This "extreme circumspection" is "identified with loosely framed and non-generalizable theories, biased case selection, informal and undisciplined research designs, weak empirical leverage (too many variables and too few cases), subjective conclusions, non-replicability, and causal determinism."[209]

Therefore, there are a number of issues to be aware of. The literature labels critical junctures as rare events.[210] While this is the case at the macro level of analysis (regime change and ehealth system chosen), where there is a clear status quo of paper health records broken by a critical juncture that established a new path of electronic health records, the length of the time period between critical junctures was shorter at the other levels of analysis (organisations, unit of comparison - NEHRs).[211] While the overall policy aim of moving from paper health records to electronic health records persisted, changes in policy at the organisational and NEHR levels of analysis were more rapid than at the macro level. Institutional change in ehealth systems chosen, organisations created or changed to implement NEHRs, and policy regarding NEHR interoperability, usability, meaningful use and control of patient health information (the categories of analysis) had clear critical junctures at much shorter intervals. These critical junctures changed

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[207] Tuohy, "Shall We Dance? The Intricate Project of Comparison in the Study of Health Policy," 23.

[208] Gerring, *The Case Study: What It Is and What It Does*, 4.

[209] Gerring, 3.

[210] Sven Steinmo and Jon Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," *Journal of Health Politics, Policy and Law* 20, no. 2 (1995): 329–89; Carolyn Hughes Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.* (Oxford University Press, 1999).

[211] The three levels of analysis I diagram in Figure 3.1 (more fully discussed in Chapter 4) adapted de Percy's and Batainah's three main levels of analysis – macro (institutional choices and preferences at the national level), miso (industry or sectoral level) and micro (individual firms or projects) levels – to more clearly delineate interactions between institutions and organisations over time, the changes they produced, or stasis that developed. Michael de Percy and Heba Batainah, "Government-Business Relations," in *Australian Politics and Policy: Senior Edition*, ed. Peter Chen et al., 2019.

the status quo at their level of analysis, as can be seen in Figure 3.1. I wanted to analyse the interaction of institutional change between levels to help answer the research questions. The levels of analysis may also cause confusion because they may infer that the things being centralised are rather different. This is true in that the US left NEHR development and implementation mostly up to the private sector whereas Australia and England had much more state control over these two things. However, it the regulatory frameworks, the organisations created or amended, and the categories of analysis that were centralised and exhibited similar outcomes.

The research had to make some trade-offs. First, I sacrificed a quantitative approach to the research question that may have yielded its own set of important insights in favour of a qualitative approach. I chose a small selection of cases and a small scale set of interviews. Three case study countries allowed for depth and richness in the analytical narrative and the individual perspectives of a small set of interviewees was more valuable to me than a larger set of data about responses to the same questions. However, case selection bias limited generalisation from a small number of cases for the purposes of understanding a larger class of similar cases. Second, the benefits and risks[212] of using interview material from experts and partisan policy actors had to be effectively balanced. Benefits included: privileged access to information and specific policy and program knowledge that was technical, process oriented and explanatory; the interviewees were often networked so the snowballing technique could be applied; and they were mostly willing to cooperate. However, these benefits had to be balanced against risks that included: the lack of neutrality of the information obtained; interviewer/interviewee interaction that was not rigorously standardised due to the semi-structured nature of the questions; and the occurrence of non-structured dialog in interviews (particularly with two or more participants) in which the interviewer actively participated; and the danger of anecdotal and illustrative information that might prove difficult to confirm or triangulate. Third, data collection and analysis took place as NEHR policies continued

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[212] Leo Van Audenhove, “Expert Interviews and Interview Techniques for Policy Analysis,” 2007.

to be developed, implemented and underwent regulatory change. Case selection, data collection and the generalisability of findings are discussed in more detail below.

Process for Gathering and Analysing Data

The research established and then analysed a thick empirical narrative of NEHR development (the primary object of inference) in three roughly similar case study countries from the late 1990s to 2015 (the temporal boundaries). It was a retrospective and parallel, multiple country study at the national level. Each case study country broadly expected similar benefits from NEHRs in the form of more efficient and effective healthcare service delivery resulting in better health for patients. Policy issues concerning privacy and the rights of patients to control their health information, while showing "varieties of particularism,"[213] were broadly similar. However, there were differences in the role of the state in the funding and provision of healthcare which led to initially different approaches to state efforts to pursue NEHRs.

Case Selection

Case study countries were chosen on the following basis. Each case study country was attempting to implement and regulate an electronic health record that was shareable nationally at all points of care. This was the primary object of inference across cases. The cases had observable similarities and differences in analytical phenomena, such as interoperability, usability, meaningful use and control of patient health information. They were relatively information rich due to my access to proximate ehealth/NEHR actors who spoke English and the availability of English language literature regarding ehealth programs. Analysing if policy convergence across case study countries occurred with NEHRs required a detailed contextual description of each case study country to identify patterns of elements that have an impact on, and can explain, policy divergence or policy convergence. It was expected at the start of the research that NEHR policy divergence would persist given the constraints of path dependency and an emphasis

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[213] de Percy, Michael, "Connecting the Nation," pp. iii, 28. de Percy uses the term varieties of particularism to refer to "the unique social, political, economic, technological and geographical peculiarities that exist at the nexus of government, business and communications technology." I use it here to specifically refer to health information technology in the form of NEHRs.

identified in the literature that institutional structural barriers, particularly in the US, may make institutional reform impossible.[214] The divergence between actual results and what was expected was unexpected and will be examined in Chapter 10.

Australia was selected because it was similar enough in NEHR policy direction to effectively compare approaches and outcomes with the other case study countries. However, it was different enough in its overall approach to both ehealth and NEHRs to provide points of contrast that would answer key question about institutional implementation, development and regulation. Australia was also an appropriate place to undertake the research as I had lived there most of my life and was familiar with its health system and somewhat familiar with health policy. Being based in Australia gave me access to proximate ehealth/NEHR actors, particularly as many of them were based in Canberra and near the ANU. This gave me access to multiple stakeholders at the national and state level, in the public service, medical profession, healthcare consumer advocates, industry and ehealth/NEHR critics.

England was selected as it had tried a top-down centralised approach to the implementation of health information technology in the form of the NPfIT, had created numerous organisations to implement ehealth and NEHR programs, had failed to achieve desired outcomes, and at the starting point of the research was contemplating a change in policy. This was particularly interesting in framing the research questions as Australia had tried to learn from England's failures and partial successes. England was also chosen because English was my first language and I could travel to, and conduct research in, England with few barriers.

The United States was chosen because the literature indicated that major healthcare reform was unlikely, or even impossible given structural constraints, yet major NEHR reform occurred. Structural constraints that made health policy consensus rare[215] led the

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[214] See Sven Steinmo and Jon Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," *Journal of Health Politics, Policy and Law* 20, no. 2 (1995): 329–89, where they discuss how the institutional context in the US "explains (and could be used to predict) the failure of national health care reform in America," 330.

[215] Steinmo and Watts; Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*

US to take an initially different policy approach to Australia and to England regarding both ehealth and NEHRs. However, through the HITECH Act the US adopted a number of similarities in institutional design as Australia and England. I wanted to find out if the centralising tendencies of policy in areas such as funding, implementing and regulating NEHRs were similar or different to the other two case study countries and what NEHR policy lessons may therefore be learned. The US was also chosen because the dominant language was English, I had lived in the US for approximately 14 years and had some familiarity with the healthcare system and broader political culture, and I could travel to, and conduct research in, the US with few barriers. However, barriers were encountered including vast distances between interviewees from San Francisco, to Salt Lake City to Washington D.C. and more interviews were conducted by phone than with any other country.

Data Collection

Ethics approval was obtained at the end of 2012 from the ANU Human Research Ethics Committee. Based on ethics approval an information sheet was sent to every person I endeavoured to interview. The information sheet introduced me, explained why the research was being carried out, the purpose for collecting the data, why I selected that person as a potential participant and what the interview would entail, how the research was to be used, any risks to the person in participating, and contact and phone numbers the person could use to contact me, my supervisor and the ANU Human Ethics Officer. Every person who agreed to participate in an interview was sent or given a consent form that asked them whether or not they agreed to participate as an interviewee and consent to the publication of the results of the research, a choice of how the information they provided me would be attributed, that they could withdraw from the research at any time as well as withdraw any information they provide (no-one did), and whether or not I could record the interview, and if not, asked if I could take written notes.

Interviews

The research in this thesis relied on qualitative data, primarily data collected through interviews with proximate actors in each of the case study countries. It was felt that these sources would be most appropriate to answer the research questions given their familiarity and experiences with ehealth and NEHR policy, programs and regulation. The rationale for selecting the range and types of interviews in each country was my access to actors and my preference for face-to-face interviews which often gave me more time with actors and positive responses when I asked for follow-up interviews. I tried to interview actors who had a variety of experiences and perspectives on both ehealth and NEHRs. The range of interviewees included former and current senior officials responsible for policy and program implementation, management and regulation; medical professionals involved in policy and practice; NEHR industry actors whose practical application of health information technology linked policy and practice together; academics, many of whom were also medical practitioners or whose research focus was ehealth and EHRs; media actors who were able to identify criticism of both policy and program as well as give insight into political processes; and healthcare consumer advocates who had a variety of perspectives regarding ehealth/NEHR policy, implementation and regulation. Face-to-face interviews also allowed me to ‘read’ actors in a way not possible via phone interviews leading to different follow-up questions and an exploration of issues and context that did not always present itself in phone interviews.

Interviewees were selected firstly by identifying proximate NEHR actors and emailing them to request an interview. A limited schedule of initial actors was used for each country as a starting point. Secondly, I used the snowball technique, asking those I had interviewed if they could connect me with other proximate actors. This proved to be quite a successful technique, particularly in Australia. Physically being located in Australia, and for four weeks in England and four weeks in the US assisted in obtaining access to proximate actors and many face-to-face interviews. Questions to interviewees were semi-structured in order to both focus on specific topics such as interoperability, usability and meaningful use of patient health information, and to allow for topics of interest raised by interviewees to be explored in a way that would elicit useful information and allow triangulation questions that interrogated interview responses. The questions I asked interviewees depended on their role and perspective, and were based on the questions that emerged from the theoretical framework I used (see questions later in this chapter) and the literature review in Chapter 2. Interviews were mostly recorded on an electronic tape recorder and then transcribed. One interview of a senior official in England was recorded by taking notes at the time of the interview. Data analysis of transcribed interviews is explained later in the next section of this chapter.

The rationale of using interviews as a key source was that the research collected extensive amounts of original primary data and interviewees gave numerous insights into NEHR institutional stasis and change that were not readily available from other sources. Interviews gave me insights into each country's particularities of their ehealth systems and NEHR programs regarding interoperability, usability, meaningful use and control of health information that was often not well covered in the literature. However, this approach was limited through its reliance on participants being available and accessible, particularly in England and the United States.

Early on in the research I was unsure how valuable interviews would be in providing data to answer the research questions. At that stage I primarily relied on consultancy, government committee and academic reports and assessments of ehealth and NEHR programs. However, as the interviews progressed it became clear that they provided a much more nuanced and detailed assessment of policy success or failure. For example, government funded reports assessing Australian ehealth/NEHR programs often painted a picture of process success glossing over the fact that outcomes such as patient information being available at all points of care had not been met.[216] In England, parliamentary committee reports were often scathing in their assessments of the NPfIT and the SCR whereas interviewees were able to identify areas of success on both the local

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[216] For example, the National E-Health Transition Authority, "Evolution of EHealth in Australia Achievements, Lessons, and Opportunities" (Sydney, 2016), report noted achievements in the delivery of foundations, the My Health Record, the contribution of HealthConnect, and the establishment of strong relationships and collaborative partnerships between policy makers, governments, vendors, healthcare providers, and peak professional bodies. Interviewees painted a more nuanced and detailed picture of some process success in these areas but overall failure to deliver an NEHR that was widely used to improve patient health outcomes, which had been the policy outcome rhetorical goal for nearly two decades. Interviewees were also able to explain, from their perspective, why this was the case and these explanations often challenged the official narrative regarding outcomes.

and national level.[217] In the US it was easy to assume early in the research that the partisan divide between Democrats and Republicans was absolute on healthcare reform due to the rhetoric that emanated from each party and the voting patterns on major pieces of legislation. Interviewees were able to identify areas where both parties had some policy congruence, particularly at the NEHR level.[218]

A list of interviewees for each country can be found in the Bibliography. The reference list is arranged by primary and secondary sources.

Theory and Literature

The structure of the literature review was revisited multiple times over the course of writing the thesis as key themes emerged leading to interesting new questions and the thesis structure itself underwent revision. The initial literature search profile was partially embryonic and as such failed to adequately clarify the scope and parameters of the study. Keywords such as ehealth and electronic health record were far too general, even when combined with country of study. Major scholars in the field, such as Greenhalgh, had produced large quantities of work from a variety of theoretical and methodological perspectives. The result was that "an overwhelming number of potentially useful articles" [219] were retrieved. At times, I was side-tracked down interesting, but ultimately irrelevant, byways that often focused on the clinical usefulness of specific health information technologies that were, or had the potential to be, integral components of an overall ehealth framework but were not specifically relevant to answering the thesis question. As the research progressed, key themes emerged and were categorised and I refined the literature search as follows:

1. By date: 1998 to 2015.
2. Language: English.
3. Country of study: Australia, England, the United States.

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[217] See Chapter 6 for further detail.

[218] See Chapter 7 and the analysis in Chapter 10 for further detail.

[219] Kathryn Jones, "Doing a Literature Review in Health," *Researching Health: Qualitative, Quantitative and Mixed Methods*, 2007, 37.

4. Key terms: NEHR or nationally shareable electronic health record, interoperability, usability, meaningful use and control of patient health information (including privacy), Summary Care Record (SCR), HealthConnect, Personally Controlled Health Record (PCEHR).
5. Theoretical concepts that were NEHR related: historical institutionalism, path dependence, critical junctures, incremental institutional change, comparative public health policy.
6. Other concepts relating to the provision, funding and governance of NEHRs. Doing so was particularly useful for analysing the regulatory environment that established institutional rules, norms and values.

I used the Australian National University Library's 'supersearch' to search all available databases at ANU, Google scholar, as well as snowballing from references and bibliographies. The literature search identified key scholars relevant to the research such as Steinmo and Watts, Greenhalgh et al., Tuohy, Blank and Burau, McLoughlin et al., Timmermans and Berg, Wyatt et al, Black et al, among many others.

There were some issues encountered with specific terms and key concepts:

1. Interchangeable use of the acronyms EHR, MHR, EPR, PHR, SEHR. I discuss this issue in Part 3 of Chapter 2.
2. General usage without well-defined definitional parameters of the concepts. I define many of these in the glossary:
    a. Patient-centred care
    b. Patient-centric care
    c. Continuity of care
    d. Co-ordination of care
    e. Safety of care
    f. Quality of care
    g. Efficiency of care
    h. Effectiveness of care
3. Contested terms:

   a. Consumer vs patient. I chose patient most of the time as the terms patient-centred/centric were most relevant and widely used in the literature whereas consumer-centred/centric was not.

4. Spelling: differences between Australian, English and American spelling when searching databases.

Primary source data was also collected from legislative acts and informed much of the analysis on the provision, funding and governance of NEHR policy. Secondary data was analysed from parliamentary and congressional reports, organisational and academic reports and submissions to NEHR reviews, academic literature, and the grey literature including ehealth blog posts. Most of these sources were obtained online. The strengths of this approach included triangulation with interviews and primary sources. There were limitations in that there is an enormous body of relevant ehealth literature and I had to be selective in its use by focusing on NEHRs.

Theory and literature were used as starting points and I chose to integrate the relevant literature within the following chapters rather than adopt a traditional literature review. This was due to the absence of similar research and the nature of case studies that rely on "multiple sources of evidence, with data needed to converge in a triangulating fashion."[220] It became apparent as the research progressed, especially as interviews were being conducted, that the explanatory narrative would be more interesting and better supported incorporating "rich, 'thick' descriptions that draw on multiple sources of evidence and on some theoretical insights"[221] using the case study method.

Data Analysis

Data from interviews was central to answering the research questions. Two primary methods of data analysis were used. The first was comparative inductive reasoning. This involved identifying, categorising and comparing key themes that emerged both during and after data collection. Those key themes were interoperability, usability, meaningful

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[220] Yin (2009), in Exworthy et al., *Shaping Health Policy: Case Study Methods and Analysis*, 4.
[221] Exworthy et al., 5.

use and control of patient health information. Interviewees answers to the questions in Part 2 of this chapter directly informed the main arguments in the thesis and also the answer to the research questions. Case study country similarities and differences in the development, implementation and regulation of NEHRs that emerged in the empirical chapters were identified and explained in Chapter 8, including important different conditions and similar outcomes. The results of this comparative evaluation were then used to inform the theoretical analysis. The theoretical analysis focused on a comparative public policy evaluation and an historical institutionalist explanatory framework. Comparative public policy evaluation addressed policy process, goal attainment, distributional outcomes, political consequences and normative justification. Historical institutionalism examined path development through the lens of path dependency, critical junctures and incremental institutional change. I used theory replication to shine a light on health initiatives. The combination of comparative inductive reasoning and theoretical analysis provided a plausible explanation in answer to the thesis question as well as addressing questions set out in the theoretical framework section of this chapter.

Generalisability of Findings

Given the level of specificity of the empirical narrative, the comparative analysis later in the thesis produced some generalisations that have some potential for "prediction ... [and] drawing lessons across countries."[222] However, there are limitations to the generalisability of the findings in this thesis due to selection bias and the nature of a qualitative triangular comparison. Selection bias is present as the cases were not chosen randomly. They were selected due to their basic similarities as English speaking liberal democracies, their initially different approaches to NEHRs, their broadly similar outcomes in pursuit of NEHRS, and because of the practical need to undertake PhD research in accessible countries with access to proximate actors. This was a most similar political and cultural systems design approach which helped limit the number of potential comparable variables and more effectively highlighted that the cases had different conditions but similar outcomes. Qualitative triangular comparison leaves the

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[222] Hague and Harrop, *Comparative Government and Politics: An Introduction*, 47.

door open for many factors remaining "as possible explanations for an observed difference"[223] or similarity. However, the research design allowed the research to test the relationship between NEHR development, implementation and regulation and resulting efforts to increase the interoperability, usability and meaningful use of patient health information to improve the efficiency and effectiveness of healthcare. While the research "remains sensitive to the details of the particular countries and policies" studied, similarities and differences were identified allowing "research findings to accumulate"[224] that may be informative in the study of other countries NEHR programs. Therefore, the most compelling explanation that emerged based on the methodological framework was that similar barriers to, and enablers of, NEHR interoperability saw decentralisation give way to the attempted centralisation of patient health records forcing a level of conformity on all three NEHR programs.

Empirical Limitations and Boundaries of the Research

The research encountered the following empirical limitations:

1. Access to key actors. Australia provided the most-ready access to proximate actors. Therefore, I conducted more than twice as many interviews with Australian actors than actors in England and the United States. The quality of responses was highest in Australia, followed by the United States then England and this was directly related to the number of proximate actors involved in the policy process interviewed in each country. Therefore, the research was supplemented by secondary sources to a greater extent in England and the United States than in Australia.

2. Funding for the research. The level of funding normally given for PhD research limited the time available for research outside of Australia. This limited the results of interview snowballing to the time available in each country. It also limited the geographical extent to which I was able to travel for interviews,

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[223] Hague and Harrop, 51.
[224] Hague and Harrop, 51.

particularly in the United States, though this was to some extent ameliorated by phone and Skype interviews when available.

3. Time bounds of the research. The vast majority of the research was concluded during 2014. The death of my wife in October 2015 and subsequent illness on my part delayed the project by three years. However, I have included some recent developments where appropriate to further develop the empirical knowledge presented in the thesis and enhance the plausibility of the findings and arguments.

The next part of this chapter outlines the theoretical framework and the concepts applied in the analysis of NEHRs.

Part 2

Theoretical Framework – Concepts Applied in the Analysis

Embedding theory into the comparative method enables the researcher to "illuminate some of the central animating questions of comparative health policy research"[225] as discussed in Part 1 of this chapter. In this thesis, historical institutionalism (HI) and comparative public policy evaluation are the theoretical lens through which a plausible explanation of why substantially similar NEHR interoperability, usability, meaningful use and control of patient health information outcomes were experienced in all three case study countries despite adopting initially different approaches. These theories informed the questions asked in the semi-structured interviews and contributed to further development of the research questions and the subsequent analysis of the qualitative data.

Comparative Evaluation of Cases

The empirical research conducted for each case study country in chapters 5, 6 and 7 is comparatively evaluated in Chapter 8. The similarities and differences between institutional criteria are evaluated. These institutional criteria include structural

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[225] Tuohy, "Shall We Dance? The Intricate Project of Comparison in the Study of Health Policy," 21.

antecedent conditions, shock events, ideational change, political agency and converging social, medical professional, technical and fiscal trends. The intent is to develop an explanation of how, why and to what extent institutional pressures and tensions led to policy problems and issues that states addressed through NEHR policy. It aims to identify major ehealth and NEHR policy problems in each case study country and analyse the similarities and differences in the approaches taken to address those policy problems and the outcomes that resulted. Whether or not each country had similar or different approaches, goals and outcomes will be comparatively examined. This addresses some of the key questions raised by Blank and Burau regarding those problems that spring from common roots and those that spring from specific national circumstances and whether or not diverse systems make a difference in policy outcomes as identified in Chapter 2. Doing so will also set up a comparative public policy evaluation of policy success or failure in Chapter 9.

Comparative Public Policy Evaluation

The extent of the success or failure of public policies to achieve NEHR outcomes is explored through the application of comparative public policy evaluation. Doing this enhances the plausibility of the explanation in support of the main arguments made in the thesis while providing the opportunity for a more detailed exploration of some of the institutional complexities that both states and stakeholders encountered as NEHR programs progressed. Comparative public policy evaluation is a useful theoretical framework within which to discuss policy success and failure as outlined in the literature review. Newman notes that “no agreement has emerged on what constitutes a successful policy” and policies can experience “different modes of success and failure … at the same time.” [226] This became apparent during the research as achieving organisational objectives may have been seen as a success by some but was at the same time unsuccessful in achieving desired policy outcomes. Newman argues that:

> public policy should be divided into four separate areas for the purposes of evaluation: a) process – the path along which policy statements are converted

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[226] Joshua Newman, “Measuring Policy Success: Case Studies from Canada and Australia,” *Australian Journal of Public Administration* 73, no. 2 (2014): 192.

> into instruments for implementation; b) goal attainment – the degree to which originally stated goals are achieved; c) distributional outcomes – who benefits from a particular policy, who is punished, and to what extent these outcomes are experienced; and d) political consequences, by which I mean electoral dividends and rewards in popular opinion accrued to governments, oppositions, and organised political parties.[227]

This thesis adopts Newman's four categories of policy evaluation to assess the extent of policy success or failure in pursuing NEHR programs and achieving interoperability, usability and meaningful use outcomes. The thesis makes a contribution to both theory and to the literature by adding two further categories. Programmatic and operational dilemmas provides more depth to explanations of NEHR program success, partial success and failure. Normative justification aligns policy evaluation with a society's public values. This addresses a gap in the policy evaluation literature in which concepts such as the public good, rights and values are often incidentally subsumed under other headings without a clear indication of normative consensus. This thesis will use Bozeman's definition, set out below, to structure an argument regarding policy success or failure along normative lines.

> A society's public values are those providing normative consensus about (a) the rights, benefits, and prerogatives to which citizens should (and should not) be entitled; (b) the obligations of citizens to society, the state and one another; and (c) the principles on which government and policies should be based.[228]

The issue of power – who has it, and what it is used for – is a perennial question in political science. Normative justification will address the issue of power through the concept of power relationship ratios.

The main question that emerges from a comparative public policy evaluation is to what extent was each country's NEHR policy successful? Specific sub-questions based on each of the six categories of policy evaluation are as follows.

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[227] Newman, 192.

[228] Barry Bozeman, *Public Values and Public Interest: Counterbalancing Economic Individualism* (Washington, DC: Georgetown University Press, 2007), 13.

Process

1. Was policy converted into substantive legislation or public programming?

Goal Attainment

2. Were stated policy objectives achieved?

Programmatic and Operational Dilemmas

3. What programmatic and operational dilemmas were encountered and how were they resolved by the state?

4. Did some dilemmas persist for some time or even go unresolved?

5. What trade-offs did the state make between stakeholders in its attempts to resolve dilemmas?

6. Were attempts at resolving dilemmas successful?

Distributional Outcomes

7. Which stakeholder groups benefited or dis-benefited from their country's NEHR policy?

8. What were the specific ways each stakeholder group benefited or dis-benefited from NEHR policy? (The degree to which each stakeholder group benefited or dis-benefited, in comparison to other stakeholders, from NEHR policy will be left to the normative justification category and the discussion on power relationship ratios.)

Political Consequences

9. To what extent did governments, or other political actors, benefit from the public reaction to, or perception of, NEHR policy?

Normative Justification

10. To what extent did NEHR policy reflect the normative consensus regarding the rights, benefits and prerogatives to which citizens of each country should, and should not, be entitled?

11. To what extent did NEHR policy reflect the normative consensus regarding the obligations of citizens to society, the state and one another in each country?

12. To what extent did NEHR policy reflect the normative consensus regarding the principles on which government and policies should be based in each country?

13. To what extent did NEHR delivery models reflect prevailing government (political executive and public service) norms on procurement and development?

The detail presented in Chapter 9 informs the historical institutional analysis conducted in Chapter 10 as well as the findings and contribution to knowledge.

Historical Institutionalism – A High Level Analysis

Historical institutionalism is a useful framework to explore whether or not patterns of institutional stasis and change occurred over time. The HI framework also enables a diagrammatic representation of path dependency and critical junctures presented later in this chapter. These models build on the work of Michael de Percy whose visual representation of path dependent punctuated equilibrium clearly showed where critical junctures disrupted the *status quo*, how subsequent policy choices were influenced by initial policy choices and the resulting new *status quo*.[229] Identifying processes of incremental institutional change may inform both the development of critical junctures and how feedback loops build the pressures and tensions that lead to critical junctures. Finally, as part of applying an HI methodological approach, it is important to link the various components of the institutional story together. This will be done in Chapter 10

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[229] Michael de Percy, "Connecting the Nation: An Historical Institutionalist Explanation for Divergent Communications Technology Outcomes in Canada and Australia" (The Australian National University, 2012); Michael de Percy and Heba Batainah, "Identifying Historical Policy Regimes in the Canadian and Australian Communications Industries Using a Model of Path Dependent, Punctuated Equilibrium," *Policy Studies*, February 20, 2019.

where, drawing on the scholarship of Theda Skocpol, important variations and common patterns in the outcomes between case studies will be identified and explained.

Diagrams representing each case study country's NEHR journey from paper to the NEHR unit of comparison under study will be presented in Chapter 10 in an effort to simplify the telling of the institutional story of change. As the research progressed, it became increasingly clear that four levels of analysis interacted with each other. Based on de Percy's scholarship, I felt that a diagrammatic representation that captured different levels of path dependence and critical junctures might more clearly identify patterns of institutional stasis and change over time. The method used was to analyse each level to clearly show if the status quo was changed by a critical juncture and, if so, what new path was initiated as a result of that change. Diagrams were used to identify if centralising tendencies in each jurisdiction persisted or were reversed, and if they persisted identify if centralisation at each level increased or remained constant. It was expected at the start of the research that centralising tendencies at all four levels of analysis would not only persist but increase in each case study country. That this process was not uniform across all four levels for each country, and was reversed in one, was surprising.

As each level of analysis is discussed vertical examination diagrams of critical junctures will complement the text. These will be combined into one diagram showing the case study country's story that reflects top-down drivers of change and the bottom-up feedback loop which incorporates elements of incremental institutional change discussed later in this chapter. The vertical examination is a useful counterpoint to the horizontal examination presented at each level which Hannigan and Evans see as the typical process for examining "significant turning points … [or] pivotal moment[s] when actions have enduring consequences which are hard to reverse." [230] A vertical examination also illustrates how institutional instability at different levels of analysis drive changes in other levels as shown in Figure 3-1.

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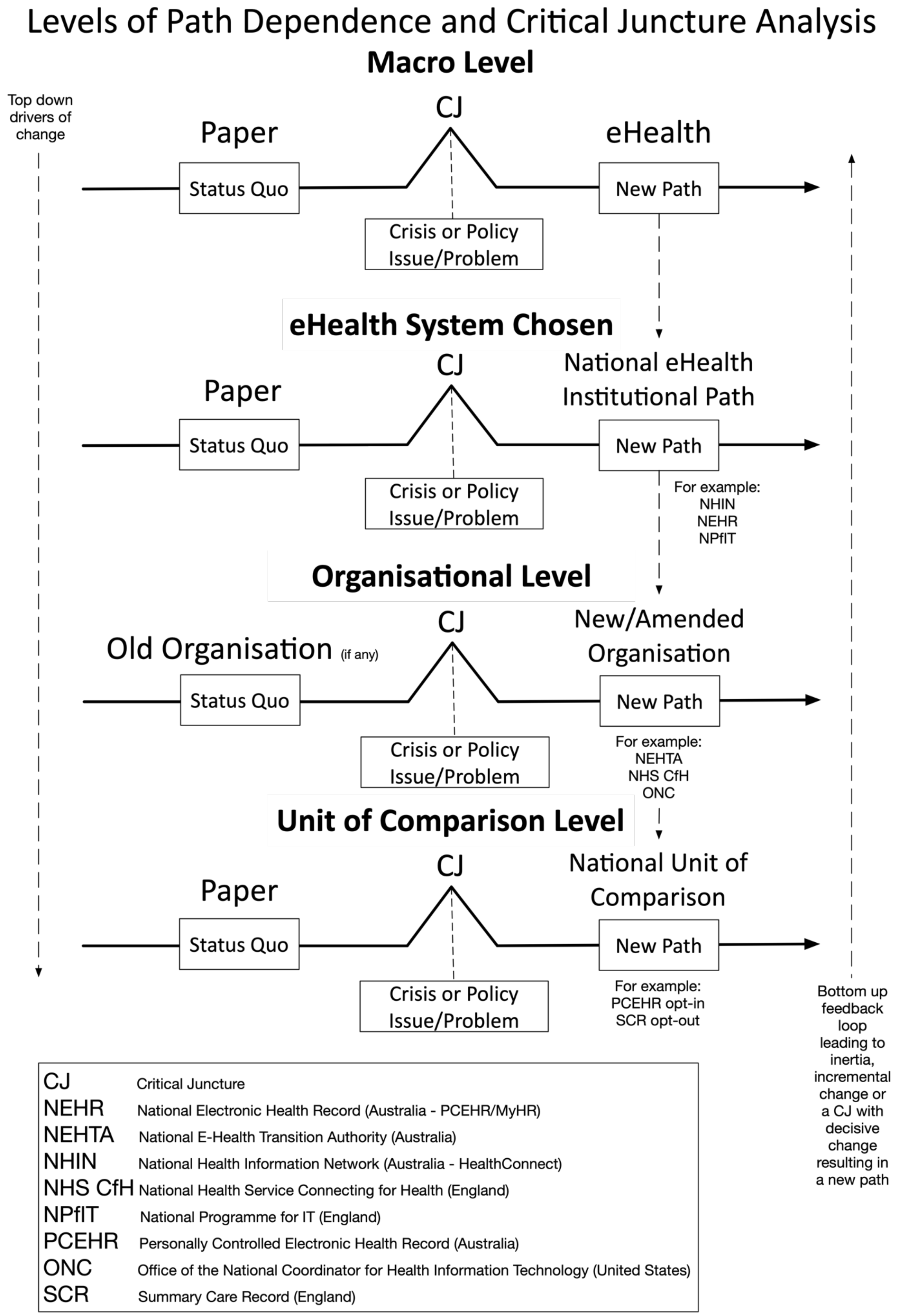
[230] Ben Hannigan and Nicola Evans, "Critical Junctures in Health and Social Care: Service User Experiences, Work and System Connections.," *Social Theory & Health* 11, no. 4 (2013): 439.



CJ	Critical Juncture
NEHR	National Electronic Health Record (Australia - PCEHR/MyHR)
NEHTA	National E-Health Transition Authority (Australia)
NHIN	National Health Information Network (Australia - HealthConnect)
NHS CfH	National Health Service Connecting for Health (England)
NPfIT	National Programme for IT (England)
PCEHR	Personally Controlled Electronic Health Record (Australia)
ONC	Office of the National Coordinator for Health Information Technology (United States)
SCR	Summary Care Record (England)

Figure 3-1: Levels of Path Dependence Analysis

Significant questions for the research to address that emerge from this framework and contribute to the historical narrative are:

1. What decisions were made to develop, implement and regulate NEHRs in each of the case study countries?
2. Why were those decisions taken?
3. What other options were available or considered?
4. Who favoured competing options?
5. Why was one option chosen and not others?

Theoretically, path dependence explains stability and stasis, critical junctures explain how change is generated. Path dependence questions therefore focus on path resilience, persistence and legacy. Critical juncture questions probe the development of critical junctures, the nature of the crisis or policy problem/issue that leads to a window of opportunity for change, the policy response to the crisis or policy problem/issue, and post crisis or policy problem/issue path development.

The questions that emerge from a study of each country's path dependency and critical junctures are as follows:

Major Questions

To what extent were the main NEHR institutional outcomes in Australia, England and the United States path dependent?

To what extent were the main NEHR institutional outcomes in Australia, England and the United States a result of critical junctures?

Path Dependency Questions

1. How does path dependency explain NEHR stability and/or stasis?

2. To what extent are the options available to policy makers at decision points limited by previous decisions that resulted in the current *status quo*?
3. To what extent are decisions made by policy makers contingent upon path dependent criteria such as lock-in, sunk costs, positive feedback, increasing returns and self-reinforcement?
4. Why do some paths (institutional arrangements) exhibit resilience to change?
5. Why do some paths (institutional arrangements) persist even though a new path has been adopted resulting in a new, more valued *status quo*?
6. Why do some old paths still have a legacy influence on institutional NRPPs that may create barriers to institutions adopting innovative options, adhering to new path institutional NRPPs or achieving the desired and/or predicted outcomes associated with the new path?

Critical Juncture Development

1. Why did a moment of structural indeterminacy and fluidity occur? This question will explain the role played in the critical juncture by the development of institutional pressures and tensions examined elsewhere in this thesis.

Nature of the Crisis or Policy Problem/Issue

2. What was the crisis or policy problem/issue?
3. Were there several options for radical institutional innovation available?
4. Was there more than one option that was physically and technologically possible?
5. Did actors have real choices? This question examines the practical feasibility of policy options.
6. Were those choices politically viable options?

Response to the Crisis or Policy Problem/Issue

7. Was one option selected? The option selected could be institutional re-equilibration which would either return to a previous *status quo* or maintain the current *status quo*.
8. Was this choice made as a result of political interactions and decision making? Answering this question involves examining the political processes through which institutional choices are made and identifying whether or not these processes unfolded in a well-defined context.
9. What structural antecedent conditions existed prior to the critical juncture that influenced the institutional outcome of the critical juncture?
10. To what extent was the institutional outcome constrained, but not pre-determined, by antecedent conditions?
11. What role did political agency play in the critical juncture?
12. Was there a direct connection between macro-structural antecedent conditions and the strategic interactions and political choices that led to the adoption of the NEHR institutional arrangement?

Post Crisis or Policy Problem/Issue Path Development

13. Did the initial selection result in a long-lasting institutional legacy?
14. What strategies were designed to embed and legitimize new institutions through ideational change?

Incremental Institutional Change

To the extent that path dependency and critical junctures fail to adequately explain institutional outcomes, the application of incremental institutional change as developed by Thelen will be used to provide supplementary explanatory scholarly rigour. Criticism of critical juncture theory as presented in the theory and literature review in Chapter 2 highlights the importance of incremental institutional change and offers the chance to test assumptions embedded in both path dependency and critical juncture theory. Path development that does not exhibit critical junctures produced by exogenous shocks may still undergo processes of change over time. Capoccia notes that "critical junctures are *rare* events in the development of an institution" and path dependent institutional change may be incremental as shown by the work of Thelen and others who have conceptualised "five modes of incremental change: layering, conversion, drift, displacement, and exhaustion."[231] The major question that emerge from criticisms of critical juncture theory and the study of incremental institutional change is: to what extent were the main NEHR institutional outcomes in Australia, England and the United States a result of incremental institutional change? Sub-questions are as follows.

1. Were the effects and decisions long lasting or were they reversed immediately, or even shortly afterwards? If reversed, was this a result of weak institutions?
2. Did the event/s or decision/s change one or more current structural antecedent conditions?
3. Was it an endogenous event or decision that resulted in incremental change and not a critical juncture? If so, did it result in layering, conversion, drift, displacement, and/or exhaustion?

Identifying Common Patterns of Change and Important Variations in Outcomes

Finally, it is important to identify common patterns of change and important variations in outcomes from a higher level of analysis than the detailed approach used in the earlier parts of the thesis. This will be done using questions that emerge from Skocpol's theoretical perspective on the role of the state as presented in *States and Social Revolutions* (1979). Skocpol is fundamentally concerned with the questions of what changed and why those changes happened. Her approach links case study narrative, policy evaluation and theoretical explanation in a big picture way (at a high level) and is a valuable framework through which to explain NEHR institutional change and

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[231] Jeroen Van Der Heijden, "Institutional Layering: A Review of the Use of the Concept," *Politics* 31, no. 1 (2011): 537.

outcomes across the three case study countries and inform my key findings. Asking what changed and why guides the research in the following ways. At the macro level the focus is firstly on:

1. An explanation of ehealth that includes "systematic reference to international structures and world-historical development."[232]

   From here the focus moves to each state in order to identify and explain:

2. Patterns of change that are common to all three case studies as well as identifying the important variations in the outcomes of the Australian, English and US case studies. These commonalities and variations include:
   a. Fundamental and enduring structural transformations.
   b. Changes in privilege and institutional power bases.
   c. Impediments to change remaining or being removed.
   d. Emerging institutions being challenged by disunity and push back from powerful stakeholders.
   e. Building of new state organisations to consolidate change.
   f. Success in meeting challenges because of the mobilisation of new groups formerly excluded from power-sharing relationships.
   g. Winners and losers – who lost out to whom. This expands on the distributional outcomes examined in the section on comparative public policy evaluation by asking the following questions:
      i. Was there a greater popular incorporation into state-run affairs?

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[232] Skocpol, *States and Social Revolutions*, 14.

ii. Were the new state organisations forged during the development, implementation and regulation of NEHRs more centralised and standardised than those of the old regime (previous *status quo*)?

iii. If new state organisations were more centralised and standardised did this give them more potency in society?

This chapter has outlined the relationship between the research questions, the existing scholarship in the field, and the method and theoretical framework I will use to arrive at my conclusions. The following chapter will present the aspirational narrative contextualising claims made about ehealth and NEHRs that justified NEHR programs and their funding.

Chapter 4 The Aspirational Narrative – Contextualising Claims Made About eHealth and Nationally Shareable Electronic Health Records

Patients don't want to tell their same whole medical history every time they see a different health professional.[233]

Introduction

Australia, England and the United States pursued institutional change in health records because they anticipated NEHRs would positively address a variety of policy issues and problems that had emerged over time due to the development of institutional pressures and tensions. Policy makers, and various stakeholders in the healthcare system, argued that ehealth and some form of a nationally shareable EHR made sense in that these innovations had the potential to wring numerous efficiencies out of the system and dramatically increase the effectiveness of care.[234] This was part of a global trend to think about ehealth and NEHRs as a significant part of the solution to healthcare problems and from the late 1990s governments around the world started to fund ehealth and the development and implementation of EHRs. They also developed NEHR regulatory regimes, especially in relation to patient control of health information and related privacy issues. While each ehealth system and associated NEHR had its critics, who were quite vocal at times, there was a broad feeling within the health sectors of all three case study countries that this was a future worth pursuing. The policy intent can be distilled as follows.

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[233] Kingshuk Pal (GP and Researcher at the eHealth Unit, University College London), Interview, 2013. This seems to be a major distress to all patients that was repeatedly mentioned by numerous interviewees in all case study countries, and a focus of government rhetoric when claiming potential benefits for NEHRs.

[234] This included improved communication between health professionals and patient engagement. Elin Lehnbom argued that "if you really want to improve communication between health professionals I think it is better to link systems so they have access to everything that they all do and if you want to engage patients I think it's better for them to have access to everything, have a copy." Elin Lehnbom (Postdoctoral Research Fellow, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, UNSW Medicine), Interview, 2014. This viewpoint was widely supported in interviews.

Firstly, paper records were increasingly seen by many stakeholders as inefficient and, in comparison to EHRs, a barrier to effective healthcare. The major problems of paper records were essentially the same in all three case study countries: siloed patient health information negatively impacted the process, safety, quality and cost of care. In this context, NEHRs were seen by many stakeholders, and especially the state, as having the potential to improve the efficiency and effectiveness of care. Efficiencies were projected to occur in the areas of healthcare costs; the process, co-ordination and continuity of care; and by improving the public good through the efficient use of health information in NEHRs. The potential to improve the effectiveness of care was focused on getting more value for money; improving the safety and quality of care; increasing patient engagement with, and co-production of, their healthcare; and improving the public good through the effective use of health data in NEHRs.

Secondly, control of patient health information was a growing issue. In all three countries the state saw NEHRs as having the potential to give patients more control over their health information. Consumer advocates shared this view, provided NEHRs were well regulated. Developing, implementing and/or regulating NEHRs gave the state the opportunity to address pressing issues over the ownership and use of information; privacy controls; information access and transfer; and the ability to change patient health information in health records.

Thirdly, ehealth, and NEHRs as a mechanism for institutional change gave states the chance to respond to, and harness, converging social, medical professional, fiscal and technical trends that were driving some stakeholders to facilitate institutional change across a number of dimensions including values, norms, rules, practices and procedures (NRPPs). The key change in values was to move from a clinician-centred to a patient-centred system of care. New norms revolved around the concept of interoperability[235]

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[235] Russell McGowan explained this in the Australian context. "In the last fifteen years or so worldwide, and particularly in Australia, there has been this emphasis on systems designed for safety, therefore interoperability between places where you might be receiving care. There were silos then within health between acute care and specialist care and primary health care and none of that was actually in the interests of the patient, in the best outcomes for the patient. So all of that was a bit of a dog's breakfast." Russell McGowan (Vice President, Health Care Consumers Association of the ACT), Interview, 2012.

and focused on relevant, reliable and useful patient health information being available at all points of care.[236] Rules targeted the usability and privacy of patient health information and aimed to ensure that patient information in the NEHR was in a format that could easily be actioned by both patients and clinicians, while at the same time being protected by a privacy regime. Institutional change in the areas of practices and procedures was centred on the meaningful use of patient information. It was expected that the NEHR would be used in the normal process of providing care and thus improve patient outcomes, enhance the efficiency and effectiveness of care and improve the public good.

This chapter provides a brief historical outline of the development of ehealth and nationally shareable electronic health records (NEHRs) in each of the three case study countries and presents the aspirational claims made in support of adopting NEHRs. This will develop the enabling narrative. A historical chronology of events table, comparing the longitudinal development of each case study country's ehealth system and their various units of comparison, is provided at the end of the introduction. The chapter presentation is historically sequential and longitudinal. The cases are presented in chronological order, beginning from when each country legislated its intent to establish, and/or incentivise, a national ehealth system with an EHR component that would be interoperable across both jurisdictional and healthcare provider boundaries. Accordingly, as shown in Table 4-1, Australia will be the first case discussed with the launch of HealthConnect in 2000, followed by England with the establishment of the National Programme for Information Technology (NPfIT) in 2002, then the United States with the passage of the *Health Information Technology for Economic and Clinical Health Act of 2009* (HITECH).

Part 1 will examine Australia, Part 2 England and Part 3 the United States. Each part tells the brief institutional story of what happened in ehealth, why it happened, and how it happened at three different levels of analysis, as shown in Figure 4-1 below. Level 1

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[236] John Vinen explained that "people are very mobile and you can get sick or injured anywhere at any time. And again, that's the thing I impress on patients that one of the reasons why your ehealth record is important. It can make a big difference and in fact at times it can mean the difference between life and death." John Vinen (Director of Medical Services for Calvary Health Care), Interview 1, 2014.

examines regime change at the macro level, explaining the rationale for changing from paper health records to ehealth. Level 2 examines organisational change. In the Australian context this is the pathway from the creation of HealthConnect in 2000 through to the National eHealth Transition Authority (NEHTA) and then the Australian Digital Health Agency (ADHA). In England this begins with the start of the NPfIT in 2002 which led to significant organisational change culminating, for the purposes of this thesis, in the Health and Social Care Information Centre (HSCIC) in 2013. HSCIC was rebranded NHS Digital in 2016. In the United States these changes begin with the creation of the Office of the National Co-ordinator for Health Information Technology in 2004 through to the integration of the Centers for Medicare and Medicaid Services (CMS) into the regulatory and incentive framework of ehealth in the US as a result of the 2009 HITECH Act. Level 3 briefly explains the unit of comparison in each case study country. In Australia this is the Personally Controlled Electronic Health Record (PCEHR) which was preceded by the National Health Information Network (NHIN) and succeeded by the My Health Record (MyHR). In England it is the Summary Care Record (SCR). In the United States the unit of comparison is the regulatory efforts to incentivise the adoption of interoperable EHRs that are nationally shareable and that achieve meaningful use standards. The institutional story then moves to health service delivery outcomes and briefly explains why ehealth mattered politically in each of the case study countries. Boxes illustrating the claims made at each level, for improvements to service delivery and why ehealth mattered politically will provide further support for the arguments made in favour of institutional change.

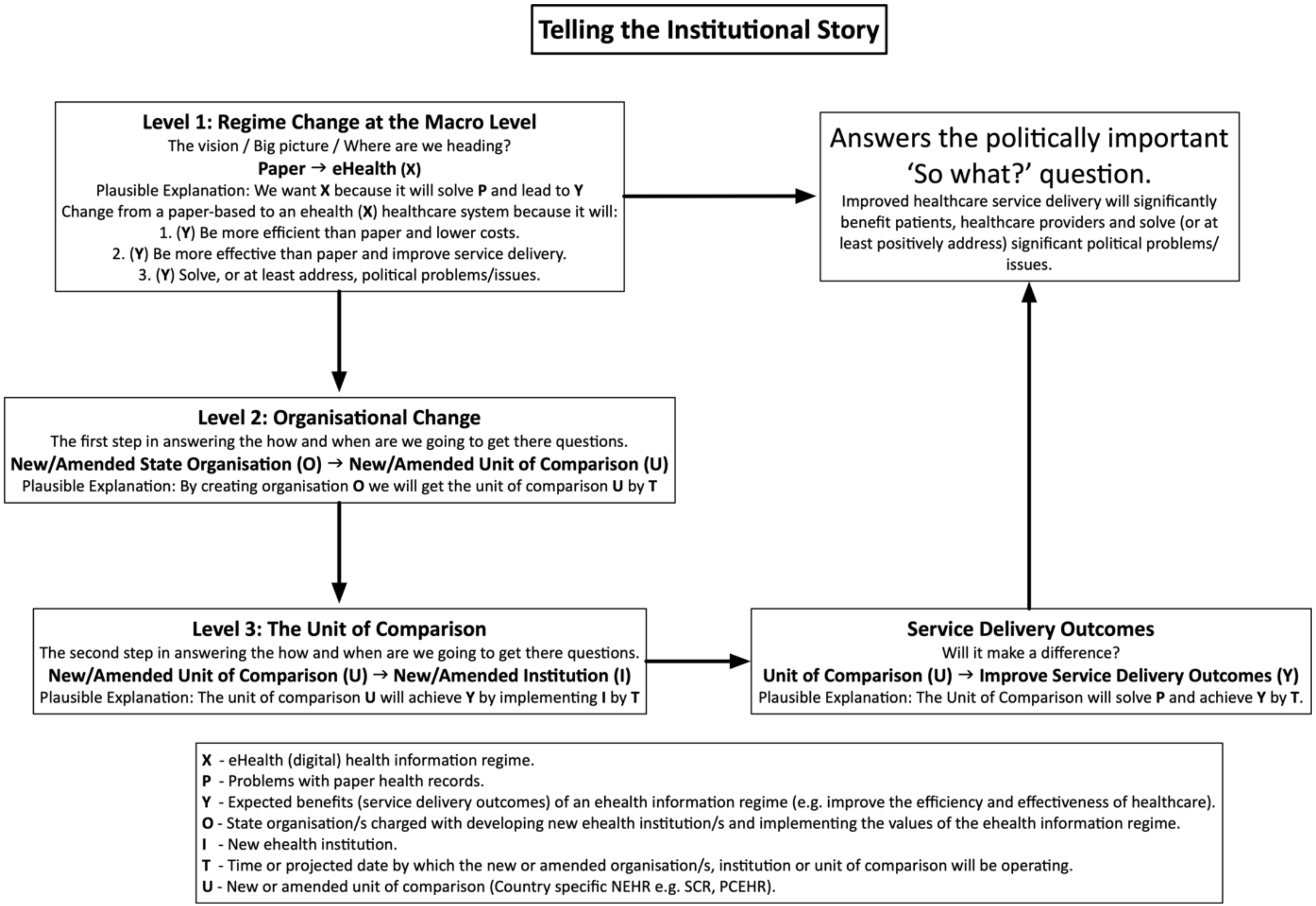

Figure 4-1: Telling the Institutional Story

Each part will then outline the role of the state at the national level in the development, implementation and regulation of ehealth and each country's unit of comparison. Figure 4-2 explains ehealth institutional stability and change over time by illustrating a heuristic framework that outlines structural changes instituted by the state in moving from paper health records to NEHRs.

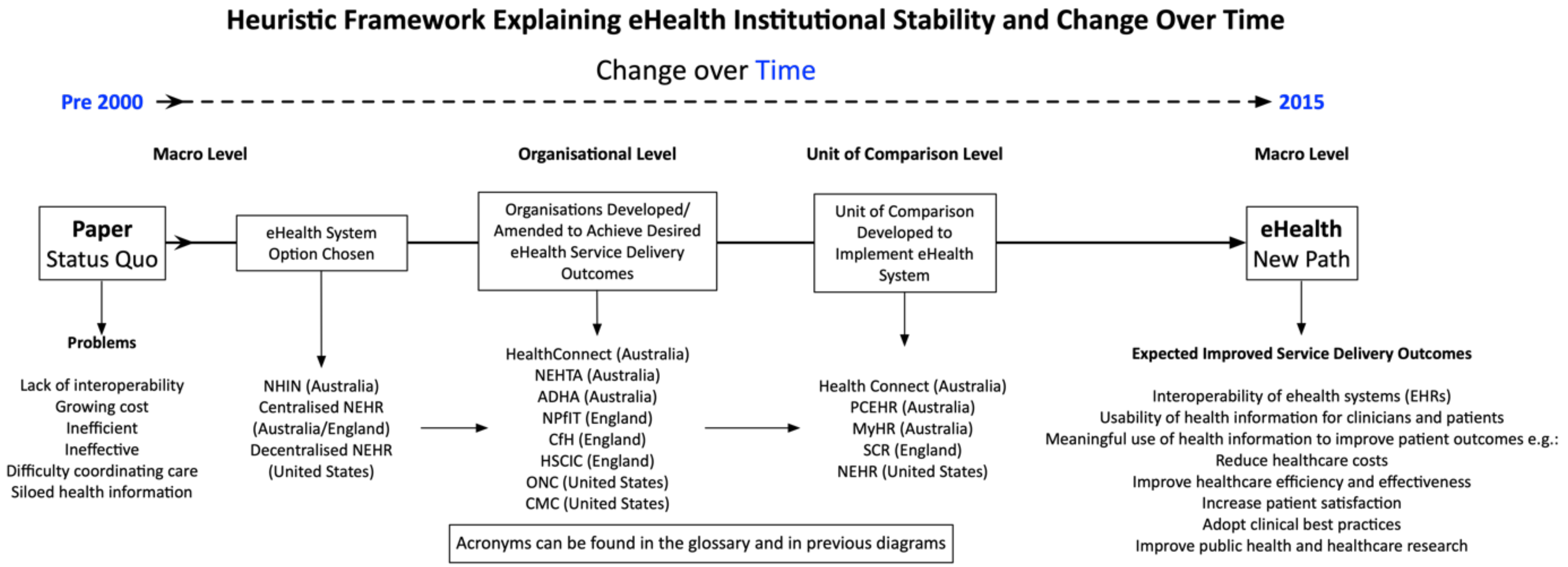

Figure 4-2: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time

Deeper analysis of the cases, including the state's role in the policy-making process, has been left to the later case study chapters.

Table 4-1: Historical Chronology of Main Events

Date	Timeline of Major National Events		
	Australia	**England**	**United States**
2000	**Decentralised approach:** Launch of HealthConnect.		
2002		**Centralised approach:** Establishment of NPfIT and the Integrated Records Care Service (IRCS) to deliver a nationally available Summary Care Record (SCR).	
2004		The NHS National Care Record Service (NCRS) replaced the IRCS and took responsibility for delivering the SCR.	**Non-binding standards approach:** Establishment of the National Health Information Technology Coordinator (ONC).
2005	HealthConnect effectively shelved. Establishment of the National E-Health Transition Authority (NEHTA).	The NHS Connecting for Health (CfH) assumed responsibility for the NPfIT and the NCRS.	
2009	**Centralised approach:** Development of the Personally Controlled Electronic Health Record (PCEHR) approved.		**Centralised regulatory approach:** Health Information Technology for Economic and Clinical Health Act (HITECH).
2010		Department of Health (DoH) signalled the end of the centralised approach. Limited version of the SCR proceeded.	Rules for the meaningful use of EHRs, to be rolled out in three stages, began.
2012	Launch of the PCEHR as an opt-in EHR.		
2013		NPfIT and CfH cease to exist. Delivery of the SCR taken over by the Health and Social Care Information Centre (HSCIC).	
2015	PCEHR rebranded as the My Health Record (MyHR) and changed to an opt-out EHR.	Milestone of 50 million SCRs created.	

Note: acronyms can be found in the glossary.

Part 1

The Aspirational Narrative – Australia

Table 4-2: Phases - Australia

Date	Australia
1991–2000	**Phase one:** Testing the potential of ehealth and EHRs.
2000–2008	**Phase two:** Tentative steps towards a national health information system with a decentralised NEHR in the form of HealthConnect.
2008–2015	**Phase three:** Adopting a centralised approach to NEHRs through the development and implementation of the Personally Controlled Electronic Health Record (PCEHR).

In Australia, the role of the state at the national level was crucial in framing and implementing ehealth policy. This included working with the states and territories on a common policy framework to create an ehealth environment to develop core systems and services that prioritised "a solution to the interoperability problem."[237] The initial framework was a decentralised NHIN approach based on trials and building stakeholder capability from the ground up. This approach failed to deliver an NEHR and was replaced by a centralised top-down system of delivering an NEHR in the PCEHR. The centralised approach was somewhat similar to that taken by England with the NPfIT and CfH in attempting to deliver an NEHR but with some key differences, such as Australia's significant foundational work on interoperability standards including "patient and provider identifiers, interoperable systems between providers, secure messaging, and clinical and medicines terminology sets."[238] Some of this work was undertaken early on by HealthConnect but the bulk of development was done by NEHTA.

Figure 4-3 shows the ehealth institutional story in Australia and is a heuristic adaption of historical institutionalism (HI) theory explaining both stability and change over time utilising three levels of change. These levels of change will be further examined in the comparative analysis chapter (Chapter 10) that focuses on path dependency, critical junctures and incremental change. Level 1 looks at regime change at the macro level.

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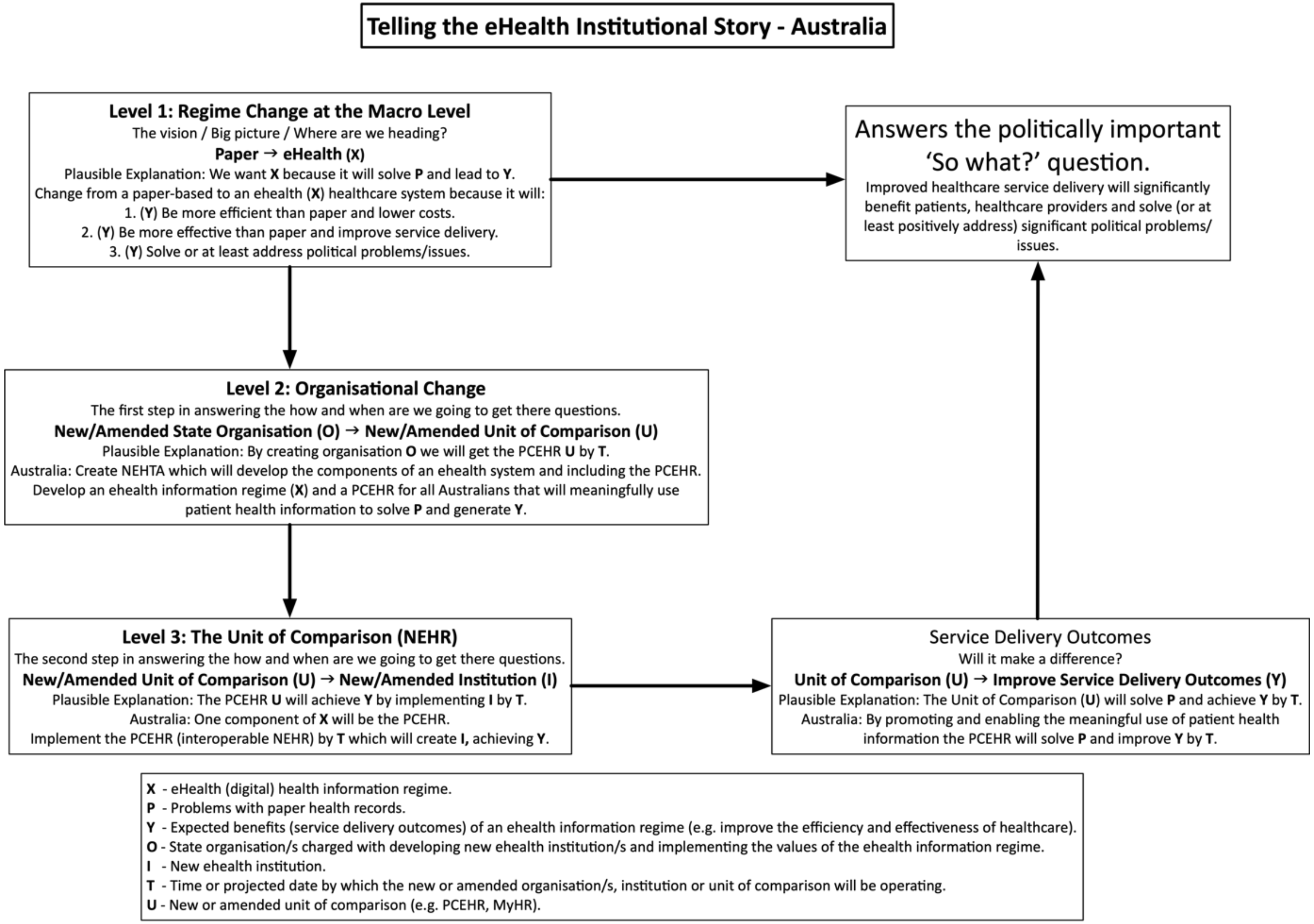
[237] National E-Health Transition Authority (NEHTA), *Evolution of EHealth in Australia: Achievements, Lessons, and Opportunities* (Sydney, 2016), 13.

[238] NEHTA, 13.

Level 2 examines organisational change and the consequent development, implementation and regulation of the unit of comparison (PCEHR). Level 3 explains institutional change as a result of the PCEHR. All three levels impact service delivery outcomes.



Telling the eHealth Institutional Story - Australia

Level 1: Regime Change at the Macro Level
The vision / Big picture / Where are we heading?
Paper → eHealth (X)
Plausible Explanation: We want **X** because it will solve **P** and lead to **Y**.
Change from a paper-based to an ehealth (**X**) healthcare system because it will:
1. (**Y**) Be more efficient than paper and lower costs.
2. (**Y**) Be more effective than paper and improve service delivery.
3. (**Y**) Solve or at least address political problems/issues.

Answers the politically important 'So what?' question.
Improved healthcare service delivery will significantly benefit patients, healthcare providers and solve (or at least positively address) significant political problems/ issues.

Level 2: Organisational Change
The first step in answering the how and when are we going to get there questions.
New/Amended State Organisation (O) → New/Amended Unit of Comparison (U)
Plausible Explanation: By creating organisation **O** we will get the PCEHR **U** by **T**.
Australia: Create NEHTA which will develop the components of an ehealth system and including the PCEHR. Develop an ehealth information regime (**X**) and a PCEHR for all Australians that will meaningfully use patient health information to solve **P** and generate **Y**.

Level 3: The Unit of Comparison (NEHR)
The second step in answering the how and when are we going to get there questions.
New/Amended Unit of Comparison (U) → New/Amended Institution (I)
Plausible Explanation: The PCEHR **U** will achieve **Y** by implementing **I** by **T**.
Australia: One component of **X** will be the PCEHR.
Implement the PCEHR (interoperable NEHR) by **T** which will create **I,** achieving **Y**.

Service Delivery Outcomes
Will it make a difference?
Unit of Comparison (U) → Improve Service Delivery Outcomes (Y)
Plausible Explanation: The Unit of Comparison (**U**) will solve **P** and achieve **Y** by **T**.
Australia: By promoting and enabling the meaningful use of patient health information the PCEHR will solve **P** and improve **Y** by **T**.

X - eHealth (digital) health information regime.
P - Problems with paper health records.
Y - Expected benefits (service delivery outcomes) of an ehealth information regime (e.g. improve the efficiency and effectiveness of healthcare).
O - State organisation/s charged with developing new ehealth institution/s and implementing the values of the ehealth information regime.
I - New ehealth institution.
T - Time or projected date by which the new or amended organisation/s, institution or unit of comparison will be operating.
U - New or amended unit of comparison (e.g. PCEHR, MyHR).

Figure 4-3: Telling the eHealth Institutional Story – Australia

Level 1: Regime Change at the Macro Level – from Paper Records to eHealth

The vision of level 1 regime change at the macro level was to transition from the continuing widespread use of paper health records to a digital ehealth system that would include the widespread use of electronic health records. The explanation for why this was necessary and worth funding was that ehealth, and in particular an NEHR, would solve many of the problems associated with paper health records and lead to numerous expected healthcare service delivery benefits. The major problems with paper health records were centred around siloed health information in paper repositories making it difficult to transfer patient health information between points of care.[239] This lack of interoperability negatively impacted both the efficiency and effectiveness of healthcare. There was also a view that the dozens of ehealth projects underway in healthcare provider organisations "depended on the direction taken in the public sector"[240] which required federal government leadership. The impetus for change from paper records to ehealth was the desire by numerous stakeholders, particularly the state at the federal level, to implement or action values that were patient-centred. This reflected an emerging trend within western democracies to shift power away from the state and traditional entrenched decision makers to the citizen. These values included patient-centred healthcare, privacy, trust and a desire for a new model of healthcare payment that would focus on payment-for-outcomes as opposed to the ubiquitous fee-for-service model that had dominated healthcare for centuries.

From former health minister Michael Wooldridge's 2001 claim that: "HealthConnect is an exciting concept with the potential to enhance the quality of care by revolutionising the way health records are managed. When implemented it will give health care providers and consumers instantaneous access to concise and accurate clinical information at the point of care, while ensuring individual privacy is protected."[241] to

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[239] There was also the issue of accessing records out of normal business hours resulting in a delay in obtaining information that might impact patient care and outcomes. This was a problem even in hospitals: "sometimes in the middle of the night, there's nobody in the medical records department, somebody has to be found, and it's usually the archive manager to go down there and unlock medical records." Vinen, Interview 1.

[240] Bruce McCabe, "Opportunities Going Begging in Health," *The Australian*, September 14, 2004, C02.

[241] Michael Wooldridge, "Development of HealthConnect Commended," 2001.

Greg Hunt's, the Australian Minister for Health, statement in 2018, that "digital health is the penicillin of our time"[242] the hyperbole remained remarkably similar and positive.

Box 4-1: Level 1 Claims – Paper to eHealth – Australia

In Australia the promised benefits[243] of ehealth broadly focused on improving the management of chronic disease, preventing medication errors and reducing waste and harm through unnecessary duplication of tests. These benefits were articulated as follows:

> A national approach is designed to create greater coherence, establish national standards and provide a framework for compatible systems across the nation – so that information can be exchanged at a clinical level no matter what state or regional borders are being crossed.[244]
>
> E-Health will enable a safer, higher quality, more equitable and sustainable health system for all Australians by transforming the way information is used to plan, manage and deliver health care services.[245]
>
> E health is seen by some as possibly the most important revolution in healthcare since the advent of modern medicine. For Australia, e health holds great potential in many areas, such as resolving the tyranny of distance or reducing the costs associated with caring for an ageing population.[246]
>
> Bruce McCabe[247] argued that improving healthcare is a priority for all Australians and that information technology can target the value locked up in vast amounts of medical data improving the delivery of new treatments, medicines and patient outcomes.

It was claimed that HealthConnect would cut down on doctor shopping saving the Pharmaceutical Benefits Scheme $27.1 million annually:[248]

> People tend to see different doctors for different things. Other people would get 27 different prescriptions from 27 different doctors. With HealthConnect, doctors would be able to say they cannot prescribe unless they have permission to view the patient's records. For the average person this is not really a problem, but it would catch others.[249]

Level 2: Organisational Change – from HealthConnect to NEHTA to the ADHA

Level 2 examines organisational change in relation to the effort to develop, implement and regulate an ehealth system and an NEHR. It is the first step in answering the how and when are we going to get an ehealth system and PCEHR questions. The state

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[242] Australian Digital Health Agency, "New Global Digital Health Partnership," (Australian Government, 2018).

[243] NEHTA, *Evolution of EHealth in Australia*, 12.

[244] Lynelle Briggs, "A National Approach to Electronic Health Records," *Health Information Management Journal* 30, no. 1 (2001).

[245] Australian Health Ministers Conference (AHMC), "National E-Health Strategy Summary," 2008, 5.

[246] Rhonda Jolly, "The e Health Revolution – Easier Said than Done," no. 3 (2011).

[247] Bruce McCabe, "What the Doctor Ordered," *The Australian*, June 1, 2004, C02.

[248] Tracey Grayson, "IT Snags Put Database on Hold," *The Australian*, June 26, 2004, C26.

[249] Dr Sue Page (President of the Rural Doctors Association of Australia), cited in Grayson, C26.

recognised early on that it would have to be the major player in creating an ehealth system, including creating or amending state organisations that would develop, implement and regulate the ehealth system and its crucial component, the PCEHR. The plausible explanation was that by creating NEHTA, and amending other organisations, the state would develop the components of an ehealth system and get the PCEHR by 1 July 2012. By developing a digital health information (ehealth) regime and a PCEHR for all Australians that would link patient information from all points of care together, patient information would be meaningfully used to solve the problems of paper health records and reap the benefits of improved service delivery outcomes.

Box 4-2: Level 2 Claims – Organisational Change – Australia

In 2004 Boston Consulting recommended "the creation of a single, national entity to co-ordinate the adoption of a common infrastructure and standards across the healthcare sector"[250] due to the numerous, thinly funded HealthConnect projects that resulted in "slow decision making and fragmented accountability."[251]

> There is a strong case for decisive national action now if we are to avoid a rail-gauge problem.[252]

As part of the policy implementation process the Department of Health and Aging (DoHA) developed a business architecture that defined what it wanted an EHR to be able to do. To achieve this, organisational change was needed. As Fitzgerald argued:

> There's a lot of underpinning stuff that needs to be developed to have electronic health records work and some of the standards work. And that's why NEHTA was established.[253]

NEHTA had always been a "non-government organisation"[254] and a transitional authority. One of the key findings of the Royle Review was that a permanent entity was required to take digital health forward.[255] NEHTA was replaced by the ADHA which was different in that it was a Commonwealth entity with a different staffing organisation and structure set-up.[256]

Mark Doran argued that from an organisational point of view "when we talk about eRecords, what we are really talking about is relevant information following the patient. That has been the Holy Grail, crossing all those boundaries that currently exist, all those silos that currently exist, and it's the transition between those segments and the population, and particularly primary care, that creates the problems that we have in healthcare today. We have to organise around the client, the customer, not dissimilar to a lot of other industries but we are not structured in a way that we organise around the customer. We're around what we do. Integrated care is what we are saying is the only way we are going to get there. Now that is distinct from coordinating care. Our vision is for a health care system that is not only a source of healing, but is a source of

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[250] Karen Dearne, "Health IT Short of Funds and Fragmented," *The Australian*, May 4, 2004, 30.

[251] Dearne, 30.

[252] Dearne, 30.

[253] Paul Fitzgerald (Former Senior Official, HealthConnect Program Office, Australian Department of Health and Ageing), Interview, 2014.

[254] Margaret Riep (Health ICT Project Manager and Health Informatician), Interview, 2015.

[255] Richard Royle, Steve Hambleton, and Andrew Walduck, "Review of the Personally Controlled Electronic Health Record," December (2013): 1–91.

[256] Tanya Harch (Former Director, National eHealth and Information Co-ordination Unit for Queensland Health), Interview, 2018.

hope and nurturing for a community and our understanding that if we don't do something over and above just being a healing factory then what's the point?"[257]

Level 3: The Unit of Comparison (PCEHR)

Level 3 analyses the NEHR unit of comparison and is the second step of answering the how and when are we going to get there questions. The broad plausible explanation of the goals of the PCEHR was that it would start to achieve the expected efficiency and effectiveness benefits of improved healthcare service delivery within an ehealth system upon implementation. The PCEHR was seen as the crucial component linking patient information within the ehealth system.[258] In order to link patient information between points of care the PCEHR would need to be interoperable and contain patient health information that was usable by both clinicians and patients. This would lead to the meaningful use of health information in a patient-centred ehealth system that would then produce the expected healthcare service delivery benefits. It was also seen as "providing a mechanism and a framework to support consumer perspectives,"[259] as consumers had often been left out conversations about their own health, and thus had the potential to shift power relationship ratios towards the consumer.

Box 4-3: Level 3 Claims – Unit of Comparison – Australia

In Australia it was thought that an NEHR would "improve the quality of health care services, promote a more integrated approach to care and offer consumers an opportunity to better manage their own health care."[260] Integration was to be a key outcome of the HealthConnect program:

> The integrated system will provide secure electronic records for consumers wherever they go in the health system, providing the basis for improved decision-making and delivering streamlined care.[261]

It was claimed that HealthConnect would cut down on doctor shopping saving the Pharmaceutical Benefits Scheme $27.1 million annually:[262]

> People tend to see different doctors for different things. Other people would get 27 different prescriptions from 27 different doctors. With HealthConnect, doctors would be able to say they

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[257] Mark Doran (National CEO, Little Company of Mary Health Care), Interview, 2014.

[258] This point of view was supported by a number of interviewees. For example, John Vinen stated that the "lack of interoperability is because each state implements their own systems without reference to a national system. There really should be a national medical health record." Vinen, Interview 1.

[259] Rebecca Vassarotti (Acting CEO, Consumers Health Forum), Interview, 2013.

[260] Amanda Cornwall, "Electronic Health Records: An International Perspective," *Health Issues*, no. 73 (2002): 1.

[261] Tony Abbott (Federal Minister for Health), cited in Karen Dearne, "Abbott Forces Pace on E-Health," *The Australian*, March 16, 2004, 31.

[262] Grayson, "IT Snags Put Database on Hold," C26.

> cannot prescribe unless they have permission to view the patient's records. For the average person this is not really a problem, but it would catch others.[263]

Using NEHRs to improve patient safety, particularly in relation to adverse medication events, was seen as an easily achievable outcome.

