

**e-Healthcare:  
A Critical Examination of the  
Patient Portal Initiative in New Zealand**

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*This research is dedicated to my grandparents,*

*John and Joan McIntosh*

## ABSTRACT

This research examines patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand. A patient portal is an electronic platform that allows patients to perform various tasks, such as securely messaging their doctors, viewing their medical records, booking appointments, and requesting repeat medication prescriptions. Using a critical approach, I examined promotional material for patient portals in New Zealand before undertaking a series of semi-structured interviews with patients and doctors, which were analysed using thematic analysis. I found that some of the patients viewed the patient portal as a way of managing tasks and facilitating relationships, while others thought it posed the risk of depersonalising medicine. The patients who frequently used a patient portal described how it can result in crucial social and psychological benefits. On the other hand, the doctors I interviewed generally believed that patient portals could increase patients' engagement and health literacy but considered them to be expensive and time-consuming. Many felt that digital communication could be a way to connect with patients and to preserve patient-doctor relationships but despite the probable advantages to communication, I found that patient portals were not used effectively in many practices, due, in part, to insufficient promotion. In fact, my overall conclusion is that many of the potential benefits of patient portals were not being realised. In the light of this finding, this research questions whether the limited use of patient portals is contributed by a philosophical conflict about how much autonomy and decision-making patients should have.

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# **ATTESTATION OF AUTHORSHIP**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Phoebe Elers

5 May 2017



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# 1: INTRODUCTION

There is a trend in which patients are becoming more engaged and involved in their healthcare (Prey et al., 2014). Research has found that positioning patients as active participants in managing their health conditions can improve their satisfaction with their care (Adinolfi, Starace, & Palumbo, 2016; D. Wolf, Lehman, Quinlin, Zullo & Hoffman, 2008) and their health outcomes (Adinolfi et al., 2016; Little et al., 2001). This trend is being driven by the healthcare industry, as well as patients, who are becoming more informed about their health conditions (Cayton, 2006). It has led to a proliferation of information and communication technologies (ICTs) that support people in capturing, monitoring, understanding and sharing their personal health information (Kalra & Fernando, 2013). In line with these changes, New Zealand's Ministry of Health appointed a National Health IT Board (NHITB) which set priorities for regional and national ICT investments in 2010. The NHITB (2010) maintained that information systems needed to connect with one another more easily to place the individual, who often has more than one health condition, in the centre of healthcare delivery.

In 2013, the NHITB began promoting patient portals among primary healthcare practices, which they maintained would lead to more efficient healthcare delivery and increase patients' ability to manage their conditions (National Health IT Board [NHITB],

2013a). At the most basic level, patient portals give patients online access to elements of their medical records (Rigby et al., 2015), but some portals can also allow patients to perform various tasks such as exchanging secure electronic messages with doctors, booking appointments, accessing educational materials, paying bills and requesting repeat medication prescriptions (North et al., 2013). It is commonplace for patient portals to be promoted as a way for patients to “become proactive participants in their care” (Orion Health, 2014a, p. 3) and to “take a more active role in the management of their health and wellbeing” (Medtech, 2012, para. 1).

Patient portals are only one example of the increasing number of ICTs that connect patients with elements of their healthcare. However, it seems that while these technologies are developing rapidly, their anticipated benefits are not always actualised. Most ICT healthcare projects fail in some sense, with many being abandoned, overshooting budgets and timetables, or failing to meet business and users’ requirements (Kaplan & Harris-Salamone, 2009). Furthermore, systematic reviews have frequently commented that there is insufficient evidence to prove many of the proposed benefits of ICTs used in healthcare (e.g., Fischer, David, Crotty, Dierks, & Safran, 2014; Khosravi & Ghapanchi, 2016). As Gaddi and Capello (2014) suggested, there are criticalities in healthcare that these technologies fail to address, including those related to the effect of illness on individual patients, their next of kin, their environment, and more generally “the complex nature of humanity, in which health is only part of a whole” (p. 3).

My interest in the impact of patient portals as a subset of a much broader trend led me to an overarching research question:

*What are patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand?*

This question is not focussed on the technological attributes of patient portals or on the potential to increase efficiency or productivity. Rather, it is centred on how the patient portals contribute to altering the delivery of healthcare and how this in turn might change perceptions and expectations of healthcare of both patients and doctors. I chose the word ‘perspectives’ because it implies a thoughtful assessment of a phenomenon. Although I considered the word ‘views’ or even ‘experience’, I felt that ‘perspectives’ is more reflective of the moment. In this research, I use the word ‘doctors’ to refer to individuals who are licensed to practice medicine and who work in general practice. The word ‘patients’ refers to individuals seeking medical care from these doctors. I chose these two groups because they were the primary target audiences of the promotional material for patient portals.

My decision to use the word ‘patients’ was based on much deliberation. Coming from a communication discipline, I know that labels matter, in that they conjure up different identities, relationships and power dynamics (McLaughlin, 2009), or, as McDonald (2006) explained, they are a means of deciphering who is who, and what characteristics adhere to various categories. The labels assigned to the receivers of healthcare change how practitioners view these individuals, which in turn shapes material experiences (McDonald, 2006), and so, perhaps unsurprisingly, these labels have been the centre of a longstanding academic and professional debate (Deber, Kraetschmer, Urowitz, & Sharpe, 2005; Oliver, 2017). Consider, for example, if an individual receiving medical care complains about the service, the conceptualisation of this individual as a ‘patient’, ‘citizen’ or ‘consumer’ is significant, for it is associated with exercising different rights - human rights, citizens’ rights’ or consumers’ rights (Mold, 2014). The same can be said of the reception of medical care: citizens might assert their right to *receive* certain services, but consumers might instead assert their right to *choose* certain services.

The debate about the ideologies present in these labels and the restrictions that they impose is philosophical, and, as semiotic theorist Umberto Eco (1992) stated, “One way of understanding philosophical concepts is often to come back to the common sense of

dictionaries” (p. 26). The word ‘patient’ is derived from the Latin word ‘patiens’ from ‘patior’, which means to suffer or bear, and so critics have argued that it constructs the individual as a passive recipient of interventions, in deference to doctors (Neuberger, 1999). The word ‘customer’ is derived from the Middle English word for tax collector and is defined as an individual that purchases a commodity or service (Deber et al., 2005). This has some similarity to the word ‘client’, derived from a Latin root meaning dependent, which has been defined as an individual that is under the protection of another, and thus carries connotations of an agency relationship, whereby one individual purchases professional services from another (Deber et al., 2005). Another word used to describe these individuals is ‘citizen’, which comes from Latin word for city (Hilton & Masters, 2002). This word can invoke rights and democracy, but it has been associated with the exclusion of refugees, prisoners, and children (Oliver, 2017) and it does not suggest that the individual is receiving healthcare.

The word ‘patient’ contains imbalances in power dynamics deriving from its original. Accordingly, critics have argued that the word fits poorly with modern conceptions of healthcare, where people consulting healthcare professionals are often seeking advice or undertaking preventative measures and are not necessarily ill (Herxheimer & Goodare, 1999; Neuberger, 1999). Although a counter argument is that the words used in healthcare acquire new meanings that reflect the clinical context (Tallis, 1999), some analysts have argued that the word ‘patient’ should be replaced with terms that imply more active participation (Herxheimer & Goodare, 1999; Neuberger, 1999). Yet the connotations embedded in alternative terms have also been the focus of criticism. Implicit in the words ‘consumer’, ‘customer’ and ‘client’ is the notion that medical services are commodities to be managed in a market (Deber et al., 2005; Downie, 2017). These words suggest a managerialisation of relationships (McLaughlin, 2009), whereby the individual receiving healthcare is the sole arbiter of his or her needs, and the practitioner’s role is to satisfy these needs (Deber et al., 2005; Downie, 2017). This turns the nature of healthcare delivery

into a business transaction, discounting relationships of trust and compassion implicit in the word 'patient'. As Tallis (1999) stated:

The distinctiveness of patient reminds us of the vulnerability of the ill person and the often harrowing responsibilities of the doctor or nurse; something frequently forgotten in the consumerist world picture. So while the term patient may be steeped in the abuses of the past, is also captures what is positive about the special relationship between health workers and ill people. (p. 1757)

This left me with a kind of conundrum. I felt that in choosing between the word 'patient', or the alternatives, 'consumer', 'customer' or 'client', I would be 'taking sides' in what I perceived as an ongoing debate. Furthermore, I did not want to pre-empt the relationships experienced by my participants, by framing healthcare as being either of a paternalistic or a consumerist nature. Significantly, the argument to change the word 'patient' may not be based on the wishes of those receiving healthcare, as a survey by Deber et al. (2005) of over nine hundred participants with chronic illness determined that respondents moderately liked the word 'patient', while the alternatives evoked moderate to strong dislike. Nevertheless, my decision to use the term 'patient' was difficult, partly because there were no obvious alternatives that did not even more undesirable connotations (Tallis, 1999). One consideration that influenced my decision stemmed from the nature of my research subject: because both patients and doctors are consumers of the patient portals (although from different perspectives), I felt that the word 'patient' would be universally clear for the reader. The same practicality guided my decision to use the word 'doctor': it would be understood by the readers, and it does not group professions, like the terms 'practitioners' and 'providers'. However, I acknowledge that there are shortcomings in the words 'patient' and 'doctor', and there are times in this thesis where the word 'consumer' was unavoidable, such as when describing how individuals receiving healthcare are constructed in Emanuel and Emanuel's (1992) relationship models and in the advertisements analysed in chapter six.

## 1.1. EXPLORING THE RESEARCH CONCEPT

### Patient Portal Case Studies from the NHITB

I use my portal to monitor my health by checking lab test results, looking back at my medical notes, and consulting my list of medications when I'm in countries where medicines are usually bought over the counter without a prescription...

– Michael Dunn (as cited by the NHITB, 2015a, para. 5)

I find knowing the patient will be notified of their lab results when I file them useful on the whole... We've decided that this is sufficient notification of smear results, so I write when their next smear is in the comments section, enter the result in the screening tab and reset the recall myself... [which is] more efficient for the practice...

– Dr Emma Dunning (2015, para. 18)

I can just log on, see all of my medications and tick the ones that need renewing, press “send” and then pick up the script from my doctor's office... If I need to ask my GP a question, I can just send a message instead of having to phone his office...

– Blair Polly (as cited by the NHITB, 2015b, para. 7)

Since 2014, the adoption of patient portals in New Zealand has been increasing and in May 2016 331 primary healthcare practices offered a patient portal and 136,600 patients were registered with a patient portal service (NHITB, 2016). As indicated by the above excerpts, this could result in some added conveniences for patients, particularly those managing chronic illness. For example, Blair Polly (quoted above) has diabetes and so renewing prescriptions electronically could save him a significant amount of time. In Michael Dunn's case, his work requires him to travel to remote regions of the world and a patient portal gives him access to his medical record and has provided him with the



evidence needed to renew his visa. Indeed, it is difficult to dispute some of the potential benefits of the portals. Yet for these benefits to be realised they involve significant changes in delivery practices. It is these changes and their impact that is the focus of this research.

The notion of a patient-controlled health record has been referenced since the 1960s (Kim, Jung, & Bates, 2011). With the rise of the internet, patients started creating digital versions of these records, and as healthcare organisations began using electronic medical records, it became possible to link patients to this information (Zieth et al., 2014). This has been referred to as a tethered personal health record (e.g., Tang, Ash, Bates, Overhage, & Sands, 2006), although it is also a patient portal in its most basic form. Unlike other personal health records where patients may document and manage their health information independently, a patient portal is linked to a healthcare provider's electronic medical record. Today patient portal packages offer multiple functions which the healthcare practice may choose to install (e.g., Medtech, n.d.; Orion Health, 2013) and this variability can make it difficult to make generalisations about its outcomes or to compare studies in the field.

One of the speculated advantages of patient portals for healthcare practices is the financial benefit from reducing the labour costs of processes, such as appointment scheduling, repeat prescriptions, and patient education (North et al., 2011). As Dr Dunning (2015) discussed, ten months after installing a portal her practice received prescription requests through it from one to three patients each day and patients were using it to book appointments and view lab results electronically. With such functions, the idea that a portal would enhance organisational efficiency may seem clear-cut, especially when comparing these streamlined processes with traditional methods of patients calling or visiting practices. In spite of this, Dr Dunning (2015) also stated that "it has been fairly

**Table 1.1: Perspectives of Patients Using Portals Overseas**

Citation	Study design	Findings		
		Communication Function	Access to Information	Overall Satisfaction
Britto, Hesse, Kamdar and Munafo (2013)	Interviews with 24 parents who have a child with cystic fibrosis	Removed barriers. Encouraged parents to ask nonurgent questions.	Reduced hassle in finding information and increased convenience; control and independence.	Parents perceive portals as beneficial. Providing a sense of control, and reassurance.
De Leon et al. (2012)	Pre-survey with 856 patients and post-survey with 523 patients	Post-survey, patients were more likely to want e-mail communication with the practice.	Most patients saw benefits and believed their information was secure and accurate	Those with internet access were satisfied with their experience
Fisher, Bhavnani and Winfield (2009)	Interviews with 43 patients.	Portal did not have this function.	Helped prepare patients for consultations and compensate poor verbal communication	Record access reinforced trust and confidence in doctors.
Haun et al. (2014)	Interviews of 33 patients.	Useful for managing health care needs	The study only examined the communication function	Most patients were satisfied with the portal,
Kelly, Hoonakker and Dean (2016)	296 parents used a portal. 90 completed a survey.	Most parents reported that it improved communication	Information helped parents monitor, understand, make decisions, and care for their child.	Parents were satisfied, reporting ease of use and improved care
Neuner, Fedders, Caravella, Bradford and Schapira (2015)	Survey of 2989 patients	Satisfaction with portal-based e-mails was high.	Most participants were satisfied or very satisfied about the information	Most patients of were very satisfied or satisfied with the patient portal.
Ozok, Wu, Garrido, Pronovost, and Gurses (2014)	Observations, surveys, interviews and focus groups with 22 patients	It improved some patients' communication	Information motivated patients to get screenings and tests on time. Patients valued information.	Patients' perceptions regarding the usefulness of the portal were high
Urowitz et al. (2012)	Survey of 854 patients, interviews with 17 patients.	Some patients wished their doctor had more interest.	Information access increased awareness of side effects and co-morbidities and encouraged better disease management.	Patients were satisfied with the portal features and felt more aware of their health status.
Wade-Vuturo, Mayberry and Osborn (2013)	Focus groups /surveys with 54 patients with diabetes	Provided access to clinical care outside face-to-face visits.	Enhanced efficiency and quality of face-to-face visits	Enhanced patient satisfaction overall.
Woods et al. (2013)	Focus groups with 30 patients	Focused on accessing information.	Improved communication and self-care.	Patients felt it is beneficial overall.

neutral with respect to workload and remuneration” (para. 27). Mirroring her experience on an international scale, a systematic review by Goldzweig et al. (2013) could not empirically verify that patient portals lead to efficiency gains. This could suggest that some of the speculated organisational benefits of patient portals are not as simple to achieve in real world settings.

In New Zealand, the implementation of patient portals is still in its infancy and research concerning its use is relatively limited (Gu & Orr, 2015). However, patient portals have gained considerable academic attention internationally. Because of the extensive research on this topic, I summarised ten studies that examined patients’ perspectives of patient portals overseas in Table 1.1 opposite. These studies indicate that portals can improve patient-practitioner communication, such as by making patients feel encouraged to ask non-urgent medical questions and by removing communication barriers (e.g., Britto et al., 2013). Research has also found that communication can be more effective as a result of the portals (e.g., Ozok et al., 2014), including face-to-face communication, because portals can help patients to prepare for consultations (e.g., Fisher et al., 2009; Wade-Vuturo et al., 2013). Additionally, increased access to information can assist patients in understanding and managing their health conditions (e.g., Kelly et al., 2016; Urowitz et al., 2012). Overall, research has shown that patients using portals are satisfied with the services (e.g., Neuner et al., 2015; Wade-Vuturo et al., 2013).

Patient portals have been associated with various other benefits for patients. Patient portals have been found to assist in updating health records (e.g., Murray et al., 2013; Cochran et al., 2015), increase the utilisation of health services (e.g., Druss, Ji, Glick & von Esenwein, 2014; A. Wright et al., 2012) and strengthen medication safety (e.g., E. Wright et al., 2015; Heyworth et al., 2014) and adherence (e.g., Sarkar et al., 2014). In spite of this, systematic reviews have been unable to draw definite conclusions due to a lack of empirical evidence in regard to the impact of patient portals on health outcomes (e.g., Kalra &

**Table 1.2: Healthcare Practitioners Perspectives of Patient Portals**

Citation	Study design	Findings	
		Advantages Perceived	Disadvantages/ Concerns Perceived
Hill et al. (2017)	Interviews with 26 practitioners at Spinal Cord Injury Centres	Could coordinate information and care, support self-management activities, and provide reliable information to patients	Increased workload burden, potential liabilities and the ability of patients to understand clinical information.
D. Miller et al. (2016),	Interviews with 20 practitioners	Could improve communication and enhance information sharing	Increased workload and time burden, the alienation of non-users and patients' ability to understand clinical information.
Nazi (2013)	Interviews with 30 practitioners	Improve patient communication and satisfaction, convenience,	Increased workload and time burden for training,
Ozok et al. (2014)	Interviews with 8 practitioners	Could improve quality and efficiency. Found several functions useful, including medical histories, tailored preventive screening recommendations, and medical education provided to patients.	Recommended including generic and brand-name medications for patients to enter, have pop-up boxes providing more information on conditions, tests and medical terms, and automatically link information on best practices for better patient education.
Vydra, Cuaresma, Kretovics and BoseBrill (2015)	Surveys with 54 doctors. A focus group with doctors from one practice	Could improve office workflows, supplement care and to increase patient engagement and satisfaction.	Increased workload and time burden, lack of reimbursement.
Urowitz et al., 2012	Open-ended survey with 64 practitioners about diabetes management through a portal	Patients recorded their blood sugar frequently. Provided an added source of motivation especially useful for "new diabetics" learning to manage their disease.	Increased workload and time burden
Witry et al., 2010	Focus groups with 28 practitioners	A source of medical information for when the patient's medical record is not available. Could benefit certain patient groups.	Could facilitate narcotic abuse, have a low uptake among certain patient groups

Fernando, 2013; Goldzweig et al., 2013; Kruse et al., 2015)<sup>1</sup> and on the quality of care (e.g., Ammenwerth, Schnell-Inderst & Hoerbst, 2012; Giardina, Menon, Parrish, Sittig, & Singh, 2014; Kruse et al., 2015).

Furthermore, the potential impact of patient portals goes beyond the organisational setting to intervene in the way that an individual receives healthcare. A report by Love and Boyle (2015) which reviewed the patient portals in New Zealand determined that the substitution of online clinical queries with co-payments for some face-to-face consultations can result in a net gain to a general practice. The patient portal offers more convenience for some patients, such as Blair Polly (cited above) who found it easier than calling his doctor when he has a question. However, research has determined that some patients still prefer to phone their healthcare practices because they find patient portals too cumbersome (e.g., Dontje, Corser & Holzman, 2014). It is also difficult to definitively state whether portals actually reduce the number of practice visits as this is also conflicting in the literature (Giardina et al., 2014); for example, C. Chen et al. (2009) longitudinally examined the impact of a patient portal in the United States with 225,000 members and found that the annual total office visit rate decreased, while Palen, Ross, Powers and Xu (2012) found that another patient portal in the United States with 375,620 members significantly increased office visits. Nevertheless, the introduction of patient portals could raise questions about its human implications and how it changes the meaning of receiving and proving care.

However, despite the various advantages reported, the adoption of patient portals by healthcare practices in New Zealand has been slower than anticipated (Castaneda, 2014). As outlined in Table 1.2 opposite, although practitioners have expressed that patient portals could have advantages, such as for improving practice workflow (Hill et al., 2017;

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<sup>1</sup> An exception to this is a systematic review by Price et al. (2015) which found some limited evidence of benefit for asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension, although the authors emphasised that more research needs to be conducted that accesses the patient portals' impact on health outcomes

**Table 1.3: Studies Examining the Adoption and Use of Patient Portals**

Citation	Study design	Uptake Disparity Reported			
		Age	Income	Race	Health Status
Goel et al. (2011)	Portal adoption and use of 7,088 patients from primary care practice.	Oldest patients less likely to enrol.	<i>Not reported</i>	White patients more likely to enrol.	<i>Not reported</i>
Hsu et al. (2005)	Longitudinal, population-based study (1999–2002) of members of an integrated delivery system.	Adoption most common in age 50–64 years.	Lower adoption among lower socio-economic areas	Higher adoption among white individuals.	Lower adoption among those with low expected clinical need.
Jhamb et al. (2015)	Portal adoption and use for 2803 patients from four nephrology practices.	Lower adoption by older adults	Lower adoption by individuals with lower income.	Lower adoption by African-American individuals.	<i>Not reported</i>
Ketterer et al. (2013)	Portal adoption and use for 84,015 children from a hospital.	<i>Not reported</i>	Lower adoption among low-income families.	Lower adoption among Asian and Hispanic individuals.	Higher adoption for those with autism.
Nielsen et al. (2012)	Portal adoption and use of 240 patients at a multiple sclerosis centre.	Average adoption age: 45.4	<i>Not reported</i>	<i>Not reported</i>	Adopters had minimum physical disability.
Roblin, Houston, Allison, Joski, and Becker (2009)	Portal adoption and use among 1,777 patients from a health service.	<i>Not reported</i>	<i>Not reported</i>	Lower adoption by African-American individuals.	<i>Not reported</i>
Tenforde et al. (2012)	Portal adoption and use among 10,746 adults with diabetes from a health practice.	Adopters were younger	Adopters had higher incomes.	Adopters more likely to identify as Caucasian.	Adopters had better diabetes quality measure profiles.
Weingart et al. (2006)	Portal adoption and use and compared 100 randomly selected enrollees and 100 nonenrollees.	Adopters were, on average, 10 years younger	<i>Not reported</i>	Adopters were more likely to be white.	Non-adopters had more medical problems.
Weppner et al. (2010)	Portal use among 6,185 enrollees aged over 65 years with diabetes.	Adopters were younger	Adopters were from a higher socioeconomic status area.	<i>Not reported</i>	Adopters more likely to have clinical characteristics of overall morbidity.
Yamin et al. (2011)	Portal adoption and use among 75,056 patients from a health system.	<i>Not reported</i>	Lower income less likely to adopt.	Blacks and Hispanics less likely to adopt.	Adopters were likely to have more than two comorbidities.

Vydra et al., 2015) and patient communication (e.g., D. Miller et al., 2016; Nazi, 2013), significant concerns have been raised concerning time constraints, the potential to increase workload (D. Miller et al., 2016; Hill et al., 2017) and a lack of remuneration (e.g., Vydra et al., 2015). Practitioners have also expressed concerns that patients may not understand the clinical information on a patient portal (e.g., Hill et al., 2017; D. Miller et al., 2016).

Other literature has alluded to the low uptake of patient portals by patients (Otte-Trojel, de Bont, Rundall & van de Klundert, 2016; Zieth et al., 2014) and the varying use of the patient portal functions (e.g., Osborn, Mayberry, Wallston, Johnson, & Elasy, 2011; S. Smith et al., 2015). For example, Osborn et al. (2011) determined that the utilised portal functions of 129,800 enrolled patients were: viewing test results, electronic messaging, scheduling appointments, accessing educational materials, and managing a medical bill. S. Smith et al. (2015) examined 534 enrolled patients' usage and determined that the most common functions were checking test results, electronic messaging, followed by requesting repeat prescriptions.

Furthermore, research has established patient portal enrolment inequalities among patients. Again, there is extensive research investigating this topic, and so ten large-scale studies which examined portal adoption and use are summarised in Table 1.3 opposite. These studies make correlations between the likelihood of portal adoption with race (e.g., Jhamb et al., 2015; Yamin et al., 2011), although I am hesitant to apply this to the New Zealand context. They also show that individuals with higher than average clinical need are generally more likely to adopt a portal (Weppner et al., 2010; Yamin et al., 2011), while those with lower incomes or from lower socioeconomic groups are less likely to adopt a portal (Jhamb et al., 2015; Ketterer et al., 2013). As lower socioeconomic groups tend to have higher rates of illness (Ministry of Health, 2013b), this indicates that this is a significant barrier to the adoption of portals. There is also lower adoption among elderly patients (e.g., Hsu et al., 2005; Nielsen et al., 2012), who are also more likely to have health conditions.

Overall, it seems that there are many potential benefits from patient portals, including the potential to improve patient satisfaction (e.g., Haun et al., 2014), communication between patients and providers (e.g., Kruse et al., 2015) and organisational processes (e.g., Druss et al., 2014), and efficiency (North et al., 2011) in a sector facing growing financial pressures. However, many of these benefits have not been empirically verified (Kruse et al., 2015), and the implementation of patient portals abroad has experienced challenges in patient uptake (Otte-Trojel et al., 2016), including enrolment inequalities (e.g., Ronda et al., 2015). In many respects, New Zealand embarked on an unknown venture with the patient portals, an acting director of the National Health Board said in regard to the portals: “GP Practices have led the implementation on an incremental basis rather than running trials and therefore formal evaluations and resulting reports by the Ministry have not been undertaken” (Hurdleby, 2014, para. 2). Thus, with over four hundred primary healthcare practices offering a patient portal (Johnathan Coleman, 2017), and with its impact in a New Zealand setting being largely unexplored (Gu & Orr, 2015), this is a subject that warrants further investigation.

## **1.2. THE THESIS STRUCTURE**

As I discuss in this research, there are several assumptions which have motivated the implementation of patient portals – that people need and want more information about their healthcare, that people should and want to make their own healthcare decisions, that people should, can and want to use technology, and that healthcare is more efficient with ICTs. Throughout the next two chapters, these assumptions are explored in greater detail. Chapter two introduces some ideologies underpinning various healthcare ICTs, before mapping the changing landscape of healthcare and discussing its impact on patient-provider communication and on social constructions of health, illness and disease. Chapter three examines the introduction of ICTs into the healthcare arena, considering the governance of health information, the use of computer-mediated communication for



health matters in the home, and the challenges in implementing healthcare ICTs, including the equitable uptake, as well as some exploratory models. Many of these issues concern other healthcare ICTs, and so while I have a focus on patient portals, they are frequently discussed in conjunction with other technologies.

Chapter four focuses on the New Zealand context. It gives a basic overview of the New Zealand health sector and the National Health IT Plans, before examining the patient portals and the implications of these technologies for Māori<sup>2</sup>, and closing with a discussion about aspects of the introduction of the portals that I had not addressed elsewhere, but I deemed to be important. Chapter five outlines the methodology for the gathering and the analysis of the primary data. Guided by a critical paradigm, this involved analysing promotional texts for the portals in New Zealand influenced by Dryzek (1997) to contextualise the patient portals in New Zealand. I then conducted semi-structured interviews with patients and primary healthcare doctors. To recruit the participants, I used purposeful and snowball sampling, and the interviews were thematically analysed with an inductive approach influenced by the works of Boyatzis (1998), Braun and Clarke (2006) and Braun, Clarke and Terry (2015). The results are provided in chapters six and seven. Finally, chapter eight evaluates the implications of the findings in the light of existing literature and the consequent subjects which warrant future investigation.

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<sup>2</sup> The Indigenous people of New Zealand.

## 2: THE SOCIAL CONTEXT OF HEALTHCARE

The patient portal is one of many ICTs used for healthcare purposes. On the whole, ICTs are thought to make healthcare more efficient and responsive to patients' needs (European Commission, 2012; World Health Organization, 2012a). However, these technologies can have significant social implications. For instance, research has found that electronic patient-provider communication can improve relationships (C. Chen et al., 2009; Wallwiener, Wallwiener, Kansy, Seegar, & Taufiek, 2009) and that giving patients electronic access to their health records can increase their engagement in their healthcare (Ozok et al., 2014). ICTs can also alter other aspects of healthcare delivery, such as on the roles and responsibilities of users (Oudshoorn, 2008, 2011), medical power and authority (Lupton, & Jutel, 2015), and, more broadly, about what it means to care and be cared for (Capello & Luini, 2014; M. Martin, 2014).

A speculated benefit of patient portals for healthcare practices is that costs from labour processes will be cut (North et al., 2013), because, in a similar vein to internet banking or self-scan checkouts, work is 'delegated' to the technology, but, although less

obvious, it is in fact the patient. Thus, the work has moved from the practice to the patient. In promotional material, manufacturers have recommended that practices “stress patient convenience and access to avoid any inference that the portal is a self-service tool designed to reduce health system workload” (Oldenburg, 2013, p. 242). This statement indicates that part of the motivation of patient portals is to reconstruct human work in a way akin to Fuch’s (2015) theorisation of digital labour, in which users’ unpaid labour is veiled by free access to a digital platform. The workload is externalised to an online medium, and patients are tasked with specialised processes to increase the productivity and efficiency of the practices.

Although the shifting of labour may increase convenience for some people in the doctor-patient relationship, the presence of technology also has a social effect (McLuhan, 2015). For example, a patient portal could potentially impact: the way that medical advice is sought and delivered, who can and cannot access services, relationships, trust and communication, the care environment, how information is viewed, managed and governed, organisational processes, conceptualisations of wellness and sickness, and on the assigned roles and responsibilities that accompany the aforementioned points. Today, ICTs have blurred the lines between an array of once stable distinctions: between work and play, production and consumption, coercion and choice, and publicity and privacy (Nealon & Girous, 2012).

Gumbrecht (2004) maintained that materialities can become ‘present’, impacting human senses, emotions, and bodies. Hence, agency resides in “a joint mediation between the built-in properties of objects and the intentions and purpose of human subjects” (Fairhurst & Putnam, 2004, p. 18). Gumbrecht’s (2004) point can be demonstrated by considering the electronic medical record. As Petrakaki, Klecun, and Cornford (2016) discussed, it might be implemented so that information can be accessed more efficiently, but it also impacts behaviours and social processes by standardising aspects of professional practice, curtailing professional autonomy, and redistributing clinical work within and

across professional boundaries. Furthermore, the act of viewing and updating these records and the physical presence of an electronic device changes the interaction between patients and healthcare providers (McGinn et al. 2011).

Another rationale of patient portals is to empower patients to “take a more active role in the management of their health and wellbeing” (Medtech, 2017, para. 1). This statement may signal a cultural shift from the paternalistic style of healthcare delivered in the past. Nikolas Rose (2007) discussed how the power once held by doctors has been constrained by the apparatus of bioethics, evidence-based medicine, and patients’ demands for autonomy, and patient portals correspondingly have the potential to reduce paternalism by relocating power from practices to patients, who can access more information about their own healthcare. At the same time, with consideration to the cost-savings associated with the re-delegation of tasks, I wonder whether this claim is a way of shifting the burden of care onto civic responsibility. Similar concerns have been made by analysts concerning the use of empowerment and self-management discourses in healthcare (Bury, 2008; Kendall, Ehrlich, Sunderland, Muenchberger & Rushton, 2011). It also appears to have some correlation with the concepts of ‘healthicisation’ (Conrad, 1987) and ‘healthism’ (Crawford, 1980) discussed in the following section.

Furthermore, Lupton (2014) claimed that the idea of ICTs empowering patients to take more control of their healthcare is a “fantasy” (p. 1351) that is challenged by the realities of everyday use, as interviews and observational research have revealed that some of these technologies can be tedious, frightening and frustrating to use. Lupton’s comment implies that these technologies are designed with envisaged applications that are underpinned by ideology. This can be observed in the discourses surrounding them. According to Henwood, Harris, Burdett and Marshall (2008), the ‘e-health discourse’ constructs health information as empowering individuals and it considers the internet as a tool to access that information. They claimed that it combines elements of two other dominant discourses: the information society discourse where new technologies are

thought to support greater freedom, and the new public health discourse. This latter discourse is characterised by the transference of agency from healthcare providers to consumers who have a capacity for independent decision-making and therefore an obligation to manage their health conditions. Greenhalgh, Procter, Wherton, Sugarhood and Shaw's (2012) analysis identified four discourses that describe these technologies: the modernist discourse which offers solutions to complex problems; the humanist discourse which is disruptive and disempowering; the political economy discourse which exposes a lucrative business market; and the change management discourse which is dependent on good project management and processes. Throughout this research elements of these four discourses are explored.

This chapter demonstrates that many conceptions underpinning the development of patient portals and some other ICTs used in healthcare can be traced back to events in time, including the notions of person-centred care and increasing patient involvement. In the following section, I map the historical formation of modern medical conventions. In section 2.2, I relate this to the communication between patients and healthcare providers, drawing from Emanuel and Emanuel's (1992) four models of the patient-doctor relationship. Finally, in section 2.3, I examine social constructions of health, illness and disease, before closing with a brief chapter summary.

## **2.1. THE CHANGING LANDSCAPE OF HEALTHCARE**

The notion of empowering 'consumers' to 'manage' their healthcare, or to incorporate 'patient-centred' models of healthcare delivery underpins much of the documentation rationalising patient portal services (e.g., NHITB, 2012; Orion Health, 2013). Even outside the realm of digital healthcare communication, these phrases seem to be increasingly used, indicating a new approach or philosophy to healthcare delivery (e.g., Ministry of Health, 2013a). Yet on their own, these words have little meaning. As Bury (1997) maintained, self-managing illness has been evident long before the introduction of

these documents, and as Lorig and Holman (2003) argued, it is near impossible not to manage one's health. However, set against the historical backdrop, these words certainly exemplify a shift in the role of the patient and in the way that healthcare is delivered. This history provides valuable insight about the movement that created the conditions for the development of patient portals.

It is recognised that many foundations of modern medicine were established in the nineteenth century (Chamberlain, 2013). With the process of modernisation, past religious and superstitious ideologies of illness and disease transferred into more secular paradigms before being embraced by scientific discourses (B. Turner, 2000). In the years following the enlightenment and industrial revolution, geographical exploration and scientific discovery flourished (Larkin, 2011) and traditional regimens were increasingly replaced by a highly specialised hygiene in the nineteenth century (Berridge et al., 2011). The formulation of the germ theory in the 1860s rendered new possibilities, resulting in the acceleration of the progress in medical science and technology (Baronov, 2008). By the twentieth century, public health interventions began moving away from the collective management of the environment to targeting individuals in the home (Berridge et al., 2011). The accidental discovery of Penicillin in 1941 and then cortisone in 1949 further transformed perceptions of medicine's possibilities (Le Fanu, 2000; L. Thomas, 1977).

These progressions contributed to the dominance of biomedicine, which is prominent in modern medicine (Larkin, 2011) and so it is significant when considering patient portals. Biomedicine seeks to diagnose ill health in terms of a malfunction of an internal biological mechanism of the body (Knight, 1998). It encompasses the following assumptions: the mind is completely separate from the body; the body is akin to a machine as it has parts that can break down; technology should be used to mend the broken body; the reductionist explanation of illness as only being from changes within the body; and the doctrine of etiologies of disease, where every disease is caused by an identifiable agent (Nettleton, 2006). The adoption of biomedicine assisted in sanctioning the

professionalisation of medical occupations (Starr, 2009) and illness became further aligned as an individual affair under medical authority, rather than religion (Herzlich & Pierret, 1985).

In 1938, New Zealand established the historic Social Security Act, which involved the introduction of a free access to an array of health services (Gauld, 2001). This appeared to be founded on the principle that health is a public good and the government has a responsibility to participate in maintaining it. By the 1950s, the medical sciences increasingly focused on the social causes of disease (Le Fanu, 2000), addressing concepts of risk and risk factors (Berridge, Gorsky, & Mold, 2011). Although the ideologies underpinning social medicine had been explored for some time, there were significant developments in the mid-twentieth century which influenced this change, such as discovering the association between smoking and lung cancer in 1950 (Berridge et al., 2011). This was also during an era when biomedicine had cured many infectious diseases; however, chronic health conditions, such as coronary heart disease, were becoming increasingly prevalent (Rothstein, 2003).

By the 1970s, the medical establishment suffered a loss of public confidence (Sobo & Loustanaunau, 2010). The mandates of the 1950s, where increased medical care was required, and medical professionals were considered best to organise this, was running out, which was exacerbated by rising health sector costs (Starr, 1982). There was a growing scrutiny of medical power, with the paternalism among doctors being challenged by academics (Waitzkin, 1979; Baszanger, 1985) and the public (Cartwright, 1967; Brody, 1980; P. Jensen, 1981). Research criticised medicine's monopoly over the definition and treatment of disease (e.g., Begun, 1979; Freidson, 1970; Illich, 1975; Irving, 1972; Navarro, 1976), maintaining that the medical establishment posed a threat to civil liberties. Sociologists disputed biomedical claims of neutrality, alleging that medicine frequently sides on social issues and that the nature of allocating medical categories is reflective of the moral order of society (Kottow, 1980). In 1976, McKeown published his renowned thesis

claiming that medical invention did not in fact bring about the decline of diseases, but it was rather attributed to environmental improvements. McKeown was not the first to make this observation, for instance, it was raised by Dubos in 1959 and later in 1980, posing the fundamental question of whether public health should be individually focused or target broader populace measures.

It was during this era that the term ‘medicalisation’ was used to describe the scope of medicine expanding to define and treat new conditions, which appeared to strengthen the breadth of influence and prestige awarded to the medical institution (Zola 1972; Illich, 1975) while promoting capitalist interests (Ehrenreich & Ehrenreich, 1978; Navarro, 1986). A commonly cited example of medicalisation is homosexuality, which was once considered a sin before being medicalised into a sickness and has since been demedicalised into a sexual preference (Conrad & Schneider, 1992). Another example is childbirth, which was medicalised as needing medical treatment at a hospital; however, more recently, there has been a ‘natural childbirth movement’, whereby childbirth is undertaken with as little drug intervention as possible (Barry & Yuill, 2002). This demonstrates how the definition of some diseases are part of a social and historical process. Illich (1975) argued that medicalisation caused a clinical, social and cultural iatrogenesis: where the clinical iatrogenesis concerns the direct physical harm from medical treatment, the social iatrogenesis refers to medicine extending into social life, promoting its consumption, and the cultural iatrogenesis robs people of the ability to cope with minor ailments, making them dependent on medicine. For example, in medicalising menopause, a woman’s identity may change to becoming ill and she may consequently seek medical treatment such as oestrogen replacement therapy, which can increase the likelihood of gynaecological cancer. Although medicalisation is generally presented adversely, in some instances, such as epilepsy, medicalisation can lead to social awareness and the production of beneficial therapies (Weitz, 2007).



In the 1970s, several public health developments addressing the social causes of disease also took place, including the diffusion of the Surgeon General's Report on Smoking, the publication of various epidemiological findings and the identification of a succession of environmental health hazards (Crawford, 2006). Governmental reports began highlighting concepts of 'individual responsibility' and 'self-imposed risk' (Minkler, 1989; Graham, 1980), or 'victim blaming' as characterised by Crawford (1977) and Hancock (1986). Subsequently, a new emphasis on social marketing in the 1960s (Berridge et al., 2011) accelerated in the 1970s (Crawford, 2000) as a strategy to create the conditions for healthier behavioural changes (Niblett, 1975). These advancements influenced in a new health consciousness where health was framed as a duty, earned by living a good life of moderation (Conrad, 1987, 1994; Cornwell, 1984; Crawford, 1984, 2006; Reiser, 1985). For instance, in 1984 the Minister of Māori Affairs Hon Ben Couch stated: "People who enjoy good health have earned it. The rules are the same for people of all races; good eating, plenty of sleep and exercise, and moderation in all things" (as stated in Durie, 2007, p. 56). Such a portrayal, in my view, is simplistic, ignoring the broader social conditions, which show that many people who are unwell are also those with less power in society. This is described in the concepts of 'healthicisation' (Conrad, 1987) and 'healthism' (Crawford, 1980).

Conrad's (1987) concept of healthicisation is when behavioural and social definitions and treatments are offered for previously medically defined events, and unlike medicalisation which moralises medicine, healthicisation moralises health. Alternatively, Crawford (1980) claimed this as healthism, in which health is moralised to a heightened value and is presented as a result of individual choices. In this realm, the quest for wellness is a moral pursuit and striving to stay healthy is a good in itself (Conrad, 1994). As illness is framed as a consequence of the individual, the onus of external causes is removed and the adoption of the 'sick role' becomes an acceptance of moral culpability (A. Davis, 1979) and is presented as a burden to the 'responsible well' (Crawford, 2006). This social creation of

the diseased or infected ‘other’ was exemplified by the 1980s HIV/AIDS<sup>3</sup> epidemic (Crawford, 2006; Joffe, 1997), where media representations fuelled a moral panic, constructing the disease as a plague-like, even spiritual response to deviance (Kinsella, 1989).

Central to the debate about healthicisation or healthism is the question of whether people are entirely responsible for their decisions or if they are predestined by their wider social environment; known as the structure-agency debate. Sociologists contend that decisions do not occur in a vacuum, but are rather situated in economic, cultural, and political settings which make healthy behaviours more or less viable (Weitz, 2007; White, 2009). For instance, some analysts consider that attributing poorer health outcomes among lower socioeconomic groups to individual behaviours is blaming people already victimised by their circumstances (Dougherty, 1993). Accordingly, health promotional campaigns have been criticised for stigmatising illness and diverting governmental accountability (e.g., Conrad, 1994; Cho & Salmon, 2007; C. Salmon, 1989; Wikler, 1987), and the moral imperative between the considered virtuous healthy and the irresponsible or even blameworthy unhealthy, continues to be documented (e.g., Becker, 1993; Kendall et al., 2011; Lowenberg, 2007; Petersen & Lupton, 1996; Pond, Stephens & Alpass, 2010).

By the 1990s analysts were observing a shift in the engines of medicalisation, where the doctor’s role was becoming more subordinate and aspects such as biotechnology were extending the boundaries of medicine (e.g., D. Armstrong, 1995; Clarke, Shim, Mamo, Fosket & Fishman, 2003; Clarke & Shim, 2011; Conrad, 2005; Faulkner, 2009; Rose, 2001, 2006). Although technology also progressed the early development of biomedicine, by the 1990s it underwent a rapid advancement (Faulkner, 2009) and the expansion of surveillance technologies broadened medicine’s scope to examine whole populations (D. Armstrong, 1995). Some analysts described this as the ‘medicalisation of risk’ where doctors identify,

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<sup>3</sup> Abbreviated from: Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome.

treat and manage patients who have risk factors for future disorders. They argued that as the rhetoric of prevention extended to manage behaviours and proportions of risk, judgments were no longer organised into normality or pathology and the familiar distinction between health and disease blurred. An example of the medicalisation of risk that was discussed by Rier (2010) and Savard (2013), is when women who are high risk of developing breast cancer undergo a mastectomy prior to cancer developing for prevention.

However, Figert (2011) and Furedi (2008) contended that medicalisation had become driven by the patient. This was partly attributed to patient activist groups impelling social change (Shapiro, 1993; Gillett, 2003) but it also reflected social changes and the increasing commercialisation in healthcare, where the doctor-patient relationship was transforming into a provider-consumer transaction (Sobo & Loustau, 2010; Figert, 2011).

Correspondingly, by this time there had been a global shift toward strategies that aim to empower the 'consumer' to self-manage their healthcare and to promote 'shared decision-making' (Glass, 1996; Gabe, Olumide & Bury, 2004). While this attention towards chronic illness is significant, as health services traditionally focused on acute care (Glasgow et al., 1999), the promotion of empowerment and self-management in healthcare has been criticised as being simplistic and politically naïve (Greenhalgh, 2009), encouraging a more individualistic, consumerist culture (Laing & Hogg, 2002) and as being another medium emphasising the citizen's responsibility to maintain their health, while absolving liability from the state (Bella, 2010; Bury, 2008; Kendall et al., 2011; Savard, 2013; Veinot, 2010; Wilson, 2001).

Furthermore, as empowerment and self-management policies are generally applied to the medical regimen, Wilson (2001) claimed that these strategies are unlikely to reconstruct illness as there is no corresponding strategy to challenge doctors' assumptions. Empowerment and self-management discourses have also been accused of disguising health resource rationing which shifted the burden of care onto civic responsibility (Bella, 2010; Veinot, 2010), while undervaluing the structural conditions which make self-

management possible (Kendall et al., 2011; Morden, Jinks & Ong, 2012). As such, it has been argued that contrary to their ostensible purpose, these strategies may legitimise doctor knowledge while framing citizens as being in need of instruction (Kendall et al., 2011).

To date, systematic reviews on self-management interventions have had mixed results. For example, Chodosh et al. (2005), Jovicic, Holroyd-Leduc and Straus (2006) and Lennon, McKenna and Jones (2013) established positive results for self-management interventions regarding some conditions, but Millard, Elliott and Girdler (2013) and Lindsay, Kingsnorth, McDougall and Keating (2013) claimed there was insufficient evidence on its outcomes. However, these studies are unlikely to capture the lived experience of self-managing illness, which can be physically, emotionally and socially demanding (Hinder & Greenhalgh, 2012). From a broader sense, the idea of the state seeking to empower citizens to manage their healthcare is arguably paradoxical, as the very structure that puts one group in a position to empower another, undermines the act of empowerment (Gruber & Trickett, 1987).

Another factor that could potentially increase individuals' ability to self-manage their healthcare was the rise of the internet which provided users with a medium to easily access and communicate health information (Serlin, 2010). With the accessibility and anonymity of the virtual world, patients' illness narratives, which were once suppressed, were given a new voice (Bury, 2001), being an effective medium for providing and receiving social support (N. Armstrong & Powell, 2009; Sharf, 1997; J. Turner et al., 2001). This led to the creation of illness subcultures, in which illness-based social movements legitimated and empowered medicalisation or demedicalisation (Barker, 2008; Conrad and Stults 2010). However, while the internet has been praised for assisting individuals in self-managing more aspects of their healthcare (e.g., Kalichman, Bentosch, Weinhardt, Austin & Luke, 2002) and for levelling patient-provider power relations (Hardey, 2001, 2002; Loader, Muncer, Burrows, Pleace, & Nettleton, 2002; Nettleton, Burrows, & O'Malley 2005), some research has established that online support groups replicate biomedical discourses (Pitts,

2004; Fox, Ward, & O'Rourke, 2005), reproduce existing social divisions, and increase medicalisation and healthism (Korp, 2006). Not surprisingly, the widespread access of online health information has been the focus of debate since the late 1990s, with critics raising concern of the poor quality of information and its potential ramifications (e.g., Fast, Deibert, Boyer, Hraby, & McKiernan, 2012; Hargrave, Hargrave, & Bouffet, 2006; Lawrentschuk, Abouassaly, Hackett, Groll, & Fleshner, 2009; Maloney, Ilic & Green, 2005).

Additionally, this increased 'self-care' was both fostered and capitalised by enterprises ranging from pharmaceutical companies to food retailers (Rose, 2001). For instance, pharmaceutical companies are known to sponsor the definition of new diseases and then normalise their treatments through marketing (A. Robinson et al., 2004). This is particularly troubling in New Zealand and the United States where television advertising of pharmaceutical products is permitted and has been increasing since the late 1990s (Ministry of Health, 2006). These advertisements endorse biomedical understandings; where a drug is presenting as 'fixing' one component of the body, while neglecting its threat to the rest of the being (Petersen, Seesacker & Schawtz, 2001). Some analysts have argued that notions of health and illness have evolved to incorporate a far wider conception, encompassing various commercial goods and services such as foods, aromatherapy, vitamin pills and even footwear (Burrows, Nettleton & Bunton, 1995; Nettleton, 2006a).

Healthcare ideals in the twenty-first century appear to have extended from the 1990s, where patients are becoming more informed and taking more control of their health conditions, showing a cultural shift from the more paternalistic delivered healthcare of the past (Cayton, 2006). Yet there is a contradiction present: while medicine has brought major improvements in life expectancy and individuals are more involved in their care, there is a growing sense of anxiety and insecurity about illness and disease (Crawford, 2004, 2006; Wainwright, 2008). Since death and suffering are rarely diagnosed from ageing, the perceptions of risk are exacerbated, and death is presented as a preventable event

(Buckingham, 2008). Further, the concept that disease can be predicted places an onus on the individual to take judicious steps to ensure protection against misfortune (Lupton, 1995), and so prevention becomes a subtle and effective means of populace control (Castel, 1991).

The medicalisation of risk and some other developments described correspond with the concept of governmentality. Foucault (2007) described governmentality as:

The ensemble formed by institutions, procedures, analyses and reflections, calculations, and tactics that allow the exercise of this very specific, albeit very complex, power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument (p. 108).

Foucault's (2007) concept focuses on the development of apparatuses, institutions and scientific thinking, which generate taken for granted classifications and practices. As Ferlie, McGivern and FitzGerald (2012) discussed, this creates power relations underpinned by specialist knowledges and apparatuses that are difficult to challenge. Foucault's concept also focuses on the changed personal identity produced through governmentality. For example, as mentioned, the expansion of surveillance technologies broadened medicine's scope to examine entire populations (D. Armstrong, 1995). Furthermore, some analysts have claimed that technology shaped the physiological, biochemical, and biomolecular entities that define and recognise concepts of health and disease, such as ultrasound turning pregnancy into a medical process and the foetus into a patient separate from its mother (e.g., Verbeek, 2008; J. Taylor, 2008). This could, in turn, change the way that women view or manage pregnancy. According to Rose (2001), immersing technologies into common sense assumptions affiliated to political rationalities and so concepts of health and illness became further aligned as tools of the state.

Corresponding to modern health ideals are the ICT's used in healthcare such as the patient portals, which encapsulate patient-centric health and patient self-management. Patient portals provide individuals with online personal health information and a means to electronically engage with healthcare providers and claim to empower patients to be more

proactive in their health (Medtech, 2017; Orion Health, 2014a). As Wynia and Dunn (2010) remarked, the desire to increase patient engagement is what makes patient portals “so alluring, so promising, and so threatening at the same time” (p. 65). However, as indicated by the literature explored, while personal empowerment appears to be a strategy to contain rising health sector costs, some analysts consider concepts of individual responsibility and victim blaming to sometimes blur (Conrad, 1987, Crawford, 1980). Given the expanding nature of medicine (Conrad, 2013), it could be argued that patient portals are another example of technology further entrenching medicine into citizens’ lives.

## **2.2. COMMUNICATION IN THE CONTEXT OF CONSUMERISM**

The previous section evidenced a social trend, where there have been changes in the way that healthcare is delivered, and correspondingly, in people’s expectations of their healthcare providers. Many individuals who now want an active role in decision-making for their treatment options may seek out more information about their health conditions (Prey et al., 2014). A number of terms have accompanied this change, including 'patient empowerment', 'patient self-management' and 'shared decision-making', all of which have been used in reference to patient portals. At the centre of this topic are the patients, the doctors, and the relationships between them which have been fundamental to the delivery of healthcare, arguably over the last three millennia. As asserted by Cassell (1985), “all medical care flows through the relationship between physician and patient; and the spoken language is the most important tool in medicine” (p. 1). It is this relationship which could be impacted from the changing healthcare context moving toward consumerism.

Underpinning the events described has been a struggle between the amount of autonomy and responsibility that an individual should have over their own health and healthcare options, influenced by patients, doctors, scientific and technological advancements, and commercial entities. It presents two extremes: paternalism and patient empowerment or consumerism. These are outlined in Emanuel and Emanuel’s (1992)

renowned four models of the patient-doctor relationship. In the paternalistic model, patients have limited participation and doctors act as their agents or guardians with the assumption that they can discern what is in their best interest. This relationship can be nurturing and supportive, which patients may draw comfort from, particularly when they are unwell (Roter, & Hall, 2006). The informative or consumer model is one in which doctors impart information and treatment options to their patients and the patients are in control as the ultimate decision-makers (Emanuel & Emanuel, 1992). Emanuel and Emanuel's (1992) model assumes that patients are fully empowered by their personal values, to the point of being able to assess the facts their doctors offer to make the best clinical decisions. However, many patients may not be so empowered for this model to be universally applicable, and there are external factors that Emanuel and Emanuel (1992) did not take into account in this model, such as patients' education.

The shift towards the consumer model can be seen in the adoption of business terms in healthcare, with patients becoming consumers and doctors becoming providers (Emanuel & Emanuel, 1992). Consumerism from this perspective tests goods and services and supports the free market to function, which allows consumers to have information to enable them to make informed choices. This could rearrange the power dynamics in healthcare as it focuses on the consumers' rights and the providers' obligations. However, Rowe and Moodley (2013) argued that if the patient becomes a consumer then the doctor is a supplier of a commodity, which could see the replacement of professional ethics with marketplace or business ethics. In this sense, the consumer model takes the care and compassion out of medicine, turning it into a commercial transaction. It also assumes that knowledge alone is sufficient to enable patient decision-making, which is not always the case, as research has determined that many patients undervalue their capability to contribute to decision-making (Joseph-Williams, Elwyn, & Edwards, 2014)<sup>4</sup>. In addition, it

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<sup>4</sup> Although this was not mentioned by Joseph-Williams et al. (2014), patients could also potentially overvalue their capability to contribute to decision-making.



frames individuals as personally responsible for their health status. Perhaps both models could be criticised for their exclusivity in the decision-making; the paternalistic model for discounting the patients' views, and the consumer model for restricting the doctors to the status of technical consultants.

With this reasoning, Roter and Hall (2006) claimed that the optimal relationship may be one that embraces both the patient's and doctor's contributions. The notion of shared decision-making has some similarities with the consumer model as it has its origins in the consumer rights movement, it involves the doctor informing the patient, and it is a way of decreasing the patient-doctor power asymmetry (Charles, Gafni, & Whelan, 1997). However, the decision-making involves the mutual participation of the patient and the doctor, where they both agree with the decisions made (Charles et al., 1997). Nevertheless, Emanuel and Emanuel (1992) argued that as shared decision-making emphasises the doctor's role of informing the patient who contributes his or her aims and values, it poses the risk of re-embodying the consumer model. They proposed two alternative models where the doctor uses the patient's values to determine the best treatment options. In the first, the interpretive model, the doctor works with the patients to explore and determine their values and then selects the treatment that best fits these values. In the second, the deliberative model, the aim of the patient-doctor interaction is to help the patient determine the best health-related values that can be realised in the clinical situation. Emanuel and Emanuel (1992) argued that this last model may be the best for the relationship as it allows doctors to guide patients in a caring manner, without limiting patient independence. Yet under time constraints, both models have the potential for doctors to insert their values and to metamorphose into paternalism (Emanuel & Emanuel, 1992). In addition, it has been claimed that there is a default model, when the patient's and doctor's expectations are at odds, characterised by unclear or contested goals (Roter, & Hall, 2006).

Significantly, although there has been a movement to involve patients in decision-making, this is far from being all-inclusive in practice. A study by Bensing et al. (2006) compared videotaped consultations in 2002 with 1986 and found that a more equal patient-doctor relationship was not reflected, although there had been a change toward a more business-like, task-oriented communication pattern. Additionally, although patients generally want information about their conditions and treatment options (Beisecker & Beisecker, 1990), survey research has found that they still more often prefer doctors to play the primary role in decision making (Bradley & Hamilton, 1996; Burton, Blundell, Jones, Fraser, & Elwyn, 2010; Levinson, Kao, Kuby, & Thisted, 2005; Stiggelbout & Kiebert, 1997). For instance, Beisecker and Beisecker (1990) determined that while patients express a high desire for medical information, they do not always exhibit information-seeking behaviours in their medical consultations and they prefer to delegate the decision-making responsibility to doctors. Furthermore, the preference for information and control in healthcare has been associated with being female, white, younger, more educated (Krupat, Bell, Kravitz, Thom, & Azari, 2001; Levinson et al., 2005) and free from medical conditions (Biley, 1992; Degner & Sloan, 1992; Stiggelbout & Kiebert, 1997), which begs the question of whether technologies like patient portals will predominantly serve those who are often referred to as the ‘worried well’<sup>5</sup>.

Given this variability in the preferences for decision-making and the complex nature of medicine, the patient-doctor relationship may require fluidity, where the appropriate model is adopted to the clinical situation. Yet in reality, doctors frequently fail to elicit if and how patients want to be involved in decision-making (Burton et al., 2010) and research has associated unsatisfactory interpersonal communication with issues such as poor patient compliance (Beck, Daughtridge, & Sloane, 2002; Ong, de Haes, Hoos, & Lammes, 1995). In view of these findings, some analysts have criticised the medical profession’s reluctance

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<sup>5</sup> These are individuals who do not need medical treatment, but who visit the doctor to be reassured. For further discussion on this matter see Bowers (1997) and Wagner and Curran (1984).

to change their approach to communication, such as White (1988) who questioned why “we continue to behave as if (this knowledge) did not exist?” (p. 6). However, while poor communication is often blamed for failures, dissatisfaction and complaints, there are few recommendations that unequivocally help in these situations (Brown, Crawford, & Carter, 2006). This is unfortunate, as patient-doctor communication has been described as one of the most essential dynamics in healthcare (Matusitz & Spear, 2014) and analysts have alluded to its importance for informing patients and ensuring compliance with treatments (Fallowfield & Jenkins, 1999; Travaline, Ruchinskas, & D’Alonzo, 2005). What can be interpreted from the literature is the complexity of this interaction (Ong et al., 1995) and that it is not performed in a vacuum; it is political because it reflects power imbalances, it is historical because it exhibits changes over time, and it is cultural because socio-cultural values emerge in the interaction (Cordella, 2004).