> We knew that electronic prescribing would reduce medication error rates by a defined percent.[264]
>
> Certainly there are instances where the clinician's writing has been problematic, for want of a better word, which leads to confusion sometimes in regard to medications.[265]

It was expected that ehealth interoperability would improve patient safety and save lives:

> Poor health information is believed to be responsible for up to 3,600 deaths in hospitals each year and the Federal Government hopes to cut this figure by improving the availability and timeliness of information to reduced misdiagnosis and incorrect treatment.[266]

Service Delivery Outcomes

Interoperability and usability were seen as the basis for developing the meaningful use of patient health information. These three features combined were seen as having the potential, through the PCEHR, of improving the service delivery of healthcare. As noted earlier, numerous stakeholders argued that there was the potential to improve both the efficiency and effectiveness of care. The efficiency of care included: lowering the cost of care; improving the process of care, including the co-ordination and continuity of care; and improving the public good through the efficient use of health data in the PCEHR. In addition, it was thought that by increasing patients' engagement with, and co-production of, their healthcare all these potential benefits would be enhanced.[267] An example of the health outcome benefits patients might see from an NEHR as a potential mechanism for information transfer was given by Rebecca Vassarotti from the Consumers Health Forum who explained that Kaiser Permanente's EHR allowed this

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[263] Dr Sue Page (President of the Rural Doctors Association of Australia), cited in Grayson, C26.

[264] Paul Dugdale (Canberra Hospital Health Services Specialist and Academic at the Australian National University), Interview 1, 2014.

[265] Kaye Borgelt (Executive Director of Corporate and Quality Services at the West Wimmera Health Service), Interview, 2014.

[266] Edward Mandla, "Consulting on the E-Health Vision," *The Australian*, August 10, 2004, 35.

[267] Stuart Stapleton argued that an NEHR had the potential to lower costs and improve the efficiency of healthcare service delivery, especially by reducing repetition including tests. Stuart Stapleton (Director, Emergency Department at Calvary Health Care ACT and form Clinical Lead for NEHTA), Interview, 2015.

provider to know who had a particular knee implant and that "when something went wrong they were able to contact every single one of their patients within 24 hours to tell them that there was an issue and what to do about the issue. The rest of America, it took a year to contact all of those patients."[268]

Box 4-4: Service Delivery Claims – Australia

> The medical records is an area where you can see immediate advantages. There are estimates about the number of deaths that occur in hospitals through contraindicated medication. If, in hospitals, they could click their fingers and see the list of medications a person is on, they'd say, "Oh, we shouldn't do that," then you can see the immediate advantages. Your computer system automatically says "Warning. Warning. Don't do that."[269]

> It is estimated that 5,000 Australians die each year due to adverse medical events; 18% of medical errors in Australia occur from inadequate information; nearly 30% of unplanned hospital admissions are associated with prescribing errors; and approximately 13% of healthcare provider consultation suffers missing information. Patients may need to undergo the same tests with different healthcare providers. It is not unusual that same questions are asked every time when a patient deals with a different provider.[270]

According to government budget figures the establishment of electronic medication records, if done in 2001, was "expected to generate $25 million in savings during the first four years of operation."[271]

Improving the patient journey and lowering costs by eliminating repetition was seen as a potentially positive outcome of implementing NEHRs.

> The ehealth record shows a patient's journey, how many times has a patient been through this round of testing, analysis, medication and you are still not seeing anything so you don't want to waste time repeating things, like futile cycles, so I think it will help orient the system to be more efficient and patients to become more oriented towards their own healthcare.[272]

> Because everyone can see that patient's healthcare information with their permission it means that people don't drop between the cracks as they go from one provider to another because they have lost the providers of care from different aspects of their known disease.[273]

> Clearly it would be beneficial for people who had chronic illness and were bumping up against the system continually. They would be the great individual beneficiaries of electronic health records.[274]

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[268] Vassarotti, Interview.

[269] Fitzgerald, Interview.

[270] Xiangzhu Gao et al., "Implementation of E-Health Record Systems in Australia," *The International Technology Management Review* 3, no. 2 (2013): 93.

[271] Jenny Macklin (Shadow Minister for Health), "Wooldridge Fails on E-Health," in National Rural Health Alliance E-forum – 3 August 2001.

[272] Priyanka Rai (Policy and Communications Officer, Consumers Health Forum), Interview, 2013.

[273] Mukesh Haikerwal (Former President of the Australian Medical Association and Head of Clinical Leadership, Safety and Stakeholder Management for NEHTA), Interview, 2013.

[274] Philip Hagan (Assistant Secretary ,Policy Strategy Group, Australian Department of Health and Aging), Interview, 2014.

It was also expected that NEHRs would change patient behaviour by increasing patient engagement with, and co-production of, their health conditions and outcomes.

> From a patient point of view having EHRs brings better patient outcomes full stop. The reason for that is that patients have better information about their own healthcare which helps them make better health decisions about the way they live their lives and recruit the right people into their healthcare so that they can get the right care at the right time.[275]

Lindsay Bevege, CEO of SmartWard, argued that an EHR could also address "the issue of the waste of nursing resources in particular on a hospital ward where international studies and our own observations are concerned, nurses are spending around about thirty percent of their time on paper-based records."[276]

Why eHealth Mattered Politically

The essential claim in Australia was that state intervention at the federal level in the form of NEHRs would lead to improved healthcare service delivery that would significantly benefit patients, healthcare providers and the state. This would solve, or at least potentially address in a positive way, the significant political problems and issues discussed in this thesis. In particular, ehealth mattered politically because claimed benefits resonated with the public, who saw the technical modernisation of government services through the integration of information in mechanisms to improve service delivery, such as the PCEHR, as a normal step in the process of delivering better government services that benefitted them personally.

Box 4-5: Policy Value Claims – Australia

The Royle Review of the PCEHR in 2013 stated:

> The value of having a personal health summary to share with selected health professionals will be that relevant information is available at the right time for the right people. Improved access, speed and accuracy of health information will benefit health providers, consumers and Government to deliver greater efficiency, less duplication and waste, safer, faster consultation, greater options for location of health provision and mobility of patients, greater consumer choice, and ultimately better health service delivery overall.[277]

There was also a contested view that EHRs would be more secure, and would thus more strongly support patient privacy, than paper records.

> Paper-based records are generally insecure, electronic record systems are, in general, much more secure than paper-based systems. [The issue here is] breaches of information privacy and

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[275] Haikerwal, Interview.

[276] Lindsay Bevege (CEO of SmartWard), Interview, 2014.

[277] Royle, Hambleton, and Walduck, "Review of the Personally Controlled Electronic Health Record," 13.

> unauthorised use. Generally, we will expect to see those breaches being significantly lower than the paper-based records.[278]

A higher level summary of patient health information that would be held in an NEHR was also thought to have value as a "secondary source of information for a clinician because we don't collect data from outside of our ecosystem."[279]

Clinical benefits were highlighted by many interviewees. For example, Vinen explained:

> We spend a lot of time seeking information about patients – other hospitals, their GPs, their specialist and so on. Being able to access that information via a single number through a PCEHR would improve efficiency, reduce wastage, improve decision making, reduce time in decision making, so there are enormous benefits in that respect considering there are hundreds of thousands of patients involved. Getting access to electronic records electronically – it's very quick and efficient, you put the number in and you've got access to files on that patient, it's fantastic, just makes decision making and processing of the patient so much more effective and efficient. The investment in IT, if it's done properly and effectively, will save an enormous amount of money.[280]

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[278] Dugdale, Interview 1.

[279] Harch, Interview.

[280] John Vinen (Director of Medical Services for Calvary Health Care), Interview 2, 2015.

What was Achieved by the State in Developing and Implementing a National Shared EHR in Australia by 2015?

Figure 4-4 presents a heuristic framework explaining ehealth institutional stability and change over time in Australia. This is a useful way of showing how the policy decision to move from paper health records to EHRs led to important structural decisions on which

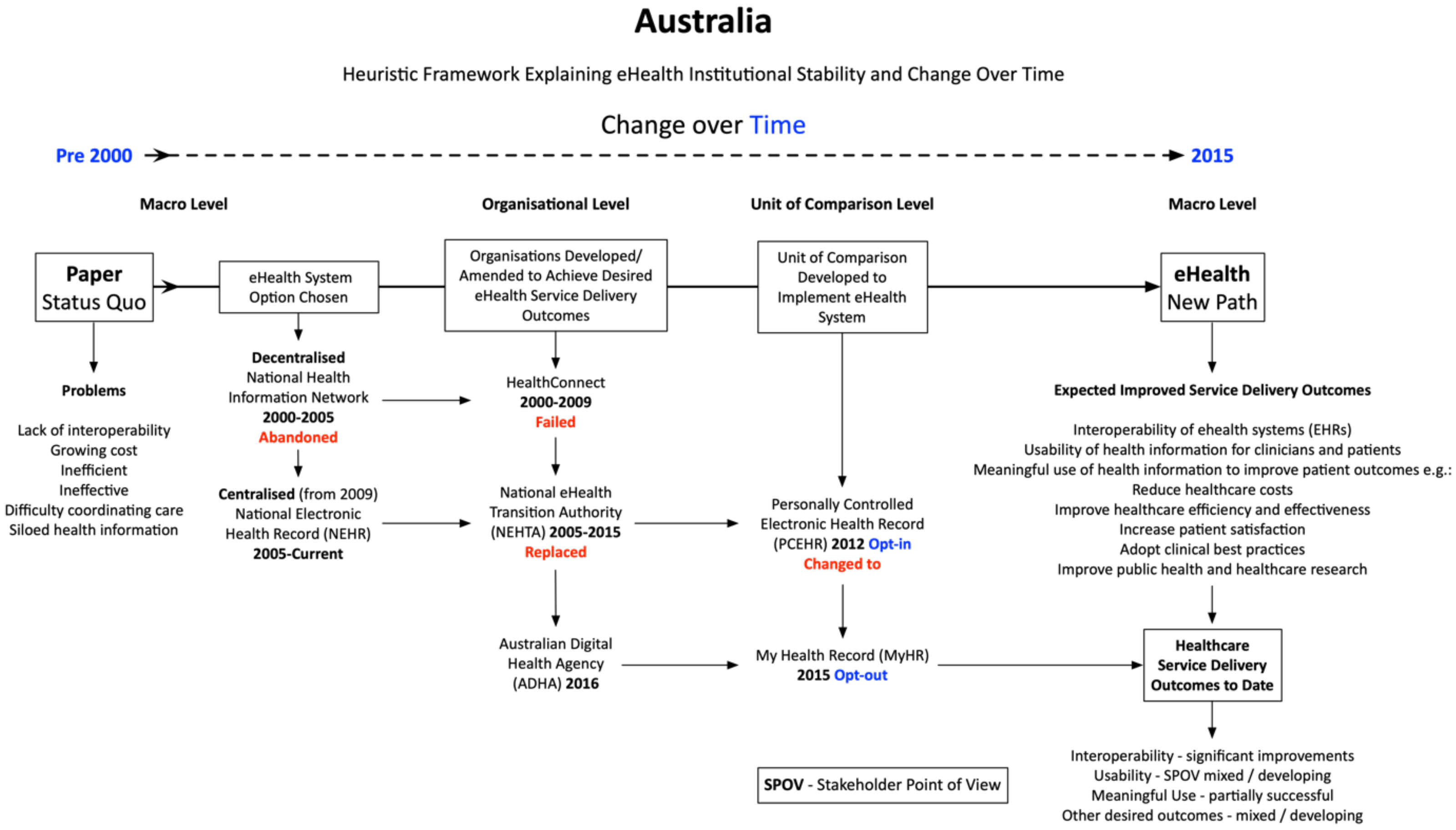

Figure 4-4: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time in Australia

ehealth system option would be chosen, what organisations would need to be created or amended to implement the desired ehealth system option, and the nature of the unit of comparison (NEHR) that was meant to be the mechanism by which improvements to healthcare service delivery were to be achieved.

The state's policy solution to the problems of paper records was firstly to attempt to develop and regulate a decentralised NHIN as the ehealth system of choice. To do so the state amended the DoHA by adding an ehealth unit that, over time, grew to be a division and created new organisations including HealthConnect which conducted trials and, over time, transitioned to exploring the potential of an NEHR. When HealthConnect failed to deliver the NHIN and its desired outcome it was replaced by NEHTA and the policy solution shifted to developing and regulating an NEHR. NEHTA started developing the foundations of ehealth and from 2010 transitioned in to developing, implementing and regulating the PCEHR. NEHTA also contracted with private developers to build and implement parts of the ehealth infrastructure. The PCEHR went live on 1 July 2012 but it was heavily criticised for lacking clinically useful information and for poor up-take. There were also significant stakeholder tensions over privacy provisions that gave patients personal control over the information in the record, whether the PCEHR should be opt-in or opt-out, a lack of focus on who the PCEHR was for (clinicians or consumers), the usability of the system, and effective engagement with various stakeholder groups regarding the implementation and governance of the PCEHR.[281] In 2016 the ADHA took over the troubled PCEHR, by then renamed the MyHR, building on NEHTA's work though with significant changes – most importantly moving from opt-in to opt-out. These changes were designed to increase the usefulness of the information in the NEHR, its uptake and use by clinicians, and its value to the state and other stakeholders.

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[281] Royle, Hambleton, and Walduck, "Review of the Personally Controlled Electronic Health Record," 14.

Part 2

The Aspirational Narrative – England

Your record saves lives.[282]

Table 4-3: Phases – England

Date	England
1998 – 2010	**Phase One:** The aspiration of compiling centralised EHRs through the National Programme for Information Technology (NPfIT) and the Summary Care Record (SCR).
2010 – 2015	**Phase Two:** Muddling along – abandoning the centralised IT approach, scaling back the SCR and working to increase uptake and the clinical usefulness of the NEHR.

The role of the state at the national level in England was crucial in framing and implementing ehealth and NEHR policy. A centralised, top-down approach to delivering an NEHR in the form of the SCR was adopted. A plethora of organisations were created and/or amended to develop, implement and regulate ehealth and the SCR. The SCR was seen as a mechanism to apply and action the values of patient-centred healthcare, including choice and trust, within an ehealth institutional framework. The public's perception that the benefits of ehealth were worth pursuing and that the SCR was likely to benefit them suggested some support of the concept, but people mostly disengaged with institutional developments unless these personally impacted their wellbeing or where criticism of the NPfIT and the SCR resonated with their own belief sets about the failures of government. These attitudes reflected the impact of converging trends that resulted in the perception that ehealth was something the government should do.

The ehealth institutional story in England is shown in Figure 4-5 below and is the same heuristic adaption of HI theory, explaining both stability and change over time using three levels of analysis, as used for Australia. The major difference is that the unit of comparison is the SCR as opposed to the PCEHR in Australia.

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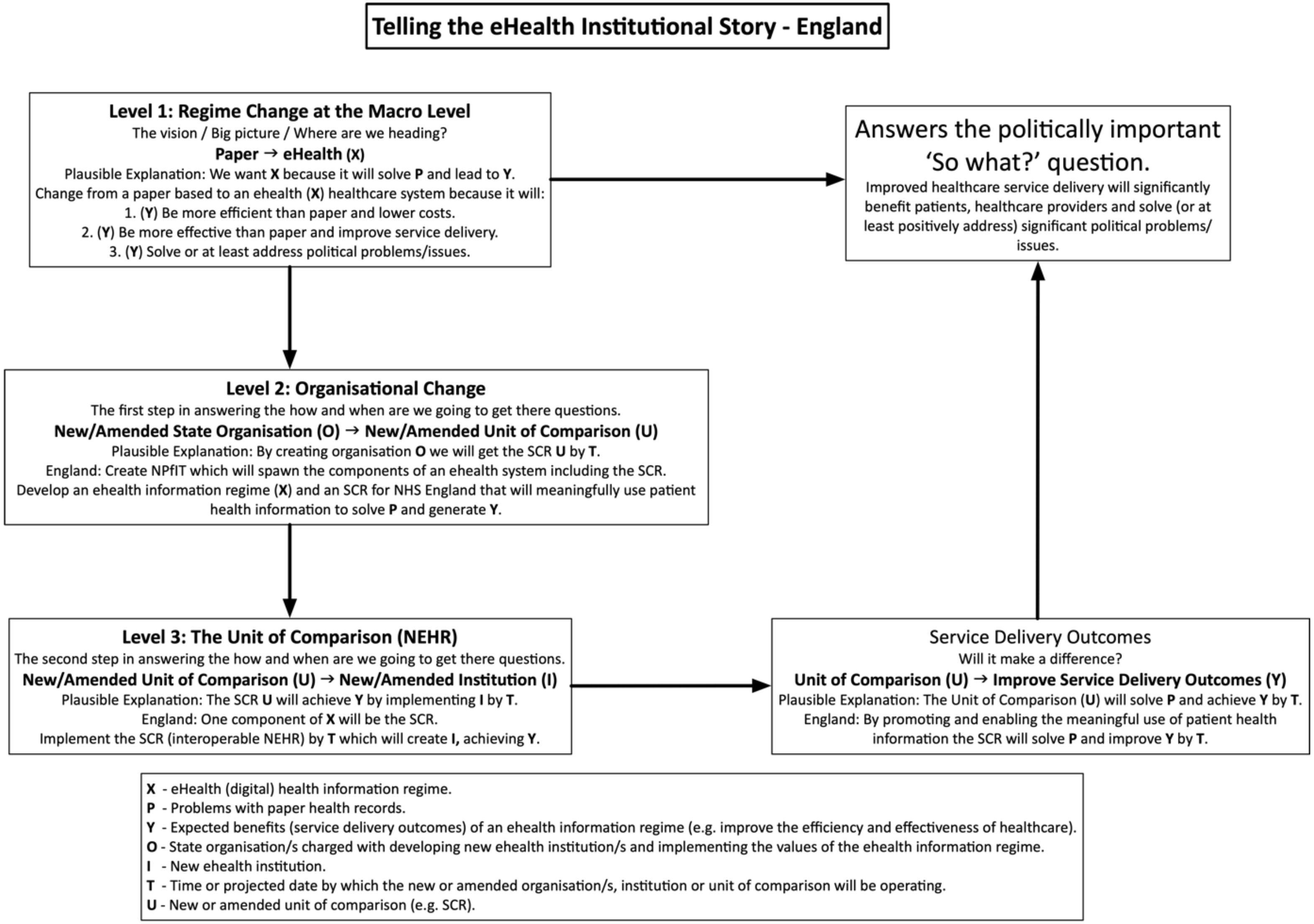
[282] Peter Knight (Head of Research Information and Intelligence at the UK Department of Health), Interview, 2013.



Telling the eHealth Institutional Story - England

Level 1: Regime Change at the Macro Level
The vision / Big picture / Where are we heading?
Paper → eHealth (X)
Plausible Explanation: We want **X** because it will solve **P** and lead to **Y**.
Change from a paper based to an ehealth (**X**) healthcare system because it will:
1. (**Y**) Be more efficient than paper and lower costs.
2. (**Y**) Be more effective than paper and improve service delivery.
3. (**Y**) Solve or at least address political problems/issues.

Level 2: Organisational Change
The first step in answering the how and when are we going to get there questions.
New/Amended State Organisation (O) → New/Amended Unit of Comparison (U)
Plausible Explanation: By creating organisation **O** we will get the SCR **U** by **T**.
England: Create NPfIT which will spawn the components of an ehealth system including the SCR.
Develop an ehealth information regime (**X**) and an SCR for NHS England that will meaningfully use patient health information to solve **P** and generate **Y**.

Level 3: The Unit of Comparison (NEHR)
The second step in answering the how and when are we going to get there questions.
New/Amended Unit of Comparison (U) → New/Amended Institution (I)
Plausible Explanation: The SCR **U** will achieve **Y** by implementing **I** by **T**.
England: One component of **X** will be the SCR.
Implement the SCR (interoperable NEHR) by **T** which will create **I,** achieving **Y**.

Service Delivery Outcomes
Will it make a difference?
Unit of Comparison (U) → Improve Service Delivery Outcomes (Y)
Plausible Explanation: The Unit of Comparison (**U**) will solve **P** and achieve **Y** by **T**.
England: By promoting and enabling the meaningful use of patient health information the SCR will solve **P** and improve **Y** by **T**.

Answers the politically important 'So what?' question.
Improved healthcare service delivery will significantly benefit patients, healthcare providers and solve (or at least positively address) significant political problems/issues.

X - eHealth (digital) health information regime.
P - Problems with paper health records.
Y - Expected benefits (service delivery outcomes) of an ehealth information regime (e.g. improve the efficiency and effectiveness of healthcare).
O - State organisation/s charged with developing new ehealth institution/s and implementing the values of the ehealth information regime.
I - New ehealth institution.
T - Time or projected date by which the new or amended organisation/s, institution or unit of comparison will be operating.
U - New or amended unit of comparison (e.g. SCR).

Figure 4-5: Telling the eHealth Institutional Story – England

Level 1: Regime Change at the Macro Level – from Paper Records to eHealth

In England, the enabling narrative stayed remarkably similar over time. It focused on improving patient care, often through systemic change that revolved around the development and implementation of technical solutions to the problems of interoperability and usability of patient health information. Box 4-6 shows how the benefits and process of achieving these goals were articulated.

Box 4-6: Level 1 Claims – Paper to eHealth – England

The efficiency benefits[283] of transitioning from paper health records to ehealth were to be delivered by:

1. Improving clinical decision making.
2. Reducing medication errors.
3. Speeding up the consultation process.
4. Reducing test duplication.

These benefits were to be achieved through the NPfIT which was to be "a powerful force for improving patient care."[284]

The national strategy for moving from paper health records to ehealth and achieving an integrated model for information was to circularly link knowledge with treatment and care and analysis as in Figure 4-6 below.

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[283] NEHTA, *Evolution of EHealth in Australia*, 16.

[284] Sir Christopher Bland (Chairman of British Telecom), cited in digitalhealth, "Reid Announces £2.7 Billion of NHS IT Contracts," 2003.

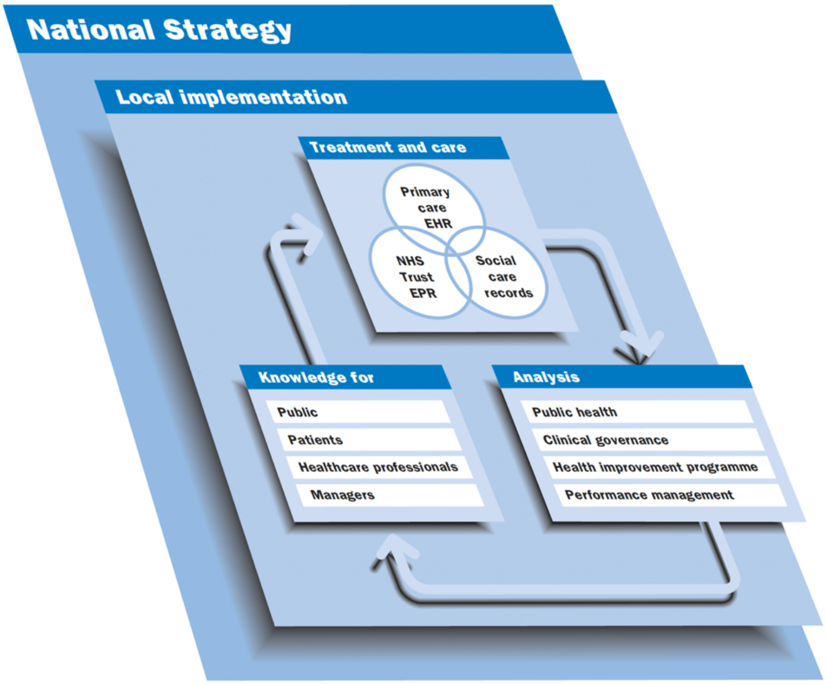

Figure 4-6: Information for Health – an Integrated Model for Information[285]

Level 2: Organisational Change – from NPfIT to HSCIC

In England, the state was determined to be the major player in creating an ehealth system right from the start and therefore imposed a top-down model of development, implementation and regulation. As a consequence, numerous state organisations were either amended or created to develop, implement and regulate the ehealth system and its crucial component – the SCR. The top-down approach accompanied by organisational change was justified, firstly, to tightly control the entire technology acquisition and implementation process in order to mitigate criticism of past failures; secondly, to drive down costs and make technology vendors responsible for any failure to implement programs as per tight contracts or for cost overruns; and thirdly, the modernisation of technology effort was to implement interoperable systems in a consistent way across the entire NHS thus linking patient information from all points of care together, solve the problems of paper health records and reap the benefits of improved service delivery outcomes.

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[285] Reproduced from Frank Burns, *Information for Health: An Information Strategy for the Modern NHS 1998-2005*, (NHS Executive, 1998), 18.

Box 4-7: Level 2 Claims – Organisational Change – England

> "To put it simply, the [NHS IT] programme is a key part of delivering modern, safe, joined-up health care. It is supporting the ongoing reform of the NHS by giving choice and convenience to patients. The NHS could not function without it."[286]

Level 3: The Unit of Comparison (SCR)

The enabling narrative in England for NEHRs was very similar to Australia in that it emphasised increased patient control over health information, systems interoperability, and the potential to improve the efficiency and effectiveness of care and thus provide patients with better health outcomes. The 1998 Information Strategy for the NHS argued that the practical benefits of EHRs to patients and staff included convenience and confidence, integration of care, improving outcomes, using evidence, supporting analysis and improving efficiency.

Box 4-8: Level 3 Claims – The Unit of Comparison – England

> The arguments for a move towards an electronic record are compelling. Such records are more likely to be legible, accurate, safe, secure, and available when required, and they can be more readily retrieved and communicated. They better integrate the latest information about a patient's care, for example from different "departmental" clinical systems in a hospital. In addition, they can be more readily analysed for audit, research and quality assurance purposes.[287]
>
> Information technology can undoubtedly improve NHS professionals' use of information in day-to-day care … provid[ing] direct benefits to patients in their use of NHS services.[288]
>
> There are certainly many benefits to patients, clinicians and the NHS with the introduction of this programme. Easier access to comprehensive patient details will enable a link between community or primary health care and secondary care to be set up. This will improve communication between healthcare professionals and promote a multidisciplinary approach, speeding up referrals and handover of patient care. This may reduce the number of hospital admissions and increase the level of care within the community. The programme promotes a patient-centred approach, where people have access to their own health records (with the ability to add personal details and initiate corrections), which helps to educate people and encourage them to assume responsibility for their health.[289]
>
> Well GPs' records are reasonably good but the problem comes when you get your letter back from the hospital, updating it so that's where things could improve. It's the other way round, I think, is where the major problems arise. So if the patient fetches up in A&E with a bag full of

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[286] Andy Burnham (Secretary of State for Health), HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 21.

[287] Burns, *Information for Health*, 24.

[288] Burns, 14.

[289] Su-Yen Khong, Ian Currie, and Simon Eccles, "NHS Connecting for Health and the National Programme for Information Technology," *Risk Management*, 2008, 30.

> medication and they're having to assess that patient and make decisions without having any knowledge of that patient, which … from my memory of A&E is a major thing, you end up having to do everything, repeat all the tests and everything unless that patient just happens to have been at that hospital before and has an electronic record there but even so it's not an account for what's happened in the meantime, unless they're kind of in and out so frequently, so that's where there's an awful lot of duplication and waste in the system. So if everybody had, or if the patient had, [an NEHR] then everyone can see what everyone else has done and you know follow the line through. The patient also knows what's happened so they can quickly update and they have a bit more ownership of their health. So I can imagine then someone pitching up to A&E and they've got their hand-held record and they go "there you go Doc. This is what's happened," and they can just tweak it and it's a lot more efficient but that would be in my kind of ideal scenario.[290]

Service Delivery Outcomes

The focus of the NHS in the era of ehealth was the value of "high quality care for all."[291] According to the former Prime Minister Gordon Brown, the SCR would "drive improvements in the quality of care … [and give] us real control and real choices over our care and our lives."[292] Interoperability was a key function of the SCR and its importance was emphasised by Andy Burnham, the Minister for Health, when he stated: "It is safer for patients if their records can be accessed across the system."[293] The Department of Health (DoH) maintained the narrative in 2012 when it argued that:

"Better quality information and sharing information is critical to modernising the NHS and care services. Information can be used to:

1. Improve the quality of care;
2. Improve our health and care outcomes;
3. Reduce inequalities; and
4. Increase productivity and efficiency."[294]

The DoH went on to argue that:

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[290] Fiona Hamilton (Senior Clinical Research Associate, eHealth Unit, University College London), Interview, 2013.
[291] Lord Darzi, *High Quality Care For All - NHS Next Stage Review Final Report*, 2008.
[292] Gordon Brown (Prime Minister), in Darzi, 2.
[293] Burnham, Column 21.
[294] Department of Health (DoH), *The Power of Information: Putting All of Us in Control of the Health and Care Information We Need, 2012*, 11.

> Professionals providing our care can use connected information to support safer, more integrated care for us, for example, through online access to GP records in hospitals, electronic prescribing and barcode-scanning in care homes and hospitals to reduce medication errors, and electronic access to results, X-rays and scans.[295]

Box 4-9: Level 4 Claims – Service Delivery – England

Practical benefits of EHRs to patients and staff as identified by the NHS:[296]

Convenience and confidence – patients will be spared the ritual of repeating their name, address, previous and recent medical history to every NHS person they have to deal with. Patient confidence is increased if they know that all healthcare professionals have access to all relevant parts of their medical history. Patients should also have access to their own records.

Integration of care – on-line communication between GPs and hospitals will speed access to services and information, and test results. The coordination of multi-professional and multi-agency care for elderly, frail, vulnerable patients and those with challenging behaviour will be substantially improved and seamless care become a reality rather than a cliché.

Improving outcomes – NHS professionals can make better decisions with up-to-date test results at their fingertips, together with relevant alerts and reminders. Patients gain too. For example, repeating an X-ray because the result of a previous one has been lost or cannot be easily retrieved involves the patient in unnecessary exposure to radiation. GPs can have expert and easily accessible desktop guidance on medication options through on-line support systems to improve the efficacy of primary care prescribing.

Using evidence – by integrating EPRs with active clinical systems, GPs and other primary healthcare professionals can have desktop access to referral guidelines and advice on first line treatment agreed with local specialists. This will improve the quality and appropriateness of referrals to hospitals. Hospital clinical staff, and especially junior doctors, will have on-line guidance and personal access to latest research findings, treatment and medication options.

Supporting analysis – analysing the data held within records will create the information needed to meet the requirements for clinical governance and support local planning.

Improving efficiency – the 1995 Audit Commission report For Your Information – a study of information management and systems in the acute hospitals – estimated that 25% of doctors' and nurses' time was spent collecting data and using information. EPRs will reduce the amount of time spent on this activity, and free more time for direct patient care. Achieving efficiency and productivity benefits through the use of EPRs will be important in supporting the national policy objective of reducing waiting lists, which will require increases in elective hospital activity over the period of the strategy.

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[295] DoH, 28.

[296] Burns, "Information for Health: An Information Strategy for the Modern NHS 1998-2005," 24–25.

Why eHealth Mattered Politically

Improving the efficiency and effectiveness of care was a common enabling narrative in all three case study countries. Right from the start, with the release of Information for Health in 1998, the policy argument in England for the adoption of ehealth IT was about "how efficiency of services can be improved to release resources to further improve their quality,"[297] significantly improving the management and delivery of healthcare services providing the "value for money that citizens deserve."[298] This became contentious over time, as will be examined in Chapter 6, as by 2010 approximately £12.7 billion had been spent on the NPfIT without achieving its aims, thus resulting in significant political criticism that the major parties when in government struggled to address effectively.

Overall, bureaucrats and politicians pushed the view that the SCR would "provide accurate, up-to-date information, while reducing administrative work."[299] NEHTA, in its review of the English SCR program, argued that "the Department of Health believes that Summary Care Records are a necessary component of care in the 21st century and that they will prove to be essential for better, safer out of hours and urgent care provision."[300]

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[297] Burns, 12.
[298] Burns, 12.
[299] Khong, Currie, and Eccles, "NHS Connecting for Health," 30.
[300] NHS leaflet cited in Thomas Powell and Gavin Thompson, "Electronic Patient Records: The Roll-out of the Summary Care Record," 2010, 9.

What was Achieved by the State in Developing and Implementing a National Shared EHR in England by 2015?

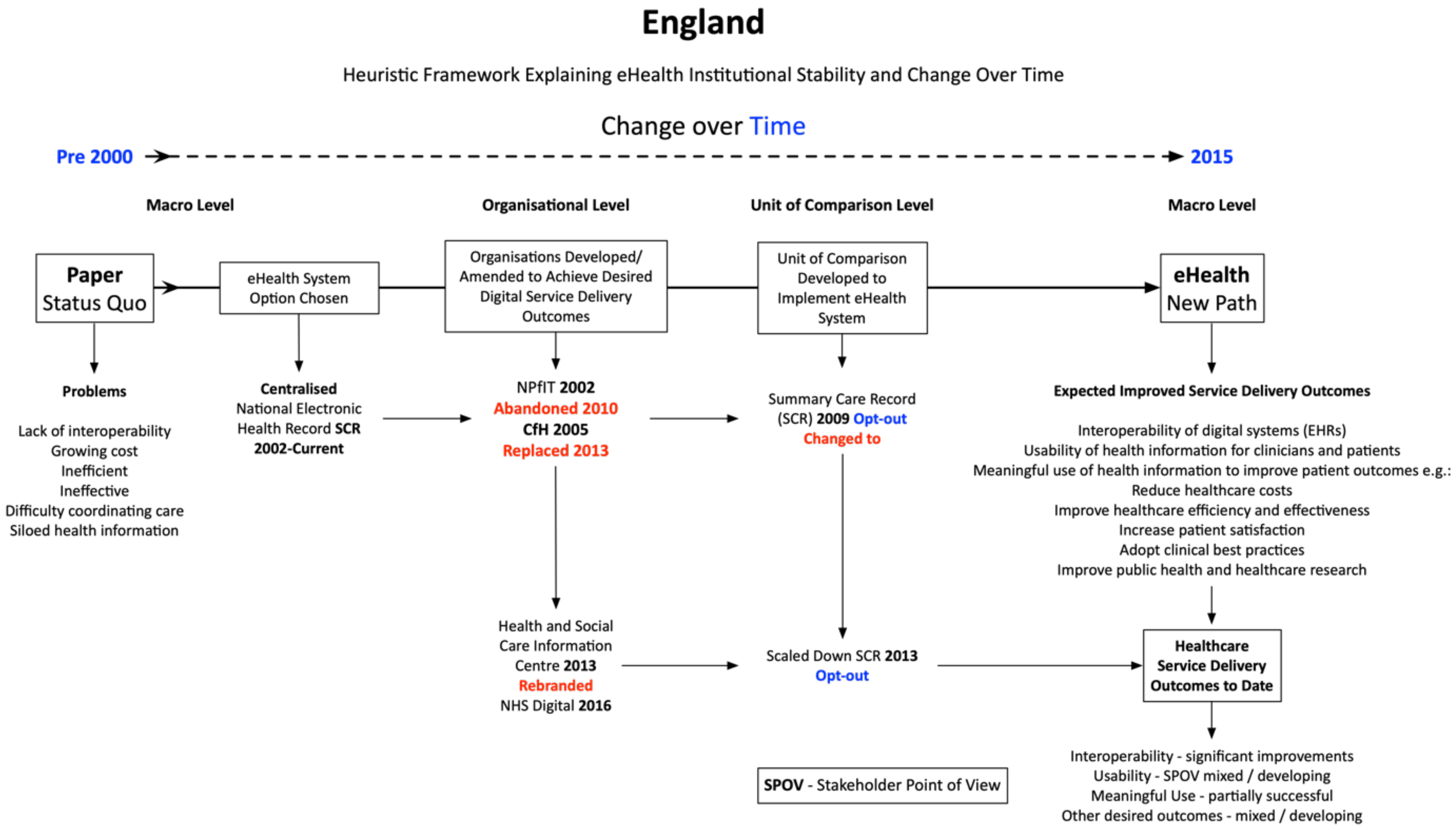

Figure 4-7: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time in England

The various components of ehealth were tied together through the National Programme for Information Technology (NPfIT), which began in 2002, and the NHS Information Authority (NHSIA) which had been established in 1999. To implement the SCR (initially called the NHS Care Record) the Integrated Care Record Service was created but was soon replaced by the NHS National Care Record Service in 2003. This was essentially a name change "intended to more clearly convey to NHS staff and the public what joined-up electronic patient records actually are and do."[301] NHS Connecting for Health (CfH) subsequently assumed responsibility for the NPfIT and the NCRS in 2005 and was itself replaced by the Health and Social Care Information Centre (HSCIC) in 2013. The NPfIT faced sustained criticism for not achieving objectives and the centralised IT approach was abandoned in 2010. The SCR survived but in a scaled-down form with both the HSCIC and later NHS Digital progressively adding capability to the record.

Part 3

The Aspirational Narrative – The United States

Table 4-4: Phases - The United States

Date	The United States
1996–2008	**Phase One:** Privacy regulation through HIPAA and interoperability guidance through the National Health Information Technology Coordinator (ONC).
2008–2015	**Phase Two:** Policy development of the interoperability, usability and meaningful use of NEHRs through generous incentives and significant penalties established by the *Health Information Technology for Economic and Clinical Health Act of 2009* (HITECH Act) and subsequent regulatory frameworks.

The state at the national level in the United States had many similar goals to Australia and England in the pursuit of NEHRs, however there was a significant difference in the way the United States approached the framework for an ehealth system and, consequently, NEHRs. Similar goals included those of interoperability (i.e. patient information is available at all points of care) and usability (i.e. patient health information is in a format that is useful for both patients and clinicians). The major difference was

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[301] digitalhealth, "Farewell ICRS, Hello NHS Care Record Service," 2003.

that the United States focused on meaningful use. Both interoperability and usability were steps to enhance the meaningful use of patient health information in an effort to improve the service delivery of healthcare and get better health outcomes for patients through improvements to the efficiency and effectiveness of care. Meaningful use was not just about the patient: benefits were expected to accrue to other stakeholders including healthcare providers, clinicians and the state. Therefore, the state "invested significant funding on incentive programs for providers who demonstrated meaningful use of EHRs"[302] which increased their use but left major interoperability and usability barriers in place. This was due, to some extent, to the United States having a different ehealth institutional value set than Australia and England.

The United States' ehealth institutional value set differed from that of Australia and England primarily because the United States favoured a free market approach to healthcare far more strongly than either Australia or, in particular, England. The value of individual choice was prioritised over values tied to the rhetoric of patient-centred healthcare and thus the US can best be described as having a patient-centric rather than a patient-centred ehealth system. This reflects the relative power relationships that emerge between stakeholders when healthcare is often a commodity in a mostly market-dominated system of care provision. Clinicians, healthcare providers and insurance companies – the producers and controllers of patient health information – were powerful actors that saw the system in terms of the patient being at the centre of connected, and somewhat coordinated, care. Consequently, patients were often part of a system where outcomes were driven by these powerful actors rather than by patients.

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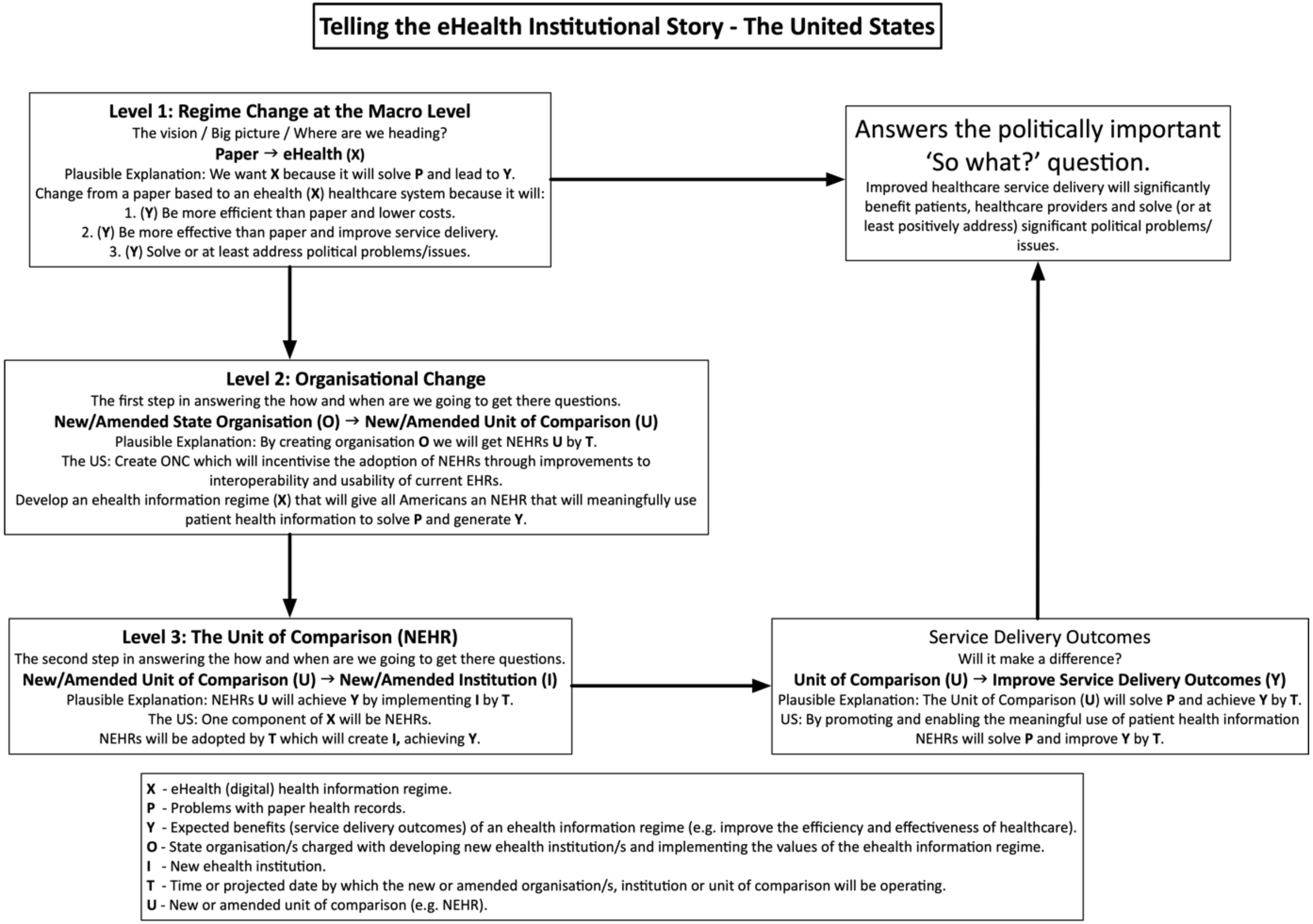
[302] NEHTA, *Evolution of EHealth in Australia*, 14.



Telling the eHealth Institutional Story - The United States

Level 1: Regime Change at the Macro Level
The vision / Big picture / Where are we heading?
Paper → eHealth (X)
Plausible Explanation: We want **X** because it will solve **P** and lead to **Y**.
Change from a paper based to an ehealth (**X**) healthcare system because it will:
1. (**Y**) Be more efficient than paper and lower costs.
2. (**Y**) Be more effective than paper and improve service delivery.
3. (**Y**) Solve or at least address political problems/issues.

Answers the politically important ‘So what?’ question.
Improved healthcare service delivery will significantly benefit patients, healthcare providers and solve (or at least positively address) significant political problems/ issues.

Level 2: Organisational Change
The first step in answering the how and when are we going to get there questions.
New/Amended State Organisation (O) → New/Amended Unit of Comparison (U)
Plausible Explanation: By creating organisation **O** we will get NEHRs **U** by **T**.
The US: Create ONC which will incentivise the adoption of NEHRs through improvements to interoperability and usability of current EHRs.
Develop an ehealth information regime (**X**) that will give all Americans an NEHR that will meaningfully use patient health information to solve **P** and generate **Y**.

Level 3: The Unit of Comparison (NEHR)
The second step in answering the how and when are we going to get there questions.
New/Amended Unit of Comparison (U) → New/Amended Institution (I)
Plausible Explanation: NEHRs **U** will achieve **Y** by implementing **I** by **T**.
The US: One component of **X** will be NEHRs.
NEHRs will be adopted by **T** which will create **I,** achieving **Y**.

Service Delivery Outcomes
Will it make a difference?
Unit of Comparison (U) → Improve Service Delivery Outcomes (Y)
Plausible Explanation: The Unit of Comparison (**U**) will solve **P** and achieve **Y** by **T**.
US: By promoting and enabling the meaningful use of patient health information NEHRs will solve **P** and improve **Y** by **T**.

X - eHealth (digital) health information regime.
P - Problems with paper health records.
Y - Expected benefits (service delivery outcomes) of an ehealth information regime (e.g. improve the efficiency and effectiveness of healthcare).
O - State organisation/s charged with developing new ehealth institution/s and implementing the values of the ehealth information regime.
I - New ehealth institution.
T - Time or projected date by which the new or amended organisation/s, institution or unit of comparison will be operating.
U - New or amended unit of comparison (e.g. NEHR).

Figure 4-8: Telling the eHealth Institutional Story – The United States

Level 1: Regime Change at the Macro Level – from Paper Records to eHealth

As with Australia and England the vision of level 1 regime change at the macro level was to transition from the continuing widespread use of paper health records to a digital ehealth system that would include the widespread use of NEHRs. The rationale was also the same in that NEHRs would increase efficiency and improve service delivery outcomes in healthcare. The original concept of EHRs replacing paper records was widely considered a smart one. Schulte and Fry argued that:

> the wave of digitization had swept up virtually every industry, bringing both disruption and, in most cases, greater efficiency. And perhaps none of these industries was more deserving of digital liberation than medicine, where life-measuring and potentially lifesaving data was locked away in paper crypts – stack upon stack of file folders at doctors' offices across the country.[303]

Box 4-10: Level 1 Claims – Paper to eHealth – United States

> Medical errors happened en masse in the age of paper medicine, when hospital staffers misinterpreted a physician's scrawl or read the wrong chart to deadly consequence.[304]
>
> Health information technology has the potential to transform health care delivery, bringing information where it is needed and refocusing health care around the consumer. This can be done without substantial regulation or industry upheaval. It can give us both better care – care that is higher in quality, safer, and more consumer responsive – and more efficient care – care that is less wasteful, more appropriate, and more available. The changes that will accompany the full use of information technology in the health care industry will pose challenges to longstanding assumptions and practices. However, these changes are needed, beneficial, and inevitable. Action should be taken now to achieve the benefits of HIT [Health Information Technology]. A well-planned and coordinated effort, sustained over a number of years, can deliver results that will better support America's health care professionals and better serve the public.[305]

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[303] Fred Schulte and Erika Fry, "Death By 1,000 Clicks: Where Electronic Health Records Went Wrong," *Kaiser Health News*, 2019.

[304] Schulte and Fry.

[305] Tommy G. Thompson and David J. Brailer, "The Decade of Health Information Technology: Delivering Consumer-Centric and Information-Rich Health Care," *Department of Health & Human Services*, 2004, h.

Level 2: Organisational Change – from ONC to CMS

The US slowly increased state intervention in ehealth and then NEHRs by creating and empowering organisations to incentivise, penalise and otherwise regulate EHRs in an effort to increase interoperability and improve the meaningful use of patient information in order to improve patient health outcomes. This started with ONC in 2004 and after HITECH in 2009 included CMS and other federal regulatory agencies. There was some effort made to increase the centralisation of authority for NEHRs at the federal level in order to further incentivise the adoption of NEHRs and develop an ehealth information regime.

Box 4-11: Level 2 Claims – Organisational Change – United States

> Pew Charitable Trusts argued that a single organization should help guide efforts to improve patient matching.[306] ONC can help advance the standardisation of data as it is the federal agency that oversees EHRs.

Level 3: The Unit of Comparison (Regulation, Incentivising and Coercing NEHRs)

NEHRs were expected to overcome the problems with paper health records and give patients more control over their health information. This was to be done by ensuring all Americans had an NEHR that would meaningfully use their health information to improve their health outcomes.

Box 4-12: Level 3 Claims – Unit of Comparison – United States

Blake recounted the optimistic rhetoric used to justify the HITECH Act in 2009 as President Obama reiterated the claims made by President George W. Bush earlier in the decade:

> Speaking in early 2009 at George Mason University, President-Elect Barack Obama reaffirmed the nation’s commitment to having “all of America’s medical records computerized” within 5 years. According to Obama, doing so would “cut waste, eliminate red tape, and reduce the need to repeat expensive medical tests.” Moreover, it would “save lives by reducing the deadly but preventable medical errors that pervade our health care system” (*NY Times* 2009). That was the vision. One far different than the reality that has ensued.[307]

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[306] Ben Moscovitch, “New Report Lists Steps to Improve Patient Matching Across Electronic Health Records,” 2018.

[307] Robert S. Blake, “Review of The Digitalization of Healthcare: Electronic Records and the Disruption of Moral Orders,” *Public Administration Review* 79, no. 1 (2018): 141.

Service Delivery Outcomes

The meaningful use of patient health information in NEHRs had the potential to improve the efficiency and effectiveness of care. Efficiencies were to be gained by lowering cost and improving the process of care. More effective care was to be achieved by increasing the safety and quality of care; encouraging patient engagement with, and co-production of, their care; and emphasising that the care provided should represent value for the money spent and contribute towards the public good.

Box 4-13: Service Delivery Claims – United States

Kaiser Permanente's integrated EHR system was seen as a model of interoperability that had valuable lessons for many countries as recounted by a number of interviewees. The Director of Kaiser Permanente International explained why it enjoyed a measure of success.

> We're committed to helping shape the future of health care. Because we always say that if you connect all your health IT and you don't change the way that you deliver care, then you've wasted your money. It's like pouring the foundation for a house. You then need to build the house. So now we are building the house. We've got the foundation. We're both a health plant and a delivery system which is not true of most of the rest of the world. So this is just the concept that of being an organisation that you continuously improve and we use data a lot. Our electronic records allow us to collect a lot of data, to disseminate a lot of data, to give a lot of performance feedback to everyone who works here.[308]

Why eHealth Mattered Politically

In the US ehealth mattered politically for a number of reasons. First, government expenditure through the incentive program offered as part of the HITECH Act was expected to return efficiency and effectiveness benefits to all stakeholders. Second, the logic of ehealth and the benefit of NEHRs were widely supported and the state, particularly when Democrats controlled government, was determined to alleviate citizen frustrations with how the healthcare system in the US worked in practice as much as possible. Third, while EHR systems and their implementation were initially based on billing and compliance, there was a growing sense that increased interoperability, as incentivised by the state at the federal level, was the key to increasing patients' control over their health information and meaningfully using that information

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[308] Director, Kaiser Permanente International, Interview, 2014.

to improve patient health outcomes. Not achieving interoperability was likely to result in intense political criticism.

Box 4-14: Policy Value Claims – United States

Promised benefits:[309]

1. Avoid medication and diagnostic errors.
2. Track and intervene with at-risk patients.
3. Share information with other providers.
4. Reduce administrative burdens.

> The most important piece of portability, for me at least, is the fact that we are transmitting accurate information about patients from one entity to the other so as to improve care coordination and to make sure there are no missed opportunities.[310]

Billing and compliance systems in EHRs were a way of digitising the accounting side of health in the United States and Doran argues that "they save a load of money."[311]

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[309] NEHTA, "Evolution of EHealth in Australia," 18.

[310] Kamal Jethwani(Senior Director of Connected Health Innovation at Partners HealthCare), Interview, 2014.

[311] Doran, Interview.

What was Achieved by the State in Incentivising, Regulating and Coercing Nationally Shareable EHRs in the United States by 2015?

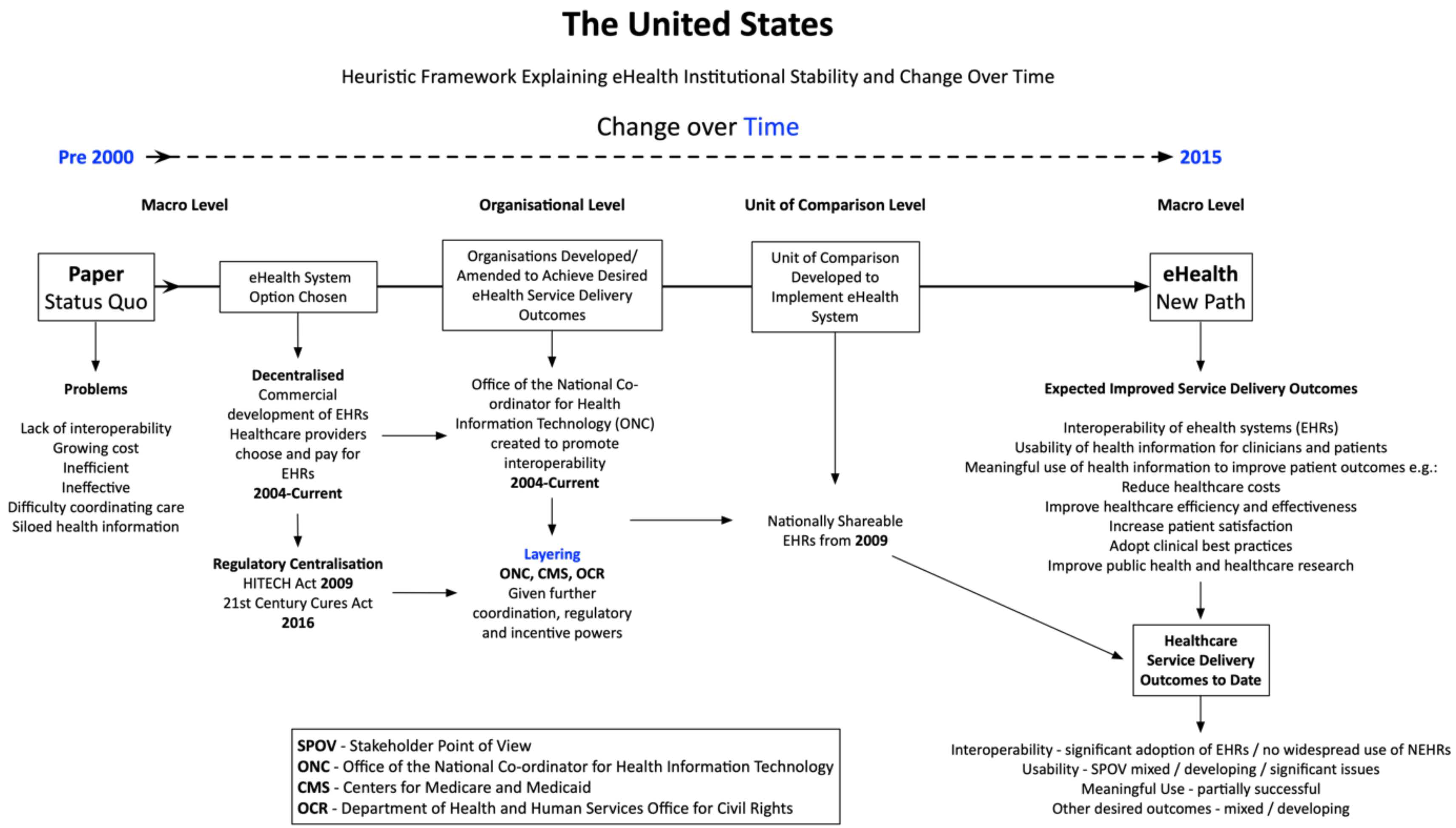

Figure 4-9: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time in the United States

The US initially adopted a decentralised approach to EHRs due to the nature of a market-driven system in which healthcare providers chose and paid for EHRs that were commercially developed. The exception to this was the Department of Veterans Affairs (VA), which developed and implemented its own EHR system. As a result, the state at the federal level at first attempted to guide and influence the interoperability of EHRs through the creation of the ONC in 2004 in the hope that records would eventually be nationally shareable. This had not been achieved by the time of the Global Financial Crisis (GFC) and the state took the opportunity to increase regulatory centralisation of EHRs through the HITECH Act in 2009. Subsequently, three organisations were given more authority to coordinate, regulate and incentivise the adoption of criteria that would make EHRs interoperable and thus nationally shareable. This process has persisted through to the writing of this thesis and considerable funding has been expended on incentivising the adoption of ICT and achieving meaningful use standards. This will be discussed in detail in Chapter 7.

Conclusion – The Significance of the Aspirational Claims for this Research

The rhetoric of ehealth has focused on two major targets. The first was to sell the state-sanctioned NEHR concept to stakeholders (patients, clinicians, medical professional bodies, healthcare organisations, healthcare consumer groups). The rhetoric here focused on values that emphasised moving from clinician-centred to patient-centred care and improving the public good, and on norms that emphasised interoperability which if adopted would lead to better processes and practices. The potential benefits were couched in terms of improving the efficiency and effectiveness of care and thus improving patient outcomes. This had varying levels of success, fluctuating significantly in all three case study countries over time. The rhetoric of this first target also initially centred around interoperability and patient rights, especially privacy rights. The second target was to justify budgetary funding for the chosen NEHR concept. eHealth and the funding of NEHRs has been, and continues to be, a significant public policy issue because of the cost of implementation, the impact new institutional NRPPs have on stakeholders, and the potential to transform healthcare service delivery. Funding has been remarkably consistent from the initial start of NEHR programs until the present, particularly in Australia and England.

These hyperbolic claims clash with the contested reality of the limited success so far (see chapters 5, 6, 7, 8, 9 and 10) of many major ehealth implementations in Australia, England and the United States. The hyperbolic claims continued as this thesis was being written with a good example being the Australian Health Minister claiming that "digital health is the penicillin of our time."[312] One result is responses like that made by the editors of Pulse+IT who, after seeing Hunt's statement, wrote that "we openly admit to a tendency to launch into Olympic-class eye-rolling when hyperbole on eHealth gets too heavy … we found ourselves looking at the back of our skulls and had to have a Dramamine and a bit of a lie down."[313] This criticism is representative of two decades of a significant and continuing, though closing, gap between rhetoric and ehealth systemic implementation experience and reflects a desire for "less talk and more action."[314] However, the talk has been vitally important in establishing the enabling policy narrative that sold the concept of, and secured funding for, ehealth including in the form of state-sponsored NEHRs.

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[312] Pulse+IT, "Digital Health Is Neither Penicillin nor Panacea," Pulse+IT Magazine, 2018.

[313] Pulse+IT.

[314] Pulse+IT.

Chapter 5 Case Study – Australia

This chapter explains the history of ehealth and NEHR development, implementation and regulation at the national level in Australia. The political system in Australia was similar to England in that it was a parliamentary system with both countries having had long traditions of local autonomy for various constituents and stakeholders in the policy sector. It was different in that England had a unitary system and Australia was a federation with a bicameral legislature that provided a set of veto points where policy opponents could block reform.[315] The Australian political system was similar to the US in that it was a federal system with two layers of government, each with distinct as well as overlapping powers, but different in that the US had a presidential political system that distinctly divided legislative and executive power. Therefore, in broad terms, Australia had more political actors who had veto power at the state and local levels than did England, but less than the US. With the introduction of Medicare, and the subsequent institutional acceptance of universal healthcare,[316] Australia's funding of healthcare increased public financing. Public financing considerably outstripped private financing, with the major private component consisting of private healthcare insurance. As a result, "a new and vigorous for-profit private sector, encouraged by government subsidies," dominated the provision of healthcare services except for public hospitals funded by the state and federal governments. Thus, medical professionals were a powerful stakeholder with considerable veto power over healthcare policy reform. Given the institutional structure of the Australian healthcare arena, successful reform depended on alliances with powerful stakeholders and the degree to which NEHR policy "was in accord with the priorities of multiple levels of government."[317]

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[315] Anne-marie Boxall and James A. Gillespie, *Making Medicare: The Politics of Universal Health Care in Australia* (UNSW Press, 2013), 9.

[316] For a comprehensive account of the institutional acceptance of Medicare, see Boxall and Gillespie, *Making Medicare: The Politics of Universal Health Care in Australia*.

[317] Boxall and Gillespie, 9. Boxall and Gillespie also argue that interests matter and that the medical profession can be both a driver of reform and a structural interest that can "block change without needing to act consciously, or as mendacious professional monopolists, vigorously defending its rent-seeking claims in the face of public interest." (10)

The first part of the chapter will examine the development of both endogenous and exogenous institutional pressures and tensions that led to institutional change. Structural antecedent conditions, shock events, ideational change, political agency and converging trends all combined to create critical junctures, or brief windows of opportunity for institutional change, that enabled health record change from paper to ehealth and NEHRs. The second part of the chapter will examine the role of the state at the national level in Australia in developing an NEHR. This will be done by explaining change over time through three phases of development. Phase one covers the period 1991–2000 where Australia was testing the potential of ehealth solutions to address the problems of paper health records. Phase two covers the period 2000–2009 which can best be characterised as tentative steps towards a national health information network. Phase three covers the period 2009–2015 where policy makers focused on patient control of their health information while at the same time desperately trying to increase the uptake and use of the Personally Controlled Electronic Health Record (PCEHR). This was the era where policy makers pursued the concept of patient-centred healthcare in an effort to bring patients into the PCEHR as a way to achieve efficiency and effectiveness outcomes.

Both parts of the chapter will examine the policy-making process by explaining what happened, why it happened, how it happened and who was involved in the policy making process. Important public policy questions regarding the role of the state are addressed including: what did the state want to do, why did the state want to do it, how did the state go about doing it, and how did the state pay for it? A timeline of major events is included in Part 2 as a reference point for the reader and may be a useful guide through what was a complex series of events. The key themes of interoperability, usability and the meaningful use of patient health information are woven into the discussion as are stakeholder trade-offs made by the state which affected institutional stasis and change. Key issues here are the role of the state in the market for NEHRs, who the NEHR was for – clinicians or patients – and how much control over their health information the state was going to give patients. Unintended consequences of pursuing ehealth and NEHR institutional change that emerged from stakeholder trade-offs during the development, implementation and use of the NEHR also form part of the discussion. Stakeholder trade-offs and unintended consequences of attempted institutional change are explained in further detail in Chapter 8. The chapter concludes with a summary of just how far Australia came in the long journey of developing, implementing and regulating an NEHR. The summary will provide a good stepping-off point to the comparative evaluation of cases in Chapter 8, the public policy evaluation in Chapter 9, and the findings presented in Chapter 10.

Box 5-1: Brief Glossary of Key Abbreviations and Terms Used in Chapter 5

AMA	Australian Medical Association.
COAG	Council of Australian Governments. It is the peak intergovernmental forum comprising the Commonwealth government, the governments of the six states and two territories and a representative from the Australian Local Government Association.
DoH	The Australian Commonwealth Department of Health. Preceding it was the Department of Health and Ageing (DoHA) 2001 to 2013.
EHR	Electronic Health Record.
IHI	Individual Healthcare Identifier – used to match patients with their records.
MyHR	My Health Record.
NASH	National Authentication Service for Health allowing providers to access the PCEHR and securely share health information.
NEHR	Nationally shareable Electronic Health Record.
NEHTA	National eHealth Transition Authority.
Negative Structural Alignment	where policy goals do not align with desired outcomes due to value conflicts that negatively affect stakeholder habitual behaviour.
NRPPs	Norms, rules, processes and procedures.
PCEHR	Personally Controlled Electronic Health Record.
Positive Structural Alignment	where policy goals do align with desired outcomes due to value trade-offs that positively affect stakeholder habitual behaviour.

Part 1

The Development of Institutional Pressures and Tensions

Health is one of the most important issues in Australian politics.[318]

Significant institutional pressures and tensions that developed in the 1980s and 1990s led to the critical juncture that produced institutional change to health records in the form of ehealth and NEHR programs in Australia. These pressures and tensions were both endogenous and exogenous in nature. Many persisted over time after the initial critical juncture, resulting in a policy feedback loop that led to subsequent critical junctures and incremental institutional change. Those institutional pressures and tensions included structural antecedent conditions (some of which proved resilient and persisted over time) shock events, ideational change, political agency and converging trends. Shock events opened a brief window of opportunity for new ideas to be pursued through policy change. The result was significant institutional change in the area of health records.

Structural Antecedent Conditions

The structural antecedent conditions that existed in Australia before the development of ehealth and the start of NEHR programs such as HealthConnect and the PCEHR had many similarities with England and the United States as well as some important differences. Paper records and widespread use of the fax machine to transfer patient health information were the norm. Healthcare costs were increasing and were projected to continue to become a larger burden on national expenditure over time. There were two major reasons for the scenario of increased costs. Firstly, people were living longer and a larger aged population accessed the health system more often and required more resources. Secondly, as people lived longer the rate of acute disease went down and there was a substantial increase in more expensive to treat chronic diseases. The 1970s and 1980s saw a contentious policy battle over the value of universal healthcare resulting in

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[318] Anne-marie Boxall and James A. Gillespie, *Making Medicare*, 5.

the establishment of Medicare in 1984. Medicare "remained under siege"[319] until 2003 when it became clear that stakeholders, such as healthcare providers, had become accustomed to, and were benefitting from, the new norm and "the once hostile Coalition parties begrudgingly accepted Labor's reforms and announced that they were now Medicare's 'greatest friend.' "[320] The adoption of universal healthcare, with a co-existing and substantial private health system, increased the role of the state in paying for healthcare. It also resolved equity questions in favour of the social good and led to what Leeder characterised as an ongoing discussion "about health risk not only to us as individuals but as communities, the divide between private and public payment, what it is reasonable to expect from the healthcare system, our ideas about universality of benefits and payments, and much more besides."[321] Richards argued that the emergence of this more egalitarian point of view emanating from the Whitlam and Hawke governments, which led to the growing acceptance of a citizens right to healthcare, set the stage for future policy and legal battles over patient control of health records.[322] NEHRs became a mechanism to resolve some of those policy issues and the arguments for equality, fairness and other values became enablers for institutional change.

Another structural antecedent condition of importance is Australian federalism. Numerous interviewees noted how difficult it has been at times for the Commonwealth to make things happen a certain way in healthcare because the states feared "a loss of power." [323] This happened during the development of the PCEHR over privacy, confidentiality, legal, and security issues where "the Commonwealth would say it should

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[319] Boxall and Gillespie, 2. Andrew Podger disagreed somewhat arguing that John Howard "changed his mind in 1996 and went to the 1996 election saying, 'I'm no longer going to an election with a policy to dismantle Medicare.' Every election up till then the Liberals would dismantle Medicare. This time he said, 'we will maintain it in its entirety but we would also like to have private health insurance play a bigger part.' "By 2003, using the phrase Medicare's greatest friend was "stepping up the rhetoric." Andrew Podger (Former Secretary of the DoH and Public Service Commissioner), Interview, 2019.

[320] Boxall and Gillespie, *Making Medicare: The Politics of Universal Health Care in Australia*, 3.

[321] Professor Stephen Leeder (Editor-in-Chief, Medical Journal of Australia), cited in Boxall and Gillespie, vii.

[322] Brian Richards (The Australian National University), Interview, 2014.

[323] Stuart Stapleton (Director, Emergency Department at Calvary Health Care ACT), Interview, 2015; A former senior official, Interview, 2014; Robert McMahon (Former Senior Public Official), Interview, 2019.

happen this way and then they would have to negotiate with seven people around a table to try and make it work every time."[324]

Structural antecedent conditions also provided some barriers to the adoption of NEHRs. The widespread use of paper records persisted well into the era of the PCEHR and has a continuing strong legacy effect on the adoption and use of NEHRs in provider practices. The cost of acquiring and implementing the technology required to transition to EHRs/EMRs, and thus provide a platform for an NEHR, was seen by many providers as a barrier to change. Governments responded to this challenge with generous payment incentive programs which eventually saw most eligible providers adopt the requisite technology. Similarly, some technologies were ubiquitous prior to ehealth and persisted well into the PCEHR era and are still being used by providers. While the value of patient-centred healthcare was widely appreciated from the start, it meant different things to different stakeholders. For providers it often meant the patient at the centre of a process of care where clinicians were still the experts who had most of the power in the clinical decision-making process and thus over patient outcomes. Patients, the state and consumer advocates often saw this very differently. To them, patient-centred care was an informed patient at the centre of the clinical decision-making process with clinicians as one among many sources of expertise. This view was predicated on patient choice and control over outcomes, which could vary considerably, and which might or might not follow clinical expertise of doctor knows best or one way for all. The *status quo* was clinician-centred care and in practice this proved very difficult to change.

Shock Events

There were three major shock events that provided windows of opportunity for ehealth and NEHR institutional change. Each shock event allowed alternative ideas to the *status quo* to be considered as viable, resulting in political agency driving those ideas in pursuit

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[324] Stapleton, Interview. Marcus Dawe argued that the Commonwealth, through DOHA and trying to control the states through COAG, wanted to drive change. "This is the problem with a federated system. What they're missing here is that the market, the health market, is able to move quicker. They should just be focusing on regulation, incentives and things like that and let the market provide." Marcus Dawe (Former Chief Strategist in Health for Computer Sciences Corporation), Interview, 2015.

of institutional change. Those exogenous shock events were the elections of 1996, 2007 and 2013.

The election in 1996 of a Coalition[325] government led by John Howard, after a long running Labor government, had in part been predicated on conducting an election campaign promising to make Medicare more efficient without substantively changing the system. This was a big shift in Coalition policy, made because Howard recognised that Medicare was quite popular with voters and he wanted to diffuse it as an election issue. By 1996 doctors, one of the Coalition's natural groups of constituents,[326] had shifted their view to be much more supportive of Medicare because "Medicare put every doctor on a drip feed of money being paid by the taxpayer"[327] and this system reduced the amount of time and resources doctors used in chasing up billing issues. The result of the increasing popularity of Medicare with voters and the shift in doctors' views was that the state was now willing to play a larger role in healthcare and be more supportive of ideas favouring ehealth and NEHRs, but still with a strong strain of liberal individualism as part of the policy process.

By 2007, the Coalition's support for ehealth and NEHR initiatives had withered and the election of a Labor government led by Kevin Rudd brought the Commonwealth back into the ehealth process. The result was a change in NEHR focus to patient-centred healthcare and increasing the rights of patients to control their health information.

The election of a Coalition government led by Tony Abbott in 2013 resulted in both stasis and change in the *status quo*. An NEHR was still pursued as policy but there was a significant shift in emphasis that reflected the previously mentioned natural affinity of the Coalition for the doctors as significant stakeholders in the NEHR. This will be discussed further in the next sections on ideational change and political agency.

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[325] The Coalition combined the Liberal and National parties, with the Liberals being in the majority.

[326] John Wanna (Sir John Bunting Chair and Professor of Public Administration and Director of Research of the Australian and New Zealand School of Government), Interview, 2019.

[327] Wanna.

Ideational Change

NEHRs extended the boundaries of the concept of universality from equal access to healthcare provided by Medicare to equal access by patients to their health information and the right to control the transfer, use and privacy of that information. This ideational change blended two ideological perspectives: Labor's use of "the state to achieve limited objectives"[328] such as equality through collective responsibility and the Coalition's desire to expand liberal individualism and choice. The Coalition initially saw the potential value of an NEHR in the utility it would bring to the health system by improving the efficiency and effectiveness of care. Lowering cost and increasing the health information available to both patients and providers of care had the potential to benefit all stakeholders and satisfy consumers through choice and increased engagement with their healthcare. Labor saw value in the NEHR through the state regulating control of patient health information in favour of the patient yet at the same time making more information available throughout the health system and therefore achieving many of the same benefits as the Coalition anticipated. Similarly to both England and the US, ideational change in values and norms persisted across administrations, particularly in support of a change from clinician-centred to patient-centred healthcare and the interoperability of health records.