In summary, while there has been a movement toward consumerism and increasing patients’ involvement in decision-making, the literature examined does not entirely show that this is widespread in medical practice or reflected in all patients’ viewpoints (e.g., Burton et al., 2010; Stiggelbout & Kiebert, 1997). This highlights the issue in adequately assessing patients’ preferences in decision-making. Emanuel and Emanuel’s (1992) models of the patient-doctor relationship reveal how the dynamics of negotiation can take on several forms. Emanuel and Emanuel’s (1992) models are a kind of continuum of the patient-doctor relationship; on one end is the paternalistic model, where the doctor is in control and acts in the patient’s interests, and on the other is the consumer model, where the doctor informs the patient of the treatment options and the patient is in control of the decision-making. If the power of decision-making changes from the doctor to the patient, this does not only impact the individual’s agency, but it also alters the purpose of medicine, away from delivering care and support. This may suggest that there is some legitimacy in the concept of shared decision-making or in Emanuel and Emanuel’s (1992) deliberative

model discussed yet achieving this in the demanding field of medicine could be problematic.

### **2.3. SOCIAL CONSTRUCTIONS OF HEALTH, ILLNESS & DISEASE**

As discussed in section 2.1, modern ideals of healthcare have constructed illness as an individual affair, where political, social and commercial pressures to maintain good health has led to shame and disparagement among the unwell. Yet the continued moral pursuit of health and avoidance of illness is increasingly unobtainable. In western societies, medical advancements and rising life expectancies have resulted in more people experiencing longer durations of chronic illness (OECD, 2015). With a growing proportion of ageing, chronically ill and disabled this has raised concerns of its financial implications, prompting a global policy shift toward self-management strategies (Sanders & Rogers, 2011). This is of particular consequence to chronic sufferers, as this may be a lifelong task. In this section, I survey literature to explore the social constructions of health, illness and disease.

Sontag (1991) proclaimed that there is a kingdom of the well and a kingdom of the sick and if we are lucky, we spend our time dwelling in the first, although most of us at some point are passport holders of both domains. However, it seems that these are abstract subjects surrounded by ambiguity. They are commonly applied as social metaphors, such as a 'sick society' or being 'sick in the mind', and personal conceptions of these terms often reflect fundamental religious and moral beliefs (B. Turner, 2000). Consequently, studies continue to confirm the variance in the perceptions of health and illness (e.g., Calnan, 1987; Cornwell, 1984; Crawford, 1984; Herzlich, 1973; Miles, 1991; Pill & Stott, 1982; G. Williams, 1984) and frameworks explaining health and illness are wide-ranging including being defined: in accordance with biomedicine, as the absence of disease; as the ability to manage everyday activities; and positively, as fitness and well-being (Blaxter, 1990). While the World Health Organization (1946) adopted the definition of

health as: “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (as cited by the World Health Organization, 2003, para. 1), Kottow, (1980) criticised this description for its vagueness, and medical extraterritoriality.

Yet health is clearly a difficult condition to empirically measure. More recently, perceptions of health have expanded to conceptualise individuals’ approach to life; being presented as an unstable property requiring constant maintenance (Crawford, 2000; Petersen & Lupton, 1996) and being endowed with moral faculties of individual choice and freewill (Greco, 1993; Lowenberg, 2007). Notions of health have also blurred with imageries of youth, where the perceived ‘healthy’ are not only free from illness, but also appear fit and muscular (Gavin, 2002). Perhaps with such broadening concepts of health, this strengthens Dubos’ (1959) viewpoint that seeking complete health is “almost incompatible with the process of living” (p. 54).

Furthermore, distinguishing illness from disease is also problematic as these terms are frequently used interchangeably (Schneider & Conrad, 1983). Some analysts have cited disease as a biological abnormality, where illness is a social and physiological construction which may or may not rest on disease as a foundation (Atkinson, 1995; Cathébras, 1997; Feinstein, 1967). However, there are many diseases which do not fit this classification and there has accordingly been an ongoing debate as to what constitutes a disease (King, 1954; Clouser, Culver, & Gert, 2004; Humber & Almeder, 1998; Tikkinen, Leinonen, Guyatt, Ebrahim & Järvinen, 2012). For instance, Engelhardt (1975) claimed that calling a phenomenon a disease implies a commitment to medical intervention, which Boorse (1977) contested, arguing that some diseases do not require treatment and not all diseases make their bearers ill. Nevertheless, while the reality of disease is frequently legitimised with a biological reference, the emergence and the continued existence of these labels is generally sanctioned by medical frameworks (D. Armstrong, 2014). Consequently, it is acknowledged that disease is a categorisation which is diagnosed or recognised by a

healthcare provider (Wikman, Marklund & Alexanderson, 2005), or as explained by Cassell (1976), disease is what the doctor sees, while illness is what a person lives.

Although biomedicine tends to overlook illness beyond its functional limitations (Kleinman, 1988), Stewart and Sullivan (1982) claimed that doctors still control the legitimisation and consensus of illness; a notion which resonates to this day. Research continues to document a strong sense of de-legitimation among people who fail to obtain a diagnosed disease for their illness (e.g., Glenton, 2003; Nettleton, 2006b; Nettleton, Watt, O'Malley & Duffey, 2005; Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999) and are living in what Corbin and Strauss (1988) describe as the 'diagnostic limbo'. It seems that one of the biggest hurdles faced by these people is that society does not grant permission to be ill in the absence of a diagnosed disease (Glenton, 2003; Nettleton, 2006b). While some analysts claim that illness is not given in the nature of medical fact (Gusfield, 1967), Freidson (1970) proposed that in labelling a condition (or perhaps legitimising) attaches a social state, and in this sense doctors construct illness in the same way that they construct disease. Correspondingly, Foucault (1963) maintained that medical discourse constructs knowledge about the body which in turn influences behaviours, alters subjective experiences and legitimatises medical intervention.

As such, despite changes in the way healthcare is delivered, biomedical judgements and assumptions continue to underlie conceptions of health and illness (Radley, 1994). For instance, smoking cessation strategies have influenced the blame and exclusion of individuals living with lung disease (Halding, Heggdal & Wahl, 2011) and many women with a diagnosed genetic risk of developing breast cancer exhibit self-blame for the potential of passing this onto their children (Mozersky, 2012). Biomedical ideologies also reflect and sanction the suppression of illness. With its Cartesian dualism between the body and mind and the notion that the body can be repaired like a machine, illness is often reified to a diseased organ or bodily part, or as something that is alien to the body (Helman, 1990). Accordingly, individuals who show unfavourable symptoms may have difficulty

incorporating this into their view of themselves as a physical being (Olesen, Schatzman, Drees, Hatton & Chico, 1990). Underpinning this is a fundamental denial of human mortality; in a youth-obsessed society (Kearl, 1989), where death has long been concealed and repudiated from the world of the living (Ariès, 1974, 1981) becoming the “lyrical core of man: his invisible truth, his visible secret” (Foucault, 1963, p. 172).

Nevertheless, while the underlying notions which frame illness and disease are often unspoken assumptions, these concepts shape the lives of those inflicted (Conrad & Barker, 2010; Drakos, 2008). For instance, cardiac disease may be indicative of a mechanical failure (Sontag, 1991), while HIV/AIDS is surrounded by the globally and locally distributed silences (Drakos, 2008) and various conditions draw stigmatisation including obesity (Boero, 2013; Puhl & Heuer, 2010; Saguy & Gruys, 2010) and mental illness (P. Thomas, Phipps-Jones & Flanagan, 2004). This stigmatisation is often internalised (Else-Quest, LoConte, Schiller & Hyde, 2009), which has been established among sufferers of breast cancer (Bennett, Compas, Beckjord & Glinder, 2005; L. Friedman et al., 2007) and mental illness (Corrigan & Watson, 2002; Pyne et al., 2004; E. Wright, Gronfein & Owens, 2000). Yet Sontag (1991) asserted that illness is not a metaphor and that wrapping conditions in metaphors discourages, silences, and shames patients. She wrote her renowned text ‘Illness as a Metaphor’ in 1978 while receiving treatment for breast cancer and she wrote about public perspectives of cancer and tuberculosis. She stated that society considers cancer as a disease of the “psychically defeated, the inexpressive, the repressed — especially those who have repressed anger or sexual feelings” (Sontag, 1978, p. 100). She maintained that the clearest, most truthful way to consider illness, and the healthiest way to live it, is resistant to metaphoric reasoning, but this is made impossible by the lurid metaphors which have shaped the illness landscape.

Furthermore, as the ‘kingdom of the sick’ is a socially constructed state, it encompasses specific social scripts or expectations. According to Parsons’ (1951) sick role theory, sickness is a form of deviance as it inhibits individuals from fulfilling their function

in society, and while the sick are exempt from normal social roles, they are under the obligation to cooperate with the doctor and endeavour to get well. Although the sick role theory has essentially been abandoned (Larsen, 2013; Burnham, 2013), being challenged by numerous theorists (Berkanovic, 1972; Gerson, 1976; Gallagher, 1976; Gerhardt, 1978), there are still present expectations of the unwell. Sufferers are encouraged to resist or control their symptoms (Townsend, Wyke & Hunt, 2006). For example, the term ‘survivor’ has been adopted to breast cancer discourses, to encourage individuals to fight their disease and be proactive towards their treatments (Lively & Smith, 2011). Townsend et al. (2006) further established that chronic sufferers often feel compelled to fulfil social responsibilities such as paid work and parenting to demonstrate their moral worth. Within this realm there are different gender expectations; where men often resist talking about their illness as personal revelation is unsuitable within traditional masculine discourse (Seale & Charteris-Black, 2008, 2010).

Accordingly, living with illness entails more than managing physical symptoms and receiving care; rather, daily encounters challenge prior meanings and ways of knowing one’s self (Charmaz, 1983, 2000). It is perhaps no wonder that chronic illness is experienced with themes of uncertainty (Charmaz, 2000; Mishel, 1988; Weiner, 1975) and disruption (Bury, 1982, 1991; G. Williams, 1984). For instance, Bury (1991) claimed that illness causes a physical disruption from the symptoms and impending impairment to everyday life, as well as a closely related disruption to a person’s identity. This disruption also impacts the sufferers’ perceived future where they are confronted with redefining their goals, and ultimately themselves. Of further consequence is the illness disruption that extends to family members and careers of the chronically ill (Mohr et al., 1999; Theobald, 1997); where partners of the inflicted also frequently experience fear, uncertainty and concerns for the future (Gotay, 1984; Sabo, Brown & Smith, 1986; Zalis & Shands, 1991).

In summary, it appears that concepts of health, illness and disease are not concrete conventions, but are rather wide-ranging and malleable, being embedded within



cultural, religious and moral frameworks. Yet biomedical assumptions continue to hold a strong influence; where illness and disease are synonyms for death, being experienced as something to suppress or hide (Sontag, 1990). As such, managing illness entails more than the physical detriments, but it also affects the way that people live, their personal identity and their relationships. With a rising proportion of chronically ill this has created new challenges set against a backdrop of social expectations. As discussed by Radley (1994), the chronically ill do not continuously occupy the status of the sick, but rather have to balance between both worlds. Given the documented physical, social and psychological impact of illness, developments which reframe illness towards individual self-management are of particular consequence.

## **2.4. SUMMARY**

I opened section 1.1 with some assumptions which have motivated the patient portals, including that people need and want more information about their healthcare, and that people should and want to make their own healthcare decisions. This chapter has shown that these assumptions are part of a broader movement in which patients are given more control over decision-making for their healthcare. The purpose of this chapter was to contextualise these ideals which have informed and underpinned the development of patient portals and some healthcare ICTs. Section 2.1 provided a historical backdrop to the changing landscape of healthcare ideals. Section 2.2 then related this to healthcare communication, by examining Emanuel and Emanuel's (1992) four models of the patient-doctor relationship. Finally, section 2.3 explored social constructions of health illness and disease. Now that I have provided a backdrop to these ideas, I will investigate the benefits, challenges and critical challenges concerning ICTs for healthcare.

# **3: IMPROVING HEALTHCARE THROUGH DIGITAL CONNECTION: BENEFITS, CHALLENGES & CRITICAL ISSUES**

The changing ideologies of health and healthcare described in chapter two are arguably reflected, reinforced and contributed to by the rise of ICTs. Put simply, the internet provides users with a medium to access and communicate health information, giving them more opportunity to understand and manage their health conditions (Serlin, 2010). For instance, today online support groups help individuals to deal with a range of health matters, including cancer (e.g., Shim, Cappella, & Han, 2011; Wen, McTavish, Kreps, Wise, & Gustafson, 2011) and diabetes (e.g., A. Chen, 2012; Loader et al., 2002). This can alter the illness experience, from once being private, to becoming a shared and public affair (Conrad & Rondini, 2010; Conrad & Stults, 2010). Many ICTs adopted by the healthcare sector reinforce changing practices in healthcare; by shifting responsibility from

healthcare providers to patients (Blobel, 2008) and assisting in user-centred healthcare (Ausín, Duque-Carrillo, Ramos & Torelli, 2013). These technologies, then, have become the focus of an academic field, although one containing much ambiguity.

Obviously, the introduction of ICTs is not unique to healthcare, as the immersion of technology is increasingly a requirement to successfully participate in society (Foster & McChesney, 2011). Moreover, the healthcare sector is a notoriously late adopter of ICTs when compared to other industries (Aanesen, Lotherington, & Olsen, 2011; A. Norris, Stockdale, & Sharma, 2009). This has been attributed to several causes, including a perceived lack of benefit by some healthcare providers (Harrop, Wood-Harper & Gillies, 2006) and the various costly failures of high profile healthcare ICT projects (Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010; Heeks, 2006). Many of these initiatives have struggled to adequately address the complexity of healthcare and those implemented within organisations can involve significant changes to organisational processes, as explored in chapter four. Nonetheless, there has been a movement towards using ICTs in the delivery of healthcare (Gaddi & Capello, 2014), and its international development has been promoted by the European Commission (2012) and the World Health Organization (2012a).

The increased attention towards healthcare ICTs has been driven to some extent by the needs of the public as well as the capabilities offered by the technologies. A number of ICTs assist in managing non-critical care within the community, which could reduce rates of hospitalisation, improve patients' quality of life and help to control costs (Norris et al., 2009). These technologies have the potential to profoundly impact individuals' lives by giving them more information about their conditions and in some cases, allowing them to reside in their homes away from residential care for a longer period of time. Some examples of these healthcare ICTs include home monitoring devices (Canally, Doherty, Doran, & Goubran, 2015), purpose built smart homes (Loane, O'Mullane, Bortz, & Knapp, 2012), intelligent cognitive assistants (Wolters, Kelly, & Kilgour, 2015; Wu,

Faucounau, Boulay, Maestrutti, & Rigaud, 2010), online health information resources (Nyman & Yardley, 2009), and patient portals, among many others.

Some ICTs could also alter the experience of receiving healthcare. This is not only in the location but also in the traditional order of care, where patients are expected to take a more active role in the delivery of their healthcare (Oudshoorn, 2011). With some ICTs, patients carry out tasks which were previously performed by doctors or other health practitioners, which has the potential to alter the social obligations for the healthy and the unwell. An example of this is a telemonitoring technology where patients apply an ambulatory ECG recorder and send the recordings to be interpreted by a doctor (Oudshoorn, 2008). Although this gives patients more control and understanding of their healthcare, Oudshoorn (2008) argued that it demonstrates how ICTs can redistribute work onto patients, aligning with the accusation that self-management discourses shift the burden of care onto civic responsibility (e.g., Bella, 2010; Veinot, 2010). It also shows that the functions of self-monitoring through ICTs and the devices traditionally used by healthcare practitioners are overlapping.

Notably, healthcare ICTs have had varied success. Despite extensive support from policymakers, there is a gap between their postulated benefits and those that are empirically demonstrated (Black et al., 2011). van Gemert-Pijnen et al. (2011) claimed that “the relationship between the visions... proposed strategies, and research methods is obscure, perhaps due to a rather conceptual approach that focuses on the rationale behind the frameworks rather than on practical guidelines” (p. 111), and this appears to still be applicable. Recent systematic reviews have established that many healthcare ICT initiatives do not have a clear evaluation criterion (e.g., Eikey, Reddy & Kuziemy, 2015; Mackert, Champlin, Holton, Munoz & Damasio, 2014; Sanchez et al., 2013) and that insufficient attention is paid to their effect on health outcomes (e.g., Slev et al., 2016; Watkins & Xie, 2014). Furthermore, ICTs targeting patients are less likely to report a beneficial outcome than those targeting doctors (Tarver & Menachemi, 2015), and systematic reviews have

identified a number of barriers to the uptake and use of these technologies among patients, including cost (e.g., Yusif, Soar, & Hafeez-Baig, 2016; Kapadia, Ariani, Li & Ray, 2015; Laxman, Krishnan, & Dhillon, 2015), usability (e.g., Fischer et al., 2014; El-Gayar, Timsina, Nawar & Eid, 2013; Peek et al., 2014), privacy concerns (e.g., Collins et al., 2016; Laxman et al., 2015; Liu et al., 2016), and the perception that it is not required (e.g., Kapadia et al., 2015; Tarver & Menachemi, 2015; Yusif et al., 2016). In the case of the patient portal, it has often had a low uptake (Irizarry et al., 2015; Otte-Trojel et al., 2016; Zieth et al., 2014) and systematic reviews examining its outcomes have been unable to draw definite conclusions due to a lack of empirical evidence (e.g., Giardina et al., 2014; Kruse et al., 2015).

This is not to say that there are no positive outcomes of the ICTs used in healthcare, but rather the results appear as varied as the technologies. There are a large number of ICTs that help individuals to manage different health matters, such as stroke rehabilitation (e.g., van der Linden, Waights, Rogers, & Taylor, 2012) and the prevention of falls (e.g., Nyman & Yardley, 2009). Although these examples have reported positive outcomes, they have the inherent limitation of only targeting one condition in isolation, rather than the patient as a whole, who may be dealing with a range of health concerns. This demonstrates the common issue that many healthcare ICTs are disconnected from one another, which has been highlighted by various analysts (e.g., Gaddi & Capello, 2014).

Another issue is the number of terms used to describe the wide range of healthcare ICTs, frequently with misconception. For instance, the umbrella term ‘e-health’ appeared sometime during the 1990s (Rinaldi, 2014) and it generally describes electronic or computer-based applications used in healthcare (Cunningham, Wake, Waller, & Morris 2014). However, it has been characterised by disparate concepts (Oh, Rizo, Enkin, & Jadad, 2005; Pagliari et al., 2005), such as: electronic healthcare communication (Deluca & Enmark, 2000), e-commerce for health products (Fecteau, 2002), the use of the internet for health purposes (Provost, Perri, Baujard & Boyer, 2003) and broader notions including “an

attitude, and a commitment for networked, global thinking” (Eysenbach, 2001, para. 3). Because of this contention, I have consciously avoided the term e-health in this thesis as well as various other commonly used terms in the health informatics field for the purposes of simplification, including ‘health informatics’, ‘medical informatics’, ‘nursing informatics’, ‘consumer informatics’, ‘health information technology’, ‘m-health’, ‘telemedicine’, ‘telehealth’ and ‘telecare’.

There is also the discrepancy in the terms used to describe the functions offered by patient portals. For instance, the ‘digital health record’, ‘digital medical record’, ‘electronic medical record’, and ‘electronic health record’ have been used by some texts interchangeably, although there are divergences in their literal meanings (Ackerman, 2008). The digital health records and digital medical records are web-based, while electronic medical records and electronic health records can be in any electronic format (Thielst, 2007; Häyrynen, Saranto, & Nykänen, 2008). Conversely, medical records refer to one practice’s notes, while health records contain all health information (Thielst, 2007; Ackerman, 2008). Again, for simplicity, in this thesis I adopt only the term electronic health record (EHR) to encapsulate these four domains. There are also the ‘personal health records’ which are owned and controlled by the patient (Thielst, 2007; Emont, 2011) and they can be independent, or they can connect to a healthcare provider’s EHR and be operated through a patient portal (Tang et al., 2006).

Ultimately, there are a wide range of ICTs being used in the healthcare domain, and this may account for some of the confusion surrounding defining terms. The diversity in these ICTs’ functions may also contribute to the ambiguity concerning their outcomes, as success in one area does not imply success in all. The purpose of this chapter is to scope the crucial issues surrounding these technologies. In the following sections I discuss the governance and ownership of clinical information and computer-mediated communication theory. I then investigate the difficulties in implementing ICTs for healthcare purposes as

well as the theoretical models that may provide some insight into the reasoning for this. I close this section with a discussion of the unequal uptake of these ICTs.

### **3.1. THE GOVERNANCE & OWNERSHIP OF PERSONAL HEALTH INFORMATION IN THE DIGITAL AGE**

Concerns regarding the privacy and confidentiality of personal health information have been widely reported as a barrier to the uptake of healthcare ICTs (Laxman et al., 2015)<sup>6</sup>, including patient portals (Thompson et al., 2016)<sup>7</sup>. Contributing to this concern could be the frequent media coverage of cases where the security of electronic health records has been breached, leading to thousands of patients' information being unlawfully exposed (e.g., Broder, 2014; Hicks, 2014). While the potential for breaches of confidentiality within a healthcare setting is not new, the scale of these examples indicates that the digitisation of clinical information can magnify the severity of this problem. The information becomes more transferrable, shareable and thus potentially more vulnerable. Accordingly, M. Martin (2014) has claimed that the use of electronic databases in healthcare signals a change in the governance of clinical information. Underpinning this subject are ethical questions regarding the ownership of personal health information and who should be responsible for its protection and maintenance. With paper records, it is generally assumed that doctors own the tangible vessels which store the information, but with the transferability of digitised and increasingly networked records, the lines demarcation lines of ownership become blurred.

In 2011, New Zealand's Office of the Privacy Commissioner acknowledged the changes in the healthcare sector from the introduction of ICTs, stating that "Much more of our health information is now held in digital form and transmitted online. Health

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<sup>6</sup> For further discussion on this matter see Collins et al. (2016), Fischer et al. (2014), Peek et al. (2014), Liu et al. (2016), Kapadia et al. (2015), McGinn et al. (2011), Young et al. (2014) and Yusif et al. (2016).

<sup>7</sup> For further discussion on this matter see Ancker et al. (2015), Cochran et al. (2015), de Lusignan et al. (2013), Dontje et al. (2014), Gagnon et al. (2016), Kleiner, Akers, Burke and Werner (2002), Hobbs et al. (2003), Pyper et al. (2004), Tieu et al. (2015), and Vodicka et al. (2013).

information is consolidated in a wider range of centralised repositories” (p. 3). At this time, EHRs were already widespread, as 99% of New Zealand health practices used a computerised patient management system and almost three-quarters of these used it for storing patients’ notes (Didham, Martin, Wood & Harrison, 2004). The Office of the Privacy Commissioner (2011) also emphasised that the stringent protection of this information would remain, stating that “some things do not change. Privacy and confidentiality are still absolutely central to our health system” (p. 3).

The collection of personal health information in New Zealand is regulated by the Health Information Privacy Code 1994. As outlined by the Privacy Commissioner (2008), it can be loosely summarised in twelve principles that govern the collection and use of information about patients<sup>8</sup>. It is noteworthy that these principles do not delineate the ownership of personal health information. For example, while the sixth principle gives patients the right of access to their information, it also specifies that this does not equate to ownership. That said, patients cannot be refused access to their records on the basis that they do not own the records. The Code of Health and Disability Services Consumers’ Rights 1996 also states that patients have the right to be fully informed, including an explanation of their conditions and results from tests or procedures, as well as a written summary of the information provided on request. Similarly, the Health Act 1956 (section 22F) requires any person holding health information to disclose it to the individual about whom the information is held on request.

The Palliative Care Council of New Zealand (2010) addressed the subject of information ownership more directly, claiming that personal health information belongs to the patients and their healthcare providers are custodians of this information. However,

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<sup>8</sup> They are as followed: 1) information should only be collected if required; 2) information should be collected from the people concerned; 3) patients should be informed of what will happen to the information; 4) doctors should be considerate while receiving it; 5) doctors should take care of the information; 6) patients can see their information; 7) patients can correct incorrect information; 8) doctors should ensure that information is correct before it is used; 9) information should be disposed once the doctor is done with it; 10) information should be used for the purpose that it is collected; 11) information should only be disclosed with a good reason; and 12) unique identifiers should only be assigned when permitted (Privacy Commissioner, 2008).



this notion, along with the codes discussed, arguably aligns more closely with previous models of care, in which a practice is responsible for making, storing, and maintaining a patient's records, documenting the care provided, the plan for future care, and their communications. Reflecting the time in which the codes were produced, they are less suited to the current information age, where records can often be shared, copied, duplicated, merged, and combined by various health providers across multiple sites. For instance, the Health Information Privacy Code states that doctors should take care of patients' information, but the precautions listed are simplistic and dated, saying to lock filing cabinets and unattended rooms. While it does mention that if digital media containing personal health information is posted then it should be encrypted, this does not specifically consider electronic transfers. In New Zealand, the NHITB (2015c) is working to provide a single national EHR and is perhaps necessitated by the fact that 80 percent of general practices use 'GP2GP' which allows them to electronically transfer medical records to one another (Ministry of Health, 2013b).

There are clear advantages for doctors being able to access patients' information. Through a survey of 2500 New Zealand doctors, McKenna (2010) identified an inference gap between the information available to doctors and the evidence needed to support best informed decisions. Although this study is somewhat dated for such a progressive field, it significantly determined that when information follows patients across care settings this gap is narrowed, and a shared decision-making process is supported that involves patients, doctors and care teams. Over three-quarters of the participants considered that better electronic access to healthcare information would improve the way they provide health services (McKenna, 2010). Alternatively, if patients were to determine which information should be available on their health record, then this could be ineffective for doctors' decision-making. As Wynia and Dunn (2010) stated:

Many patients want complete control over what data shows up in their PHR [patient portal] and who gets to see it; yet if doctors believe a PHR is incomplete or inaccurate, and if they cannot share it with colleagues consulting on the case, then

they will be less likely to use it and PHRs will not achieve the benefits they should. (p. 70)

At the same time, while doctors need adequate information to make diagnoses, this should not overshadow the significance of the boundaries that determine the ownership and governance of personal health information. When multiple actors can be involved, this brings to question the decision-making processes regarding the information's safeguarding, such as where it is uploaded, how it is stored, what it says, when it is modified and who has access. Providing non-medical personnel with access to health information gives them new responsibilities, even though they do not function under the same degree of regulation as healthcare providers. According to Halamka, Mandl and Tang (2008), "By placing the patients at the center of health care data exchange and empowering the patients to become the steward of their own data, protecting patient confidentiality becomes the personal responsibility of every participating patient" (p. 6). Furthermore, analysts have frequently raised concerns about whether minors should be given access to patient portals and whether patients should be able to assign proxy access to their informal caregivers (Otte-Trojel et al., 2016). This highlights issues of when individuals should be given access to their information, and further, when this access is provided to other parties who are not registered practitioners, how their activities will be regulated.

The contention concerning patient consent and the governance of personal health information has been raised regarding the 'opt-out' method used in some initiatives, where records are automatically uploaded to an ICT if patients are enrolled in a participating practice unless they indicate that they do not want to be involved. This has been used in the United Kingdom (Greenhalgh, Morris, Wyatt, Thomas, & Gunning, 2013). A New Zealand Privacy Commissioner's (2014) report which maintained that the opt-out method used for shared care records is required so that they are clinically useful, but a balance has been attempted to ensure that they respect the wishes of patients. It stated that, "requiring patients to opt-in to having their information placed on their shared care record, would

reduce the amount of patient information held on the record very significantly and make the record much less useful to doctors” (p. 13). However, the problem that this presents is that patients can be unaware that their information is uploaded, which is inconsistent with the principles of informed consent.