Specifically, the Howard-led Coalition's first attempt at an NEHR, HealthConnect, was a decentralised concept but its failure saw both the new Labor government after the 2007 election and the Coalition government after the 2013 election support a more centralised approach in the PCEHR and subsequently the My Health Record (MyHR). Ideational change also occurred in the areas of patient control over their health information and opt-in vs opt-out. Patient control over their health information was contentious right from the start. Labor supported a bigger role for the federal government in mandating patient control over their health information as part of the systemic and regulatory structure of the PCEHR, therefore making it opt-in and including a patient-centric privacy model. The Coalition and some providers, especially

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[328] Boxall and Gillespie, *Making Medicare*, 8.

clinicians, argued that opt-in and significant patient control would make any NEHR fundamentally flawed, limiting uptake and resulting in a lack of information that would significantly reduce its clinical value.[329] The Coalition had envisaged all Australians having an NEHR during the HealthConnect years. However, mandated universality was opposed by some consumer and privacy advocates and Labor strongly pushed for an opt-in system[330] which it introduced with the PCEHR in 2012. After the election of 2013, the coalition supported a change to opt-out. This option emerged strongly from the Royle Review of the PCEHR.[331]

Political Agency

The shock event of 1996 and subsequent ideational change was followed through with political agency on the part of the Coalition government. It established the National Electronic Health Records Taskforce (NEHRT) and followed up on its recommendations by establishing and providing ongoing funding for HealthConnect. HealthConnect was unable to successfully introduce an NEHR and political agency on behalf of the Commonwealth then waned until after a new shock event, the election of 2007. This shock event resulted in both ideational change, evidenced by strong state involvement in the creation of an NEHR, centralisation of the process, and strong state regulation over the control of patient health information, and in renewed political agency that saw Labor support the recommendation from the National Health and Hospital Reform Commission to create an opt-in PCEHR. A further shock event occurred in 2013 with the Coalition winning the election and this was followed by ideational change from opt-in

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[329] For example, Paul Dugdale argued that “the logic of improved service delivery seems to keep butting up against established privacy or systemic norms. Everybody who sits on committees like I do, knows that it is far more sensible in IT design to go for opt-out.” Paul Dugdale (Canberra Hospital Health Services Specialist and Academic at the Australian National University), Interview, 2014 1.

[330] Opt-in was strongly supported by some healthcare consumer advocates including Russell McGowan, who argued that “ the opt-in system better protects patients’ rights than an opt-out system” and that it strengthened informed consent. Russell McGowan (Vice President of the Health Care Consumers Association of the ACT), Interview, 2012.

[331] The Review of the Personally Controlled Electronic Health Record was commonly called the Royle Review and was undertaken by Richard Royle (Executive Director, UnitingCare Health); Steve Hambleton (President, Australian Medical Association); and, Andrew Walduck (Chief Information Officer, Australia Post). The review was completed in six weeks and was submitted to the government in December 2013. However, it was not released until May 2014.

to opt-out with the Coalition throwing its support behind provider criticisms of the PCEHR.[332] The PCEHR was rebranded as the MyHR in 2015.

Converging Trends

Richards argued that HealthConnect and the PCEHR came about as result of a long history of converging social, medical professional, fiscal and technical trends.[333] Key social trends that gathered pace in the 1970s and 1980s included citizen rights to healthcare as a social good, privacy and to access the information in their medical record.[334] Medical professional trends saw the role of clinicians changing from "doctor as God / doctor knows best to doctor as a partner in care [resulting in] quite significant structural changes in the way in which medicine [was] practised."[335] Technical trends saw the development of a "raft of technologies to support meaningful practical change within medical practice … without any significant stimulus from outside."[336] Fiscal trends extended directly out of the social trend to regard healthcare as a social, rather than a personal, good. This led to the value that it was the "responsibility of the taxpayer to subsidise, on some equitable basis, people's access to healthcare and that create[d] significant outlays for government which then government [became] very focused on controlling."[337]

Social trends also produced a change in healthcare values and norms. As noted above, healthcare became a social good, rather than a personal good, establishing an egalitarian view of healthcare as a citizen's right that would be subsidised by the taxpayer. There was also an ongoing change in doctor/patient relationships. A value shift from a clinician-centred to a patient-centred healthcare system occurred accompanied by greater patient health literacy, choice, consent and a desire for patients to be more engaged with, and to co-produce, their health outcomes. This value shift resulted in

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[332] See Richard Royle, Steve Hambleton, and Andrew Walduck, "Review of the Personally Controlled Electronic Health Record," December (2013): 1–91.
[333] Richards, Interview.
[334] Richards.
[335] Richards.
[336] Richards.
[337] Richards.

increased patient expectations of access to their health information and set in train a slow shift in power from the clinician to the patient.

Medical professional trends that resulted in a structural change to the way medicine was practised included a change in clinical organisation and responses to demographic changes in the burden of disease. There was a shift from solo GP practices isolated from other parts of the health system to group practices, then branch practices, and to multi-disciplinary teams often embedded in large provider organisations.[338] As in England and the US, the burden of disease was changing from acute to chronic illness and this led to a rise in allied health professions due to the complexity of disease management.[339] These structural changes were seen by many interviewees as a more effective way to provide continuity of care.

Fiscal trends extending out of the value of healthcare as a social good resulted in a significant increase in the Commonwealth government's subsidisation of healthcare and thus saw ehealth become a major concern for government. Both ehealth and an NEHR were seen by the state in efficiency terms as a way of controlling costs while improving healthcare outcomes for all stakeholders. Fiscal pressures that added cost to the health system included an ageing population, growth in chronic diseases, new drugs, new diagnostic equipment, new surgical equipment and genomics. These fiscal pressures combined to contribute to more information being added to health records and an NEHR was seen as a way to extract stakeholder benefits from health data. Fiscal

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[338] Shaun Gath described the change. "The old model of basically doctors working in suburban shopping centres with their own GP practice with maybe one other or out on their own, that type of idea is really becoming less and less common now. Most or a lot of doctors are now working in corporate practices where they are, even though they would not use the word themselves, they are as a matter of law employees of the company, they are on a kind of pay for performance type deal, they get paid a percentage of their … so there is a sort of correlation between their work and their financial position, but the corporate elements of the practice – the rent, the staff, the IT and all that sort of stuff – is paid for by a corporate entity and of course the records now sit within the corporate environment rather than in the personal property environment of the individual doctor. So … these sorts of changes are altering the way in which things are working and then it scales up to hospitals and other locations as well." Shaun Gath (CEO of the Private Health Insurance Administration Council), Interview, 2014.

[339] Richards put this change in terms of acute/chronic illness moving from 80/20 to 20/80. Richards, Interview.

pressures therefore became an important driver of state intervention in the EHR marketplace.[340]

Like England and the US, technical trends saw the Australian government adopt positive rhetoric regarding the potential stakeholder benefits of an NEHR. Advances in information communication technology (ICT) opened up new work practices and approaches to care that significantly changed clinical workflows. Clinical practices adopted electronic billing and patient administration systems, and the electronic availability of pathology results and diagnostic imaging rapidly increased. Successive governments offered incentives for the adoption of health technology and there was a consensus among interviewees that government policy towards ehealth was driven to some extent by the lure of technology as a medium through which desired benefits could be obtained and mountains of patient health data usefully harnessed.[341] However, technology adoption came with numerous issues that would lead to interoperability and usability issues in all three case study countries. These issues included a plethora of ehealth and EHR systems and attempts by vendors to block information sharing and lock customers into their product ecosystem. However, in Australia the technology behind an NEHR was expected to have the potential to "alter relationships between care givers and care receivers"[342] changing the "locus of control to the patient … while still maintaining appropriate levels of privacy and confidentiality."[343]

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[340] Andrew Podger provided some nuance in explaining that because GPs and specialists were small businesses "the whole argument has got to be around effectiveness and patient improvement. If you come in and say 'we do this and it's going to make Medicare more efficient' they say 'get stuffed,' they're not going to do it unless they're convinced it's in their interests and in their patients' interests. So Wooldridge [Minister for Health] kept on saying to us 'do not ever present any of this stuff on an efficiency argument. We can talk about that internally, but do not say that publicily. The whole argument has got to be around effectiveness and patient improvement.' " Podger, Interview, 2019. This helps to explain why some of the rhetoric presented in Chapter 2 was used by policy makers.

[341] Andrew Podger supported the notion that technology change had made the concept of a national EHR more viable and to some extent was driving policy, particularly given the successes organisations such as Kaiser Permanente were having in the US. Podger argued that the focus was less on costs and more on technology offering opportunities to improve the effectiveness of care, particularly better continuity and coordination of care, given the rising concern about increasing chronic illness. Podger, Interview, 2019.

[342] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians, National Health and Hospitals Reform Commission Final Report* (Commonwealth of Australia, 2009), 64.

[343] National Health and Hospitals Reform Commission, 64.

Part 2

The Development of a Nationally Shareable EHR in Australia to 2015 (HealthConnect and the PCEHR)

> *When I was in charge there was a lot of goodwill. We even had conferences, summits where people would turn up and they were really excited. They wanted it to happen and they wanted it to happen quickly and they could see that the feds [federal government] were the only ones that could possibly make it happen because they had the money. But the feds got progressively mired within their own bureaucracies here. It was very difficult to progress, and I think because a lot of people said, "Well, these aren't serious issues. We'll just suck it and see and just try and press on. We'll crash or crash through. We'll try it." Well, I think they crashed. If politics is the art of the possible, so were electronic health records.*[344]

The role of the state at the federal level in Australia was crucial in the development, implementation and regulation of an NEHR. As Philip Hagan noted above, "the feds were the only ones that could possibly make it happen because they had the money."[345] Using the theoretical framework developed in Chapter 3 on research design, this part of the chapter will examine the role of the state in the institutional development of ehealth and an NEHR with the rationale that doing so would improve healthcare service delivery. It draws on Skocpol's research in highlighting "the interconnections of institutions and organisations"[346] in explaining what happened, why it happened and what the outcomes were.

Contextual History – Australia

The development of a shareable summary of patient health information at the Australian national level, a nationally shareable EHR (NEHR), can be divided into four distinct phases. These phases are:

1. the lead-up to the adoption of ehealth as federal government policy on a de-centralised basis

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[344] Philip Hagan (Former Assistant Secretary, Policy Strategy Group, Australian DoH), Interview, 2014.
[345] Hagan.
[346] Theda Skocpol, "Why I Am an Historical Institutionalist," *Polity* 28, no. 1 (1995): 103.

2. the HealthConnect years
3. the more centralised Personally Controlled Electronic Health Record (PCEHR)
4. the My Health Record (MyHR) phase which will be covered as a post-2015 update in Chapter 10.

Each phase had its own unique goals but there was an underlying intended outcome based on the interoperability, usefulness and meaningful use of *patients health information* based on the use of EHRs. All four phases reflect both continuity and change, transforming ehealth as an institution in a way that brought it "in line with changing social, political, and economic conditions"[347] but also exhibiting the "sticky legacies of previous political battles."[348] Continuity and change within the framework of historical institutionalism will be explored in more detail in the comparative analysis contained in chapters 8 and 10.

Table 5-1: Australia—Historical Chronology of Main Events

Date	Timeline of Major National Events in Australia[349]
1980s	Efforts to uniquely identify Vietnam veterans by matching up longitudinal health information in the 1980s led to the start of national standards for data collection and data quality definitions as a way to look at health causes and distribution of disease and to guide policy on locating health services.
1991	Joint statement by state, territory and federal health ministers proposed the development of a "national health information systems and technology strategy covering both in-hospital and community-based care."
1991–1999	"No overarching national strategy … trials and pilots in e-health were small, sporadic, and fragmented in nature."

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[347] Kathleen Thelen, *How Institutions Evolve: The Political Economy of Skills in Germany, Britain, the United States, and Japan* (New York: Cambridge University Press, 2004), 293.

[348] Thelen, 293.

[349] Sources: Margaret Riep (Health ICT Project Manager and Health Informatician, Interview), 2015; Ian P. McLoughlin, Karin Garrety, and Rob Wilson, *The Digitalization of Healthcare*, 1st ed, (New York: Oxford University Press, 2017), 30–38; Commonwealth of Australia Department of Health and Ageing, "COAG Health Services Establishing the Foundations for a National Electronic Health Records System," 2006; Australian Government: Department of Health, "Budget Delivers Certainty for EHealth System," 2012; Sussan Ley (Minister for Health and Sport), "Health Legislation Amendment (EHealth) Bill 2015 Explanatory Memorandum," 2015, 3; Laura Jakob, "HealthConnect Evaluation," 2009, 10. Tanya Harch (Former Director, National eHealth and Information Co-ordination Unit for Queensland Health), Interview, 2018.

Date	Timeline of Major National Events in Australia[349]
1997	House of Representatives Standing Committee on Family and Community Affairs released Health Online, the report of the Inquiry into Health Information Management and Telemedicine.
1999	Health ministers established the National Electronic Health Records Taskforce (NEHRT) "to evaluate the potential of electronic health records for the Australian health care system."
2000	NEHRT report recommended the creation of a national health information network (NHIN) to link health information between healthcare providers.
2000–2005	MediConnect, which started as the Better Medication Management System, was established with the aim of providing an Australia wide electronic medication record.
2000–2005	Health ministers accepted NEHRT recommendation and launched HealthConnect "Australia's first attempt to build a national EHR system." Expected to take five to ten years.
2004	$AU128 million in funding allocated for the national roll-out of HealthConnect.
2005	HealthOnline effectively shelved. HealthConnect became a change management strategy to some extent incorporated by NEHTA.
2005–2009	National E-Health Transition Authority (NEHTA) established to identify and develop the necessary technical and governance foundations for ehealth and an individual national EHR.
2006	Federal and state governments budget $AU129.3 million (50/50) to accelerate work on a national health records system.
2008 (Dec)	National E-Health Strategy released.
2009	The federal government accepted the National Health and Hospital Reform Commission recommendation to develop a Personally Controlled Electronic Health Record (PCEHR) by 2012.
2010—2016	NEHTA tasked with the development and implementation of the PCEHR.
2010	Federal budget allocated $AU466.7 million over two years for the development of the PCEHR. *Healthcare Identifiers Act* was passed to improve positive patient identification and enhance the link between patients and their EHR.
2012	Federal budget allocated $AU233.7 million "to continue the rollout of a national, secure eHealth system." June – *Personally Controlled Electronic Health Record Act* passed by the federal Parliament (modified 2016), then in July – PCEHR launched. Patients must opt-in to get a record.
2013	Federal government commissioned the Review of the Personally Controlled Electronic Health Record (commonly called the Royle Review) of the PCEHR.
2014	Royle Review is released recommending major changes to the PCEHR including moving from an opt-in to opt-out model. Federal budget allocated $AU140.6 million to keep PCEHR going.

Date	Timeline of Major National Events in Australia[349]
2015	Federal budget allocated $AU485.1 million "rescue package" for the PCEHR. PCEHR rebranded as the My Health Record (MyHR).
2016	NEHTA replaced by the Australian Digital Health Agency.
2017	Federal budget allocated $AU374.2 to fund the expansion of the national ehealth record system for two years.

Phase One: 1991–2000 – Testing the Potential

In phase one, the lead up to the adoption of digital healthcare as federal government policy was more aspirational than operational. This period links to, and comes out of, the federal governments efforts to uniquely identify Vietnam veterans in order to match up longitudinal health information in the 1980s.[350] It is the start of the Australian journey to develop national standards for health data collection and quality definitions. A joint statement by state, territory and federal health ministers in 1991 proposed the development of "a national health information system and technology strategy covering both in-hospital and community based care."[351] Subsequently, in 1992, the Australian Health Ministers Advisory Council (AHMAC) recommended the "construction of a Health Communications Network (HCN) which would connect healthcare organisations electronically."[352] However, despite the decentralised nature of the proposed HCN initial public support evaporated due to opposition by the Australian Privacy Foundation[353] and the lingering negative effects of the Labor government's failed attempt to introduce a national identification scheme popularly referred to as the

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[350] Riep, Interview.
[351] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 31.
[352] McLoughlin, Garrety, and Wilson, 31.
[353] McLoughlin, Garrety, and Wilson, 31.

Australia Card, in 1986[354]. After the HCN legislation was rejected twice by the Senate it was abandoned by the Labor government[355] in 1993. Thus, McLoughlin et al. argue that between 1991 and 1999 there was “no overarching national strategy … trials and pilots in e-health were small, sporadic, and fragmented in nature.”[356]

However, while practical progress in developing an NEHR was fragmented and lacking in coordination[357] the discussion of the benefits of linking health information, and interest in ehealth in general, continued to develop in this period. Philip Hagan, former Assistant Secretary for Health, thought at the time that “electronic records was an idea whose time was about to come.”[358] For example, during the mid 1990s the Health Insurance Commission (HIC) pursued an information management agenda that aimed to make use of data it was collecting for the purposes of administering health programs, such as Medicare and PBS data, to inform both policy, and potentially clinical, decision making.[359] The HIC also had a brief to make consumer information more available. One example was the introduction of the Australian Childhood Immunisation Register. This “became a critical thing for consumers, with access provided through a consumer-based portal, and was then used as a policy instrument by governments to determine access to things like childcare.”[360]

As Table 5.1 shows, in 1997 the House of Representatives Standing Committee on Family and Community Affairs released *Health Online*, the report of the Inquiry into Health

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[354] The legacy of the Australia Card lingered through to the PCEHR and amplified the influence of privacy advocates. Harch noted that “a lot of people say they remember the conversations about being still freaked out by the Australia Card and I think there were probably people who feared government having access to their electronic information.” Harch, Interview. Podger supported this point of view noting the issue of big data banks led to continuing political concern over the privacy of patient health information.” Andrew Podger (Former Secretary of the DoH and Public Service Commissioner), Interview 1, 2015. For a more detailed examination of the social concern over, and the political ramifications of, the potential of the information behind the Australia Card to “expand without social or democratic checks,” including in healthcare, see Peter G. Graham, “The Australia Card: A Technology Driven Policy?” (Griffith University, 1990).

[355] Clarke 1998, cited in McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 31.

[356] McLoughlin, Garrety, and Wilson, 31.

[357] Paul Fitzgerald (Former Senior Official, HealthConnect Program Office, Australian Department of Health and Ageing), Interview, 2014.

[358] Hagan, Interview.

[359] Anthony Honeyman (Former Senior Executive Australian Health Insurance Commission and Chairman, APIS), Interview, 2018.

[360] Honeyman.

Information Management and Telemedicine marking "the beginning of a renewed interest in the development of a national EHR system."[361] This report was followed up by the establishment by health ministers of the National Electronic Health Records Taskforce (NEHRT) "to evaluate the potential of electronic health records for the Australian health care system."[362]

Phase Two: 2000–2008 – Tentative Steps Towards a National Health Information Network

Phase two began in 2000 when the NEHRT recommended a national, but decentralised, approach to EHRs[363] resulting in the policy decision to create a national health information network (NHIN) known as HealthOnline,[364] which was Australia's first effort to share patient health information nationally. HealthOnline had a number of key areas of activity including telehealth and the development of a national electronic health record, as well as supply chain management, the development of standards, and the development of privacy policy.[365] The decentralised NEHR component became HealthConnect "Australia's first attempt to build a national EHR system"[366] which was expected to take five to ten years. Funding for HealthConnect was jointly provided by the Commonwealth and state governments, however during the period of 2000 to 2005 the Commonwealth adopted a leadership role during which time the "senior Australian Health Information Management Advisory Council (AHIMAC) was leading the charge."[367] Significant stakeholders who were represented on AHIMAC included Commonwealth and state officials, the AMA, the pharmaceutical industry, the medical colleges, the Privacy Commissioner, the Health Insurance Commission (HIC) which is now Medicare Australia, and a consumer advocate.[368]

HealthConnect implemented state and territory-based research projects and trials focusing on EHRs, hospital admission and discharge, care planning, directory

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[361] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 30–31.

[362] McLoughlin, Garrety, and Wilson, 30.

[363] Lynelle Briggs, "A National Approach to Electronic Health Records," *Health Information Management Journal* 30, no. 1 (2001).

[364] Fitzgerald, "Interview."

[365] Fitzgerald.

[366] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 30.

[367] Fitzgerald, Interview.

[368] Fitzgerald.

development and e-referral. The focus was on issues of consent (whether to adopt a system of opt-in or opt-out); whether it was better to target particular disease categories (hence the number of diabetes trials that were done); and Aboriginal, rural and remote communities.[369] In parallel the Department of Health (DoH) started a second project called the Better Medication Management System, which became MediConnect, through a different yet competing part of the department. MediConnect was focused only on medication information and prescriptions with the rationale that "there was proven research information to show that improving the accurate sharing of medication information would really improve patient health outcomes and that the more generalised electronic health record was less certain." [370] The result was that MediConnect was designed as a national system that would host a Medicare database. This reflected the HICs view that it was "pretty uniquely placed to manage and run the National Health Directory which would provide easy use of the transfer of information, particularly amongst health professionals."[371] However, having two competing projects going on simultaneously was eventually seen as a "big waste of resources."[372]

In 2004 there was a change in focus and it was decided to bring the two projects together. A political decision was made to abandon the centralised nature of MediConnect and rather than work with Medicare, as MediConnect had been doing, go instead with the idea of interoperable distributed databases that, through standard-setting, could be made to work. This decision came out of the bureaucratic policy conflict[373] alluded to above, a feeling that the DoH had let "a thousand flowers bloom in that space"[374] with little to show for it, and a desire by the then Minister for Health, Tony Abbott, to

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[369] Riep, Interview.
[370] Riep.
[371] Honeyman, Interview.
[372] Riep, Interview.
[373] Riep argued that "the HealthConnect lot were more powerful than the MediConnect group", distrusted Medicare and favoured the Howard government's idea of contestability and open tenders for a system of distributed databases which, according to Riep, "added an infinite additional layer of complexity." The idea that interoperable distributed databases could be made to all work together using standards continues to persist in the era of a more centralised approach, with the PCEHR/MyHR, as a foundation for improving both the efficiency and effectiveness of care discussed elsewhere in this thesis.
[374] Honeyman, Interview.

accelerate the rollout of HealthConnect.[375] Abbott's announcement in March 2004 of a rollout of a NHIN by 1 July "stunned stakeholders."[376] Abbott claimed that:

> the integrated system will provide secure electronic records for consumers wherever they go in the health system, providing the basis for improved decision-making and delivering streamlined care.[377]

A modest $80 million was committed to the project over three years however confusion was apparent from the start. Small pilot trials of MediConnect and HealthConnect were not yet complete, HealthConnect was still in the early phases of a ten-year development schedule, MediConnect was beset by technical and legal difficulties, stakeholders had no prior warning of the plan, the Federal Privacy Commissioner Malcolm Crompton warned that a lot of work was still needed on privacy and consent issues for sensitive patient data, and DoH officials "were unable to shed further light on the plan, saying it would take some time to sort out the fine detail."[378]

By 2004–2005 HealthConnect was losing political favour at the federal level as it failed to deliver anticipated results on the accelerated timeline pushed by the Minister for Health, Tony Abbott.[379] There was a view that the series of trials it had undertaken "really went nowhere. It achieved very little."[380] This was in large part due to the lack of scalability associated with many of the trials as "they were more often than not an extension of what was already happening within a jurisdiction anyway."[381] The result was a lack of ability to move them outside the boundaries within which they were operating.

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[375] This view was supported by Carole McQueeney who explaind that Tony Abbott said "If banks can do it in 12 months, why can't we?" She then noted that "the advice we were giving was that we are talking a different language and we are talking far more complex information." Carole McQueeney (Former Senior Official in HealthConnect), Interview, 2014.

[376] Dearne, "Abbott Forces Pace on E-Health."

[377] Dearne.

[378] Dearne.

[379] David More's critical view was that "Tony Abbott achieved a spectacular bit of nonsense" with his initial enthusiasm for ehealth that quickly evaporated when he found out the cost would be "roughly of the order of a billion dollars." More went on to say "that, of course, caused Tony to faint, whereupon what was actually going to be an IT project became, as they termed it, a change management strategy with no dollars at all attached to it – with not a single cent, indeed attached to it – albeit there were all these process releases saying how well it was progressing and how all these people were doing wonderful things." David More (Health IT Consultant, Creator of the Australian Health IT Blog), Interview, 2014.

[380] Honeyman, Interview.

[381] Honeyman.

The new fast track approach then "added an infinite additional layer of complexity,"[382] however there was still a view among some bureaucrats that rolling out MediConnect nationally at a very basic level had more potential for success, but that was not the political view.[383]

A former Department of Prime Minister and Cabinet official, Isi Unikowski recounts:

> My recollection, and what made up most of my briefs to the PM [Prime Minister], was that we had high hopes, were spending a lot of money but getting very little in terms of results.[384]

In fact, by 2005 the national ehealth system in Australia hit a crisis[385] largely for three reasons: the already discussed failure of HealthConnect to produce desired outcomes; tensions between key stakeholders; [386] and changes in governance structure. HealthOnline and the concept of an NHIN was effectively shelved[387] in 2005. Essentially, HealthConnect "was seen to have run its course." [388] However, it had "got the Commonwealth and states talking and it had also got health professionals involved in debates about ehealth and the opportunities around it. It was a means of working on a range of programs or sharing case studies, sharing programs, [and] understanding successes and failures."[389]

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[382] Riep, Interview.

[383] Riep.

[384] Isi Unikowski (Former Official, Australian Department of Prime Minister and Cabinet), Interview, 2018.

[385] Fitzgerald, Interview.

[386] Rob Wooding (Former Division Head of HealthConnect), explained stakeholder tensions: "There were a lot of competing and conflicting views about what people wanted to have happen and various vested interests that were making their views heard. One of the bureaucratic things that has a big impact on whether you can get things done or not in the bureaucracy is when various decisions are made that unfortunately set up turf wars. The Health Insurance Commission and its board decided, though, was that the big future for them was to get into the e-health world. So their vision was to have them just take over all ehealth and become a central repository and system for all electronic health. They were pushing this, and it was a bit of a scary agenda for many, I think, particularly the doctors who didn't really like the idea of the people who could put them in jail for defrauding Medicare also being the people who would have access to all their patient records. So that was a big factor that was floating around there." Rob Wooding, Interview, 2014.

[387] Fitzgerald, Interview.

[388] Honeyman, Interview.

[389] Honeyman.

In June of the same year HealthConnect was reconfigured into a modest[390] change management strategy.[391] This had two major impacts. Firstly, HealthConnect "lost its focus as a very specific project and got redefined as projects that might further the development of electronic health records into the future."[392] The project changed from "delivering a thing to a concept and a journey"[393] stopping what some saw as a lot of fruitful development with the result that HealthConnect "shed a whole heap of staff who had a huge amount of knowledge … and the department lost its control over it."[394] Secondly, the concept of a decentralised NHIN was abandoned and "HealthConnect in this period was very specifically a national electronic health record".[395]

The reconfiguration of HealthConnect was followed in July 2005 with the creation of a new organisation, the National eHealth Transition Authority (NEHTA) as a stand-alone statutory body, to further develop the building blocks for electronic health records. NEHTA was born out of HealthConnect's failure to meaningfully change the *status quo* of siloed health records. As Richards noted:

> All the EMR systems in the public hospitals, the private hospitals, the GPs rooms, the specialists' rooms, allied health – they were all on completely non-standardised different platforms. It was like, if you thought the rail gauges were bad you should have seen it.[396]

Richards argued that NEHTA was meant to be a short-term transitional agency, a vehicle which could use the infrastructure pieces already developed by the HIC, such as identifiers and encryption software, "to negotiate and define the set of agreed standards across industry and across the sector and then to work out a migration path to get all those disparate systems onto a common set of standards so that information could be

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[390] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 30.
[391] Jakob, "HealthConnect Evaluation."
[392] Fitzgerald, Interview.
[393] Riep, Interview.
[394] Riep.
[395] Fitzgerald, Interview.
[396] Richards, Interview. The rail gauge problem refers to Australia's colonial states having different rail gauges at the time of Federation in 1901 and the long-term standardisation problems that ensued.

exported into an EHR in a seamless automated way."[397] The result was that over the next four years "HealthConnect disappeared from the program as the money went to NEHTA."[398]

There were also tensions between key stakeholders. Central to these tensions was a "difference of view about how things should proceed"[399] between HealthConnect and the HIC. Fitzgerald argued that:

> HealthConnect's approach was to work more incrementally in the development of the design of the thing rather than just hastily put things together. The Health Insurance Commission saw that there was data already held in the HIC that could be used to quickly scale up an electronic health record and there was a bit of a push from the HIC that they were the natural home for the actual development and implementation of a national electronic health record, and that hadn't been agreed. NEHTA had been created and they were another powerful influence that was arguing in a particular direction.[400]

Another interview made a similar point more bluntly:

> There were all sorts of ructions in health at that time, and that just characterises the whole business – warring parties not working effectively together to deliver a really, really important transformational reform. That was the case with NEHTA when they came in. They wouldn't work effectively with Medicare Australia and that undermined the process. There was a lot of state stuff which is about, "We will control our data. We don't want to give data to Medicare." All of these appalling bunches of behaviour around a really important policy reform, and it just characterises Commonwealth-State relations, health issues and health reform more generally. It seems harder to do anything sensible in health in terms of the policy and financial framework than most other areas I've ever worked in.[401]

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[397] Richards. This was supported by Paul Fitzgerald who noted that "there's a lot of underpinning stuff that needs to be developed to have electronic health records work and some of the standards work. And that's why NEHTA was established." Fitzgerald, Interview. Developing foundations supported by Harch, Interview. Supported by Chris Mount who noted that "all states and territories and the Commonwealth were joint owners in the transition authority." Chris Mount (Director of eHealth Policy, DoH, Australia), Interview, 2014.

[398] Fitzgerald, Interview.

[399] Fitzgerald.

[400] Fitzgerald.

[401] A former senior official, Interview. This point of view is support by Andrew Podger who explains that the states were reluctant to share data with the Commonwealth because of the insight it would give the Commonwealth into the cost shifting games the states were playing. Podger, Interview 2, 2019.

These stakeholder tensions would have significant flow-on effects producing longstanding barriers to interoperability and usability that negatively impacted the potential of portability to improve healthcare service delivery.

Tensions between stakeholders discussed above led to changes in governance structure that resulted in AHIMAC losing its authority and being "effectively downgraded to something called the Australian Health Information Council (AHIC)."[402] The AHIC was replaced with "an independent authority called the National Health Information Group (NHIG) [which] was a group of state officials [who then] steered the ship."[403] Thus, a transfer of leadership from the Commonwealth to the states effectively occurred in ehealth between 2005 and 2009 as "central agencies were of the view that a lot had been expended for not very much"[404] and as a result ehealth within the DoH shrank in size.

The DoH asked the health and human services consultancy firm Communio to conduct an evaluation of HealthConnect. Communio's report, released in 2009, was generally positive about HealthConnect's impact on "ehealth infrastructure across Australia," including making "significant inroads in altering the landscape in which eHealth operates," while acknowledging that "the program faced new and sometimes unexpected challenges" that meant that it was "unable to achieve the deadlines and/or deliver the specified project outcomes detailed in the original funding agreements."[405]

Phase Three: 2008–2015 – Bringing the Patients In

Phase three effectively began in 2009 with the National Health and Hospital Reform Commission (NHHRC) report recommending the creation of a patient-centred Personally Controlled Electronic Health Record (PCEHR). However, this was preceded by a Boston Consulting review of NEHTA in 2008 and the National E-Health Strategy released in December 2008 which, according to David More, failed to gain funding traction.

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[402] Fitzgerald, Interview.
[403] Fitzgerald.
[404] Honeyman, Interview.
[405] Jakob, "HealthConnect Evaluation," 10–11.

> The national strategy said that the Boston Consulting Group was right and that NEHTA had lost its way completely. But, of course, that was dutifully ignored. And the other thing you need to remember, of course, about the national strategy was that everyone endorsed it at the absolutely highest levels—at the level of COAG [Council of Australian Governments]. But, guess what? The endorsement was not associated with a single dollar of funding."[406]

There was a reinvigorated sense emerging, and subsequently a wide-reaching view, that "technology would be useful or important to improve the way in which business was done in healthcare to get better health outcomes if we had better information at the time of consultation."[407] Politically, and in a pragmatic sense, the Australian health system was seen as fragmented, under growing pressure and facing significant challenges for which it was ill-equipped.[408] Those challenges included "large increases in demand for and expenditure on health care, unacceptable inequities in health outcomes and access to services, growing concerns about safety and quality, workforce shortages, and inefficiency."[409] The report identified three reform goals, with ehealth – in particular a PCEHR – as potentially transformative in achieving them. Those goals[410] were:

1. Tackling major access and equity issues that affect health outcomes for people now.
2. Redesigning our health system so that it is better positioned to respond to emerging challenges.
3. Creating an agile and self-improving health system for long-term sustainability.

Specifically, it argued that:

> 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 the continuity and health outcomes for patients. Giving people

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[406] More, Interview.
[407] Mukesh Haikerwal (Former President of the AMA and National Clinical Lead NEHTA, WHO), Interview, 2013.
[408] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians*, 3.
[409] National Health and Hospitals Reform Commission, 3.
[410] National Health and Hospitals Reform Commission, 3.

> better access to their own health information through a person-controlled electronic health record is also essential to promoting consumer participation, and supporting self-management and informed decision-making. We want the Commonwealth government to legislate to ensure the privacy and security of a person's electronic health data.[411]

This clearly indicated that the state, in this case the Commonwealth government, would have to play a significant role in ehealth in order "to fulfil the real promise of e-health."[412] That included establishing a more EHR-specific privacy regime; ensuring that broadband and telecommunication networks would be capable of making interoperability practical; and supporting clinicians and health care providers to "get out of paper and adopt electronic information storage, exchange and decision support software."[413] It would also involve setting secure standards for the confidential exchange of patient health information; making health information available to consumers to help them make informed choices and enable health performance reporting on healthcare providers for comparative clinical performance purposes; and agreeing to, and implementing, a National Action Plan on E-health with state and territory governments.[414]

Numerous benefits of a PCEHR were claimed. Reflecting the conceptual move from patient to healthcare consumer[415] the PCEHR was to strengthen consumer engagement, choice and participation giving consumers a voice in their healthcare journey.[416] It was also expected to improve health literacy, making patient healthcare choices easier and thus enabling patients to make healthier choices and consequently achieve better health outcomes, both personally and in terms of population health.[417] The PCEHR was supposed to shift healthcare from a clinician-centred (doctor knows best) to a patient-centred system. Donald Berwick suggested that patient-centred healthcare really meant

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[411] National Health and Hospitals Reform Commission, 8.
[412] National Health and Hospitals Reform Commission, 8. This point of view was supported by Harch who argued that "it was very much driven by the Australian Government" in consultation with the states and territories. Harch, Interview.
[413] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians*, 8–9.
[414] National Health and Hospitals Reform Commission, 8–9.
[415] The terms consumer and patient are often used interchangeably in the literature. I have chosen to use patient unless the term consumer seems more applicable in context throughout the thesis.
[416] National Health and Hospitals Reform Commission, 121–23.
[417] National Health and Hospitals Reform Commission, 122.

"that evidence-based medicine 'sometimes must take a back seat' if clinicians are truly to respect the wishes of patients. And that 'non-compliance' legitimately reflects the different values and priorities that individuals have in their lives, as well as highlighting the challenge of better information exchange between clinician and patient."[418] Patient-centred healthcare was also expected to lead to "empowering consumers to make fully informed decisions" as part of "shifting [the] power balance between consumers and clinicians." [419] Practically that would mean the "implementation of advanced care planning to support people making informed decisions about their dying."[420] This power balance is explored in the section on power relationship ratios later in the thesis. The PCEHR was also expected to enable the smart use of data, information and communication through successful ehealth system interoperability, trust and the development of required standards and health identifiers.[421]

> Data should enhance decision-making, drive improvements in clinical practice, guide how resources are marshalled and deployed and provide the basis for feedback loops to promote improvement in access to, and quality and efficiency of, care.[422]

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[418] Donald Berwick, 2009, cited in National Health and Hospitals Reform Commission, 123. Supported by Chris Mount who explained that "the patient centred rhetoric is very much about empowerment, consumer empowerment and allowing them to help manage their health care better and also to be able to make better choices about their health care in conversation with their clinicians, etc. This is also a significant challenge to clinicians." Mount, Interview. Andrew Podger remembered Donald Berwick being "very influential on things." Podger, Interview 2, 2019.

[419] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians*, 123.

[420] National Health and Hospitals Reform Commission, 124.

[421] John Vinen (Medical Director of Calvary Health Care), illustrated just how important the development of a single health identifier for a patient was to their health outcomes. "Patient information in the Emergency Department is key to successful management of the patient. Very, very commonly in probably around 50 per cent of patients who present, whether it's because of age, infirmity or because of their illness or they are unconscious, they can't tell you their medical details. So you often are assessing and managing a patient without any information, or minimal information. Nursing staff, especially in an Emergency Department, are very adept at riffling through pockets and purses and wallets and things and they look for medical information, doctors' appointment cards or anything that might give us information about the patient, pills they might have in their purse or their pocket to get useful information. But at the end of the day there's often huge knowledge and information gaps that can be very very problematic, and in fact at times can compromise a patient's life." Vinen demonstrated that a single IHI is a necessity due to the numerous identifications a single patient may have, including aliases and multiple drivers licences. See the Vignettes on Health in Box 1 of Chapter 1. John Vinen, Interview 1, 2014.

[422] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians*, 127.

The system was to connect "all participants with relevant, accurate and secure information in real-time."[423] Trust, consumer participation and self-management, and informed decision making involve people being able to:[424]

1. control access to their own health information (including what information they will share with health practitioners)
2. add information relevant to self-management and healthy lifestyles (such as home monitoring of blood pressure or diabetes control)
3. choose where and how their health record will be stored, backed-up and retrieved.

This focus on a patient's right to control their health information reflected the strength of the privacy and patient advocate stakeholders. Organisations such as the Australian Privacy Foundation[425] made numerous submissions regarding the PCEHR supporting opt-in and personal control which reflected earlier privacy battles around the Australia Card and government access to citizens personal information.[426] Harch thought that "privacy was a huge aspect which was why they went with the personally controlled

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[423] National Health and Hospitals Reform Commission, 127.

[424] National Health and Hospitals Reform Commission, 129.

[425] The Australian Privacy Foundation, as of October 2019, had as its website banner "Defending your right to control your personal information" and referred to the MyHR as "the Australian government-controlled online copy of parts of your health information." Its message was very clear: "it is not designed for patients, and it is not designed for health care professionals. And it is being foisted on you." This perspective was supported by David More in his Australian Health Information Technology Blog and in many of the comments to posts in the blog.

[426] Elin Lehnbom's research supports the view that, for some people, privacy was extremely important. She explained that she "talked with students with stigmatised conditions like HIV and hepatitis and they said that they don't trust the government. They see the PCEHR as controlled by the government and they don't want the government to know what conditions they have so they have different doctors for different conditions. The one patient that I am thinking of in particular, he said he travels a lot and because he has HIV a lot of different countries when you enter countries they ask if you have HIV and he was afraid that if he said that he had HIV he wouldn't be allowed into the country, so he would always say 'No' and he thought that if he had a PCEHR and his HIV status was on the PCEHR these other countries could look it up and would deny him entry." Elin Lehnbom (Postdoctoral Research Fellow, Centre for Health Systems and Safety Research, Australian Institute of Health Innovation, UNSW Medicine), Interview, 2014. Many interviewees spoke of significant privacy concerns that would cause people to want to hide aspects of their medical history or not have some aspects of their medical history go into the medical record. These concerns related to sexual health, terminations, genetically unrelated family members who are unaware of their status (including adoption), clinicians who have social relationships with patients potentially being able to access their records, mental health, and insurance.

electronic health record. It was probably the only way that people thought it was palatable."[427] Over time it would lead to significant systemic issues with the PCEHR and clinician pushback[428] which would essentially make some of the aspirations above unworkable in practice.

Given past experiences in implementing such significant systemic change in short periods of time it was rather ambitious to recommend that every Australian should have a PCEHR by 2012 that would "at all times be owned and controlled by that person."[429] This set the stage for considerable contestation between ehealth stakeholders over such issues as a workable privacy regime;[430] how much control consumers should have over the information in their PCEHR; how government was to mandate and incentivise clinician, hospital and other healthcare provider uptake and meaningful use of the PCEHR; and how technical standards to achieve interoperability goals were to be developed and implemented. Immediately there was resistance from clinicians specifically about who the PCEHR was meant to be designed for, and if not for them then why would they use it. There were also tight timeframes for development and implementation, with identifiers to be available by 1 July 2010, hospitals and pathology providers to be able to send key data by 1 July 2012, and all healthcare providers

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[427] Harch, Interview. Harch's point of view was supported by David More who stated that the bureaucracy "were so terrified that privacy would completely unravel them that they shot over the other way." He outlined the back story as follows: "NEHTA had been beavering away in the background on a sort of HealthConnect version II, a shared record version II, and a fairly senior bureaucrat who was on secondment to the NHHRC process was given where NEHTA was up to on this shared record and said, 'Oh, hell. We can't have something like this. We've done the Australia Card and we got nailed and we tried the Human Services access card and we got nailed by the privacy lobby, so we're going to come up with a shared record that is privacy cuddly to the extent that absolutely no-one can believe.' So they said, 'Well, the obvious thing to do is make it personally controlled.' And there it was, with no thought as to how it might be implemented, how it might impact anything else, where it fitted strategically or any of that. We suddenly had this 30-page document described as the PCEHR, which, of course, then meant that NEHTA ran away for two years trying to come up with a concept of operations for it." More, Interview.

[428] Andrew Podger saw some clinician pushback as "eminently sensible – genuine concern to make the system work." Podger, Interview 2, 2019.

[429] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians*, 34.

[430] Andrew Podger explaind that privacy issues slowed the implementation of ehealth initiatives. "There were several principles that the privacy people would have is that you could only use information for purposes that were given to you and if you wish to use them for something else you'd have to go back to them and ask them if it was okay to use them." Podger, Interview 2, 2019.

including GPs being able to accept and send data from other healthcare providers by 1 January 2013.[431]

NEHTA had taken over from HealthConnect but had declined to use much of the foundation that HealthConnect had built in terms of its underlying concept, standards and documentation, and essentially "started from scratch."[432] The major systemic change was the move from a decentralised NHIN to a centralised data storage approach with the PCEHR being a summary of patient health information.[433] The Apis Group managed the business case that negotiated funding between the Commonwealth and the states and territories and then built the sourcing strategy for the PCEHR.[434] This was then passed on to Accenture which was the successful party contracted to build and operate the national infrastructure. NEHTA tested the PCEHR to ensure that it met requirements then signed it off to the Department of Health and Ageing (DoHA) which did the final acceptance – including clinical function, safety and privacy reviews – before it went live.[435] The eHealth System Operator was the Secretary of the Department of Health.[436] The distributed system legacy of HealthConnect had led some to fear that the PCEHR "could potentially turn into a HealthConnect Mark Two" so there was a push for a core national infrastructure including a repository to hold patient health information.[437] Centralisation was supported by the DoHA as a pragmatic way to achieve the Labor government's keen desire to get an EHR in place in a very short period of time and assure the purpose and credibility of the core assets of the program.[438]

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[431] National Health and Hospitals Reform Commission, *A Healthier Future for All Australians*, 34.
[432] Riep, Interview.
[433] Andrew Podger commented as follows: "One wonders about the loss of IT expertise in DoH and the over reliance on consultants and contractors." Podger, Interview 2, 2019. This supported Riep's view that much expertise was lost after HealthConnect fell apart.
[434] Honeyman, Interview.
[435] Bettina McMahon (Head of Risk and Assurance, Former Head of Policy and Information Services, NEHTA), Interview, 2014.
[436] Commonwealth of Australia Department of Health and Ageing, "Personally Controlled Electronic Health Record System Operator Annual Report 1 July 2012 to 30 June 2013," 2013, 4. By 2013 the DoHA had been abolished and replaced by the DoH – essentially a name change with some change in responsibilities. The ADHA became the system operator in 2016. The independent privacy regulator was the Office of the Australian Information Commissioner (OAIC).
[437] Honeyman, Interview.
[438] Honeyman.

In order to enable the ehealth system, and in particular the PCEHR, to accurately identify, assign and transfer patient data a unique healthcare identifier was needed. This had been seen as a crucial component of the system since the days of HealthConnect and was one of the projects NEHTA had been developing as a foundation for the standards that would underpin the entire ehealth system. The Healthcare Identifiers Service (HI Service) was established by the *Healthcare Identifiers Act 2010* (HI Act) as an initiative of COAG, jointly funded by the Commonwealth, states and territories; it commenced on 29 June 2010.[439] The HI Service Operator was the Chief Executive of Medicare.[440] One of the key claims for the utility of EHRs was that "consistently identifying individuals, healthcare providers and healthcare provider organisations … [using an NEHR would] improve safety for patients, support safe and efficient sharing and storage of health information, and increase efficiency for healthcare providers."[441] This was to counter the documented problem of historically poor medical records management resulting in mismatched patient records that led to avoidable harm to patients.[442] The HI would also be used to support secure messaging and the "implementation of a security and access framework to ensure authentication of providers who access national eHealth infrastructure."[443] The HI Service Review, delivered in 2013, found that the "core functionality of the HI Service is operating and working effectively," however it noted that the impact on clinical workflow highlighted emerging risks and issues that would need to be addressed.[444]

The PCEHR, with limited functionality, went live on 1 July 2012 thus achieving the anticipated start date. Consumer take-up of the PCEHR was initially slow, as were clinician use and clinically useful document population. This, to some extent, was to be expected as "registration in the eHealth record system [was] entirely voluntary."[445] As an

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[439] Commonwealth of Australia Department of Health, "Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper," 2015, 4-5.
[440] Commonwealth of Australia Department of Health, 5.
[441] Commonwealth of Australia Department of Health, 5.
[442] Commonwealth of Australia Department of Health, 5.
[443] Commonwealth of Australia Department of Health, 5.
[444] Commonwealth of Australia Department of Health, National Response to the Healthcare Identifiers Act and Service Review - Final Report, June 2013, 4.
[445] Australian Government Department of Health and Aging, "Personally Controlled Electronic Health Record System Operator Annual Report 1 July 2012 to 30 June 2013," 2013, 6.

opt-in system registration was up to consumers and the vast majority of Australians simply did not exhibit enough personal interest to register.[446] Registration was, in the early years, technically difficult requiring an extensive time commitment on the part of consumers.[447] Consequently, only 397,742 people registered for a PCEHR in the first year of operation.[448] This increased to 1.7 million Australians by the end of 2014, still a small fraction of the overall population. The issue was recognised by the DoHA who started to fund assistance for registration resulting in 70 per cent of successful registrations being assisted.[449] An indication of the slow start to consumer registrations and the impact of assisted registrations is provided by the graph shown in Figure 5.1 below.

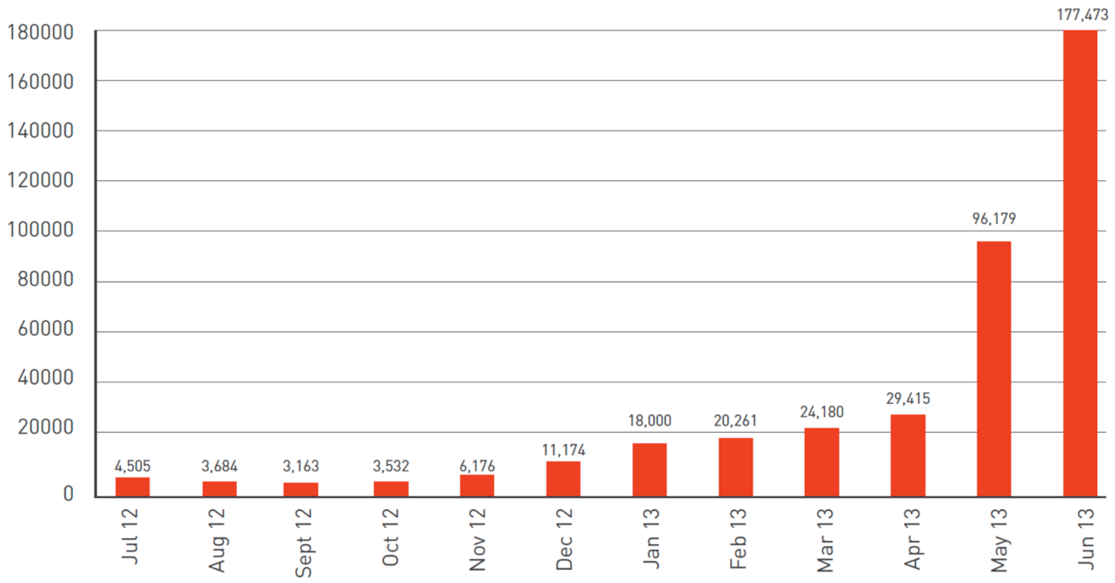

Figure 5-1: Indication of the Number of People Registered for a PCEHR Per Month, July 2012 to June 2013[450]

There was also significant opposition from clinicians and healthcare providers. While they often supported some of the key concepts of the PCEHR – patient centred

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[446] Andrew Podger added "without GP encouragement, why would people sign up? People aren't going to register if their GP doesn't tell them 'this is good for you.' You've got to start with the GP." This shows just how important it was for the state to get GPs onside if it wanted to make NEHR policy work. Podger, Interview 2, 2019.

[447] Michelle Austin (Director of People and Culture, Calvary Healthcare ACT), Interview, 2014; Herman Karsten (Former Project Manager, Calvary eHealth Project, ACT), Interview, 2015.

[448] Commonwealth of Australia Department of Health and Ageing, "Personally Controlled Electronic Health Record System Operator Annual Report 1 July 2012 to 30 June 2013," 5.

[449] Commonwealth of Australia Department of Health and Ageing, 9.

[450] Reproduced from the Commonwealth of Australia Department of Health and Ageing, 8.

healthcare, digital interoperability of health information, healthcare identifiers – they had significant issues with the PCEHR. These included concerns about its impact on clinical workflows, patient control and subsequent issues of the completeness and accuracy of information in the record, clinical legal liabilities in using that information, cost, and patient access to the record.[451] Subsequently, effective use of the PCEHR was low with only 7,233 healthcare organisations – out of a total of 63,620 – registering by the end of 2014.[452] After two years there were more than 140 million documents in the system but only 288,368 clinical documents (mostly prescription and dispensing records) and 61,674 documents uploaded by consumers which could not be seen by healthcare providers.[453] Most clinicians and other healthcare providers did not actively use the PCEHR as part of their clinical workflow, with PCEHRs being viewed only 26,117 times over this two-year period.[454] Dearne argued that "clearly doctors don't see any value in the system as it stands."[455] Consumers also seemed rather uninterested, with less than one-third of those people with a PCEHR looking at their record.[456]

However, despite criticism from outside groups, NEHTA claimed that it had "exceeded all of our targets based on the international bench marks, so we have actually had much more uptake in consumers, GPs and hospitals, than we would have expected based on international experience in introducing systems like this for the amount of investment

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[451] Marcus Dawe illustrated the conflict between stakeholders, arguing that DoHA was the major driver "on the funding side. What we have here is government versus doctors – wanting better value, less costs in the health system, less health inflation, and DOHA drives that. Also, it's a federated system, so it's the states themselves looking to get better advantage and possibly getting the government to subsidise their change programs. COAG is really important, and also AHMAC. So, DOHA was HealthConnect. COAG and AHMAC behind the scenes all pushing for national EHR, and the establishment of NEHTA, obviously. And PECHR, IHI, and then also you've got Medicare, which back here was the Health Insurance Commission, which then became Medicare and whatever. So, there's a transition of Health Insurance Commission to Medicare then a separation, then Centrelink then Human Services. There was a transition of power in the health insurance game across into general. So now human services and DOHA, DOHA policy and human services delivery or systems and whatever, and there's a big tension between those two. It's political tension. Different ministers, delivery versus policy. DOHA still wanting to drive change and that kind of thing and then control of states through COAG." Dawe, Interview.

[452] Karen Dearne, "An Analysis of Commonwealth Government Annual Reports Covering E-Health and PCEHR Activities in 2013-14," 2014, 6.

[453] Dearne, 3.

[454] Dearne, 7.

[455] Dearne, 8.

[456] Petter Gottschalk, "Maturity Levels for Interoperability in Digital Government," *Government Information Quarterly* 26, no. 1 (2009): 75–81.

we've put in."[457] Medicare locals were tasked with helping GPs improve the usability of their records. Paul Campbell, the eHealth Project Manager at the Western Sydney Medicare Local, stated that:

> one of our major tasks was assisting the GPs to what they referred to as "cleansing their records." In other words, taking out all of the old diagnoses that were no longer relevant. There was a huge effort in, we had to put forward in getting the GPs to strip out all the unnecessary, remove all of the drugs, the medications that had expired because a shared health summary holds four elements: the medical history as it exists right now, the medications the patient is on right now, allergies and adverse reactions the patient has and any vaccinations that are current. Once that is done then it's a simple task for the GP to then set up a shared health summary through the desktop of the clinical information system.[458]

Privacy also had a big impact on the initial roll-out of the PCEHR. NEHTA was keenly aware that there were two opposing views that were the basis of a quite contentious debate.[459] On one side was the trust argument being pushed by privacy advocates and the desire for control of the information in the record by some consumers. They argued that in a patient-centred healthcare system privacy controls, including consumer control over who could see and use their health information, trumped clinician demands for complete access based on clinical views that subsequent clinical outcomes for patients would be improved. Bettina McMahon gave the following example which was echoed by many interviewees:

> Consumers were quite clear that, they currently have the ability when they go and see a healthcare provider to provide whatever information they deem appropriate – so if I go see my dentist I might say to them what medications I'm on, I might let them know I'm pregnant if they are offering me an X-ray, there are things which I'll disclose to them and they'll often ask a question on the form to help guide me to know what's relevant to tell them. The consumers were clear that they didn't want that ability stripped from the consumer such that a dentist for example would be able to see their full medical record including any sort of psychiatric assessments, any reproductive issues like they had an abortion or things like that. There were some sensitive areas, or HIV status, there are other laws in various states that contain that sort of information about a person. So, that was the consumer

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[457] Bettina McMahon, Interview.

[458] Paul Campbell (eHealth Project Manager, Western Sydney Medicare Local), Interview, 2013.

[459] Bettina McMahon, Interview.

> perspective. They said look, I've got this ability right now and I don't want this system to erode that the control I have over the information I provide to different providers.[460]

This produced considerable tension with clinicians who tended to favour the argument that they needed to see everything in the record in order to trust it.

> The clinical community on the other side said: here's an opportunity for us to get a more complete view of a person's health status, consumers are not trained clinicians, they do not know what is relevant information and what is not, and often some of the problems that we have is because a consumer didn't think it was relevant to raise an issue with their healthcare provider and actually it was a critical piece of information. For example, if I am a dentist and I am about to anaesthetise someone, I need to know if they are on warfarin or what their medications might be, but they might not see that as relevant at the time. So, the consumer is not equipped to make that decision, we are, we're medically trained, and we should see everything and we will make a decision as to what's relevant or not. And, of course, we are professional people and we are not going to breach their privacy and they should trust us.[461]

The strength of the privacy advocate stakeholders also resulted in the PCEHR being opt-in even though there was widespread criticism that this approach would limit take-up and end up with the PCEHR unable to achieve the critical mass which would make it clinically useful. Institutionally, from a policy development perspective, it was interesting to see that NEHTA ended up articulating both points of view. Bettina McMahon explained:

> We escalated that one through the DoH to the minister, and the minister made a decision – based on the advice from Health – that consumers would be able to remove any document from the PCEHR, but they had to take the whole document down, they couldn't take parts of the document down because if they were to take parts of a document out that could create clinical safety concerns because you are effectively doctoring a complete document that had been authored by somebody else. So that's an example of an issue where we couldn't achieve consensus and the process we took to actually solve that where the policy was made at a government level.[462]

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[460] Bettina McMahon. This was supported by Andrew Podger who stated that this was a "serious issue, also critical to clinician take-up." Podger, Interview 2, 2019.

[461] Bettina McMahon, Interview.

[462] Bettina McMahon.

Unsurprisingly, this approach was criticised by clinicians who mounted a fightback that resulted in the Royle Review of 2013 and the subsequent report into the PCEHR which was released, seemingly reluctantly and after a lengthy delay, in 2014. This followed the Coalition winning government in the election of September 2013 replacing the previous Labor government. In announcing the Royle Review, the new Minister for Health, Peter Dutton, acknowledged poor uptake and participation in the PCEHR by both doctors and patients which "defeats the purpose of having a national, electronic system that is meant to help save lives."[463] This he blamed on the Labor opposition.

> While the previous Coalition government laid the foundations for ehealth by getting computers into doctors' practices, Labor comprehensively messed up the next stage and has wasted over a billion dollars in its failed attempt at the second phase – moving to personal electronic health records.[464]

The Coalition continued to support the concept of EHRs but was far more sympathetic to clinician considerations and a greater role for the private sector than Labor had been. Dutton stated that "it [the PCEHR] must be fit for purpose and cost effective"[465] and this was reflected in the ensuing terms of reference for the Review of the Personally Controlled Electronic Health Record which focused on, but were not limited to, the implementation, uptake and clinical use of the PCEHR. The Review panel consisted of Richard Royle, the Executive Director of UnitingCare Health, Dr Steve Hambleton, the President of the Australian Medical Association, and Andrew Walduck, the CIO of Australia Post.

The Royle Review found that the low level of utilisation of the PCEHR was most likely the consequence of issues raised by stakeholders around its usability and clinical value.[466] There was a recognition that technical interoperability on its own was insufficient and that careful integration with clinical workflows was needed to increase the usability of health information. It was recommended that the PCEHR be rebranded as the My Health Record (MyHR) and shift to a decentralised model with multiple data

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[463] Peter Dutton, "Federal Government to Review Electronic Health Records" (DoH, 2013).
[464] Dutton.
[465] Dutton.
[466] Richard Royle, Steve Hambleton, and Andrew Walduck, "Review of the Personally Controlled Electronic Health Record," December (2013): 6.

repositories linked by the Healthcare Identifier (HI). This would have been a fundamental systemic change building on the review's recommendation that the MyHR be seen as "a supplementary source of information that may, but does not always need to be, used by clinicians in caring for their patients."[467] This went to the heart of the clinician/consumer tension over control and use of patient health information in a supposedly patient-centred health system which will be discussed in more detail in Chapter 8. The review also recommended that in order to improve uptake and increase the amount of clinically relevant information in the MyHR the model should shift from opt-in to opt-out[468] and the ePractice Incentive Payment (ePIP) be modified to "link ongoing funding with actual usage of the MyHR."[469]

The review argued that, with intervention and correction, the investment in the PCEHR would realise great value for the health industry over time.[470]

> The value of having a personal health summary to share with selected health professionals will be that relevant information is available at the right time for the right people. Improved access, speed and accuracy of health information will benefit health providers, consumers and Government to deliver greater efficiency, less duplication and waste, safer, faster consultation, greater options for location of health provision and mobility of patients, greater consumer choice, and ultimately better health service delivery overall.[471]

This statement reinforced previous justifications for ehealth and a national EHR and the review argued that it was supported by "strong international evidence that data aggregation and management has led to better outcomes and is likely to lead to similar benefits for health care for Australia."[472]

There was also the implied linkage of three key concepts to produce better health outcomes. That is, if consumers and their care providers were provided with more

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[467] Royle, Hambleton, and Walduck, 16.
[468] Opt-out was supported by many providers. For example, Mark Doran (National CEO of the Little Company of Mary Health Care group) stated: "Absolutely opt-out. And I don't know why anybody would want to opt-out. If you've understood the benefits." Mark Doran, Interview, 2014.
[469] Royle, Hambleton, and Walduck, "Review of the Personally Controlled Electronic Health Record," 17.
[470] Royle, Hambleton, and Walduck, 13.
[471] Royle, Hambleton, and Walduck, 13.
[472] Royle, Hambleton, and Walduck, 13.

complete and timely information they would make better healthcare choices which would in turn lower the unit cost of delivering said healthcare.[473] This reflected an ongoing shift in the role of, and terminologies used to label, the patient in the healthcare system. The change from patients as citizens, who were collective taxpayers and individual users of healthcare services, to consumers[474] was reinforced. Patients sought competent professional help to get well or treat illness, giving up choice in healthcare delivery in a clinician-centred system in exchange for exemption from responsibility for their incapacity. In comparison, consumers had rights of choice in the health market place and a responsibility to actively engage with their healthcare providers in an effort to meaningfully use health information to achieve improved health outcomes including lowering the cost for the chief payer – the state. The role of patient tended to support the fee-for-service model of healthcare whereas the role of the consumer might be considered more favourable for the desired shift to a payment-for-outcome model. The review also justified the cost and supported the expected public benefit of the 2008 National eHealth Strategy's case for collective action and coordination at the national level to establish national standards and build a PCEHR that would facilitate desired systemic and consumer outcomes.[475]

The year 2015 marked the beginning of another period of crisis for ehealth in Australia and the development of a NEHR. It was clear that the PCEHR faced significant issues and the federal government announced a "$485m 'rescue' package to reboot Labor's e-health failures."[476] There was a general recognition by the federal government that a number of changes were needed as less than ten per cent of Australians had a PCEHR and it was acknowledged that "this was not a large enough sample to make it an effective national system or worth the time and effort for patients and doctors using it."[477] The rescue package changes aimed to:

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[473] Royle, Hambleton, and Walduck, 7–8.

[474] Christopher Morris Showell, "Citizens, Patients and Policy: A Challenge for Australia's National Electronic Health Record."

[475] Royle, Hambleton, and Walduck, "Review of the Personally Controlled Electronic Health Record," 7.

[476] Sussan Ley (Minister for Health), "Patients to Get New MyHealth Record," 2015.

[477] Ley.

> increase the number of individuals and healthcare providers participating in the PCEHR system, increase the clinical utility and usability of the PCEHR system to support meaningful use by healthcare providers, and to improve the overall operation of the PCEHR system and HI Service, and eHealth more generally.[478]

By this time stakeholder positions had changed and opt-out[479] was seen in a more favourable light, mostly because of poor uptake and lack of effective use (and therefore a lack of meaningful outcomes) of the opt-in system. Acting on recommendations from the Royle Report into the PCEHR (released in 2014), the federal government renamed the PCEHR the My Health Record (MyHR then later MHR) in 2015, changed the access regime from 'opt-in' to 'opt-out' and announced that in 2016 NEHTA would be wound up and replaced with a new organisation, the Australian Digital Health Agency, tasked with delivering the MyHR. However, one significant recommendation of the Royle Review – decentralisation – was not implemented. After nearly a decade of funding a centralised systemic national EHR model with a centralised data repository for the EHR the federal government stuck with this approach. To some extent this reflected NEHTA's stance that, notwithstanding the challenges discussed above, "Australia's focus on building the foundations for a national system which delivers interoperability across jurisdictions and healthcare organisations places it in a strong position for the next phase of the program."[480] Taking this approach had interesting path dependency implications that will be discussed later in the thesis.

Conclusion

The state in Australia pursued institutional change in the area of ehealth through the mechanism of an NEHR primarily in order to improve the efficiency and effectiveness of healthcare and improve patient health outcomes.

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[478] Commonwealth of Australia Department of Health, "Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper," 1.

[479] Walter Kmet agreed. "I think it means that health records aren't seen as something that are voluntary, I think they're seen [as] something that [is] are mandatory. Why wouldn't we see everyone (when they come into hospital) having an electronic health record that's timely, accurate and accessible, is absolutely fundamental in this day and age." Walter Kmet (CEO WentWest Medicare Local), Interview, 2013.

[480] NEHTA, "Evolution of EHealth in Australia Achievements, Lessons, and Opportunities" (Sydney, 2016), 14.

> The driving factor was that this made more sense than paper. When it's all running smoothly it should be a lot more efficient and less prone to human error, because if there is an automated process that once the discharge summary is completed and cleared by the doctor it is then saved and sent automatically. If the patient has a PCEHR it is sent to their record. That takes a whole step out of it for us where we don't have to fax it to the GP's office. It would go automatically to the patient and there were also ways the GPs could receive them too.[481]

There was a widespread view among Australian interviewees that by 2015 neither HealthConnect, nor the PCEHR, had transformed healthcare service delivery.[482] However, there was a general perception that the PCEHR still had the potential to transform healthcare service delivery and by 2019, at the time of writing this thesis, there was a view that "absolutely"[483] the MyHR – the successor to the PCEHR - had transformation potential.[484] However, this positive view of potential was contested. While David More saw some scope for EHRs to make a difference in patient outcomes his main contention about Australia's attempt at an NEHR was that "what they've built is basically a system which is a barnacle on a battleship; a detached system which is asynchronous with what the GP is using or what the specialist will be using or what the hospital will be using."[485] There was also the view that "we are still in really early stages in Australia."[486] By 2015, a number of factors were influencing the transformational potential of the NEHR. The move from opt-in to opt-out dramatically increased the numbers of Australians with a MyHR. The agreement and implementation of standards

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[481] Austin, Interview.

[482] Honeyman, Interview.

[483] Honeyman.

[484] This view was supported by Mark Doran who argued that "every cloud has a silver lining" that was reflected in rapid technological change resulting in changing clinical practices that benefited both clinicians and patients. As an example, he stated that in 2005 the best computer technology "you could get was a laptop. Too slow for doctors. Absolutely too slow. They move at a great pace. They weren't going to hang around. Now essentially it is the same software we are using today. But tablets, smart phones, bigger pipes, all those things have a massive effect and a generation of doctors who come through and know how to use thumbs. They walk around. They have a smart phone. They're digitally savvy. That's the change. In that ten years." Doran, Interview. Paul Dugdale supported the transformation potential and stated that "the advent of a truly useful and high function patient controlled electronic health record at a national level could be a complete game changer for reformulating the relationships and the models of care between different agencies." Paul Dugdale, Interview 2, 2015. Paul Fitzgerald stated, "the question you asked me was: are medical records likely to help people and help service delivery, and the answer's yes." Fitzgerald, Interview.

[485] More, Interview.

[486] Harch, Interview.

relating to the content and transfer of EHRs was slowly improving interoperability. More clinically useful information was populating the MyHR including health summaries, discharge summaries, medications, prescriptions, and allergies which increased the likelihood of clinicians and patients using the MyHR. Systems for eHealth were becoming increasingly interoperable. Finally, and perhaps most importantly as it influenced all of the above, the shift in policy from patients having personal control of their EHR to patients being at the centre of their healthcare which aligned more closely with clinical workflows and, to some extent, the way both clinicians and patients thought the ehealth system should operate.

However, significant barriers remained. They included: transparency, trust, interoperability and usability issues, and privacy. Issues of trust impacted the uptake and use of the PCEHR and, as has been discussed, were instrumental influencers of its privacy regime. There was widespread clinical distrust of the accuracy, completeness, timeliness and clinical usefulness of the PCEHR and early difficulties with IHI matching that led to a perception that “it [was] failing. There’s no matches so you can’t upload the data.”[487] This was reinforced by an initial lack of any real “financial incentive [for GPs] to get their practices ready for this point, to compensate them for loss of income while they are getting their systems ready and guides ready.”[488] Successive governments realised this was a significant problem holding back NEHR uptake and use and responded with Practice Incentive Payments (PIPs) and information campaigns.[489] There was also a generational mistrust[490] relating to the privacy of patient health information in the PCEHR and some patients worried that their health information

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[487] Karsten, Interview.

[488] Karsten.

[489] Andrew Podger explained: “From the Commonwealth’s point of view they realise that they have to persuade doctors of the good of things and doctors have to see it for themselves, otherwise they don’t get involved and won’t have a bar of it.” Podger, Interview, 2015.

[490] This view was supported by Michelle Austin, Interview.

would be “in the cloud where everyone will see it.”[491] Clearly, there was some way to go for the state to achieve its goals with an NEHR.

The empirical evidence for institutional stasis and change presented in this chapter will be comparatively evaluated with the other case study countries in chapters 8, 9 and 10.

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[491] Hamish Jeffrey thought that “electronic health records are absolutely the way of the future and we have just got to get smarter about how we sell it to the community who are already on Twitter and all those other wonderful things and are happy to share their stuff on the Cloud. My nephew was telling me a story of his best friend who showed him a picture of his bum on Facebook, so if these kids are willing to do that, they will have no problem with sharing their health records.” Hamish Jeffrey (Acting Director of Nursing Midwifery Services Calvary Health Care), Interview, 2014. Herman Karsten explained: “It was just trust and you could see that through the different generations that signed up to PCEHR. As we went through with the sign up you would see young people, students, etc. when we went to O Week, or O day, we set up at ANU and Canberra University just for the young ones to sign up and get their Medicare cards etc. They wouldn’t care about privacy because they are the social media generation. They probably shared their lives, so they couldn’t be bothered if anyone can see their medical history whereas the older generations, and you probably see that in the 40+, maybe 50+ generation, you just struggle to convince them. You really struggle because maybe there is more in their medical history, but they just weren’t that keen to sign up and the main thing was that Google was able to see it and ‘Ah, it’s hackable. Then anyone can see my information.’ And we developed this whole proposition around this, it’s the same as internet banking and sometimes it’s more secure than internet banking and that whole field and it was really difficult to convince them.” Karsten, Interview.

Chapter 6 Case Study – England

Chapter 6 explains the history of ehealth and NEHR development, implementation and regulation at the national level in England. England had a unitary parliament that fused the executive and legislative power into one body. Unlike in the US, the funding and provision of healthcare had, since the creation of the NHS, been mostly centralised by the state –publicly financed and publicly provided - with many healthcare professionals acting as independently contracted professionals. The literature review foreshadowed that major healthcare policy reform was more likely in unitary parliamentary systems, such as England, because despite having important political and stakeholder veto points they have fewer than presidential systems typically have and therefore limit the ability of those opposed to reform to block change.[492]

However, attempts at major healthcare reform in the 1970s and 1980s had maintained the "general principles of NHS corporatism" that effectively gave independent medical professionals "veto rights on decision-making bodies at each level of the hierarchy."[493] Attempts to introduce private-market mechanisms and the rise of managerialism did not produce the same fundamental change in decision-making structures that occurred in Australia and the US. Unlike corporate entities in the US, managers in the NHS saw investment in information technology as a cost or "budgetary expenditure for which an ongoing case would have to be made"[494] rather than an investment that would increase revenue. Reforms had fragmented decision-making regarding the acquisition of information systems to the individual hospital level failing to achieve the desired policy outcome of an increase in competition among providers for contracts. The large-scale introduction of information technology saw the NHS implement contract requirements that increased contract specificity and performance monitoring in the 1990s but failed to effectively integrate information systems with decision-making systems leading to

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[492] See Jeremy Shiffman, "Political Context and Health Financing Reform," *Health Systems and Reform* 5, no. 3 (2019): 257–59; Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*; Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America."

[493] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, 163.

[494] Tuohy, 166.

ICT fragmentation. However, the election of a centre-left Labour government that saw social welfare-oriented concerns as best solved by combining social solidarity with individualism supported a corporatist pattern of interest group activity that was more likely than the conservative opposition to link and promote cooperation among business, labour and government. These factors combined to make opposition to information technology reform less likely and a major investment in an NEHR more likely in the late 1990s.

The chapter is presented in the same manner as the case study on Australia focusing on a comparative study of ehealth and the unit of comparison, which in England's case is the Summary Care Record (SCR). The role of the state will be examined as will the key themes of interoperability, usability and the meaningful use of patient health information as they are woven into the contextual history provided.

The first part of the chapter will outline the development of endogenous and exogenous institutional pressures and tensions that influenced both stasis and the critical junctures that led to institutional change in health records in England. Those institutional pressures and tensions included: structural antecedent conditions, shock events, ideational change, political agency and converging trends. This will be followed by historical chronology of main events. Similarly to the Australian case study, Part 2 of the chapter will examine the role of the state at the national level in England in creating an ehealth institution and developing, implementing and regulating an NEHR in the form of the SCR. This will be done by explaining change over time through two phases of development. Phase one covers the period 1998–2009 when England attempted an ambitious, top-down, centralised effort to modernise ICT through the National Programme for Information Technology (NPfIT), with the SCR as its major ehealth component. Phase two covers the period 2010–2015 where policy makers in the new Conservative government abandoned the centralised approach and scaled down Labour's ambitious goals for the SCR while still maintaining rhetorical support for the SCR's potential to positively benefit patient health outcomes.

At times, similarities to and differences from the other case study countries will be highlighted. These similarities and differences will be further evaluated in chapters 8, 9 and 10. As with the other empirical chapters, the role of the state in pursuing institutional change, consideration of stakeholder trade-offs and the emergence of unintended consequences will form part of the discussion, however a more detailed analysis will be left to Chapter 8. The conclusion completes the chapter.

Box 6-1: Brief Glossary of Key Abbreviations and Terms Used in Chapter 6

DoH: Department of Health.
EHR: Electronic Health Record.
ERDIP: Electronic Record Development and Implementation Programme.
HSCIC: Health and Social Care Information Centre.
ICRS: Integrated Care Record Service.
NAO: National Audit Office.
Negative Structural Alignment: where policy goals do not align with desired outcomes due to value conflicts that negatively affect stakeholder habitual behaviour.
NEHR: Nationally interoperable Electronic Health Record.
NHS: National Health Service.
NHS CfH: National Health Service Connecting for Health, referred to as the **CfH**.
NHSIA: NHS Information Authority.
NHS CRS: National Care Record Service, referred to as the **NCRS**.
NPfIT: National Programme for Information Technology.
Positive Structural Alignment: where policy goals do align with desired outcomes due to value trade-offs that positively affect stakeholder habitual behaviour.
SCR: Summary Care Record.

Part 1

The Development of Institutional Pressures and Tensions

> *You know, the national health service is very, very, very well supported here. You can't do anything. The government really struggles. It's one of the reasons why the NHS reforms so badly because anything that's going to make it seemingly not work as well, or they are going to make cuts to it, it's just not politically acceptable so every time you have an election they have to do something like pump more money in. They never leave anything for long enough for it to actually work its way through because, you know, they can't afford to pay. The NHS is a real political hot potato.*[495]

As with Australia, significant institutional pressures and tensions that developed in the 1980s and 1990s led to the critical juncture that produced institutional change to health records in the form of ehealth and an NEHR in England. In similar ways, these pressures and tensions were both endogenous and exogenous in nature and resulted in critical junctures that provided windows of opportunity for policy change that led to ehealth and NEHR institutional change. Stasis was also part of the institutional story, particularly with the persistence of outmoded technologies as was incremental institutional change, particularly noticeable in the rebranding and replacement of the many organisations related to the NPfIT and subsequently the SCR. Again, institutional pressures and tensions included structural antecedent conditions – some of which proved resilient and persisted over time – as well as shock events, ideational change, political agency, and converging trends.

Structural Antecedent Conditions

The structural antecedent conditions that existed in England before the development of ehealth and the introduction of the SCR were very similar to those that existed in Australia and, to a large extent, the United States with some important differences. Paper records and widespread use of the fax machine to transfer patient health information were the norm in the 1990s. Healthcare costs were increasing and were projected to continue to become a larger burden on national expenditure over time. The two major reasons for the scenario of increased costs were the same in England as in

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[495] Fiona Stevenson (Co-director of the eHealth Unit, University College London), Interview 1, 2013.

Australia and the US: people were living longer and were using more health resources due to a dramatic increase in chronic diseases and co-morbidities. There were, however, a number of key differences from Australia and the US. The NHS had a stronger commitment to the value of healthcare being free at the point of care and equated this value with better healthcare for patients. Healthcare was centralised through the NHS with a much smaller private health system than in Australia or the US. Therefore, healthcare was seen primarily as a public good which justified taxpayer funding of the NHS and led to the widespread sense that government had a responsibility to seek better health outcomes for its citizens.[496] Another key difference was that English GPs had adopted computer technology earlier and in greater numbers than their counterparts in Australia setting up the technological potential for the state to develop and implement an NEHR.

Shock Events

Shock events resulted in ideational change followed by political agency that produced institutional change. There were two major shock events that led to institutional change in health records. The first was the election of a Labour Government in 1997. Wanna argued that the Conservative government, led by John Major, had been drifting and that the Labour leader, Tony Blair, put forward a lot of policy ideas when in opposition and subsequently implemented many of them when in government:[497] ehealth was one of those ideas. Similarly, the 2010 election saw the Labour government led by Gordon Brown defeated by the Conservatives led by David Cameron and a corresponding change in ideas regarding health records and the political agency to effect such changes.

Ideational Change

Following the 1997 election the new Labour government's health reform program included a push to change from paper health records to an ehealth system that would be linked through an NEHR eventually called the SCR. This involved the creation of the

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[496] Brian Richards (The Australian National University), Interview, 2014.

[497] John Wanna (Sir John Bunting Chair and Professor of Public Administration and Director of Research of the Australian and New Zealand School of Government at The Australian National University), Interview, 2019.

NPfIT which was to be a centralised top-down construction that would enable system-wide interoperability and which was expected to deliver the many benefits of ehealth and NEHRs discussed elsewhere. This represented a major shift in ideas. Initially many supported Blair's modernisation agenda,[498] which combined all of government budgets and IT services and which was seen as an approach that could massively revolutionise Britain.[499] The NPfIT was one component of this broader vision. However, opposition grew as targets were not met and benefits went unrealised resulting in intense criticism and an ideational shift within the Conservative opposition. The 2010 election saw the Conservatives campaign on an anti-centralisation of health records platform claiming that if they won they would "put patients in charge of making decisions about their care, including control of their health records."[500] The subsequent Conservative government was also ideationally different from its Labour predecessor in that it favoured an SCR with more patient-centred options, such as increased patient control over the record, easier opt-out procedures and a focus on more clinically useful patient health information in the SCR rather than the plethora of embellishments Labour had pursued.

Interestingly, the initial ideational change in values and norms persisted across administrations. Moving from a clinician-centred to patient-centred system of healthcare was seen as a value worth pursuing by both Labour and the Conservatives as was the norm of interoperability. John Reid, the Labour Health Secretary, argued that:

> the NHS Care Record will completely revolutionise the way that information is accessed and will make available efficient, secure and integrated records to the right people at the right time. Patient records will be available 24 hours a day, seven days a week to ensure that vital information about an individual's health and care history can be available instantly to health professionals who

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[498] Supported by Ela Klecun who stated that most health professionals "liked IT, just this perfect imagination of IT. They would say 'Of course we are so behind, we've got to be in the 21st century so we need to modernise.' Specially the younger doctors, they already picked up the government rhetoric about modernisation and moving, finally catching up with the 21st century." Ela Klecun (London School of Economics), Interview 2, 2013.

[499] Wanna, Interview.

[500] The Coalition Programme for Government published on 20 May 2010, in Powell and Thompson, "Electronic Patient Records: The Roll-out of the Summary Care Record," 12.

> have authorised access. The key point is that information will be mobile and follow the patient.[501]

Similar language continued to be used nearly a decade (in 2012) later by the Conservative government:

> Using digital and online services can simplify the more routine aspects of care, such as booking appointments, requesting repeat prescriptions, or self-assessment for social care. The strategy sets out ways to reduce the frustrations we experience, such as repeating or recording the same information many times for different staff, or travelling long distances for services that could be delivered better in other ways. Not only is this more convenient, but it can also help care professionals to focus more time on face-to-face aspects of care and provide more support for those who need it to benefit from technology and information.[502]

Political Agency

The shock event of 1997 and subsequent ideational change was followed through with political agency on the part of the Labour government. It established the NPfIT, created and amended numerous organisations in order to develop and implement the SCR and followed through with some effort to establish a workable privacy regime. On the systemic side, “many commentators viewed New Labour’s focus on ‘big IT’ as a mechanism to bring about public sector reform, partly due to technology’s potential to challenge organisational inertia and prompt transformational change.”[503]

Similarly, the election of 2010 also resulted in ideational change and a renewed political agency from the new Conservative government. Responding to intense criticism of Labour’s efforts, the new government initially scaled back the scope of the SCR in 2010, effectively disbanded the NPfIT in 2011 and pursued organisational change by disbanding or rebranding numerous organisations such as HealthSpace[504] which was

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[501] John Reid (Secretary of State for Health), cited in *digitalhealth*, “Reid Announces £2.7 Billion of NHS IT Contracts,” 2003.

[502] Andrew Lansley (Secretary of State for Health), in Department of Health, *The Power of Information: Putting All of Us in Control of the Health and Care Information We Need* (2012), 2.

[503] Trisha Greenhalgh et al., “Introducing a Nationally Shared Electronic Patient Record: Case Study Comparison of Scotland, England, Wales and Northern Ireland,” *International Journal of Medical Informatics* 82, no. 5 (2013). This view was supported by John Wanna. Wanna, Interview.

[504] HealthSpace was the NHS portal though which patients were to be able to access the information in their SCR.

closed down in 2012. However, the government followed this up by recommitting to the SCR in 2011 and pursing citizen uptake and clinical use of the SCR. These actions exhibit elements of path dependency which will be discussed more fully in Chapter 10.

Converging Trends

Converging social, medical professional, fiscal and technical trends were key drivers of the development, implementation and regulation of ehealth and the SCR in England. Converging trends in England were very similar to Australia but with some key differences. Social trends resulted in the dominant political and social view of healthcare as a social good in both countries. However, this took longer in Australia and was state centric in England. Medical professional trends were influenced by social trends, including the rise of chronic disease, and led to a change in the role of clinicians and their collection, storage and transfer of patient health data. Fiscal trends led to considerable state funding and the direct provision of healthcare, both of which were projected to increase costs into the foreseeable future. The major difference was that Australia shared the cost of healthcare with citizens through a larger subsidised private insurance market. Technical trends in England were well integrated within the other three trends. Technically, an SCR could equitably reinforce healthcare as a social good by enabling patient information to be available at any point of care, help manage chronic disease by improving the process of care, and give patients access to their health information in an effort to improve co-production and patient engagement.

The NHS was a product of the view that healthcare was a social, rather than a personal, good[505] and was premised on the notion that citizens had a right to healthcare services which should be free at the point of care. Systemically, only the state had the capability to provide free healthcare for every citizen in an equitable way which resulted in the state at the national level taking a significant level of responsibility for the healthcare of

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[505] Richards, Interview. In England this is the post-World War II period.

its citizens. Political actors saw their role as "giving the people of this country the best system in the world."[506]

Unlike Australia and the United States, which both tended to compartmentalise ehealth as separate from other social services, social trends regarding the role of government in providing social services saw England link the two together. The policy argument was that linkage was a means of ensuring that "information, services and support [were] available to help people remain healthy … and live their lives with maximum dignity and independence"[507] by ensuring a "seamless service for patients."[508] This is reflected in the 2000 plan for the NHS:

> The health and social care system must be shaped around the needs of the patient, not the other way round. The NHS will develop partnerships and co-operation at all levels of care – between patients, their carers and families and NHS staff; between the health and social care sector; between different Government departments; between the public sector, voluntary organisations and private providers in the provision of NHS services – to ensure a patient-centred service.[509]

It was envisioned that technical trends would enable a whole-of-government approach to the use of IT for the benefit of citizens and the state who would reap the benefits of greater efficiency.

Medical professional trends in England showed both similarities to and differences from Australia and the US. Similarities included a shift from solo to multi-disciplinary team practice with the difference that practice organisation and funding was repeatedly impacted by structural changes to NHS Trusts as a result of policy changes over time, particularly over the issues of competition and choice. The burden of disease had moved from acute to chronic illness which meant that old models of care no longer applied.

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[506] Frank Burns, *Information for Health: An Information Strategy for the Modern NHS 1998-2005* (NHS Executive 1998), 9.
[507] Burns, 12.
[508] NHS England, "The NHS Plan," 2000, 5.
[509] NHS England, 5.

> About 70 per cent of the NHS budget is spent on treating chronic diseases, i.e. diseases that are lifelong, they can't be cured, they tend to get worse with time.[510]
>
> What is acknowledged by the Department of Health and in fact most health care systems is that our health care systems were never devised to look after patients with chronic diseases … and multiple morbidities.[511]

This led to structural changes, including attempts to integrate allied health professions and private care within the umbrella of the NHS's provision of medical services in an attempt to lower costs and improve the continuity of patient healthcare.[512] There were also unintended consequences of change, particularly in the drive to implement ehealth and the SCR, which resulted in clinician burnout and subsequent early clinician retirement, and rising costs due to new equipment and the training of staff.

Fiscal trends were closely tied to the social trend of health as a public good and funding of the NHS "out of public expenditure, primarily by taxation, … [as] a fair and efficient means for raising funds for healthcare services."[513] The NHS principle to provide free services at the point of care, based on need rather than an individual's ability to pay, increased fiscal pressure on successive governments which sought ways to reduce costs. Fiscal pressures were similar to Australia and the US and included: an ageing population, growth in chronic diseases, new and expensive drugs and diagnostic/surgical equipment, and cutting-edge medicine in the area of genomics. These fiscal pressures combined to contribute to more information being added to health records and became a driver of added cost as well as generating privacy and consent concerns. As a result, policy makers sought technical solutions that had the potential to lower cost and improve patient outcomes.

Technical trends saw political actors frame the ehealth information technology debate within the NHS as between the past – "up to now the use of IT in the NHS has not been

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[510] Jonathan Rachman (Map My Health), Interview, 2013.

[511] Rachman.

[512] This was particularly true of *The Information Strategy* launched by Andrew Lansley (Minister of State for Health), in 2012 which focused on using information to "drive integrated care across the entire health and social care sector, both within and between organisations." Department of Health, *The Power of Information*, 5.

[513] NHS England, "The NHS Plan," 5.

a success story"[514] – and the future of a "radical programme to provide NHS staff with the most modern tools to improve the treatment and care of patients and to be able to narrow inequalities in health by identifying individuals, groups and neighbourhoods whose health care needs particular attention."[515] After winning the general election of 1997, a central theme of the new Labour government was "modernising Britain"[516] and this government saw modernising the NHS as crucial to achieving that objective.

Modernising the NHS meant taking advantage of the potential offered by rapidly accelerating technical trends. Information was seen "as the key to the modern age"[517] and IT as having the potential to transform the way people lived. In ehealth, IT was seen as a tool to improve the efficiency and effectiveness of care – something that, in hindsight, current policy makers argued had not been up to the standards they thought appropriate. The low standards were framed in terms of the current reliance on paper and fax and previous efforts to integrate IT into clinical settings were portrayed as having held back otherwise excellent NHS staff. The result had been, from the perspective of this framework, that "clinicians working in the NHS came to see data collection not as a help but as a hindrance to their work."[518] Labour claimed that its "new information strategy will help staff do the jobs they came into the NHS to do and to do them better."[519] Prime Minister Tony Blair put it this way: "the challenge for the NHS is to harness the information revolution and use it to benefit patients."[520]

The SCR was therefore a technical response to converging trends and the mechanism by which the state was to achieve its outcome goals. It was to action the value of patient-centred care as an interoperability mechanism that established the availability and use of patient health records at all points of care, and that through its rules sought institutional change in clinical and patient practices and procedures.

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[514] Frank Dobson (Secretary of State for Health), cited in Burns, *Information for Health*, 5.
[515] Frank Dobson (Secretary of State for Health), cited in Burns, 5.
[516] Burns, 9.
[517] Tony Blair (Prime Minister), cited in Burns, 10.
[518] Frank Dobson (Secretary of State for Health), cited in Burns, 5.
[519] Frank Dobson (Secretary of State for Health), cited in Burns, 5.
[520] Tony Blair (Prime Minister), cited in Burns, 5.

Part 2

The Development of a Nationally Shareable EHR in England to 2015 (the SCR)

> *The biggest and most pressing challenge for the future in terms of primary care use of IT is that we now need to make sure that that information isn't just available in the few hours that the GP practice is open but it's available for whoever is looking after our patients in primary and secondary care. That the amount of information is available in a properly governanced way under patient control for other clinicians who are also trying to do the best for our patients. We've had problems in secondary care IT of finding a solution for a hospital trying to put things on to a one size fits all which I don't think is tenable, given the way we need to move in the future and hospitals in the States have found very successful solutions of having disparate systems that are brought together in one view, so it looks like one clinical record but actually it's bringing it from different systems and that's where I think we need to look in the UK.*[521]

The development of an NEHR in England had many similarities with the Australian experience. The major difference was that England opted for a top-down centralised ehealth and SCR system from the start whereas Australia first pursued a decentralised National Health Information Network (NHIN) with bottom-up trials, and only when that did not produce the desired results switched to a top-down centralised system in the PCEHR.

Contextual History – England

The development of an NEHR in England, called the Summary Care Record (SCR), can be divided into two broad phases. Those phases are:

1. 1998–2009: the ambitious, top-down approach with the SCR being a key component of the NPfIT.

2. 2010–2015: the centralised approach of the NPfIT being abandoned and a new focus on delivering the SCR in a more limited form.

As in Australia, interoperability, usability and meaningful use of patient health information underlay key desired healthcare service delivery outcomes. Key drivers of

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[521] Gillian Braunold (Clinical Director, NHS Connecting for Health), "Nuffield Trust Audio Recording," 2010.

change were similar to those in Australia. Technical advances were projected to provide efficiencies in the delivery of healthcare; these included cost savings, linking previously siloed health information, reducing the need for patients to constantly repeat information,[522] and reducing duplicate testing. Technical interoperability was supposed to increase the effectiveness of healthcare service delivery outcomes including improving coordination, safety and quality of care as well as fostering patient engagement with, and consequent coproduction of, their healthcare outcomes.[523]

However, there were some significant differences. From the start, England adopted a centralised, top-down, approach through the NPfIT which reflected a different perspective over the control and use of health information. Privacy was a significant issue. While government assurances of system security, the protection of individual patients' personal health information, and the clinical use of patient health information were somewhat similar to Australia, control of that information was initially very different, due to the centralised, mandatory (and then opt-out) design of the system. This, to some extent, was because of the different approach to patient centredness of the two health systems. Patient centredness in Australia was about using the NEHR as a mechanism to give patients control over their health information, not just access to their health record. In England, the SCR was seen as a mechanism to put the individual at the centre of their clinical care, albeit with increased choice and access to some of their health information, but with less emphasis on patient control in the Australian sense: thus, in England, the term patient focused was often used.[524]

Fiona Stevenson stated that patients have a right to look at their general practice records but very few ever do. However, GPs still have a lot of control over what information they

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[522] Patients having to repeat information as they moved through the health system was seen as a major annoyance by many interviewees and featured prominently in political rhetoric about the benefits of NEHRs. Charlotte Dack (Research Associate, eHealth Unit, University College London), Interview, 2013; Kingshuk Pal (GP and Researcher at the eHealth Unit, University College London), Interview, 2013; Fiona Hamilton (Senior Clinical Research Associate, eHealth Unit, University College), Interview, 2013.
[523] Brian Fisher explained that while the "most likely maximum" of patients would actually engage with their health record those with long-term conditions would get the real benefit as they "are going in and out of hospital, seeing the doctor in the practice a lot and for those the evidence is really good, that it makes a substantial difference to their lives, to their health lives, but for the rest you have to be realistic about what you can expect." Brian Fisher (GP and Director of PAERS), Interview, 2013.
[524] Department of Health, *The Power of Information*, 19, 68.

will show patients in their record and "if the GP knows that you're sensitive about that then they may not let you see that medical record anyway because they have the right to make a decision that you don't see it."[525] Stevenson agreed that this is "absolutely clinician controlled."[526]

Table 6-1: England – Historical Chronology of Main Events

Date	Timeline of Major National Events in England[527]
1998	The DoH set out a long-term information strategy for the NHS called "Information for Health" in which the NHS Executive committed to detailed electronic health records.
1999–2005	Establishment of the NHS Information Authority (NHSIA) which aimed to bring together NHS IT and information bodies and deliver IT infrastructure and information solutions to the NHS in England, including the Electronic Record Development and Implementation Programme (ERDIP).
2000	Based on Information for Health the DoH released the NHS Plan which "sets out a new vision of a health service designed around the patient."
2002–2010	Establishment of the National Programme for Information Technology (NPfIT) and the Integrated Care Records Service (ICRS) to enable the exchange of healthcare data seamlessly across all care settings including a nationally available Summary Care Record (SCR).
2004–2013	The NHS Care Record Service (NCRS) replaced the ICRS and took responsibility for delivering the SCR.
2005–2013	The NHS Connecting for Health (CfH) assumed responsibility for the NPfIT and the NCRS.
2007	First critical report on the NPfIT by the House of Commons Public Accounts Committee. Preliminary version of HealthSpace introduced allowing patients to access their SCR.
2009	Second critical report on the NPfIT by the House of Commons Public Accounts Committee. Enhanced version of HealthSpace was introduced allowing "patients and their clinicians to access, store and amend elements of their personal medical information. It was intended to offer users access to information including summary care records, test results and x-rays, along with allowing the exchange of information between clinicians and patients, the booking of appointments and requests for repeat prescriptions."

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[525] Fiona Stevenson (Co-Director, eHealth Unit, University College London), Interview 3, 2013.

[526] Stevenson.

[527] Burns, *Information for Health*; Ann Robertson et al., "Implementation and Adoption of Nationwide Electronic Health Records in Secondary Care in England: Qualitative Analysis of Interim Results from a Prospective National Evaluation," *BMJ (Online)* 341, no. 8163 (2010); Ian P. McLoughlin, Karin Garrety, and Rob Wilson, *The Digitalization of Healthcare*, 1st ed, (New York: Oxford University Press, 2017), 46–47; Greenhalgh et al., "Introducing a Nationally Shared Electronic Patient Record," 3; Guardian Government Computing, "NHS Axes HealthSpace: 'Just Too Difficult' to Use," 2012; Department of Health, *The Power of Information*, 4.

Date	Timeline of Major National Events in England[527]
2010	DoH signalled the end of the centralised approach of the NPfIT. The government decided the SCR was to proceed with limited information uploaded.
2011	National Audit Office report raised doubts over whether NPfIT benefits would ever be realised. Third critical report on the NPfIT by the House of Commons Public Accounts Committee.
2012	DoH released a ten-year framework known as "The Strategy" which acknowledged that the current patient health information picture was disjointed and to a large extent still relied on paper records which got lost. The Strategy set a ten year framework for transforming the use of health and care information by harnessing new technologies to achieve higher quality care and improve outcomes for patients and service users.
2013	NPfIT and CfH ceased to exist with some projects and responsibilities, including delivery of the SCR, assumed by the Health and Social Care Information Centre (HSCIC). Closure of HealthSpace.
2015	Milestone of 50 million SCRs created.

Phase One: 1998 to 2009 – The Aspiration of Compiling Centralised Records

The NHS in England pursued the transition from paper records to electronic health records as part of its goal to achieve "what has widely become known as healthcare's Triple Aim: better health, better healthcare, and lower cost."[528] Phase one in England launched what would be called "the biggest civilian IT project in history"[529] and began with the Department of Health (DoH) setting out a long term information strategy for the NHS called "Information for Health" in 1998.[530] At the time, Prime Minister Tony Blair announced "the idea of the Summary Care Record … with these words (which subsequently became widely quoted and ridiculed by critics): 'If I live in Bradford and fall ill in Birmingham then I want the doctor treating me to have access to the information he needs to treat me.' "[531] The strategy's objectives included lifelong

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[528] Robert Wachter, Ann Slee, and David Brailer, "Making *IT* Work: Harnessing the Power of Health Information Technology to Improve Care in England," *NHS [Online]*, 2016, 3.

[529] Brian Randell, ed., "The NHS's National Programme for Information Technology (NPfIT) A Dossier of Concerns," 2010, 42.

[530] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 46.

[531] Greenhalgh et al., "Introducing a Nationally Shared Electronic Patient Record," e132. Stevenson made the point that not all patients would see A&E having access to their record as "making any difference," as they would feel that they can share that information anyway and are used to doing so with "medi-bands and things like that" if they have allergies to certain medications. Stevenson, Interview 3.

electronic health records, 24-hour access to patient records, seamless care for patients moving between points of care, patient access to records, and expansion of the data and capability of the record over time.[532] These objectives were to support the value of patient-centred care by ensuring "that patients, carers and the public have the information necessary to make decisions about their own treatment and care, and to influence the shape of health services generally."[533]

Implementation

In the late 1990s a number of pilot initiatives were subsequently carried out by the NHS Information Authority's Electronic Record Development and Implementation Programme (ERDIP), however "the NHS remained stubbornly attached to its huge legacy of thousands of stand-alone systems from hundreds of different suppliers."[534]

In 2000 the DoH released the NHS Plan, setting out a "new vision of a health service designed around the patient."[535] To implement this new vision the NPfIT was established in 2002 to enable the exchange of healthcare data seamlessly across all care settings including a nationally available SCR.[536] Sir Christopher Bland called the NPfIT "one of the biggest and most ambitious healthcare IT projects in the world."[537] NPfIT's effort to "reform the way the NHS in England uses information"[538] was centred around the SCR which was delivered initially by the Integrated Care Records Service (ICRS) from 2002 then by the NHS Care Records Service (NHS CRS) from 2004. In 2005 NHS Connecting for Health (NHS CfH), a newly minted organisation, replaced the abolished NHS Information Authority and assumed responsibility for the NPfIT and the NHS CRS.

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[532] Burns, *Information for Health*, 9.

[533] Burns, 9.

[534] Sean Brennan, *The NHS IT Project: The Biggest Computer Programme in the World … Ever!* (Oxford: Radcliffe Publishing, 2005), 73.

[535] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 46.

[536] McLoughlin, Garrety, and Wilson, 48.

[537] Sir Christopher Bland, Chairman of British Telecom, cited in digitalhealth, "Reid Announces £2.7 Billion of NHS IT Contracts."

[538] National Audit Office, *The National Programme for IT in the NHS*, (London: The Stationary Office, 2006), 1.

NPfIT's rhetorical emphasis was on improving "services and the quality of patient care … rather than to reduce costs."[539] However, there was a desire to reduce IT procurement and development costs. This led to a strongly centralised approach which was openly critical of previously haphazard NHS IT procurement and development processes. It was expected that procurement costs would be further contained by speedily completing contracts, the inclusion of incentives and penalties, and the adoption of an "intrusive but supportive approach to the management of its suppliers"[540] by the NHS CfH. Specifically, the National Audit Office (NAO) report on the NPfIT in the NHS stated that:

> NHS Connecting for Health bought the systems at a fixed competitive price transferring financial and delivery risk to the suppliers, and it does not pay suppliers until services are proven to be delivered and working. The procurement of contracts centrally, rather than through local NHS units as had been the practice in the past, is independently estimated, in a report commissioned by NHS Connecting for Health, to have saved £4.5 billion in terms of the prices paid for goods and services.[541]

Ironically, the procurement process, management of suppliers, and over centralisation were later cited as key reasons for failure.[542]

A significant strategic difference between Australia's HealthConnect NHIN and England's consolidation of records was that the NHIN was decentralised and the SCR was to be centrally held on the NHS Spine.[543] Greenhalgh explained that centralisation was seen in two ways.

> One version of the story holds that centrally-stored electronic summaries, accessible by patients and authorised staff, are linked with unassailable common goods like choice, empowerment, quality, safety, efficiency and personalised care – and that the "tipping point" for their widespread adoption

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[539] National Audit Office, 1–2. Fiona Stevenson argued that many of these "advantages are all about the system … and not the patient." Even though they might make care smoother for the patient they "act like a driver for self-management to reduce time in the system." Stevenson, Interview 3.

[540] National Audit Office, *The National Programme for IT in the NHS*, 1–2.

[541] National Audit Office, 2.

[542] Alistair Maughan, "Six Reasons Why the NHS National Programme For IT Failed," ComputerWeekly.com, 2010; Trisha Greenhalgh et al., "The Devil's in the Detail: Final Report of the Independent Evaluation of the Summary Care Record and Health Space Programmes," no. May (2010); R. Wachter, "Making IT Work."

[543] Kathrin Cresswell and Aziz Sheikh, "The NHS Care Record Service (NHS CRS): Recommendations from the Literature on Successful Implementation and Adoption," *Informatics in Primary Care* 17, no. 3 (2009); Greenhalgh et al., "Introducing a Nationally Shared Electronic Patient Record" 2013.

> is imminent. Another version depicts policymakers as seduced by a vision of technological utopia, professional leaders as obsessed with standardisation, the public as largely disengaged, and the government as extending electronic surveillance into intimate parts of citizens' lives. Both versions can, to some extent, be backed up by "evidence."[544]

Keen argued that centralisation was justified in the early stages of the project as "individual NHS organisations – and private firms providing NHS services – do not typically have the skills or the political clout to manage large contracts for building infrastructure."[545] However, centralisation was criticised for having "relatively little clinical involvement early on" resulting in the program "not being doctor friendly" and it was felt that "clinicians and suppliers need to work closely together if the more ambitious elements of the programme – notably the shared electronic health and social care record – are to be successful."[546]

The main component of the NPfIT was the SCR, which was to be "an electronic summary of key health data … drawn from a patient's GP-held electronic record."[547] The centrality of the SCR to the NPfIT was stated by the Minister for Public Health, Caroline Flint, in the following way:

> A key element of the national programme for information technology is delivery of a national summary care record. In the first instance it is expected that the service will be predominantly of use in unscheduled care settings where knowledge of allergies, medicines and major diagnoses will improve patient care and safeguard patient safety.[548]

Secure patient and clinical access to the SCR was to be provided by HealthSpace. "HealthSpace was intended to offer users access to information including summary care records, test results and x-rays, along with allowing the exchange of information between clinicians and patients, the booking of appointments and requests for repeat prescriptions."[549] Both patients and clinicians would also be able to amend information.

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[544] Greenhalgh et al., "The Devil's in the Detail," 5.

[545] Justin Keen, "The NHS Programme for Information Technology," *British Medical Journal* 333, no. 7557 (2006): 1.

[546] Keen, 1.

[547] Greenhalgh et al., "The Devil's in the Detail," 6.

[548] Caroline Flint (Minister for Public Health), in Powell and Thompson, "Electronic Patient Records," 4.

[549] Guardian Government Computing, "NHS Axes HealthSpace: 'Just Too Difficult' to Use."

Policy makers were intent on delivering what they called 21st century support for the NHS National Strategic Programme. This support had three components: a vision which supported patient-centred values and interoperability norms; a strategy which focused on rules, practices and procedures; and recognition of the benefits of having an SCR which had the potential to transform the service delivery of healthcare. These three components were expressed by the DoH as follows:

Vision:[550]

1. Support the patient and the delivery of services designed around the patient, quickly, conveniently and seamlessly.
2. Support staff through effective electronic communications, better learning and knowledge management, cut the time to find essential information (notes, test results) and make specialised expertise more accessible.
3. Improve management and delivery of services by providing good quality data to support NSFs, clinical audit, governance and management information.

Strategy:[551]

1. The core of our strategy is to take greater central control over the specification, procurement, resource management, performance management and delivery of the information and IT agenda. We will improve the leadership and direction given to IT, and combine it with national and local implementation that are based on ruthless standardisation. [This was done and was cited by many critics as a key reason for failure.]
2. Develop electronic records and national standards and specifications for Phase 1 from April 2002 to April 2003 (Phase 0).

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[550] DoH, "Delivering 21st Century IT Support for the NHS: National Strategic Programme," 2002, i.
[551] DoH, i–ii.

3. Phase 1 April 2003 to December 2005: Full National Health Record Service implemented, and accessible nationally for out of hours reference.[552]
4. Phase 2 January 2006 to December 2007: Full National Health Record Service, with core data and reference links to local EPR systems for full record access.[553]

Benefits:[554]

1. Patients: trust – see that NHS staff have high quality, up-to-date information always available, can answer any questions they have, and are relying on up-to-date treatment and prescribing protocols as well as the latest medical knowledge and clinical practice. Patients will be able to access their health information 24/7.
2. Healthcare professionals: time with patients will be spent more effectively in delivering safe, high quality care based on universally available, secure, accurate, up-to-date electronic records. See and review case histories, schedule care plans, prescribe drugs, commission tests and view results quickly and conveniently.
3. Healthcare managers: reliable, accurate data (financial and clinical) will enable better workforce planning and management of scarce resources, will improve clinical governance and promote high quality care. Public Health, the planning of services for populations, as well as analytical and statistical services will be based on better quality data. Joined-up services will be the norm as organisational boundaries are blurred in the interests of focusing on customers' needs and information is securely shared in 'real time' among appropriate professionals.

The Public Accounts Committee in England outlined the scope of the project in its 2007 report on the NPfIT stating that:

> the central vision of the Programme is the NHS Care Records Service, which is designed to replace local NHS computer systems with more integrated systems and make key elements of a patient's clinical record available electronically throughout England (e.g. NHS number, date of birth, name and

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[552] DoH, 5.
[553] DoH, 6.
[554] DoH, 1–2.

> address, allergies, adverse drug reactions and major treatments) so that it can be shared by all those needing to use it in the patient's care.[555]

Trials of the SCR were undertaken in 2007 and 2008 with a full rollout scheduled for 2009. As Powell and Thompson have noted, "the costs for the SCR programme are difficult to disaggregate from the other elements of the 'spine' database, and, more generally, from the overall costs of the NHS National IT programme."[556] By 2008, the NAO had "reported that the estimated cost of the National Programme for IT had risen to £12.7 billion."[557]

Achieving the value of patient-centred care was inextricably linked with successfully implementing the norm of interoperability which was central to the potential success of the SCR.

> Patient-centred care requires information to follow the patient so that it is available wherever and whenever it is needed. The NHS Care Records Service will allow this to happen. For the first time, information about patients will be mobile – as patients are themselves – and not remain in filing stores in the buildings where treatment or care has been received.[558]

The anticipated claims for benefits that the NPfIT and the SCR would bring were numerous.[559] They included:

1. Better care through improved clinical decision making.
2. Safer care by reducing the risk of harm, especially medication errors.
3. More efficient care, for example, making consultations quicker.
4. More equitable care as the SCR would be particularly useful for patients who were unable to communicate or advocate for themselves.

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[555] Powell and Thompson, "Electronic Patient Records," 11.
[556] Powell and Thompson, 11.
[557] Powell and Thompson, 12.
[558] NHS Connecting for Health, "NHS Care Records Service," 2018.
[559] Greenhalgh et al., "The Devil's in the Detail: Final Report of the Independent Evaluation of the Summary Care Record and Health Space Programmes," 6.

5. A reduction in onward referrals such as unnecessary ambulance callouts, accident and emergency (A&E) attendances and hospital admissions.

6. Greater patient satisfaction by allowing people to state care preferences, receive better care and access their record via HealthSpace.

Additionally, by giving patients access to their health information through HealthSpace further benefits were anticipated.[560] They included:

1. Personalisation of care by supporting choice and increasing access options adapting NHS care to individual needs.

2. Patient empowerment whereby patients entering and accessing their health data through HealthSpace would be better able to manage their illnesses, especially long-term conditions.

3. Accountability, quality improvement and safety. Patient input, supported by high-quality, accessible information, would drive up quality in the NHS – for example, by patients spotting data quality errors on their SCR.

4. Reduction in NHS costs. For example, more self-management would potentially reduce the cost of managing long-term conditions.

5. Improvement in health literacy as the availability of HealthSpace would improve people's ability to understand and manage their illnesses.

In summary, the SCR was seen by the state as a key source of data that would allow patients to make informed choices about the care they needed and hold public services to account for the money they spent and the services they provided. It was part of the drive for transparency and open data that the state argued "underpins getting better value for money in public spending."[561] Releasing patient health and social data that maintained patient confidentiality was also expected to "deliver economic benefits by

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[560] Greenhalgh et al., 6.
[561] Department of Health, *The Power of Information*, 98.

enabling businesses and not-for-profit organisations to use public data to develop innovative applications and tools that in turn support the public, patients and carers, service providers and commissioners to make better, more evidence based decisions."[562]

As part of the shift in values from clinician-centred to patient-centred care, in which patients' engagement with, and co-production of, their healthcare became a norm, NHS England argued that there was "a case, too, for giving the public more systematic access to information to support self-treatment and care."[563] The SCR was seen as a mechanism to help support this value shift and the creation of new norms in healthcare service delivery that also had the potential to improve the public good. The NHS went on to state that:

> the public wants the opportunity to access information such as good health and lifestyle advice. But people are also interested in understanding how the health service is performing in the delivery of healthcare services, both in terms of the efficiency of the service – for example, as indicated by waiting lists and waiting times – and also increasingly in its effectiveness in terms of outcomes.[564]

Providing the consumers with more information was thought to have significant public value as it would provide benefits for the consumer and for providers of care and, through both of these avenues, national health policy. The NHS articulated this argument, which remained remarkably consistent through to the end of the period covered by this research, as follows:

> The public wants access to comparative clinical information relating to local NHS services. People also need easy access to good quality information to enable them to influence local service development, as well as local and national policy.[565]
>
> Information for Health introduces a new way of working which recognises how the information derived as a result of the fundamental purpose of the

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[562] Department of Health, 98.
[563] Burns, *Information for Health*, 17.
[564] Burns, 17.
[565] Burns, 17.

> NHS in treating and caring for patients can be subsequently analysed for the benefit of all, and continuously improve treatment and care in the future.[566]

Growing Criticism

By 2006 the NPfIT had "been subjected to hostile media coverage"[567] for its entire four year history. A significant problem was identifying benefits, which Keen argued was not surprising "given that systematic reviews show relatively modest benefits associated with information technology projects." [568] Privacy was also an area of concern. Greenhalgh[569] argued that "civil liberties were especially vocal in England [as NPfIT had] become associated in the minds of the press and citizens with other aspects of the 'Database state' (notably the Blair government's contemporaneous attempt to introduce a national ID card)."[570] These concerns paralleled those in Australia where recent battles over the Australia Card had heightened civil liberty fears and led to overly draconian privacy protocols that significantly impacted the ease of access to, and use of, patient health information by both patients and clinicians.

Consent issues, particularly related to access to the SCR, persisted throughout the SCR program with government responding to criticism by changing the consent model and emphasising the robustness of security arrangements. During the early adopter phase an implied consent model was used for creating, and granting clinical access to, the SCR. In response to the University College London (UCL) initial evaluation report (2008) NHS CfH changed to an explicit consent model requiring clinicians to ask for a patient's consent before accessing their SCR, with a record kept of who accessed the record and what entries were made.[571] As Powell and Thompson noted "Patients are asked for their permission on every occasion before any clinician views their record … [an] explicit request for consent."[572] The exception was when a patient was unconscious or unable to

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[566] Burns, 18.

[567] Keen, "The NHS Programme for Information Technology."

[568] Keen.

[569] Greenhalgh et al., "Introducing a Nationally Shared Electronic Patient Record," e132.

[570] The notion that privacy advocates were more likely to get their way because they were vocal and more likely to demand things was supported by Hamilton's comment that "the squeaky gate gets the oil." Hamilton, Interview.

[571] Powell and Thompson, "Electronic Patient Records: The Roll-out of the Summary Care Record," 8.

[572] Powell and Thompson, 9.

communicate in the A&E, which was one of the benefits of NEHRs consistently promoted by governments in all three case study countries.

However, while privacy advocates continued to pressure the government to give patients more control over their health information, most patients and clinicians were more interested in patient information being available to improve care. Brian Fisher explained:

> Well this is part of the moral panic I think. The people that are very anxious about data being used badly on behalf of people are very vocal and are in the press a lot. Our experience of focus groups and patients talking, studies of patients, suggests that the vast majority are not that bothered actually and in fact they are consistently astonished that data is not already shared. They just kind of assume that if you go to hospital, well of course they'll have your General Practice record. Why on earth would they not have your General Practice record and they're surprised that we don't and they can see the problems that if you go to A&E and no one knows anything about you. There's no way of finding out some of the time. So they are rather irritated by that. Quite rightly. So in fact our experience is and the research suggests that they're more interested in accuracy than in confidentiality. So it's really unusual for people to say "I hope the records you're holding on me are secure." It's not very common, but it does happen, that when they have access to their records that they come to us and say "This says that I had a heart attack in '76 and I didn't have a heart attack in '76" and so on. And sometimes we find that they did have a heart attack in '76 and nobody told them and sometimes we find that they're right, they didn't have a heart attack in '76 and that's great. It helps us to get more accurate records.[573]

In response to concerns about the security of the SCR and the confidentiality of patient health information, the NHS stated that:

> the security arrangements are robust and are at the leading edge of national and international standards. Only staff with an NHS Smart Card can access the record, and then only for people to whom they are delivering care – people with whom they have a Legitimate Relationship.[574]

Patients' control over the transfer of information in their SCR was fairly clear and further reinforced the value of patient-centred care. Once an SCR[575] was created patients could decide:

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[573] Fisher, Interview.
[574] NHS leaflet cited in Powell and Thompson, "Electronic Patient Records," 9.
[575] Powell and Thompson, 8.

1. Not to share the information in it.

2. To share the information in it with others providing care.

3. To add information from [their] other health records they would like included.

The evaluation report on the SCR and HealthSpace programs by Greenhalgh *et al.* in 2010 found little evidence of direct benefits. Many stakeholders initially had unrealistic expectations that "the SCR would be near-universally accessible to staff and patients, that it would offer complete and accurate information and that it would 'work' with minimal maintenance effort."[576] Further, Greenhalgh *et al.*[577] found that:

1. There was evidence of improved quality in some consultations, particularly those which involved medication decisions.

2. There was no direct evidence of safer care, but findings were consistent with the conclusion that the SCR may reduce rare but important medication errors.

3. There was no consistent association between use of the SCR and consultation length.

4. There was evidence that the SCR was particularly useful in patients unable to communicate or advocate for themselves.

5. There was no evidence that the use of the SCR was associated with a reduction in onward referral.

6. The impact of the SCR on patient satisfaction was impossible to assess.

There were even fewer benefits found for HealthSpace. Greenhalgh *et al.*[578] found that:

1. There was no evidence to date of improved personalisation of care, increased patient empowerment, increased ability to manage long term conditions,

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[576] Greenhalgh et al., "The Devil's in the Detail," 17.
[577] Greenhalgh et al., 8.
[578] Greenhalgh et al., 8.

improved literacy in patients as a result of using HealthSpace, or reports of reduced NHS costs.

2. No patients were found who had used HealthSpace to input to the data quality process, few practices or patients had yet used Communicator, so the anticipated benefits of improved accountability, quality improvement and safety as a result of such input or use were impossible to assess.

While some risks had been clearly identified early on and "successfully mitigated"[579] issues emerged that led to the SCR being viewed as "difficult to access, 'clunky' to use, offering considerably less functionality than expected and raising numerous ongoing operational challenges."[580] These issues included complexity, technical problems with interoperability, "unanticipated administrative workload"[581] and "low use at the clinical front line."[582] Pervasive, seemingly insoluble problems persisted in the content and scope of the SCR, its consent model, information governance and staff training.[583] For example:

> The scale of the SCR programme, along with the struggles of the Information Commissioner to apply data protection legislation in a way that keeps pace with technological innovation … created new ambiguities about who now 'owns' patients' medical records, who is responsible for assuring the quality and confidentiality of the data on those records and in what circumstances consent should be asked for sharing these data.[584]

The huge scale of the project exacerbated "tensions between 'national coordination' and 'local ownership' … [and] between standardisation and contingency."[585] The result was that by 2010 only "1,243,911 SCRs existed and 14,266 had been accessed"[586] out of an initially projected 50 million SCRs.

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[579] Greenhalgh et al., 18.
[580] Greenhalgh et al., 17.
[581] Greenhalgh et al., 10.
[582] Greenhalgh et al., 18.
[583] Greenhalgh et al., 12–13.
[584] Greenhalgh et al., 18.
[585] Greenhalgh et al., 18.
[586] Greenhalgh et al., 8.

In the lead up to the 2010 national election the Labour government committed to continuing with the NPfIT overall while paring back the program to the core elements seen as critical by clinicians in an effort to increase flexibility and reduce the lifetime costs of the program by £600 million.[587] This approach was met with derision by the Conservative opposition:

> Oh dear, Mr. Speaker. Rarely have we seen a more abject example of the Government's incompetence. They took central control of NHS IT – £7.5 billion in central contracts and £5 billion in associated costs on top of that. Seven years on, they are over budget and under-delivered. The electronic patient record is four years late at the very best – if it will ever happen. Everyone told them that big IT projects had to be user led, but that one was not. We told them that the system should be decentralised, with local procurement and patient control over health records, but they did not listen. Now the Chancellor of the Exchequer says it has to stop. The Secretary of State is clearly not in charge. The Government got it wrong and the Treasury is now belatedly putting a stop to the continuing disaster.[588]

The key criticism, jointly shared by most stakeholders, was that the government had pursued a highly centralised top-down approach in its haste to realise the expected benefits of the program without adequately collaborating with key stakeholders.[589] While the NPfIT program had achieved the delivery of many computer systems to both primary and secondary care, the approach had proved to be more expensive than anticipated, and interoperability through the integration of computers at all points of care much more difficult to achieve than expected. This was despite, and to some extent because of, the incentives the state had provided to GPs and hospitals to adopt ICT. By 2009 there was a widespread perception that the NPfIT and the SCR had both been failures.

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[587] Andy Burnham (Secretary of State for Health), HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 21.

[588] Andrew Lansley (Con) HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 21.

[589] National E-Health Transition Authority, "*Evolution of EHealth in Australia Achievements, Lessons,* and *Opportunities*" (Sydney, 2016), 16.

Phase Two: 2010 to 2015 – Muddling Along

Re-evaluation – End of the NPfIT and Scaling Back the SCR

The 2010 election saw the Conservatives replace Labour in government. The Conservatives had criticised the NPfIT for losing large amounts of money and recommended scrapping the national database of health records arguing that "a central database is not required in a localised version of NHS IT."[590] As opposition leader, David Cameron stated:

> Things like the big top down decisions like the NHS computer, that should go, that's where you can make a genuine reduction in government spending.[591]

Growing criticism led to the new government abandoning the centralised approach of the NPfIT in 2010 and deciding that the SCR would proceed with limited information being uploaded. The NPfIT was closed down in 2011 and CfH followed suit in 2013 with the responsibility for the delivery of the SCR assumed by the HSCIC.[592] In 2013 HealthSpace, which had been intended to securely allow clinicians and patients access to their SCR, was also closed down. Dr Charles Gutteridge, the National Clinical Director for Informatics at the DoH concluded that: "It is too difficult to make an account; it is too difficult to log on; it is just too difficult."[593]

Based on the failure to achieve desired outcomes of the centralised, top-down approach to health IT that characterised phase one, the DoH embarked on a bottom-up approach that included a scaled down SCR. This was part of Health Secretary Andrew Lansley's *Choice and Information Revolution* contained in the new information strategy (known as The Strategy) that prioritised extending patient choice and abandoning the centralist approach of the NPfIT: it aimed to move to "an innovative new system driven by local

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[590] Channel 4, "The Conservative Party's Credibility Deficit Updated Tax and Spending Commitments," 2010, 100–101.

[591] David Cameron (Prime Minister), Jeff Randall Show, Sky News, January 26, 2009, cited in Channel 4, 100.

[592] McLoughlin, Garrety, and Wilson, *The Digitalization of Healthcare*, 47.

[593] Charles Gutteridge (National Clinical Director for Informatics at the Department of Health), in Guardian Government Computing, "NHS Axes HealthSpace."

decision making."[594] While the "good intentions"[595] of The Strategy were acknowledged by some in the media many stakeholders had a feeling of de ja vu.

> Sceptics who have seen the DH [Department of Health] launch several information strategies over the past 20 years may say that these latest launch documents are, once again, idealistic and impractical to implement.[596]

Unlike Australia, where the PCEHR was open for all Australians to opt-in from the start, the SCR was "implemented in a phased approach." [597] Like Australia, limited demographic and other basic patient information – prescription and allergy details, HI number, name and date of birth – were the first items included, with more detailed patient information to follow as the system progressed in capability. Opt-out was continued with a greater focus on patients controlling their health information.

> Uploading of information to the summary care record will continue to take place, where the relevant general practitioner (GP) practices and primary care trusts (PCTs) agree that patients have been adequately informed about the process, and properly enabled to opt out should they wish, and GP practices and PCTs are satisfied that data are of an appropriate quality for sharing.[598]

Interestingly, appropriate quality from providers uploading documents was not an Australian requirement for uploading patient information to the PCEHR.

While patients could opt-out of the SCR, if they did not do so during the 12-week Summary Care Records Information Programme their SCR would become accessible to clinicians providing them with care or treatment. Patients had several opt-out[599] options:

1. Not to have a SCR created, in which case they would have to complete an opt-out form and read the accompanying information to ensure that they understood both the risks and benefits before making their choice.

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[594] Andrew Lansley (Minister of State for Health), in Andrew Hough, " 'Disastrous' £11.4bn NHS IT Programme to Be Abandoned," *The Telegraph,* September 21, 2011.
[595] Tony Collins, "DH Launches 'Choice and Information Revolution,' " *ComputerWorld,* 2010.
[596] Collins.
[597] Powell and Thompson, "Electronic Patient Records," 10.
[598] Simon Burns (Minister of State for Health), in Powell and Thompson, 13.
[599] Powell and Thompson, 10.

2. If a patient decided not to have an SCR then subsequently changed their mind, a record could be created for them.

3. If a patient decided to have an SCR and subsequently changed their mind, the record would be suppressed and no longer available to support clinical care.

4. Patients could also request to have their record deleted. This would only be possible in those cases where the record had not been relied upon to provide care.

There was also an effort to change the widespread perception that the SCR was still big government being imposed from above. The new conservative government was keen to stimulate patient engagement with their healthcare as a way of reducing costs and improving patient health outcomes. This was expressed as follows:

> Using SCRs effectively depends on patients and doctors feeling an ownership of these records, rather than them being perceived as something imposed by a central arm of government.[600]

Similarly to Australia, England pursued "consistent use of information standards that enable data to flow whilst keeping our confidential information safe and secure"[601] as part of the SCR. This was to enable the SCR to securely share information between points of care. An NHS number was to be used as the primary identifier to connect records across the whole system as patients moved between services thus, by 2015, "connecting information for integrated care."[602]

While significant systemic changes occurred in phase two, the desired outcomes based on the interoperability, usability and meaningful use of patient health information were remarkably similar to phase one. The focus was still on extracting "the potential benefits that could be achievable through the more efficient and effective use of information and technology in the NHS and social care." [603] Harnessing information and new

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[600] Simon Burns (Minister of State for Health), in Powell and Thompson, "Electronic Patient Records." 13.

[601] Department of Health, *The Power of Information*, 28.

[602] Department of Health, 28.

[603] PricewaterhouseCoopers, "A Review of the Potential Benefits from the Better Use of Information and Technology in Health and Social Care: Final Report," *Study on the Impact of Digital Technology in Health and Social Care*, 2013, 5.

technologies was seen as crucial to transforming the healthcare system in order to "achieve higher quality care and improve outcomes for patients and service users."[604] In 2012, the DoH released a ten-year framework to improve the interoperability, usability and meaningful use of health information, known as The Strategy. The emphasis was again on patient centred healthcare by "putting people truly at the heart of care"[605] in support of "a culture of 'no decision about me without me' "[606] whereby patients could "access, contribute to and choose to share [their] health and care records."[607]

Interestingly, many interviewees thought that state rhetoric on privacy and patient access to their SCR missed the mark. For example, Atherton thought a lot of patients didn't care about the confidentiality and privacy of their SCR, particularly when it was well explained to them, and assumed that sharing of their health information was already happening in the course of their care.[608] Tamar Koch, GP, went further, suggesting that patient privacy, access and control regimes were state attempts to satisfy a small but vocal stakeholder advocacy group:

> I don't know of any strong evidence that patients really want access to their medical records, that they will know what to do with them. I think it's part of the government pandering to a small sector of society who are wanting more autonomy and control over their own information. Patient demand for access to records appears very slight.[609]

Additionally, many interviewees supported Elizabeth Murray's view that there was "a very strong professional resistance to patients being able to access their record."[610] Clinicians were "adamantly opposed"[611] to patients inputting data into the SCR so by 2013 patients were unable to do that. They were able to "collect self-monitoring data,

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[604] Department of Health, *The Power of Information*, 4.
[605] Department of Health, 2.
[606] Department of Health, 6.
[607] Department of Health, 6.
[608] Helen Atherton (Primary Care and Digital Health Researcher), Interview, 2013. Supported by Tamar Koch who explained that while there is a fear among practitioners about getting consent from patients as to who sees what. "patients probably don't care, they just see the benefits [of sharing their health information among clinicians providing them care] over the burdens." Tamar Koch (GP), Interview, 2013.
[609] Koch, "Interview." This point of view was supported by other interviewees including Klecun, Interview 2
[610] Elizabeth Murray (Director, eHealth Unit, University College London), Interview, 2013.
[611] Murray.

print it out and take it on a pdf to the doctor who, if they wish, may then scan it into the patient record."[612]

The DoH Impact Assessment of the strategy if fully implemented identified "the potential to deliver a total net present value of £5,059 million over 10 years."[613] In 2013, a report by PwC stated that an additional £4,400 million of potential benefits could be achieved if all of the report's actions were fully implemented.[614] The strategy's main ambitions, and the PwC report's priority potential actions identified very similar priorities to drive transformational change, as in phase one. Broadly, they aimed to: "capture person-based information at the point of care, link and share person-based electronic records,"[615] and stimulate patients' engagement with their care.

However, progress in achieving these aims was patchy at best. While bureaucratic factsheets and NHS websites focused on the positive narrative, especially the increasing potential of the SCR to transform healthcare delivery, policy makers were sometimes more blunt in acknowledging continuing barriers to achieving desired benefits. In 2013, the then Health Secretary Jeremy Hunt criticised the NHS for remaining "stubbornly attached to using archaic fax machines for a significant proportion o[f] their communications. This [he said] is ludicrous."[616] He went on to say that the "NHS should 'go paperless' by 2018 in an effort to 'save billions' and improve services."[617]

Efforts to increase the utility of the SCR and see it used as "a vital tool to make care provided to patients safer, timelier and more effective"[618] continued apace. The core dataset of information in the SCR (personal identifying data, medications, allergies and previous adverse reactions) was still derived from a patient's more detailed GP records but, with the consent of the patient, could now include significant medical history, care

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[612] Murray.
[613] PricewaterhouseCoopers, "A Review of the Potential Benefits," 5.
[614] PricewaterhouseCoopers, 8.
[615] PricewaterhouseCoopers, 8; Department of Health, *The Power of Information*," 5-6.
[616] Henry Bodkin, "NHS World's Biggest Fax Machine Buyer Due to 'Stubborn' Resistance to New Technology, Say Medical Leaders," *The Telegraph*, July 12, 2018.
[617] Bodkin.
[618] Health and Social Care Information Centre (HSCIC), "Summary Care Record Factsheet," 2014.

plans, patient wishes or preferences and other relevant information.[619] Clinical use of the SCR also expanded to include hospital pharmacies, GP out-of-hours services, GPs seeing temporary residents or holiday makers, accident and emergency clinicians, clinical staff in hospital wards, staff at walk-in centres and minor injury units, and multidisciplinary teams.[620] However, clinical use still relied on providers successfully implementing interoperability initiatives, which continued to face significant barriers, resulting in a slow increase in clinical views of the SCR.

The enabling narrative stating the benefits of the SCR continued to be very similar to the past for all stakeholders. The HSCIC found that the SCR was adding value to clinical practice and improving the care provided to patients. This included improving the provision of healthcare experience for patients and their carers, allowing for the sharing of health information, improving the equality of care, and lowering cost by reducing the time, effort and resources used to obtain health information and reinvesting directly in patient care.[621] Brian Fisher gave a GP's perspective on the benefits of a continued roll-out of the SCR:

> The summary care record continues to be rolled out across the country which is the ability for clinicians to look at patients' data wherever they are. The data that the clinicians will see will be thin, so it will be problem titles, allergies, immunisations, drugs. Nothing else, but still dramatically better than not having any of that data. And as I understand it that's going to continue and within three years or so the whole of England will be covered, so you turn up in an A&E your casualty officer should be able to access your record. As I understand it it's a pretty clunky system, it takes a minimum of five minutes to get the data up, so probably it's pretty hard to use in the real world. But as I understand it, it hasn't been abandoned and I still think that there are studies that show that it hasn't been wasted money. In fact rather efficient apparently, a rather efficient use of money so it hasn't been £12 billion down the drain. The patient access side, which was never funded properly, has been abandoned, but the core of it, continues.[622]

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[619] HSCIC.
[620] HSCIC.
[621] HSCIC.
[622] Fisher Interview."

By 2014, 40 million people[623] had an SCR and in 2015 uptake had increased to 97 per cent of the population. This was a significant, yet long delayed, achievement made possible by an initially inflexible opt-out system of automatically giving patients an SCR and making it difficult to opt out, incentivising GPs to create patient records that contained clinically useful patient information, and broadening the types of information the SCR contained. However, uptake did not reflect actual clinical use which lagged behind due to provider issues with interoperability and a continuing, though shrinking, lack of widespread provider belief in the clinical usefulness of the SCR. Views, use and stakeholder benefits of the SCR relied on it being integrated within clinical workflows and achieving the norm that it would be available at all points of care and used in the regular provision of healthcare. This would still take some time and post 2015, despite significant barriers remaining, improvements would continue to be made and the potential for transformation of the delivery and outcomes in healthcare would remain a central part of the enabling narrative.

Conclusion

The state in England pursued institutional change in the area of ehealth through the mechanism of an NEHR, in this case the SCR, for many of the same reasons as Australia and the US. England's NPfIT and SCR had a rhetorical logic of positive structural alignment, where policy goals align with desired outcomes due to value trade-offs that positively affect stakeholder habitual behaviour. In summary, this can be expressed as: making sure primary and secondary care have computer systems and EHRs; linking the computer systems together using ICT; developing and implementing an SCR that draws a summary of patient health information from all points of care; and making that summary available at all points of care. This results in healthcare efficiency and effectiveness outcomes that benefit patient health, lower costs and give patients more choice about what happens to them in their healthcare journey through the NHS system.

In phase one, the state laid the foundations for ehealth by setting out a long-term information strategy and releasing the NHS Plan in 2000. A centralised approach to

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[623] NHS England, "Summary Care Record Hits 40 Million Milestone," 2014.

health ICT and an NEHR was adopted. Organisational change quickly followed with the establishment of the NPfIT in 2002 and the creation of the ICRS followed by the NCRS in order to deliver and operate the SCR. In 2005, CfH assumed responsibility for the NPfIT and the NCRS and a preliminary version of HealthSpace, the portal to allow patients to access their health information online, was introduced. An enhanced version followed in 2009.

By 2010 both NPfIT and the SCR were reeling from sustained criticism and phase two saw a change in policy. The new Cameron Conservative government signalled the end of the centralised approach of the NPfIT and, while critical of the progress to date of the SCR, decided that it was to proceed with limited information. A new framework, known as The Strategy, was released which set a ten-year framework for transforming healthcare by transforming technology. This included a recommitment to the SCR which was still to be stored centrally on the NHS Spine, particularly as its capability, uptake and use increased over time and by 2015 50 million SCRs had been created. However, low (but growing) clinical use of the SCR limited its impact on patient health outcomes. Organisational change proceeded apace, with the NPfIT and CfH ceasing to exist in 2013 after more than £12.7 billion had been spent on the program, HealthSpace being closed in the same year, and HSCIC assuming responsibility for the delivery of the SCR.

Inevitably, there were unexpected outcomes, many of which were due to state decisions regarding stakeholder trade-offs. Initially, the state had assumed that positive structural alignment would come from many of the decisions it made. Those stakeholder trade-offs included: a rigid approach to contracting, favouring the state at the expense of vendors; privileging GPs and hospitals with ICT adoption incentives; having privacy provisions that favoured patients and patient advocate groups, with the exception of adopting an opt-out model, which raised serious concerns amongst clinicians and other healthcare providers; adopting an opt-out model that favoured the state's collection and use of patient health information at the expense of all other stakeholders; and adopting the view that more information would lead to competition and patient choice which in turn would help bring about the desired benefits thus actualising a patient-centred healthcare system.

However, negative structural alignments emerged, often because benefits that were acquired by one stakeholder alienated or disincentivised other stakeholders and led to unintended consequences. The provision of computer systems to primary and secondary care proved to be more expensive than anticipated, though up-take by GPs proceeded quickly. Gillian Braunold argued that “the story of GP primary care computing in the UK is a great success story,” particularly through an incentive program that provided “free computers to practices that gave anonymous data back to the centre.”[624] She noted there are problems with some GPs who “struggle with hunt and peck with their finger on the keyboard” and that “record keeping isn’t as good as it should be” and “people aren’t writing the amount of narrative that they would have done with a paper record but at least its legible.”[625] Integrating computer systems using ICT and making an SCR available at all points of care proved to be extremely difficult and much of the program was abandoned or downsized. Significant normative issues around privacy and consent amplified practical issues involving integrating the SCR with clinical workflows, clinician burnout and/or opposition to changing work practices, administrative overload, and a constant struggle to build the capability of patients to effectively use the SCR to benefit their health outcomes. All these combined as barriers to achieving desired efficiency and effectiveness goals.

The empirical evidence for institutional stasis and change presented in this chapter will be comparatively evaluated with the other case study countries in chapters 8, 9 and 10.

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[624] Gillian Braunold, “Nuffield Trust Audio Recording,” 2010.

[625] Braunold.

Chapter 7 Case Study – The United States

This chapter explains the development of federally driven interoperable electronic health records (EHRs) in the United States between 1996 and 2015. The literature review foreshadowed that such a major health reform was unlikely to occur in the US because of institutional structural barriers[626] embedded in the healthcare arena. Traditionally, the funding and provision of healthcare had been based on private market mechanisms supplemented with public provision. The exception was a minority of Americans who were insured under the Medicare or Medicaid programs, or who were uninsured. Tuohy notes that "the hallmark of American health policy … has been its incrementalism"[627] which maintained private markets and pursued improvements through regulation rather than, as in England and to a lesser extent Australia, supplanting them. Change in the healthcare arena was fostered by incremental policy changes that focused on incentives, constraints and guidance – particularly from the federal level – that resulted in a "logic of entrepreneurialism which generated a cycle of increasingly complex market strategies and regulatory responses."[628] This led to the growth of for-profit healthcare providers and insurers, the nationalisation of healthcare markets and an "increasing reliance on hierarchical mechanisms on the part of both the state and private financial actors."[629] The political terrain for major healthcare reform had been transformed from one dominated by the medical profession to one where corporatisation and the state were emerging as the major players. Subsequently, major attempts at healthcare policy change faced fewer institutional structural barriers than in the past. If one political party could control the presidency, both house of Congress and exploit a significant exogenous event that allied corporate healthcare with policy interests through incentive funding – major reform became possible.

Unlike Australia and England, the state at the national level in the United States did not develop and implement an NEHR. The unit of comparison in this chapter is the

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[626] See Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America."

[627] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, 127.

[628] Tuohy, 128.

[629] Tuohy, 128.

coordination and regulatory approach – including incentives and penalties – the state adopted for the purpose of making EHRs interoperable. This was the first step in actioning the goal of meaningfully using patient health information to improve the efficiency and effectiveness of healthcare service delivery and achieving better health outcomes for patients.[630] This approach also included attempts to give patients more control over their health information. The goal of the federal government was to firstly provide leadership in attempting to coordinate, then secondly to coerce and incentivise, EHR providers and users to adopt EHRs that would share information nationally. As per the chapters on Australia and England the key public policy questions regarding the role of the state addressed in each section will be: what did the state want to do, why did the state want to do it, how did the state go about doing it, and, how did the state pay for it? Again, key themes of interoperability, usability and the meaningful use of information will be woven into the discussion as those themes influence the core empirical similarities and differences between the case study countries. The discussion proceeds using the same structure as the previous two empirical chapters.

Part 1 will examine the development of institutional pressures and tensions that influenced both stasis and the critical junctures that produced institutional change in health records in the United States. Again, those institutional pressures and tensions included: structural antecedent conditions, shock events, ideational change, political agency and converging trends. Part 2 will examine the role of the state at the national level in the United States in Coordinating and regulating EHRs so that they would be shareable nationally. The chapter will end with a conclusion.

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[630] For example, Jerry Van Wieren argued that “there’s better accountability and recall of the plan with better patient compliance. The patient sees the plan in black and white. When they get home their spouse sees the plan and says ‘Well look right here. The doctor said that you needed to cut back on your salt and you can’t have that food now. Doctor said.’ ” Jerry Van Wieren (GP of a small practice in internal medicine), Interview, 2014.

Box 7-1: Brief Glossary of Key Abbreviations and Terms Used in Chapter 7

ARRA: *The American Recovery and Reinvestment Act of 2009*.
CEHRT: Certified electronic health record technology.
CLIA: The Clinical Laboratory Improvement Act of 1967.
CMS: Centers for Medicare and Medicaid Services.
DoD: Department of Defense.
EHR: Electronic Health Record.
FTC: Federal Trade Commission.
GFC: Great (or global) Financial Crisis of 2008-09, often referred to elsewhere as the Great Recession.
HHS: Department of Health and Human Services.
HIPAA: *The Health Insurance Portability and Accountability Act of 1996*.
HITECH: *The Health Information Technology for Economic and Clinical Health Act of 2009*.
MHR: Medical Health Record.
NEHR: Nationally interoperable Electronic Health Record.
NRPPs: Norms, rules, processes and procedures.
ONC: Office of the National Coordinator for Health Information and Technology.
PHR: Personal Health Record – drawn from multiple sources; patients can contribute information; controlled by the patient.
DVA: Department of Veterans Affairs, commonly referred to as the VA.

The terms used for electronic records of health-related information in the United States differ somewhat from those used in Australia and England. This is because elements of patient control common to the Personally Controlled Electronic Health Record (PCEHR) and Summary Care Record (SCR) are often missing from US EHRs but are instead part of a US Personal Health Record (PHR) which may be electronic or paper-based. Common to all three countries is the electronic record conforming "to nationally recognized interoperability standards."[631] However, the EHR is defined as being "created, managed, and consulted by authorized clinicians and staff across more than one health care organization," whereas a PHR "can be drawn from multiple sources while being managed, shared, and controlled by the individual."[632] While the term NEHR is not commonly used in the US, it is used in this thesis to combine elements of both EHRs, where the bulk of information is created by and for clinicians, and PHRs where patients have some control over key portability criteria such as privacy, sharing and access to the

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[631] The National Alliance for Health Information Technology, "Report to the ONC on Defining Key Health Information Technology Terms," 2008, 6.
[632] The National Alliance for Health Information Technology, 6.

information contained in the record. This is done for two reasons. First, to simplify "the existence of too many differing and even conflicting definitions"[633] and to incorporate the key component of nationally recognised interoperability standards as published by the Office of the National Coordinator for Health Information Technology (ONC). Secondly, it allows for a much more robust comparison between the units of comparison in each case study country using the themes of interoperability, usability and meaningful use. Integral to all three themes is the concept of patient control over health data as referred to above.[634]

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[633] The National Alliance for Health Information Technology, 8.

[634] For more detail on definitions and acronyms please see the Glossary and Abbreviations section at the front of this thesis.

Part 1

Stowed in steel cabinets, the [paper] records were next to useless. Nobody — particularly at the dawn of the age of the iPhone — thought it was a good idea to leave them that way.[635]

The Development of Institutional Pressures and Tensions

Similar endogenous and exogenous institutional pressures and tensions to those in Australia and England developed in the US during the 1990s and 2000s leading to ehealth and NEHR institutional change over time. In particular, privacy of personal health information and a patient's right to control their health information slowly developed as a policy issue at the federal level. These issues were increasingly tied to the use of EHRs, both in terms of the potential benefits of improving the efficiency and effectiveness of healthcare service delivery and the growing societal concerns over the impact big data might have on citizen welfare in a market driven economy. Increasingly the potential patient health outcome benefits drove positive rhetoric from providers and politicians about EHRs. However, there was significant resistance to the "theory that EHRs have this wonderful potential,"[636] especially among patient and privacy rights stakeholder groups. Marla Durben Hirsh explained the issue this way:

> What people seem to forget is that an EHR is just a tool. It's not always designed, or used, right and people have differing expectations about how they are supposed to work. And sometimes these expectations are not met. Patients don't know their rights, what their data is used for, don't read or understand privacy consent forms, and may not care.[637]

Incremental institutional change gave way to a critical juncture in 2008–2009 allowing a window of opportunity for policy makers at the federal level to enact policy change and pursue new ideas in the area of health records.

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[635] Fred Schulte and Erika Fry, "Death By 1,000 Clicks: Where Electronic Health Records Went Wrong," *Kaiser Health News*, 2019.

[636] Marla Durben Hirsch (Healthcare Journalist), Interview, 2014; This view was supported by Deborah Peel (MD, Founder and President of Patient Privacy Rights), Interview, 2014.

[637] Durben Hirsch, Interview.

Structural Antecedent Conditions

The structural antecedent conditions that existed in the United States before the state attempted to regulate health information privacy and incentivise interoperable EHRs developed in an extremely complex healthcare system. In the US there has historically been a sharper political divide between the major political parties than in Australia and England over the role of the state in pursing the public good in a manner that results in the state competing with privately operated systems. This political divide has, particularly since Reagan in the 1980s, been between Democrats who have tended to favour policy that aims to ensure fairness, equality, equity and consumer protection and Republicans who have tended to favour free markets with minimal intervention by the state and to emphasise concerns that competition from the public sector would create a chilling effect on the private sector.[638] This was seen in the Congressional votes on the *American Recovery and Reinvestment Act of 2009* (ARRA) which provided $787 billion in stimulus funds, and the *Health Information Technology for Economic and Clinical Health Act of 2009* (HITECH) which was part of the ARRA and provided incentives and penalties for ehealth, as a response to the GFC. No House Republicans, and only three Republican senators, voted for the ARRA and Republicans have been trying to undo much of what was achieved by HITECH ever since.[639] This is a values clash, a desire for different norms, and therefore a different set of rules, practices and procedures that result from competing policy frameworks. It is reflected in the development of pressures and tensions that led to institutional change in the area of health records as well as in the barriers to change that tended to reinforce the *status quo*, maintain stasis and disrupt desired outcomes.

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[638] John Wanna argued that “healthcare was much more of a polemical issue in the US than in England and Australia as the affluent didn’t want to pay for the healthcare of the poor.” John Wanna (Professor of Public Policy and Chair of the Australian and New Zealand School of Government), Interview, 2019. This view is an extension of the idea emanating from the concept of the Protestant work ethic that a person deserved subsidised access to healthcare from their employer as a direct result of (usually) full-time employment and that the unemployed were somewhat undeserving of the state, through taxation expenditure, providing this benefit.

[639] Ben Davoren thought that the lack of a bipartisan approach to NEHRs reflected “a fair amount of grandstanding and not much understanding [without] a lot of long-range vision in Congress.” Ben Davoren (Associate Chief of Staff for Clinical Informatics, San Francisco Veterans Affairs Medical Center (SFVAMC)), Interview, 2014.

Complexity in the US healthcare system resulted firstly from multiple levels of often overlapping government jurisdiction due to federalism. The federal and state governments, as well as counties and cities ran, provided funding for, and often regulated the provision of healthcare directly influencing norms, rules, practices and procedures (NRPPs). Secondly, as Marla Durben Hirsch argued, "the US has an unusual healthcare system which has a lot of managed care and insurance company influence that serves as a middleman between the patient and the provider."[640] The combination of both is like a "soup" with the state "trying to enforce the soup."[641] Third, insurance tended to lock people into organisational systems and it was expensive to acquire care outside of the system. All three complexity issues promoted data silos and other barriers to EHR interoperability.