Furthermore, research has determined that a significant proportion of patients do not want their health information to be shared among health professionals without their consent. A survey of 982 patients who presented to an emergency department in the United States found that 54.3 percent (533 of 982 participants) wanted to sign consent before their data is transferred electronically (Medford-Davis, Chang, & Rhodes, 2016). In New Zealand, Hunter, Whiddett, Norris, McDonald and Waldon (2009) conducted a phone survey with 1828 respondents in 2008 which used vignettes to assess the participants’ willingness to share health information. In one scenario the information provided was restricted to information relevant to the current health problem for the purposes of receiving care and the person would be identifiable with their name and address, and the proportion of participants who said they would agree to such information sharing varied from 95 percent for a doctor or nurse working in a hospital to 51 percent (932 of 1828 participants) for a government health agency. The study also found that participants were significantly less likely to be open to sharing information with allied health professionals and pharmacists, when compared to their general practitioner or practice nurse.

A more recent New Zealand based study by Hunter, Haining, Ede and Whiddett (2014) surveyed patients attending sexual health services and found that confidentiality remains a significant concern and the routine sharing of patient information could create barriers to attendance. The authors concluded that sexual health services may be able to change their information management practices to an opt-out consent system to share health information with other health providers, but further public discussion to ensure informed consent is needed before this can happen. Other literature has found that

while the privacy and security of information can be a barrier to patients adopting healthcare ICTs, individuals with poorer health have considerably lower privacy demands (e.g., Lafky & Horan, 2011; Wilkowska & Ziefle, 2012).

With the vulnerabilities inherent in digital systems and the nature of the information, it is understandable that some patients and doctors have expressed apprehension about the digitisation of health records in the past. Yet the question of the ownership of personal health information is complex and cannot be entirely answered in this section. It is clear that patients have rights in regard to their personal health information, but enacting these may be difficult, especially given that some of the influential codes are outdated for current practices. As demonstrated by the opt-out method discussed, the governing of clinical information seems to be with healthcare providers by default, where they act on the patient's behalf unless the patient proactively asserts otherwise. This may have advantages for ensuring that doctors can access the information required to support clinical decisions, but as digital records can often be viewed and controlled by various actors across multiple locations, this poses the risk of the patient being left in the dark.

### **3.2. COMPUTER-MEDIATED COMMUNICATION IN THE HOME**

As shown in the literature explored, there is a large number of studies quantitatively examining healthcare ICTs, even though systematic reviews on their outcomes are still often inconclusive. However, the focus of this literature does not adequately address the technologies' sociological implications and how it influences the nature of providing and receiving care. For instance, while healthcare ICTs have become an area of interest in prominent communication journals, studies with quantitative methods triple those that are non-quantitative (Hu, 2015). This gives a limited view of the complexity of the communicative event between patients and their healthcare providers that is mediated by these technologies. This matter is arguably philosophical and difficult to test, but it has significant repercussions at a micro level, such as changing the communication between

individual patients and their healthcare providers, as well as at a macro level, such as structurally altering the processes for delivering healthcare communication. To explore this subject, it is useful to consider theories which endeavour to explain how computer-mediated communication (CMC) changes the social dynamics of interpersonal interaction when compared to face-to-face communication.

The research concerning CMC has generally been approached from two broad perspectives. The first perspective views CMC as impersonal, distant, and unable to establish relationships of the same depth as face-to-face communication, while the second considers CMC to be complex but with the potential to be just as, or even more personal than face-to-face communication (Parks & Floyd, 1996; Walther, 1996). The early CMC research took the first of these perspectives, arguing that it can never achieve the intensity of face-to-face communication because of its limits in sensory perception (Soukup, 2000; Walther, 1996). Two of the most influential theories on this topic were the social presence theory and media richness theory (Thon, 2006). Social presence is defined as, “the degree of salience of the other person in the interaction and the consequent salience of the interpersonal relationships” (Short, Williams & Christie, 1976, p. 65) which has been interpreted as people’s perceptions and awareness of the other person or people as being real or there, and as the interpersonal and emotional connection between communicators (Lowenthal, 2010). In short, this theory considers social presence to be a significant aspect of communication and that the face-to-face medium has the most social presence, while written mediums have the least. A similar continuum is suggested in Daft and Lengel’s (1986) media richness theory, which proposes that mediums differ in their ability to facilitate changes in understanding and that managers are more effective when richer mediums, like face-to-face communication, are used for complex tasks and leaner mediums, like memos, are used for less complex tasks.

Although this school of thought is no longer dominant in the CMC field, it aligns to many patients’ perspectives of ICTs. Older people have expressed concern that if they

start using healthcare ICTs, then this could take away personal relationships with their caregivers and contribute to social isolation (Kang et al., 2010; Walsh & Callan, 2011). In many cases their desire to age-in-place as opposed to being in residential care is not only with the intent to have control over their lives, but also to avoid social isolation, and face-to-face contact is seen as being critical to this (Milligan, Roberts, & Mort, 2011). Another identified hesitancy to adopting healthcare ICTs is that patients often value their existing communication practices with their healthcare providers which they do not want to disrupt (Sanders et al., 2012).

As the CMC research moved from the laboratory to the field it became apparent that this communication medium could and was being used to develop meaningful relationships with high levels of intimacy (Parks & Floyd, 1996; Soukup, 2000). Correspondingly, patients in various studies have reported satisfaction with ICTs that connect with their healthcare providers (e.g., Sabesan, Kelly, Evans, & Larkins, 2014; Shah et al., 2013). For example, Sabesan et al. (2014) examined perspectives of patients using the Townsville Tele-oncology clinic which uses video-consultations and found that 26 of 32 patients interviewed were satisfied with the interaction and that the technology was mostly accepted and welcomed by the patient participants. Brandt, Dalum and Thomsen (2013) determined that users of a smoking cessation program even established a relationship with the technology. Another study determined that participants frequently reported feeling 'less of a nuisance' when they could provide their own self-monitoring results for healthcare professionals (A. Rogers, Kirk, Gately, May, & Finch, 2011).

The original perspective that suggested that CMC was inferior or more impersonal was challenged by critics. Parks and Floyd (1996) alluded that the results of the studies may in part reflect the time restrictions placed on the interaction. Furthermore, Soukup (2000) argued that studies failed to consider the multimedia communicative possibilities of CMC that are impossible in a traditional face-to-face setting, such as emoticons, three-dimensional greeting cards or popular songs. For example, Collins et al. (2016) conducted

interviews and focus groups with 84 participants and a survey with five institutions and found that patient and family connection with the care team could be enhanced by the use of multimedia personalisation tools in patient portals such as a functionality to identify hobbies, post photographs, and link to social media accounts.

The second research perspective concerning CMC included Joseph Walther's (1996) concept of 'hyperpersonal communication'. Walther contended that individuals using CMC may use directive communication behaviours, which can be socially desirable at times, but they can also adapt to the context and develop intimacy. He argued that CMC can provide the opportunity to selectively self-present and edit, without the interferences of environmental reality, and this can render hyperpersonal communication, that is "forms of interaction that exceed what we may accomplish FtF [face-to-face] in terms of our impression-generating and relational goals" (p. 28). Walther was not the first scholar to emphasise the importance of context in CMC, as Hiltz and Johnson (1990) had already argued that the, "Characteristics of the users and the social context of the application... will strongly influence its acceptance and use" (p. 760). Yet Walther's theory highlighted the issue of self-disclosure in CMC, as when users are in control of self-editing, they might inadvertently or purposefully choose to withdraw important information, which can be problematic for some healthcare ICTs such as patient portals.

In spite of the potential for CMC to be as personal as face-to-face communication, preferences for healthcare are still often rooted in traditional models. Some research gaining perspectives of ICTs has found that there is a reluctance to select an intervention that is seen to undermine person-to-person contact in a care environment (e.g., Loh, Flicker, & Horner, 2009; Milligan et al., 2011; Walsh & Callan, 2011). According to Milligan et al. (2011), while many older people consider that ICTs can help them to cope with daily life within the home, this is viewed as a resource that should be in addition to, and not at the expense of, person-to-person care. Inevitably, this is dependent on the individuals' health conditions. Söderlund (2004) assessed elderly clients with severe

disabilities and argued that monitoring healthcare ICTs would not be enough and human labour was essential for their care. Conversely, A. Rogers et al. (2011) found that an ICT could provide an adequate substitution for traditional services when the nature of the patient work involved is 'low level' and that it offers additional benefits such as minimising the need to travel. However, the authors commented that it led to patients feeling that their condition was more closely monitored by health services, which may be contradictory to the notion of ICTs assisting patients in self-managing more aspects of their healthcare.

It is difficult to determine how the aforementioned CMC theories apply to the communication fostered through healthcare ICTs. An early study by Dedding, van Doorn, Winkler and Reis (2011) proposed an analytical framework which claimed that internet health sites can be a replacement for face-to-face consultations, supplement existing forms of care, create favourable circumstances for strengthening patient participation, disturb relations, and/or demand more intense patient participation. The idea that a website could potentially bring about one or a mixture of such contrasting outcomes arguably align with aspects of Walther's (1996) hyperpersonal communication concept, although the scholars acknowledged that their framework must be considered as a "first attempt" (p. 52) in this field.

### **3.3. THE DIFFICULTIES IN IMPLEMENTING HEALTHCARE ICTs**

Healthcare is an information-intensive industry. It relies on information arguably for every facet of its delivery (Conrick, 2006) and almost all of its processes are measured, from the quality and outcome of care, to the cost of that care (McWay, 2014). With this in mind, the healthcare environment might seem ideal for the use of ICTs, as they enclose various benefits for patients and healthcare practices, irrespective of time and space. However, healthcare ICTs have generally been difficult to implement (Stokke, 2016) and paper-based systems are still frequently used within healthcare practices (Gaddi & Capello, 2014). Furthermore, there have been various costly, high profile failures in healthcare ICT



initiatives (Greenhalgh et al., 2010; Kaplan & Harris-Salamone, 2009), such as the dismantled national programme for information technology in the National Health Service in the United Kingdom (House of Commons - Committee of Public Accounts, 2013) and the cancelled healthcare exchange website Cover Oregon (Lane, 2014). This section considers the issues that have been reported in implementing ICTs into the healthcare sector.

A logical place to begin this investigation is with an examination of electronic health records (EHRs), given that they are pivotal to many ICT systems used within healthcare practices, including patient portals. There are numerous potential benefits of digitising health records; they use little physical space, they can be easily and cheaply duplicated, and they can be viewed at multiple locations simultaneously (Coiera, 2015). Accordingly, studies have confirmed that the introduction of EHRs can improve documentation quality, increase administration efficiency, and contribute to better quality, safety and coordination of care (Nguyen, Bellucci, & Nguyen, 2014). While paper records also have some advantages, including being portable, easily annotated and not requiring special training (Coiera, 2015), these are far outnumbered by the those reported of EHRs. In spite of these advantages, the implementation of EHRs has been met with resistance from healthcare practitioners in the past (e.g., Sicotte, Denis, & Lehoux, 1998; Poon et al., 2004; Zandieh et al., 2008). This is not a trivial matter, given that timely access to patient information has the potential to save lives in a clinical setting.

To understand the implementation of EHRs more thoroughly, the role that health records play within an organisation should be examined. According to Coiera (2015), health records have a number of formal and informal functions, including being a means of communication among staff, a view into the collected data of a patient's illness, a 'workplace' to capture ideas and impressions of patients' conditions, and a historical archive. Therefore, healthcare practitioners may resist EHRs, not only because of their practicality, but because of their role in social processes (Berg & Bowker, 1997). For

example, following the introduction of an EHR in a residential aged care home, nurses and care workers still preferred verbal communication about residents because of concerns about access, increased documentation burden, the reduction of communication, lack of space for computers and increasing difficulties in delivering care services (Yu, Zhang, Gong & Zhang, 2013).

Digitising health records also changes the volume and the type of data captured, the time and effort devoted to record creation and the data layout and presentation (Coiera, 2015). Furthermore, the act of checking and updating EHRs and the physical presence of the electronic device can affect the interaction between patients and healthcare providers (McGinn et al., 2011). A study by Sinsky et al. (2016) examined how doctor time is spent in ambulatory practice by recording 57 doctors in the United States. It found doctors spent 27 percent of their total time in the office day on direct clinical face time with patients and 49 percent of their time on EHRs and desk work. While in the examination room with patients, they spent 53 percent of the time on direct clinical face time and 37 percent on EHRs and desk work. All of this indicates that the introduction of EHRs involves significant changes to organisational processes and service-delivery models. The same can be said of patient portals, as the potential to change organisational practices has been reported as an impediment to the its uptake among doctors (Grünloh, Cajander, & Myreteg, 2016).

Before implementing an ICT into a healthcare organisation, it is necessary to consider the organisation's processes and how these can be facilitated under the new system (Kapadia et al., 2015). Many functions of EHRs are not used to their fullest capacity and healthcare practitioners have frequently reported that they do not meet their clinical requirements (Nguyen et al., 2014). Correspondingly, various analysts have emphasised the importance of involving end users in the design of healthcare ICTs (e.g., Darlow & Wen, 2015; Lugtenberg, Pasveer, Weijden, Westert & Kool, 2015). However, this can be difficult as there is a range of stakeholders involved in healthcare and a

deficiency in the coordination between them has been highlighted as a shortfall of a number of ICT healthcare proposals (e.g., Greenhalgh, Russell, Ashcroft & Parson, 2011; He, Yang, Compton & Taylor, 2012). Contributing to this difficulty is that doctors are often paid on a fee-for-service basis, which can limit their willingness to investigate, procure, implement and then get properly trained in how to use an ICT (Ludwick & Doucette, 2009).

This lack of financial motivation is a particular issue for the uptake of patient portals, as the time required to train staff in the various functions could prevent them from completing other responsibilities (Nazi, 2013). It is widely documented that financial issues are a significant barrier to the uptake of patient portals by healthcare providers (e.g., Lester et al., 2016; D. Miller et al., 2016; Vydra et al., 2015). Obviously, some patient portal functions are less financially viable than others. For example, it is visible how booking appointments electronically could generate administrative savings, but it is less clear how giving patients access to their EHRs benefits the organisation (Otte-Trojel et al., 2015). Unfortunately, it seems that the functions that are the most complex and generate the least financial return tend to be those that facilitate the most patient engagement. Nevertheless, Vydra et al. (2015) significantly determined that while financial issues are a barrier to providers' engagement in patient portals, they still voice motivation to use them because they perceive the potential for improved patient communication and satisfaction.

Nevertheless, as much of the evidence about patient portals is from large practices, where it often complements a disease management program, it is difficult to ascertain why some patient portals work and others do not (Otte-Trojel et al., 2014). Patient portals influence workflow, work practices and communication including the flow of information between patients and members of their healthcare team (Nazi, 2013). According to Otte-Trojel et al. (2015), the success of a patient portal requires synergy with existing IT infrastructure and operations, doctor-led governance, continuous innovation, and an emphasis on a patient-centred design. Correspondingly, Greenhalgh et al. (2008) examined

the implementation of patient portals into four organisational settings and concluded that they, “are not plug-in technologies. They are complex innovations that must be accepted by individual patients and staff and also embedded in organisational and inter-organisational routines” (p. 7). Like other analysts (e.g., Prey et al., 2016), the authors emphasised that the implementation of a patient portal is complicated by a variety of political and sociotechnical barriers, stating:

This process is heavily influenced at the microlevel by the material properties of the technology, individuals’ attitudes and concerns, and interpersonal influence; at the meso-level by organisational antecedents, readiness, and operational aspects of implementation; and at the macro-level by institutional and socio-political forces. (Greenhalgh et al., 2008, p. 8)

Another challenge identified in the implementation of patient portals is the low uptake by patients (Irizarry et al., 2015; Otte-Trojel et al., 2016). A systematic review by Jacobs, Lou, Ownby and Caballero (2016) found that tailoring content to make healthcare ICT interventions more personally relevant promotes patient engagement and is related to post-intervention behaviour change. Correspondingly, the requirement for patient portals to meet users’ needs has also been emphasised by analysts (e.g., Irizarry et al., 2015; Zieth et al., 2014). Yet tailoring ICTs for patients to use in their homes can be problematic. Unlike healthcare organisations, the workflows are generally loose, their roles and responsibilities are undefined (T. Miller et al., 2015) and their needs are often ambiguous (T. Miller, Pedell, Sterling, Vetere, & Howard, 2012).

Furthermore, just as for healthcare practitioners the role of medical records extends beyond storing information, so does for patients the role of medical care extend beyond curing ailments. Gaddi and Capello (2014) suggested that while ICTs may be useful administratively, medicine is more complex than this and these technologies often ignore the social role of individuals in making decisions and governing their health. Medical services clearly differ from other products or services; being frequently characterised by uncertainty, complexity and a patient-provider information asymmetry, where the product

cannot always be tested and its success is not guaranteed. As a result, relationships between patients and practitioners often rely heavily on trust, and their consultations not only involve conveying information, but they also concern relieving patients' experiences of stress and anxiety (Andreassen, Trondsen, Kummervold, Gammon, & Hjortdahl, 2006). With this in mind, it is understandable that there has been some hesitance among patients in adopting some healthcare ICTs.

In summary, the main challenge in developing ICT healthcare strategies is no longer in constructing a conceived technological capacity, as almost any function can be delivered, but rather determining who is providing it, for what purposes and under what governance arrangements (M. Martin, 2014). The research examined demonstrates that introducing ICTs into the healthcare sector requires changes in roles, relationships, and business processes (e.g., Coiera, 2015; Kapadia et al., 2015; Yu et al., 2013). It entails a process in which social, economic and medical interests meet (Faulkner, 2009). This is because healthcare is complex, both as an industry and a service, and so is its ICT requirements which raise technical, administrative, and security challenges.

### **3.4. PATIENT PORTALS AND THE DIGITAL DIVIDE**

For more than a decade, research has reported inequalities in the adoption of patient portals. Because of the extensive research on this topic, I selected ten large-scale studies which examined portal adoption and use and have outlined some of their findings in Table 1.1 on page 8. These studies show that elderly patients are less likely to adopt patient portals, as well as patients under the age of thirty (e.g., Hsu et al., 2005; Nielsen et al., 2012). Furthermore, individuals with lower incomes or from lower socioeconomic groups are less likely to adopt a portal (Jhamb et al., 2015; Ketterer et al., 2013), although those with higher clinical need are more likely to adopt a portal (Weppner et al., 2010; Yamin et al., 2011).

Several analysts have related the disparity in the uptake of patient portals to the digital divide (e.g., Graetz, Gordon, Fung, Hamity, & Reed, 2016; Ross et al., 2005; Weingart et al., 2006). The digital divide originally referred to the distinction between those who do and do not have access to new forms of digital technology (Riggins & Dewan, 2005), but it has more recently been conceptualised as encompassing multi-dimensional aspects of inequality in a digital age (Bruno, Esposito, Genovese, & Gwebu, 2010; Wessels, 2013), contributed by a variety of factors, including individuals' motivations, skills, and opportunities (van Dijk, 2006). The digital divide is concerning for the implementation of healthcare ICT, as it poses the risk that digital inequalities could be extended further into the realm of healthcare, accentuating the gap between the privileged and the disadvantaged. In this section I examine the three levels of digital divide, all of which could impact the patient portal initiative in New Zealand.

#### 3.4.1. The First Level of the Digital Divide

Information technology is seen by many analysts as underpinning the social and economic progression throughout the beginning of the 21st century (Selwyn, 2004). In the second half of the 1990s, there was increasing attention toward the digital divide (van Dijk, 2006; Warschauer, 2004), and between 2000 and 2004, hundreds of scientific and policy conferences were dedicated to the topic (van Dijk, 2006). The initial concept of the digital divide, now termed the 'first level' of the digital divide, concerned the inequality in the access of new forms of digital technology (Riggins & Dewan, 2005). A principle concern about the unequal access to digital technology is that individuals can become further marginalised in societies where computer skills are increasingly necessary for personal advancement, educational prospects, and opportunities for civic engagement (P. Norris, 2001), as it tends to align with existing inequalities (van Dijk, 2006).

The first level of digital divide is an inevitable issue for the uptake of patient portals, which require patients to use the internet to access the services. This has been

demonstrated in research overseas. De Leon et al. (2012) examined the implementation of portals into three healthcare practices and determined that older patients and those with lower education levels or chronic diseases were significantly less likely than their counterparts to use the internet. More recently, Graetz et al. (2016) conducted a survey with 1042 patients enrolled in an integrated health care delivery system to investigate whether socio-demographic differences in patient portal use for secure messaging can be explained by differences in internet access. The authors found that patients' internet access could significantly impact their use of patient portals; as being able to use their own computers to access the internet accounted for 52 percent of the association between race and secure messaging use and 60 percent of the association between income and overall usage of the portals. In New Zealand, lower socio-economic groups have lower access to the internet, compared to their counterparts (Gibson, Miller, Smith, Bell & Crothers, 2014; Statistics New Zealand, 2014b), and, significantly, these groups also have higher rates of chronic illness nation-wide (Ministry of Health, 2013b).

Nevertheless, the problem with conceptualising the digital divide as an issue relating to access, is that it aligns to a kind of technological determinism, with the view that digital disparities could be fixed through a technological approach (van Dijk, 2006). Only considering access to technology can lead to an oversimplification; because the digital divide aligns with other inequalities, it can become difficult to determine whether the uptake of healthcare ICTs is attributable to this divide or to other aspects of social deprivation. Webster (1995) claimed that simply distinguishing between the 'information rich' and 'information poor' is lacking sociological sophistication, as it avoids an elucidation of who these groups are. The digital divide metaphor has also been criticised for suggesting that there are two distinctively divided groups (e.g., Selwyn, 2004) and the gap between them is static and difficult to bridge (e.g., Van Dijk, 2006).

Furthermore, the disparity between those who do, and do not, have access to digital technologies appears to be narrowing (Gibson et al., 2014). As Van Dijk and Hacker

observed in 2003, divides regarding the possession of digital hardware was likely to close, but the gap between individuals' skill levels and usage was likely to increase. Additionally, research as far back as 2011, discussed how other disparities in the uptake of patient portals extend beyond limitations in access to technologies or the internet (e.g., Sarkar et al., 2011; Sander et al., 2013). A survey conducted by Sander et al. in 2013 showed that access to the internet among 694 underserved patients in the United States was not the main barrier to uptake, but it was rather the participants' readiness for change. The authors maintained that their findings are "evidence that the digital divide extends beyond access" (318).

#### 3.4.2. The Second Level of the Digital Divide

In the early 2000s, analysts were commenting on other aspects of the digital divide, relating to how people use the internet and what benefit they get from it, rather than focusing on issues concerning access (e.g., Attewell, 2001; Castells, 2001; Warschauer, 2004). The digital divide was increasingly conceptualised as a "a multidimensional phenomenon" (Bruno et al., 2010, p. 27), and the definition expanded to include "the dynamics of socio-economic position, geographic location, ethnicity and language, as well as educational capacities and digital literacy" (Wessels, 2013, p. 23). Analysts considered digital inequality to be a consequence of different motivations, skills, use and opportunities (van Dijk, 2006), which has been described as the 'second level' of the digital divide (Muschert, Ragnedda, & Ruiu, 2018; Ragnedda, 2017).

Aspects of the second level of the digital divide have been demonstrated in research examining the uptake of patient portals. The opportunity to enrol in patient portals has been shown to have an inherent impact on its uptake; a survey of 3677 respondents in the United States found that while individuals who use and do not use portals fall along the lines traditionally defined as the digital divide, younger, more educated white adults are more frequently offered an invitation to access a patient portal and are therefore more likely to engage in this behaviour (Peacock et al., 2016). In New Zealand, there may an



inequity in the opportunity to use portals, as a low proportion of practices offer the service (see: NHITB, 2017), and on the NHITB website, Dr Dunning (2015) commented that her practice has a portal, but purposefully excludes anxious patients from enrolling.

Furthermore, health literacy can impact patients' perceptions (Dontje et al., 2014), uptake (Thompson et al., 2016; S. Smith et al., 2015), and use (Czaja et al., 2015; S. Smith et al., 2015; Tieu et al., 2016) of patient portals. Health literacy has been defined as, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services that are needed to make appropriate decisions" (Moore & Perry, 2013, p. vii). It is related to self-efficacy, which is an individual's belief in his or her ability to succeed in specific situations (Bohannon et al., 2013). Czaja et al. (2015) showed how health literacy can impact the usability of a patient portal, determining that most of their sample of 54 adults from underserved populations had difficulty completing tasks through a portal and needed assistance. The authors concluded that using portals is challenging for many adults, especially for those with low health literacy. Similarly, Tieu et al. (2016) examined the portal use of 23 patients and two caregivers and found that participants with limited health literacy required two additional minutes to complete each task and experienced more inaccuracies in interpreting a test result and finding a treatment plan, compared to participants with adequate health literacy. According to the Ministry of Health (2010b), over half of New Zealand's adult population is believed to have low health literacy, and this includes four out of five Māori males and three out of four Māori females (unfortunately, there are no available updates on these figures to date).

Additionally, there are patient portal adoption disparities by age, income, and race, as outlined at the beginning of this section, which could indicate that the portals may not reach those most in need. In one study, practitioners described patients not using a portal as: "as fearful, old, and having less social support" (Butler et al., 2013, p. 160). It is difficult to ascertain why these groups use portals less. It could be a mixture between access, opportunity, computer and health literacy, and motivation. It should be noted that using

the internet for health matters is also adopted less by elderly and lower socioeconomic groups (Hong & Cho, 2016; Kontos, Blake, Chou, & Prestin, 2014), and so the uptake of patient portals could reflect use of ICTs for healthcare.

### 3.4.3. The Third Level of the Digital Divide

The first and second levels of the digital divide are significant, because they can result in individuals experiencing unequal benefits from digital technologies, known as the ‘third level’ of the digital divide (Muschert et al., 2018; Van Deursen, Helsper, & Eynon, 2016). The digital divide has been described a kind of “virtuous cycle” of inequality (Wessels, 2013, p. 25), as those with fast access to the internet, good education and high socioeconomic backgrounds are in good positions to take advantage from digital technology, while those who lack access to these recourses are at a disadvantage. Accordingly, Castells (2001) argued that the digital divide “adds a fundamental cleavage to existing sources of inequality and social exclusion in a complex interaction” (p. 247).

For example, digital technologies can foster social inclusion (for users) by nurturing and assisting the formation of social connections, which can be a form of social capital (Muschert et al., 2018). Bourdieu (1986) related ‘good social capital’ to the amount of connections that each individual has and claimed that the assets gained from social ties is almost like a profit earned through the investment in these relationships. Applying Bourdieu’s (1986) ideas, connecting certain individuals who use digital technologies is one way that these technologies could help to privilege the privileged. This aligns to Castells’ (2001) view that digital exclusion is one of the most damaging forms of exclusion in society.

Furthermore, as the internet can provide users with a wealth of information, this can widen the ‘knowledge gap’ between certain sectors of society. The knowledge gap theory posits that when increased information is infused into a social system through mass media, “segments of the population with higher socioeconomic status tend to acquire this

information at a faster rate than the lower status segments, so that the gap in knowledge between these segments tends to increase” (Tichenor, Donohue, & Olien, 1970, p. 159). This theory was proposed in 1970, but it goes hand-in-hand with the concepts of the second and third level digital divides, as it suggests that simply measuring access or exposure to information does not adequately the social inequities within communities (Eastin, Cicchirillo, & Mabry, 2015). Significantly, Wei and Hindman (2011) determined that the differential use of the internet in finding information is associated with a greater knowledge gap than that of the traditional media from which the theory was developed.

Assisting patients to foster relationships and acquire knowledge are two key functions of the portals for patients. Research has associated the use of patient portals with enhanced patient-provider communication (e.g., Kruse, Bolton, & Freriks, 2015). It is promoted to patients as a way to access and control their health information, receive health related reminders, have a more active role in decisions in their healthcare, and improve their health outcomes (Medtech, 2017). Considering these reported benefits and the unequal in the adoption of portals in the past, it is hard to argue that the digital divide is not a concern when considering the NHITB’s target for the widespread implementation of patient portals across New Zealand. With the exception of patients that have someone else using portals on their behalf, every benefit promoted to patients would not be experienced by those featuring undesirably on the digital divide.

### 3.4.3. Final Thoughts Moving Forward

In this chapter, I offered suggestions from scholarship relating to the digital divide that may be applied to the patient portal initiative in New Zealand. S. Smith (2009) described digital inclusion for healthcare ICTs as “often a recruitment issue” (p. 533). While I am sure that there is more complexity to this, research has shown that healthcare practitioners have a strong influence on the uptake of patient portals (e.g., Sarkar et al., 2010; Wells, Rozenblum, Park, Dunn, & Bates, 2014). Correspondingly, analysts have

emphasised the need for strategies to monitor and reduce disparities in the use of patient portals (e.g., S. Smith et al., 2015; Wells et al., 2014). Unfortunately, research has also reported that this is not being undertaken in practice (e.g., Wells et al., 2014). It is difficult to say why this is the case; perhaps it reflects preconceptions by practitioners, or a deficiency in strategic planning. Significantly, the NHITB does not address the unequal uptake of patient portals or how to target higher risk groups in its publicly available documents. For example, there is no mention of these issues in the implementation guide by The Royal New Zealand College of General Practitioners in conjunction with the NHITB. In addition, research has emphasised the need to tailor the patient portal functions to meet users' needs (e.g., Zieth et al., 2014). Other than these points, I cannot offer other suggestions from the scholarship, as studies have tended to make an observation of an unequal uptake of portals, without providing solutions to counter it.

Returning to the New Zealand context, while all users could potentially benefit from patient portals, I have always been concerned about the possibility of an unequal uptake among patients, reflecting experiences overseas (e.g., Jhamb et al., 2015). The NHITB (2016) reported that in May 2016, 136,600 patients were registered with a patient portal service (NHITB, 2016). As there is no further available information about these patients, I wonder whether these people possess the education, access to resources, skills, and socioeconomic conditions that have been aligned with those on the 'desirable' end of the digital divide. I find it concerning that the NHITB does not directly address the potential unequal uptake of patient portals in promotional reports (e.g., The Royal New Zealand College of General Practitioners, & National Health IT Board, 2015). I can only offer speculation for the reasoning for this. At one extreme it could reflect a disregard of those most in need, who have less access to resources and higher rates of chronic illness (Ministry of Health, 2013b). However, I wonder if this, and the patient portals initiative as a whole, is rather a case of decision-makers projecting what they would benefit from onto others. As Showell and Turner (2013) stated:

Healthcare systems are developed by white, educated middle class professionals... This tendency to design for ourselves... results in patient instructions using complex language; patients receiving complex verbal descriptions of health issues using terminology; and the explicit assumption that online tools are an important and appropriate option for health service delivery. (p. 278)

Another consideration is that certain groups may not want to use digital technologies, including patient portals, which they may not view as beneficial. The digital divide seems to place a kind of deficit on those that do not use technology, who are framed as needing to change their behaviours for their benefit. As Wise (1997) stated in regard to questions of technology accessibility: “they reify whatever it is that we are to have access to as something central to our lives without which we would be destitute. They, therefore, redirect debate away from the technologies or services themselves” (p. 143). With this in mind, perhaps the question should not be how to create the conditions for portal use amongst disadvantaged groups, as using a patient portal to facilitate communication or information gathering may not be desired by these people. A more appropriate question could concern the needs of these people.

In closing, there seems to be an assumption that giving patients electronic access to information will lead to better outcomes. However, simply providing a patient portal is not enough to ensure its effective uptake and use (Czaja et al., 2015; Graetz et al., 2016). In this section I examined the three levels of digital divide. The first level concerns the distinction between those who do and do not have access to new forms of digital technology (Riggins & Dewan, 2005), while the second considers different motivations, skills, use and opportunities regarding these technologies (van Dijk, 2006). The third level of the digital divide concerns the inequality of the benefits received from digital technologies. For instance, if there is an unequal uptake of portals reflecting the digital divide, then this could potentially increase healthcare inequity. Even if a patient uses a portal, this does not mean that they can interpret the data in a meaningful way, as indicated by the low levels of health literacy in the general population (i.e., Ministry of Health, 2010).

In consideration to the documented challenges and the little scholarly research concerning portals in New Zealand, Gu and Orr (2015) urged that more research is conducted to address how patient portals will work and for whom.

### **3.5. EXPLANATORY MODELS**

Section 3.3 demonstrated the requirement for healthcare ICTs to address real needs. However, even when a technology can meet these needs and the audience has the means to access them, this does not mean that it will be adopted. Despite their potential benefits, healthcare ICTs have generally proven to be difficult to implement and adopt (Stokke, 2016). Similarly, a significant amount of scientific knowledge is unused, leading Berwick (2003) to question “Why do clinical systems not incorporate the finding of clinical science or copy ‘best known’ practices reliable, quickly and even gratefully into their daily work simply as a matter of course?” (p. 1969). To address the question of why some healthcare ICTs have been successful while others have not, it is useful to consider the theoretical models which endeavour to explain why individuals choose to engage in particular behaviours. Most pertinent to this discussion are the health belief model (i.e., Rosenstock, 1966; Becker & Rosenstock, 1984), the theory of planned behaviour (Ajzen, 1988), the diffusion of innovations model (i.e., E. Rogers, 1993) and the technology acceptance model (F. Davis, 1989). These theoretical models are dominant in scholarly literature, and they offer insight into why individuals might adopt a behaviour or use and engage with a particular technology.

The health belief model is one of the most widely recognised conceptual frameworks of health behaviour (Green & Murphy, 2014). It was originally developed by Rosenstock (1966), although it was later extended by Becker and Rosenstock (1984) and Rosenstock, Strecher and Becker (1988). As illustrated in Figure 3.1 on the following page, the model proposes that the severity of a perceived threat and the individual susceptibility to a particular health problem, motivates people to take action. However, the beliefs about

potential behaviours determine the specific plan of attack, such as the perceived benefits and barriers of taking a particular action. In 1988, Rosenstock, Strecher and Becker extended the model to add self-efficiency. As discussed by Hayden and Paterson (2014) the model proposes that even if an individual perceived benefit in a new behaviour, if this individual does not think that he or she is capable of doing it, then it is unlikely to be tried. The health belief model has been applied to a variety of health behaviours, such as smoking, dieting and exercise (Sheeran & Abraham, 1996), and it is significant for the patient portal initiative because scholars have shown how it can be used to explain the uptake of healthcare ICTs (e.g., Ahadzadeh, Ong & Khong, 2014; Kim & Park, 2012). For example, Ahadzadeh et al. (2014) determined that the perceived health risk and health consciousness positively influences health-related internet use.

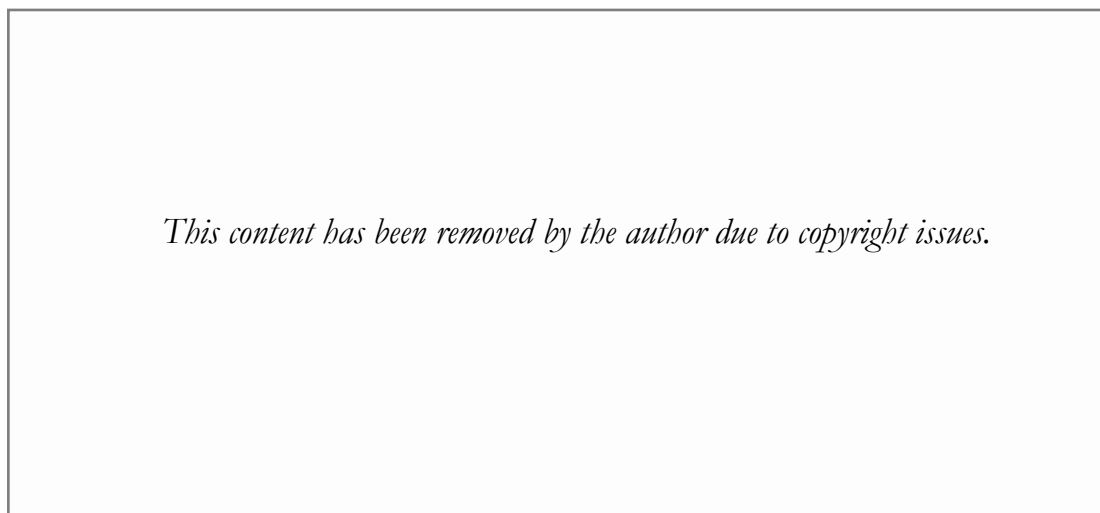


Figure 3.1: The Health Belief Model  
Retrieved from Berry (2006, p. 31)

The health belief model has been criticised on the grounds that there are no clear guidelines for the variables rules of combination, such as the links between perceived susceptibility, severity and overall threat perception (Sheeran & Abraham, 1996). However, some quantitative reviews have correlated the model's variables with behaviours. For instance, Janz and Becker (1984) determined that there is substantial empirical support for the model, although a meta-analysis by Harrison, Mullen and Green (1992) found only a weak correlation between the model and behaviours.

Explanation about why individuals adopt certain health behaviours can also be found in Azjen's (1988) theory of planned behaviour, which, like the health belief model, has served as the basis for many health ICT interventions (W. Riley et al., 2011). The theory of planned behaviour proposes that intentions should be conceptualised as plans of action in pursuit of behavioural goals (Azjen, 1988). The intentions result from three factors or beliefs, these being, the attitude towards the behaviour, subjective norms (including social norms and pressures) and perceived behavioural control or self-efficacy (Berry, 2006). This was demonstrated in a survey of 2,252 health practitioners by Kortteisto, Kaila, Komulainen, Mäntyranta and Rissanen (2010) which found that all three variables were associated with the participants' intention to use clinical practice guidelines for their area of specialisation. The model also acknowledges that perceived behavioural control can have a direct effect on behaviour itself (Berry, 2006). Since its development, several reviews have provided support for Azjen's model (e.g., Ajzen, 1991; Godin & Kok, 1996; Sheppard, Hartwick & Warshaw, 1988). This model is illustrated below.

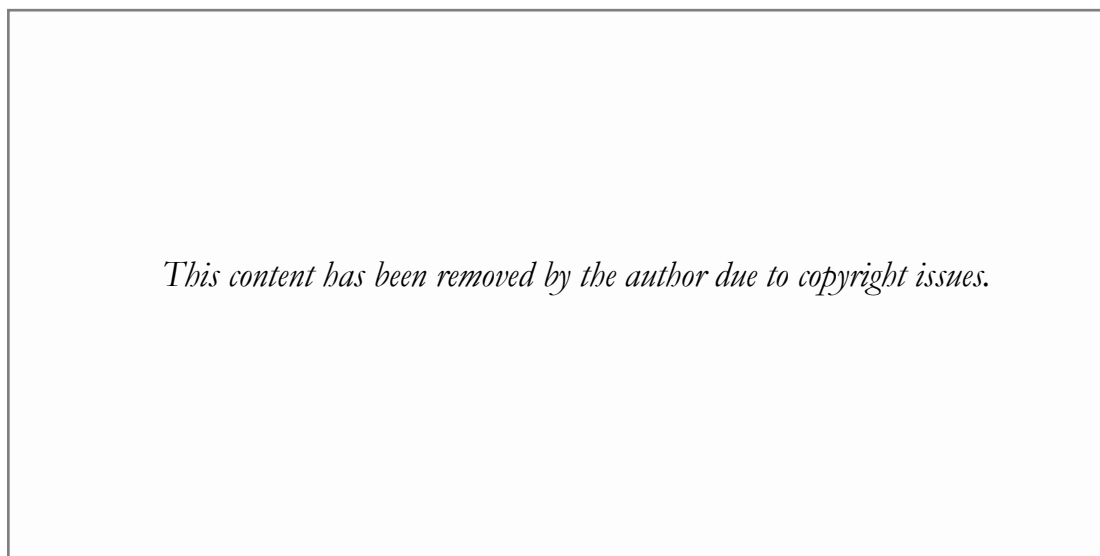


Figure 3.2: The Theory of Planned Behaviour Model  
Retrieved from Berry (2006, p. 33)

However, W. Riley et al. (2011) argued that the static, linear nature of these theories appears to poorly fit with the uptake of mobile technology interventions. Perhaps giving more depth to this topic, are the models that focus specifically on the uptake of



innovations. E. Rogers (1993) argued that while many technologists think that the benefits of new innovations will be realised and that it will therefore diffuse rapidly, most innovations diffuse at a surprisingly slow rate. In his text, 'The Diffusion of Innovations' which outlined his renowned model of the same name, he described diffusion as a form of social change where "an innovation is communicated through certain channels over time among the members of a social system" (E. Rogers, 1993, p. 5). In this definition the innovation is an idea, practice, or object that is perceived to be new, while the communication channels are the means by which information about the innovation is passed from individual to individual and interpersonal communication has a particularly high degree of influence. The influence of interpersonal communication was demonstrated in James Coleman, Katz and Menzel's (1966) study which revealed how doctors' willingness to prescribe an antibiotic was diffused through professional contacts. It is also arguably shown by doctors' endorsement of patient portals being related to patient uptake (e.g., Irizarry et al., 2015) and further that a lack of familiarity of the technology is an impediment to its use (e.g., Gagnon et al., 2016).

E. Rogers' (1993) model (illustrated on the following page) is framed in the context of time, where users are categorised by the time it took for their adoption. The first 2.5 percent are the innovators, the next 13.5 percent are the early adopters, followed by 34 percent as the early majority, then another 34 percent as the late majority, and the remaining 16 percent as the laggards. This is illustrated on the following page. By grouping these individuals, commonalities could be established. E. Rogers (1993) found that the early adopters tend to have a higher socioeconomic status, access to communication methods, upward mobility within their social culture, intelligence, and a capacity for embracing change. Aligning to this model, research has established that patients who use patient portals tend to have higher incomes (e.g., Tenforde et al., 2012) and health literacy (e.g., Tieu et al., 2016). Furthermore, the correlation between the diffusion of innovations model and the uptake of patient portals was shown in a survey by

Emani et al. (2012) which applied a statistical analysis to group 760 participants into Rogers' five categories. It found that the non-adopters reported a lower score on personal innovativeness in information technology and it verified that the ease of use, relative advantage, observability, and trialability influences their uptake.

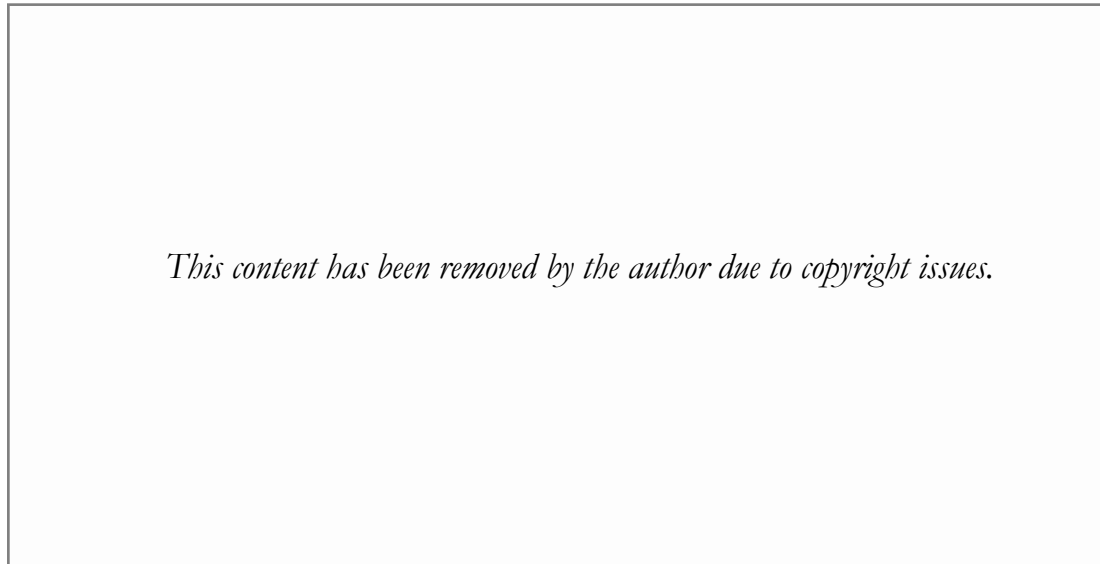


Figure 3.3: The Diffusion of Innovations Model  
Retrieved from E. Rogers (1993, p. 95)

Addressing the question of what makes an innovation more likely to be adopted, E. Rogers (1993) outlined five attributes. The first is its relative advantage, that is an individual's perception that the innovation will be better or worse than similar ideas. This was highlighted by Nazi (2013) as influencing healthcare practitioners' use of patient portals. The second is the compatibility which is the perception that a particular innovation is similar and congruent with existing understandings of similar and past ideas. For instance, ICTs are not popular among older people, in part because they have difficulty in appreciating their potential benefits (Kapadia et al., 2015). The third is the complexity, or how difficult it is to comprehend the innovation and accordingly, various studies have found that the uptake of patient portals is influenced by its ease of use (e.g., Gagnon et al., 2016; Collins et al., 2016; Irizarry et al., 2015). E. Rogers' forth attribute is the trialability which refers to the accessibility of an innovation to an individual for experimentation, and the last is the observability, characterised by how available and visible an innovation is to an

individual. For example, individuals who do not have access to the internet, are less likely to use a patient portal (Emani et al., 2012).

E. Rogers (1993) theory has some alignment with F. Davis' (1989) technology acceptance model. This model suggested that when users are presented with a new technology, individuals' decisions about how and when they will use it is influenced by the perceived usefulness of the technology. That is, "the degree to which a person believes that using a particular system would enhance his or her job performance" (Davis, 1989, p. 320), as well as the perceived ease of use, that is "the degree to which a person believes that using a particular system would be free of effort" (p. 320). F. Davis' (1989) technology acceptance model is illustrated below.

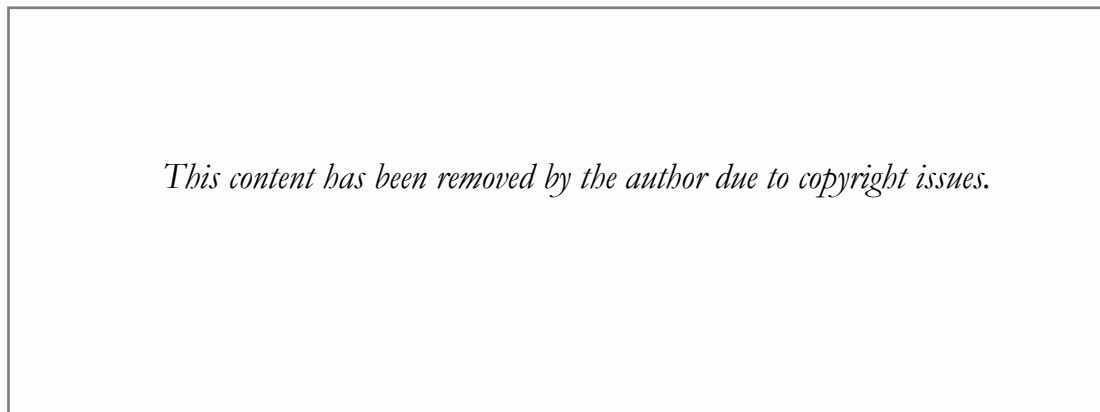


Figure 3.4: The Technology Acceptance Model  
Retrieved from Al-Suqri and Al-Kharusi, (2015, p. 193)

In summary, there are various theories which offer insight into why and when an individual may adopt a particular behaviour (Anderson, 1996). E. Rogers' diffusion of innovations theory provides particular insight into uptake of innovations over time, who is engaged in the uptake, as well as the innovation's characteristics. This may provide some explanation into the implementation of patient portals, as many of the theory's principles align with the documented challenges of their implementation to date.

### **3.6. SUMMARY**

Patient portals are one example of the many ICTs adopted in the healthcare arena. It is necessary to broadly consider these technologies as a whole, in part because patient portals provide a number of functions which overlap with other ICTs, but also because they give an insight into the wider healthcare climate. The purpose of this chapter was to scope the potential benefits of these technologies, some of the challenges experienced with the implementation, and the critical issues surrounding them. It started with a brief introduction, before discussing issues concerning the governance of personal health information in an age where health records are increasingly digital. It then went on to explore theories relating to how computer-mediated communication mediums alter social interaction, which was related to the literature concerning healthcare ICTs. The next three sections were focused on different topics about the uptake of technology, providing insight into why an individual or an organisation may or may not choose to use a healthcare ICT. Section 3.3 explored why ICTs have often been difficult to implement, section 3.4 examined the unequal uptake of the internet and healthcare ICTs, and finally section 3.4 outlined some relevant, explanatory theoretical models. Many of the topics in this chapter are relevant when considering the ICTs used in the New Zealand healthcare sector, which is discussed in the following chapter.

**SCREENSHOTS OF FOUR PATIENT PORTALS IN NEW ZEALAND<sup>9</sup>**

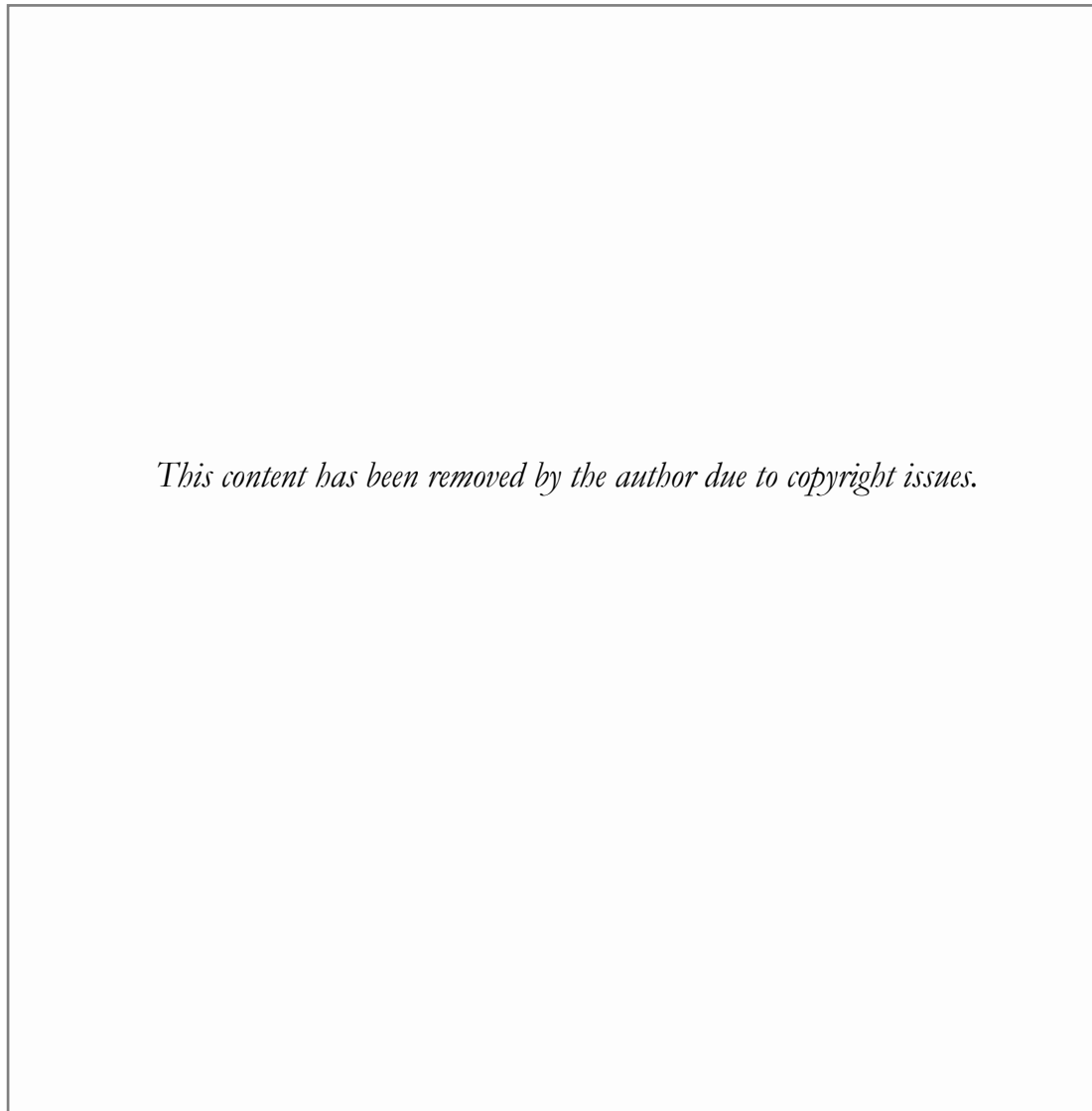


Figure 4.1: Screenshots of Four Patient Portals in New Zealand

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<sup>9</sup> Please turn to Appendix A on page 307 to see larger views of these screenshots

## **4: ICTs CLOSER TO HOME: NEW ZEALAND'S EXPERIENCE**

On the facing page are screenshots of the websites for four patient portals, which, at the time of writing, were those most commonly used in New Zealand (R. Brown, 2017). Patient portals are widespread, albeit not to the degree originally targeted by the National Health IT Board (NHITB) in 2014. The portal websites make a number of claims about portals: for instance, that portals allow patients to control their health information (ConnectMed, 2016) and manage their health and wellness (Medtech, 2016), and “reduce the day-to-day hassle of practicing healthcare, without compromising on quality” (MyPractice, 2017, para. 2). Within the scope of my research, I cannot definitively state the impact of the portals for every practice or individual patient, especially given that the use can vary significantly. For example, in September 2014, it was reported that only 80 healthcare practices allowed patients to access their medical records (Hurdleby, 2014), even though 96 practices offered patient portals at that time (NHITB, 2016). However, insight into this matter can be found by

examining the portals' broader context in New Zealand, including its history and the reported issues surrounding it.

The patient portal websites captured on page 75 indicate that there are two target markets: the patients and healthcare providers. Portals are framed as being for one purpose for patients (to improve communication with their healthcare providers and to provide information), and another for healthcare providers (to improve organisational efficiency) and the benefits suggested in the promotional messages on page 75 bear some similarity to the benefits suggested overseas, another words, it is thought that patient satisfaction (e.g., Haun et al., 2014; Kelly et al., 2016), and improve organisational processes (e.g., Cochran et al., 2015; Druss et al., 2014) will be improved. Wynia and Dunn (2010) critiqued the kind of messaging depicted on the patient portal websites on page 75, arguing that when a tool is claimed to both improve quality and reduce costs, users could believe that the “real” (p. 69) motivation is cost-savings rather than quality improvement, which could, in turn, hinder trust, cooperation, and, ultimately, adoption.

It may be, however, that the drawbacks Wynia and Dunn (2010) have delineated are endemic to patient portals, which have diverse functions that could service different purposes. The uptake of portals in New Zealand can be attributed, at least in part, to government-sponsored initiatives. The portals featured as an initiative in the updated New Zealand Health IT Plan (2013b), and the NHITB has promoted their uptake. Like other healthcare ICTs, the implementation of patient portals is complicated by a variety of political and sociotechnical barriers (Greenhalgh et al., 2008; Prey et al., 2016), including attitudes towards the technology (Greenhalgh et al., 2008), and, more broadly, whether it is part of a nation-wide patient portal strategy (Prey et al., 2016). In this chapter I discuss issues arising from the patient portals that are specific to the social and cultural contexts of New Zealand. In section 4.1, I provide a background to the New

*This content has been removed by the author due to copyright issues.*

Figure 4.2: The Structure of the New Zealand Health and Disability Sector  
Retrieved from the Ministry of Health (2016b)



Zealand healthcare sector, before I discuss the initiatives undertaken by the NHITB in section 4.2 and describe the promotion and implementation of the portals in section 4.3. In section 4.4, I investigate the implications of the introduction of patient portals and similar technologies for Māori. Finally, in section 4.5, I address questions and concerns that have been commonly raised about the patient portals since the commencement of my doctoral research.

#### **4.1. NEW ZEALAND HEALTHCARE IN CONTEXT**

To appreciate the patient portal initiative in New Zealand, it is necessary to have a basic understanding of the healthcare sector, and the key challenges it faces. The New Zealand healthcare sector has been described as a “complex system, working together” (Ministry of Health, 2016a, para. 1). As outlined in Figure 5.1, the Minister of Health provides leadership and develops policy for the health and disability sector. The district health boards administer about three quarters of the funding, and they plan, manage, provide and purchase health services for their district’s population. The Ministry of Health is the principal advisor to the Minister and it funds various national services and has a number of regulatory functions. Public health units, primary health organisations, non-government organisations, Crown entities, health professionals, and professional and regulatory bodies have important roles in providing services and ensuring efficiency and quality. This structure is illustrated in Figure 5.1 on the facing page.

The New Zealand healthcare sector has, like other developed nations, an ageing population and rising rates of chronic disease (OECD, 2016), which the elaborate structure has been designed to address. While New Zealand was ranked in a top third among the OECD countries for its low smoking rates, it was a bottom third performer for obesity rates among the population in 2014 (OECD, 2015). In that year, it was ranked as a middle third performer for cancer survival, but in the bottom third for

diabetes, asthma and hospital admission from chronic obstructive pulmonary disease (OECD, 2015). In 2015, there were 3.0 practicing doctors and 10.3 practicing nurses for every 1000 inhabitants, and 9.4 percent of the nation's gross domestic product was spent on healthcare (OECD, 2016). The Ministry of Health (2016c) has said that the cost of providing health services in New Zealand will be unsustainable in the long term unless there are changes in the way that services are funded and delivered.