As was the case elsewhere, paper records, some non-interoperable EMRs, and fax machines were the norm. The adoption of computer technology was extremely fragmented across the country with numerous small medical practices still relying on paper records.[642] When adopted, EMRs were mostly proprietary and expensive to implement. Patient health information was therefore siloed and patients had limited control over their health information. Healthcare, and therefore health insurance, costs were rapidly increasing as people lived longer and developed more expensive to treat chronic diseases and therefore accessed more health resources. Healthcare costs were significantly higher per person in the US than in any other developed country and were projected to become a larger burden on personal and government expenditure at all levels over time.[643] There was a strong political commitment to the provision of healthcare as a private good, rather than a public good, though there were significant exceptions with the most prominent being Medicare, Medicaid and the VA.

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[640] Durben Hirsch, Interview.
[641] Durben Hirsch.
[642] John Carlson (MD) Interview, 2014; Van Wieren, Interview.
[643] Durben Hirsch, Interview; Kamal Jethwani (Senior Director of Connected Health Innovation at Partners HealthCare), Interview, 2014; Deven McGraw (Director of the Health Privacy Project), Interview, 2014.

Shock Events

There were two key shock events that resulted in ideational change followed by political agency. Both happened in the same period. The Great Financial Crisis (GFC) occurred in the years 2008-2009 and during this time the Democrats took control of the House of Representatives, the Senate and the presidency in the national elections of 2008. These events were preceded by both legislation and a presidential executive order that set the stage for increased government involvement in healthcare. *The Health Insurance Portability and Accountability Act of 1996* (HIPAA) provided data privacy and rights of access to, and portability of, an individual's medical information; it was administered by the Centers for Medicare and Medicaid (CMS). The Office of the National Coordinator for Health Information Technology (ONC) was established by executive order to promote the interoperability of EHRs.

Ideational Change

The GFC and the subsequent Democrat control of government resulted in a window of opportunity for healthcare reform. The new agenda was part of a broader pursuit of public sector reform that was to be built upon achieving efficiency through technology. Ideational change saw the re-emergence of progressive era ideological concepts of the public good while still acknowledging the ideological dominance of the *status quo* philosophy of healthcare primarily being a private good, hence the continued prominence of health insurance and managed care.[644] However, the GFC provided Democrats, supported by many healthcare stakeholders, with the opportunity to make the argument that government intervention in free markets through stimulus was now required and that the value proposition of EHRs would support "the triple aim in the US of better care, better health, and lower costs."[645] Ideational change justified government subsidisation of the healthcare market on the premise that EHRs would promote the meaningful use of health information and thus improve healthcare outcomes.

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[644] Durben Hirsch, Interview.

[645] Joy Lewis (Manager, Institute for Health Policy and Kaiser Permanente International), Interview, 2014.

Political Agency

Ideational change was followed through with political agency on the part of the new Democrat-controlled Congress and keenly advocated by the new Democrat President Barack Obama who saw EHRs as having multiple benefits that would ultimately save lives.[646] HITECH was enacted in 2009 and promoted the use of technology through ehealth to gain efficiencies in, and improve the effectiveness of, healthcare. It authorised ONC and CMS to regulate EHRs and promote their meaningful use through a system of regulatory coordination and incentives and penalties. Funding was extensive reaching $35 billion by 2017.

Converging Trends

Converging trends were very similar in the United States to Australia and England although in the US the market was to play a larger role in the way converging trends led to the implementation and regulation of EHRs. Also, there was never a top-down centralised NEHR as in Australia and England though there was a strengthening of a centralised regulatory approach with the national application of incentives and penalties in an effort to drive clinician and other healthcare provider adoption of NEHRs.

Social trends slowly produced some change in healthcare values and norms over time. Access to healthcare in the US was regarded as a personal good that was subsidised through participation in the workforce with the exceptions of Medicare, Medicaid and the VA mentioned above. However, the notion of citizens rights to healthcare as a social good was slowly gathering support, especially in the area of patients' control of their health information. This shift in values towards egalitarianism was the basis for arguing that citizens had limited healthcare rights that could be regulated by the state and subsidised by the taxpayer. Patients increasingly expected to be able to access and transfer their health information and this had been facilitated through state action (HIPAA) and social expectations about the way technology should work given the innovations in other areas of the market. However, in practice, access to and transfer of,

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[646] Robert S. Blake, "Review of The Digitalization of Healthcare: Electronic Records and the Disruption of Moral Orders," *Public Administration Review* 79, no. 1 (2018): 141.

patient health information was difficult for many patients in many care settings and significant privacy and consent concerns began to drive institutional change.

Medical professional trends resulted in rapid structural changes to the way medicine was practised. There was a shift from solo practices to corporate multi-disciplinary teams within large organisations that spanned the continuum of healthcare. This change was driven by the burden of disease changing from acute to chronic illness and the increase in the complexity of disease management. Jonathan Rachman explained:

> If you look at the US statistics they are absolutely staggering. One in two adults, this is all from the Centres for Diseases Control and Prevention (CDC), one in two adults in the US today has a chronic disease, at least one chronic disease. Many have multiple chronic diseases and if you look at the dollar cost in direct terms, so not indirect cost which includes people who have been off work because they are ill or they are hospitalised, etc., if you look at the direct costs for something like cardio-vascular disease and stroke, in 2009 in the US in one calendar year [they] cost $314 billion. Diabetes $176 billion US dollars in 2012. But probably the scariest health care statistic I've ever seen is that the CDC have looked at the obesity trends in the United States and they've looked at how that's translating into type 2 diabetes trends and their own data suggests, and this is again a direct quote, that one in three Americans born in the year 2000 and beyond will develop diabetes. They are predicting that a third of their population will have diabetes. So, think of the impact in terms of the chronic complications with increased risk of heart attack, stroke, blindness, kidney failure, amputations – well that is absolutely shocking. And if you want to turn it directly just into dollar costs, then 2012 data from the American Diabetes Association showed that if you include the indirect costs of diabetes with the direct costs it is about a quarter of a trillion US dollars. If you do a straight extrapolation and say well if 32% of the population have got diabetes, in direct terms you are talking about a trillion dollars again so these [are] actual catastrophic statistics.[647]

Given the projections of chronic illness numbers structural changes in the way healthcare was provided were seen as the only way to effectively provide continuity of care. The adoption of EHRs increased the amount of information in the record and led to some unintended consequences. Costs rose as healthcare providers purchased new equipment, trained staff and spent more time interacting with technology which

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[647] Jonathan Rachman (Founder of Map My Health), Presentation at the eHealth Unit, University College London, 5 June 2013.

reduced the number of patients some individual clinicians were able to see thus lowering their income. Other clinicians increased charges. Jerry Van Wieran explained:

> Probably the greatest plus financially has not been efficiency because it takes longer, but we charge according to the time that is spent caring for the patient and I would say the electronic health record takes me about 25% longer to do my patient care per patient and so actually my income has gone up using the electronic health record, just by virtue that it takes longer and I end up with more hours to charge for my panel of patients.[648]

There was also an increase in clinician burnout and early clinician retirement.[649]

As elsewhere, fiscal pressures were aggravated by social, medical professional and technical trends. These included people living longer with chronic disease that was expensive to treat as well as a growing demand for new and expensive drugs, diagnostic and surgical equipment. The new value of the taxpayer subsidising some costs in healthcare (Medicare, Medicaid and the VA) led to a government focus on controlling "entitlement" costs, but not necessarily private healthcare costs, particularly in Republican administrations. The market approach to healthcare saw health insurance premiums continually rise and consume an ever larger portion of individual and family budgets. The state saw EHRs as a way of controlling costs, providing more information and choice, and improving healthcare outcomes for all stakeholders.

Governments in the US progressively adopted positive rhetoric regarding the potential benefits of EHRs to all healthcare stakeholders. Starting with HIPAA and expanding through the National Committee on Vital Health Statistics Information for Health (NCVHS) report in 2001 and the HITECH Act in 2009, successive governments actively promoted technology as the key to building a modern information infrastructure in healthcare that would improve the quality and efficiency of healthcare.[650] In the US, computers were first adopted by healthcare providers as an attractive option for

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[648] Van Wieren, Interview.

[649] Carlson, Interview; Ellen Michael (Registered Nurse and Patient Care Coordinator at Kaiser Permanente), Interview, 2014; Van Wieren, Interview.

[650] The National Committee on Vital Health Statistics (NCVHS), "Information for Health: A Strategy for Building the National Health Information Infrastructure," 2001; Tommy G. Thompson and David J. Brailer, "The Decade of Health Information Technology: Delivering Consumer-Centric and Information-Rich Health Care," *Department of Health & Human Services*, 2004, 1–178.

clinicians who saw the value of electronic billing systems. EHR technology innovation in EHR development and implementation proceeded apace in the 2000s but tended to be layered on top of previous implementations of billing systems. This layering process led to provider-centric EHR systems and a desire amongst policy makers to harness technology trends to force change by focusing on interoperability and breaking down health data silos. This was a policy shift to more patient-centred EHRs where patient health data would be meaningfully used to primarily improve patient health outcomes.

Part 2

The Role of the State at the National Level in the United States in Coordinating and Regulating EHRs in an Effort to Make Them Nationally Shareable

Introduction

The role of the state at the federal level in the United States was crucial in the regulating and incentivising NEHRs. As in Australia and England it was the federal government that had the money to spend on the pursuit of interoperability and meaningful use. The major difference between the United States and the other case study countries was that in the United States development of EHRs, and making the information in them portable, was left to the companies developing the EHRs with the expectation that state incentives and coercive measures, such as regulations and penalties, would both result in interoperable NEHRs and achieve desired service delivery outcomes. So, in the United States development and implementation of EHRs that had the potential to be nationally shareable was left to the market and private vendors, whereas in both Australia and England development and implementation of NEHRs was directly undertaken by the state at the national level. All three case study countries subsequently regulated and incentivised EHRs in an effort to make them nationally shareable. As in previous chapters, this section will examine the role of the state in relation to the development of ehealth as an institution more broadly and NEHRs in particular thus explaining what happened, why it happened and what the outcomes were.

Contextual History – The United States

The United States approached the issues of interoperability, usability and meaningful use of EHRs differently from Australia and England. Both Australia and England adopted a centralised/bureaucratic approach with their national governments both funding, building and regulating a NEHR. By contrast, the United States adopted a market regulation and incentives approach relying on the private sector to create and implement EHRs that eventually would meet the requirements of an incentive and penalty program. The goal of these regulations and penalties was to improve the interoperability, usability and meaningful use of EHRs. In particular, interoperability goals were meant to break down or eliminate organisational, healthcare provider and jurisdictional barriers to the sharing of patient health information.

There were two major phases in the development of federally driven interoperable EHRs in the United States:

1. 1996–2008: pre-HITECH where the focus was on developing portability standards, privacy, guidance and promoting aspirational outcomes.
2. 2009–2015: post-HITECH where significant funding supported a regulatory and incentive and non-compliance penalty approach.

Table 7-1: United States – Historical Chronology of Main Events

Date	Timeline of Major Events in The United States[651]
1996	Health Insurance Portability and Accountability Act (HIPAA) provided data privacy, rights of access to, and portability of, an individual's medical information. Administered by CMS.

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[651] The National Committee on Vital Health Statistics (NCVHS), "Information for Health"; Thompson and Brailer, "The Decade of Health Information Technology", 1–178; George W. Bush, "Executive Order 13335" (2004); Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress; Durben Hirsch, Interview; Karen B. DeSalvo, Ayame Nagatani Dinkler, and Lee Stevens, "The US Office of the National Coordinator for Health Information Technology: Progress and Promise for the Future at the 10-Year Mark," *Annals of Emergency Medicine*, 2015; United States Department of Health and Human Services (HHS), "HIPAA for Professionals," 2018; Carolyn T Lye et al., "The 21st Century Cures Act and Electronic Health Records One Year Later: Will Patients See the Benefits?," *Journal of the American Medical Informatics Association* 25, no. July (2018): 1218–20; Randall D Cebul et al., "Electronic Health Records and Quality of Diabetes Care.," *The New England Journal of Medicine* 365, no. 9 (2011): 825–33.

Date	Timeline of Major Events in The United States[651]
2001	The National Committee on Vital Health Statistics (NCVHS) Information for Health report detailed a "consumer-centric" Strategy for Building the National Health Information Infrastructure under the leadership of the Department of Health and Human Services.
2004	Establishment by Executive Order 13335 of the position of the National Coordinator for Health Information Technology (ONC) to "provide leadership for the development and nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care."
2009	Passage of the *Health Information Technology for Economic and Clinical Health Act 2009* (HITECH Act) which was Title XIII of the *American Recovery and Reinvestment Act 2009*. Funding of US$2 billion was allocated to ONC to promote the use of health information technology (HIT), the adoption of HIT standards, and to improve HIT privacy and security provisions. HITECH's goal was to improve health care quality, safety and efficiency. HITECH authorised and funded the Centers for Medicare and Medicaid Services (CMS) establishment of the Medicare and Medicaid EHR Incentive programs. Funding for these programs reached US$35 billion by 2017.
2010	Meaningful Use of EHRs Stage 1 began as part of the CMS EHR Incentive Program promoting the adoption of EHRs.
2012	Meaningful Use of EHRs Stage 2.
2014	ONC released a ten-year roadmap outlining three, six and ten year milestones for achieving interoperability. CLIA final rule was introduced strengthening patients' rights to access laboratory test reports.
2015	Meaningful Use of EHRs Stage 3.
2016	21st Century Cures Act charged ONC with implementing activities that would advance interoperability by building Health Information Exchanges (HIEs) and discourage information blocking.

Phase One: 1996 to 2008 – Privacy Regulation and Interoperability Guidance

A major issue that had developed in the United States by the mid 1990s concerned the disclosure and use of patient information in a "messy,"[652] complex, siloed, multi-jurisdictional health information environment. It was complex because technologies used to store and access patient health information varied from paper to digital health records, were provided by a plethora of vendors and installed across hundreds of thousands of healthcare provider settings. This led to clinically useful patient health

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[652] Durben Hirsch, Interview.

information being siloed within provider organisations severely limiting the portability of that information. Also, the regulation of health information, including portability and privacy, varied significantly between the various states. The federal response was the *Health Insurance Portability and Accountability Act of 1996* (HIPAA) which had the purpose of improving "the efficiency and effectiveness of the health care system, by encouraging the development of a health information system through the establishment of standards and requirements for the electronic transmission of certain health information."[653]

The Health Insurance Portability and Accountability Act of 1996 (HIPAA)

HIPAA was the primary regulation under which the sharing of health information was governed in the United States.[654] It "provides data privacy and security provisions for safeguarding medical information"[655] for covered entities.[656] The key part of the Act, in regards to the portability and privacy of patient health information, was Title II which dealt with (among other things) privacy and security standards, and breach notification through an enforcement rule. Privacy, security and limited interoperability standards were mandated through five compliance requirements. They were:

1. The National Provider Identifier Standard which mandated a unique ten-digit national provider identifier for each healthcare entity.[657]
2. The Transactions and Code Sets Standards mandating a "standardized mechanism for electronic data interchange in order to submit and process insurance claim forms."[658]

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[653] Health Insurance Portability and Accountability Act of 1996, United States Congress.

[654] Joy Pritts (Chief Privacy Officer, Office of the National Coordinator for Health Information Technology), Interview, 2014.

[655] Searchhealthit, "Guide to Healthcare Compliance Resources & Agencies," TechTarget, 2015.

[656] HHS, "Summary of the HIPAA Privacy Rule," 2003. According to HHS, covered entities refers to health plans, healthcare clearing houses, and to any healthcare provider who transmits health information in electronic form in connection with transactions for which the Secretary of HHS has adopted standards under HIPAA.

[657] Margaret Rouse, Jacqueline Biscobing, and Shaun Sutner, "HIPAA (Health Insurance Portability and Accountability Act)," SearchHealthIT, 2015.

[658] Rouse, Biscobing, and Sutner.

3. The HIPPA Privacy Rule which, for the first time, established a set of national standards for the use and disclosure of individuals' protected health information (PHI)[659] while still allowing for the "flow of health information needed to provide and promote high quality health care and to protect the public's health and well-being."[660] This reflected HHS's longstanding view that sharing information securely "for the purposes of treatment, care coordination, public health and other important purposes"[661] was not only permitted by the Privacy Rule, but actively encouraged as a way to achieve improved service delivery outcomes for both patients and providers.

4. The HIPAA Security Rule which set "standards for patient data security."[662]

5. The HIPAA Enforcement Rule which established "guidelines for investigations into HIPAA compliance violations."[663] Penalties ranged from $100 for unknowing violations through to $100,000 and 10 years in prison for violations under false pretences.[664]

While HIPAA established privacy rules, privacy advocates argued that restrictions on the sharing of patient information without patients' consent were gutted by the HHS in 2002 when it amended the privacy rule. Deborah Peel explained:

> [In 2001] President Bush implemented the Privacy Rule [that gave] Americans a federal right to provide consent before any of their health information could be used or disclosed for treatment, payment or healthcare operations. We [therefore] had the same rights roughly for electronic health records that we have always had with paper records. A year into his presidency the agency that broke the rule that operationalised the federal law reopened the HIPPA privacy rules for comments [with the] intent of eliminating consent and that's what they did, they reopened the rule, they amended the privacy rule. The amended privacy rule was put out in 2002, it was given notice that

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[659] Protected health information refers to "individually identifiable health information held or transmitted by a covered entity" with the exception of "records subject to, or defined in, the Family Educational Rights and Privacy Act" of 1974. HHS, "Summary of the HIPAA Privacy Rule."

[660] HHS.

[661] Jocelyn Samuels (Director, Office of Civil Rights, HHS), cited in ONC, *FINAL Interoperability Roadmap – Statements of Support*, (2015).

[662] Rouse, Biscobing, and Sutner, "HIPAA (Health Insurance Portability and Accountability Act)."

[663] Rouse, Biscobing, and Sutner.

[664] Rouse, Biscobing, and Sutner.

> it was the new rule and the final dates for compliance was 2003, so basically this was a very obscure federal process, that no-one knew about. Congress did not realise that a federal agency was about to eliminate the right to privacy that they expected American citizens to have. They never knew that there was no federal oversight and the media did not understand that this was happening either, so I watched this unfold and there were only a few of us that noticed that this critical right to control the flow of your data was eliminated in the new rule.[665]

While the amended privacy rule did not mandate that healthcare providers eliminate consent, privacy advocates argued that "in practice everyone eliminated it."[666] This view was to have ongoing implications for privacy advocates after the passage of the HITECH Act in 2009.

The Office of the National Coordinator for Health Information and Technology (ONC)

In 2004, President George W. Bush established the ONC, as part of the Department of Health and Human Services (HHS), "to provide leadership for the development and nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care."[667] The ONC was tasked with an aspirational vision of interoperability and the meaningful use of health information by providing guidance "in developing health information technology infrastructure that:

1. Ensures that appropriate information to guide medical decisions is available at the time and place of care;
2. Improves health care quality, reduces medical errors, and advances the delivery of appropriate, evidence-based medical care;

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[665] Peel, Interview.

[666] Peel.

[667] Bush, Executive Order 13335. As an example of the drive for connectivity the Director of Kaiser Permanente International explained that her organisation had "been using IT since the sixties. The problem was not getting used to computers it was getting rid of a lot of the old systems and connecting the ones that remained and creating a new clinical core which was the EPIC system. So, what's new since 2004 is the connectivity." Interview, 2014.

3. Reduces health care costs resulting from inefficiency, medical errors, inappropriate care, and incomplete information;

4. Promotes a more effective marketplace, greater competition, and increased choice through the wider availability of accurate information on health care costs, quality and outcomes;

5. Improves the coordination of care and information among hospitals, laboratories, physician offices, and other ambulatory care providers through an effective infrastructure for the secure and authorized exchange of health care information; and

6. Ensures that patients' individually identifiable health information is secure and protected."[668]

HHS and the newly established ONC responded quickly to the President's executive order. Within six months they had developed the Framework for Strategic Action that emphasised the "need for information tools to be used in the delivery of health care" and promoted a "vision for consumer-centric and information-rich care."[669] The framework had four goals[670] supported by a set of strategies and related specific actions:

1. To inform clinical practice by bringing EHRs directly into clinical practice thus reducing medical errors and duplicative work resulting in improved patient care – supported by incentivising EHR adoption, reducing the risk of EHR investment, and promoting EHR diffusion in rural and underserved areas.

2. To interconnect clinicians, allowing information to be portable between points of care – by fostering regional collaborations, developing a national health information network, and coordinating federal health information systems.

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[668] Bush, Executive Order 13335.
[669] Thompson and Brailer, "The Decade of Health Information Technology," a.
[670] Thompson and Brailer, b–c.

3. To personalise care by making consumer-centric information available to individuals so that they can manage their own wellness and assist with their personal healthcare decisions – to be realised by encouraging the use of personal health records (PHRs), enhancing informed consumer choice, and promoting the use of telehealth systems.

4. To improve population health through the collection of timely, accurate and detailed clinical information that would be used to evaluate healthcare delivery and report critical findings to public health officials, clinical trials and other research, and provide feedback to clinicians. This was to be realised by unifying public health surveillance architectures to allow the exchange of information, streamlining quality and health status monitoring between states and organisations allowing a complete look at quality and other issues in real-time and at the point of care, and accelerating research and the dissemination of evidence.

ONC programs were funded by the federal government but participation in them was voluntary. Initially ONC and HHS argued that interoperability and the transformation of healthcare could be achieved "without substantial regulation or industry upheaval."[671] Neither would prove to be the case, redefining over time, as in Australia and England, the role of the federal government in the delivery of healthcare.

The American vision for ehealth and its related goals was remarkably similar to those in Australia and England in that information technology was to be used to "improve care, decrease costs, and improve overall health through [the collecting, sharing] and use [of] electronic health information." [672] Key shared characteristics included a role for government at the national level to fund EHR adoption and incentivise changes to current clinical practice; increase consumers'/patients' access to their health information in an effort to enable individual values based choice (patient-centred healthcare) to give patients better control over their healthcare experiences and improve

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[671] Thompson and Brailer, h.

[672] DeSalvo, Dinkler, and Stevens, "The US Office of the National Coordinator for Health Information Technology," 507.

their service delivery outcomes; and promote and actively facilitate the exchange of health information for the public good.

Phase 2: 2009 to 2015 – Policy Development Through Generous Incentives and Penalties

Phase 2 saw the United States move to a stronger, more centralised, regulatory ehealth system. While the messy, cross-jurisdictional, multi-EHR system remained in place the federal government saw an opportunity with its response to the GFC to strengthen existing federal regulations, and promote the interoperability, usability, and meaningful use of EHRs through incentives and penalties. This was achieved through the HITECH Act of 2009, final rule amendments to HIPAA and the CLIA, the ONC ten-year road map, the issuance of meaningful use standards in three stages, and steps to increase interoperability and decrease information blocking in the *21st Century Cures Act of 2016*.

The Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH)

The HITECH Act of 2009 was part of the United States federal government's massive $787 billion stimulus package response to the GFC. It provided $19.2 billion in incentives in a "carrot and stick approach … to encourage healthcare organizations to convert to electronic healthcare record (EHR) implementations."[673] HITECH further strengthened, and "significantly accelerated"[674] ONC's aspirational vision for interoperability and the meaningful use of health information. This was done by authorising regulatory regimes for interoperability, standards, oversight, rule-making, enforcement and the coordination of health technology policy with the specific goal of achieving "the utilization of an electronic health record for each person in the United States by 2014."[675] The exchange of health information across provider, organisational and jurisdictional boundaries was further supported with the creation by ONC of the Standards and

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[673] Neil Roiter, "HITECH Act Incentives Translate to Opportunities for VARs," SearchITChannel, 2009. This point of view is supported by Marla Durben Hirsch who characterised the HITECH Act and subsequent meaningful use laws as "a great big carrot and stick thing that was imposed in 2009. They earmarked $20 billion in incentive money to get our hospitals and our professionals to use EHRs and they've already spent $19 billion [as of the beginning of 2014] on it." Durben Hirsch, Interview.

[674] Desalvo, Dinkler, and Stevens, "The US Office of the National Coordinator for Health Information Technology," 507.

[675] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-117.

Interoperability Framework which aimed to increase collaboration among EHR technology developers in the areas of "data transport, privacy options, and electronic clinical quality measurement."[676] As the VA noted, the HITECH Act aimed "to increase the use of EHRs by physicians and hospitals … [and] sent a strong message that the US government firmly believed in the benefits of using EHRs and was willing to invest in its use."[677]

The interoperability concepts in HITECH were, to some extent, a political desire to replicate the success of the DVA EHR which at that time was the closest thing the US had to an NEHR. Ben Davoren, the Associate Chief of Staff for Clinical Informatics at the San Francisco Veterans Affairs Medical Center (SFVAMC), explained that the DVA system was a "very much clinically driven and not billing driven … integrated electronic healthcare system"[678] where the EHR had replaced paper and became the primary communication tool. It had advanced over time to be very "consumer oriented [containing] medication refills, prescriptions, laboratory results, radiology reports and more recently, clinical notes"[679] that with the Blue Button[680] concept enabled the transfer of the contents of the EHR to other care settings.

Achieving interoperability between the DVA and DoD in an effort to create a veteran's lifetime electronic record was complicated by differences in internal policy making and each organisation's "day-to-day execution of the task at hand"[681] and the political realities of appropriations. Davoren explained:

> The DoD method is "We're not going to build, we're going to buy. We are going to pay a contractor and they are going to do a giant implementation." The history of the VA is we built it because we wanted to support the clinical care we have now. We don't want to go buy something and retrofit it to what we do. We've been building it all along. So just for VA and DoD to have some

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[676] Desalvo, Dinkler, and Stevens, "The US Office of the National Coordinator for Health Information Technology," 507–8.

[677] Department of Veterans Affairs, *History of IT at VA,* (VA Information Technology, 2016).

[678] Davoren, Interview.

[679] Davoren. This point of view is supported by Jerry Van Wieren who stated that the VA "has the best interchangeable electronic health record in the US." Van Wieren, Interview.

[680] The Blue Button allows veterans to select the date and range of health information they would like to download in a single electronic file.

[681] Davoren, Interview.

> true interoperability has been a war on the acquisition front as well as the control front. Each side saying “Look, we’re different than you. We need to do things differently” and there’s been some frustration. Our clients [ask] “why can’t this happen? Can this issue be really technical” and the answer is “No. It’s not really technical. The issue is political. There are some technical issues of course, but we have a political one to fight.” So depending on who is the chair of the house Veteran’s Affairs Committee, whether it is a Democrat or a Republican, the angle is a little bit different. I testified before the House Veteran’s Affairs Committee in 2007, after we had an extended down time for 17 different medical centres and this was at the time when IT was being split from VA, which is an absolutely horrible idea, and so I got to see this sausage being made, as it were, in Congress and it upset me!

Interestingly, the DVA chose an opt-in system to mitigate political risks around privacy concerns. Davoren explained:

> Well, fundamentally the issue for this is that it is a political issue for privacy, that is not necessarily grounded in a true privacy risk benefit analysis, but is very much vetted by that. What would this look like to Congress and House Veterans Affairs Committee or to the front page of the *New York Times* and the *Washington Post* if there were a problem, if somebody got the information and we didn’t have this process to say “Well, we had two forms of ID, it wasn’t just a letter that we mailed to somebody’s house not knowing if the address was right” and that sort of thing, so it was very much a political decision. It’s really about positive patient ID, so that the risk to the VA politically is minimised.[682]

Opt-in presented some of the same issues as in Australia, particularly a lack of up-take. There were significant hurdles to opt-in to Blue Button, especially for patients who had to travel hundreds of miles to register and remember to bring two forms of identification with them. There was also the issue of not necessarily having “the patient population that is as interested in access to their records as probably the general public. I think in the VA we have a larger fraction of patients who, when asked about ‘Do you want access to your information so you can have more informed healthcare decision making’ would say ‘I trust my doctors. That’s why I come here.’ ”[683]

The systemic structure of the DVA differed from the overall US health system, and thus the DVA concept of an NEHR might not necessarily translate across to all EHR users

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[682] Davoren.

[683] Davoren.

throughout the US in a way that would give patients more options and control over the information in their medical record. Davoren argued:

> I think we all support that and that's one of the nice things about being an integrated healthcare system and frankly, having salaried physicians, in all honesty I think that makes us, we are much more like a UK or Australian or European model of healthcare in the sense that we really have a fixed budget, we own the buildings, we own the staff and so we don't get paid any more or any less to do a test or not do a test. I have the luxury of being able to do the right thing.[684]

ONC "worked closely with CMS on the Medicare and Medicaid Electronic Health Records Incentive Program (also known as the Meaningful Use program) to provide incentive payments to eligible professionals and hospitals, and critical access hospitals, to offset their costs as they adopt, implement, upgrade, or demonstrate the meaningful use of certified electronic health record technology"[685] (CEHRT). Significant incentives were provided to support "health information architecture that will support the nationwide electronic exchange and use of health information in a secure, private, and accurate manner."[686] Incentives included cash payments, loans, grants (often requiring some percentage of matching funds) and the provision of technical assistance with the goal of using "information technology to improve health care quality and efficiency through the authorized and secure electronic exchange and use of health information."[687] For example, up to $63,750[688] per eligible professional,[689] and "$11 million per hospital"[690] were available if the meaningful use of EHR rules were met. Medicare incentives could total $44,000[691] over a five-year period and Medicaid

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[684] Davoren.

[685] Desalvo, Dinkler, and Stevens, "The US Office of the National Coordinator for Health Information Technology," 507.

[686] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-132.

[687] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-138.

[688] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-378.

[689] See the Glossary for a definition of eligible professional.

[690] Roiter, "HITECH Act Incentives Translate to Opportunities for VARs."

[691] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-354.

incentives could total $63,750[692] over a six-year period per eligible professional. Payment duplication was avoided by restricting eligible professionals and eligible providers[693] to either a Medicare or Medicaid claim, but not both, as per the language of the HITECH Act and any subsequent process for ensuring against duplication developed by the Secretary of Health.[694]

Rapid adoption of certified EHR technology (CEHRT) was required to qualify for the full amount. Under the Medicare incentives for eligible physicians, 2013 was the last year eligible professionals could apply for the first full payment for adoption and meaningful EHR use of CEHRT with nothing being available from 2014.[695] Hospitals had longer to comply with reductions to incentive payments beginning in the fiscal year 2015 starting at 33 and 1/3 per cent and rising to 100 per cent for 2017 and subsequent fiscal years.[696] Medicaid incentive payments could last for a period of six years, and up to 85% of the average allowable cost of implementing CEHRT could be claimed, but the first payment had to be claimed by 2016.[697]

While adoption and meaningful use of CEHRT was voluntary, eligible professionals and providers who received Medicare and Medicaid payments would be penalised for non-compliance. Penalties included failure to qualify for incentives and a percentage reduction in Medicare and Medicaid payments. Incentive payments for eligible professionals were eliminated if first adoption occurred from 2014 onwards.[698] Medicare and Medicaid payments were reduced if meaningful use phases one through three were not met by specific deadlines. Medicaid and Medicare fees were to be reduced for non-compliance to 99 per cent in 2015, 98 per cent in 2016, and 97 per cent in 2017 and each

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[692] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-378.

[693] See the Glossary for a definition of eligible provider.

[694] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-371.

[695] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-353,354.

[696] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-368.

[697] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-376,378,379.

[698] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-354.

subsequent year.[699] This could add up to significant money for healthcare providers whose Medicaid and Medicare fees were in the billions per year.

Despite incentives and penalties many smaller practices declined to participate and this proved to be a significant barrier to achieving NEHRs. John Carlson, MD, volunteered:

> When I get referrals from outside physicians, some of whom refuse to use the EMR, you know the xerox or faxed piece of paper where the handwriting is still legible, I think a lot of the smaller practices, family practices, internal medicine are just refusing to use EMR and they are going to not use it to the day they absolutely have to retire because they are not using it. Right now the penalties aren't severe enough to make people want to use it and stimulus money that was spent to encourage you to buy the system is not enough to pay for it, it means you are losing money, so there are several groups in this town that have no intention of using an EMR and will just wait until they can't do it.[700]

Historic systemic organisational structures meant that not all practices and organisations were incentivised to adopt meaningful use through payments and penalties. This was particularly the case for the DVA which pursued meaningful use for a different reason. As Davoren explained:

> We're going to pursue meaningful use, although there is no incentive to do so in the VA. It's very interesting. Meaningful use was set up as a specific incentive that had cash on the other end of it: 44,000 bucks per position in the small practices and then potentially millions for integrated healthcare systems to meet meaningful use. But that's really because everybody bills Medicare. We are prevented from billing Medicare because it is a sister federal agency so we can't take money from them. So, there's actually no incentive for us to meet meaningful use [criteria], at least historically. The thing that everybody is anticipating, though, and the reason why we are pursuing it is that with the *Affordable Care Act* presumably there will be opportunities for veterans to be able to have their care outside of the VA who before, a lot of pre-existing conditions, a lot of things that made them very difficult to insure, then they'll be able to get their care anywhere and that we need to convince them that they should stay with us because we do a better job. So, we are going to pursue meaningful use so that we can have the same

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[699] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-358.

[700] Carlson, Interview.

> score card for all the things that other healthcare systems are getting judged by.[701]

Initially, as with Australia, qualifying for incentives had a relatively low bar. During the qualifying period eligible professionals simply had to report that they were “using certified EHR technology in a meaningful manner”[702] as determined to be appropriate by the Secretary of Health. The threshold for qualifying for incentives was progressively raised over time as Congress specifically tasked the Secretary of Health with seeking “to improve the use of electronic health records and health care quality over time by requiring more stringent measures of meaningful use.”[703] Congress was particularly interested in incentivising the use of electronic prescribing and the connection of technology in a standardised manner that enhanced “the electronic exchange of health information to improve the quality of health care, such as promoting care coordination.”[704] Qualifying for incentives is discussed later in this chapter in the section on Meaningful Use Stages 1–3.

HITECH also aimed to improve privacy and security provisions of EHRs with the establishment of the Office of the Chief Privacy Officer (CPO), and privacy enforcement authorisation which was enforced by the Federal Trade Commission (FTC). The CPO’s key responsibilities were “to ensure that patient’s rights to data sharing and privacy”[705] were met as EHR technology was developed and implemented “through better policy and education.”[706] HHS, ONC and CMS approached privacy from a “more educational, less punitive standpoint”[707] whereas the FTC regulated “data breaches from an interstate

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[701] Davoren, Interview.

[702] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-356.

[703] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-356.

[704] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-356.

[705] Desalvo, Dinkler, and Stevens, “The US Office of the National Coordinator for Health Information Technology,” 508.

[706] Desalvo, Dinkler, and Stevens, 508.

[707] Pritts, Interview.

commerce perspective."[708] FTC penalties ranged from $100 to $50,000 for each violation capped at a total amount for an identical violation from $25,000 to $1,500,000.[709]

In 2013 the HHS Office for Civil Rights (OCR) announced the Omnibus (final) Rule which strengthened "the privacy and security protection for individuals PHI."[710] This included:

1. Tightening standards for "assessing healthcare provider's liability following a breach."
2. Strengthening "privacy protections for genetic information."
3. "Outlining OCR's data privacy and security enforcement strategies, as updated for the EHR era and as mandated by the HITECH Act."
4. "Holding HIPAA business associates to the same standards for protecting PHI as covered entities, including subcontractors of business associates, in the compliance sense."
5. "Stipulating that, when patients pay by cash, they can instruct their provider not to share information about their treatment with their health plan."
6. "Setting new limits on how information is used and disclosed for marketing and fundraising purposes."
7. "Prohibiting the sale of an individual's health information without their permission."
8. "Making it easier for parents and others to give permission to share proof of a child's immunization with a school."

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[708] Pritts.

[709] Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress, 1-146,156,159.

[710] Rouse, Biscobing, and Sutner, "HIPAA (Health Insurance Portability and Accountability Act)."

9. “Streamlining an individual's ability to authorize the use of his health information for research purposes.”
10. “Increasing penalties for noncompliance based on the level of negligence, with a maximum penalty of $1.5 million per violation.”
11. “Guaranteeing that organizations can operate with certainty that their privacy and security policies comply with all the applicable regulations.”

While patient advocacy and privacy groups supported stronger national-level regulations giving patients more control over their health information and stronger privacy protections, they expressed concerns with these issues somewhat differently than the state. There was a view that the previously mentioned amended privacy rule of 2002 had resulted in at least two major negative outcomes that were exacerbated by the HITECH Act and associated incentive programs. The first was that the state was coercing healthcare providers to adopt EHRs that gave patients very little control over their health information. Deborah Peel complained:

> Now the federal government in HITECH, passed in 2009, is incentivising all positions in hospitals to adopt electronic health records that eliminate consent. And that if you don’t adopt and want to take their $44,000 bonus then you will get penalised so we now have state action because the federal government is ordering everyone to buy these defective products because virtually none of the EHRs have any type of meaningful consent process, almost none. There are some selected ones in certain parts of healthcare, for mental health and for addiction treatment, where consent rules still apply. There really are electronic health records that have very robust consent systems but that was ignored by a lot of the big players.[711]

The second negative outcome identified by privacy advocates was that market forces were not working with EHRs because institutions were the paying customers for EHRs, not doctors and patients, which “created a disaster … in the US and many other countries.”[712] Adrian Gropper argued that this arrangement was both abusive and coercive, particularly in the areas of patient privacy and consent, and left patients

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[711] Peel, Interview.

[712] Adrian Gropper (Chief Information Officer for Patients Privacy Rights), Interview, 2014.

without meaningful choice.[713] Clinicians also had to work within the institutional EHR system whether they liked that EHR or not. Gropper saw the "institutional system as a commodity" and argued that EHRs should be "regulated as commodities" to fix a broken market system.[714] Gropper explained:

> It [the EHR] should be just completely irrelevant. They should be a regulated commodity because they are like the plumbing in the hospital, it's fine. If the doctor doesn't buy the plumbing as long as the water is clean, it comes out of the tank, there's water coming out of the tank, that's all you care about.[715]

Privacy advocates welcomed continued legislative and rule making efforts to strengthen patient privacy rights and give patients more control over their health information. However, advocates ultimately saw the practical results as having too many loop-holes through which healthcare providers and data aggregators could operate and thus ignore the privacy intent of the legislation. There would be an ongoing battle between legislators, EHR vendors, healthcare providers, clinicians, patients and patient advocates over these issues. This conflict was firmly rooted in the clash between most citizens firmly believing that there was "at least 150 years of consensus in this nation about the fundamental rights to privacy" [716] and the growing market imperative that the longitudinal aggregation of individual data was a valuable commodity to be exploited for financial gain.

HIPAA, HITECH and subsequent legislation can also be seen through the lens of policy responses to exogenous technology development. Suarez said:

> Normally, we all say policy should drive technology. Right? We define the policy of what can be done with data for example. Then technology is developed to allow that to happen. But we feel that, in many cases, technology is now driving policy because technology evolution is showing us new capabilities of doing things rapidly and now we are having to develop

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[713] Gropper.

[714] Gropper. Kamal Jethwani states that "one thing EHRs allow you to do is to commoditise data," a key concern of patient and privacy advocate groups. Jethwani, Interview.

[715] Gropper, Interview.

[716] Peel, Interview.

> the policy in order to apply that technology that already exists or has evolved.[717]

A number of interviewees raised the issue that EHR and data regulation, especially at the federal level, had not kept up with quickly developing technology and the rapid adoption of EHR systems. Policy was slow to respond to critical issues in an extremely complex healthcare environment: how health information held in EHRs was handled in terms of privacy, consent, patients' control of their health information; information blocking, data protection by private companies where people voluntarily choose to store their health information (such as in Microsoft's Health Vault); and the disclosure of protected health information for the purposes of payment, utilisation review and clinical research.[718] The criticism that policy lagged behind technical innovation reflects patients' lack of trust in healthcare providers, based around concerns that providers would use their information "used outside the purpose of treatment."[719] Deven McGraw argued that it was important to think "through what privacy protections will enhance people's ability to use those technologies and their willingness to trust it, ultimately seeing technology as a good."[720] This has proved a difficult policy balancing act given both the potential benefits and misuses of patient health information.

> There are lots and lots of benefits to be gleaned from it, but, of course, when you put the data in digital form lots of opportunities for people to misuse it arise, misuse being both people using it to discriminate against somebody or to harm somebody, but even in terms of uses that the individual did not imagine or could not conceive was happening with their information when they allowed it to be collected in the first place. What uses are reasonably expected given the nature of the service and what uses are beyond that. We frequently use the principle that the patient shouldn't be surprised about what happens to their information. But we like to use the word "reasonable" protections because, the fact is, health information has a lot of benefits and you don't want to create an environment where people are afraid to share it, afraid to use it, reluctant to have it collected and shared because that doesn't advance some of the other goals that we have with respect to health, which

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[717] Walter Suarez (Executive Director for Health IT Strategy and Policy for Kaiser Permanente), Interview, 2014.

[718] Lewis, Interview; Suarez, Interview; Gropper, Interview; Peel, Interview.

[719] Suarez, Interview.

[720] McGraw, Interview.

> is not just allowing people individually to have better health, prevent disease or manage a chronic condition, especially here in the US.[721]

The Clinical Laboratory Improvement Amendments Act of 1988 (CLIA) Final Rule 2014

In 2014 patients' rights to access lab test reports were strengthened by a final rule amendment to the CLIA[722] allowing them to directly access their reports from the laboratory "as part of an ongoing effort to empower patients to be informed partners with their health care providers"[723] and applied to covered and non-covered entities.[724] However, while patients or their authorised representatives have had the right to see or receive a copy of their protected health information under HIPAA, in most cases within 30 days,[725] barriers to access remained. These barriers included information holders requiring written requests for information and patients having to pay for the delivery of that information.[726] Pritts argued that CLIA is an example of regulation being used as a stop gap measure to improve interoperability and enhance patient rights in a healthcare system where health data is a big business and there is a hesitancy for businesses to share their data with others.[727] However, Pritts noted that some large hospital systems do "seem willing to share it [patient data] with the patient and let the patient share it with others."[728]

Meaningful Use Stages 1–3

The incentive program authorised by the HITECH Act was designed to increase the interoperability, usability and meaningful use of patient health information. It was based on eligible professionals (EPs) and hospitals demonstrating achievement of criteria defined as core or menu objectives structured into meaningful use stages 1, 2 and 3. Meaningful use stages were designed to be achieved sequentially over time starting with Stage 1 and culminating in Stage 3. Changes, based on stakeholder feedback and federal reviews of progress, were implemented as the program progressed. The goal was to

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[721] McGraw.
[722] The Clinical Laboratory Improvement Amendments of 1988 (CLIA), United States Congress.
[723] HHS, "HHS Strengthens Patients ' Right to Access Lab Test Reports," 2014.
[724] HHS.
[725] HHS.
[726] HHS.
[727] Pritts, Interview.
[728] Pritts.

rapidly incentivise the adoption and use of CEHRT to improve healthcare service delivery and achieve the potential benefits of CEHRT already discussed in this chapter.

The meaningful use criteria in Stage 1 focused on "electronically capturing health information in a coded format, using that information to track key clinical conditions, communicating that information for care coordination purposes, and initiating the reporting of clinical quality measures and public health information."[729] Stage 1 requirements represented "the initial steps necessary to support the overall goal of developing an interoperable electronic health system."[730] There were 15 core objectives, five out of ten objectives from a menu set (exclusions could apply if not applicable to a provider's clinical practice), and six total clinical quality measures EPs had to report they had met in order to qualify for incentive payments.[731] Additionally, at least 80 per cent of patients had to have records that met CEHRT standards.[732]

Stage 2 continued to incentivise the adoption, implementation and upgrading of CEHRT.[733] Adding, layering and adaption changes were made to the eligibility criteria for incentives by modifying core and menu objectives in a way that reflected stakeholder feedback and ONC and CMS evaluations of progress. Some measures were eliminated from both Stage 1 and Stage 2 while others were incorporated into other substantially similar criteria. New objectives were added, such as EPs being required to "use secure electronic messaging to communicate with patients on relevant health information."[734] Many of the objectives in Stage 2 involved an increase in the patient population target use threshold that providers had to meet to qualify for incentives.[735] For example, the computerised provider order entry (CPOE) use threshold was increased from "more than 30% of unique patients with at least one medication list seen by the EP hav[ing] at least

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[729] CMS.gov, "Fact Sheet: CMS Finalizes Definition of Meaningful Use of Certified Electronic Health Records (EHR) Technology," 2010. As the Director of Kaiser Permanente International put it "it wasn't just for buying computers, it was for using them in a meaningful way." Interview.

[730] Strategic Management, "HITECH Act Update: An Overview of the Medicare and Medicaid EHR Incentive Programs Regulations," 2010, 8.

[731] Centers for Medicare and Medicaid Services (CMS), "Medicare & Medicaid EHR Incentive Program Meaningful Use Stage 1 Requirements Overview," 2010.

[732] CMS.

[733] CMS, 28.

[734] CMS, "Stage 1 vs. Stage 2 Comparison Table for Eligible Professionals," 2012, 7–8.

[735] CMS, "Stage 2 Overview Tipsheet Stage 2 Timeline Core and Menu Objectives," 2012, 2.

one medication order entered using CPOE"[736] to "more than 60% of medication, 30% of laboratory, and 30% of radiology orders created by the EP … recorded using CPOE."[737] Adoption and initial claim timelines were lengthened with the onset of Stage 2 delayed until 2014 and the last year to initiate participation in the Medicare EHR Incentive Program moved from 2014 to 2017.[738]

Meaningful use for both EPs and hospitals continued to evolve [739] with the implementation of Stage 3 in 2015. As in Stage 2, adding, layering and adaption changes occurred, some due to stakeholder pressure and others due to ONC and CMS evaluations of progress. Meaningful use thresholds again increased reflecting a desired higher level of interoperability and improved healthcare service delivery outcomes. For example, patient electronic access to their health information provided by EPs was enhanced in four ways. Access was required to be timely, to include patient specific education using clinically relevant information from the CEHRT, and to be provided to more than 80 per cent of patients seen by the EP (up from 50 per cent), and exclusions were tightened.[740] Stage 3 incentive payments could be collected from 2017. Dugdale thought that meaningful use was a "great conceptual phrase for describing purpose in relation to a claim for government payment because it [put] the onus on the claimant to demonstrate meaningful use," enabling the government to be flexible in determining if the claim had been met, and allowing the definition and payment system to evolve which was "quite clever for a rapidly evolving technology."[741]

However, the drive to use EHRs as a mechanism to enhance compliance with rules and regulations in an effort to achieve meaningful use goals missed the point of having an NEHR for some. Davoren explained:

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[736] CMS, "Stage 1 vs. Stage 2 Comparison Table," 1.

[737] CMS, 1.

[738] CMS, "Stage 2 Overview Tipsheet," 1.

[739] CMS, "EP Stage 2 vs Stage 3 Comparison Tool – Updated," 2016, 1; CMS, "EH Stage 2 vs Stage 3 Comparison Tool - Updated," 2016, 1.

[740] CMS, "EP Stage 2 vs Stage 3 Comparison Tool - Updated," 10.

[741] Paul Dugdale (Canberra Hospital Health Services Specialist and Academic at the Australian National University), Interview 2, 2015.

> I'm sort of unhappy that that's the case because I think what we, in terms of looking at the goals of the electronic health record that we really wanted to get to the point where the electronic health record was going to really facilitate our work flow and improve the care that we gave patients but to do so in a very supportive, creative way, heading for that mentor relationship that's in the Gartner list of how electronic health records can develop and that they are not exactly telling you what to do but they're supporting your existing decision making. And that unfortunately what we really have done is we've created the electronic version of the paper chart, even though we knew relatively early on that that was the way to get buy-in but it's truly a mistake, it was not what we needed. The paper chart wasn't really that great, it was pretty good, but what we really want is something that can reduce the cognitive load that we have and help us with our documentation while we are performing what we are doing. And so far what we still have is an incredible reliance on human beings to actually decide what needs to be passed, the computer insisting that we do so, rather than doing in the background so that we can be compliant and be sure that we are coding correctly, or that we didn't leave something out, or that this item is about family history and not about something else. There is still too much effort on the human side to identify what the computer wants and not enough on the computer side to suggest "Hey, by the way, you know, this patient's had a low Vitamin D level and nobody's ever prescribed Vitamin D which I'd like to."[742]

The ONC Roadmap

ONC was committed to advancing the vision of an interoperable health system that empowered individuals and improved the efficiency and effectiveness of care "expeditiously, systematically and in a sustainable fashion."[743] Progress towards nationally interoperable health records accelerated in 2013 with ONC's publication of its *Principles and Strategy for Accelerating Health Information Exchange (HIE)*. It stated that "as a nation, we are transforming health care delivery into a system that is patient-centered and value-based … facilitat[ing] greater coordination of care and improved quality."[744] ONC claimed that "real-time interoperable HIE among a variety of health care stakeholders (clinicians, laboratories, hospital, pharmacy, health plans, payers and

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[742] Davoren, Interview.

[743] Office of the National Coordinator for Health Information Technology (ONC), *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap – Executive Summary,* (2015), 2.

[744] ONC, *Principles and Strategy for Accelerating Health Information Exchange (HIE)*, (2013), 1.

patients) … [was] critical to the success of … new initiatives and programs … and the ultimate goal of a transformed health care system."[745]

This was followed by the 2014 release of ONC's *10-Year Vision to Achieve an Interoperable Health IT Infrastructure*. The timing and title were somewhat ironic given that it was "10 years since then-President George W. Bush promised to deliver interoperable electronic health records to most Americans,"[746] and created the ONC. "President Obama upped the ante to all Americans in 2009, but didn't change the 2014 target date."[747] While ONC acknowledged that there was still "much work to do to see that every individual and their care providers can get the health information they need in an electronic format when and how they need it"[748] they claimed that there had been "dramatic progress in building the foundation of a health IT infrastructure across the country … [where] the majority of meaningful use eligible hospitals and professionals have adopted and are meaningfully using health IT."[749] The 10-Year Vision continued the rhetoric of reliable interoperable health records enhancing care, lowering health care costs, improving population health, empowering consumers through informed shared decision making, supporting critical public health functions, and driving innovation.[750] "Data aggregation for research and value-based payment that rewards higher *quality* care, not necessarily a higher *quantity* of care"[751] were seen as important. This was to be achieved by setting three, six, and ten-year agendas based on nine guiding principles and implementing five building blocks. The three-year agenda focused on sending, receiving, finding, and using health information to improve health care quality.[752] The six-year agenda aimed at realising enhanced interoperability by integrating health information into an "interoperable technology ecosystem."[753] This would enable integrated data aggregation, monitoring and use; improved methods of measuring

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[745] ONC, 1.
[746] Neil Versel, "New ONC 10-Year Plan for Interoperable Health IT Seems Attainable," Forbes.com, 2014.
[747] Versel.
[748] ONC, *Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable* Health *IT Infrastructure*, (2014), 1.
[749] ONC, 1.
[750] ONC, 2–3.
[751] ONC, 3.
[752] ONC, 8.
[753] ONC, 7.

clinical quality; linking of medical devices; sharing of information across organisational and care provider boundaries; and the delivery of "targeted clinical decision support that fits into a clinician's workflow to close care gaps and improve the quality and efficiency of care."[754] The ten-Year agenda envisioned a "learning health system"[755] that would result in "better health for all through a more connected health care system and active individual health management."[756]

The 2015 ONC *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap* (Roadmap) gave stakeholders a clear guide on how to achieve the ten-year vision. It claimed that:

> "the nation needs an interoperable health system that empowers individuals to use their electronic health information to the fullest extent; enables providers and communities to deliver smarter, safer, and more efficient care; and promotes innovation at all levels."[757]

While the ultimate goal was still for every American to have access to their electronic health information it was acknowledged that in 2015 interoperability remained a work in progress.[758] The roadmap envisioned achieving nationwide interoperability by 2024 enabling "a learning health system, with the person at the center of a system that can continuously improve care, public health, and science through real-time data access."[759] The roadmap was intended to be a living document that would evolve based on

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[754] ONC, 7. One of the drivers of EHRs was the idea that more data would strengthen evidence based medical care that could be enhanced through clinical decision support. However, and counter-intuitively, some clinicians argued that much of what we accept as evidence is based on a lot of assumptions that reflect biases rooted within the process of medical care. One example is the benefit of early diagnosis. Marshall Yacoe argued that "one of the things that gets in the way of an actual health outcome is something called the lead time bias where let's say we do one of these screening CT scans and we see a mass in the pancreas and you think 'Oh, my God, that's the greatest thing ever. We've got it, we've got it in time.' Well the question is by finding it now and in doing all these medical interventions will you live any longer than you would have if we hadn't found it?" Marshall Yacoe (Radiologist at Kaiser Permanente), Interview 2, 2014.

[755] ONC, *Connecting Health and Care for the Nation: A 10-Year Vision*, 8.

[756] ONC, 8.

[757] ONC, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap – Executive Summary*, 2.

[758] ONC, 2.

[759] ONC, 3.

stakeholder input.[760] Four critical pathways were identified for health IT stakeholders to focus on: improve technical standards; shift and align payment policies across jurisdictional and payer boundaries to promote a value-based as opposed to a fee-based model; clarify and align privacy and security requirements; and promote and align business practices that improve rather than impede interoperability.[761]

The roadmap was organised into three main sections: drivers, policy and technical components, and outcomes. The main driver identified was "a supportive payment and regulatory environment"[762] which was an incentive to promote interoperability. The policy and technical components[763] were:

1. Shared decision-making, rules of engagement and accountability.
2. Ubiquitous, secure network infrastructure.
3. Verifiable identity and authentication of all participants.
4. Consistent representation of authorization to access electronic health information.
5. Consistent understanding and technical representation of permission to collect, share and use identifiable health information.
6. Industry-wide testing and certification infrastructure.

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[760] ONC, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap,* (2015), xvii. Kamal Jethwani argues that the major negative of the fee-for-service model is that "it incentivises utilisation which increases cost. If I get paid every time you come to see me I would want you to come to see me every day. Whereas if I'm paid based on how healthy you are, and it's a fixed amount – no matter how many times you come to see me I don't want you to come and see me that often because I don't get anything additional just because you're coming to see me again." Jethwani, Interview. This was a practice derived from the desired norm of structurally aligning positive stakeholder habitual behaviour to obtain the value of normatively optimal ehealth policy through the mechanism of an NEHR. The norm was negative structural alignment driven by who paid for care. The Director of Kaiser Permanente International put it this way: "most of the fee-for-service world is being reimbursed by multiple insurance companies, maybe ten or twelve, and that means different billing systems, different measurements. I mean, it's crazy."

[761] ONC, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap – Executive Summary*, 3–4.

[762] ONC, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*, xv.

[763] ONC, xv–xvi.

7. Consistent data semantics.

8. Consistent data formats.

9. Standard, secure services.

10. Consistent, secure transport technique(s).

11. Accurate individual data matching.

12. Healthcare directories and resource location.

The outcomes[764] expected were that:

1. Individuals [would] have access to longitudinal electronic health information, [could] contribute to that information, and [could] direct it to any electronic location.

2. Provider workflows and practices [would] include consistent sharing and use of patient information from all available and relevant sources.

One of the roadmap's goals was to make EHRs more useful for patients by improving their online functionality. The Director of Kaiser Permanente International explained:

> I have actually had online access since, it's a long time, for ten years but the only the thing I could do ten years ago was to order prescription refills online. I couldn't make appointments, I couldn't email my doctor. I never used it. Now I got online access in 2003. I only started using it in 2007 because it became useful because I could schedule my appointments, could email my doctor or anyone else I'd seen, I could get the prescription sent through the email, through regular mail which I could do before but that was the only thing that I could do. So, I would say the key is having enough functionality online. People aren't going to go just to surf the web. You have to make it so "Oh, you can make the appointment, you can change the appointment, you can schedule your mammogram." You have to make it really useful.[765]

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[764] ONC, xvi.

[765] Director of Kaiser Permanente International, Interview.

ONC published numerous statements of support for the roadmap. The key themes included commitments to improve the quality, safety, interoperability, efficiency and effectiveness of healthcare delivery and the value these changes would bring. Coupled with themes of improved outcomes were statements in support of patient-centred care, privacy and patient rights to access their health information. While statements broadly supported the roadmap they were often tinged with a note of caution that this process would need to be carefully monitored and adapted as time went by. For example, the roadmap included the following statements by stakeholders:

Statements in Support of Improved Service Delivery Outcomes

> America's hospitals strongly support the creation of an efficient and effective infrastructure for health information exchange that supports the delivery of high-quality, patient-centered care across health care settings.[766]
>
> HIMSS reaffirms its commitment to improving the quality, safety, access, and cost effectiveness of healthcare by achieving widespread secure, electronic exchange of health information. We appreciate that ONC's Shared Nationwide Interoperability Roadmap puts us on the path to a Learning Health System – where standardized, electronic health information is securely available when needed for patients and providers to engage and drive actionable outcomes.[767]
>
> We support ONC's efforts to shift its focus towards outcomes over means and to shine a light on the information blocking behaviours that prevent this the [*sic*] actual exchange of health information.[768]
>
> Interoperability plays a necessary and important role in supporting patient-centered care and better outcomes in health care. It is also plays a critical role in advancing medical innovation in the United States.[769]
>
> The Interoperability Roadmap is key to achieving seamless, secure exchange of information for purposes of treatment, care coordination, public health and other important purposes.[770]

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[766] Rick Pollack (President and CEO, American Hospital Association), quoted in ONC, *FINAL Interoperability Roadmap – Statements of Support*.

[767] Carla Smith (Executive Vice President, HIMSS North America), quoted in ONC.

[768] Stephanie Zaremba (Senior Manager, Government and Regulatory Affairs, athenahealth), quoted in ONC.

[769] Janet Marchibroda (Director of the Health Innovation Initiative and Executive Director of the CEO Council on Health and Innovation at the Bipartisan Policy Center), quoted in ONC.

[770] Jocelyn Samuels (Director, Office of Civil Rights, HHS), quoted in ONC.

Statements in Support of Patient Rights

> Health IT Now supports ONC's ongoing efforts to address the systematic lack of interoperability in our healthcare system. The final Roadmap reflects input, serious thought and consideration from many stakeholders, and addresses issues of concern to our members, including information blocking and patient access to health information. … Specifically, we support consumers having easy and secure access to their own electronic health information, an ability to direct it to any desired location and to learn how their information can be shared and used, and to be assured that this information will be effectively and safely used to benefit their health and that of their community.[771]
>
> The Roadmap works towards "meaningful interoperability … [which] is foundational to support a state of data liquidity that must exist for timely diagnosis and treatment to occur and emphasizes what we believe is a self-evident ethical understanding that a person's health data belongs to the person."[772]
>
> Patients have a fundamental right to access their health information and to empower their healthcare providers to do the same.[773]
>
> Interoperable exchange of health data is critical to delivering high-quality, coordinated care to patients. Alignment of federal and state privacy and security requirements is essential to enabling interoperable systems that protect patient privacy and autonomy while also assisting providers in more effectively treating patients and reducing overall costs. NGA looks forward to working with ONC and states on advancing shared interoperability goals.[774]
>
> We have made important progress in making health records available to patients and shareable among their doctors. Today, we are taking another important step forward by releasing a comprehensive strategy to engage government partners and the private sector to develop a network where health information can be safely and securely accessed from different sources. This shift will put patients at the center of their health care [*sic*], improve the quality of the services they receive and advance safety overall.[775]

Statements Supporting Governmental Action

> We strongly believe that this roadmap will provide important guidance that will help improve consumer access to health data and the sharing of electronic health information among providers. We also support the

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[771] Joel White (Executive Director, Health IT Now Coalition), quoted in ONC.

[772] Neal Patterson (Chairman, CEO and Co-founder, Cerner), quoted in ONC.

[773] Arien Malec (VP Data Platform, McKesson Corporation), quoted in ONC.

[774] National Governors Association (NGA), quoted in ONC.

[775] HHS, quoted in ONC.

> roadmap's recommendations for broader, governmental action to promote consistent, national interoperability standards, including the use of open source application programming interfaces (APIs) to support the secure transfer of information between and among different HIT platforms.[776]

Commitments of Support from EHR Providers

> The vision outlined in the Roadmap aligns perfectly with our shared end goal of healthcare technology solutions, which is to provide patients and providers secure and meaningful access to healthcare information pertinent to longitudinal care.[777]
>
> We affirm our ongoing commitment to … encourage and accelerate the progress of widespread interoperability of healthcare organizations that use our EHR with any standards-compliant destination, regardless of technology provider. We have not and will not engage in information blocking.[778]

Notes of Caution

> Progress will take combined efforts from all stakeholders, including vendors and providers. We look forward to working with the Department of Health and Human Services (HHS) to create a policy environment that supports these efforts and accelerates the transition to the health care system of the future. Given that the hospital field's recent large investments in deploying IT systems, we urge HHS to focus first and foremost on efficient ways to share the data currently being collected to build a foundation for the future.[779]
>
> Providers must be able to confidently and consistently link patients with their health data before our healthcare delivery system will truly be interoperable.[780]

Remaining Barriers to Success

While the language in the various legislative acts, rules, plans, roadmaps and statements of support mostly inferred that a successful effort to achieve desired outcomes was on a

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[776] Blair Childs (Premier Inc.), quoted in ONC.
[777] Meditech, quoted in ONC.
[778] Epic, quoted in ONC.
[779] Rick Pollack (President and CEO, American Hospital Association), quoted in ONC.
[780] Charles Christian (CHIME), quoted in ONC.

strong path to success, numerous interviewees[781] and the ONC[782] indicated that there were still significant barriers to be overcome. These barriers included:

1. Major clinical and institutional issues centred on the design, implementation and use of EHRs including integration within clinical workflows, changing current clinical practice, and easy patient access to their information.

2. The high cost of purchasing, implementing and integrating EHRs within clinical and administrative practice including compliance with meaningful use criteria and privacy legislation.

3. The fragmented nature of the healthcare marketplace that makes coordinating stakeholder commitment towards common policies and standards that improve interoperability difficult.

4. Major privacy issues:

    a. Multiple jurisdictional levels, regulatory, rule-making and enforcement organisations, providers, information repositories and payers.

    b. Lack of patient awareness of their rights, including what their data is used for.

    c. Providers and their staff not following the regulations.

    d. Continuing evolution of the dispute over who owns health data.

    e. Unauthorised access to EHRs.

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[781] Durben Hirsch, Interview; McGraw, Interview; Gropper, Interview; Jethwani, Interview; Deborah Peel told a story that illustrated the continuing issues with privacy: "My sister-in-law was at a party with some strangers. One of them happened to be a doctor and she was talking about how she recently got pneumonia or something, and he pulled up on his iPad her chest x-ray. Yes, that is what I mean. Any of the 7,000 doctors or nurses can get access to any patient record, even to a stranger. This is really incredibly primitive, bad technology, it needs to be ripped and replaced really." Peel, Interview.

[782] ONC, *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap - Supplemental Materials,* (2015).

5. Responsibility for, and levels of, data accuracy.
6. Countervailing market forces including proprietary EHR systems, information blocking, and the difficulty in moving from a fee-for-service to a value-based or outcomes-based payment model.
7. Uncertainty about how much government regulation was needed to make EHRs truly portable, achieve meaningful use and improve service delivery outcomes.
8. Mixed results on EHR service delivery outcomes.

These barriers exhibit significant similarities with those described in Australia and England and will be evaluated in the analysis chapters that follow. This chapter will conclude with a plausible explanation of the state's funding the adoption of EHRs that were supposed to be interoperable and achieve meaningful use with the result that the "$3.7 trillion US health care system [is] idling at the crossroads of progress … [beset by] a slew of unintended consequences – the surprising casualties of a big idea whose time had seemingly come."[783]

Conclusion

The state in the US pursued institutional change in the area of EHRs through a process of legislation and regulation that was intended to both incentivise and coerce the interoperability of EHRs and the meaningful use of the patient health information they contained. This was the state's response to converging social, medical professional, fiscal and technical trends which had contributed to the development of institutional pressures and tensions that made EHRs significantly more desirable than paper health records for some, but not all, healthcare providers. Healthcare providers who had implemented EHR systems within their organisations did so in a market-driven system where interoperability was not the norm, significant privacy issues rapidly arose and it was unclear if patients were benefitting from the rapid systemic changes to the way their health information was gathered, stored and used.

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[783] Schulte and Fry, "Death By 1,000 Clicks."

Federal policy goals were slow to align in support of the desired outcomes of EHRs which aimed to improve healthcare efficiency and effectiveness and benefit patients.[784] This was due to the complexity of the US healthcare system and an initial reluctance on the part of the state to adopt a market failure hypothesis justifying its intervention in the EHR marketplace. Institutional complexity was the result of a federal system resulting in four levels of government with involvement in the provision and regulation of healthcare; numerous EHR vendors who had a vested interest in building a customer base using proprietary EHRs that could not share patient information nationally reflecting a lack of national standards including no unique patient identifier;[785] extremely large numbers of healthcare providers who chose to stay with paper records, or older technology such as the fax machine, or who implemented ICT systems that were not interoperable; and significant, and highly contested, issues over the privacy, ownership and use of patient health information. The state's initial reluctance to intervene in the EHR market was due to a broad societal preference for the private provision of healthcare, personal choice and individual rights.

The above issues were addressed slowly by the state, first by establishing a privacy and healthcare data transfer regulatory regime through HIPAA in 1996, and then supporting and providing guidance for interoperability through the creation of the ONC in 2004. The GFC of 2008–2009 provided a window of opportunity for increased state intervention in the EHR market. This reflected a growing perception amongst stakeholders and policy makers on the left that private EHR vendors and healthcare providers were "years behind the times in terms of how one EHR talks to another EHR."[786] A unified Democrat government passed the HITECH Act in 2009 with the aim of incentivising the interoperability of EHRs and the meaningful use of patient health

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[784] The rhetoric that an NEHR had the potential to improve the efficiency and effectiveness of healthcare service delivery and improve patient health outcomes was widely supported. Marla Durben Hirsch summarised this support by saying: "Its got great potential. It's got great potential to serve as a better tool within a clinician's work. Its got great potential for secondary uses, such as research and the public trust in serving public health. It has the potential of bringing costs down and creating efficiencies. It has the potential of improving patient outcomes with clinical decision support. It really has a wonderful potential, but it's not a magic bullet. It's a tool. It just needs to be used wisely." Durben Hirsch, Interview.

[785] Suarez, Interview.

[786] Durben Hirsch, Interview.

information. Incentive funding totalled more than $35 billion by 2017, rapidly increasing the digitalisation of health records. The ONC promoted the use of health information technology (HIT), the adoption of HIT standards, and worked to improve HIT privacy and security provisions. CMS incentivised the meaningful use of patient health information in EHRs through payments to eligible professionals and eligible providers and penalised those who did not meet the published outcome standards.

Many healthcare provider organisations successfully adopted EHRs that had some level of interoperability, though for most this was limited to sharing information within an organisational structure or wider health network but not nationally to every provider. There were some successes for healthcare providers who implemented integrated EHR systems across their organisation, particularly those that were interoperable to some extent outside organisational boundaries. The Director of Kaiser Permanente International framed the benefits of an interoperable EHR for Kaiser Permanente as follows:

> It's a better use of the dollars we spend. Your costs never go down. They just go up a little less. So essentially what we've done over the years is taken money out of the ER and hospital and put it into information technology alerts and reminders and care managers and health educators. So, you're just moving the money upstream. It's better health. Much better health. Does it end up saving you money? Well, it ends up having happier patients, usually they live longer and act well. It controls chronic conditions better. There's an investment to be made in the information technology, in the proactive support because our doctors are not sitting back and waiting for you anymore. The whole team is saying "Who do I have to reach out to? Who's missed their medication? Crystal's smoking." They're on this whole crusade to keep you healthy. Our malpractice rates have gone down. We estimated an 8.5% per year on return of investment from a financial standpoint. 8.5% per year is a long time for a private firm to wait or for governments to wait, but for us we thought it would take ten years and it did. But we're getting that return. Now that's just the costs. That's just what paper tells us. The quality improvements are much more rapid. The quality improvements you can see in a year because already you've got the electronic prescribing, the alerts and reminders, and the quality just keeps getting better.

Schulte and Fry stated that "few would deny that the swift digitization of America's medical system has been transformative."[787] Walter Suarez noted the positive benefits achieved by more than a decade of state efforts to promote and incentivise NEHRs.

> I think we have invested more than ten years of a transition towards an integrated electronic health record system and by many measures, it has paid off significantly. Just starting with saving lives, literally and saving life years. I mean it's one thing to save a life in an emergency. Another is to prevent an early death of a consumer … because we were able to, through an electronic health record system, better manage the care of a person.[788]

However, both normative and practical issues remained. State regulation and incentivisation of EHRs in an effort to make them nationally shareable involved stakeholder trade-offs that critics argued favoured EHR vendors and the providers of healthcare at the expense of patients.[789] Significant areas of contestation remained over privacy, patient control over their health information, transparency and trust. The integration of ICT and EHRs into established clinical workflows proved difficult and at times led to clinician burnout and unsatisfactory patient experiences.[790] Proprietary EHR systems hindered interoperability goals and when government chose not to regulate and let stakeholders evolve their own form of governance the result was "all sorts of messes and another layer of complexity in cost."[791] Vendor gag clauses proved problematic and, as Marla Durben Hirsch argued, were "bad for the evolutionary design of EHRs, improving safety, achieving interoperability and making them truly portable." [792] The state progressively attempted to address these issues through Meaningful Use Stages 1 to 3 but many barriers to achieving desired efficiency and effectiveness goals remained.

The empirical evidence for institutional stasis and change presented in this chapter will be comparatively evaluated with the other case study countries in chapters 8, 9 and 10.

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[787] Schulte and Fry, "Death By 1,000 Clicks."
[788] Suarez, Interview.
[789] Peel, Interview; McGraw, Interview.
[790] Martha Yacoe-Daly, Interview, 2014; Yacoe, Interview 2
[791] Durben Hirsch, Interview.
[792] Durben Hirsch, Interview.

Chapter 8 Comparative Evaluation of Cases

Introduction

Chapter 8 begins the comparative evaluation section of the thesis. It outlines the similarities and differences in the comparison criteria used to explain how and why institutional pressures and tensions led to policy problems and issues that resulted in attempts to develop, implement and regulate NEHRs in all three case study countries. It is followed by chapters 9 and 10 which continue to build on the explanatory value of the case study method through a comparative public policy evaluation and an historical institutionalist explanation of why initially different NEHR approaches led to broadly similar outcomes.

Part 1 of this chapter will focus on the similarities and differences in institutional pressures and tensions across the three case study countries. These institutional criteria include structural antecedent conditions, shock events, ideational change, political agency and converging social, medical professional, technical and fiscal trends. The explanatory value of these criteria is their capacity to explain how and why the development of institutional pressures and tensions led to policy problems and issues that states felt compelled to address. As Chapter 10 will show, this point is the first critical juncture in moving from paper health records to NEHRs for each state.

Part 2 examines similarities and differences in the policy problems and issues each country faced with a view to examining in Part 3 the aspirational claims that ensued. This leads to a comparison of the different NEHR approaches taken by each country in Part 4. The major policy problems and issues in all three countries centred around the following three topics: paper health records being seen as inefficient and acting as a barrier to effective healthcare; stakeholder conflict over the control of patient health information; and what approach states might take to effect institutional change in the area of health records. The major similarities were that each state saw ehealth, and NEHRs in particular, as a significant part of the solution to these problems and issues which resulted in some similar NEHR goals. The major goals were to make health records interoperable, improve the usability of the information in health records, and meaningfully use patient health information to improve patient health outcomes. Despite these similarities, key differences – or varieties of particularism – led to each state initially adopting different approaches to NEHRs. The major drivers of different approaches were how each state saw the role of government, primarily through the lens of healthcare as a social or private good, and how to balance competing stakeholder interests over the control of patient health information.

Part 1

Comparative Evaluation of the Development of Institutional Pressures and Tensions: Similarities and Differences

Structural Antecedent Conditions

The structural antecedent conditions that were drivers of, and barriers to, institutional change in Australia, England and the United States had many similarities as well as some important differences. Similarities led to similar policy problems and issues, in particular with the interoperability of health records, which will be discussed in Part 2. Differences that resulted in each country initially adopting a different approach to NEHRs will be discussed further in Part 4 with a focus on varieties of particularism.