It is against this backdrop that the patient portal initiative began. There are various factors that allowed New Zealand to make progress in the development of ICTs in the healthcare sector included the single tier of government, clinical leadership, collaboration amongst stakeholders in the public and private sectors, and national leadership from groups like the NHITB (Bowden & Coiera, 2013). There is little doubt, that the challenges facing the healthcare sector contributed to the kind of thinking that assisted in the push toward ICTs. The NHITB's (2010) initial IT plan listed drivers of rising costs in the healthcare sector, and then stated, "It is clear that health IT solutions can and will play a significant part in supporting, enabling and in some cases creating sustainable health care solutions for the future" (p. 14). This was reinforced in the NHITB's (2013) updated plan which stated, "Improvements in productivity and patient safety through the use of information systems are essential for achieving the long-term sustainability of the health system" (p. viii). The Ministry of Health has said that when doctors and patients have easier access to health information, this leads to "Better, safer health care, closer to home" (p. 2), which, they argued, is advantageous for managing a scarcity of resources and for catering for patients who progressively require longer durations of medical support.

The Ministry's assertion is perhaps too optimistic in that it gives the impression that universal success will be the outcome of implementation. While the portals could be successful for some patients, common sense suggests there will be others from

whom the portals are frustrating, difficult to use, and, offer limited and therefore, inadequate communication. My opinion is that the portals are a technology that could have an immense future providing that implementation and marketing match the overall capability of the technology. In other words, at the moment potential outstripped performance, but it would not take much to baleen that inequality. However, here, one needs to be careful of how one measures ‘success’ because if even a single life is improved by the portals that must be counted as a success.

The implementation of ICTs into the healthcare sector impacts the health workforce, which is experiencing its own challenges. Reflecting the general population, New Zealand’s health workforce is ageing (Ministry of Health, 2016f). For example, the proportion of medical doctors aged fifty or over rose from thirty-four percent in 2009 to forty percent in 2014 (Ministry of Health, 2016f). This meant that largest age group of doctors in 2014 was between fifty and fifty-four, which increased from being in the forty-five and forty-nine age brackets in 2009 (Ministry of Health, 2016f). This could affect the level of acceptance of ICTs, given that older adults have had a lower uptake of patient portals (Peacock et al., 2016; Ronda et al., 2015), and of the internet for health matters (Hong & Cho, 2016; Kontos et al., 2014), which may signal that they are less receptive to ICT.

New Zealand’s health workforce has a high dependence on internationally recruited professionals. In 2015, New Zealand had the second highest proportion of doctors trained overseas of the OECD countries, at 42.6 percent, and the highest proportion of nurses trained overseas, at 24.5 percent (OECD, 2016). Although recruiting medical staff overseas can serve as a quick and relatively low-cost fix for health-worker shortages (Buchan, Naccarella, & Brooks, 2011), it raises ethical concerns of out-migrating of skilled health workers, often from the developing world. New Zealand’s population is also becoming increasingly diverse. In 2013, 25.2 percent of

Table 4.1: The Uptake of the Internet by Individual Characteristic in 2012

Individual characteristic	Total number of individuals	Individuals with internet access at home	Individuals who are recent internet users
	(000)	Percentage of all individuals	
<b>All individuals</b>	<b>3,454</b>	<b>83</b>	<b>82</b>
<b>Sex</b>			
Male	1,677	84	81
Female	1,776	83	82
<b>Age group (years)</b>			
15–24	620	85	93
25–34	566	88	94
35–44	584	89	91
45–54	612	87	85
55–64	496	86	77
65–74	339	76	61
75+	237	52	32
<b>Highest qualification</b>			
Not tertiary level	1,623	76	72
Tertiary level	1,831	90	91
<b>Employment</b>			
Not employed	1,300	73	68
Employed	2,154	90	90
<b>Ethnic group<sup>(4)</sup></b>			
European	2,320	86	84
Māori	438	68	77
Pacific peoples	182	65	62
Other ethnicity	514	92	84
<b>Annual personal income (\$)</b>			
Loss	6	88	85
under 10,000	480	84	88
10,001–20,000	764	71	63
20,001–30,000	601	79	75
30,001–40,000	377	85	85
40,001–50,000	316	89	89
50,001–60,000	260	92	93
60,001–70,000	197	94	94
70,001–80,000	79	95	97
80,001–90,000	89	96	95
90,001–100,000	87	95	95
100,001 or more	196	96	96

Retrieved from Statistics New Zealand (2014b)

people were born overseas which increased from 22.9 percent in 2006 (Statistics New Zealand, 2014a). From a communication perspective, this could impact the interaction between patients and healthcare practitioners, as cultural influences permeate values, practices, and govern how people conduct themselves in interpersonal communication (Berry, 2006) including nonverbal communication cues, such as gestures, gaze and interpersonal space (Matsumoto, 2006). It can also alter perceptions and beliefs about health and illness (Bakić-Mirić, 2011). Furthermore, J. Martin and Nakayama (2010) argued that the absence of nonverbal cues in mediated contexts can make communication more difficult and can lead to misunderstandings, and that this can be compounded when communicating across cultures.

I cannot say with certainty whether patient portals will help address the challenges experienced by the healthcare sector, and how they will be received. As I discuss in section 4.2, it has been reported that New Zealand has had a high uptake of ICTs in the healthcare sector in the past (Didham et al., 2004; Jha, Doolan, Grandt & Bates, 2008; Schoen et al., 2009). The general population has a high internet uptake, reported at 88.2 percent in 2014 by The World Bank (2017). The most extensive study on the internet use in New Zealand to date is the 2012 Household Use of ICT Survey by Statistics New Zealand (2014b) which surveyed 13,046 households and found that 83 percent had access to the internet at their homes, and 82 percent of participants were recent users<sup>10</sup>. However, as outlined on the facing page, the proportion of recent internet users varied depending on the level of education (only 72 percent of participants with no tertiary level qualifications), employment (68 percent of participants who were unemployed), and income (63 percent of participants with between \$10,001 and \$20,000 annual

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<sup>10</sup> Recent users were those who used the internet in the 12 months prior to the survey being undertaken.

**Table 4.2: Some ICTs Recently Introduced into the New Zealand Health Sector**

<b>Name</b>	<b>Description</b>
Beam	A remote-controlled screen on wheels used for video conferencing for the Ministry of Health (Moir, 2017).
Care Insight	An information sharing portal used to view patient information from practices by after-hours providers and emergency departments in Northland, Hawke's Bay, Tairāwhiti, and Nelson-Marlborough (Nursing Review, 2014).
ePrescription	Provides a secure messaging channel for prescribing and dispensing systems to exchange prescription information electronically (NHITB, 2016a).
eReferrals	A system of electronically referring patients for treatment (Ministry of Health, 2013).
Health One	Formerly known as electronic Shared Care Record View (eSCRv), this is the Canterbury and West Coast shared care record platform for health professionals to view relevant patient information shared by public hospitals, community pharmacies, and general practices. As of 2014, it had 118 general practices and 106 pharmacies contributing data, as well as hospital-held data, and it could be accessed by 5000 doctors, nurses, and pharmacists (Nursing Review, 2014).
Health Kiosk	Allows patients to self-register at a hospital and have their height, weight, BMI, blood pressure, pulse and oxygen saturation measured electronically and was introduced to Thames Hospital in November 2014 (McDonald, 2014).
GP2GP	Enables medical records to be electronically transferred from one GP to another (Patients First, n.d.).
Inviga	A telehealth management program which offers remote monitoring of vital signs. It includes a response service from hospital to home and 7-day support program to link person to pharmacy, GP, outpatients and support programs (Inviga, 2016)
Listen Please app	An application which allows doctors to ask simple questions that would be covered in a standard consultation (National Health IT Board, 2014b)
MedChart Computers on Wheels	A portable electronic med-chart which replaces the traditional clipboard at the end of hospital beds and is now used at various hospitals in New Zealand (Ashby-Coventry, 2015)
National EHR	A national health record that provides electronic access to patient information (NHITB, 2015d).
Plunket's ePHR	An electronic record that captures children's health records digitally (Plunket, 2017).
Preventative Health IT Platform	Captures information relating to current and future population screening programmes for individuals (NHITB, 2015d).
Shared Care Record	A single shared care record developed by the patient and their health providers, which stores historical health information as well as problems, goals, actions, timeframes and accountabilities for the patient's future care (NHITB, 2013a).
TeleDOT Foundation Project	Allows TB patients to undergo directly observed therapy (DOT) in the Auckland region through a software downloaded onto their computers (NHITB, 2014a)
Virtual DHB	An application that allows patients to have virtual consultations in the Waikato region (Waikato District Health Board, 2016).
vMoko	An initiative that uses mobile technology to remotely diagnose and treat skin conditions in schools in the Far North (NHITB, 2015c).

personal income)<sup>11</sup>. This does raise the questions about whether the uptake of ICTs like patient portals will be equitable.

#### **4.2. NEW ZEALAND'S NATIONAL HEALTH IT PLANS**

Since the commencement of this doctoral research project in 2014, several ICTs have been launched into the New Zealand healthcare sector. Thames Hospital introduced a Health Kiosk that allows patients to self-register and have their blood pressure and other indicative measures taken and recorded electronically (McDonald, 2014), Kaitia Hospital implemented a system so that their neonatal patients can be viewed from Whangarei Hospital via real-time video (NHITB, 2015d), and many hospitals replaced the traditional clipboards at the end of patients' beds with MedChart Computers on Wheels (Ashby-Coventry, 2015). In this time, technologies have allowed patients to undergo health consultations from a distance; 'vMOKO' allows doctors to remotely diagnose and treat skin conditions in schools in the Far North (NHITB, 2015e) and the Auckland TeleDOT Project observes tuberculosis and prescribes therapy directly from their computers (NHITB, 2014f). In addition, smartphone applications are now helping New Zealanders to make everyday decisions about their healthcare, such as the 'Self-Management Support for Blood Glucose' application for individuals with diabetes (Dobson et al., 2015), and the SaltSwitch application which helps users make more informed decisions about their diet (Eyles et al., 2014). These examples show how technology is changing healthcare delivery, and they are outlined in more detail in Table 4.2 on the facing page.

Most of these technologies were supported by grants from the Ministry appointed NHITB. Since its formation in 2009, the NHITB has led the development of major

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<sup>11</sup> There was also an ethnic divide in terms of the internet uptake and use which is discussed in section 4.4.

national ICT projects in the health and disability sector. The NHITB Chair Dr Murray Milner stated that "... well-designed information technology solutions help us work smarter to reduce costs, improve efficiency and give patients better, safer treatment" (NHITB, 2013, p. iii). As Gaddi and Capello (2014) discussed, this is not an isolated viewpoint, as there is a widespread belief that ICTs will play a vital role in shaping healthcare systems in the twenty-first century and will contribute to providing safer, higher quality healthcare in an environment facing increasing pressures. According to the European Commission (2012), aspects of these technologies could also deliver more personalised, citizen-centred healthcare, and Milner similarly claimed that "[these] solutions enable us to integrate services across hospitals and communities to put consumers' needs at the centre of how care is provided" (NHITB, 2013, p. iii).

Dr Milner also stated, "The feedback I am getting is that New Zealand is up there with world leaders when it comes to having a good road map for the sector's use of IT" (NHITB, 2013, p. iii). Indeed, New Zealand has been cited as a world leader in its uptake of IT within a healthcare setting in the past (e.g., Didham et al., 2004; Jha et al., 2008; Schoen et al., 2009). Schoen and Osborn (2009) compared healthcare IT systems in eleven developed nations and found New Zealand to have the highest use of electronic medical records by general practitioners. In 2004, 99% of New Zealand health practices used a computerised patient management system (Didham et al., 2004). In spite of this, New Zealand experienced challenges in the coordination of national IT projects spanning an 18-year period.

The first ministerial strategy for health IT was issued in 1991, in response to growing issues in the provision of relevant, timely, and accurate health information (Ministry of Health, 1991). Its proposals were disrupted by the marketisation of the health sector in 1993, which caused IT projects to be disjointed, amplifying many of the original problems highlighted (Gauld, 2004). In 1996 a second ministerial strategy



**Table 4.3: Timeline of the Healthcare ICT Developments Prior to the NHITB**

<b>Year &amp; Name</b>	<b>Description</b>
1991 – First Ministerial Strategy for Health IT	This strategy cited significant issues with health IT including: the uncoordinated, multiplicity of overlapping collections of information; the loss of patient confidentiality; the poorly maintained National Master Patient Index; and the lack of consistency in interpretation of definitions, among many other concerns (Ministry of Health, 1991). It recommended merging all health information activities of the Department of Health under one establishment; including the Health Statistical Services, the Health Research Services, and the Information Management Strategy (Ministry of Health, 1991). It was largely disrupted by the marketisation of the health sector in 1993. Although the newly formed New Zealand Health Information Service commenced health IT projects such as establishing a new National Health Index, with the competitive system in place, information collection and management was further disjointed across agencies, amplifying many of the problems originally identified (Gauld, 2004).
1996 - Second Ministerial Strategy for Health IT	This strategy acknowledged that while progress had been made, there continued to be serious issues with IT fragmentation, a lack of agreement about information access and issues of privacy protection, among many other concerns (Ministry of Health, 1996). It recommended the formation of a Health Information Council to act in an advisory role and a Health Information Advisory Board to be responsible for operational developments to assist in the development of health IT (Ministry of Health, 1996). However, there was another health sector restructuring, where the four regional health authorities were centralised into the Health Funding Authority, responsible for national planning; essentially suspending many of the developments by the Health Information Council (Gauld, 2004).
1999 – Health Funding Authority Strategy	The subsequent Health Funding Authority Strategy issued in 1999 continued to emphasise the need to coordinate NHI use, formalise management of data collection and key health databases (Gauld, 2004).
2001 – Working to Add Value to E-information Report	In 2000, the Director-General of Health appointed an Advisory Board to develop an 'Information Management and Technology plan', which was renamed Working to Add Value to E-information (WAVE) in 2001 (WAVE Advisory Board, 2001). The WAVE project discussed similar concerns raised in past reports such as IT fragmentation of health information systems and a lack of coordination. It listed seventy-nine recommendations including the establishment of two independent central organisations (WAVE Advisory Board, 2001). The WAVE report was only intended to give broad recommendations and was not a plan of action (WAVE Advisory Board, 2001). However, when the WAVE Report was published, the Ministry considered that the sector was not in a position to prepare a detailed plan for implementing the recommendations (Controller and Auditor General, 2006). Subsequently there were difficulties surrounding the effectiveness of leadership and progress was slower than anticipated (Controller and Auditor General, 2006).
2009 – Ministerial Review Group Report	This was a comprehensive report of the New Zealand health sector, with 170 recommendations. It cited a number of issues hindering the development in health IT, including insufficient national leadership, changes in policy settings, a lack of alignment, and funding deficiencies. It found that multiple IT health systems did not easily connect with one another which neglected the fact that people often have multiple conditions needing treatment and future initiatives needed to be patient-centred.

acknowledged that although some progress had been made, such as establishing a new National Health Index, there were still serious gaps and problems, such as in fragmentation, conflicts around information access and problems with privacy protection (Ministry of Health, 1996). This second ministerial strategy also failed. It was disrupted by a restructuring of the health sector and concerns similar to those in the second ministerial strategy were raised in the subsequent Health Funding Authority Strategy in 1999 (Gauld, 2004). In 2001 an advisory board published the Working to Add Value to E-information report, which also discussed similar concerns and listed 79 recommendations (WAVE Advisory Board, 2001). However, the Ministry considered that the sector was not in a position to prepare a detailed plan for implementing their recommendations, and progress was slower than anticipated (Controller and Auditor General, 2006). In 2005 the Health Information Strategy for New Zealand set new goals over a three to five-year period, but once more, little progress was made (Ministerial Review Group, 2009). These developments are outlined in more detail in Table 4.3 on the facing page.

In 2009 the Ministerial Review Group reflected on the state of affairs, stating, “Our position as a world leader in many areas of health IT... is slipping... The sector, including the Ministry, is struggling to cope with a myriad of IT projects” (p. 39). They argued that each health IT strategy had resulted in more systems which did not easily connect with one another and had neglected the fact that people often have multiple conditions requiring treatment, and consequently, future initiatives needed to be more patient-centred. They discussed a number of issues which had hindered the sufficient development of health IT, including inadequate national leadership, a lack of alignment, and funding deficiencies.

In response to the Ministerial Review Group’s recommendations, Cabinet established the National Health Board in October 2009, which contained a business unit within the Ministry of Health, and a Ministerial appointed board (National Health Board, 2010). As a subcommittee of the appointed National Health Board, the newly established NHITB replaced the Health Information Strategy Advisory Committee to provide strategic

leadership on healthcare IT (NHITB, 2014b), as well as the Capital Investment Committee which allocated national health capital funding (National Health Board, 2010). There was little reported opposition to this change, except for an editorial by Fountain (2011) which questioned the NHITB's ability to make progress with the various stakeholders involved in the healthcare sector, stating, "The National Health IT Board sounds like a grand idea... but what sway does it have with disparate DHB IT folk and a primary sector dominated by private providers?" (para. 12). Figure 4.3 below illustrates the structure of NHITB in relation to the National Health Board.

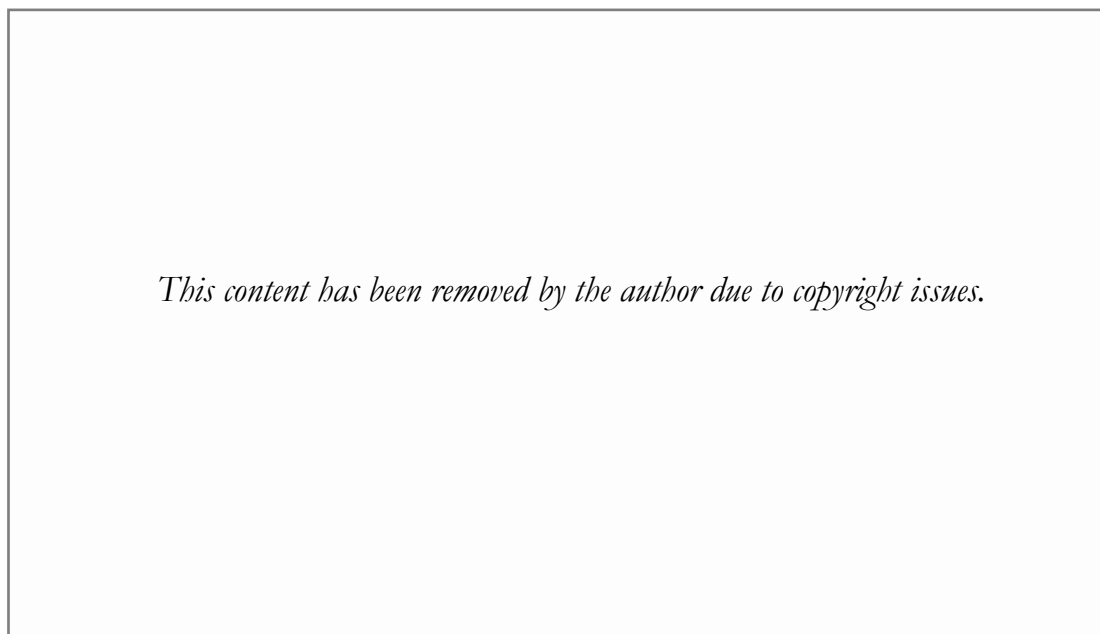


Figure 4.3: The Structure of the Ministry of Health and Associated Entities  
Retrieved from the National Health Board (2010, p. 2)

Most of the NHITB board members had a medical or a health administration background, which the NHITB director, Graeme Osborne said was a strategy to get doctors to "design the health system the way that they want it to operate" (Riley, 2014, para. 27). In 2010 the NHITB published their first National Health IT Plan, which set priorities for regional and national IT investments over a five-year period. As Osborne discussed in the Foreword of the report the successful implementation of the plan would help to attain "person-centred" healthcare, as it would take away the barrier of patients' information being held across separate locations (NHITB, 2010). This phrase is significant

in planning for portals: it is a clear differentiation between illness-centred and person-centred, and between doctor-centred and patient-centred medicine. The plan's vision was: "To achieve high-quality health care and improve patient safety, by 2014 New Zealanders will have a core set of personal health information available electronically to them and their treatment providers regardless of the setting as they access health services" (NHITB, 2010, p. 5).

The first phase of the plan aimed to increase healthcare organisations' consistency in health IT with aspects such as the access and transfer of health information between organisations, the primary health care practice management systems, and the systems managing patient, practitioner and organisation identity. The second phase endeavoured to deliver shared care planning for ongoing health management that is supported by a single shared care record developed by the patient and their health providers, which stores historical health information as well as problems, goals, actions, timeframes and accountabilities for the patient's future care. To assist in achieving this goal, the National Health Shared Care Plan Programme (2011) was established in partnership with the NHITB and the Auckland Regional District Health Boards in 2010 to trial a shared care programme in various health care practices within Auckland.

The 2013 update to the National Health IT Plan raised concerns that the underpinning vision required a stronger focus. It claimed that there were three main challenges to fast progress, namely that regional decision-making and leadership needed reinforcement; that funding needed to be 'freed up', and that professionalism in project delivery and support required improvement (NHITB, 2013). The updated plan also reported major achievements that had been made, including the formation of various working groups such as the Consumer Panel and the National Information Clinical Leadership Group. This is illustrated in Figure 4.4 on the following page.

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Figure 4.4: The Governance and Delivery of the National Health IT Plan  
Retrieved from the NHITB (2013a, p. 25)

Significantly, the updated report focused on patient portals, which were mentioned only once in the initial plan as a “supported” initiative (NHITB, 2010, p. 49). It is unclear why the NHITB turned their attention towards the portals, although the plan had a stronger emphasis on the active engagement of patients so that they can make more of their own decisions in healthcare. This was associated with a financial benefit to the health sector, as shown in the following statement:

...People who feel able to make decisions about their health care often end up choosing lower-intervention and lower-cost options compared with the decisions often made by doctors in traditional health care settings... to do this, patients and consumers need reliable access to their health information and to understand the various clinical options available to them. (NHITB, 2013a, p. 4)

In spite of the aspirations in the quote above, the patient portals were part of a new ‘tree diagram’ in the report which outlined how an individual’s health information would be collected during their continuum of care. In this diagram, approximately 10 percent of the population in the illness branch would have an electronic shared care record, while the

remaining population in the wellness branch would have access to a set of personal health information through a patient portal (NHITB, 2013a). It was then that the NHITB set a target of having fifty percent of general healthcare practices offering a patient portal by the end of 2014, which was reported in various media articles (e.g., Newlove, 2014; Carville, 2014, para. 1).

In the same year as the NHITB's (2013a) updated plan, the National Institute for Health Information published their report evaluating the National Shared Care Plan Programme trail which started in 2010. It found that there were low participant numbers and among the users, few used the system anywhere near to its full capability (National Institute for Health Innovation [NIHI], 2013). It identified various issues which required attention, including poor alignment and clarity of the overall strategy and an insufficient involvement of patients and families (NIHI, 2013). Another challenge identified was health practitioners' confusion of the target patient cohort as, "it has proven difficult for some to accept that it [the shared care programme] has the potential to serve the entire population, in the provision of case management and the use of a patient portal" (NIHI, 2013, p. 3). The NHITB, therefore, was receiving conflicting messages who differentiated between the individuals who would have a share care plan from those who would use a patient portal, while the National Institute for Health Information's (2013) report suggested that these groups could essentially be combined.

To date, the NHITB's initiatives have received mixed responses. In July 2012, media outlets reported on an open letter from HealthLink chief executive Tom Bowden which called for an independent review of the sector IT strategy claiming that the NHITB was managing IT projects rather than encouraging innovation, and that it "has expended considerable resources in this area and some four years on we have yet to see much in the way of material progress" (Jackson, 2012, para. 9). Conversely, Bowden and Coiera (2013) praised the NHITB's efforts, claiming that they encourage convergence on the best available options, without restricting choice or interfering with market dynamics, by issuing

comparisons and reviews of competing products and services and letting purchasers decide which solutions best fit their needs.

In April 2016, the NHITB held its last meeting, as it was disbanded and essentially replaced by the Digital Advisory Board, following a major restructure of the Ministry of Health (R. Brown, 2016). The precise reason why this change took place is unknown (R. Brown, 2016), particularly given that a report commissioned by the Ministry of Health in 2015 recommended that the National Health IT Board remain in place (Suckling, Connolly, Mueller, & Russell, 2015). The Digital Health 2020 strategy is focused on achieving five core components<sup>12</sup>, which does not include patient portals, although it is listed on the as an initiative supported by the Ministry of Health (2017b).

#### **4.3. THE PATIENT PORTAL INITIATIVE IN NEW ZEALAND**

Since 2013, the NHITB has encouraged primary healthcare practices to implement patient portals by including promotional material in their general documents, through the Primary Health Organisations, and more recently with an advertising campaign targeting patients and healthcare providers (Johnathan Coleman, 2015). The NHITB (2014a) has outlined various benefits from the patient portals, such as reducing the administrative burden for healthcare practices and increasing patients' awareness and ability to manage their health conditions. Despite these efforts, uptake of the portals has been slower than anticipated and desired.

The initial approach taken by the NHITB to encourage the uptake of patient portals among primary healthcare practices was one of promotion rather than direct funding and regulation, based on the idea that the sector would respond to the increased demand and self-fund the services (Patients First, 2014). The cost of the patient portal software has been reported to be between \$1,500 to \$4,500 in 2014 depending on the vendor and

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<sup>12</sup> The strategy is to take place between 2016 and 2020 and it is focused on: a single electronic health record; health and wellness dataset to support evidence-based decisions; a preventative health IT capability to support and improve the targeting of screening, immunisation and other public health initiatives; digital hospitals; and regional IT foundations.

practice size (Hudleby, 2014), but this on its own is not meaningful as it does not include the cost for the ongoing maintenance and annual licencing. The NHITB's aim was to increase the proportion of general practices offering patient portals to fifty percent by the end of 2014 (Carville, 2014; Newlove, 2014). Accordingly, from 2013 the NHITB's promotion of and interest in patient portals seemed to accelerate. A newsletter published in May had the headline "Patient portals: the way of the future" (NHITB, 2013b) and the first issue of 2014 opened with "The year of the portal" (NHITB, 2014c). In February 2014, the NHITB (2014d) elected seven doctors with experience using patient portals as eHealth ambassadors to assist in the uptake of patient portals through the dissemination of their experiences and advice in using the technology. However, from an early stage there were signs that the uptake of portals would not be as high as desired. In a conference held in December 2013, a NHITB appointed eHealth ambassador Dr Richard Medlicott called for incentives to encourage patient portal uptake to meet the NHITB's target (Castaneda, 2013).

The release of promotional material with the NHITB's approval gave some insight into their hopes for the use of patient portals. For instance, while the material did mention efficiency gains, the focus was on the way patient portals can be used to strengthen and preserve patient care and safety. In a NHITB (2014b) brochure, Dr Eade stated, "We've been able to reduce some of our transactions... which has freed up staff to focus on other aspects of patient care" (p. 2) and Dr Nicolls stated, "Don't be afraid to start simple... you could introduce appointment bookings first, then other services when you have established robust workflow to ensure success, and understand better how the portal will work for you" (p. 2). On an NHITB (2014f) webpage, eHealth ambassadors offered advice for portal implementation, stating: "Think about how to better engage with patients as a service first, before looking at tools" (para. 1) and "when using the portal they should work to their own level of comfort, which may mean bringing patients in for a face-to-face consultation" (para. 4). There was also an emphasis on how portals increase patients'



convenience. For instance, a NHITB Consumer Panel member Sheldon Ngatai maintained that patient portals make life “a heck of a lot easier” (NHITB, 2014g, para. 5).

External groups issued their own reports about the patient portals. An implementation guide made by The Royal New Zealand College of General Practitioners in conjunction with the NHITB in 2015 promoted the uptake of patient portals, but it also gave an insight into the considerations required for each function and the complexity of its implementation. For example, before implementing the booking appointments function, practices need to decide the quantity and times available, whether it will be fully automated or require approval; whether appointments for all doctors and the practice nurse will be available, and the terms and conditions. Another report by Love and Boyle (2015)<sup>13</sup> modelled the financial impact of the portal and found that it can redeploy practice staff time from low productivity tasks and the substitution of online queries for some face-to-face consultations with co-payments can result in a net financial gain to a general practice. The modelling was based on practices with 2500-10000 patients achieving a 20%, 40% and 80% patient uptake and it showed the impact of different co-payments and varying amounts of clinical queries through the portals.

However, most practices using a patient portal either did not have 2500-10000 patients or a 20% patient uptake, as shown in Figure 4.5 on the following page. A month after the report was published, each practice using a patient portal had on average only 414 patients registered. Figure 4.5 also shows that the uptake of patient portals was far from their target of 50% of practices by the end of 2014. In December 2014, out of the 1080 practices in New Zealand (Hurdleby, 2014), only 132 practices offered a patient portal (NHITB, 2016). This is illustrated in Figure 4.5 on the following page.

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<sup>13</sup> Love and Boyle are part of Sapere Research Group and they were commissioned by Patients First on behalf of the National Health IT Board to model the impact of patient portal implementation on general practice costs and revenues.

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Figure 4.5: The Uptake of Patient Portals in New Zealand  
Retrieved from the NHITB (2016)

A survey conducted by NZDoctor.co.nz among general practitioners in 2015 found that awareness of patient portals had increased among primary care physicians, but that many were yet to be convinced of the advantages. The article reporting on these findings quoted Dr Reid who stated, “I still say it won’t make my day any more efficient... But it will make care of the patient better.” (para. 21). In another media article, Castaneda (2014) discussed how the uptake of patient portals had been lower than anticipated, and it quoted a doctor who “had nothing but bad experience” (para. 28) with the technical issues of a portal and another disapproving of its underlying philosophy, stating:

I don’t like patient portals as an idea... Patients are terrible judges of their own needs... Patients may own their records but on some level you still own the practice and therefore the intellectual property...would patients make sensible use of it if this information is available? It’s good to keep some patients in the dark in some aspects. I am happy to reply to emails, but do emails really save time, improve care or make money for the practice? (para. 25)

Perhaps responding to the lower uptake than targeted, in November 2014 the Ministry of Health announced that they would invest \$3 million to expand the roll out of patient portals (NHITB, 2014h). Of this, \$500,000 was spent on an advertising campaign (Johnathan Coleman, 2015), which, aside from some news articles quoting eHealth

ambassadors (e.g., Carville, 2014; Dunn, 2014; Newlove, 2014), was the first time that the NHITB focused their promotional efforts on the public. These advertisements (provided in Appendix B on page 311) are the focus of the analysis in chapter six.

Throughout this time the patient portals in New Zealand received relatively little academic attention. I could find only two exceptions to this from my exhaustive searching. The first was published in two conference proceedings by Day and Gu (2012) and Gu and Day (2013) in which ten patients were interviewed and observed using a patient portal in Wellington. The patients found the portal easy to use, and nine patients used the patient portal to communicate directly with their health provider (Gu & Day, 2013). They placed a high value on the transparency fostered through the portal, and the most common function used was viewing laboratory results, followed by checking their medicines list and ordering repeat prescriptions (Gu & Day, 2013). The participants' perception was that the portal provided convenient, time-saving efficiency and effectiveness of care, as well as health literacy, and reduced some financial concerns (Day & Gu, 2012). The perceived efficiency was not just for themselves, but also for their healthcare providers, for as one patient stated, "I don't want to be crashing into his day and ringing him directly on his phone when he's a busy guy" (p. 42).

The only other study that I found concerning patient portals in New Zealand was by Day and Wells (2015). They conducted semi-structured interviews about the governance of health information with 30 people from a range of backgrounds, including five consumer representatives, seven general practitioners (two of whom used patient portals at their workplace), and eighteen people who had been involved in the policy development, evaluation or implementation of health information technology projects. Some of these participants wanted a clear and transparent process in place should there be a breach in privacy breach through a patient portal, "so that you will know if your data gets leaked you will be told what the outcome is, and there will be an outcome and it won't be a wet bus ticket" (p. 32). The authors concluded that there was uncertainty about the potential

design and extent of giving people access to their medical records, that existing policies about patient authentication, proxy, and privacy need modification, and that the existing governance structures and functions require examination and adjustment. While Day and Wells' (2015) study is significant, particularly in a field with relatively little exploration in New Zealand, more investigation is warranted because they interviewed participants from such diverse backgrounds about a wide range of topics. In fact, the authors themselves recognised that the study, "only scratches the surface of the implications on governance of people assess/using their records" (p. 34).

In December 2016, 445 primary healthcare practices offered a patient portal, and 297,255 patients were registered with a portal service (Johnathan Coleman, 2017). It is difficult to say how they are being used in these practices with the limited evidence available. The promotional efforts by the eHealth ambassadors and the NHITB have been careful not to imply that patient portals take away the time spent in face-to-face consultations and have focused instead how portals can enhance patient-provider relationships (see: NHITB, 2014b, 2014f, 2014g). The limited research examining patient portals in New Zealand (i.e., Day & Gu, 2012; Day & Wells, 2015; Gu & Day, 2013) provide insight into why a patient might choose to use a patient portal and issues regarding the governance of health information. However, as these authors have acknowledged, more academic attention is required in this field.

#### **4.4. EXPLORING THE IMPLICATIONS OF PATIENT PORTALS FOR MĀORI**

It seems that patient portals were promoted in New Zealand by the NHITB with the idea that the technology could assist patients in becoming informed and managing aspects of their health conditions. However, studies conducted overseas has shown that lower socioeconomic groups are less likely to adopt a portal (Jhamb et al., 2015; Ketterer et al., 2013). Like other indigenous groups (McNeish & Eversole, 2005), Māori experience poorer educational outcomes, unemployment and social deprivation compared to non-

Māori and non-Pacific New Zealanders (World Health Organization, 2012b). Māori also have poorer health outcomes statistically; with an almost 1.8 times higher health loss per capita (Ministry of Health, 2013c), and Māori children experience two times poorer health compared to non-Māori New Zealand children (Public Health Advisory Committee, 2010). While all inequality is of concern, health disparities are particularly poignant, as they represent the differences in access to the benefits of society and reduced ability for people to contribute to future generations. In this section I explore crucial issue of whether patient portals will be of benefit to Māori, with particular attention to they support a Māori framework of health, their impact on health inequality, and their implications on the provision of care for Māori people.

In discussing any ethnic group there is a risk of presenting them as being homogeneous, but this is particularly concerning for Māori, as they commonly identify by their *iwi* (tribe or tribes) and *hapū* (subtribe or subtribe) and not as a single nation-wide group, so in this thesis I use of the term ‘Māori’ with the acknowledgement that Māori are heterogeneous, and there are likely to be iwi, hapū and individual divergences. For example, 29 percent of Māori currently do not know their *marae*<sup>1</sup> (Statistics New Zealand, 2014b), and only one in five can hold a conversation in Māori language (Statistics New Zealand, 2013). This can be attributed to the colonisation of New Zealand, which resulted Māori experiencing major losses in land, epidemics of infectious diseases, political disempowerment, a loss of language, and, with the settlers’ policy of cultural assimilation, a loss of intellectual traditions. In the 1970s there was a movement to reclaim Māori culture and identity, when a younger generation of Māori began challenging the dominant hegemony across multiples sites of disparity, many of which were significant to health outcomes (Moon, 2013). Although many Māori appeared ‘westernised’ by this time, a large number still felt alienated in the health sector, because their traditional world view and their perceptions of health and illness clashed with the dominant biomedical frameworks in

western medicine (Durie, 2007). It seemed that postulated breaches of *tapu*<sup>14</sup> which were the traditional explanations of illness, continued to influence many Māori people (Durie, 1985). A Māori framework that gained wide acceptance during this time was Durie's (1985) four-sided health construct, which likened Māori perceptions of a healthy individual to a house: each house, to be complete, needed one wall spiritual wellbeing, one of mental wellbeing, one of physical wellbeing and one of family wellbeing. The analogy of the house illustrated the interdependent relationship between all four aspects, where poor health is regarded as a break-down between the individual and the wider environment.

A key question to ask how healthcare ICTs align with Māori frameworks of health, particularly a holistic model such as that of the 'healthy house'. As I discussed in chapter two, a rising burden on the health sector among other factors have shifted responsibility on individuals to prevent illness and manage their healthcare. Accordingly, the NHITB's strategies enable: "patient self-management - making the patients co-producers of their own health care to take the burden away from a diminishing and ageing health workforce" (NHITB, 2010, p. 54). This presents healthcare ICT as allowing patients to control their healthcare, with little reference to the broader social structures which influence an individual's ability to do so. This is an issue for Māori, as they experience higher rates of social deprivation (World Health Organization, 2012b) and have lower health literacy overall (Ministry of Health, 2010), making self-managing healthcare a more strenuous task. Furthermore, presenting only a functionalistic view of healthcare discounts aspects of Durie's (1985) four-sided health construct. Nevertheless, it could be argued that healthcare ICT initiatives justifiably align with biomedical assumptions, and that Durie's (1985) health model allows Māori to manage their physical health in accordance with modern medicine, while acknowledging other aspects which are essential to Māori health.

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<sup>14</sup> The term *tapu* in this sense refers to Māori rules and regulations regarding the sacred, prohibited and unclean.

In some respects, this separation between Māori and biomedical assumptions relates to other potential cultural barriers of healthcare ICT programmes. Māori have been found to prefer face-to-face communication regarding health issues (Cullen, 2009), and so technologies which facilitate email correspondence at the expense of personal encounters may not be culturally suitable. Furthermore, Māori traditionally consider personal information to be a treasured object (Kamira, 2007; Cullen & Reilly, 2008; Cullen, 2009), and so there could be cultural issues regarding the digitisation of their health records. For instance, in a study examining perspectives of uploading personal information onto governmental websites, Māori expressed greater concern than other ethnic groups about the amount of information held about them and about losing control of this information (Cullen, 2009). Māori are also guaranteed the right of ownership of health information under the Treaty principle of *rangatiratanga*<sup>15</sup> (Kamira, 2007).

The uptake of patient portals by Māori will inevitably be impacted by individuals' access to and use of the internet. In 2012, Māori and Pasifika had a lower uptake, at 77 percent and 62 percent, compared to 84 percent of *Pākehā*<sup>16</sup>. This disparity worsened with regard to the proportion of with access to the internet at their homes: only 68 percent of Māori and 65 percent of Pasifika had home access, compared to 86 percent of *Pākehā*. Correspondingly, a smaller survey in 2015 by Crothers et al. (2016) of 1137 respondents found that Māori and Pasifika had a higher rate of internet non-use or low use at 26 percent and 33 percent, compared to *Pākehā* at 22 percent, and Asian participants at 1 percent. In relation to patient portals, this disparity is troubling, as Māori and Pasifika are more likely to require ongoing healthcare management, because they have a higher rate of health loss nation-wide (Ministry of Health, 2013c). Such findings suggest that there is a digital divide present in New Zealand, in which Māori and Pasifika are situated unfavourably. However, Greenwood, Te Aika and Davis (2011) rejected the deficit implied

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<sup>15</sup> The term *rangatiratanga* translates to chieftainship, and it relates to responsibility, authority, or sovereignty.

<sup>16</sup> For this research the term *Pākehā* refers to non-Māori New Zealanders who originally derive from Europe.

in the term ‘digital divide’, arguing that Māori have a history of adapting to new technologies and maintaining that the internet is valuable for the resurgence of indigenous peoples. Furthermore, there are inequalities in the access to the internet by more than ethnicity: the participants’ incomes, employment statuses, and tertiary education also influence individuals’ uptake of the internet (Statistics New Zealand, 2013). For instance, while the Māori population is younger, Māori have lower employment, educational outcomes, and a higher proportion residing in the urban centres, all of which may affect their ability or aspiration to purchase internet access. Optimistically, the uptake and usage of the internet by Māori is increasing (Crothers et al., 2016), and Māori are more likely to own a smartphone than Pākehā, at 70 percent compared to 55 percent, and are correspondingly more likely to use applications for social interaction than Pākehā, at 87 percent compared to 74 percent (Research New Zealand, 2014). The use of the internet by activity is outlined in Table 4.4 below.

**Table 4.4: The Use of the Internet by Activity\***

	<b>Pākehā</b>		<b>Māori</b>		<b>Pasifika</b>		<b>Other</b>	
	2009	2012	2009	2012	2009	2012	2009	2012
Social networking	44%	61%	52%	75%	51%	74%	50%	74%
Finding information about health/health services	36%	52%	28%	45%	26%	41%	35%	44%
Finding information about education	18%	25%	23%	33%	26%	28%	31%	32%
Downloading/listening to music	36%	46%	47%	56%	45%	57%	47%	54%
Downloading/reading books, newspapers, or magazines	34%	42%	25%	34%	28%	33%	45%	48%
Downloading/watch movies, short films, or images	31%	44%	34%	34%	32%	43%	45%	57%
Downloading/Playing computer/video games	17%	25%	24%	33%	26%	28%	24%	25%
Sharing files via peer to peer exchange	8%	9%	10%	10%	10%	6%	14%	12%

*\* Comprises of individuals who used the internet 12 months prior to the survey. 13,046 households were surveyed. Individuals may belong to more than one ethnic group.*

Retrieved from Statistics New Zealand (2014b)



The 2012 Household Use of ICT Survey shows that the internet usage also varies by ethnicity, which is outlined in Table 4.4 on the previous page. Māori who used the internet in the year prior to the survey had the highest proportion of individuals who reported using social networking at 75 percent, compared to all other ethnic groups categorised. Significantly, a lower proportion of Māori and Pasifika reported using the internet to obtain information about health or health services, compared to Pākehā.

In closing, this section provided an overview of some potential barriers which may hinder the uptake of healthcare patient portals among Māori. On the surface, with Māori featuring undesirably on the digital divide and having a lower proportion using the internet to search for health topics, as well as the various cultural issues discussed, it may seem that healthcare ICTs are not appropriate for many Māori people. This concern is heightened when considering the various healthcare ICTs which have failed to reach the socially deprived; illustrating how healthcare ICTs could facilitate the infiltration of disadvantage further into the realm of healthcare. However, as there has been an increasing uptake of the internet among Māori, especially for communication, this gives another depiction; perhaps aligning with claims that Māori are historically adaptive to new technologies (Greenwood et al., 2011). This is encouraging for the patient portal initiative as it indicates that many Māori have accepted online communication. However, whether this will translate into the adoption of patient portals has yet to be seen.

#### **4.5. PATIENT PORTAL DISCUSSIONS**

While undertaking this research project, there have been occasions when I have been asked to speak about patient portals. This includes times when I have given formal conference presentations (e.g., Elers, 2014a, 2014b, 2016; Elers & Elers, 2016), as well as informal discussions with friends, family members, co-workers, and whomever else I have fallen into conversation with about my doctoral research. For the most part, the discussions have been centred around topics already considered in this thesis: privacy

concerns, information governance, implementation issues, and the potential inequitable uptake. However, some questions have either taken me by surprise, or are distinctive as they do not ‘fit in’ to the previous chapters. These questions are addressed in this section.

Question One: *“Couldn’t the funding be better spent elsewhere?”*

I like the scepticism, simplicity, and directness of this question. By funding, the individual asking this question, referred to both the cost to the NHITB for promoting the patient portals and the cost to the primary healthcare practice for its implementation. The individual went on to say that the money might be better spent on employing medical staff or on “more beds in hospitals”. As I explained, with the increasing demand on the healthcare sector, there has been a move toward supporting people to remain in their communities (Ministry of Health, 2012), and endeavour to remove the hospital from the centre of the healthcare system (Timmins & Ham, 2013).

It is understandable that the individual asked this question. Compared to other costs in the healthcare sector, the product of any expenditure is less tangible. For healthcare practices, the portal is essentially a data management program, but for the patients, the product is for the most part their personal health information. The websites captured at the beginning of this chapter go as far to imply that the product could even be the individual’s health and wellness. The benefits directly attributed to patient portals can be difficult to definitively measure. Even if a practice implements a patient portal, then there is no guarantee that it will be used effectively. Complicating this matter further is that the promoted benefits for patients and doctors vary significantly.

The answer to this persons’ question is that I cannot definitively say whether a patient portal is a worthwhile investment. They were not trialled or formally evaluated in a New Zealand setting before the NHITB’s promotion (Hurdleby, 2014), and while there have been some positive results reported overseas, these generally have not been empirically verified regarding health outcomes and financial benefits (Ammenwerth et al.,

2012; Giardina et al., 2014; Kruse et al., 2015). In many respects, the portals in New Zealand have been a venture in the dark, the outcomes of which have yet to be seen.

Question Two: ***“Should the government promote the patient portals?”***

This is an issue that is often brought up by academics when I mention how the NHITB promoted the uptake of the patient portals to primary healthcare practices (NHITB, 2013a) and to the public (Johnathan Coleman, 2015). Currently, the patient portals in New Zealand are provided by private companies, the most common being MyPractice, Intrahealth, ConnectMed and ManageMyHealth (R. Brown, 2017). This varies in other countries. For instance, the Personally Controlled Electronic Health Record connects to patients and healthcare providers and it was set up by the Australian government (Minter Ellison, 2015). In addition, the HealthSpace patient portal was introduced to the English National Health Service in 2007 (Greenhalgh et al., 2010).

In a free market, healthcare practices should decide what is best, and private companies should promote their services without public sector interference. Private companies reap benefits from the NHITB’s promotion, which are not directly returned. For instance, is ManageMyHealth is overseas owned, as shown in Figure 4.6 (on the following page), and it is the largest patient portal in New Zealand, having 160,000 of the 240,000 total patients registered in December 2016 (R. Brown, 2017). The NHITB has directed the public to “ask your GP about patient portals” (2015j, 2015k, 2015l, 2015m), and a website by the Ministry of Health (2017a) allows individuals to search for practices with a portal. This holds healthcare practices to a kind of ransom – regardless of the owners’ views towards the portal, they are forced to implement it or they may lose patients. This is also discouraging for smaller practices, which cannot afford the services, compared to their larger counterparts.

The justification for the NHITB’s promotion of the patient portals depends largely on the answer to question one. If they are successfully utilised and the anticipated benefits

are realised, then it is worthwhile. For patients, portals could improve their communication with their healthcare providers and to give them easier access to their health information. This could assist them to prevent illness and manage their health conditions, which could, in turn, result in a healthier population and less costs to the healthcare sector. For healthcare providers, the portal could improve organisational efficiency and streamline processes, which giving them more time to spend with their patients or allowing them to see more patients, which is advantageous given the shortages of general practitioners in New Zealand (Ministry of Health, 2016f).

Closely related to this concern is whether patient portals should be publicly provided. If patient portals are for the greater good, then there is an argument that there should be one portal provided by the government, rather than being controlled by the private sector. An issue of the having the portals offered by the private sector is that there is a potential for shortcuts to be taken and the safety of personal information to be compromised. Orion Health (2017) have reported that their software currently manages over 110 million patients globally. At the same time, information managed by public organisation is not always safe. For example, the National Health Service shared medical records of 1.6 million patients with Google without their consent, to develop a health application which can help recognise kidney injury (Fenton, 2016; M. Robinson, 2016).

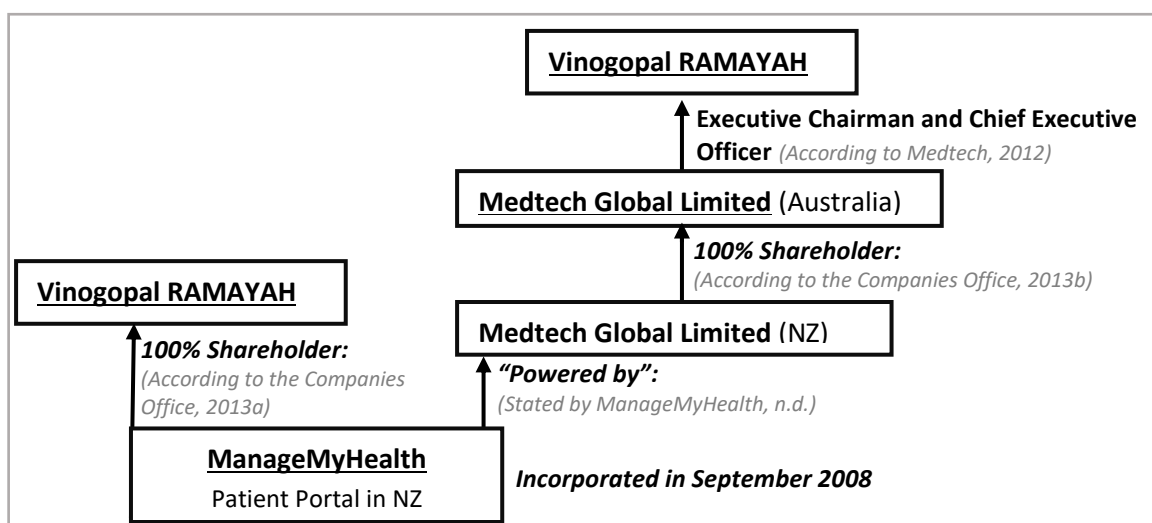


Figure 4.6: The Company Information for the ManageMyHealth Patient Portal

**Table 4.5: Some Recent Privacy Breaches Reported in New Zealand**

Date	Incident
2012	More than 9000 ACC claims were emailed to a person who should not have received them. The information included full names, the nature of each claim and dispute, and individual claim numbers. Some of the names were public figures, and others were victims of violent and sexual crimes (Kitchin, 2012).
2013	Following extensive media coverage, 33 health workers were disciplined for snooping at x-rays and information on a man who had an eel removed from inside him (Tait, 2013)
2014	There was a significant attempt to hack a nationwide patient database, in which a single IP address made over 20 million attempts to guess the passwords of practices, PHOs and DHBs (Hartley, 2014).
2015	The personal details of more than 600 females who had abortions in the central North Island were accidentally given to a reporter (Devlin, 2015).
2015	A spreadsheet of National Health Index numbers, containing the birth and death dates of 24,092 people, was accidentally emailed from the Ministry of Health to around 950 pharmacists (Plumb, 2015).
2015	Medical records from 20 years ago were found in a house at a Taranaki Building Removers' yard (B. Smith, 2015).
2016	A doctor accidentally sent a message to all patients signed up to the centre's patient portal about a patient's diet, medication instructions, and cholesterol and thyroid levels (Crayton-Brown, 2016).
2016	Whanganui District Health Board's computers were infected with a ransomware attack, which restricts people from accessing files until a ransom is paid to the hacker (Ryan, 2016).
2016	The names and email addresses of 47,000 members of the nursing union were sent to an unknown person who emailed impersonating the organisation's chief executive (F. Thomas, 2016).

### Question Three: *“Is the information safe?”*

In 2014, I investigated this question when I visited the Orion Health headquarters in Auckland, and I was impressed to find staff dedicated to finding flaws in their technologies’ security, so that they could be corrected. However, history has shown that there is the potential for errors in digital systems. In 2011 a doctor called for safeguards in place against the possibility of referrals being sent to the incorrect location for an electronic system in New Zealand (de Montalk, 2012). More recently, a doctor accidentally sent a message to all patients signed up to his practice’s portal, which was intended to be a reply to a single patient, and contained advice about diet, instructions about taking medication, and a discussion of the patient’s cholesterol and thyroid levels (Crayton-Brown, 2016). This example shows how information can be compromised, not only because of a breach of security into the system, but also from human error. On the facing page, Table 4.5 outlines some recent privacy breaches in New Zealand.

## 4.6. SUMMARY

The promotion of patient portals in New Zealand by the Ministry appointed NHITB is part of a wider National Health IT Plan which aims to support the delivery of person-centred healthcare by providing patients with a core set of personal health information which is accessible regardless of the healthcare setting. To be able to appreciate why patient portals are being implemented and their significance, it is necessary to have a broad understanding of the corresponding ICT developments taking place in the health sector and the history to this. The purpose of this chapter was to give an overview of the past and present national ICT healthcare initiatives in New Zealand. This chapter opened with a brief outline of the New Zealand health sector, the issues it faces, and how this relates to the introduction of healthcare ICTs. It then discussed some the initiatives undertaken by the NHITB, before examining the patient portals in New Zealand. Following on from this was an exploration of some of the potential implications of patient portals and similar

healthcare ICTs for Māori. In the last section I addressed questions that I have been asked about the portals since the commencement of my research. This is the last literature review chapter, before I outline the methodology and method that I used to conduct primary data gathering and analysis.

## 5: METHODOLOGY & METHOD

The research in this thesis was driven by belief in the importance of the question: “What are patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand?” The reason that this question is so important is that the portals have the capacity to change the way health is conceptualised and delivered, and there is (arguably) nothing more important to the nation than the health of its citizens. Therefore, to discover and understand the way that patients and doctors interact with both the portals and with one another through the portals is to see how the nature of healthcare might change as a result implementing the technology.

In the previous four chapters, I have presented and reviewed literature, theories, and ideas that contextualise and situate my research within its broad field of enquiry, which is health communication. At this point of the thesis, I turn to laying out the methodological orientation that framed the research and the methods I used to operationalise my enquiry. This chapter, Methodology and Method, is a kind of pivot: here, I move from examining what has already been established in previous research, is known, to setting out and interpreting my data and my contribution to new knowledge.

I open this chapter in section 5.1 by ‘setting the scene’ in which the research was carried out. In section 5.2, I outline the methodological orientation of my research, by



introducing critical theory, which has heavily influenced the thinking that underpinned my investigation, and then discussing qualitative research. In section 5.3, I enter upon the operationalisation of my research. First, I summarise Dryzek's (1997) discourse analysis, which I applied to examine a range of promotional texts by the National Health IT Board and the private company Medtech. I should note that my analysis was also influenced by a range of other scholars (e.g., Cheney, 1983; Fairclough, 1992, 2001). Second, in section 5.2.2, I discuss how I recruited participants and analysed the data from the interviews, and finally, in section 5.2.3, I show how I conducted the semi-structured interviews with doctors and patients.

### **5.1. SETTING THE SCENE**

This section grounds the operationalisation of my research in the time it was carried out, because, as Letiche and Lightfoot (2014) stated, "The performativity of research is connected to the context of its production" (p. 68). With this in mind, time is a variable that should not be overlooked in research, as it has a strong effect on the findings. Remenyi and Williams (1998) define cross sectional research as a "snapshot of a situation" (p. 47). This may involve measuring the actions, attitudes, and characteristics of participants at only one point of time (Schutt, 2015), and this is what I have done in my research, by conducting interviews with a cross sample of patients and doctors that had familiarity with patient portals. My research is reflective of 2015, which, as I will discuss, was a time when the uptake of the patient portals in New Zealand was slower than anticipated.

In many respects, New Zealand experienced an optimistic outlook in 2015. The fiscal position had improved over the previous few years, with an operating surplus being recorded for the first time since 2007-2008 (Treasury, 2016). The government accounted an additional \$1.7 billion for New Zealand's public health services over the next following four years, increasing the total health investment to \$15.9 billion in 2015-16 (English,

2015). New Zealanders reported optimistic attitudes towards their health; with most adults rating their own and their children's health as good, very good or excellent, and most adults having confidence and trust in the doctor they last visited (Ministry of Health, 2016g). The uptake of the internet appeared to be high; a survey conducted among 1377 participants found that 1293 declared themselves to be active internet users (Crothers, Smith, Urale, & Bell, 2016). Taking these things into account, there is a connection with the ICT in the healthcare sector, as there had been recent successful initiatives led by the NHITB, such as the GP2GP system, which allowed patient notes to be transferred between practices and was used in more than 80 percent of primary healthcare practices (NHITB, 2013).

However, while the progress in other areas of the healthcare sector was encouraging, the same progress did not occur with the patient portals. In March 2015, only 160 primary healthcare practices offered patient portals (NHITB, 2016), out of the 1080 primary healthcare practices in New Zealand (Hurdleby, 2014), which was far below the NHITB's target of having fifty percent of practices offering the portals by the end of 2014. It did not seem that this outcome was anticipated by the NHITB director, Graeme Osborne, as he confidently said in relation to the target: "This is more than a hope. Each region and each district in New Zealand will roll this out" (Carville, 2014, para. 4). I cannot definitively state why the uptake differed so much from the NHITB target, although there were some signs that the implementation could be more difficult than anticipated; with an eHealth ambassador in 2013 calling for incentives to encourage practices to uptake patient portals (Castaneda, 2013) and a limited online survey in 2015 concluding that many doctors were yet to be convinced that there would be advantages from the portals (NZDoctor.co.nz, 2015).