The major structural antecedent similarities were as follows. Prior to all three countries adopting an NEHR program paper-based health records were the norm. Where clinical practices and hospitals used electronic medical records (EMRs) these were proprietary and lacked interoperability, and the fax machine was the primary technology used for the transfer of patient health information between providers. Patient health information was therefore siloed and mostly resided with the treating healthcare provider or clinician. The provision of healthcare was becoming increasingly expensive for three major reasons. As stated in the case study chapters people were living longer and accessing healthcare resources more often, and there was a substantial increase in chronic diseases and co-morbidities which were expensive to treat and required larger medical resources including more expensive technology. Healthcare costs were projected to continue to rise in all three countries over time increasing the burden on government expenditure.

The key contextual differences related to federalism, ideological perceptions of a citizen's right to healthcare, and the uptake of EMRs. England had a unitary political system and was therefore able to centralise its approach to healthcare at the national level. GPs, from whom information for an NEHR would flow and who would be expected to use the NEHR in the provision of care, were essentially employees of the National Health Service (NHS) and locked into the system.[793] Both Australia and the US were federal systems though federalism produced far more complexity in the US healthcare system than in the Australian healthcare system. In Australia the federal government was the largest funder of healthcare but the states were the largest providers of healthcare. This arrangement often required agreement at the level of the Council of Australian Governments (COAG) for major changes in health policy to be successfully implemented and proved crucial in the pursuit of an NEHR. The Australian health system also relied on GPs who were running their own independent businesses and it was essential to get them onboard if policy change was going to be successful. Therefore, persuasion rather than direction was needed.[794]

The US healthcare system was characterised by fragmentation and complexity. Four levels of government (federal, state, county and city) could be both providers and funders of healthcare services, as well as a plethora of private healthcare providers strongly influenced by insurance companies and managed care systems that acted as middlemen. However, private systems were able in some cases, such as Kaiser Permanente, to successfully integrate health records within their organisational boundaries but often lacked the capacity to cross other boundaries and make their electronic health records nationally shareable. In both Australia and England there was a broad consensus that citizens had a right to healthcare and that healthcare was a social good. This was very different in the US where healthcare was seen a private good and subsidisation of healthcare costs by employers was earned through participation in the

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[793] Andrew Podger (Former Secretary of the DoH and Public Service Commissioner), Interview 2, 2019.
[794] Podger.

workforce. The exceptions were Medicare, Medicaid and the Department of Veterans Affairs (VA). At the start of each country's NEHR program differences in existing systems were clear: Australia's uptake of EMRs was low; in England GP computer use and EMRs were rapidly increasing; and in the US, while some providers had well established EMR systems, many healthcare providers were still reliant on paper-based health records. In all three countries clinician-centred care was the norm before NEHRs.

Table 8-1 summarises the similarities and differences in structural antecedent conditions between the three case study countries.

Table 8-1: Structural Antecedent Conditions – Similarities and Differences

Structural Antecedent Conditions	Australia	England	United States
Drivers of Institutional Change			
Paper health records	Yes – the *status quo*.	Yes – the *status quo*. However, GP computer use and EMRs rapidly increasing.	Yes – the *status quo*. However, some providers had well established EMR systems.
Fax machine	Yes – the *status quo* for the transfer of patient health information between providers.	Yes – the *status quo* for the transfer of patient health information between providers.	Yes – the *status quo* for the transfer of patient health information between provider organisations.
Proprietary EMRs	Yes – not widespread.	Yes.	Yes.
Increasing life expectancy	Yes.	Yes.	Yes.
Increase in chronic disease	Yes.	Yes.	Yes.
Increasing cost of healthcare	Yes.	Yes.	Yes.
Healthcare as a social good	Yes.	Yes.	No – healthcare as a private good.
Healthcare as a private good	No.	No.	Yes.
Barriers to Institutional Change			
Resilience of paper records	Yes.	Yes.	Yes – though very much provider centric with some providers such as Kaiser Permanente early and enthusiastic adopters of EHR/EMR technology.

Resilience of non-NEHR technology	Yes – particularly the fax machine.	Yes – particularly the fax machine.	Yes – particularly the fax machine.
Cost of acquiring technology	Yes – state attempted to resolve this through practice incentive payments (PIPs).	Yes – state attempted to resolve this through the National Programme for Information Technology (NPfIT).	Yes – the state attempted to resolve this through incentive and penalty programs.
Clinician-centred care	Yes.	Yes.	Yes.
Federalism	Yes – successful policy change required buy-in from state and territory governments and from key stakeholders such as GPs.	No – unitary system.	Yes – very complex health system with multiple levels of government and a strong private component that made it very difficult for health information to cross organisational and other boundaries.

Shock Events

Shock events that produced drivers of institutional change included changes in government due to elections, a financial crisis in the US, and significant legislation supporting NEHRs. Elections resulting in a change in government produced institutional change in all three countries. Change in government[795] allowed new ideas to influence policy agendas and, when acted upon, provided the political agency for institutional change. Institutional stability was also observed as, despite intense criticism of government NEHR policy while in opposition, both Australia and England retained significant aspects of their NEHR programs on a change in government and continued to fund NEHRs. The key similarities were that elections in Australia in 1996, England in 1997 and the US in 2008 resulted in the start of NEHR programs. Subsequent changes in government in Australia and England led to changes in NEHR policy but continued support for NEHRs under the premise that they were a public good that would eventually produce the desired benefits. There were also similarities in that there were varying levels of opposition from clinicians to aspects of NEHRs, particularly

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[795] Numerous interviewees expressed the view that changes in government often resulted in plans, including research, being "put on hold" because funding became uncertain. This resulted in failures to implement good systems and strategies in all three countries. John Parkinson (Director of the Clinical Practice Research Data Agency) Interview, 2013; Margaret Riep (Health ICT Project Manager and Health Informatician), Interview, 2015.

around privacy and opt-in/opt-out regimes. All three countries adopted significant legislation in support of NEHRs.

The major difference was the role crisis played in providing a critical juncture for NEHR policy action. While changes in government led to all three countries adopting an NEHR policy, only in the US did the crisis of the GFC arguably lead to Democrats controlling both houses of Congress and the presidency allowing them to pass HITECH in 2009 thus setting up and funding support for NEHRs. This was done with virtually no Republican support.[796] David Blumenthal, the National Coordinator for Health Information Technology in the period 2009-2011, explains how the crisis of the GFC led to HITECH:

> Congress had made several bipartisan attempts to pass such legislation during the administration of President George W. Bush, but the political will for a major federal investment in health information technology did not exist at that time. The economic crisis of 2008 broke the logjam, and the HITECH Act emerged.[797]

Table 8-2 summarises the similarities and differences in shock events between the three case study countries.

Table 8-2: Shock Events – Similarities and Differences

Shock Events	Australia	England	United States
Drivers of Institutional Change			
Change of government	Yes – 1996, 2007 and 2013 elections.	Yes – 1997 and 2010 elections.	Yes – national elections of 2008 gave Democrats control of both houses of Congress and the presidency enabling political agency.
Crisis	No.	No.	Yes – GFC.

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[796] David Blumenthal states that the HITECH Act was drafted with "persistent bipartisan support." David Blumenthal, "Wiring the Health System - Origins and Provisions of a New Federal Program," *New England Journal of Medicine* 365, no. 24 (2011): 2324. However, the stimulus provisions ARRA Act as a whole, of which HITECH was a part, were opposed by most Republicans hence the lack of Republicans support in both the House and Senate votes.

[797] David Blumenthal, "Wiring the Health System," 2325.

Significant transformative legislation	NEHRT report leading to HealthConnect. National Health and Hospital Reform Commission recommendations leading to the PCEHR.	NPfIT and subsequent SCR legislation.	1996 HIPAA 2009 HITECH
Barriers to Institutional Change			
Stakeholder backlash	Yes – especially clinician response to opt-in and privacy concerns.	Some.	Some – particularly over meaningful use timelines.
Change of government	2013 election of the Abbott Coalition government resulted in a shift of emphasis in favour of clinicians.	Yes – 2010 election resulted in the abandonment of the NPfIT and scaling back of the SCR.	No significant change to NEHR policy due to changes in government.

Ideational Change – Variations in Systemic Visioning

While new governments were able to bring in new ideas which led to institutional change, the driving logic behind NEHRs that they would facilitate the meaningful use of patient health information and improve patient health outcomes did not change. Similarities in ideational change were common across all three case study countries but it was the differences which were most influential in each country adopting an initially different NEHR approach. The argument that government intervention in the NEHR market to promote the public good was required was widely supported in all three countries and justified government subsidisation, or outright funding, of NEHR programs. This justification was closely tied to the concept that the efficiency and effectiveness of healthcare service delivery, and thus better patient health outcomes, could be improved through the application of technology at a scale that only the government had the resources to fully fund. Therefore, states attempted to change values from a clinician-centred to a patient-centred healthcare system and make NEHRs with full interoperability the norm for every citizen.

However, differences in emphasis were crucial in affecting outcomes. Government intervention in support of the public good was tempered in both Australia and the US by desires to expand liberal individualism and choice far more than in England, though the rhetoric of patient choice became popular there as well. In Australia the value of an

NEHR was seen by Labor as closely tied to government regulation over the control of patient health information and patient rights, especially having an opt-in system. The Liberal Coalition saw the NEHR more in terms of lowering costs and benefitting both patients and providers by encouraging information sharing that would lead to patients being more engaged with, and therefore co-producing, their healthcare. They argued that their support for an opt-out system would make clinically useful information more widely available at every point of care. This was similar to the Conservatives in England who also argued that information would give patients more choice and control over their care. The difference was in emphasis and the result was that Australia, heavily influenced by privacy advocates, initially favoured decentralisation and an opt-in system. Privacy was also a significant issue in England but the emphasis there was on centralisation, a top-down implementation of the SCR and an opt-out system that focused on ensuring that every citizen had an SCR. In the US privacy was contested and consumer advocates argued that healthcare providers had the upper hand[798] due to the strong role the private sector played in delivering healthcare and influencing policy.

Table 8-3 summarises the similarities and differences in ideational change between the three case study countries.

Table 8-3: Ideational Change – Similarities and Differences

Ideational Change	Australia	England	United States
Drivers of Institutional Change			
Enabled by a change in government	Yes.	Yes.	Yes.
Modernisation agenda	In practice yes, but limited in scope in comparison to England.	Yes – Blair's modernisation agenda sought to impose a centralised, top-down, NPfIT and SCR which was part of an all of government approach that was to revolutionise Britain.	In practice yes.

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[798] Adrian Gropper (Chief Information Officer for Patients Privacy Rights), Interview, 2014; Deborah Peel (MD, Founder and President of Patient Privacy Rights), Interview, 2014.

Values	Move from a clinician-centred to a patient-centred health system.	Move from a clinician-centred to a patient-centred health system	Move from a clinician-centred to a patient-centred health system
Norms	Make NEHRs with full interoperability the norm.	Make NEHRs with full interoperability the norm.	Make NEHRs with full interoperability the norm.
Barriers to Institutional Change			
Change in government	Yes – changed policy.	Yes – changed policy.	No.
Values	Some clinicians and healthcare providers defined patient-centred very differently from consumer advocates and the state.	Some clinicians and healthcare providers defined patient-centred very differently from consumer advocates and the state.	Some clinicians and healthcare providers defined patient-centred very differently from consumer advocates and the state.
NRPPs	Complexity in the healthcare system made interoperability difficult to achieve. Privacy and control over patient information contested.	Complexity in the healthcare system made interoperability difficult to achieve. Privacy and control over patient information contested.	Complexity in the healthcare system made interoperability difficult to achieve. Privacy and control over patient information contested.
Role of the private sector	Weak – state the most powerful policy influencer.	Medium to strong – the state was the most powerful policy driver BUT private GPs and healthcare providers were very influential.	Strong – due to the passage of HITECH the state was able to establish an incentive and penalty based regulatory regime BUT private health providers had the choice of participating and strongly influenced regulatory refinement.

Political Agency

New ideas were actioned through political agency. Political parties that controlled the political process were able to pass significant NEHR legislation in all three countries. In both Australia and England recommendations from various committees and taskforces on ehealth and EHRs had built a positive narrative regarding the potential benefits of an NEHR and these benefits were used as a justification by political parties to implement and fund NEHR programs in both countries. Similarly, when initial efforts failed to achieve desired outcomes and new political parties gained control of government, NEHR policy changed but funding was maintained and political actors continued to espouse the claims of potential benefits as part of the enabling narrative. In the US, Republican opposition to the suite of health policy changes commonly called ObamaCare continued, however Republicans were supportive of some of the goals of the HITECH Act that encouraged the interoperability of EHRs and the meaningful use of health information to improve patient outcomes though from a private market perspective. Thus funding for incentives continued.

Similar barriers to institutional change were prevalent in all three countries. In particular, clinicians and some healthcare providers opposed various aspects of the legislated privacy regimes. In Australia the opposition focused on the impact privacy would have on clinical workflows and the reliability of information in an NEHR due to patient control over health information. This led to low take up and use of the PCEHR. Some GPs had similar concerns in England, but not to the same extent as in Australia, and uptake of the SCR was to some extent overcome by the state making it mandatory for every person to have an SCR unless they went through the difficult opt-out process. In the US funding was extensive with an initial allocation of $20 billion reaching $35 billion by 2017. GPs and other healthcare providers could choose whether or not they participated in the incentive programs to increase the interoperability and meaningful use of health records. This resulted in a patchwork of implementation with some organisations achieving high levels of record integration across their organization while others simply chose not to participate or struggled with the timelines imposed by regulators.

In each country many regulatory decisions were left to bureaucrats. A former senior public official, Robert McMahon, explained that:

> even at a more micro level, bureaucrats are policy makers. Politicians don't get themselves involved in departmental procedure. They don't get themselves involved in policy to make decisions on individual circumstances. That's absolutely left to the bureaucrats.[799]

In Australia HealthConnect, then NEHTA, developed regulatory foundations for an NEHR; in England a plethora of NPfIT and related organisations did the same; and in

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[799] Robert McMahon (Former Senior Public Official), Interview, 2019.

the US the ONC and CMS developed and enforced interoperability and meaningful use regulatory regimes.

Table 8-4 summarises the similarities and differences in political agency between the three case study countries.

Table 8-4: Political Agency – Similarities and Differences

Political Agency	Australia	England	United States
Drivers of Institutional Change			
Control of the political process	Yes – successive governments were able to pass NEHR legislation.	Yes – successive governments were able to pass NEHR legislation.	Yes – Democrats controlled the political branches of the federal government.
Legislation	2000 – HealthConnect 2010 – Healthcare Identifiers Act 2012 – PCEHR	2002 – NpfIT and ICRS 2004 – NCRS 2005 CfH	1996 HIPAA 2009 HITECH 2016 21st Century Cures Act
Executive order			2004 Establishment of ONC
Funding	Approximately $2.5 billion by 2018.	Approximately £12.7 billion by 2010.	Initially $19.2 billion rising to $35 billion by 2017.
Barriers to Institutional Change			
Political opposition to legislation	Political opposition to opt-in from the Liberals and some stakeholders including clinicians.	Political opposition to centralised approach and to opt-out from the Conservatives.	Intense opposition by Republicans to Democrat health policy change though supportive of some of the goals, especially regarding interoperability.
Organisational capacity to implement legislation	Low at the start and built through organisational creation and change.	Low at the start and built through organisational creation and change.	Low at the start and built through organisational creation and change.
Stakeholder opposition to NEHR policy	Yes – particularly by clinicians.	Intense criticism of the roll-out of the NPfIT and the SCR.	Criticism of optimistic timelines for meaningful use and lack of progress with interoperability.

Converging Trends

One of the key findings of this research is that NEHR programs came about as a result of converging social, medical professional, fiscal and technical trends. These four trends reflect structural antecedent conditions that, when combined with shock events, enabled the political actioning of new ideas. These new ideas for ehealth and NEHRs were situated in the premise that innovations in technology, in particular ICT, had the potential to break down health information siloes, make EHRs interoperable, improve the efficiency and effectiveness of healthcare service delivery and benefit patient health outcomes.

This section of the chapter will compare the similarities and differences in converging trends leading up to the implementation of NEHR programs in all three case study countries. The summary boxes include some information that impacted the success and/or failure of NEHR programs and that influenced post-program start critical junctures that resulted in further institutional change. Success/failure and further institutional change will be discussed in detail in chapters 9 and 10 respectively, but the information has been included in the summary boxes as it further informs the particular trends under discussion over time.

Social Trends

Social trends leading up to the implementation of NEHR programs were remarkably similar in all three case study countries with a few important differences. Healthcare was increasingly seen as a social, rather than a personal, good in both Australia and England justifying funding by the state of NEHR programs due to the benefits publicly funded health systems would potentially receive. This was part of the enabling narrative that justified healthcare as a citizens right subsidised by the taxpayer. Starkly different was the US perception of healthcare as a personal good subsidised through participation in the workforce. This led to a market-based healthcare system favouring individual choice. The notable exceptions were Medicare for the elderly, Medicaid (always contentious and often opposed by Republicans) for the poor, and veterans care. There were also similar changes in doctor-patient relationships. In terms of values the state and many stakeholders actively promoted, and tried to implement through NEHRs, a shift from clinician-centred to patient-centred care. As part of this shift five major changes were underway. Patient health literacy was slowly increasing as more information was made available to patients about their healthcare. More information gave patients more choice in their healthcare options and this was actively supported by the state and health consumer advocates. Information and choice was touted as having the potential to increase patient engagement with, and coproduction of, their healthcare and thus benefit their health outcomes. There was increasing pressure, particularly from healthcare consumer advocates and often from patients themselves, for the state to regulate control of patient health information in favour of the patient as part of a patient-centred healthcare system. The state saw privacy issues, especially those related to consent, access, transfer and use of patient health information, as potentially solvable through regulation of NEHRs and increasing interoperability. In all three countries there was limited patient engagement with their NEHR or EHR.

The important differences were that in Australia and the US clinicians tended to interpret patient-centred healthcare as the patient at the centre of a coordinated and connected health system with clinicians as the experts, not so much as patients in control of their healthcare journey. In particular, in the US clinicians retained more power and control over decision making in a more complex health system than in Australia and England. Thus, the shift in power from clinician to patient was more pronounced, though still weak, in England. In response to increasing patient expectations of access to their health information the state in Australia and England facilitated privacy, access and patient control over their health information through NEHR programs. While all three shifts were also facilitated through state action and social expectations about the way technology should work, in the US, in practice, it was still more difficult for many patients in many care settings to access or exert similar controls over their health information than in Australia and England. An intense privacy backlash and concerns over consent in Australia resulted in high numbers of people (nearly 10%) opting out of having an NEHR. In England and the US privacy and consent concerns were moderate with 97% of people in England having an SCR. In the US, most people who received healthcare had the health record of choice of the particular organisation that provided care with corresponding differences in patients' control over their health information.

Table 8-5 summarises the similarities and differences in social trends between the three case study countries.

Table 8-5: Social Trends – Similarities and Differences

Social Trends	Australia	England	United States
Healthcare as a social, rather than a personal, good.	Yes, from the 1970s onwards.	Yes, from the 1940s onwards.	No. Healthcare as a personal good subsidised through participation in the workforce. Three major exceptions: Medicare for the elderly, Medicaid for the poor, and veterans care. Post-2009, trend towards healthcare as a social good – "Medicare for all."
Egalitarian view of healthcare as a citizen's right to be subsidised by the taxpayer.	Yes	Yes	Mostly no – see exceptions above. Gradual shift towards patients gaining more control over their health information.
Change in doctor/patient relationships: **1. Shift from clinician to patient-centred ehealth system** **2. Increase in patient health literacy and information** **3. Patient choice** **4. Patient engagement and co-production** **5. Informed consent** **6. Shift in power from clinician to patient**	Significant change. Concept of patient-centred healthcare the norm for more than a decade however clinicians tend to interpret that as the patient at the centre of a coordinated and connected health system with themselves as the experts not so much as patients in control of their healthcare journey. Yes to 2–4.	Significant change. Yes to 1–6 with marginally more emphasis on patients' control of their outcomes through technological innovation and informed consent than Australia.	Significant change. Yes to 1–6 with less emphasis on patient-centred healthcare in practice and clinicians retaining more power and control over decision making and outcomes than in Australia and England.
Increasing patient expectations of access to their health information.	Yes – facilitated through state action: privacy and access legislation, state-sponsored NEHR, NEHR adoption leading to a change in norms where both clinicians and patients expect access to records.	Yes – facilitated through state action: privacy and access legislation, state sponsored NEHR, NEHR adoption leading to a change in norms where both clinicians and patients expect access to records.	Yes – facilitated through state action and social expectations about the way technology should work. In practice still difficult for many patients in many care settings.

Result of the above: increased expectation by the patient of control of the information in their NEHR.	Yes – patient control of the information in their NEHR mandated by the state.	Yes – patient control of the information in their NEHR mandated by the state.	Yes – some patient control mandated by the state but in a more limited form than in Australia or England.
Unintended outcomes:			
1. **Privacy backlash**	Intense privacy and consent concerns force institutional change.	Moderate privacy and consent concerns force institutional change.	Moderate privacy and consent concerns gradually lead to institutional change.
2. **Patients opt-out of NEHR**	10% of Australians choose to opt out.	Over 1% opt out rate.	No data – difficult to opt-out once in.
3. **Limited patient engagement with EHR**	Yes.	Yes.	Yes.

Medical Professional Trends

Medical professional trends developed along similar lines in all three countries despite differing health systemic structures. Structural changes in the way medicine was practiced were changing for organisational, burden of disease and technological reasons. There was a shift from solo practices isolated from other parts of the health system to group practices then branch practices and ultimately to multi-disciplinary teams. To some extent this was driven by health provider organisations that incorporated health insurance with the provision of care, such as Kaiser Permanente in the US, which encouraged patients to seek care within a specific provider system. There was also a rise in allied health professions. These organisational changes were in response to the increasing complexity of disease management due to the burden of disease changing from acute illness to chronic illness (approximately 80/20 to 20/80[800]). The rise of chronic illness resulted in a broad acceptance by stakeholders that the old models of care no longer applied and that in order to improve the process of care, in particular the coordination and continuity of care, accurate and timely patient health information had to be available at all points of care. This view was a key driver of NEHR policy and overtime saw the limited amount of patient health information contained in paper records replaced by substantially more information in EHRs.

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[800] Brian Richards (The Australian National University), Interview, 2014.

There were also similar unintended consequences that will be discussed in further detail in Chapter 9. They included clinician burnout due to the extra demands of implementing and using EHRs. Interviewees noted this as particularly prevalent for GPs in solo or small practices in Australia and the US, and within the NHS system in general in England. There were rising costs due to new electronic equipment and the need to train staff despite often generous incentive payments provided by the state. Negatively impacted clinical workflows saw some clinicians reducing the number of patients they saw each day thus lowering their income. These issues led to early retirement for some clinicians.

Social drivers supporting the adoption of an NEHR and leading to efforts by the state to give patients access to, and control over, their health records were different to the drivers motivating doctors to use EHRS. In the case of Australia, both Richards and More argued that they are fundamentally different records for each stakeholder as the PCEHR did not fit into the attractive value technology model for clinicians.[801]

Table 8-6 summarises the similarities and differences in medical professional trends between the three case study countries.

Table 8-6: Medical Professional Trends – Similarities and Differences

Medical Professional Trends	Australia	England	United States
Structural changes in the way medicine is practised:			
1. Shift from solo practices isolated from other parts of the health system to group practices to branch practices to multi-disciplinary teams.	Yes.	Yes.	Yes.
2. Rise in allied health professions due to the complexity of disease management.	Yes.	Yes.	Yes.

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[801] Richards; David More (Health It Consultant, Creator of the Australian Health IT Blog), Interview, 2014.

3. Burden of disease changing from acute to chronic illness (80/20 to 20/80).	Yes.	Yes.	Yes.
4. Old models of care no longer apply	Rapid change but still significant use of paper/fax in 2015.	Rapid change but still significant use of paper/fax in 2015.	Rapid change but still significant use of paper/fax in 2015.
5. Shift from limited patient health information on paper records to substantial information in EHRs.	Yes.	Yes.	Yes.
6. Structural changes seen as the only way to effectively provide continuity of care.	Yes.	Yes.	Yes.
Unintended outcomes:			
1. Clinician burnout	Yes – particularly for GPs in solo or small practices.	Yes.	Yes – particularly for GPs in solo or small practices.
2. Rising costs	Yes – new electronic equipment, training staff, time spent interacting with technology reducing the number of patients seen and thus lowering income.	Yes – new electronic equipment. Also, failure to successfully implement all parts of the NPfIT and problems with achieving content goals with the SCR impacted clinical workflows.	Yes – new electronic equipment, training staff, time spent interacting with technology reducing the number of patients seen and thus lowering income.
3. Early clinician retirement	Yes.	Yes.	Yes.

Fiscal Trends

Fiscal trends in each of the case study countries were very similar resulting in ehealth and NEHRs becoming a major budgeting concern of government. Fiscal pressures were aggravated by social, medical professional and technical trends including an ageing population, growth in chronic diseases, and the subsequent increased cost of treatment including new drugs, diagnostic and surgical equipment and genomics. Subsidised healthcare created significant outlays for government which governments became very focused on controlling. These fiscal pressures combined to contribute to more information being added to health records, generating privacy concerns, and NEHRs, particularly in the US, were seen as a way to extract stakeholder benefits from health data. Similarities in unintended outcomes will be discussed in Chapter 9.

There was a major difference in fiscal trends that strongly influenced the initial approaches taken with NEHRs by each country. In Australia and England healthcare was seen as a social good that led to a responsibility on the part of the taxpayer to equitably subsidise access to healthcare. Consequently, Australia had a two-tier system combining universal healthcare and private health insurance, as well as heavily subsidised care for specific categories of people such as the elderly, the poor and Indigenous Australians. In the UK, healthcare as a social good was the source of the NHS principle to provide free healthcare services at the point of care based on need rather than an individual's ability to pay. As a result, both countries initiated NEHR programs where the state was the major funder and directly developed, implemented, incentivised (through practice incentive payments – PIPs) and regulated NEHRs. By contrast, in the US healthcare was seen as a private good, with the major exceptions of Medicare, Medicaid and VA healthcare. US administrations, particularly Republican administrations, were therefore more focused on controlling entitlement costs and supporting NEHRs as a mechanism to lower cost and increase individual choice. The result was still that fiscal pressures drove state intervention in the marketplace in similar ways to Australia and England but the US chose to incentivise the adoption of interoperability and the meaningful use of patient health information through regulation leaving NEHR system development and implementation to the free market.

Table 8-7 summarises the similarities and differences in fiscal trends between the three case study countries.

Table 8-7: Fiscal Trends – Similarities and Differences

Fiscal Trends	Australia	England	United States
eHealth a major economic concern of government.	Yes – particularly from 2000.	Yes – particularly from 2002.	Yes – particularly from 2009.
Healthcare as a social good led to a responsibility on the part of the taxpayer to equitably subsidise access to healthcare.	Yes – Medicare plus heavily subsidised care for specific categories of people such as the elderly, poor,	Yes – NHS principle to provide free services at the point of care based on need, not an individual's ability to	No – healthcare as a private good with the major exceptions of Medicare, Medicaid and VA healthcare.

	Indigenous. Contributions scheme.	pay. Contributions scheme.	
Subsidised healthcare created significant fiscal outlays for government which government became very focused on controlling.	Yes.	Yes.	Yes – but more focused on controlling entitlement costs particularly in Republican administrations.
Fiscal pressures included: **1. Ageing population** **2. Growth in chronic diseases** **3. New drugs** **4. New diagnostic equipment** **5. New surgical equipment** **6. Genomics**	Yes.	Yes.	Yes.
Fiscal pressures combined to contribute to more information being added to health records.	Yes – became a driver of state intervention in the EHR marketplace supporting NEHRs through regulation and incentives such as PIPs.	Yes – became a driver of state intervention in the EHR marketplace supporting NEHRs through regulation and incentives such as PIPs.	Yes – became a driver of state intervention in the EHR marketplace supporting NEHRs through regulation and incentives such as PIPs.
Unintended outcomes:			
1. Fiscal pressures became a driver of added cost, privacy and consent concerns, efforts to shift control of patient information towards the patient, value for money of new electronic systems – to what extent would they improve the efficiency and effectiveness of care?	Yes – privacy and consent significant issues as the state tried to shift control of patient information towards the patient. Difficulty in achieving efficiency and effectiveness of care benefits led to intense criticism of the NEHR program.	Yes – privacy and consent significant issues as the state tried to shift control of patient information towards the patient. Difficulty in achieving efficiency and effectiveness of care benefits led to intense criticism of the NEHR program.	Yes – often a focus on information providing more choice for patients and increasing the efficiency of healthcare providers.

Technical Trends

In all three case study countries governments progressively adopted positive rhetoric regarding the potential benefits of improving the interoperability of EHRs using innovative and rapidly developing technologies in order to make patient health information available at all points of care and integrate disparate health record systems.

This positive rhetoric led to claims that new technology would enable NEHRs to improve the efficiency and effectiveness of care, in particular the safety, quality and process of care. Harnessing the power of technology to usefully process large amounts of health data was projected to have many benefits including improving the coordination and continuity of care, advancing research and altering relationships between patients and care givers making patient-centred care a reality. Advances in ICT had opened up new work practices and approaches to care and produced significant changes in clinical workflows. Electronic billing systems and the electronic availability of pathology results and diagnostic imaging reports were seen as attractive for many clinicians, who adopted them for their own commercial or professional reasons. In Australia and England the issue of the usability of health information in health records led to a focus on standards often driven by new organisations created to develop the foundations for ehealth and NEHRs. In the US, standards were often left to EHR vendors and healthcare providers resulting in multiple competing products that lacked interoperability and proprietary products that spawned issues such as information blocking.

The main difference here was the order of reasons for adoption. Australia and the US adopted health ICT for commercial reasons first (billing and administration), then to improve clinical workflows, then to improve clinical outcomes. In England billing was not as important as in the other two countries, therefore patient and practice administration were the key drivers followed by improved clinical workflows and outcomes. In particular, England saw ICT as having the potential to narrow inequalities in health by providing patients with better health outcomes. In all three countries governments had provided incentives for the adoption of health technology, however before NEHRs this was most prominent in Australia and England. In the US HITECH linked incentives and penalties to meaningful use outcomes.

Table 8-8 summarises the similarities and differences in technical trends between the three case study countries.

Table 8-8: Technical Trends – Similarities and Differences

Technical Trends	Australia	England	United States

Advances in ICT opened up new work practices and approaches to care.	Yes – significant changes in clinical workflows.	Yes – as for Australia.	Yes – as for Australia.
Initial over expectation of the utility of ehealth technology.	Yes – projected timelines for the implementation of technology and improved outcomes were unrealistically short and often unmet.	Yes – as for Australia.	Yes – as for Australia.
Development of a raft of technologies to support meaningful practical change without the need for any significant stimulus from outside:	Yes – though comparatively slow uptake of electronic systems by GPs – eventually 98%. Supported by professional bodies such as the AMA, GP computing group and the RACGP.	Yes – comparatively fast uptake of electronic systems by GPs though extensive use of fax machines persists.	Yes – mixed rate of uptake between different healthcare providers.
1. Electronic billing systems	Yes – attractive for clinicians: improved clinical workflows.	Yes – attractive for clinicians: improved clinical workflows.	Yes – attractive for clinicians: improved clinical workflows.
2. Electronic availability of pathology results and diagnostic imaging reports	Yes – attractive for clinicians: improved clinical workflows AND outcomes.	Yes – attractive for clinicians: improved clinical workflows AND outcomes.	Yes – attractive for clinicians: improved clinical workflows AND outcomes.
3. EHRs adopted within clinical practice for clinicians own commercial or professional reasons	Yes – adopted for commercial reasons first (billing and administration) then to improve clinical workflows (prescribing) then to improve clinical outcomes.	Yes – patient and practice administration the early key drivers followed by improved clinical workflows and outcomes.	Yes – adopted for commercial reasons first (billing and administration) then to improve clinical workflows then to improve clinical outcomes.
Government incentives for the adoption of health technology.	Yes – PIPs.	Yes.	Yes – but linked to meaningful use outcomes.
Unintended outcomes:			
1. Outside stimulus required for universal adoption	Yes – significant state funding for PIPs to promote the adoption of ehealth technology.	Yes – significant state funding for PIPs to promote the adoption of ehealth technology.	Yes – significant state funding for PIPs to promote the adoption of ehealth technology.
2. Increasing ehealth costs	Yes – technology change or implementation failure required the replacement or introduction of new systems, standards and workflow practices.	Yes – technology change or implementation failure required the replacement or introduction,of new systems, standards and workflow practices.	Yes – technology change or implementation failure required the replacement or introduction of new systems, standards and workflow practices.

3. Privacy and consent issues	Yes – significant.	Yes – significant.	Yes – significant.
4. Technology adoption, such as dictation machines, increased the amount of patient health information	Yes – this both increased the utility of EHRs and added complexity to the health system.	Yes – as for Australia.	Yes – as for Australia.

Part 2

Comparative Evaluation of Policy Problems and Issues: Similarities and Differences

The policy problems and issues that arose for governments from the development of institutional pressures and tensions were remarkably similar across all three case study countries. In each country paper health records were seen as inefficient and a barrier to effective healthcare. It was widely agreed among healthcare stakeholders that siloed patient health information negatively affected the process, safety, quality and cost of care. Patient information was primarily transferred between points of care by fax or paper, if transferred at all. Providers of care for new patients routinely did not have the patient's previous health information and often relied on asking the patient themselves, which was less than ideal. This negatively impacted the coordination, safety and continuity of care. Thus, healthcare systems were often seen as lacking in quality care in comparison to their potential if institutional change was adopted.

Each country had a healthcare system that was clinician or healthcare provider centric. New values were emerging in favour of changing from clinician-centred healthcare to patient-centred healthcare which was expected to drive changes in NRPPs. There was a strong desire among healthcare stakeholders for institutional change, however this differed in degree and emphasis. The state in both Australia and England saw the adoption of technology as a solution to the lack of health record interoperability and to the growing contest between stakeholders over the control of patient health information. State action in the form of NEHRs was initially widely supported by many stakeholders with the provisio that privacy concerns would be addressed by comprehensive legislation. The goal was to change norms from non-interoperable health records in a system where patients had little control over their health information to the norm of accurate, complete and timely patient health information being available at all points of care. To achieve this, rules would need to address issues that were termed the building blocks of ehealth and NEHRs. They included common standards, the usability of health information, privacy regimes and other rules relating to the control of patient health information such as access, use, transfer and ownership of patient health information.

In the US the emphasis was initially less statecentric and the above issues were often left to the market to solve with some guidance from the state. The centrality of the state's role dramatically increased with HITECH as regulations incentivising the adoption of interoperability and the meaningful use of health information developed. Incentive and penalty rules aimed to change clinician, healthcare provider and EHR vendor practices and procedures in order to change norms and meaningfully use patient health information to improve patient health outcomes.

Table 8-9 summarises the similarities and differences in policy problems and issues between the three case study countries.

Table 8-9: Policy Problems and Issues – Similarities and Differences

Policy Problems and Issues	Australia	England	United States
Values	Clinician-centred healthcare system. Strong desire among state and other stakeholders for institutional change including the adoption of technology to address problems and issues.	Clinician-centred healthcare system. Strong desire among state and other stakeholders for institutional change including the adoption of technology to address problems and issues.	Clinician-centred healthcare system. Growing desire among state and other stakeholders for institutional change including the adoption of technology to address problems and issues.
Norms	Non-interoperable health records. Paper health records ubiquitous. Patient health information siloed, usually at the point of care. Low level of clinician EMR adoption – lacked interoperability.	Non-interoperable health records. Paper health records ubiquitous. Patient health information siloed, usually at the point of care. Increasing level of clinician EMR	Mostly non-interoperable health records. Paper health records ubiquitous. Patient health information siloed, usually at the point of care. Increasing level of clinician EMR

		adoption – lacked interoperability.	adoption – lacked interoperability except within some organisational boundaries.
Rules	Control of patient information becoming a contentious issue. Increasing pressure for the state to resolve privacy, access, use, transfer and ownership of patient health information issues in the digital future. Privacy a major issue.	Control of patient information becoming a contentious issue. Increasing pressure for the state to resolve privacy, access, use, transfer and ownership of patient health information issues in the digital future.	Control of patient information becoming a contentious issue. Increasing pressure for the state to resolve privacy, access, use, transfer and ownership of patient health information issues in the digital future. Competing positions between free market and state interventionist views.
Practices and Procedures	Patient information transferred between points of care by fax or paper. The process of care, particularly coordination, continuity, safety (and therefore quality) of care less than ideal.	Patient information transferred between points of care by fax or paper. The process of care, particularly coordination, continuity, safety (and therefore quality) of care less than ideal.	Patient information transferred between points of care by fax or paper. The process of care, particularly coordination, continuity, safety (and therefore quality) of care less than ideal.

Part 3

Comparison of the Aspirational Narrative and Claims Made: Similarities and Differences

The aspirational narrative and claims made for the benefits of ehealth, and NEHRs in particular, were remarkably similar in all three case study countries. The differences in scope and emphasis on interoperability, usability and meaningful use were the result of the differences in the development of institutional pressures and tensions discussed earlier in the chapter and were partially responsible for the different approaches to NEHRs each country started with. In all three case study countries NEHRs were seen by the state as a mechanism for institutional change that would enable the value of patient-centred healthcare to become a systemic reality that would change NRPPs. It was expected that patient-centred care, as opposed to the clinical view of patients being at the centre of their care, would encourage patients' engagement with, and coproduction of, their healthcare increasing patient choice, trust and satisfaction. This value was supported by most stakeholders in Australia and England, with clinicians defining patient-centred care as per the clinical view above. In England there was also an emphasis on the public good. In the US both the state and consumer advocates supported patient-centred values that had the potential to increase choice, trust and satisfaction. The state envisioned meaningful use as the pathway to achieving patient-centred values, improving the efficiency and effectiveness of care and to improving patient health outcomes.

The state and many stakeholders in each case study country saw NEHRs as having the potential to make interoperability of patient health information the norm and thus achieve the benefits stated above. England had a more expansive vision of interoperability that went beyond patient health information being available at all points of care. The modernisation agenda was to enable an all of government approach to citizen information that would integrate care across the health and social care sectors and within and between organisations.[802] In the US, the state emphasised the meaningful use of patient information with interoperability incentivised and encouraged but essentially left to EHR vendors and healthcare providers to implement.

In Australia, NEHR rules focused on developing standards, building the foundations of ehealth and creating a privacy regime that emphasised patient control over health information. The PCEHR was opt-in. It was envisioned that these rules would achieve interoperability and support the value of patient-centred care. England privileged and rhetorically promoted technical solutions to interoperability that would enable patient health information to be used more efficiently and effectively as well as give patients access to their health information. Privacy was also important but balanced with the state's desire to access and use health information, maximise the take-up and use of the SCR and benefit the public good. The SCR was opt-out. In the US, rules focused on privacy, though this was within a complex legislative and jurisdictional environment and a regulatory regime that incentivised the meaningful use of health information to

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[802] Department of Health, *The Power of Information: Putting All of Us in Control of the Health and Care Information We Need* 2012, 5.

improve efficiency and effectiveness outcomes and penalised those providers who did not join the program or who failed to achieve goals in the set timeframe. The privacy regime was criticised by privacy and consumer advocates and meaningful use goals were adjusted and/or extended due to push back from key stakeholders such as healthcare providers and EHR vendors.

All three case study countries had the aspirational aim of changing practices and procedures by making patient health information accessible to patients, available at all points of care and well-integrated within clinical workflows. The state in all three countries saw organisational change as an important component of achieving desired institutional change. Australia and England created and amended organisations in order to develop, implement and regulate NEHRs. The US created the ONC, and amended it and the CMS through HITECH, in order to establish the regulatory regime for NEHRs.

Table 8-10 summarises the similarities and differences in the aspirational narrative and claims made between the three case study countries.

Table 8-10: Aspirational Narrative and Claims Made – Similarities and Differences

Aspirational Narrative and Claims Made	Australia	England	United States
Values	Most stakeholders supported efforts to move from a clinician-centred to patient-centred healthcare system. Encourage patient engagement with, and coproduction of, their healthcare. Increase patient choice, trust and satisfaction.	The state supported efforts to move from a clinician-centred to patient-centred healthcare system while retaining significant control over patient health information. Encourage patient engagement with, and coproduction of, their healthcare. Increase patient choice, trust and satisfaction. Benefit the public good.	The state and consumer advocates supported efforts to move from a clinician-centred to patient-centred healthcare system. Encourage patient engagement with, and coproduction of, their healthcare especially through meaningful choice stages 1-3. Increase patient choice, trust and satisfaction.
Norms	NEHRs seen by the state and many stakeholders as having the potential to improve the efficiency and effectiveness of care through interoperability.	NEHRs seen by the state and many stakeholders as having the potential to improve the efficiency and effectiveness of care through interoperability. More	NEHRs seen by the state and many stakeholders as having the potential to improve the efficiency and effectiveness of care through interoperability and

		expansive vision of interoperability integrating health information with social care information as part of an all of government approach to the modernisation agenda.	subsequent meaningful use of patient health information.
Rules	Strong privacy regime. Focus on giving patients control over their health information. Development of standards and other foundations of ehealth to support interoperability. Initially an opt-in system.	Strong privacy regime focused on the use of patient information and giving patients access to that information. Balanced by the state's desire to access and use patient health information and ensure maximum uptake of the SCR through a difficult opt-out mechanism.	Complex privacy regime based on HIPAA and HITECH highly criticised by consumer and privacy advocates. Incentives and penalties regulatory system to encourage interoperability and the meaningful use of health information primarily in a market system.
Practices and Procedures	Aspirational – patient information available at all points of care through the PCEHR. It was expected that clinicians and other healthcare providers would integrate the PCEHR within their workflows and use the information to get better health outcomes for their patients.	Aspirational – patient information to be available at all points of care and the SCR to be integrated within clinical workflows achieving better health outcomes for patients.	Aspirational – patient health information to be accessible to patients, available at all points of care and well-integrated within clinical workflows.

Part 4

Comparison of the Approaches Each Country Initially Adopted to NEHRs: Similarities and Differences

The major NEHR goals for each case study country were very similar. Those goals were to make health records interoperable, improve the usability of the information in health records, and (particularly in the US) meaningfully use patient health information to improve patient health outcomes. Despite these similarities, key differences – or varieties of particularism – led to each state initially adopting different approaches to NEHRs. The major drivers of different approaches were how each state saw the role of government, primarily through the lens of healthcare as a social or private good, and how to balance competing stakeholder interests over the control of patient health information. These are the varieties of particularism that inform the different approaches taken by each state.

Australia's initial approach to an NEHR was to develop and implement a decentralised national health information network (NHIN). The NHIN was to be opt-in and was broadly supported by most stakeholders. Australia justified the role of state intervention in the healthcare marketplace as desirable for two main reasons. First, healthcare was seen as a social good and successive governments had increased state funding of healthcare establishing a universal healthcare system. Second, the state at the national level was seen as the only actor that had the capacity to fund an NEHR, impose national standards and fund PIPs to make interoperability work. Privacy concerns were central to adopting an NHIN as past experience with big technology policy such as the Australia Card had led to a lack of trust in the governments purpose for imposing a system that would gather sensitive data. This drove the opt-in policy as well as the policy to build a system that would give patients more control over their health information even though it was criticised by some stakeholders, particularly clinicians, as unworkable.

By contrast, England's initial approach to an NEHR was very state centric resulting in a top-down, centralised and massive technology effort in the NPfIT. This approach was adopted for two main reasons. First, past cost overruns and big technology policy failures led to the Blair government's determination to control costs and tightly control the tender, development and implementation process. Determined not to make the costly mistakes of the past a centralised, top-down approach was seen as the best way to achieve uniform standards and interoperability and successfully achieve the goals of the modernisation agenda. Second, England – like Australia but even more so – saw healthcare as a social good and was keen to extend data integration between healthcare and other social services as part of an all of government approach to providing services to its citizens and improving their health outcomes. Privacy and the provision of some choice and some patient control over health information were important components of the system but balanced with the state's need for data access and use in order to achieve its goals. Centralisation of IT was seen as crucial in making that happen.

The United States adopted a very different, yet in some ways similar, approach to NEHRs than Australia and England. It was similar in that it had the same goals of interoperability and giving patients more control over their health information but differed in several major ways. The US state did not develop or implement an NEHR as the other two countries did. It opted to regulate the interoperability and meaningful use of patient health information through guidance, incentives and penalties. This approach was adopted as the US had a history of viewing healthcare more as a private rather than a social good though this was slowly changing with state funding of the VA, Medicare and Medicaid increasing over time. However, the more robust regulatory role the state adopted with the HITECH Act was only possible as part of the response to the GFC. These circumstances gave Democrats – who were more favourable to government intervention in the healthcare market place and some of whom saw healthcare as a social good – the opportunity to increase the state's role in driving institutional change in the form of NEHRs. However, this approach allowed healthcare providers to choose whether or not they would participate and when they would do so. It also left interoperability solutions to EHR vendors and their implementation and outcomes to healthcare providers. This approach raised intense privacy concerns from privacy and consumer advocates and resulted in market forces sometimes acting as barriers to interoperability and improved patient outcomes. These problems and issues will be discussed further in the next chapter.

Table 8-11 summarises the similarities and differences in the initial approaches each of the case study countries adopted to NEHRs.

Table 8-11: Initial Approaches Adopted to NEHRs – Similarities and Differences

Initial Approaches	Australia	England	United States
Values	State imposed patient-centred.	Patient-centred.	Patient-centred but left
Norms	Interoperability – decentralised NHIN then centralised PCEHR.	Interoperability – top-down centralised SCR and joined-up services.	Incentivised interoperability.
Rules	Usability – standards, privacy, patient control of their health information, opt-in.	All system components specified by government, privacy regime, opt-out.	Regulatory approach to incentivisation and penalties. Left to the market (EHR vendors

			and healthcare providers) to choose.
Practices and Procedures	PIPs to incentivise technology use and drive uptake.	Incentive payments for GP technology acquisition and state efforts to increase the usefulness of the SCR and its uptake.	Tried to drive better health outcomes through incentivising healthcare provider technology acquisition and meaningful use incentives and penalties.

Conclusion

The many similarities in the development of institutional pressures and tensions resulted in Australia, England and the US viewing NEHRs as useful mechanisms through which they could achieve healthcare policy objectives to improve the efficiency and effectiveness of healthcare service delivery through increased interoperability, usability and the meaningful use of health information and thus benefit patient health outcomes. Governments in each country adopted very similar positive NEHR rhetoric touting the potential benefits of NEHRs. Initially, as will be seen in chapters 9 and 10, these proved to be aspirational, although some progress had been made by 2015. The key lesson from the research is that similarities in institutional pressures and tensions combined to create critical junctures that enabled health record change from paper to ehealth and NEHRs and, most crucially, drove state intervention in EHR markets resulting in state NEHR programs.

The key outcome of the differences outlined in earlier sections of this chapter was that each country initially adopted a different approach to NEHRs. This was primarily due to different perceptions of the role of government and important differences in the way each country addressed key areas of concern. Those areas of concern were over the role of the state in developing, implementing and regulating NEHRs, and different emphases on how much control to give patients over their health information and how to balance those rights with other stakeholder value and norm sets. Crucial here was that both Australia and England saw healthcare as a social good while the US saw it as a private good. Therefore, Australia initially adopted a decentralised NHIN approach to an NEHR, then, when that failed to produce expected outcomes, adopted a centralised approach through the PCEHR but retained patient control over their health information and thus an opt-in system. Privacy concerns were crucial in the way Australia approached NEHRs, as was the view that only the federal government had the capacity to successfully implement a nationwide ehealth system and NEHR. England adopted a centralised, government funded, top-down, ehealth and NEHR solution for a number of reasons: its unitary (rather than federalised) system; the well-established and widely supported government funding of healthcare in the NHS; and the fact that prior efforts at more distributed IT systems had been seen as expensive failures; and the desire of policy makers to actively and quickly implement a modernisation agenda. The US, by contrast, adopted a regulatory approach using incentives and penalties to encourage interoperability and the meaningful use of patient health information. There was no central government development and implementation of NEHRs as in Australia and England. Instead, legislation and executive orders directed organisations such as the ONC and CMS to regulate, support and provide leadership for the development and nationwide implementation of NEHRs that would improve the quality and efficiency of healthcare. Legislation also addressed the contentious issue of patient control over health information but not to the same extent as in Australia and England.

Chapter 9 will provide a comparative public policy evaluation of each country’s NEHR program and make some assessment of success and/or failure in the categories of process, goal attainment, distributional outcomes, political consequences and normative justification. Chapter 10 will combine the evidence presented in previous chapters with the comparative evaluation of this chapter and the evaluation made in Chapter 9 to present an historical institutionalist explanation of why state efforts to pursue the development, implementation and regulation of NEHRs at the national level in the three case study countries resulted in substantially similar outcomes despite adopting initially different approaches.

Chapter 9 Comparative Public Policy Evaluation

"I think it's quite achievable, and I'm just appalled it still hasn't happened."[803]

Introduction

This chapter evaluates the success of NEHR policy programs in Australia, England and the United States. The analysis broadly follows that of Marsh and McConnell, McConnell, and Newman but is adapted to my own framework to fit the contours of my policy cases. The approach adopted compares the three case study countries by highlighting similarities and differences, strengths and weaknesses, and what worked well and what didn't work well in NEHR programs. I do this by answering the questions outlined in the comparative public policy evaluation section of Chapter 3 – Research Design. The evaluative discussion proceeds as follows.

Part 1 will evaluate processes used to affect policy change. Process in this context refers to "the path along which policy statements are converted into instruments for implementation."[804] Processes include substantive legislation, public programming, and the creation of new organisations and the amendment of old organisations in pursuit of policy outcomes. Part 2 will evaluate the goals and objectives of NEHR policy focusing on the extent to which stated policy objectives were achieved or not. The primary policy intent in each country was to replace paper health records with NEHRs and thus improve patient health outcomes. Four main objectives emerged from NEHR programs. They were interoperability, usability and the meaningful use of patient health information, as well as increasing patients' control over their health information.

Part 3 will evaluate programmatic and operational dilemmas that impacted NEHR policy success or failure. Dilemmas were numerous. How to move from a clinician-centred to patient-centred healthcare system required dealing with privacy issues, how much control to give patients over their health information, and whether or not to adopt an

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[803] Former Senior Official, on implementing an NEHR, Interview, 2014.
[804] Joshua Newman, "Measuring Policy Success: Case Studies from Canada and Australia," *Australian Journal of Public Administration* 73, no. 2 (2014): 192.

opt-in or opt-out NEHR system. Other dilemmas revolved around issues related to individual healthcare identifiers, function creep, federalism, the speed of developing and implementing NEHR policy programs, uptake and use of NEHRs, the cost of NEHR policy programs, data blocking, the structure of NEHR programs. Technical dilemmas also emerged over interoperability, usability and the growing realisation that delivery of NEHRs was too slow to leverage new technologies. Part 4 will evaluate the distributional outcomes for the major stakeholders. Those stakeholders were the state, healthcare providers, EHR vendors, healthcare consumer and privacy advocates, and patients.

Part 5 will evaluate the political consequences of NEHR policy programs. It asks the question to what extent did governments, or other political actors, benefit from the public reaction to, or perception of, NEHR policy? Part 6 will evaluate the normative justification for NEHR policy programs. It focuses on the characteristics of liberal democracies, such as public value/value for money/the public good, patient control/choice/trust, and power relationship ratios. The key questions addressed are stated in Chapter 3.

The chapter will conclude with an assessment that evaluates the extent to which each country's NEHR policy program was successful, including a brief discussion of positive and negative structural alignment.

Part 1

Processes Used to Affect Policy Change

> *In Australia, HealthConnect or the health record is probably the worst example of any form of government change I've ever had anything to do with. I just think it's appalling what's happened.*[805]

In all three case study countries, ehealth and NEHR public policy were converted into substantive legislation and public programming, and as such can be considered

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[805] Former Senior Official, Interview.

successful even though the process suffered setbacks (discussed in Part 2 and Part 3) in each country. The purpose of NEHR policy was to replace paper health records with EHRs that could be shared nationally. Legislation and public programming aimed to improve the interoperability, usability and meaningful use of patient health information and give patients more control over their health information. It also created new organisations and amended old organisations in order to develop, implement and regulate NEHRs; authorised NEHR funding; and set up and funded incentive programs in an effort to achieve stated NEHR goals.

The case for NEHR policy programs was well articulated in all three case study countries, as shown in Chapter 4 and the empirical chapters, and resulted in significant NEHR legislation and programming. In Australia, ehealth and NEHR policy was initially driven by the Commonwealth Government through a process that was coordinated with the states through COAG. Coordination through COAG was very important as it was the basis for shared funding of NEHR projects, the establishment of organisations such as NEHTA and the development of policy instruments such as the PCEHR. In order to pursue the NEHR goals of interoperability, usability and meaningful use the Commonwealth Government, once agreement with the states through COAG had been secured, passed legislation to establish MediConnect, HealthConnect, NEHTA, the PCEHR, ehealth and NEHR standards, Healthcare Identifiers, MyHR, and the ADHA. The legislation and public programming process, including funding, has been detailed in Table 5–1: Australia – Historical Chronology of Main Events in Chapter 5. Funding for HealthConnect, NEHTA, the PCEHR, ehealth trials, practice incentive payments, and up-take efforts was continually made available from 2000 to the present even when progress was heavily criticised, programs failed, and funding was labelled by critics as a rescue package. The process of organisational creation and amendment, and the process of developing and implementing an NEHR from HealthConnect through the PCEHR and then on to the My Health Record (MyHR) was detailed in Figure 4–4: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time in Australia in Chapter 4. Organisations such as HealthConnect and NEHTA were successfully set up and ehealth trials successfully undertaken. Some of the building blocks of ehealth and NEHRs, such as standards and health identifiers, were successfully implemented and the rules and regulations associated with the PCEHR successfully gave patients significant control over their health information.

In England, similarly to Australia, public policy in ehealth and an NEHR, in the form of the SCR, was successfully converted into substantive legislation and public programming. Information for Health (1998) and the NHS Plan (2000) resulted in the state coordinating an information strategy for the NHS that supported integrated care through NHS-wide standards and infrastructure (the NPfIT component of ehealth) and patient care (the SCR component of NPfIT that was to centralise patient information in EHRs). The legislation and public programming process, including funding, was detailed in Table 6–1: England – Historical Chronology of Main Events in Chapter 6. Funding for the development and implementation of the SCR and incentives for GPs and hospitals to adopt interoperable ICT continued throughout the program. Even though the SCR was scaled down in 2010, and the NPfIT had been criticised for losing large amounts of money, funding continued for the SCR, and over time funding to improve the utility of the SCR increased. The process of organisational creation and amendment, and the process of developing and implementing an NEHR in the form of the SCR were detailed in Figure 4–7: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time in England in Chapter 4. This is further discussed in Chapter 10 but shows both organisational success and failure.

The NPfIT and SCR programs were successfully created as were their implementing organisations. However, as with Australia they sometimes failed to achieve their objectives and were cancelled or replaced as can be seen in Figure 4–7 in Chapter 4. Centralisation was heavily criticised, and was abandoned for much of the IT process after 2010, but remained in place for the SCR as it continued to be stored centrally on the NHS spine.

As with Australia and England, public policy aimed at improving interoperability, usability and meaningful use was successfully converted into substantive legislation and public programming in the United States. A regulatory, leadership, and incentive and penalties approach to making EHRs nationally shareable, providing privacy rights and increasing patient control over health records was adopted. The *Health Insurance Portability and Accountability Act* (HIPAA), passed in 1996, was a regulatory approach that provided data privacy, and rights of access to, and portability of, an individual's medical information. In 2004, President Bush issued an Executive Order establishing the position of the National Coordinator for Health Information Technology (ONC) to provide leadership for the interoperability of EHRs in an effort to improve the quality and efficiency of patient healthcare through the widespread use of ICT. The major piece of legislation designed to drive interoperability, usability and the meaningful use of patient health information was the passage of the *Health Information Technology for Economic and Clinical Health Act 2009* (HITECH). HITECH combined a regulatory approach with incentives and penalties as discussed in Chapter 7. The legislation and public programming process, including funding, was detailed in Table 7–1: The United States – Historical Chronology of Main Events in Chapter 7. Significant funding was attached to HITECH, particularly to incentive programs, with funding reaching $35 billion by 2017.

Organisational change, including the creation and adaption of organisations, was successfully undertaken in order to implement NEHR policy. The Centers for Medicare and Medicaid Services administered HIPAA and established EHR incentive and penalty programs under HITECH. This included the Meaningful Use of EHRs program stages 1 to 3. The ONC promoted the use of health information technology (HIT), the adoption of HIT standards and the improvement of HIT privacy and security provisions. Interestingly, over the NEHR time period US organisations were not replaced but acquired more regulatory powers as part of a layering process. This will be discussed further in Chapter 10. The process of organisational creation and amendment was detailed in Figure 4–9: Heuristic Framework Explaining eHealth Institutional Stability and Change Over Time in the United States in Chapter 4.

Box 9-1: Stakeholder Reflections on Processes Used to Affect Policy Change

I think it was a fundamental flaw in the system that Medicare wasn't properly engaged in the delivery of this thing. I think that part of the development of the NEHTA concept was all the private computer companies thinking, "We're going to make more money out of a NEHTA body than out of Medicare, so we'll tell everyone the private sector can do this." And I think that was a very, very, very unhelpful intervention from companies like IBM who I think really contributed as well to the demise of some of this stuff. I think the private sector really saw this as a cash cow, and that hasn't helped. There's fashions that swing back and forth about what the private sector can do and how much better it can do from the public sector, but it certainly hasn't proven to be correct here.[806]

I think there was a disconnect, and this is very common with IT projects, the text books tell you. What was an incredibly complex and slow and painstaking exercise required to get an electronic health record was imagined by people - ministers and senior bureaucrats and decision-makers - as being, "Why couldn't they get that done much more quickly?" They were expecting a timetable which was not consistent with the timetable for the people wanting to design and implement the system. There was a disconnect there. There was a belief that the system should be rolled out more quickly, and I come back to my paradox before: what was there was torn down because it was seen to have failed, but then it was replaced with nothing really, so it ended up taking even longer. That's not unusual in government. Maybe it was fulfilling the kind of design and implementation objectives, but it wasn't fulfilling the government's policy objectives, which was to have something quickly on the ground, something to launch, something to announce and maybe also something tangible. And I can see why politicians and governments wanted those sorts of things because they wanted something that could demonstrate that there was actually something happening as opposed to just a very long-term reform agenda. Long-term reform agendas always struggle in Australian government I think it's fair to say, or really in all levels of Australian government. It is hard to get long-term agendas through because they don't meet the expectations of the elected representatives, most particularly.[807]

Of the 12 billion pounds that NPfIT, the National Program for IT spent, nearly 97% of the intended benefit was not realised. Absolutely terrifying. When you think how short we are of money."[808]

Part 2

Goal Attainment

The primary policy intent, or goal, of all three case study countries in adopting NEHR programs was to replace paper health records with EHRs that could be shared nationally with the aim of improving patient health outcomes. The plethora of objectives the state

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[806] Former Senior Official, Interview.

[807] Rob Wooding (Former Division Head of HealthConnect), Interview, 2014. Bettina McMahon argues that now "policy makers are a bit more realistic about the sort of lead times that you need to realise measurable benefits." McMahon (Head of Risk and Assurance, Formerly Head of Policy and Information Services, NEHTA), Interview, 2014.

[808] Murray (Director, eHealth Unit, University College London), Interview.

in each case study country associated with NEHRs over time can be collated under the four major challenges of interoperability, usability, meaningful use and patient control of health information. Summarising previous explanations, the challenge of interoperability was to make patient health information available at all points of care. The challenge of usability was to ensure that relevant and reliable patient information was in a format that could be used by both clinicians and patients. This included increasing clinical use of NEHRs by integrating them within clinical workflows with the expectation that they would be used in the normal process of providing care. The challenge of meaningful use was that patient health information in NEHRs would enhance the efficiency and effectiveness of care and thus improve patient health outcomes. Meaningful use was not purely focused on the patient but was to benefit other stakeholders (discussed in Part 4 on distributional outcomes in this chapter) such as the state and providers of care. Efficiency of care focused on lowering healthcare costs; improving the process, coordination and continuity of care; and efficiently using health information in NEHRs for the public good. Effectiveness of care focused on improving the safety and quality of care; increasing patients' engagement with, and co-production of, their healthcare; getting more value for money; improving patient health outcomes; and effectively using health information in NEHRs to improve the public good. The challenge of increasing patient control of health information was to protect patient health information by adopting appropriate privacy regimes; facilitate a move from clinician-centred to patient-centred care; increase patient uptake of NEHRs; and give the state a mechanism through which to address pressing issues over the ownership and use of patient health information.

Interoperability

The challenge of interoperability was to overcome the fragmentation of health information by integrating ICT systems to make patient health information available at all points of care 24/7.[809] For example, in 2008 the US envisioned EHRs being able to

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[809] Personally Controlled Electronic Health Records Act, 2012; Frank Burns, *Information for Health: An Information Strategy for the Modern NHS 1998-2005*, (NHS Executive, 1998), 15; Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, United States Congress.

exchange "information reliably and securely, regardless of where the information originates or being sent or received."[810] The key institutional characteristics that determined interoperability outcomes were the NEHR regulatory approaches taken by each state, the complexity of the NEHR institutional environment (discussed in Part 3) and the common barriers to interoperability (also discussed in Part 3) all three states faced.

> The government has also been pushing this whole need for interoperability because they recognise that what's been holding everybody up in really making good use of data, is the lack of interoperability and the lack of connectivity between systems, and that has now been recognised as the primary problem.[811]
>
> Today the biggest problem for the industry is the lack of interoperability. There are 15,000 health apps in the app store and none of them talk to each other. There is about 300 to 500 trackers and none of them talk to each other. They all work in silos, they all don't share data, their data structures – their APIs – are not open enough or friendly enough to actually use. None of these actually talk to any healthcare system or any EHR.[812]

Three different regulatory approaches to interoperability were initially adopted, one by each case study country. While both Australia and England chose to adopt a state-developed and state-implemented NEHR, Australia initially approached NEHR interoperability from a decentralised perspective with HealthConnect. As discussed in Chapter 8, this approach was driven by trade-offs reflecting strong privacy concerns over the state controlling and centralising patient health information and the fact that clinicians and other healthcare providers lacked the appropriate ICT to quickly build an effective interoperable system that could centrally store patient health information.[813] When HealthConnect failed Australia adopted the centralised PCEHR. Centralisation

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[810] The National Alliance for Health Information Technology, "Report to the ONC on Defining Key Health Information Technology Terms," 2008.

[811] Evelyn Hovenga (CEO eHealth Education and Managing Director of Global eHealth Collaborative), Interview, 2018.

[812] Kamal Jethwani (Senior Director of Connected Health Innovation at Partners HealthCare), Interview, 2014.

[813] By mid 2004 plans to create a national patient record network were seen as "little more than a pipe dream" due to a lack of interoperability. "We don't even have compatible software between GPs, specialists, hospitals and medical centres." Dr Sue Page (President of the Rural Doctors Association of Australia), cited in Grayson, "IT Snags Put Database on Hold," C26.

was adopted, and persisted in the case of England's SCR, because policy makers decided that decentralised approaches had failed to achieve desired efficiency and effectiveness goals in the past and that centralisation made systemic sense. England maintained a centralised system approach to the SCR for the entirety of the program even though much of the centralised IT nature of the NPfIT was abandoned. With the passage of HITECH the US centralised its regulatory approach to NEHR incentives and penalties and continues to do so. However, development and implementation of NEHRs was left to the private sector.

Centralisation was seen as important for achieving efficiency and effectiveness outcomes, as discussed below under the challenge of meaningful use, and for addressing privacy and patient control of health information challenges. It was thought that the process of care (coordination and continuity) would be improved by sharing patient health information between GPs, specialists, hospitals and allied health professionals, providing seamless care for patients moving between points of care. For example, interoperability supported the concept of integrated care where "the needs of patients, not the needs of institutions [were] to be at the heart of the new NHS,"[814] and the notion that information would support day-to-day clinical practice."[815] This view was shared by all three case study countries and in Australia and England required the completion of essential national infrastructure projects including the networking infrastructure, national applications and standards development. Of particular importance was the issue of the matching of patients with their health record. England adopted the NHS number and Australia the Individual Health Identifier (IHI). Because of significant political and individual opposition to a single identifying code or number the US left this

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[814] Burns, "Information for Health: An Information Strategy for the Modern NHS 1998-2005," 15.

[815] Burns, 15. Pal provides a different perspective on the state's desire for centralisation. "I think governments are interested most in monitoring and performance and I think from that perspective the more centralised it is the better and I think there are lots of superficial difficulties that fragmented records present which in theory could be very neatly solved by having systems that communicate better. I think that people always assume that if you can measure something better it will work better. I think the jury is still out on that." Kingshuk Pal (GP and Researcher at the eHealth Unit, University College London), Interview, 2013.

to provider organisations with no national resolution of the issue except in the case of the VA.[816]

Interoperability was not achieved in Australia under the HealthConnect program and by 2015 was only partially successful with the PCEHR program. For example, as of early 2015, Calvary Health Care was "actually not transmitting our discharge summaries into the PCEHR because we are still waiting for the infrastructure to be put in place."[817] In England, interoperability was marginally more successful than in Australia as SCR infrastructure made it available at more points of care. However patients' access to their health information was mediocre at best due to the failure of HealthSpace.[818] In the US, interoperability was fractured among a large number of healthcare providers and therefore only partially successful. An example of the lack of interoperability and the real difficulties patients faced in accessing their health records, despite legislation giving them access rights, was the frustration Vice President Joe Biden felt in 2015 when trying to get his son's records moved from one hospital to another.

> I was stunned when my son for a year was battling stage 4 glioblastoma," said Biden. "I couldn't get his records. I'm the vice president of the United States of America. … It was an absolute nightmare. It was ridiculous, absolutely ridiculous, that we're in that circumstance.[819]

When asked how portable patient information is and whether it is interchangeable with other systems, John Carlson, MD, stated:

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[816] Suarez argued that this lack of a unique patient identifier across all healthcare systems creates "a lot of complexity about patient matching"[816] with the result that clinicians are at a "very high risk of not being able to see all the data" and that there is a risk that some, or all, the data they are seeing is not actually the patient's data. Each healthcare system may have a single patient number that only applies to that system. Walter Suarez (e Director for Health IT Strategy and Policy for Kaiser Permanente), Interview, 2014.

[817] John Vinen (Director Medical Services Calvary), Interview 3, 2015.

[818] "Policy makers' hopes that deploying HealthSpace would lead to empowered patients, personalised care, lower NHS costs, better data quality, and improved health literacy were not realised over the three year evaluation period. Overall, patients perceived HealthSpace as neither useful nor easy to use and its functionality aligned poorly with their expectations and self management practices. Fewer than 100 of 30,000 patients expressed interest [in using email-style messaging]." Trisha Greenhalgh et al., "Adoption and Non-Adoption of a Shared Electronic Summary Record in England: A Mixed-Method Case Study," *British Medical Journal* 340, no. jun16 4 (2010): 1.

[819] Joe Biden (Vice President of the United States), cited in Fred Schulte and Erika Fry, "Death By 1,000 Clicks: Where Electronic Health Records Went Wrong," Kaiser Health News, 2019.

> No it isn't, that's a huge problem, so what the U.S. government should have done is just mandate one system be used. That's how they proved that EMR was cost effective from the Veterans Administration, the VA hospitals, that system works very well but nobody had a choice in implementing it. It came down from the top "you are using this system" and so if you were in [a] Seattle VA hospital you could look up somebody's medical record that was in West Virginia. But the problem is that they don't talk to, you know Centricity doesn't talk Allscripts. Allscripts doesn't talk to Meditec. It's a long-ways off and I think that how easy it was to get these things all camps from one to the next to the next. I mean I can send all the medical records via email or fax to anywhere, and that's very easy. I can look up John McClary's office visitor, September 4, and then send it to somebody in Pittsburgh in the next 30 seconds and it arrives 4 hours later, but the person in Pittsburgh, I can't give him a code so he can look it up in the cloud. They receive it in a PDF.[820]

In 2015, the fax machine, letters and printed documents carried by patients were still widely used to transfer patient health information between points of care in all three countries.

Box 9-2: Stakeholder Perceptions of NEHR Interoperability Success

> So let us be quite clear here. The organisation that NEHTA and DoHA will have to most rely on to gain traction with their PCEHR initiative are saying the major thrust of the plan is wrong.[821]
>
> We had religious wars between providers who were on different systems in order to get them to essentially agree to common standards in order to enable the information to flow and to be interoperable and actually accept the portability of patient health information.[822]

Usability

> *The Commonwealth Government has effectively built an electronic health record system disconnected from the provision of health services. Most EHR systems are built by health service providers, so the PCEHR is an exception to that.*[823]

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[820] John Carlson (MD), Interview, 2014.

[821] David More, "The Government Is Heading In the Wrong Direction with the PCEHR - AMA," *Australian Health Information Technology Blog*, 2010.

[822] Anthony Honeyman (Former Senior Executive Australian Health Insurance Commission and Chairman APIS), Interview, 2018.

[823] Paul Dugdale (Canberra Hospital Health Services Specialist and Academic at the Australian National University), Interview, 2014 1.

NEHRs were to be the primary mechanism for accurate and reliable patient information to be instantly available at all points of care. To achieve this, patient health information had to be in a form and format that was usable by both clinicians, as part of their regular workflow, and by patients to promote patient engagement with, and co-production of, their healthcare. Usability required common standards for coding and other health information, technical standards for the transmission of information between points of care, and data that was valued by the clinician and the patient and that was expanded over time. It also required uptake and use by both healthcare providers and patients and data that had clinical value (timely, reliable and relevant to clinical needs) which seamlessly integrated within clinical workflows. Patient health information had to be protected in order to build trust into the NEHR system.

Stakeholders were highly supportive of usability goals as they supported the argument that “if you have data accuracy you get better connectivity, better information, better linkages, better sharing, all of that.”[824] There were some successes, particularly in tightly integrated systems in the US such as the Mayo Clinic where clinical data stewards manage data through a knowledge management program “to get the best possible data from their system.”[825] Hovenga argued that as a result “clinicians have learned the value of data [including] identifying key data standards” and “absolutely” patient outcomes have been improved “because they’re just getting better care basically.”[826] Some interviewees noted that the integration of information in EHRs had improved some aspects of clinical workflows. Internal communication within a healthcare organisation was easier through the documentation of an EHR and that this ease of communication and document transfer was expanded to other organisations if they used the same EHR system making “communication much clearer and more efficient.”[827] The EHR could

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[824] Hovenga, Interview. Kmet argued that clinicians at the point of input have the obligation to make sure the information is accurate – “garbage in, garbage out.” Walter Kmet (CEO WentWest Medicare Local), Interview, 2013.

[825] Hovenga, Interview.

[826] Hovenga.

[827] Ellen Michael (Registered Nurse and Patient Care Co-ordinator at Kaiser Permanente), Interview, 2014.

also automate some workflows, producing timeliness and better patient outcomes.[828] Robin Caza explained:

> Another good thing is many different people can look at the chart at once instead of one paper chart on ICU in Room 22. I could look at it here in the Recovery Room and maybe that patient's coming down to pre-op. I can look at his chart.[829]

Australia and England successfully implemented individual health identifiers and there was some limited success in implementing secure transfer of information protocols in all three countries including NASH certificates in Australia. There was also a view that EHR "software has reduced some typical types of clinical mistakes common in the era of handwritten notes."[830]

However, there was a more widespread view, particularly amongst healthcare providers, that usability goals had only been partially achieved in all three case study countries. Criticism centred on the following characteristics of usability.

1. A lack of policy clarity in the development and implementation of standards in areas such as information management, data structures and contents, and telecommunications, with the result that policy and regulations did not get the backing and participation of all key stakeholders.

2. While NEHRs successfully increased content, clinicians did not see the data as clinically useful content that would drive uptake and use.

3. NEHR data was seen by healthcare providers as lacking in quality, containing too much information, particularly in the form of PDFs,[831] that took too much time out of a typical clinical visit to be worth the effort of going through. Paradoxically,

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[828] Jack Meyer (President of the Economic and Social Research Institute), Interview, 2014; Juan Montanez (Specialist in Health Information Technology, Health Management Associates), Interview, 2014; Capri Dye (Senior Consultant at Health Management Associates), Interview, 2014.

[829] Robin Caza, Interview, 2014.

[830] Raj Ratwani (Researcher at MedStar Health in Washington D.C.), cited in Schulte and Fry, "Death By 1,000 Clicks."

[831] Hovenga argued that "you can't readily analyse or do much with the data itself contained in those PDFs." Hovenga, Interview.

because NEHRs were designed as a summary of patient health information some clinicians did not rely on them because they did not contain as much information as their own clinical notes.

4. NEHR IT negatively structured clinicians work and the "combined burden of all of them hitting clinicians simultaneously made office practice basically impossible."[832]

5. Incomplete records (in particular due to opt-in and patient control over what information went into the NEHR and who could access it) meant that NEHRs were unable to achieve the goal of being a life-long (longitudinal) record of a patient's health information.

Box 9-3: Stakeholder Perceptions of NEHR Usability Success

A major criticism of the PCEHR was that it was not fit for purpose as a clinically useful health summary because of its initial fundamental nature as a collection of PDFs rather than a computable format.

> To be successful, the electronic medical record must be easy to use, support what doctors already do, and be compatible with current clinical practice methods.[833]

More argued that the PCEHR was a technically driven project that failed to "focus at all on actual patient outcomes" and that researchers have "really struggled to actually demonstrate any useful end point to all this. No-one that I can find actually knows just who the PCEHR is for. If it is meant to be for patients, then it's appallingly designed for them. If it's meant to be for the docs and clinicians, the it is worse than useless for them. The core of my view on all this is that this is a program that has been invented by a collection of bureaucrats who had no clue what they were doing. It has now cost us all a billion dollars and can never work because the docs are simply not going to put up with it. It's not something that suits what they want."[834]

> We haven't worked out quite how to get to that fantastic system that is both physician seductive and consumer seductive, where everyone desperately wants to be a part of it because it's so good and it's so useful. What's there, they often say a camel is a racehorse designed by a committee.[835]

> There is still much more work to be done to refine the e-health systems as they are developed and rolled out. Clinical guidance and input remains crucial to a successful implementation. There are still some fundamental aspects of the design that means the PCEHR is not useful from the medical practitioners' perspective. If the system is not being used by clinicians, we need to know

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[832] Schulte and Fry, "Death By 1,000 Clicks."

[833] Dr Andrew Pesce (AMA President), in More, "The Government Is Heading In the Wrong Direction."

[834] David More, Interview, 2014.

[835] Brian Richards (The Australian National University), Interview, 2014.

> why, and then make the necessary changes. We cannot afford to lose the significant investment the nation has made in this important health infrastructure.[836]
>
> There's a lot of usability issues with the PCEHR.[837]

Fraser Booth did not think that the SCR would be as effective at improving patient health outcomes as the state claimed because "the information that was there was never going to be particularly enough in my opinion. I think a summary is never as good as the blow by blow full data."[838]

Klecun's research showed hospitals that implemented NPfIT IT "had terrible problems, so it was almost a disaster story and then it slowly started to get better." She argued that IT "structured peoples work" thus transforming the work they did, including imposing "some constraint on their work because the way their electronic record is."[839]

One of the promises of EHRs was:

> to put all of a patient's records in one place. [However], critical or time-sensitive information routinely gets buried in an endless scroll of data, where in the rush of medical decision-making – and amid the maze of pulldown menus – it can be missed. In America, we have 11 minutes to see a patient, and, you know, you're going to be empathetic, make eye contact, enter about 100 pieces of data, and never commit malpractice. It's not possible![840]

Meaningful Use

The term meaningful use of patient health information in EHRs was primarily used in the US as part of the meaningful use incentive program. It has since been adopted, though not regularly used, in Australia and England. All three countries had broadly similar NEHR use outcome goals that aimed to "instigate and maintain meaningful usage of eHealth solutions until the point where using eHealth solutions and services becomes a part of normal 'business as usual' clinical practice."[841] The goals were as follows:

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[836] Steve Hambleton (AMA President), cited in The Australian Medical Association, "Dr Haikerwal NEHTA Resignation Raises Serious Concerns About Clinical Input to PCEHR," *Targeted News Service*, August 15, 2013.

[837] Bernard Borg-Caruana (Program Director, Information Technology Division, IT Strategy and Management Branch, Department of Health), Interview, 2015.

[838] Fraser Booth (Director, Patient Access To Electronic Records Systems (PAERS)), Interview, 2013.

[839] Ela Klecun (London School of Economics), Interview 2, 2013.

[840] John Halamka (Chief Information Officer at Beth Israel Deaconess Medical Center, who served on the EHR standards committees under both George W. Bush and Barack Obama), in Schulte and Fry, "Death By 1,000 Clicks."

[841] National E-Health Transition Authority, "Evolution of EHealth in Australia Achievements, Lessons, and Opportunities" (Sydney, 2016), 8.

1. NEHRs were to be used in the normal process of providing care.
2. The efficiency of care would be improved by lowering healthcare costs and improving the process (integration, coordination, continuity) of care.
3. The effectiveness of care would be improved by utilising NEHR information in clinical decision support, improving the safety and quality of care, and increasing patient engagement with, and co-production of, their healthcare.
4. By achieving 1–3 above, patient health outcomes would be improved.

There was a significant difference between the US and both Australia and England in terms of values and a focus on reducing healthcare costs. This reflected that the basis of development of US EHRs was billing optimisation and, to some extent, compliance. In the US quality of health information initially had more to do with coding accurately for billing purposes. Secondary purposes such as usability for clinicians and patients and achieving meaningful use outcomes, gained importance over time.

Meaningful use goals have been hard to achieve, though there has been some progress and small successes as detailed in the case study chapters. In particular, there were some successes in tightly integrated provider settings in the US. Pritts argued that "there has been, I think, a real uptake in a lot of the requirements under meaningful use. Again, I think it depends on the organisation. We've done a lot of outreach in this area to try and bring people along and up to speed."[842] Right from the start of NEHR programs, policy makers claimed that NEHRs would lower healthcare costs. For example, in Australia "according to Government budget figures the new system (HealthConnect) was expected to generate $25 million in savings during the first four years of operation."[843] Little evidence for these savings being achieved has been found by this research with the

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[842] Pritts (Chief Privacy Officer, Office of the National Coordinator for Health Information Technology (ONC), Interview.

[843] Jenny Macklin (Shadow Minister for Health), "Wooldridge Fails on E-Health," 2001.

small exception that some interviewees noted actual and potential savings due to a reduction in duplicate clinical tests and the elimination of waste in the system.[844]

> I would say it would eliminate waste. You will get much better value for the money you spend. I don't know of any country where the spending on health care goes down. Maybe they try to keep it flat but it's very rare that it goes down. The point is to try to keep it from going up. Try to keep it more where it is.[845]

Counter-intuitively, Pal argued that barriers to the flow of information do not necessarily lower costs or improve outcomes and that inefficiency can sometimes "reduce costs because if people are getting sub-optimal care perhaps that's actually cheaper. Health interventions rarely save money because if you're giving more people better care, surely that's more expensive."[846] Better healthcare and more interventions may lead to people living longer with chronic disease and co-morbidities that are more expensive to treat over time than if they died earlier from acute disease such as a stroke or heart attack.

Pal also argued that providing patients with more information in their NEHRs does not necessarily mean they will change their behaviour and improve their health outcomes. Increasing patient engagement with, and coproduction of, their healthcare has also proven difficult. Amir Hannan stated that "patients found it really helpful to be able to look at their data and found it really interesting"[847] but noted that he spent seven years trying to get patients engaged with their EHR and only achieved less than a 20% success rate.[848]

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[844] Jonathan Teich argued that EHRs have reduced costs through fewer laboratory tests being ordered, pricing information being in front of doctors so they can "make decisions that are pertinent to cost," and predictive analytics that identify "whether a patient has a high likelihood of re-admission, post-operative infection or a fall in the hospital." Jonathan Teich, Webinar, 2014.

[845] Director, Kaiser Permanente International, Interview, 2014. This view was supported by Podger who suspected "it won't be so much lower costs but achieve better outcomes, more cost effectiveness. But I think it's hard to expect that there will be direct savings." Andrew Podger (Former Secretary of the DoH and Public Service Commissioner), Interview 1, 2015.

[846] Pal, Interview. This view was supported by Yacoe who noted that "having a test can lead to higher costs because of the amount of indeterminate findings." Marshall Yacoe (Radiologist at Kaiser Permanente), Interview 2, 2014.

[847] Amir Hannan (GP and patient engagement evangelist), Interview 1, 2013.

[848] Amir Hannan, Interview 2, 2013. In comparison, "Kaiser has 70% level of patient engagement with their EHR." Director, Kaiser Permanente International, Interview.

NEHRs have had some success in improving the process, safety and quality of care including benefitting some clinical workflows. Joy Pritts outlines one of the benefits of EHRs.

> Your ability to analyse the information about what treatment you've given patients and what has worked and what hasn't worked. You can't do those kinds of analytics in a paper world.[849]

Martha Yacoe-Daley thought that EHRs are a much better system than the old paper-based one. Firstly, any life-threatening problems are in the record, even scanned copies of old paper records. "I can look at them and see if there is a problem, so it's always there. And that's a big deal. Usually I click on it, I look up, looks routine, no big deal, but if it was a big deal, it's right there and usually if there was a really big problem, a friend, one of my colleagues will write, put it on the problem list." Secondly, "My interview with patients has gotten shorter. I don't ask about things that are negative on the review of systems. I don't go over "I see you're not diabetic and you're not hypertensive. I skip all that. I know that, I read it, I just really focus on the things that are important. I will go over and say 'I see the only medications you are taking are X and Y, is that correct?' "[850]

Box 9-4: Stakeholder Perceptions of NEHR Meaningful Use Success

> If 30% of patients looked at their records at least twice a year, we think 10% of appointments in general practice would be saved.[851]
>
> GP clinical desktop computing systems improve service delivery – electronically printed prescriptions where the pharmacists don't have to decipher handwriting. This has led to a big reduction in incorrect dispensing of medication errors and also for patients moving between healthcare providers.[852]
>
> It's an evolving process and it evokes work and the idea that it saves time, or saves work, it's nine times out of ten a fallacy. It creates work. It's work at least with a higher quality and more effective healthcare so it's worth doing but I think it needs to work and I think that is true for the patient.[853]
>
> One of the most expensive areas of cost for our employee population within healthcare was pregnant employees. Physicians across the system were ordering multiple ultrasounds even though previous ultrasounds were available. Physicians often don't realise how much we are paying for these. On average each pregnant woman was getting about 13 ultrasounds, versus

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[849] Pritts, Interview.

[850] Martha Yacoe-Daly (MD, Kaiser Permanente), Interview, 2014.

[851] Brian Fisher (GP and Director of PAERS), Interview, 2013.

[852] Dugdale, Interview 1, 2014.

[853] Tony Cornford, Interview, 2013.

> the two or three they actually need. We reconfigured our EHR that way we got that number down from 13 to 4, which basically saved us $60 million dollars. That's a really interesting way in which you could use data to make choices about what problems you are targeting and how you are targeting them. Data analytics is a huge opportunity.[854]
>
> It's interesting to see when you look at the literature review of meaningful use, that was a bit of a fizzer too, because the meaningful use was just a matter of getting the documentation right and showing that you were compliant and then you got your money, so as long as they got their money for meaningful use that's what happened rather than actually getting meaningful use.[855]
>
> In the U.S. those meaningful use standards have been accompanied by a very significant investment of funds.[856]
>
> It makes a lot of sense to me in that there are reduced costs associated with fewer delays in providing care. Also in repeating studies that might have been ordered on the day of surgery because we weren't sure what the results were, if we couldn't find it in the old chart we'd order a new one right there and that would cost some money.[857]
>
> Clinician satisfaction is better but I couldn't speak for patient satisfaction. I would guess that it reduces patient frustration to reduce delays and perhaps for just being the same question multiple times.[858]
>
> Clinical decision support has improved the lives of a lot of these patients who no longer have to suffer the consequences of having an overdose of the medication. Two to two and a half percent of all the medication orders written were in fact for excessive doses.[859]

Jack Meyer argued that "one public policy issue is getting them (EHRs) used by physicians and hospitals in real time as they see patients."[860]

> A lot of the emphasis in patient safety in America is on treatment mistakes, and those are obviously critical, whether it's medication errors, anaesthesiology, patient falls, wound infections and leaving a sponge in. We've had a lot of covering up in America in the healthcare field because you get in trouble when you make a mistake. In the airlines you get in trouble if you don't report a near miss. In the hospital you sometimes get into trouble if you do report a near miss.[861]
>
> I love the idea of a national electronic health record. In Kaiser, I'm sick and I'm in southern California I can go into a Kaiser and they can see my records, but the majority of people around the country are still faxing medical records to one another and I think that a lot of money is wasted, especially because our government, through Medicare, is paying this wasted money by re-doing labs, redoing tests. If a patient comes from Valley Medical Centre over here, we're going to redo everything because we don't have time to have them courier over a picture of that CT scan. And that's happening all day long, every day, so I think if there was some sort of

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[854] Jethwani, Interview.
[855] Hovenga, Interview.
[856] Shane Solomon (Managing Director of Telstra Health), Interview, 2014.
[857] James Healzer (MD, Kaiser Permanente), Interview, 2014.
[858] Healzer.
[859] Teich, Webinar.
[860] Meyer, Interview.
[861] Meyer.

> national [EHR] soon, and I like the idea of it being patient based because I think that would help with privacy of who can see it and also you can have in there, what you want to have in there.[862]
>
> You never lose a lab report or an MRI because anyone seeing you anywhere in Kaiser will see that report. You're never going to have a lab report that doesn't get acted on.[863]

Chris Wood argued that by focusing on quality improvement, Intermountain Healthcare uses "data to improve the quality, efficiency and cost of healthcare and to help clinicians make better choices."[864] He went on to state:

> Now we find ourselves being able, every year, to demonstrate literally a couple of dozen system wide projects where we have data that shows that we improve morbidity, we improve mortality, we improve the cost of a healthcare service that we provide and we are able to build those things into our workflows and have it continue to run them so we can work on the next thing, the next year.[865]
>
> Measurement is a marketing tool. If you're really looking at the question of quality outcomes, it's a very, very difficult thing to measure because it's something that takes a very long time and you have to follow people sequentially for a very long time to determine how they actually do, to determine whether any intervention actually has a beneficial outcome or not. Because it's so difficult, it's so expensive and so time consuming to measure actual quality outcomes, what we've done for the most part is that we've substituted proxies for qualities outcomes.[866]

Patient Control

All three case study countries passed legislation giving patients more control over their health information, however outcomes differed substantially between countries. Legislation strengthened health information privacy regimes and gave patients the right to access, transfer and change the information in their NEHRs. Legislation and subsequent regulations also addressed issues of ownership and the use of health information though these issues remained contested. Overall, giving patients control of their health information was part of the state's effort to move from a clinician-centred to a patient-centred healthcare system and give patients greater choice. The NEHR and its rules were seen as a mechanism through which to change norms and achieve this goal. This will be discussed further in Part 6.

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[862] Michael, Interview.
[863] Director, Kaiser Permanente International, Interview.
[864] Chris Wood (Vice President, Intermountain Healthcare), Interview, 2014.
[865] Wood. Wood went on to state that "in the intensive care unit we were able to show that our mortality rate dropped from 25% to about 6%" by making the right piece of data available to the right clinician at the right time.
[866] Yacoe, Interview 1.

Patient control outcomes were most successful in Australia, followed by England and then the US. This was primarily because of Australia's rigid privacy regime, opt-in system, and through enabling patients to restrict what information (if any) went into their NEHR and who could access it. These goals remained remarkably similar from 2000 to 2015 as the following quotes suggest:

> Patients will have control over who has access to their personal information, although de-identified data will be made available for medical research and health planning purposes.[867]
>
> It's supposed to be patient controlled in terms of the patient sets the privacy controls, but it's clinician supplied, in terms of information.[868]

The opt-in model in Australia was controversial and, while it promoted patient control, it proved to be expensive and resulted in lower uptake and less return on investment.[869] A former senior official had very strong views on the power of the privacy advocates to influence policy:

> We went to an opt-in system because people thought they could get around the clique of the 200 privacy fanatics by giving people the option of opting in. This is the way a few pathetic individuals prevent the whole nation making a transformational step toward improvement.[870]

Opt-in failed in part because the name of the PCEHR had a negative impact[871] and the emphasis on personal control was not reciprocated by most patients and carers, as few

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[867] Karen Dearne, "National E-Health Plan Shapes Up," *The Australian*, November 16, 2004, 34.

[868] Paul Dugdale, Interview 2, 2015.

[869] Carole McQueeney (Former Senior Official in HealthConnect), Interview, 2014. Vinen noted that "mandatory has never been a very strongly supported concept in this country" and was seen as "un-Australian". John Vinen, Interview 2, 2015. However, Stapleton argued that an NEHR should be mandatory for those with chronic disease due to its "huge burden on society" and then should be opt-out. Stuart Stapleton (Director, Emergency Department at Calvary Health Care ACT), Interview, 2015. Pritchard thought that the PCEHR should be opt-out for consumers "because it's good health practice for everyone to be able to share that information," but saw a difference with providers. "For providers it is really difficult because of the infrastructure behind each provider is so different." She also noted that during "assisted registration we had a lot of people wanting to register other people because they knew they wouldn't do themselves, especially when it comes to husbands and sons we found and so, if it was just opt-out and everyone had one I think it would just make life so much easier." Eleonor Pritchard (Former eHealth Program Manager for the ACT Medicare Local), Interview, 2015. Mukesh Haikerwal summed up the policy issue: "there's a whole lot of hullabaloo around it." Mukesh Haikerwal (Formerly, President of the AMA, National Clinical Lead NEHTA, WHO), Interview, 2013.

[870] Former Senior Official, Interview.

[871] Many clinicians did not trust patient control as they thought this would make the information in the PCEHR unreliable for clinical use.

sought to take control of their PCEHR. Honeyman argued, that while patients and carers are seeking transparency and “the option of seeing things that they need to see … you don’t see a high proportion of people or their carers seeking to take control.” This, he goes on to say, is unreasonable, “particularly [for] those in most need of these services” given they are ill and not in the best position to make decisions when “they are told ‘now you need to line these five appointments up, these are the tests you need, these are the choices you’ve got, you go away, make those decisions and come back to us.”[872]

England successfully actioned a privacy regime through legislation and the Caldicott Guardians. These were senior people in all NHS organisations and local authorities which provided social services, who were responsible for protecting the confidentiality of people’s health and care information and for making sure it was used properly.[873] Giving patients access to their health information was not as smooth in England as in Australia due to the failure of HealthSpace and there were limited options for patients to change or add information. This was because the state was focused on centrally collecting and storing clinically reliable information that could be used in clinical settings and for population health research.

Ownership of patient health information issues was ameliorated through legislation and regulation but there remained no universal agreement amongst stakeholders in all three case study countries over who owned, and had rights to use, patient health information as demonstrated in the case study chapters.

> Some of the former issues were around information ownership until we just sort of said that there’s no blanket answer and so I’m sorry we can’t make a policy decision on that and then sort of people accepted that and went away.[874]

In the US patient control of information was a patchwork and rather unsuccessful. It was a component of meaningful use and required that “the technology enable patients

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[872] Honeyman, Interview.

[873] GOV.UK, “UK Caldicott Guardian Council,” accessed February 27, 2020. (This program was established in 2005). Hovenga pushes back on the notion that privacy can be achieved stating “there is no such thing as privacy in a digital world.” Hovenga, Interview. Hovenga’s view, to differing degrees, was widely supported amongst interviewees.

[874] Bettina McMahon, Interview.

to view, download and transmit their own health information. That's only beginning to be implemented."[875] Suarez stated that patients have a right to request that their health information in an EHR is restricted but a provider does not have to accept that request.

Box 9-5: Stakeholder Reflections on NEHR Patient Control Success

> The problem with opt-in is just that it requires people to be, not just happy for it to happen but motivated to actually to do something to make that happen.[876]
>
> I think that transformation is a very long process – two steps forward, one step back, one sideways. I think we get over-optimistic, that we're putting in those technologies and patients will take control. Well, most patients are not sure, but I think most patients want to be involved sometimes in decision making.[877]
>
> We tend to get very enthusiastic about it but we know also that not everyone has access to it, even internet or computer, and if they do, they don't necessarily know exactly how to use it. [878]
>
> So you can be engaged in decision making, if the solutions are there, but not an awful lot of medical care is really like that. And you just get into this really weird kind of thing where people try to change, are trying to seemingly involve patients in decisions but in actual fact they are not really decisions for the patient to make, so there isn't really much choice about it. So if somebody has something wrong with them, they have an infection that requires antibiotics, you just need to take the advice or take the medicine and follow it. What they are talking about in giving people patient choice is getting people to do more self-care.[879]
>
> A portion of meaningful use is designed to increase the functionality of an electronic health record for a patient to be able to view their own health record, to download it to their own computer or to ask that it be transmitted to a third party like a personal health kind of app like that so that they can use the data.[880]

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[875] Pritts, Interview.
[876] Fiona Stevenson (Co-director of the eHealth Unit, University College London), Interview 1, 2013.
[877] Ela Klecun, Interview 2, 2013.
[878] Eva Riboli-Sasco (Researcher at the eHealth Unit, University College London), Interview, 2013.
[879] Stevenson, Interview 1.
[880] Pritts, Interview.

Part 3

Programmatic and Operational Dilemmas

> *It seems that the transformative features of an ehealth system also bring a lot of issues with it that are hard to bring to the design in a way that is actually going to lower cost and necessarily improve service delivery.*[881]

Each case study country encountered similar, and numerous, programmatic and operational dilemmas that impacted the success of NEHR programs. At times the state made trade-offs on these dilemmas (discussed in Part 4) and at other times these dilemmas continued unresolved for some time. As such, the NEHR process suffered several setbacks and significant obstacles to interoperability, usability, meaningful use and patient control arose with some persisting throughout the NEHR programs.

Policy makers (particularly in Australia and England) often saw significant progress, with attendant attention to the major program issues, where critics of the program, while often broadly supporting ehealth initiatives, identified numerous issues of concern. These included delays in drafting legislation and implementing programs, lack of stakeholder engagement or support, and a significant underestimation by the government of privacy concerns including the transparent use of health data,[882] even though states legislated privacy provisions that favoured patients and patient advocate groups There were unrealistic timeframes for delivery, lack of uptake, higher than expected costs and a lack of stakeholder trust in the NEHR program that were very similar across all case study countries. Unrealistic timeframes imposed as a result of political pressure appear to be a staple of the policy process that are routinely impacted

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[881] Fiona Hamilton (Senior Clinical Research Associate, eHealth Unit, University College London), Interview, 2013.

[882] “The Minister has had over a year to get it right but his failure to understand the priorities of the Australian public – the need for comprehensive privacy protection and complete transparency - had resulted in further unnecessary delays in introducing E-Health to Australia.” Macklin, “Wooldridge Fails on E-Health.” The issue of being able to identify individuals through their health record data was common across all countries. Arguments were made for state use of health data, including in England where the CPRD has data going back to the turn of the century on some patients and “can compute millions of lines of healthcare data for millions of people in seconds” providing a really valuable research and clinical trial tool that comes back into the “delivery of care to an individual.” John Parkinson (Director of the Clinical Practice Research Data Agency), Interview, 2013.

by program complexity and organisational conflict, both within the public sector and between the public and private sectors. For example, in Australia one reason for the "tortuous"[883] implementation of ehealth was lack of IT expertise in senior health officials. "It has been really slow as most people who are senior in health are not IT savvy. Every decision they are making is outside their expertise. They have to check and treble check everything." [884] Trust was also an issue with not enough "consideration given to developing the common infrastructure supported by collaboration between government and key stakeholders"[885] resulting in the erosion, rather than the expected strengthening, of trust between the state and stakeholders. Other dilemmas included:

- tension between stakeholders in trying to use the NEHR as a mechanism to move from a clinician-centred to a patient-centred system;
- system centralisation versus decentralisation;
- the extent of patient control to build into the NEHR including legislation and/or regulation and whether or not it would be opt-in or opt-out;[886]
- privacy concerns about individual health identifiers which slowed the progress of all NEHR programs and was of a particular concern in the US due to its tradition of individual rights and distrust of government data collection;[887]
- competition between jurisdictions in the two federal systems which fractured privacy and NEHR implementation; data blocking due to the implementation of proprietary EHRs; and

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[883] Page, cited in Grayson, "IT Snags Put Database on Hold," C26.

[884] Page, cited in Grayson, C26.

[885] More, Interview.

[886] Marcus Dawe argues that "the federal government's approach is unworkable. Opt-in does not work. Also, it's too limited. You need a buy-in from every individual clinician effectively to then get buy-in into the national system." Marcus Dawe (Former Chief Strategist in Health for Computer Sciences Corporation), Interview, 2015.

[887] Suarez, Interview. Associated with IHIs was the issue of function creep. There were fears that IHIs would become the "Australia Card II" and the US had prior experience with Social Security numbers being used, and requested by numerous private organisations, for purposes not envisioned by the legislation. Edward Mandla, National President of the Australian Computer Society, "British ID Move Sparks Debate on Australia Card II," *The Australian*, December 7, 2004, 35.

- technical dilemmas, especially over interoperability and usability but also the issue of NEHR system delivery being too slow to leverage new technologies.

The complexity of developing and implementing an NEHR program directed by the state with multiple stakeholders who all had different priorities, along with organisational issues around the design of the NEHR, what it would do and who would deliver it, lengthened timeframes significantly. For example, in Australia "the political push at the time, it was unreasonable. It was not possible to make such a change sector wide in the time frame available."[888] This resulted in a PCEHR that "was not consumer friendly, not consumer friendly at all."[889] "The whole process of registering, the whole process of opting in, was extremely difficult."[890] This resulted in negligible take-up of the PCEHR by both consumers and health professionals, with the latter already sceptical of patient rights restricting information in the PCEHR resulting in limited information populating the health record. It also "took a while to get hospitals on board to get discharge information."[891] The flow-on effect was that many clinicians saw little value in the PCEHR and did not trust or use it, and consumers found it "underwhelming."[892] Consequently few consumers logged in to access their records and clinicians did not routinely enter information into the PCEHR, nor did they routinely use it to access information about their patients.

Walter Holland argued that in England it was a very political process that was ideologically driven. "Science played no part in computerised records."[893] Second, the need to accurately capture all the information produced by nurses and doctors resulted in system failure because "the computer company was unable to deliver promises under tender because it could not handle the data."[894] The "government destroyed the report

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[888] Honeyman, Interview.
[889] Honeyman.
[890] Honeyman.
[891] Honeyman.
[892] Honeyman.
[893] Walter Holland (Emeritus Professor of Public Health, LSE), Interview, 2013.
[894] Holland.

[on this failure] because it would prejudice their future decisions about contracts"[895] which exposed another major issue to do with tenders. Holland argues that the government "wanted to go into contract negotiations blind" and thus "kept giving contracts to companies that failed to deliver."[896] This was not surprising as "all the big IT projects in this country have failed" primarily because there were "too many stakeholders."[897] Holland went on to say that "only those concerned with GP computing have worked [because they are] owned and run by GPs and record what they find interesting and what they feel is needed."[898]

In terms of cost to the government, the goal was to impose an "innovative contract that meant that the NHS paid only once it received the system and the system had been passed over and was operational."[899] This was seen at the time as "a step forward in how the NHS paid for IT systems."[900] The 2006 NAO Report on NPfIT praised the DoH and NHS CfH for having made substantial progress with the programme commending the "tight control of central aspects of the programme"[901] provided by the top-down centralised approach which, according to the NAO, came from adopting "many of the key lessons of prior public IT failures."[902] The NAO was "satisfied that central expenditure is being managed within budget."[903]

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[895] Holland. The perspective that the tender process was botched and led to significant problems implementing the SCR was supported by many interviewees such as Klecun, and is well covered in the literature by scholars such as Greenhalgh.
[896] Holland.
[897] Holland.
[898] Holland.
[899] Andy Burnham (Secretary of State for Health), in "HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 24," 2009.
[900] Burnham, Column 24."
[901] National Audit Office, "The National Programme for IT in the NHS: Project Progress Reports," (London: The Stationary Office), 2006, 6.
[902] National Audit Office, "The National Programme for IT in the NHS," 2006, 6. The report goes on to say "they successfully placed contracts very quickly, after securing large reductions in prices from bidders, and including contract terms that include important safeguards to secure value for money for the taxpayer. Deployments of operational systems have begun and NHS Connecting for Health has taken on, and in some cases already delivered, several additional tasks which were not within the original brief for the programme."
[903] National Audit Office, "The National Programme for IT in the NHS: Project Progress Reports," 24.

However, this approach led to numerous uncompleted contracts [see Greenhalgh] and the following political criticism:

> Do the enormous compensation counter-claims by suppliers of which we read represent a contingent liability against the NHS? If so, does that mean that they will be paid at the expense of front-line services? The Government's dithering over cancellations of quite large elements of the scheme has resulted in eye-wateringly large amounts of money being sunk in a scheme that has produced nothing like the benefits claimed for it, but which has, I am afraid, used a great deal of NHS money for very little result.[904]

The project accrued significant delays. British Telecom was contracted to "provide basic NHS Care records by late 2004" which was a highly optimistic schedule of less than a year and was not achieved. "We anticipate that getting internet access to records will happen far before that … We're still working out the detail but at the moment we predict Q4, 2004."[905] The timeline for the national record system then slipped further when the Health Secretary John Reid announced in December 2003 that "every NHS patient [would have] their own individual electronic NHS Care Record by 2010" which would "contain details of care and treatment received within either the health service or social care."[906] This was expected to be fully available by 2010 with all patients being able to securely access their records online. This was not achieved resulting in the abandonment of the NPfIT and a scaled down SCR that would "store a limited amount of data (current medication, adverse reactions, and allergies) for all patients except those who opt-out."[907]

> A centralised, national approach is no longer required, and that a more locally-led plural system of procurement should operate, whilst continuing with national applications already purchased.[908]

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[904] David Heath, in "HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 24."

[905] Richard Granger (NHS IT Director-General), cited in digitalhealth, "Reid Announces £2.7 Billion of NHS IT Contracts," 2003.

[906] digitalhealth.

[907] National E-Health Transition Authority, "Evolution of EHealth in Australia Achievements, Lessons, and Opportunities," 13.

[908] Simon Burns (Minister for Health), cited in National E-Health Transition Authority, 13.

Interestingly, this happened barely two years after the then Minister for Health, Andy Burnham, had stated that the NHS could not function without the NPfIT.[909]

The United States faced some process setbacks that were similar to those in Australia and England but due to the unique nature of the US approach to NEHRs there were some significant differences. Progress on the implementation of policy was mixed and deadlines set in the HITECH Act and subsequent regulations were only partially met or were delayed. This was particularly true for EHR incentive programs as pushback from stakeholders led to adjustments in requirements and the extension of timelines. Funding was substantial with the major difference between case study countries being that the US funnelled most of its funding into the Meaningful Use program in an effort to incentivise the uptake and meaningful use of ICT rather than developing and implementing a state-run NEHR. Also, participation in the program was voluntary and not all healthcare providers did so as they saw little economic benefit as well as a disruption to their clinical workflows. Privacy advocates saw interoperable EHRs as giving patients little control over their health information and argued that the trade-offs the state made between stakeholders benefitted healthcare providers, especially large organisations, more than patients leading to the argument that market forces were not working.[910]

Blumenthal argued that four challenges slowed the implementation of the HITECH Act. First, the complexity and sheer scope of creating "a nationwide interoperable electronic health information system"[911] in a "country as large, complex, politically decentralised and diverse as the United States"[912] proved difficult to overcome. Second, the regulatory timeframes created in the law proved to be "exceedingly ambitious"[913] and delays were inevitable. Third, timings for meaningful use payments were extended and there was "considerable pressure on the ONC to use its $2billion in discretionary funds quickly to

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[909] "HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 21."
[910] Deborah Peel, Interview, 2014; Adrian Gropper, Interview, 2014.
[911] David Blumenthal, "Wiring the Health System – Origins and Provisions of a New Federal Program," *New England Journal of Medicine* 365, no. 24 (2011): 2327.
[912] Blumenthal, 2327.
[913] Blumenthal, 2327.

assist providers who wanted to begin collecting incentive payments at the program's outset."[914] Fourth, neither CMS nor ONC were fully prepared to meet what "amounted to a huge project for social change: a national campaign to modernize the U.S. health information system over a few short years."[915] Therefore, the legislative process was successful but the regulatory process lagged. However the latter ultimately succeeded in imposing the incentives and penalties in HITECH.

Box 9-6: Stakeholder Perceptions of Programmatic and Operational Dilemma Success

> There is no sector in Australia with more different individual organisations in it than the health sector. They are all very diverse. So the idea that you could somehow have a one-size-fits-all centralised approach was always somewhat ambitious I felt.[916]
>
> One of the great failings of the whole electronic health record development and roll out and so forth has been the lack of focus on actual clinical value in the system. A lot of electronic health records start from the perspective of "What data do we need? Okay, that'll drive the process and we'll design the system around getting the data … and we'll get the clinicians to collect it." And so the whole collection process becomes an added task. We know that in freeing up clinician time so they can spend more time with patients and that's been established in a lot of international studies, that that leads to better patient outcomes.[917]
>
> Look I'm a fundamental supporter. I think it's a great concept. They just got the delivery very, very wrong. Something that should be very simple was being made very complex. The complexity has come in from a combination of the various levels of government. The various issues around, as I've said before, clinician identified needs vs. political, legal, privacy perceptions and a lot of those drove patient perceptions as well within the user groups. What was interesting by the end, when I was leaving, the patient user groups were getting pissed off with the way it was going because it was just going around and around and a lot of things and they were getting annoyed, so it was starting to lose traction there. And they were very helpful, very interested people from the beginning but they were all starting to lose them as well.[918]
>
> Gaps in interoperability: Proponents of electronic health records expected a seamless system so patients could share computerized medical histories in a flash with doctors and hospitals anywhere in the country. That has yet to materialize, largely because officials allowed hundreds of competing firms to sell medical records software unable to exchange information.[919]
>
> Australia's not leading the pack, that's for sure. Australia has significant problems because of the diversity of health service providers and there are Commonwealth and state issues as well, but I think it's mainly around the data about an individual patient is spread wide and far.[920]

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[914] Blumenthal, 2327.
[915] Blumenthal, 2327–28.
[916] Rob Wooding, Interview, 2014.
[917] Lindsay Bevege, Interview, 2014.
[918] Stuart Stapleton, Interview, 2015. Delivery argument supported by Coiera and Haikerwal.
[919] Schulte and Fry, "Death By 1,000 Clicks."
[920] Shane Solomon, Interview.

The only time we get involved with identifiable information is when we have consent for it.[921]

Part 4

Distributional Outcomes (Benefits and Limitations)

Historical institutionalists "assume a world in which institutions give some groups or interests disproportionate access to the decision making process … [and] tend to stress how some groups lose while others win."[922] This was evident in all three case study countries with outcomes benefitting certain stakeholders, though benefits fluctuated over time. Distributional outcomes will be discussed amongst five major NEHR stakeholders: the state, healthcare providers (GPs, hospitals, specialists, allied health), EHR vendors, privacy and healthcare consumer advocates, and patients/healthcare consumers.

The state, followed by healthcare providers, had the most access to the decision-making process in all three countries. In Australia and England, privacy and healthcare consumer advocates also had a major influence on the decision-making process but they were somewhat less influential in the US. It was the state in all three countries that made major decisions regarding trade-offs that affected distributional outcomes including which vendors were chosen to supply NEHRs, which stakeholders received incentive payments, which stakeholders had access to the decision-making process and how influential they would be, what the privacy and patient control of information rules would be, what standards would be adopted to foster interoperability and the usability of health information, and what regulations would be imposed on stakeholders in order to achieve meaningful use goals. The state envisioned efficiency benefits such as cost savings based on a reduction in the duplication of tests and eliminating doctor shopping but these proved hard to achieve.

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[921] Parkinson, Interview.

[922] Peter A. Hall and Rosemary C. R. Taylor, "Political Science and the Three New Institutionalisms," *MPIFG Discussion Paper*, vol. 96, 1996, 9.

Distributional outcomes varied amongst stakeholders over time. The state struggled in all three countries to achieve many of the goals associated with NEHR programs, however some successes were achieved as noted earlier in this chapter. State organisations responsible for the development, implementation and regulation of NEHRs suffered constant criticism though they managed to implement NEHR programs in all three case study countries. The major criticisms of the state were that stakeholder concerns over privacy were not adequately addressed, stakeholder input into the decision-making process was not always achieved and the clinical value of the NEHR was not established.

Healthcare provider outcomes also varied over time and between different providers. GPs and hospitals were the main beneficiaries of incentive payments in all three countries and specialists and allied health often missed out. Older clinicians often struggled to adapt to NEHRs, burnout was common and many clinicians complained about the added costs of adopting NEHR systems. However, clinicians often noted how beneficial NEHRs (or provider-wide EHRs in the US) were in providing care, clinical decision support and patient satisfaction when they were well integrated into clinical workflows. Clinical influence ebbed and flowed somewhat, particularly in Australia where clinicians initially had major input into the NEHR concept and were then shunted to the side. The end result was the mass resignation in 2013 of NEHTAs clinical leads including the head of clinical leadership and stakeholder management Dr Mukesh Haikerwal, "a passionate advocate for e-health in this country on behalf of doctors and patients for more than a decade,"[923] raising "serious concerns about clinical input to decision-making in the implementation of the PCEHR".[924] Two major policy problems arose from NEHTA's stance: clinicians did not have a self-interest reason to adopt ehealth technology so the state funded the PIP program, and after the PCEHR was implemented clinician up-take was poor which led to lack of use. Essentially, the state had not made the case that clinical involvement would be worthwhile – that clinicians would benefit from the PCEHR and not just see it as a cost. The state eventually

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[923] Hambleton, cited in The Australian Medical Association, "Dr Haikerwal NEHTA Resignation Raises Serious Concerns."

[924] Hambleton.

responded with the Royle Review, which amounted to a clinician fight-back, and the abandonment of opt-in in favour of opt-out due to significant political pressure to obtain even basic outcomes given the large amount of money that had already been spent. This change favoured the state and clinicians, as did England's difficult to opt-out system.

EHR vendors were the major monetary beneficiaries of NEHR programs and vendor and consultant businesses boomed as a result. Vendors were influential in the design and implementation of products, particularly in the US, though there was some pushback by the state in terms of demanding specific NEHR systemic components in Australia and England, and in the US through the meaningful use program. Privacy and healthcare consumer advocates were particularly influential in Australia and England. They were able to push strong privacy and patient control agendas that were supported in legislation, and in subsequent regulation and in the rules governing the PCEHR and the SCR.[925] Patients (healthcare consumers) were consulted on and off by the state, particularly through focus groups and the like in Australia and England, and a significant effort made by the state to incorporate solutions to the areas of health information concern that they found relevant. This included attempting to ensure patients had access to their health information and could transfer it to any point of care, and that their information remained private and was not used by third parties in a way that would negatively affect them. As shown earlier in the chapter the state had mixed success in achieving these goals. The state struggled to achieve a patient-centred healthcare system and Podger suggested that the argument supporting NEHRs increasing the effectiveness of healthcare service delivery and patient improvement was about "patient orientation but not necessarily their choice on control."[926]

Box 9-7: Stakeholder Perceptions of Distributional Outcome Success

> The major benefit for me has been the availability of all medical records. It was very common when I was in training and up until we went electronic, that I would not have old records

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[925] Nicola Roxon – the Health Minister at the time – was "very heavily convinced about personal control" and if a different health minister had been in the mix different choices may have been made which emphasises the role of agency in critical junctures. Honeyman, Interview.

[926] Andrew Podger, Interview 2, 2019.

available to me when I was doing a patient's chart prior to surgery or seeing them for a consultation.[927]

I was a vocal critic of NEHTA for not having any clinical input into what they were doing, not having any interest in what clinicians had to say, and not having any understanding of how clinical practice works. My concerns were reinforced by a 2007 Boston Consulting report which actually pointed out the same things: that NEHTA was very much working as an island without having any internal clinical input, and certainly it was lacking external clinical processes.[928]

So if you take using technology in general practice – it costs me. I get some benefit from getting my pathology results and it helps manage my workload, but in terms of sharing information or linking up to a PCEHR or whatever there is no benefit to me. All the cost is to me. The benefit is to the patient, which is a lot, and to government and the quid pro quo from getting information back from allied health, from non-GP specialists and from hospitals. So it is not just about going group by group but actually joining up to this and proving the concepts, proving a point and then you can go on and get better usage.[929]

I have a personal frustration that incentive payments are not applied consistently across the board. General practice has benefited from a lot of government financial assistance to become IT enabled. They pay for their computers. Allied health have not, but they're expected to have the same IT infrastructure to be able to participate in these programs but they are not supported to do it and I just don't think that's fair.[930]

The electronic record has been very good for pre-operative evaluations.[931]

The electronic health record takes me about 25% longer to do my patient care per patient and so actually my income has gone up using the electronic health record, just by virtue that it takes longer and I end up with more hours to charge for my panel of patients.[932]

Using codes for diagnoses for insurance companies is easier with electronic records.[933]

Some doctors said that computerisation was the biggest part of their decision to retire.[934]

You can't call it patient controlled if you don't actually let the patient make a decision.[935]

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[927] Healzer, Interview.
[928] Haikerwal, Interview.
[929] Haikerwal.
[930] Eleonor Pritchard, Interview, 2015.
[931] Jerry Van Wieren (GP of a small practice in internal medicine), Interview, 2014.
[932] Van Wieren.
[933] Van Wieren.
[934] Van Wieren.
[935] Podger, Interview 2.

Part 5

Evaluating the Political Consequences and Fallout

> *Politicians, from my experience, will use the evidence base if it suits their agenda and, if it doesn't, then they won't and ... they are somewhat resistant to evidence in formulating their policies.*[936]

The political consequences of NEHR programs were more keenly felt in Australia and England than in the US. In Australia perceptions of policy failure drove a number of developments: a change from a decentralised NHIN to a centralised PCEHR; organisational change; and the move from opt-in to opt-out. These perceptions may also have contributed to the Coalition defeating Labor in the election of 2013. The political consequences of "Britain's expensive and high-profile e-health record system failure"[937] spread quickly to Australia, changing the formerly supportive position of the RACGP to one of concern mixed with scepticism that Australia's PCEHR would be ready to launch in 2012. Key concerns were that target groups such as the elderly were not engaged, that there was a lack of payment and information for doctors to participate in implementation and sign-up, that patients could change their clinical records, and that better government engagement with GPs was needed. In England, perceptions of policy failure led to rapid organisational change, the abandonment of the NPfIT and the scaling back of the SCR, and contributed to the Conservative victory over Labour in the election of 2010. In the US, perceptions of policy difficulties, rather than outright failure, led to regulatory change including changing meaningful use goals and delaying the implementation and completion of incentive programs. Intense criticism of NEHR programs by stakeholders was common in all three countries, particularly over the organisational efficiency and effectiveness of those bodies tasked with developing, implementing and regulating NEHR programs. There was some policy learning between Australia and England, and between both countries and the US, in an effort to learn from, and not repeat, past mistakes. For example, Kaiser Permanente and Intermountain

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[936] Fiona Hamilton, Interview.

[937] Claire Jackson (President of the RACGP), cited in David Ramli, "GP's Call for Re-Examination of e-Health," *The Australian Financial Review*, October 20, 2011.

Healthcare were seen as ideal models from which valuable lessons on interoperability, usability and the meaningful use of health information could be learned. In all three countries programs initially floundered resulting in a reboot in Australia and England and delay in the US.

Box 9-8: Stakeholder Perceptions of Poltical Consequences

> The Minister has had over a year to get it right but his failure to understand the priorities of the Australian public – the need for comprehensive privacy protection and complete transparency – has resulted in further unnecessary delays in introducing E-Health to Australia … In putting the cart before the horse, this Health Minister has seriously compromised the potential for electronic health records to be successfully introduced in this country.[938]
>
> In government, always assume if something is not working it's a leadership issue.[939]
>
> We should learn from systems that are incredibly similar to ours overseas where there has been massive amounts of funding put in for very tiny output. At the moment we've got an opportunistic approach where you update the record when the patient is there. You need a different method of involving incentivisation so practices will put aside the time and person power to actually do it well.[940]

The Labour government:

> Let me be absolutely clear: we have no intention whatsoever of cancelling the programme overall, not least because it is already making the NHS safer, more efficient and more convenient for patients.[941]

The Conservative response was:

> Labour have already spent £3.5 billion on the calamitous NHS supercomputer, which was initially planned to cost £2 billion – and IT experts have shown that the final cost to taxpayers could be

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[938] Macklin, "Wooldridge Fails on E-Health."

[939] Former Senior Official, Interview.

[940] Jackson, cited in Ramli, "GP's Call for Re-Examination of e-Health," 77. This stance was supported by AMA president Dr Steve Hambleton who "said he was worried the government seemed unwilling to change its position despite the UK e-health failures"[940] but criticised by a spokesperson for the Health Minister, Nicola Roxon, who said the "RACGP's media release ignored many of the facts and principles of its planned e-health records system and that GPs were heavily involved in its development." Ramli, 77. Mukesh Haikerwal argued that while there had been some clinical input, this changed as of 13 April 2012. "We got the horses to the water and they were really ready to drink and then I think the wheels came off, the wish to communicate and engage meaningfully went. It was driven from the government Department of Health and Aging and without any regard to any of the other people outside including the clinicians." He went on to say, "To have got so much agreement around it and that's because of the amount of engagement which went into the process to get it there. Now they are trying to do a lot more bullying of the community." Haikerwal, Interview.

[941] Andy Burnham (Secretary of State for Health), HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 21.

> £20 billion. Scrapping this disastrous and ineffective project will free up funds for improving frontline health services.[942]

The political consequence was that the NPfIT was an election issue in 2010 and the Conservatives won government from Labour.

It was "politically difficult to pick one system for all of the UK."[943]

> The Secretary of State was provoked into whistling in the dark by claiming that the programme had been a success. He quoted the NAO report, but did not the Public Accounts Committee conclude in January that the programme was, among other things, "very disappointing," and "not providing value for money," that estimates of costs were "unreliable," and that the system had "little clinical functionality," as well as reporting "understandable concerns about data security"? That does not sound like a system that is going well. Is this not the classic case of an IT programme that is too big, too expensive, too late and insufficiently planned? By building the system from the top down, the Government have smothered the option of local schemes with interoperability, which would, I agree, have been a better solution.[944]

> It [the adoption of CEHRT] was supposed to take effect on October lst, 2012 but it was postponed because there were so many doctors who couldn't comply that the Department of Health and Human Services delayed it for two years. So, Obama would have had a terrible scar if that came out six weeks before his election in November.[945]

Part 6

Normative Justification

NEHR policy in all three case study countries was normatively justified by the state in its claim that policy reflected the normative consensus in four areas: the principles on which policy should be based, citizen entitlement to various rights, citizens' obligations to the state and each other, and the prevailing norms of government program procurement and development. In essence, normative justification is the enabling narrative of state policy. However, that narrative can be intensely contested over time by various stakeholders and can change as new governments assume power.

In Australia and England it was clear that NEHR policy reflected the normative consensus regarding the principles on which government and policies should be based giving those policies legitimacy. Those principles included that NEHRs were an asset to

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[942] Conservative Party press release, 4 January 2010, p.8, cited in Channel 4, "The Conservative Party's Credibility Deficit Updated Tax and Spending Commitments," 2010, 102.

[943] Peter Knight (Head of Research Information and Intelligence, DoH), Interview, 2013.

[944] David Heath, HC Deb, 7 December 2009, NHS IT Programme, Hansard, Column 24, 2009.

[945] Carlson, Interview.

society that would directly benefit citizens and other stakeholders, implement values such as patient-centred healthcare, and establish norms of interoperability and the usability of patient health information to improve the efficiency and effectiveness of care and benefit patient health outcomes. There was also a view that "in a universal healthcare system that's a major public policy to have that, then meaningful use of data is one of the things in the chain towards value creation."[946] This view of consensus was supported over time by both sides of politics (Coalition and Labor governments in Australia and Labour and Conservative governments in England) even though the consensus on difficult issues such as privacy and opt-in versus opt-out were contested and changed over time. It was different in the US where political polarisation was more pronounced. In the US, policy reflected either a more socially based normative justification on the Democratic left or a more individual free market (economic individualism) normative justification on the Republican right. The Democrats were in power when HITECH was passed in 2009 and justified state intervention in the EHR market-place in terms of market failure[947] to provide the long overdue benefits of advances in ICT to healthcare and improve patient health outcomes. As this was contested the policy lacked legitimacy for a significant section of American society, even though a market-based approach was taken to the development and implementation of NEHRs which was left to EHR vendors and healthcare providers.

The normative consensus regarding the rights, benefits and prerogatives to which citizens of each country should, and should not, be entitled through the mechanism of the NEHR was contested in each state. In part this reflects differences expressed in theories of utilitarian, libertarian and egalitarian resource distribution. England leaned towards a utilitarian approach in that patient information was desired by the state to integrate and improve health and social care. The state in Australia had limited utilitarian goals based on efficiency, especially in attempting to reduce healthcare costs, but these were not always as strongly expressed as in England. There were also

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[946] Dugdale, Interview 2, 2015.

[947] Marla Durben Hirsch asked the question: "should the Government have made regulations that included interoperability from the beginning instead of letting the market do it, because the market is not doing it?" Marla Durben Hirsch (Healthcare Journalist), Interview, 2014.

egalitarian aspects in that equal rights of privacy were to be enforced and benefits of NEHRs equally distributed, but this was more pronounced in Australia. Libertarian goals of providing individual choice were prevalent in all three countries as was shifting power to citizens in part by moving from clinician-centred to patient-centred healthcare systems. Hall and Taylor argue that "historical institutionalists have been especially attentive to the way in which institutions distribute power unevenly across social groups" and "that power and asymmetrical relations of power play [a key role in HI] analyses. All institutional studies have a direct bearing on power relations."[948] Changing power relationship ratios also meant shifting power from the state to citizens by giving them control of their health information; enabling more choice in their health outcomes even if those choices clashed with state or clinical best practice; and building citizen capabilities to successfully navigate complex health systems thus empowering them in their interactions with clinicians and provider organisations that had traditionally been the dominant decision makers. NEHRs were to be a mechanism to achieve these aims. However, interviewees made it clear that this had not been entirely successful with power mostly residing with the state and clinicians as healthcare remained more clinician-centred than patient-centred[949] which was reinforced in Australia with the Royle Review and the move from opt-in to opt-out.

The normative consensus regarding the obligations of citizens to society, the state and one another in all three countries was based on prevailing norms in each of the three liberal democracies. Essentially, for the purposes of NEHR policy it was the state that had the largest obligatory burden to either provide benefits to citizens or ensure through regulation that citizens would benefit from NEHR policy. In the US, this clashed with widely held concepts of economic individualism and healthcare insurance subsidisation provided through employers limiting the state's role in, and subsequent legitimacy of, NEHR policy and regulation. NEHR policy did envision increased patient engagement with, and co-production, of their healthcare and strove to include carers in the provision of healthcare in order to improve patient outcomes. This was strongest in Australia,

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[948] Hall and Taylor, "Political Science and the Three New Institutionalisms," 9.

[949] There were some exceptions such as the consumer-centric approach implemented by Kaiser Permanente in the US. Director, Kaiser Permanente International, Interview.

followed by England and then the US. However, patient engagement and co-production goals have been very difficult to achieve and this is one reason why achieving meaningful use has struggled.

NEHR delivery models closely reflected prevailing government norms on procurement and development at the time they were implemented. To some extent this reflected ideational change as new governments adopted new ways of developing NEHR programs and procuring ICT from vendors. This was especially the case in England during the Blair Labour government, as previously discussed, but was also the case when the Coalition government won power in Australia in 2013. In the US, the NEHR program followed prevailing norms in the sense that development and implementation of NEHRs was mostly left to the private sector; however, the centralised regulatory approach was a change in norms that was not only contested by some stakeholders, but actively resisted. Delivery models also reflected each country's perception of public value, the public good and value for money though these were also contested within each society, particularly in the US. For example, value for money is different from cost efficiency in that it has a normative rationale of value based on stakeholder desired outcomes as opposed to an economic rationale of cost efficiency. Therefore, the state may be willing to pay for, or impose through regulation in the case of the US, some components of an EHR that are not seen as cost efficient but are valued by some stakeholders as contributing towards effective care supported by their particular value system.[950] For example, in the US legislation and regulation tried to make EHR vendors and healthcare providers give patients access to their health information and allow them to transfer that information to other points of care despite proprietary EHRs and active data blocking.

Box 9-9: A Detailed Example of Normative Justification

The US does not have a unique patient identifier along the same lines as Australia or England. Walter Suarez explained how controversial the idea was:

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[950] Public value, the public good and value for money can justify NEHR regulations. For example, Dawe argued that "What has to happen is that the government has to regulate to make a particular patient's medical record available to them in an agreed format, which is an interchange format of some sort, that they have a right to it. You can't have clinicians saying, 'That's my record, not your record.'" Dawe, Interview.

> Back in the days of HIPAA, HIPAA said "We're going to, in the 1996 law, it said we're going to standardise the way healthcare exchanges data. So we are going to create standards for messages of certain transactions, we're going to create standards for identifiers, for uniquely identifying, and we're going to create standards to uniquely identify providers, payers, employers which are involved in the coverage of health. And then they said patients." So, at some point this country is going to develop a Unique Patient Identifier. And then Congress jumped in and said "No, no, no. We're not going to let you do it. So, we are going to prohibit you from using any funds from the federal government to develop a national unique patient identifier." And that little rider, in the funding of the government, carries over every year since 1998, so since then the federal government has a tacit, well actually probably very explicit, provision around the development of a Unique Patient Identifier.[951]

Suarez argued that there is a resistance to a universal healthcare identifier because:

> this country is very, very mindful of personalised individual rights and not having someone like the government, potentially, or anybody else, to know everything about me. So that kind of sense of privacy and protection from having someone that has all the things about me connected is what has always derailed any effort to try to get [a unique patient identifier]. Now it has of course been complicated with all the realities of the world today that show how the systems are all the time at risk. Every day you see news about a new hacking. People feel that it is becoming easier to hack into their records. While my medical record might not be of any interest to anyone necessarily or, you know, they might not be that sensitive, to me necessarily, to me I don't have many sensitive things perhaps, by virtue of accessing my records I could be exposed to other things like, my records include not just medical information it includes a lot of other information, demographic and financial information that can be used against me. And that's an interesting part, a lot of the reason why people hack into health systems. Its not to see your record, or my record, its to see your financial and my financial information. So that way they can find my social security number some place there and my date of birth and my current location and all sorts of other things and they can steal identity that way.[952]

Conclusion

> *Implementation of ehealth within the NHS which has been hugely problematic, not just in the UK but also in Australia and America, and in the world over. There is a big gap between hype and reality.*[953]
>
> *"EHRs have not fulfilled their potential. I think few would argue they have."*[954]

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[951] Suarez, Interview. Deven McGraw argued that US citizens do not like the concept of a national ID card, resulting in a resistance to a unique patient identifier that reflects "a strong individual bent that is part of the United States." Deven McGraw (Director of the Health Privacy Project), Interview, 2014. This was supported by Joy Pritts who explained that "When they originally wrote HIPAA they also included in the statute a provision to create a unique patient identifier. There was such an uproar about it in this country that we have been prohibited from spending in our [ONC's] budget." Joy Pritts, Interview.

[952] Suarez, Interview.

[953] Murray, Interview.

[954] David Blumenthal (former National Coordinator for Health Information Technology), cited in Schulte and Fry, "Death By 1,000 Clicks."

It is clear from this comparative public policy evaluation that NEHR policy was only partially successful in each of the case study countries. Each country initially adopted a different approach to the development, implementation and regulation of NEHRs. Process goals were mostly achieved through successfully legislating NEHR policy and creating or amending state organisations to develop, implement and regulate NEHRs. Interoperability, usability and the meaningful use of health information varied widely in all three countries and policy outcomes in these categories were only partially successful. Australia and England were more successful in giving patients control over their health information, but the US was not. Numerous, and similar, programmatic and operational dilemmas were encountered in each country that proved hard to overcome, though there were some successes with IHIs, uptake but not use of NEHRs, and centralising NEHR systems. Distributional outcomes varied between stakeholders over time. The state remained the most powerful player though policy decisions were influenced by other stakeholders at various times. Both clinicians and privacy and healthcare consumer advocates had their time in the sun over issues of privacy, patient control of information, and opt-in versus opt-out NEHR systemic design. Politically, it was difficult to get value from NEHR policy successes and partial success or failure, while heavily criticised by many stakeholders and the media, rarely had consequential political outcomes. The exceptions were the UK elections in 2010 and the Australian elections in 2013 that resulted in changes of government and the subsequent NEHR policy changes made in both countries. Normative justification can be considered mostly a success in all three case study countries, though it was politically contested by some stakeholders. The principles on which policy should be based were clear at the time policy was enacted and programs were set up. The rights of citizens were clearly expressed in both legislation and through subsequent regulations, as were the obligations of the state to its citizens. Prevailing norms of government program procurement and development were closely followed, reflecting ideational change enacted through NEHR programs by new governments.

This research supported some specific observations made by scholars in the literature review. Policy supporters did tend to emphasise those aspects that were successful. This was particularly true of development and implementation agencies such as HealthConnect, NEHTA, CfH and ONC – particularly when process goals were assessed. While this type of process success was seen by organisations and policymakers in terms of political success, when the implementation failed to achieve its goals political backlash resulted in opponents of the NEHR programme claiming programme failure. This was reinforced by the complexity and intractability of some problems such as interoperability, privacy and control of patient health information that had multiple individual, institutional and societal causes. Privacy advocates remained critical of all three NEHR programs, even though some of their demands had been met by the state. Also, the effects of time did change conclusions of success/failure. In the 2000s it was clear that interoperability, usability and meaningful use had not been successful. However, by 2015 this picture had changed considerably with advances in all three areas.

Overall, there was a mixture of failure, partial success and some policy success. There remained a strong consensus amongst interviewees that much more needed to be done to fulfil the promise of NEHRs and that doing this will continue to be a difficult process. The frustration of trying to successfully implement NEHR policy was summed up by President Obama when he "singled out the effort as one of his most disappointing bemoaning in a January 2017 interview with Vox 'the fact that there are still just mountains of paperwork ... and that doctors still have to input stuff, and the nurses are spending all their time on all this administrative work. We put a big slug of money into trying to encourage everyone to digitalize, to catch up with the rest of the world ... that's been harder than we expected.' "[955] However, despite difficulties in successfully achieving goals the vast majority of interviewees thought that the policy pursuit of replacing paper health records with NEHRs was worthwhile, even though they might disagree on how to do it.

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[955] President Barack Obama, cited in Schulte and Fry.

Chapter 10 Historical Institutional Analysis and Key Findings

Introduction

The last three chapters of this thesis aim to give a plausible explanation of why state efforts to pursue NEHRs resulted in substantially similar outcomes in three countries, despite those countries adopting initially different approaches. In these chapters I develop an explanatory model that compares and evaluates institutional stasis and change over time, noting similarities and differences between case study countries as presented in the empirical chapters five through seven. Chapter 8 provided a comparative evaluation of four key concepts in the story of institutional stasis and change. The evaluation explored the similarities and differences between the three countries in terms of the development of institutional pressures and tensions; the institutional values, norms, rules, practices and procedures that developed as a result of NEHR policies; the aspirational narrative and claims made; and the different approaches each country initially adopted to NEHRs. Chapter 9 provided a public policy evaluation (PPE) of NEHR policy. Six categories – process, goal attainment, programmatic and operational dilemmas, distributional outcomes, political consequences, and normative justification – were used to assess policy success, partial success, and/or failure.

The plausible explanation continues in the present chapter focusing on historical institutionalist (HI) concepts that provide further clarity in explaining institutional stasis and change. Part 1 of this chapter will focus the explanatory analysis on an examination of path dependency and institutional outcomes. Part 2 will delve deeper into the concept of punctuated equilibrium through the lens of critical junctures. Part 3 will examine incremental change and institutional outcomes in an effort to provide further explanatory power in answering the thesis question. Part 4 will adapt Skocpol's framework for explaining institutional stasis and change as presented in *States and Social Revolutions* (1979). Part 5 will conclude the chapter with an assessment of the originality of the thesis and its contribution to knowledge. This will include implications for theory, implications for policy and practice, generalisations about public policy making, and where we might go from here with further research and theorising.

Part 1

Path Dependency and Institutional Outcomes

This research presents an historical institutionalist explanation of NEHR policy development. It examines temporal processes and events that influenced the origin and transformation of NEHRs and the consequential impacts on NEHR policy over time that were path dependent. The main NEHR institutional outcomes in Australia, England and the US exhibit many similarities in path dependence. Those similarities include policy options at decision points being limited by previous decisions, policy decisions being contingent upon path dependent criteria, some institutional arrangements exhibiting resilience to change, the persistence of institutional arrangements despite a new *status quo*, and the legacy of old institutional arrangements proving to be barriers to predicted outcomes associated with the new path. These similarities help explain both the origin, persistence and enduring stability of NEHRs despite stakeholder opposition or indifference.

The options available to policy makers at decision points were clearly limited by previous decisions resulting in the *status quo*. In all three countries, once NEHR programs were established they persisted despite intense criticism, perceptions of failure, stakeholder conflict and disinterest, and the emergence of unintended and unanticipated consequences that challenged the values, norms and rules embedded in the new *status quo*. For example, in both Australia and England once the decision to adopt centralised NEHR had been made other options, including decentralisation, while considered during critical junctures, were not adopted and centralisation persisted as the *status quo* despite often intense criticism by stakeholders. In the US, once HITECH was passed the regulatory approach of incentivisation and penalties persisted and grew stronger even though stakeholders were successful in pushing for delays in implementation. In all three countries values, such as using NEHRs as a mechanism to move from a clinician–centred to a patient-centred healthcare system, persisted despite the practical systemic resilience of care being clinician or provider centric. Policy makers persisted with trying to make interoperability norms and rules stick despite the repeated failure of NEHR programs over time to deliver desired interoperability outcomes.

Decisions made by policy makers were contingent upon path dependent criteria such as lock-in, sunk costs, positive feedback, increasing returns and self-reinforcement. Once adopted, NEHR programs persisted and, while paper was still an option, there was no going back to a system of solely paper health records. Policy makers also found themselves locked-in to new value systems and the pursuit of desired norms, as described above, that were initially expected to be achieved quickly but eventually took decades. There was an element of self-reinforcement in the persistence of values and norms that made some rules hard to change. For example, in Australia opt-in was seen as part of the value of patient-centred care that gave patients control over their health information and as such had been championed by privacy and healthcare consumer advocates. This proved very difficult to change despite opt-in being a key contributor to low uptake and use of the PCEHR and criticism that the program was a failure. It took a critical juncture following a change in government to shift to a new path – that of opt-out. NEHR programs were extremely expensive and there was a sense in policy circles that, even though criticism may have been intense at times and programmatic success varied, it was worth persisting in part due to the large amounts of money already spent. There were also increasing returns as programs started to deliver on some of their objectives, especially increased uptake and use, often due to successes in improving the interoperability and usability of NEHRs.

Some common institutional arrangements exhibited resilience to change in all three countries. Paper health records persist and are surprisingly prevalent. Some healthcare providers did not adopt EHRs or did not participate in NEHR programs or significantly delayed adoption. Where EHRs were adopted, and/or healthcare providers did participate in NEHR programs, often a dual paper/digital model persisted during the transition, which for many healthcare providers is ongoing. Paper records were also seen by many organisations as backups for when EHRs/NEHRs were not accessible/available. The fax machine and printed documents remained a common way to transfer patient health information between points of care, much to the dismay of policy makers. This was due to their universality in provider organisations and a longstanding reliance on them as the primary mechanism to transfer patient health information. In liberal democracies it can be difficult for policy makers to impose new ways of doing things on reluctant stakeholders. This was the case for NEHRs and all three countries had to fund extensive incentive programs to get clinicians and healthcare providers to adopt NEHRs and see the value in changing to a new *status quo*. Institutional arrangements that proved resistant to change created barriers to innovation and the achievement of desired and/or predicted outcomes associated with the new path. With NEHRs this meant that the goals of interoperability, usability, meaningful use and patient control of their health information varied in success and were often delayed.

This research shows that state intervention generated and reinforced actor preferences, power relations and patterns of resource allocation, often with unintended and unanticipated consequences. Clinician burnout was both an unanticipated and unintended consequence of NEHR programs. Some clinicians simply retired early rather than go through the adoption, implementation and use process. Higher than expected costs impacted the state and healthcare providers, especially as NEHR adoption was a longer process than originally forecast. Healthcare providers had to pay for new ICT and pressured the state to fund incentive programs to both increase the adoption of ICT and the uptake and use of NEHRs. The state was surprised that NEHRs were not seen as clinically useful by many providers and that patients in general were uninterested in engaging with them and using them to co-produce their healthcare in the pursuit of better health outcomes. The unanticipated difficulty of achieving interoperability, which had seemed an easy matter of adopting ICT, attuned policy makers over time to the complexity of healthcare systems with so many different stakeholders, often with legacy proprietary technology systems in place that made universal NEHR adoption extremely challenging. Complexity also made the development and adoption of standards, and thus usability, a long-term, often highly contested, process that was played out along the power lines of various stakeholders. Lastly, the state could never seem to satisfy privacy lobbies despite, in the case of Australia and England, some rather strict and rigid privacy regimes.

In order to clearly outline NEHR path dependency and critical junctures and contribute to theory development in terms of adding explanatory value, I have developed the following path dependency diagrams for each of the case study countries, shown in Figure 10-1, 10-2, and 10-3. They are an adaption of Michael de Percy's model of punctuated equilibrium as discussed in Chapter 2.

Australia – NEHR Path Dependency

Australia's path from paper health records to NEHRs (Figure 10-1) began as a result of the build-up of both exogenous and endogenous pressures and tensions (as discussed in chapters 5 and 8) that produced a crisis point in the period 1998-1999 that led to the policy problem of how to take advantage of ICT to address the problems of paper health records. The tipping point was reached in 1999 when the National Electronic Health Records Taskforce recommended that Australia adopt an NHIN. Policy makers made the decision to adopt the NHIN which became the new *status quo*. However, the NHIN proved to be a weak path that was unable to replace the previous paper *status quo* in practice and its failure led to it being replaced by the adoption of a new path in the NEHR. The NEHR path was strengthened when Labor won the 2007 election and then strongly supported the National Health and Hospitals Reform Commission's recommendation for a Personally Controlled Electronic Health Record (PCEHR) that would be opt-in, have strong privacy provisions and give patients extensive control over their health information. This decision locked in the NEHR as the *status quo* even though opt-in and patient control led to low uptake and use that resulted in a subsequent critical juncture. Following the election of the Coalition in 2013, policy swung in favour of clinicians who advocated for less patient control of health information and an opt-out system. While this critical juncture produced a major change in the move from opt-in to opt-out and the PCEHR being rebranded the MyHR it did not substantially weaken privacy or patient control, which reflected values that were locked into the ehealth system from the early days of HealthConnect. Organisationally, there was significant change with NEHTA being replaced by the ADHA but still pursuing an NEHR. Figure 10-1 shows Australia's journey from paper to the *status quo* of an NEHR and the critical junctures where institutional change occurred.

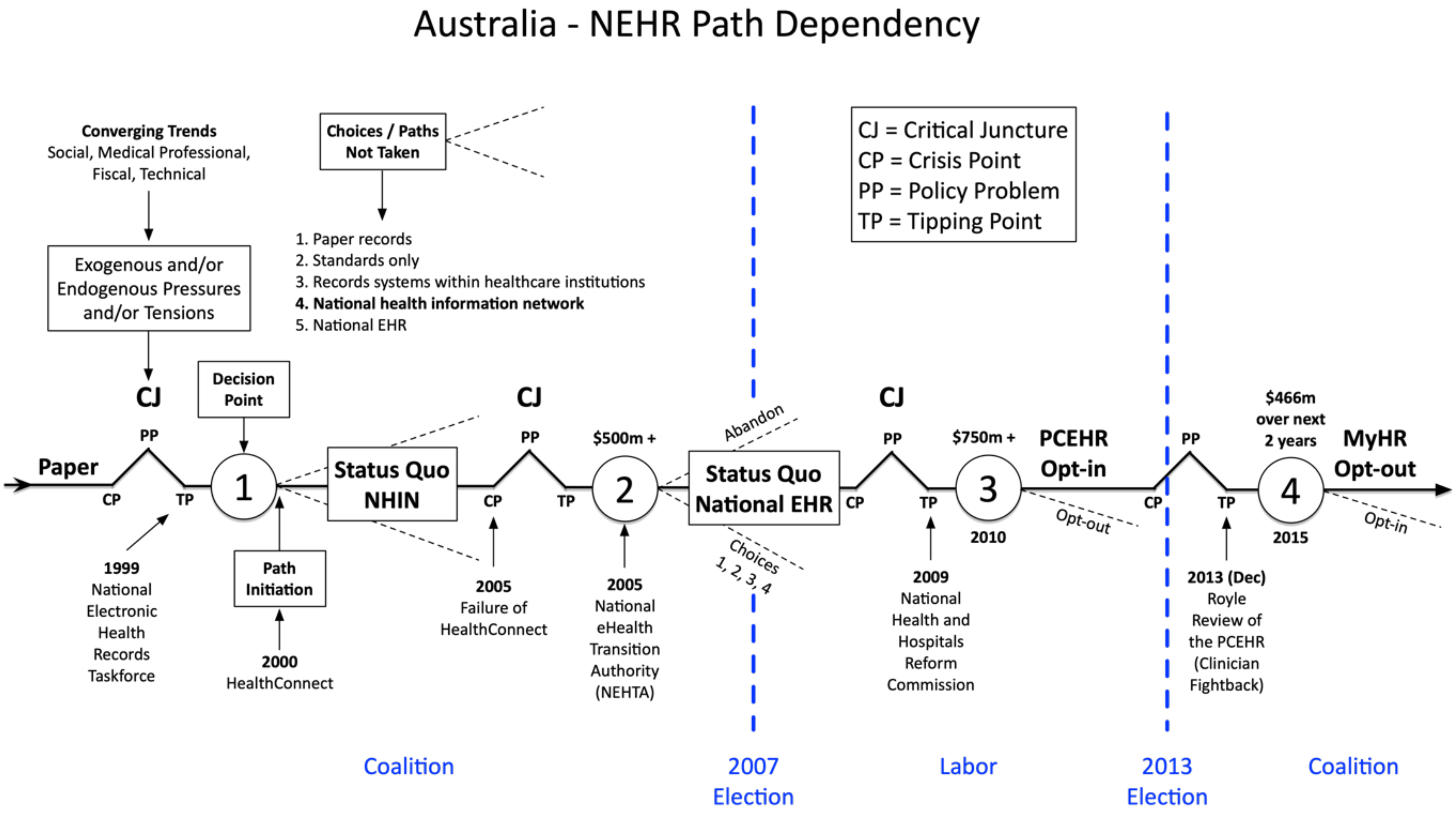

Figure 10-1: Australia – NEHR Path Dependency

England – NEHR Path Dependency

Macro level regime change in England was similar to Australia in terms of converging trends that sought to move from paper to digital health records and had the potential to "*transform* the NHS … reduce costs … and provide citizens with more *choice* over their healthcare."[956] The 2000 NHS Plan led to the decision point for an NEHR which came in 2002 with legislation to establish the National Programme for Information Technology (NPfIT) and pursue the creation of a Summary Care Record (SCR) that would centralise patient health information and make it available at all points of care. From this point in time the SCR was locked in despite ongoing intense criticism, the failure and abandonment of the NPfIT, a new government after the 2010 election that had campaigned on getting rid of the centralised SCR[957] and replacing it with a regional record, and an estimated price tag of £20 billion by 2015. The option of abandoning the SCR came in 2010-11. However, sunk costs of £12.7 billion, some limited positive feedback on outcomes, and increasing returns of some programmatic success in building the components of the SCR, including interoperability, and increasing its uptake and use left policy makers little option but to continue with the program. The new status quo of a centralised NEHR continued to weaken, but not fully replace, the old path of paper health records and fax machines and by 2015, 97 per cent of the population had an SCR. Values such as privacy, patients' control of their health information and the commitment of policy makers to giving patients more choice in the delivery of their healthcare (and therefore their outcomes) persisted over time, reinforcing the new status quo. As a result, the norm of making patient health information available at all points of care slowly became more widespread, particularly as NEHRs were integrated

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[956] Wendy L. Currie, "Translating Health IT Policy into Practice in the UK NHS," *Scandinavian Journal of Information Systems* 26, no. 2 (2014): 3–26.

[957] This episode is a good example of path resilience making change difficult. "When in opposition, both the Conservative[s] and Liberal Democrats had called for centralised patient records to be scrapped." This was primarily in an effort to reduce costs by dismantling "Labour's central NHS IT infrastructure, delivering its benefits through local systems instead." However, while the centralised IT in the form of NPfIT was abandoned centralised NEHRs in the form of the SCR was continued though initially scaled down in scope and then built up over time. Powell and Thompson, "Electronic Patient Records: The Roll-out of the Summary Care Record," 13.

into clinical workflows. Figure 10-2 shows England's journey from paper to the *status quo* of an NEHR and the critical junctures where institutional change occurred.

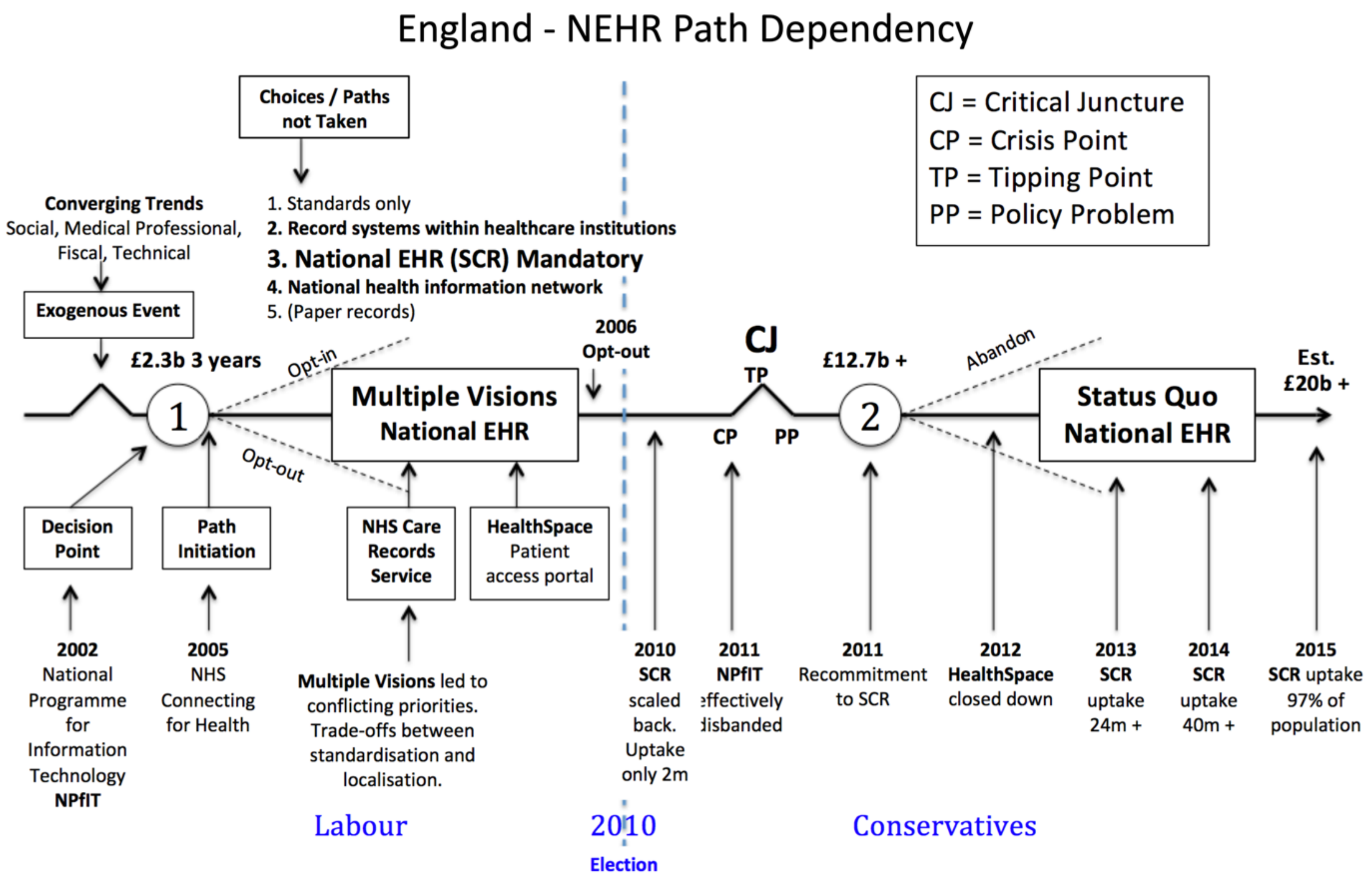
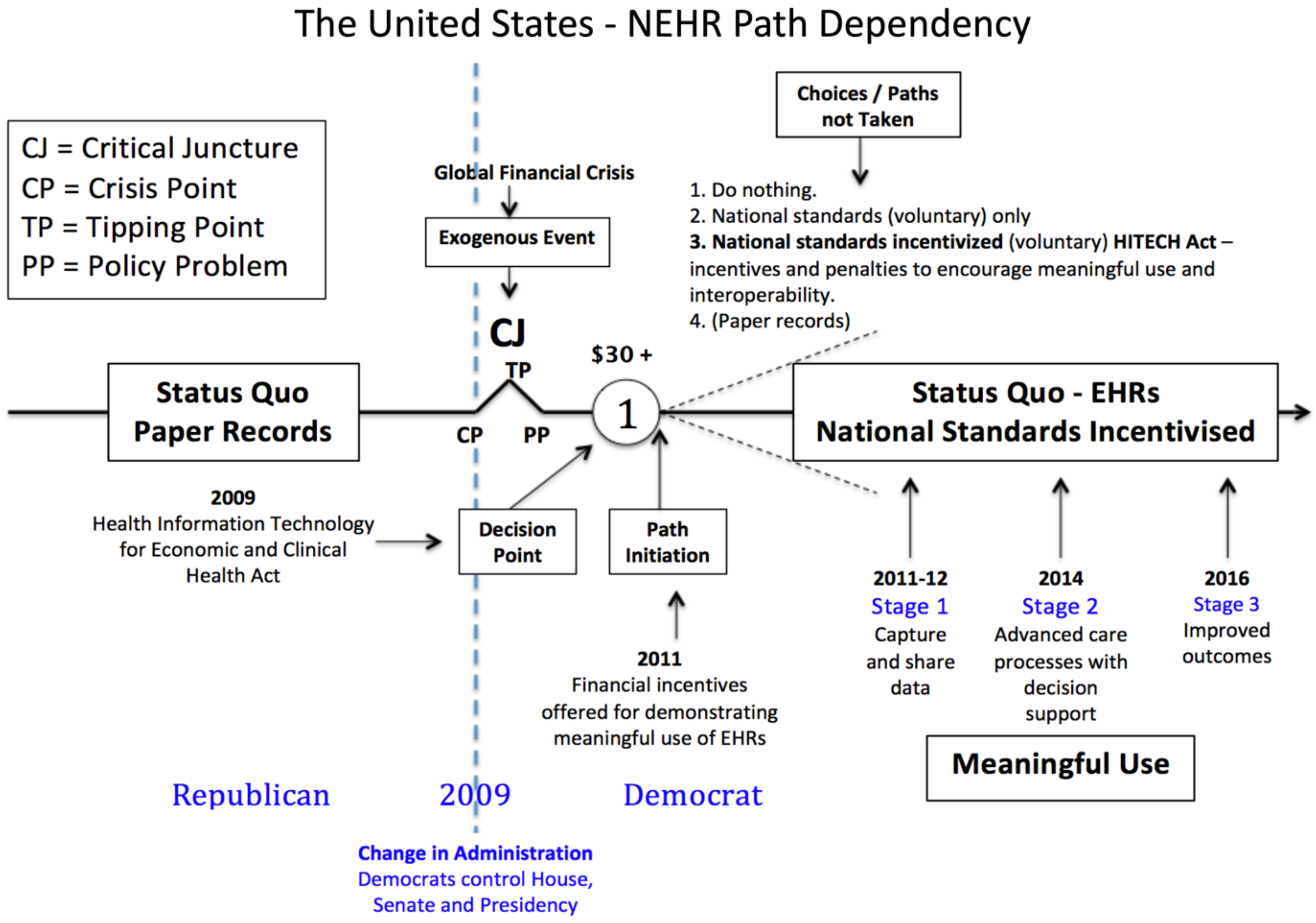


Figure 10-2: England – NEHR Path Dependency

United States – NEHR Path Dependency

The ehealth institutional situation in the United States before 2009 can best be described as a mosaic. Paper was the dominant method of health information storage and transmission and where EHRs were being used they often lacked interoperability both within and across organisational boundaries. The Office of the National Coordinator for Health Information Technology (ONC) was established by President Bush, a Republican, by executive order in 2004 to "provide leadership for the development and nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care". The ONC's emphasis was on the promotion and coordination, but not the regulation, of the vision of a nationwide interoperable health information infrastructure. This changed with the Great Financial Crisis (GFC) of 2008-09. The GFC proved to be an exogenous event that led to a moment of openness and rapid innovation. Firstly, 2008 was an election year and the Democrats won full control of the national legislature, known as the Congress (House of Representatives and Senate) and the executive (presidency). This was important as it represented an ideological shift that, combined with an economic crisis in the GFC, enabled options that might have otherwise been unrealistic to become viable. Republicans favoured austerity, cutting back government expenditure, which was essentially a do nothing option. Regulation without financial incentives or penalties was also an option but not supported by Republicans. Democrats favoured a Keynesian stimulus approach as a response to the GFC and identified ehealth as a valuable area in which to allocate government funding with the expectation of favourable healthcare outcomes. The *Health Information Technology for Economic and Clinical Health Act of 2009* (HITECH) significantly amended two institutional components of the U.S. Department of Health and Human Services (DHHS) – the ONC and the Centers for Medicare and Medicaid Services (CMS). Both had their regulatory powers and funding increased. This gave them the capacity and authority to make extensive new rules, provide incentive payments for the adoption of standards relating to the interoperability and meaningful use of EHRs, as well as allowing the CMS to apply penalties in the form of downward payment adjustments to healthcare providers who did not achieve designated outcomes as a way of coercing the adoption of interoperable EHRs that were meaningfully used. Interestingly, choices made in the past – the creation and mission of both the ONC and the CMS – restricted the viability of choices in 2009 leading to amended and strengthened institutions rather than wholly new ones. Also, the gradual strengthening of the path to a more centralised regulatory approach which started with HIPAA in 1996, was reinforced with the creation of the ONC and subsequently significantly strengthened with the legislation of HITECH and the implementation of an incentives and penalties regulatory model. This path also strengthened the option of state intervention in the marketplace, especially from Democrats who wanted to address issues of market failure in the name of the public good and as part of a broader pursuit of public sector reform based on more efficient technology. Figure 10-3 shows the US journey from paper to the *status quo* of incentivising an NEHR and the critical juncture where institutional change occurred.



1. Do nothing.
2. National standards (voluntary) only
3. **National standards incentivized** (voluntary) **HITECH Act** – incentives and penalties to encourage meaningful use and interoperability.
4. (Paper records)

Figure 10-3: The United States – Path Dependency

Path dependence analysis highlights a number of similarities across the case study countries. Similar exogenous and endogenous pressures and tensions led to the first critical junctures that saw the old *status quo* of paper health records give way to the new *status quo* of NEHRs. Second, once embarked upon, the path towards centralisation progressed despite repeated failures, partial successes and intense criticism. Likewise, once an NEHR was decided upon it became the new path, gradually replacing paper and obsolete technologies such as the fax, eventually becoming the acknowledged *status quo* for the majority of stakeholders. Fourth, critical junctures and new ideas played a key role in bringing about change which will be discussed further in Part 2. Lastly, policy decisions made by policy makers after the initial critical juncture establishing NEHRs as the dominant path were clearly contingent upon path dependent criteria such as lock-in, sunk costs, positive feedback, increasing returns and self-reinforcement.

Part 2

Critical Junctures and Institutional Outcomes

> *Critical junctures are choice points in which human agency can be decisive.*[958]

In Part 1, institutional stability was explained using the HI theoretical framework of path dependency. However, each country experienced a clear critical juncture at the macro level that changed the *status quo* from paper health records to NEHRs. Part 2 uses the HI theoretical framework of critical junctures to explain how institutional change was generated over time, while reinforcing the concept that decisions made at the initial macro critical juncture narrowed the options available and significantly influenced policy-making decisions in later critical junctures.

The development of institutional pressures and tensions discussed elsewhere in this thesis led to a moment of structural indeterminacy and fluidity in all countries resulting in critical junctures that changed the *status quo* from paper health records to NEHRs. Similar reasons for change were given by policy makers (see Chapter 4) who essentially

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[958] Hague and Harrop, *Comparative Government and Politics: An Introduction*, 55.

justified change based on the potential of NEHRs to improve the efficiency and effectiveness of healthcare, give patients more control over their health information, and improve patient healthcare outcomes.

The policy problem was that ICT was rapidly advancing and being used successfully to improve outcomes in other sectors of society but the healthcare sector was perceived to be lagging badly. There were numerous options for radical institutional transformation available that ranged from decentralised approaches to more centralised options. For example, the US initially had a decentralised approach with the state providing guidance for the adoption of standards to improve interoperability and the usability of health information but letting private sector organisations develop and implement their choice of EHR that might not be nationally shareable. Australia also initially adopted a decentralised NHIN. More centralised options included those where the state either developed and implemented an NEHR (Australia from 2005 and England from 2002) or adopted regulations to incentivise NEHRs and penalise those who did not achieve meaningful use outcomes (US from 2009).

Initially, even though all options were considered as real choices, Australia thought that only a decentralised NHIN was physically, technologically and practically feasible. It was also the only politically viable option due to the strength of the privacy and healthcare consumer lobby who strongly opposed the centralisation health data under the control of the federal government. England had similar options but the election of 1997 had brought in the Blair Labour government that was determined to adopt a modernisation agenda and use technology to transform the NHS. A centralised SCR was seen as both physically and technologically possible and was the only politically viable option. In the US, the options were slightly different. Prior to the GFC the only viable option had been limited privacy and patient control legislation as seen in HIPAA due to the US political preference for economic individuality and free markets. This changed in 2008–09 with the critical juncture of the GFC allowing a window of opportunity for the new Democrat-controlled federal government to increase the role of the state, pursue a stimulus agenda, and centrally regulate an NEHR regime through incentives and penalties.

Each country chose one option that was a result of political interactions and decision making that reflected the development of institutional pressures and tensions that influenced, but did not constrain, institutional outcomes. These included structural antecedent conditions such as an ageing population with increasing rates of chronic disease and shock events such as elections and the GFC. Ideational change allowed for the acceptance of a larger role for the state in the provision of healthcare ensuring privacy and patient control of information rights, and political agency to establish NEHR programs and related organisations. They also included converging social, medical professional, fiscal and technical trends as discussed in the case study chapters.

There was a direct connection between macro-structural antecedent conditions and the strategic interactions and political choices that led to the adoption of NEHR institutional arrangements in each country. Values such as patient-centred care, an increasing state role in the provision of healthcare, strengthening privacy regimes, a desire to expand patient control of health information, and the pursuit of the interoperability norm of making patient health information available at all points of care drove institutional change. In Australia an initial lack of state capability to implement a centralised NEHR combined with powerful stakeholders intent on expanding privacy and patient rights initially led to the NHIN. However, as the NHIN failed to deliver desired outcomes, stakeholder perceptions changed leading to new institutional arrangements. These arrangements included a new organisation tasked with developing the building blocks for ehealth in NEHTA and the adoption of a more centralised approach to NEHRs in the PCEHR while still maintaining strong privacy and patient rights regimes. In England, previous decentralised IT failures and the idea that the state had a vital role to play in modernising the provision of government services through the application of new technologies led to a centralised approach in the NPfIT and the SCR. The logic of the centralised approach was generally accepted by most stakeholders though criticism grew over time as it failed to deliver on all its promises. Despite pressure and the NPfIT being abandoned, the SCR continued as a centralised project, albeit accompanied by organisational change. In the US institutional arrangements initially reflected a small government guidance approach that favoured the free market but this changed with the GFC as explained earlier in this chapter.

As shown in Part 1, the initial NEHR selection produced long-lasting institutional legacies in all three countries, although Australia went through a transition phase of the NHIN before adopting a centralised NEHR. Institutional change occurred in a number of areas. Values changed from favouring a clinician-centred to a patient-centred healthcare system. Previously siloed health information was increasingly expected to be interoperable, available at all points of care, and subject to some level of patient control and stricter privacy regimes. Rules establishing standards, including IHIs (with the exception of the US), became widely accepted[959] and formed the building blocks of a usable NEHR. Paper health records and fax machines slowly gave way to NEHRs and the trend has not looked like reversing. Strategies that were designed to embed and legitimise new institutions through ideational change included strong state support for privacy regimes, especially by health ministers, and giving patients more control over their health information and allowing them more choice regarding their treatment and outcomes. Incentives, and penalties in the case of the US, drove uptake and the meaningful use of NEHRs and provided significant financial benefits to clinicians and healthcare providers, thus co-opting some level of support from these stakeholders for NEHR programs. The state waged an unrelenting campaign to advertise the potential benefits of NEHRs, justifying both funding and the structure of NEHR programs, and this continues today. Criticism was met with two major arguments from the state. NEHRs will get better over time, so be patient; and NEHRs will provide public value, improve the public good and eventually show value for money. These strategies reflected the normative consensus in each country and normatively justified the continuance of respective NEHR programs.

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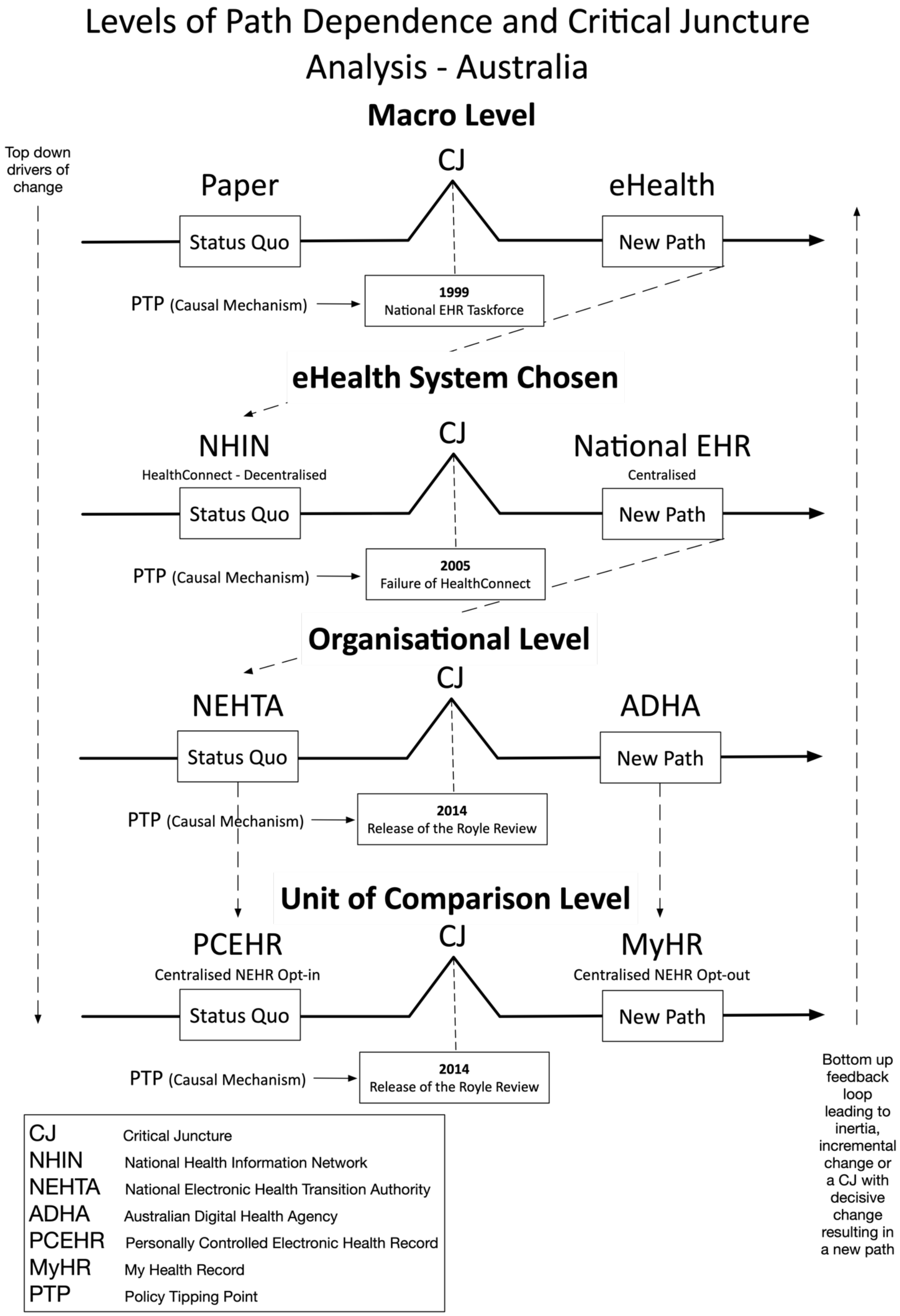
[959] The value of IHIs were widely accepted because without them outcomes for patients could be devastating. Hovenga gave an example: “I know that there was one instance in Sydney where for example there were two people in the hospital with the same name and the same date of birth and all they ever ask when they’re doing your medication is your, you check your name, they check your date of birth. And in Sydney in one instance it was the wrong drug given to the wrong patient. Well, the wrong drug was given to the patient that had the same name and the same date of birth, and she died.” Hovenga (CEO eHealth Education and Managing Director of Global eHealth Collaborative), Interview.

Deepening Path Dependency Explanations by Combining Levels of Analysis

A vertical diagrammatic heuristic, shown in Figures 10-4, 10-5 and 10-6, shows each country's institutional story that reflects top-down drivers of change and a bottom-up feedback loop. This is a useful visual counterpoint to the horizontal examination of institutional stasis and change presented earlier in this chapter. Incremental change will be discussed in Part 3.

Australia

Australia attempted to change the *status quo* from paper health records to NEHRs by adopting ehealth as the new path as shown in Figure 10-4. The adoption of ehealth initially drove the choice of the decentralised NHIN as the ehealth system developed as part of the HealthConnect program. With the failure of HealthConnect a new path was chosen, which was a centralised NEHR. This new path drove organisational change, with NEHTA replacing HealthConnect and being tasked with developing the building blocks of an ehealth system (including standards such as the IHI) and, after 2009, being charged with developing and implementing the PCEHR. The PCEHR was a centralised NEHR that was opt-in. The PCEHR failed to achieve uptake and use goals and was opposed by many clinicians and healthcare providers who pushed back against the concept. This resulted in the Royle Review, that was released in 2014 and acted upon by the new Coalition government. The two major outcomes were the move from opt-in to opt-out and the rebranding of the PCEHR to the My Health Record (MyHR).



CJ	Critical Juncture
NHIN	National Health Information Network
NEHTA	National Electronic Health Transition Authority
ADHA	Australian Digital Health Agency
PCEHR	Personally Controlled Electronic Health Record
MyHR	My Health Record
PTP	Policy Tipping Point

Figure 10-4: Levels of Path Dependence and Critical Juncture Analysis – Australia

England

England, too, pursued a change in the *status quo* from paper health records to ehealth and an NEHR as shown in Figure 10-5. However, its process was more complex than that observed in Australia and the US. England chose a centralised ehealth system that was to be delivered as part of the NPfIT. This drove organisational creation and replacement. CfH was tasked with implementing the NPfIT and the NCRS with delivering a comprehensive SCR. With the failure of the NPfIT to deliver on its goals, and facing intense stakeholder criticism (particularly over centralisation) including from the opposition Conservative party, the SCR came under pressure. An election victory in 2010 saw the conservative government change tack and abandon the NPfIT and scale back the SCR to contain only basic information that would be built up over time. This was an effort to improve uptake and use. There was also a move to force the state to abandon its mandatory data collection policy and weaken the opt-out system so citizens could more easily exercise choice in the matter. This was reluctantly adopted by government but did ease stakeholder pressure on the SCR program. CfH was replaced by the Health and Social Care Information Centre which took over some of its projects and responsibilities in 2013 and was in turn rebranded NHS Digital in 2016.

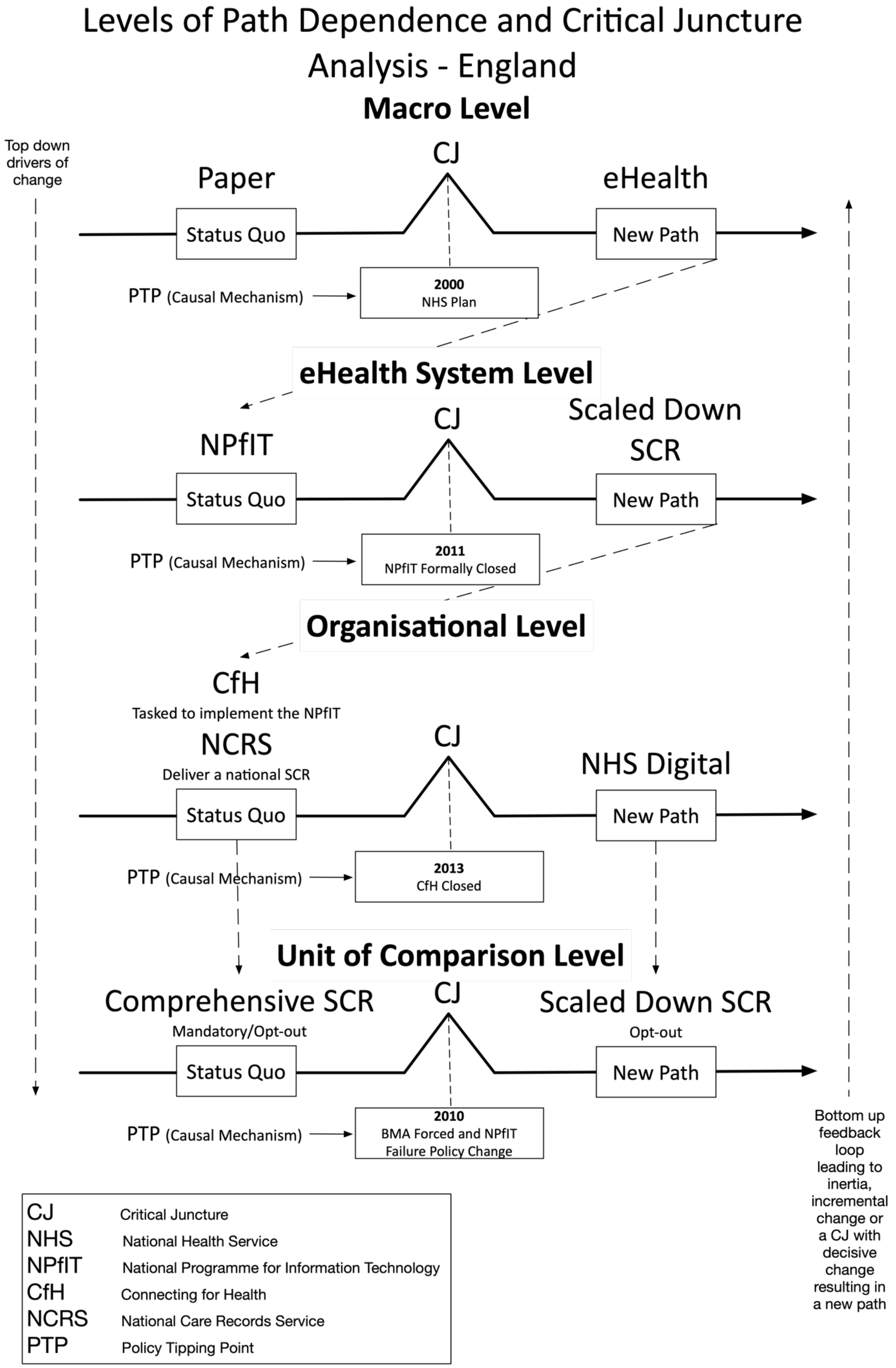


Figure 10-5: Levels of Path Dependence and Critical Juncture Analysis – England

United States

The United States showed clear critical junctures in the drive to replace paper health records with NEHRs as shown in Figure 10-6. The initial move towards an NEHR came with the creation of the ONC in 2004. This was the era of decentralised NEHRs with the ONC mandated to adopt a facilitating leadership role promoting interoperability. Paper health records and organisational implementations of EHRs that were not nationally shareable, with the exception of the VA that could share records throughout its system nationally, were the norm. The great change came in 2009 with the GFC. This gave Democrats the window of opportunity to pursue a stimulus agenda, part of which was the HITECH Act of 2009, which provided extensive funding for incentivising the interoperability and meaningful use of EHRs and making patient health information nationally shareable. This required organisational change and ONC and CMS were given new tasks and regulatory powers which they used to significantly influence NEHR institutional arrangements. Stakeholder pushback delayed and changed some incentive structures and programs instituted by ONC and CMS but in the main the process to achieve interoperability and meaningful use goals was maintained and NEHRs were the preferred path even though they still faced numerous barriers to success.

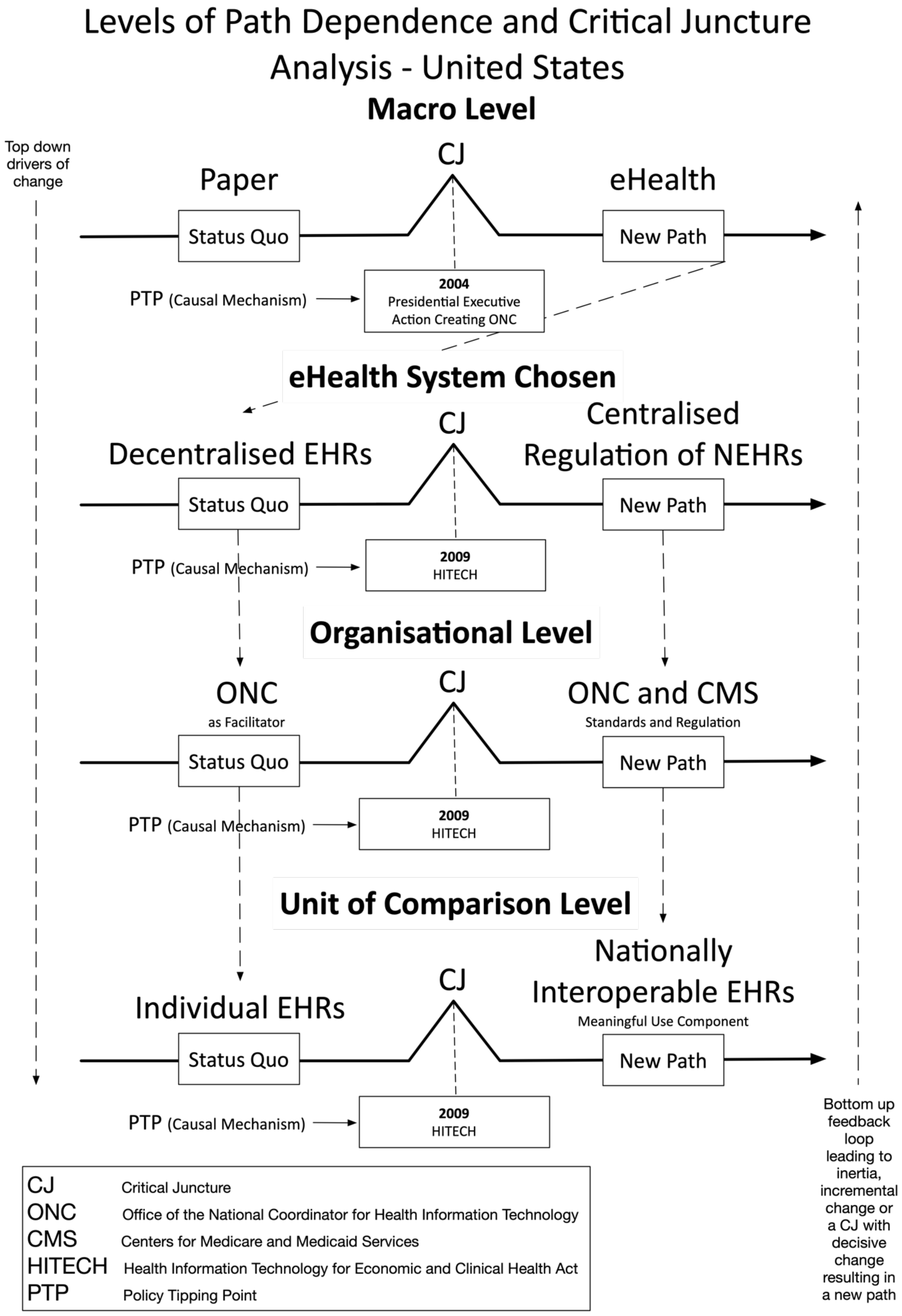


Figure 10-6: Levels of Path Dependence and Critical Juncture Analysis – United States

Part 3

Incremental Change and Institutional Outcomes

Mahoney and Thelen have argued that "once created, institutions often change in subtle and gradual ways over time" and that while less dramatic than critical junctures these types of changes "can be equally consequential for patterning human behaviour and for shaping substantive political outcomes."[960] Incremental change challenges the notion of persistence and the focus on stability and exogenous shocks prevalent in the HI literature. The incrementalist view of endogenous change is explored in this part of the chapter.

All three countries exhibited instances of endogenous incremental change that influenced NEHR institutional outcomes. In Australia the internal pressure from organisations such as the DoH and NEHTA were influential in driving the adoption of ehealth and an NEHR as national policy. Powerful actors within the health institution who were supportive of an NEHR and who decided the rules were influential in creating the structure of the privacy regime, determining what rights patients had over the control of their health information and whether or not the NEHR system would be opt-in or opt-out as discussed previously. Many of these decisions were long lasting and, particularly in the development of standards, built up layers that over time changed institutional norms, practices and procedures. An example here is the development of standards that continually enhanced the interoperability of the PCEHR and its usability by adding more components that encouraged clinicians to upload and use patient health information.

Incremental organisational change was common and, while sometimes not long lasting (particularly in the case of England), resulted in layering, conversion, drift, displacement, and/or exhaustion. For example, the layering of responsibilities can be seen in the added regulatory responsibilities of ONC and CMS following HITECH. Conversion was

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[960] James Mahoney and Kathleen Thelen, "A Theory of Gradual Institutional Change," in *Explaining Institutional Change: Ambiguity, Agency, and Power*, ed. James Mahoney and Kathleen Thelen (Cambridge: Cambridge University Press, 2010), 1.

apparent in the redeployment of NEHTA from developing standards and the building blocks of ehealth to developing and implementing the PCEHR. Interviewees observed drift with HealthConnect, in the years after the creation of NEHTA, when it became a change management strategy without much funding or policy purpose. Displacement was common. For example, NEHTA replaced HealthConnect – even though HealthConnect continued until 2009 – and in turn was replaced by the ADHA; NHS Information for Health was replaced by CfH which in turn was replaced by the HSCIC. Incremental change also occurred with NEHR rules, especially in the area of privacy. Due to stakeholder concerns, criticism and pushback against initial state privacy regimes in all three countries, privacy rules were progressively changed and strengthened shifting power from clinicians, vendors and healthcare providers in differing degrees towards patients.

The cumulative effects of these changes added up to fundamental transformations that strengthened privacy regimes, gave patients more control over their health information, aided in the centralisation of NEHR systems and slowly challenged proprietary EHRs and data blocking. They also built ICT capabilities among healthcare providers, and slowly shifted the state's focus from an ICT solution to the problem of paper records towards one of effective change management that would achieve desired efficiency, effectiveness and patient control of health information outcomes in a complex healthcare environment.

Part 4

Historical Institutionalism: A High-level Analysis

In Part 4, I adapt Skocpol's methodological framework (as presented in Chapter 3) to identify and understand important variations and common patterns in the outcomes between case studies. Linking case study narrative, policy evaluation and theoretical explanation at a high level is a valuable framework through which to explain NEHR institutional stability and change (and the consequent outcomes) across the three countries.

Both eHealth and NEHRs are firmly situated in international structures and world-historical development. Rapid technological change saw policy makers in many countries apply ICT to problems in healthcare including attempts to move from paper health records to NEHRs. These attempts varied in success and faced many of the same barriers to interoperability, usability and meaningful use faced by Australia, England and the US. Approaches ranged from highly centralised, particularly in illiberal democracies such as Singapore, to more decentralised regional systems such as found in the liberal democracy of Canada. They are also situated in ongoing discussions of the values and norms of liberal democracies, the appropriate role of government in the health space, and the rights and responsibilities of various healthcare stakeholders. For example, HITECH was controversial in the US and divided legislators along party lines as previously discussed.

There were patterns of change that were common to all three countries, as well as important variations in outcomes of the Australian, English and US case studies. Common patterns of change included the development of institutional pressures and tensions leading up to the first critical juncture in each country that set them on the path from paper health records to NEHRs. Common social, medical professional, fiscal and technical trends were identified, as discussed in the case study chapters and Chapter 9. The weakness of dividing up the development of institutional pressures and tensions into discrete sections is that there can be a tendency to write about those discrete sections rather than the more integrative picture. Examining common patterns of change allows the researcher to try and weave discrete sections together into a more integrative explanation of institutional stasis and change.

Fundamental and enduring structural transformations were identified, particularly where meaningful use efficiencies and effectiveness were sought by stakeholders implementing NEHRs. New organisations were created and old organisations were amended to consolidate change, giving state bureaucracies long term programmatic and regulatory powers (for example, ONC and CMS in the US, NEHTA in Australia, and CfH in England). While some organisations were replaced over time, their key roles of developing, implementing and/or regulating NEHRs were maintained even if new responsibilities changed the focus of the NEHR (for example, HealthConnect to NEHTA) or responsibilities were shared amongst new organisations as happened in England. The result was that the state was expected to persist with efforts to reap efficiency and effectiveness outcomes from NEHRs, thus extending its policy role in the healthcare sector. As the paper health record path weakened the NEHR path strengthened with the vast majority of clinicians and healthcare providers moving to EHRs and thus fundamentally changing clinical workflows and the amount of information stored in health records.

Changes in privilege and institutional power bases slowly developed, though at different paces, in each country. The era of doctor knows best waned, healthcare expertise was more widely shared, health records influenced clinical decision support, efficiencies were pursued despite clinical pushback and clinicians moved from solo practice to larger, multi-practice organisations shifting power to large healthcare providers. However, GPs, and to some extent hospitals particularly in the US, were seen as powerful players to whom incentive programs needed to be targeted in order to achieve NEHR programmatic goals. There was also a shift in power from clinicians and the state to patients, especially through privacy and patient control of health information laws and regulations, though this did not result in a patient-centred healthcare system but rather in a rough balance depending on organisational norms with clinician-centred healthcare. The central government became a major player in determining the system, particularly in Australia and England, with industry and healthcare providers who traditionally had not wanted state interference in their market, seeking clarity of regulation over time rather than the uncertainty that comes from political conflict.

Impediments to change remained in all three countries despite programmatic attempts to remove them. Debates persisted about privacy and how much control of health information to give to patients while still having NEHRs that were seen as clinically useful and were actually used by clinicians persisted. This was despite substantial privacy legislation and efforts by governments to increase uptake and use. Increasing the variety of clinically useful information above that contained in a basic record was a slow process that was nowhere near complete in 2015. Proprietary EHRs, particularly in the US, meant that systems lacked interoperability, data blocking continued, and clinical mistrust in the usability of NEHRs persisted. As a result of impediments, interoperability goals were only partially met and NEHRs had mixed results in improving the process (continuity, integration and coordination) of care. Emerging institutions were challenged by disunity and pushback from stakeholders. Examples included, the NPfIT and the plethora of organisations responsible over time for the SCR in England and AMA/clinician criticism of the PCEHR which resulted in the Royle Review and major changes.[961] Some impediments to change were successfully removed. ICT use was successfully incentivised in all three countries, increasing uptake and use; adopting an opt-out system also had this effect. NEHR programs went through significant opposition early on but, once firmly established, were supported by many of those that originally opposed the change; this is because, by 2015, they were benefitting from these programs in certain ways,[962] such as doctors and providers receiving incentive payments. Part of the success in meeting NEHR challenges occurred because of the mobilisation of new groups formerly excluded from power-sharing relationships. For example, privacy and consumer healthcare advocates became influential in issues of privacy, access and transfer of EHRs – particularly in Australia – with NEHR program rules that supported their positions.

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[961] Harch agreed with my analysis that uptake and use issues associated with opt-in led to the clinician fightback for opt-out and a power shift back towards clinicians. She explained, “I think it started a really great conversation and the need to look at the consumer more in their health care picture. Traditionally it has been [a] very institutional focus on either a hospital or a GP setting and the PCEHR sort of came out as like a mechanism that could support that more integrated healthcare journey that a patient actually goes on between a GP and a hospital or a specialist and those sorts of things. I think, you know, maybe at the time the fact they focused so much on it being personally controlled to address privacy concerns, I don’t know, may have been a good thing but the opt-in approach has been a bit problematic in that its taken a long time probably to get the amount of people involved that you wanted to start seeing some benefit in it.” Tanya Harch (Former Director, National eHealth and Information Co-ordination Unit for Queensland Health - currently Director, Strategic Partnerships in the Office of the Chief Executive, eHealth Queensland, Department of Health), Interview, 2018.

[962] Wanna noted that “once in, it becomes a sacred cow that is difficult to attack or significantly change in ways that beneficiaries see as negative for them.” John Wanna, Interview, 2019.

There were important variations in outcomes between countries. While state mandated centralisation and standardisation occurred in all three countries it was more pronounced in Australia[963] and England where ehealth and NEHR programs gave rise to centralised state organisations[964] that became the prime moulding forces of NEHR NRPPs. This happened in the US with ONC and CMS but not to the same extent. Centralised state organisations pursued standardisation which, combined with the incentive money they had to spend, made them more potent in society (more so in Australia and the US). There was also an effort to incorporate stakeholders into state-run affairs. Stakeholder outcomes varied. EHR vendors both won and lost, particularly in England where strict procurement contracts saw providers drop out mid-implementation when they could not achieve goals. In Australia, and particularly in the US, EHR vendors benefitted from incentive payments and NEHR programs. Bureaucracies in all three countries expanded and gained more regulatory powers; however England was seen as more successful in forcing outcomes through bureaucratic means and in the US the bureaucracy was criticised for leaving much of EHR governance to stakeholders.

Part 5

Originality and Contribution to Knowledge

This thesis presents original research in that it is the first case study comparison of NEHR institutional change focusing on the interoperability, usability, meaningful use, and patient control of their health information across the countries of Australia, England and the US. As such, it produced a rich, thick descriptive and explanatory narrative of NEHR programs at three levels in each of the case study countries. This thesis makes several contributions to new knowledge. Implications for theory included historical

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[963] Within constitutional limits that were more restrictive than in England or the US. Andrew Podger (Former Secretary of the DoH and Public Service Commissioner), Interview 2, 2019.

[964] Wanna argued that “we have an activist central government” that sometimes applies a statist tradition in the pursuit of programmatic success – “set up a large institution, make it a monopoly and then barnacle it into the Commonwealth.” Wanna, Interview.

institution generally and critical junctures in particular, public administration theory and methodology. Implications for policy and practice included digital governance, and program and project management. Such studies have been called for in the extant literature acknowledging the value of case studies in health policy.[965]

Implications for Theory

Implications for Historical Institutionalism Generally, and in Relation to Critical Junctures in Particular

This thesis provided confirmation of the utility of path dependency theory through its application to a relatively new area, NEHRs and more broadly ehealth. Path dependency has been commonly applied in relation to technology but not in relation to the technology making patient health information interoperable.[966] Sunk costs and increasing returns were observed which prolonged funding. Specific patterns of timing and sequence were identified that influenced specific outcomes despite a wide range of outcomes being possible at policy decision points. It was observed that large consequences were the result of relatively small or contingent events, with the move from opt-in to opt-out in Australia being a case in point that increased up-take from around 10% to over 90%. Once introduced, NEHR programs were almost impossible to reverse and development was punctuated by critical junctures that shaped the basic contours of stakeholders control over, and use, of patient health information.

Similar to other forms of new institutionalism, such as sociological and discursive institutionalism, the thesis found that certain values and norms contributed to path dependency, and the response to the critical junctures, exhibited a level of normative consensus. Policy reflected the normative consensus in four areas: the principles on which policy should be based, citizen entitlement to various rights, citizens' obligations

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[965] Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America"; Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*; Exworthy et al., *Shaping Health Policy: Case Study Methods and Analysis*.

[966] Pierson, "Increasing Returns, Path Dependence, and the Study of Politics;" Michael de Percy, "Connecting the Nation: An Historical Institutionalist Explanation for Divergent Communications Technology Outcomes in Canada and Australia"; Michael de Percy and Heba Batainah, "Identifying Historical Policy Regimes in the Canadian and Australian Communications Industries Using a Model of Path Dependent, Punctuated Equilibrium," *Policy Studies* 0, no. 0 (2019): 1–18.

to the state and each other, and the prevailing norms of government program procurement and development. Critical junctures that arise in major technology projects are caused by institutional pressures and tensions and there was considerable interplay between critical junctures and ideas in determining policy decisions. Ideas that influenced policy decisions over standards, incentives, privacy and control of patient health information involved trade-offs between stakeholders and reflected power relationship ratios that directed the normative consensus.

Diagramming path dependency and critical junctures challenged three prevailing views in the literature. First, that critical junctures were rare and opportunistic and that their temporal sequencing was widely spaced over time. Second, that changes in government are routine and therefore not critical junctures. Third, that critical junctures come about solely because of exogenous events. The levels of analysis approach taken showed that while there was a single critical juncture at the macro level (L1) between paper health records and NEHRs, conforming to the temporal sequencing of critical junctures in the literature, subsequent ehealth policy decisions at the organisational (L2) and unit of comparison level (L3) exhibited critical junctures that changed the status quo more frequently. This was particularly the case in Australia where changes in government proved crucial in punctuating organisational and NEHR institutional equilibria. The change from an opt-in PCHER under a Labor government that emphasised privacy and patient control of their health information rights at the expense of outcome goal attainment to an opt-out PCEHR only 3 years after its creation under a new Liberal government showed just how fast institutional NRPPs could change and that a change in government mattered. The impact a change of government can have was further emphasised at the macro level in the US. The Democrat's victory in the national elections of 2008 gave them control of the presidency and both houses of Congress. This shift in power gave them a two-year window of opportunity to achieve major reform in the healthcare arena, something that had eluded many previous administrations as noted by Tuohy and Steinmo and Watts in the literature. That it was a confluence of events – a change in government that exploited a major exogenous event in the GFC –

and the build-up of endogenous pressures and tensions illustrate just how complex critical junctures can be.

Diagramming the levels of analysis also confirmed the stickiness of path dependency and how policy decisions made at one point in time constrained future policy decisions. This thesis showed that NEHR institutional problems had common roots across case study countries and while policy options sprang from specific national circumstances common trends were apparent resulting in some policy convergence.[967] Institutional problems that had common roots fundamentally centred around barriers to interoperability and the tension between the effective provision of health information to all points of care and privacy. While specific policy options or alternatives exhibited some diversity between countries, common trends regarding how to achieve interoperability resulted in significant policy convergence on priority setting, the allocation and rationing of resources, the organisation of power within health systems, and the complexity and interdependence of health and other care systems. Funding for NEHR programs and regulatory organisations persisted despite the initial failure of programs to achieve set goals within original timeframes. The public provision of an NEHR in Australia and England, and centralised regulatory approach adopted in the US, likewise persisted despite initial setbacks and, in the case of England, abandoning the NPfIT and severely curtailing the SCR program. Once the policy decision to move from paper health records to digital health records through an NEHR program had been made the new status quo stuck and funding support remained relatively strong, despite more frequent organisational and NEHR institutional change over time. While institutional rules changed and organisations adapted or were replaced the policy direction, with the exception of the broader adoption of ICT in the NHS, was towards the centralisation of patient health records within an information privacy regime forcing a level of conformity across all three NEHR programs.

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[967] This finding aligns with comparative health policy attempts to explain change by identifying factors that are the determinants of change in health systems – as emphasized by Blank et al. Blank, Burau, and Kuhlmann, *Comparative Health Policy*.

Implications for Public Administration Theory

The thesis made an important contribution to public administration theory by moving away from simplistic descriptive narratives and 'principle-agent' models to a more sophisticated understanding of the state. Relations between the state and the ehealth/NEHR technologies each state employed showed how critical junctures in the roll out of these technologies generated new ideas about the appropriate role of the state in healthcare. The changing role of the state gave emerging technologies new possibilities to achieve state objectives. However, there was no single universal approach to NEHRs though policy goals remained similar. In the US, the state built on existing technologies and practices. In England and Australia, the state attempted to introduce entirely new systems of digital transformation. Regardless of the initial approach taken, states then had to grapple with issues of digital governance as discussed below.[968] The thesis identified the increasing power of the individual healthcare consumer and extended our understanding of stakeholder mobilization, particularly over issues of privacy where the state increased regulation and drove interoperability in order to achieve NEHR goals that directly benefited the individual healthcare consumer. The application of critical junctures theory to theories of state players was also evident in the thesis. Policy decisions made by policy makers after the initial critical juncture establishing NEHRs as the dominant path were clearly contingent upon path dependent criteria such as lock-in, sunk costs, positive feedback, increasing returns and self-reinforcement.

Implications for Methodology

Exworthy's and Powell's criticism of Yin's focus on process characteristics in teasing out the value of case studies reflects a recent shift towards outcome characteristics producing "important empirical and conceptual contributions to knowledge"[969] that exhibit methodological flexibility and generate theoretical insights that produce

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[968] "There has long been a significant divorce in the public management field between the practical and empirical centrality of IT and information changes on the one hand and their marginality, indeed almost complete absence, from the central texts of public management theory and the literature on public sector change on the other." Patrick Dunleavy et al., "New Public Management Is Dead - Long Live Digital-Era Governance," *Journal of Public Administration Research and Theory* 16, no. 3 (2006): 468–469.

[969] Exworthy et al., *Shaping Health Policy: Case Study Methods and Analysis*, 5.

detailed, narrative-like descriptions that embrace multiple sources of data. This thesis has shown the value of the case study method and "its ability to understand previous events and to explain emergent policy developments."[970] The case study chapters are sufficiently grounded in evidence to be credible, produce insights which can be applied generally and have the potential transferability of findings to different contexts.[971]

The use of diagrams as heuristic tools developed historical institutionalism as both theory and method and added explanatory capacity to both process and outcomes. By temporally sequencing punctuated equilibria for each case study country and comparing the contingent events that forced change the thesis identified and explained the choices that were made, or not made, by policy makers in developing and implementing NEHRs as a policy mechanism to improve the efficiency and effectiveness of healthcare. Despite diverse approaches a similar set of contingent events produced a crisis or policy issue/problem from which a critical juncture emerged. Political conflict over ideas as a result of the feedback on the efficacy of the institutional status quo ensued with policy makers reaching a decision point where they had a number of options to choose from. The diagrams demonstrated that these options were constrained by path dependencies. However, while path dependency led to different NEHR options being initially adopted by each country, similar barriers to, and policy makers goals for, interoperable NEHRs that made patient health information available at all points of care, resulted in substantially similar policy outcomes across the case study countries. This diagrammatic method could be used for other research, especially in relation to technology.

Implications for Policy and Practice

This thesis has important implications for public policy generally, as governments adopt more and more forms of technology to deal with crises and to generate longer term change. This can be seen in current debates about the role of technology in vaccine records and passports, which have seen a not dissimilar rollout, as per post new public management re-centralisation driven by technology. These debates have spawned major

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[970] Exworthy et al., 13.

[971] Exworthy et al., 7.

issues related to policy formulation and implementation, digital governance, program and project management, and the future development of the welfare state in the healthcare arena discussed below.

Generalisations About Public Policy Making

The research produced several generalisations that have the potential for prediction and drawing lessons across countries. First, public policy program success can rarely be based solely on the application of technology, particularly in complex environments such as health. Inserting technology is just one step in what must be seen as a comprehensive change management strategy, as was clearly shown by stakeholder resistance to NEHRs. Second, small but vocal stakeholders can, and do, significantly influence the development, implementation and regulation of policy. This was clearly seen numerous times in this research with the most potent example being privacy and patient rights advocates in Australia. Third, it is reasonable to expect organisational change that both disrupts and aids the successful implementation of public policy programs. For example, Australia's choice to create new organisations in HealthConnect and NEHTA, rather than give the job of developing and implementing NEHRs and standards such as IHIs to an existing body, caused bureaucratic infighting and, according to numerous interviewees, did not utilise existing systemic structures and expertise to achieve success. Fourth, values are hard to implement in institutions in a way that changes norms. This was seen in the failure of the notion of patient-centred healthcare replacing clinician-centred care, which also illustrated that stakeholders can define values very differently in practice.[972] Fifth, stakeholders who resist programs imposed on them may grow to accept the program as they experience increasing benefits such as incentive payments and improved clinical workflows. Sixth, the state can persist with partially successful, or even failing, programs for long periods of time despite criticism, with few major political consequences. For example, Australia persisted with opt-in to the point where uptake and use failure made it clear to nearly all stakeholders that a change to opt-out was needed to avoid program failure and give it a chance of success. Lastly, the tendency of democracies to value decentralisation (often a bottom-up approach) because of its ability to build innovative capacity and flexibility, comes at the cost of administrative complexity and inefficiency. Decentralisation results in more decision points that players can veto or at which they can exit entirely. That states then pursue centralisation (most often a top-down approach) to reduce stakeholder power and achieve outcomes seems to be a natural response to this problem.

Digital Governance

Learning for policy included exposure to risk of major scope changes, based on technology goals, as a result of changes in governments. In Australia, the new Coalition government elected in 2013 saw a major institutional change in the move from opt-in to opt-out, inflaming digital governance issues relating to privacy and control of health information. In England, the new Conservative government's persistent criticism of centralised IT and the failure of the SCR to achieve policy goals saw a move towards de-centralisation of healthcare IT and downsizing of the SCR. The centralised SCR was

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[972] The definition of patient-centred care revolved around who made outcome choices. Two approaches were revealed by the research. The first approach sees the patient having choice in outcomes: the patient choosing outcomes that might be different from other patients in the same situation and different from what the expert clinician, or best practice, or the state in its pursuit of benefits may have chosen. This is about the patient deciding what is important for the quality of their life – not what the clinician/provider/research/the state has decided is the best value, safety, quality (efficiency and effectiveness) of care. Here, the process of care (coordination, continuity, norms etc.) respond to the patient's level of engagement and willingness to co-produce their healthcare. In general, clinicians do not trust this model, with its core value of patient control over their health information. The second approach focuses on the clinician/provider/research/state deciding patient outcomes based on their metrics for efficient and effective healthcare. Here the patient is at the centre of the care model where expertise and systemic knowledge are privileged over patient choice if the resulting outcomes diverge. Here, the process of care is clinician directed and relies on, and values, clinical expertise and strives for homogenous outcomes, giving less practical consideration to patients choosing divergent outcomes that conflict with efficiency and effectiveness benefits defined by the clinician/provider/research/state.

maintained and overtime increased in scope, but post-2010 cancellation had been a serious option. In the US, the Democrats, with a window of opportunity provided by control of both houses of Congress and the Presidency, legislated major healthcare reform that was bitterly opposed by the Republican opposition.

Priority setting is a key element in theories of public administration as individuals involved in policy (formation and implementation) have many, often conflicting objectives. Priority setting prompts a concern with the competing values of interest groups and networks, and the ensuing "conflicts about resources, rights and morals.'"[973] The thesis highlighted the complexities of NEHR priority setting and found that NEHR policy was a process of evolution over time, not only an end in itself, but also concerned with the means to such ends.[974] This thesis contributed to NEHR policy knowledge by identifying which approach to policy-making was adopted, who was involved, how the NEHR issue was defined, what the policy response was and how it was implemented, identified who benefited and the trade-offs that were made (including countervailing issues of who did not benefit and which decisions were not made) in the state's effort to achieve policy goals

The thesis made clear that policy is not a neutral activity devoid of values.[975] There were both foreseen and unforeseen policy consequences. Privacy issues were tackled early on through legislation that reflected an ongoing concern with the control of health information that had widespread support for solutions mandated by state regulation. Purposive courses of action that involved public agencies and other stakeholders were implemented in order to achieve policy goals that were often subjectively defined. These goals had a normative component based on emerging digital governance values. The thesis clearly identified and explained the normative aspect of NEHR policy and resulting program processes and outcomes across the three case study countries.

The organisation of power in health systems was found to be a significant factor in determining institutional NEHR change, and the exercise of power was "central to

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[973] Klein and Marmor (2008), 892, in Exworthy et al., 10.
[974] Exworthy et al., 11.
[975] Hunter (2003), 18, in Exworthy et al., 10.

understanding and explaining the process and outcome of policy."[976] That the state was to dominate the policy process in England was to be expected, given the length of time universal healthcare had been the widely supported norm. What was surprising was the decisive role of the state in both Australia and the US in pursuing NEHR policy and programs given the neo-liberal emphasis on the role of the market and attempts to wind back expansion of the welfare state. Counter-intuitively, emphasis on the rights of the individual that developed from the 1980s, particularly in the US, promoted individual privacy rights that healthcare consumer advocates continually pushed the state to enforce through regulation and expand in scope. Ultimately, patient rights to control their health information were incorporated into NEHR policy and programs transferring power from healthcare providers and medical professionals, first to patients (discussed below), and secondly, and more importantly as far as policy outcomes were concerned, to the state. NEHRs became mechanisms for the state to drive healthcare policy outcomes through regulatory constraints that provided the rules of interoperability, usability, meaningful use and patient control of health information with sanctions backed up by the authority of government.[977] In all three case study countries, the state was the main, but not the only – as discussed below, driver of the determinants of ehealth system and NEHR change. The state: developed standards; implemented interoperability and usability rules such as opt-out encouraging adoption through the payment of incentives; and adopted regulation specifically designed to increase the meaningful use of patient health information to make it available at all points of care, in an effort to achieve the triple aim of better health, better healthcare and lower costs.[978] While there was a diversity across systems and sub-systems between case study countries, common trends towards centralisation were enhanced by the state allocating and rationing resources, stakeholders looking to the state for regulatory certainty in managing the complexity and interdependence of health and other care systems, thus increasing the power of the state in the healthcare arena.

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[976] Walt (1994), in Exworthy et al., 10.

[977] Blank, Burau, and Kuhlmann, *Comparative Health Policy*, 3.

[978] Wachter, Slee, and Brailer, "Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England," 3.

The thesis explained how extension of the state into the healthcare policy area through NEHR programs changed "public attitudes about the proper realm of public authority"[979] and effectively legitimised state intervention in all three case study countries to differing degrees. The state funding of NEHR programs was justified, though significant opposition persisted in the US. The state was also able to successfully write NEHR rules (regulation); favour one group of stakeholders (patients and their rights to control their health information through veto points) over others; extend national bureaucracies to develop, implement and regulate NEHRs; and change, or at least harness, public attitudes towards health information access, use, privacy and availability. However, there was significant pushback from various stakeholders particularly as implementation did not immediately lead to desired outcomes; entrenched political ideology led to attempts at reform; funding was constantly challenged, timeframes for outcomes were not met and were ridiculed by some stakeholders, and conservatives opposed the extension of government authority, particularly in the US and England.

Program and Project Management

The thesis identified and explained change management strategy in relation to key actors. The literature identified "professional interests trumping those of clients [as] depressingly familiar … for those reading about professional bureaucracies in the public sector."[980] However, NEHRs became a mechanism for the state to both impose its will on reluctant stakeholders while at the same time thwart professional interests that had traditionally favoured the private sector and market mechanism. The literature emphasised that major policy change in the healthcare arena depended on an alignment between political actors, significant events and stakeholders in order to minimise or eliminate effective veto points.[981] A key lesson regarding program and project management illustrated by the thesis was that for government policy to be successful it

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[979] Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," 339.

[980] Exworthy et al., *Shaping Health Policy: Case Study Methods and Analysis*, 29.

[981] See, Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America"; Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*

needed to avoid imposing undue constraints on key stakeholders and at least obtain their tacit support – often through imposing regulatory certainty and funding incentives - as one powerful player's dissent could fracture support for an initiative even if it did not constitute a veto. Hence the institution and popularity of practice incentive programs in all three case study countries, especially to stimulate the up-take of interoperable technology. Government reliance on technology, particularly early on in NEHR programs, led to project scoping that linked successful outcomes with technology implementation but did engage stakeholders with appropriate change management strategies that would achieve desired goals. Hence, initial debates about centralisation versus decentralisation were technology focused, often alienated key stakeholders and resulted in intense media criticism that contested government control of the NEHR benefit narrative. In identifying these issues the thesis has ongoing evaluative capacity in the healthcare arena.

Likely Paths of Welfare-State Development in the Healthcare Arena

The experience of Australia, England and the United States as analysed in this thesis, informs an issue raised by Tuohy regarding the likely paths of welfare-state development in the healthcare arena.[982] The thesis showed that the welfare state still maintains an interest in information rights and management, the safety and quality of healthcare, healthcare outcomes for patients and lowering healthcare costs using a variety of mechanism such as NEHRs.

Tuohy's argument about the disparities in access to information influencing the dynamics of change established the logic that "changes in the costs of acquiring and processing information, and changes in the type of information deemed relevant, should have profound implications for these dynamics."[983] NEHRs did have a profound effect on these dynamics, and while in the past the US had experienced the greater impact from information technology, NEHRs saw England, followed by Australia, advance fairly rapidly through state directed action. As discussed previously, these changing dynamics

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[982] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, 250.
[983] Tuohy, 250.

have resulted in a shift in power, despite considerable pushback, from the medical profession to the state and to private finance in the form of organisation use of NEHRs influencing and directing workflows, best practices and capital expenditure. The result is a growing homogenisation of medical practice. NEHRs also shifted power, based on access to information, towards patients and administrators. The medical profession did not so much choose to ally itself with the state but was incentivised by practice incentive payments and the intrusion of corporatisation into the profession which saw the benefits of increasing the flow of information both for outcomes and cost. Rhetoric from all three power centres focused on expected benefits, becoming increasingly aligned over time as a result of hard-fought battles around privacy, opt-in opt-out and a lack of interoperability due to proprietary EHR products. While NEHR rhetoric depended on the party in political power and the extent to which the state wanted to impose regulatory controls in order to get desired outcomes, there was a clear move in all three countries towards an increased justification of state intervention in the welfare state to achieve healthcare goals. Therefore, this thesis can inform the choices facing healthcare decision-makers in the years ahead regarding policy success and failure, change management and policy priority settings, stakeholder engagement, the opportunities and perils of technology solutions to policy issues and problems, and regulatory attempts to increase the capacity of policy to achieve desired policy outcomes.

Conclusions

A number of key lessons emerged from the application of my methodological framework in this research. Path dependency by itself would indicate that it would be more likely than not that different policy approaches to the digitisation of health records would lead to substantially different outcomes. This did not occur because the assumption that ICT solutions which had made great inroads into other sections of the economy and society at large, were the key to achieving healthcare efficiency and effectiveness goals, proved false. It quickly became apparent that big ICT implementation programs were not the sole solution and successful interoperability required an equal consideration of other categories such as the usability and meaningful use of patient health information, privacy and patient control of their health information. This revealed that the NEHR space was far more complex than policy makers and other stakeholders had originally imagined. Moving from paper health records to NEHRs was not just a policy change affecting a single part of the health system. It was a massive systemic shift that caused immense disruption as it tried to move all stakeholders into NEHRs. This explains why it caused conflict between stakeholders and engendered resistance from some.

Facing similar barriers to success all three countries eventually opted for a more centralised approach to their NEHR programs as a way to deal with complexity and fragmentation of health information issues, efficiently decide stakeholder tradeoffs and overcome barriers. Change was enabled by both critical junctures and incremental institutional change and the need to deal with complexity was progressively addressed by strengthening the regulatory powers of the state and embarking on organisational change. While critical junctures may have been triggered by shock events, they were also a result of the development of both exogenous and endogenous pressures and tensions. Ideational change was crucial in both resolving and setting the trajectory of critical juncture outcomes as it set the parameters for state intervention right from the start and influenced change in subsequent critical junctures. The similarities of the enabling narrative that touted the potential benefits of NEHRs and supported normative justification were striking and showed strong path dependencies by remaining remarkably consistent through 2015, as shown in Chapter 4.

In summary, common policy issues forced a level of conformity on all three NEHR programs resulting in centralisation that was driven by the bureaucracy, especially in Australia and England. Viewing the achievement of the intended goals by focusing on four categories (interoperability, usability, meaningful use and patient control of health information) contributed to a better understanding of the characteristics of institutional stasis and change. Doing this emphasised that the state makes institutional rules (laws, regulations) that make possible cooperation by many stakeholders with diverse interests on important public policy projects such as NEHRs. It was found that when the democratic state addressed complexity through centralisation it was able to overcome the problems of collective action and knowledge management through the facilitation of value driven norms, rules, practices and procedures. The more success it had in overcoming these problems the more success it had in achieving implementation and outcomes.

Further Research

Areas for further research include, but are not limited to, the following topics:

1. The extent to which legislated and regulated patient rights to privacy and the control of their health information impact public policy efficiency and effectiveness goals. This was addressed in this research, but could be in a thesis itself, particularly if such research adopted an Hohfeldian framework of comparing rights and obligations between stakeholders in more depth than was attempted with normative justification in this thesis.

2. A fuller exploration of normative justification and power relationship ratios that challenge broad conceptions of the role of the state. This would be particularly useful in addressing the puzzle of democratic advantage in terms of collective action and knowledge management as examined by Ober.[984]

3. It is interesting to note that the current paper to digital path *status quo* in all three countries has resulted in an increased administrative burden which is a major contributor to rising healthcare costs "particularly in the United States."[985] Bryan argues that current strategies, including data management applications, often do not work and can add to the administrative burden. She goes on to say: "if there is anything AI [artificial intelligence] can do it is to take over

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[984] Ober argued that the effectiveness of states that do not elicit adequate levels of cooperation among their members are unlikely to reach their potential effectiveness, irrespective of their abundant human and material resources. Cooperation, and the capture of its value for public purposes, can be secured through coercion by efficient autocracies and the capacity of democracies to elicit voluntary social cooperation by overcoming the problems of collective action and knowledge management. Ober argued that democratic institutional arrangements that do solve the problems of collective action and knowledge management can partially explain success in competitive environments. Josiah Ober, "Thucydides on Athens' Democratic Advantage in the Archidamian War," in *War, Democracy and Culture in Classical Athens*, ed. David Pritchard (Cambridge: Cambridge University Press, 2010), 65, 67. This line of reasoning may be apt for explaining, at least in part, the failure, partial success or success of significant components of ehealth systems such as privacy, opt-in versus opt-out EHRs, patient centred health systems, and health information governance.

[985] Sarah Bryan, "Applying AI in Healthcare: Challenges, Opportunities, and Emerging Applications" (HealthDataManagement, 2018).

administrative tasks for us."[986] This indicates that AI might provide an exogenous critical juncture, that once embedded in NEHRs, then pursues endogenous incremental change leading to the achievement of desired service delivery outcomes.

4. Applying other theoretical frameworks may be relevant to research on NEHRs. For example, a rational choice approach may provide a different perspective on issues such as vetoes, exiting, cost shifting, free-riding and rent-seeking that further informs the arguments made in this thesis. Tenbensel argues that "complexity theory can definitely be used to build satisfyingly rich and nuanced stories of health service and policy innovation."[987] Drawing on the empirical evidence presented in this research, complexity theory may give further insights into state efforts to maximise control and order in NEHR programs implemented in complex health environments, their "potentiality [and the generation of] unexpected self-organising behaviour"[988] and how that impacts NEHR goals and outcomes. Lastly, the research of Dunleavy et al. into the shift from new public management to digital-era governance "which involves reintegrating functions into the governmental sphere, adopting holistic and needs-oriented structures, and progressing digitalization of administrative processes"[989] could well be a fruitful approach to assess states adoption of NEHRs as centralising mechanisms to reduce institutional and policy complexity.

5. The linking of patient health information across domains that incorporates social and behavioural characteristics may further the whole-of government approach to public policy provision but challenges liberal concepts of individual freedom, especially from the state. Research into the benefits and drawbacks of NEHRs in this area would be both interesting and useful as governments attempt to increase the centralisation of public programs. Assessing public policy success

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[986] Bryan.

[987] Tim Tenbensel, "Complexity in Health and Health Care Systems," *Social Science and Medicine*, 2013, 182.

[988] Lesley Kuhn, in Tenbensel, 181.

[989] Dunleavy et al., "New Public Management Is Dead - Long Live Digital-Era Governance," 467.

and failure through the theoretical framework provided by Kay and Boxall[990] may be very useful in this area of research.

6. Lastly, strengthening or undermining a consensual approach to the welfare state[991] as a result of policy enacted post crisis may identify a recent trend towards a broader political acceptance of an expansion of state intervention in policy areas where the dynamics of change are traditionally influence by market forces, particularly in the US This would bring into current relief the intersection of instruments and influence at the critical junctures of the GFC (2008-2009) and the response to COVID-19 (2020-2021), identifying and explaining changes in competing bases of power, resultant regulatory attempts to increase the "capacity of the policy process to deal with matters central to the human condition,"[992] and changes to public attitudes about state intervention and the proper realm of public authority.[993]

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[990] Kay and Boxall, "Success and Failure in Public Policy: Twin Imposters or Avenues for Reform? Selected Evidence from 40 Years of Health-Care Reform in Australia."

[991] See, Exworthy et al., *Shaping Health Policy: Case Study Methods and Analysis*, 13.

[992] Tuohy, *Accidental Logics: The Dynamics of Change in the Health Care Arena in the United States, Britain and Canada.*, ix.

[993] Steinmo and Watts, "It's the Institutions, Stupid! Why Comprehensive National Health Insurance Always Fails in America," 339.

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