The NHITB's target for the portals was ambitious, and it was perhaps not achieved because of flaws in their strategic plan. However, the issue may have been broader than this – perhaps the doctors did not perceive the portals to meet their needs. The push by the NHITB for practices to implement portals without clinical trials, formal evaluations

(Hurdleby, 2014) or solid empirical evidence on many outcomes (Kruse et al., 2015), sides with a reductionist framing of technology as a progression in itself. This kind of framing does not attend to the societal-level effects of the technology, and its broader cultural, political and economic consequences (Dutta, 2016). The hesitation by doctors to adopt patient portals may have reflected a generational divide, as 40.1 percent of doctors were aged fifty or over (Health Workforce New Zealand, 2015), or perhaps they were concerned about data security, especially given the record high number of hacking incidents that caused healthcare data breaches in 2015 (Heath, 2016). Although the portals were promoted by ehealth ambassadors (doctors using portals), I also wonder if the portals would have been more successful if doctors had been involved in its design, as analysts have suggested that involving end-users in the design of technologies can make it more relevant for users and able to be integrated into daily practice (Lugtenberg et al., 2015).

It is difficult to speculate how the practices offering patient portals were using them or to evaluate their efficacy, as there was (and currently is) limited scholarship in this domain. However, the uptake trends of the portals provide some insight into this matter. Significantly, there was a more than two-fold growth from the number of practices offering of the portals in 2014; as it had risen to 180 practices, from just 96 practices in September 2014, and 69 practices in March 2014 (NHITB, 2016). The uptake of the portals by patients, however, did not rise at the same rate; there were 37,000 patients registered in September 2014, but only 44,000 patients registered in March 2016, despite the number of practices offering the portals nearly doubling in this time (NHITB, 2016). This indicates that, although more practices were reported as offering the portals, these practices were not effectively promoting the portals to their patients, or there was low acceptance by patients.

If this reflected ineffective promotion, then this is unusual given that practices pay to use the services, but it makes me wonder if practices were employing an 'at hoc' approach to its implementation. It could be that this was part of the rationale behind the implementation guide by The Royal New Zealand College of General Practitioners in

conjunction with the NHITB and the commissioned report which modelled the portals' financial impact (i.e., Love & Boyle, 2015) both published in 2015. Alternatively, if the uptake reflected a low acceptance by patients, then this indicates that the producers of the portals had failed to understand or communicate with these end users. There are many other examples where healthcare technologies have had a low patient uptake. Studies have reported a low patient uptake of portals overseas (Otte-Trojel et al., 2016). In New Zealand, Waikato district health board purchased a virtual health application in 2015, at an estimate price of \$8 million, to allow people to access to doctors via smartphones and tablets, but by 2017 it only had 8760 patients registered, and most are allegedly district health board employees (Kerr & Leaman, 2017).

There is also little information about which functions were used within the patient portals in 2015, and the impact that this was having. However, the NHITB promotional material emphasised that practices implementing portals should start with a few functions first, perhaps to counteract concerns that the portals could cause major organisational changes. For example, an ehealth ambassador stated: "Think about how to better engage with patients as a service first, before looking at tools" (para. 1) and "when using the portal they should work to their own level of comfort, which may mean bringing patients in for a face-to-face consultation" (NHITB, 2014f, para. 4). Another stated: "Don't be afraid to start simple... you could introduce appointment bookings first, then other services when you have established robust workflow to ensure success, and understand better how the portal will work for you" (NHITB, 2014b, p. 2). Interestingly, the focus of these statements tended to be on keeping current work practices, with less emphasis on functions that facilitate less patient engagement. However, Gu and Day (2013) determined that patients from a practice in Wellington used a portal to communicate directly with their health provider.

In June 2015, the NHITB began using paid advertising to promote the portals to patients and doctors. The inclusion of patients as a target audience signalled a change in

strategic direction by the NHITB, as the previous promotional efforts were generally focused on doctors. This change in strategic direction may signal that the NHITB had conceded that their previous strategy was not working. It was an interesting change, given that previous research abroad had determined that the most effective strategy for patient uptake was through health professional encouragement (Wells, Rozenblum, Park, Dunn, & Bates, 2014). However, I can see that the advertising could align to some of Rogers (1993) attributes that make an innovation more likely to be adopted for practices; the relative advantage if patients are requesting the services, the compatibility, with the portals being presented as maintaining existing practices, and the observability, with the portals becoming more visible.

It was against this backdrop that I set about the recruitment of participants. The state of the portals would influence my decision-making regarding my recruitment, as well as the participants' perspectives and the consequential findings of my research project. In summary, only 160 primary healthcare practices offered patient portals in March 2015 (NHITB, 2016), out of the 1080 primary healthcare practices in New Zealand (Hurdleby, 2014). The NHITB aimed to have half of all primary care practices offering the portals by the end of 2014, and so this figure shows that they failed in reaching this target. There are various reasons that could be attributed to this lower uptake by practices, such as the portals' cost, privacy concerns, and doctors not perceiving the portals to be of benefit, but I cannot lay claim to them without further evidence. Nor can I state how the portals were being used in 2015, and the impact of this had, although the NHITB promotional material encouraged practices to "start simple" (NHITB, 2014b, p. 2). I can say that the number of practices offering portals increased significantly from 2014 – in March 2014, 69 practices offered portals, which rose to 96 practices in September 2014, and to 180 practices in March 2015 (NHITB, 2016). The same trend did not occur with the patients' uptake, which rose from 37,000 patients registered in September 2014, to 44,000 patients in March 2016, even though the number of practices offering the portals nearly doubled in this time

(NHITB, 2016). This may suggest that the utilisation of the portals among practices that had recently began offering the portals was low, in that few patients were using the service.

## **5.2. METHODOLOGICAL FRAMING**

### **5.2.1. Critical Theory**

A paradigm is defined as “a comprehensive belief system, world view, or frame-work that guides research and practice in a field” (Willis, 2007, p. 8). Within the broader discipline of communication studies, the categorisation of paradigms is highly contentious, which is unsurprising given that “as one travels between institutions within a single country (where some departments are dominated by humanistic traditions, and others by social-scientific traditions), or between countries, there is both variation and similarity in what counts as ‘communication studies’” (Lindlof & Taylor, 2002, p. 10). The scholarship on communication theory and research provide different categories or labels of paradigms. For example, positivistic or empirical, interpretive, and critical (West & Turner, 2010); scientific, humanistic, and social-scientific (Littlejohn & Foss, 2008); positivist and critical (Oosthuizen, 1995), positivist, systems, interpretive, and critical (Baxter & Babbie, 2004), postpositivism, hermeneutics, critical, and normative (Baran & Davis, 2012), social scientific, interpretive, and critical (Croucher & Cronn-Mills, 2015).

As Guba (1990) explained, a paradigm can be defined by ontology, epistemology, and methodology – that is, the nature of reality, the nature of the relationship between the inquirer and known, and the way that the inquirer goes about finding out knowledge. Contrasting with a positivist position of research, I view reality as being socially constructed, shaped, maintained and sometimes challenged media, institutions, politics, and society. I do not see how research can ever be neutral, everything that is included and excluded is a deliberate choice by researchers, and those choices are influenced by the values, experience and worldview of the researcher.

This aligns to a critical paradigm (Alvesson & Deetz, 2000). If this paradigm were to be judged simply by its name, it would be easy to dismiss it as a negative and perhaps unproductive tool to denigrate people and ideas, but despite any pejorative connotations attaching to the word “critical”, this is the position from which I have framed my research. The critical paradigm is useful in an examination of any social situation where the complex of marginalisation and resistance could be present (McKinnon, 2009). The health sector could be one such example of a social situation where there is an inequitable allocation of resources and overriding assumptions about the nature of health and sickness, and whose voice should dominate the conversations that take place. Critical theory is connected to struggles for a fair and just society and rejecting arguments that research can and should be value-free (Fuchs, 2011). It allows researchers to examine their thoughts and theories in the light of the political worldviews they will have inevitably acquired (Fuchs, 2015). As I approached my research, I was conscious of my own experiences as part of the healthcare sector, and my awareness as a health “insider”, that all sorts of political agendas were in operation behind the implementation of patient portals. It is these factors that drew me to critical theory, which has guided my approach through my doctoral work, from the research design to the data analysis and interpretation.

Critical theory is commonly associated with a group of scholars from the Institute of Social Research, Frankfurt, Germany (Held, 1980), who are referred to as the “Frankfurt School” (Fuchs, 2016). The institute was founded in 1923 as a “Marxist-oriented research institute” (Kellner, 2001), and some of its key figures included Max Horkheimer, Theodor Adorno, Erich Fromm, Herbert Marcuse (Held, 1980), as well as Jürgen Habermas (1981a, 1981b). According to Dahms (2011), critical theory was directly influenced by the rise of national socialism in Germany, so it makes sense that the overarching principle of the Frankfurt School was the Marxist critiques of the “realities of power, exploitation and domination” (Fuchs, 2016, p. 7). Moreover, a central tenet of critical theory is that the social world should not just be understood, but also transformed for the better

(Thompson, 2017), which aligns with the aspiration that critical theory seeks to project a possible utopian state (Marshall, 1998).

While the Frankfurt School is credited with founding critical theory, the term now has multiple meanings (Fuchs, 2011). More recently, for instance, it has become a generic name for any critical scholarship (Tallack, 2014), which now encompasses several schools of thought, including Marxist analysis, psychoanalysis, feminist theory, critical race theory, and queer theory (McKinnon, 2009). Therefore, a critical theorist or critical researcher need not embrace the Marxist orientation of the original critical scholars, but instead is now defined quite simply and broadly as someone “who attempts to use her or his work as a form of social or cultural criticism” (Kincheloe & McLaren, 2008, p. 404). This straightforward definition tends to favour a qualitative approach (Baran & Davis, 2012) and it means that even as “Foucault is a critical theorist” (Lynch, 2016, p. 5), so too were Marshall McLuhan (P. Taylor & Harris, 2008), Roland Barthes (Baumlin, 2009), and Jacques Derrida (Lash, 2010). While this may seem confusing because all these scholars operated from such markedly different standpoints, Kincheloe and McLaren (2008) have argued that there are many critical theories, that the critical tradition is changing and evolving, that and there is room for disagreement among critical theorists as critical theory attempts to avoid too much specificity. A similar statement was made by Fuchs (2016):

...foundational texts make clear that the project of the Frankfurt School’s Critical Theory is not a narrow one focused on particular authors or approaches, but that Critical Theory should rather be understood as Marx-inspired and influenced enquiries into the realities of power, exploitation and domination. (p. 7)

As the study of communication is focused on shared meaning, the concepts of “ideology and hegemony” (McLuskie, 2009, p. 785) are included by default, and so a critical approach can be applied to critique power and social institutions concerning meaning construction. The application of critical theory can be seen in the communication scholarship of Mumby (1988, 2008, 2013), Bruner (2006, 2010), and L’Etang, McKie, Snow and Xifra (2016). Within the health communication scholarship, the concepts of ideology



and hegemony are highlighted by Dutta (2008) as being intrinsic in the health sector because there is a tendency to locate individual behaviours at the root of health problems. A similar assertion was made by Waitzkin (1989), who argued that medical encounters communicate ideological messages that support the prevailing social order.

Therefore, critical theory is a useful methodological orientation for examining the processes of communication to understand how “discursive constructions of health reflect and dominate power structures” (Dutta & Zoller, 2008, p. 13). Critical theory has been applied to doctor-patient communication (Scambler & Britten, 2001), healthcare decision making (Jones, 2001), lay health knowledge (G. Williams & Popay, 2001), and health informatics (Shaw & Stahl, 2011). In closer connection with patient portals, Fuchs (2014) adopted a critical stance in his examination of the exploitation of users of internet services, showing how companies are profiting from various forms of users’ unpaid labour as well as the commodification of user data.

#### 5.2.2. Qualitative Research

In this research, it was my intention to offer an in-depth but exploratory analysis of two perspectives on patient portals, and to this end, I used a qualitative approach to data collection. I say, “to this end” because one of the distinguishing characteristics of qualitative research is that, as its name suggests, it is research carried out to reveal the nuanced qualities of specific social phenomena. Because it concentrates on the richness of a comparatively small data set when compared to quantitative research, qualitative research is not focused on generalisability (Crabtree & Miller, 1999), but rather, the conclusions that can be drawn speak deeply of quite parochial truths. As Newman and Benz (1998) stated: “generalizability is the purpose of quantitative - not qualitative - research. ... if the purpose of the research is to generalize, one should employ quantitative methodology” (p. 54).

Qualitative research has long been used in the social sciences (Adams, Khan, Raeside & White, 2007), and its introduction into clinical research in the 1970s greatly expanded the

depth of information gathered in this field (DiCicco-Bloom & Crabtree, 2006). Although there is an interdisciplinary recognition of the value of qualitative research, it is far from being unified in theory and practice, for, as Hammersley (2013) has said, there are many definitions, all with some useful elements. For instance, some analysts have defined qualitative research as a strategy for understanding how people experience and interpret the social world (e.g., Sandelowski, 2004; Silverman, 2004; Merriam, 2009), while others have offered more functional definitions regarding the way that data is produced or analysed (e.g., Bryman, 2008; Guest, Namey, & Mitchell, 2013). Although these definitions are all broadly accurate, they identify diverse defining features, which indicates that qualitative research is not a simple entity which is easily classified (Hammersley, 2013). As Denzin and Lincoln (2008) stated: “complex, interconnected family of terms, concepts, and assumptions surround the term qualitative research” (p. 3). In view of this, consistent with various scholars (e.g., van Maanen, 1979, p. 520; Atkinson, Coffey, & Delamont, 2001), I understand qualitative research as a term which draws together many approaches, including narrative, phenomenology, and ethnography.

When I designed my research project, I let the question determine the method. That is, I sought to gain perspectives of the patient portals from two different groups of participants, and so it seemed natural to undertake in-depth conversations (termed ‘semi-structured interviews’ in the academy) with the patients and doctors. I chose my method of data analysis, thematic analysis, because it is a way of examining the patterns that cohere around certain ideas expressed by my participants. At the same time, I was a little wary of thematic analysis because I was worried that the term “thematic analysis” can be used as a smokescreen for atheoretical analyses without clearly delineated methods. To counter any possibility of this in my research, I have carefully and systematically applied the principles of thematic analysis outlined by Boyatzis (1998), Braun and Clarke (2006) and Braun et al. (2015), as described in section 5.3.2.

### 5.3. METHOD AND OPERATIONALISATION

#### 5.3.1. Dryzek's Discourse Analysis

The term 'discourse', which in its most straightforward use simply denotes 'sustained written or spoken language', in fact possesses a rich meaning when it is employed in the context of critical research. 'Discourse', as I wish to use the word in this thesis, refers to both the language and, simultaneously, the actions and social conventions that govern language choice (Fairclough, 2001). In critical research, the choice of language is an essential consideration, because it is through language that 'truths' are represented. The power of discourse lies in its capacity to present and codify a single set of meanings and to exclude others which might also be valid in any given situation, thus building a limited world view that seems all but impervious to questioning.

The question that drove this research is: "What are patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand?" Before I began my data collection through interviews, I felt that it was important consider and be aware of the context in which the portals were being introduced. This led me to nine advertisements, seven produced by the NHITB and two by Medtech. The advertisements were publicly available to patients and practitioners and they showed a broader perspective of the portals from another angle: the promoters. They revealed the hopes of the NHITB and Medtech for the portal technology and showed the speculated benefits for two sides of the portal's users, the patients and the practitioners. Therefore, an analysis of these advertisements was undertaken to contextualise and provide a setting of the research. The mode of analysis was discourse analysis because the advertisements are examples of contemporary health discourse, albeit from a marketing perspective.

It was with the notion of a shared world view that Dryzek (1997) was occupied. His analysis focused on discourses about the environment, and he showed the way that assumptions, judgments and contentions embedded within them can engender material

consequences. For instance, his seminal text *The Politics of the Earth: Environmental Discourses* opened with an exploration of the way that changing the terms used in environmental politics alters the construction of the environment. As he showed, language labels change perceptions at the level of action: when 'swamps', which once needed to be drained to be of any use, became 'wetlands', they required and received protection. Dryzek's point in this example is that changing the term by which an entity is labelled changes the assumptions that are made about the entities. A swamp is a place of brackish, smelly water, a waste of space that could not be used for arable farming or grazing; a wetland, by contrast, is an eco-system teeming with interesting and sometimes unique biodiversity. Dryzek (1997) demonstrated that discourses accrue power by conditioning the perceptions and values of those involved in them, either as agents or subjects.

Although the example given above seems to indicate that changing language can alter the trajectory of land use and toward a more sensitive 'environmental enlightenment', Dryzek (1997) asserted that such is not always the case, and this was one instance in his conceptualisation of discourse that shows a point of difference between him and other discourse scholars. Dryzek was influenced by Foucault, but he did not accept the Foucauldian portrayal of hegemony in which individuals are seen as being subjected to a single dominant discourse at any time and place. Rather, Dryzek believes that individuals work under, and with, multiple discourses at any time. Thus, 'environmentalism', as an order of discourse (Fairclough, 1992), is composed of whole categories of discourses which sometimes complement, but more often compete, with one another. Therefore, "An individual working in a government environmental agency may be an administrative rationalist at work, a green radical in conversations with friends, an economic rationalist in buying and selling" (Dryzek, 1997, p. 22). From Dryzek's perspective, although the meaning which discourses construct can be bound in immense power, they are not impenetrable. In other words, Dryzek's four elements of discourse can open otherwise concealed categories of meaning in the text.

The first edition of Dryzek's text was printed in 1997, and it has since guided various scholarly works in the field of environmental communication (e.g., McGee & Taplin, 2014; McGregor, 2004; S. Wolf & Klein, 2007), but his concept of discourse has not generally been applied to studies outside of environmental communication. A notable exception to this was the study by Prelli and Winters (2009) which used Dryzek's approach to show the similarities between the discourses of environmentalism and an evangelical Christian discourse that they termed "green evangelicalism". Following the four elements of Dryzek's (1997) framework, they established several interconnections between the two discourses, including identification with reformist, problem-solving conceptions, and assumptions about the association of environmental degradation and poverty.

Dryzek's (1997) method of discourse analysis employs a typology of four inter-relating elements: entities constructed or recognised within the discourse, assumptions about the natural relationships of those entities, the agents in the discourse, and finally, the rhetoric typical of the discourse. It is not possible to consider any element in isolation: entities that are recognised and constructed, for instance, intersect with and relate to one another in accordance with the various motivations and activities of the discourse agents. All of these elements are expressed and made persuasive by the employment of rhetorical devices.

The first element is the entities recognised and constructed in the language associated with a phenomenon. As Dryzek explained, "different discourses see different things in the world" (p. 17) and they rest on a number of pre-determined ideas. Some discourses, for example, consider nature exclusively as physical matter that can be studied in parts, measured and eventually understood, while others work from a holistic point of view and recognise the complex interconnectedness of ecosystems. The same principle applies in medicine. For example, biomedical discourses consider disease as a biological malfunction, neglecting the psychological, environmental, and social factors accepted by people who align with a biopsychosocial perspective (Engel, 1977). For this research, what can be

revealed through analysis of discourse can offer therefore information about users' perspectives, and even underlying motivations.

The second element in Dryzek's typology is assumptions about natural relationships between and among the entities that are constructed within the discourse. Such assumptions are present in all discourses, and this might include entities being placed competition with one another, as happens in capitalist markets, or in a hierarchy based on gender, race, wealth, and expertise (Dryzek, 1997). A frequently cited example of this is the assumed status awarded to doctors in medical encounters, which tend to operate on the assumption that patients are obliged to comply and cooperate with determinations made by doctors. This type of assumption is rooted in the dominance of biomedicine (Herzlich & Pierret, 1985), but in recent times, emerging discourses have emphasised the need for patients (now commonly termed 'consumers') to control and manage their healthcare (Harvey, 2010), or have depicted a patient-centered practice (Wainwright, 2008).

The third element in Dryzek's typology examined is the agents of the discourse and their motives. Dryzek (1997) used an example of a group being considered as expert administrators in one discourse, as selfish bureaucrats in another, and completely ignored in yet a third. In a similar vein, in healthcare, there are variances about whose voice should speak, and who is (or is not) considered to be a 'healthcare professional'. Dryzek argued that though most agents are human, they can also be nonhuman. In medicine, non-human agents can arguably be shown with the rise of surveillance technologies that place the diagnosis of disease away from the doctor and onto the machine.

The fourth and final element in the typology is the metaphors and any other rhetorical devices that are employed to build effect in the discourse. For instance, in his analysis of a "survivalism discourse", which emphasises limited environmental resources, rhetorical devices included the notions of 'overshoot and collapse' and the 'tragedy' of the commons. Metaphors, similes and other forms of rhetorical vividness are also abundant in

medical discourses. For example, the “war on obesity” (J. Friedman, 2003, p. 856) and the “battle against cancer” (Saito, Suzuki, Iwasaki, Yumura, & Kubota, 2005, p. 521).

For my research, although I did not apply Dryzek’s (1997) method mechanically (that is, I did not give equal weight to each four elements) I did systematically search the texts for all out elements. The corpus of texts I analysed was nine advertisements published in 2015, promoting patient portals. Of the nine texts, seven were produced by the NHITB and the remaining two by Medtech, the company that makes the ManageMyHealth patient portal, and all nine texts were readily available in the public domain. Half the texts were clearly targeted toward doctors, and the other half to the general public.

The distribution of the NHITB advertisements began in April 2015 as part of an advertising campaign that cost \$900,000 (Johnathan Coleman, 2015). This campaign was the only time that the NHITB used paid advertising to promote the portals, and unlike previous campaigns for the portals, included the general public in its target audiences and it is for these two reasons that the texts seemed to me to be significant: if the portals required an extensive and expensive advertising campaign in order to achieve wide social acceptance, it seemed to me that the premises on which the promotion was based was worthy of examination. I analysed all seven advertisements from the NHITB’s campaign to investigate the promises made and the ideology that underpinned those promises. I also analysed two advertisements produced by Medtech to see whether the same promises and ideologies were in play in a private company. I selected Medtech as the company because their ManageMyHealth portal is the most common in New Zealand (R. Brown, 2017), and it was used by the majority of my participants.

### 5.3.2. Qualitative Interviews: Gathering & Analysing the Data

I did not design my research as an endeavour to prove a specific hypothesis, but instead, sought to generate data about a social phenomenon from which to derive a deep understanding of the scope and significance of that patient portals in people’s lives. My

approach to this research, therefore, is consistent with inductive analysis, which allows themes to coalesce in the data without applying a pre-existing coding framework (Braun & Clarke, 2006). There has been some critique about the transparency of the process of thematic analysis (e.g., Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005). However, as I will discuss, I guarded against this by systematically applying the method outlined by Boyatzis (1998), Braun and Clarke (2006) and Braun et al. (2015).

### *Recruitment of participants*

I began the “human participant” part of my research by obtaining clearance from the university’s ethics committee on 18 February 2015 to conduct interviews with both doctors and patients, and I used both purposive and snowball sampling to find my participants (a copy of the approval document is provided in Appendix C on page 321). I started by contacting people who were involved with patient portals through the National Health IT Board or had commented on portals in different media platforms. Following up on my correspondence with these people, I asked if they could suggest other people who might be prepared to participate by giving an hour or so of their time. In line with the requirements of the ethics committee, all participants received a Participant Information Sheet detailing the purpose and scope of the research, and each one gave informed consent for their opinions and words to be used in the thesis.

I cannot provide very much demographic information about the doctors I interviewed because of the risk that someone might be able to deduce their identities. However, it does not endanger my participants’ anonymity to say that four of the doctors worked in Auckland, two were in Wellington, and the remaining worked in the Manawatu, Northland, Waikato and Marlborough, as outlined in Table 5.1 on the following page. Nine of the participants were male and one was female, which does not reflect the composition of the health professional workforce, given that in 2014, 47 percent of doctors working in general practice were female (Medical Council of New Zealand, 2015), but since



I did not set out to obtain a representative sample, this statistic did not trouble me. Eight of the doctors I interviewed were owners or part owners of an urban healthcare practices and one practice was in a rural area. All of the doctors were from different healthcare practices and nine of them were using a patient portal. It is useful to note that most of the nine practices had ten thousand or more patients, which, from my point of view, signalled that effective (or ineffective) use of portals have the potential to affect a large number of patients, and that my findings could contribute to other research for changing behaviour in practices or among patients.

**Table 5.1: Demographics of the Doctor Participants**

Identifier #	Sex	Region	Portal Experience
1	Male	Manawatu	Practice currently trialling a portal
2	Male	Auckland	Using a portal
3	Male	Auckland	Practice currently implementing a portal
4	Male	Auckland	Not using a portal
5	Female	Auckland	Using a portal
6	Male	Whangarei	Using a portal
7	Male	Waikato	Using a portal
8	Male	Marlborough	Using a portal
9	Male	Wellington	Using a portal
10	Male	Wellington	Using a portal

In general terms, the doctors who became my participants all exhibited more interest in patient portals than most of their colleagues, and in fact, several had assisted in promoting the portals. On a number of occasions, I tried to arrange interviews with doctors who had been publicly sceptical of the services, only to find that they had little interest in discussing their attitudes further, and I therefore must acknowledge that my participants tended to be at least moderately positive about the present and potential usefulness of the technology. I was not partisan in selecting my participants, but the bias that exists is an inevitable consequence of my recruitment method, and of researching a subject which was not yet widely known to the public. Furthermore, though the doctors in my interview sample generally favoured the portals, they were open about the frustrations

and limitations of the technology, giving honest opinions about the drawbacks as well as expressing their hopes for the difference portals might make to their practices and patients.

I also wanted to gain patients' perspectives of the patient portals. I originally wanted to recruit patients who were members of a healthcare practice which offered a patient portal, so that they would know about the technology. However, I found the recruitment of patient participants almost impossible: the doctors were understandably reluctant to provide information about their patients, and few patients publicly endorsed the technology. The NHITB had nominated certain doctors to act as eHealth ambassadors, but the board did not set up an equivalent among patients, and at the time I was gathering my data, only two patients on the NHITB consumer panel had access to a patient portal and only one was enrolled (S. Fletcher, Personal Communication, July 21, 2015).

Eventually, I managed to obtain interviews with two patients who frequently used a patient portal through their primary care practice, and another two who were not enrolled in a patient portal but had previously been consumer representatives in earlier implementations of portals, and so had some experience with the technology. I also interviewed a patient who had not used a patient portal but had requested the service, and already used electronic communication with her primary care practice and kept her own electronic storage of her notes. I felt that her contributions on the subject would be valuable, because she had essentially developed some of the functions of a patient portal through her own initiative, and she had researched patient portals quite thoroughly. This is outlined in Table 5.2 on the following page. At the time of the interviews, the patients were living in the Wellington, Taranaki and Manawatu regions, but I have not included this next to their identification number in Table 5.2 to avoid the risk of revealing their identities.

**Table 5.2: Demographics of Patient Participants**

Identifier #	Sex	Portal Experience
1	Female	Has knowledge of, but no experience using a portal
2	Male	Using a portal
3	Female	Some experience using a portal as a consumer representative, but not currently enrolled.
4	Female	Some experience using a portal as a consumer representative, but not currently enrolled.
5	Female	Using a portal

*The interviews*

There are various types of research interviews generally classified by degree of control that the interviewer exercises. At one end of the continuum are the structured interviews which usually involve asking a series of fixed questions, while at the other are the primarily unstructured interviews which are more consistent with ethnographic research (DiCicco-Bloom & Crabtree, 2006). In developing an in-depth understanding of perspectives of patient portal phenomenon, there were a number of questions which I wanted to explore, such as

*How do patients and healthcare providers consider the patient portal services?*

*Why do they feel this way?*

*What are their views on this?*

An indicative list of questions which I asked the participants is provided in Appendix D on page 322. The interview questions were formulated as a means of gathering data that would allow the answering of the research question, following Maxwell (2005) who stated: “Your research questions formulate what you want to understand; your interview questions are what you ask people in order to gain that understanding” (p. 92). I did not feel that it was necessary to pilot the questions, as pre-testing and post-testing for reliability is not a concern for qualitative research (Terry & Braun, 2017). As Holloway (1997) stated: “in qualitative approaches pilot studies are not necessary because the research has the flexibility for the researcher to learn on the job” (p. 121).

The favoured method of obtaining such personal perspectives is to speak to participants involved in the social phenomenon under investigation. I therefore determined that I should conduct qualitative semi-structured interviews because qualitative interviews can capture the thinking and lived experience of a person in narrations which can then be transformed into text for scrutiny by researchers and readers (Nunkoosing, 2005). Qualitative interviews have been described as “conversations in which a researcher gently guides a conversational partner in an extended discussion” (Rubin & Rubin, 2005, p. 4), and as being “merely one of the many ways in which two people talk to one another” (Benney & Hughes, 1970, p. 191).

I approached my interviews with a set of indicative open-ended questions that would allow me to guide the conversations and achieve some consistency across the whole dataset but also permitted probing and expansion of complex issues. Petrie (2005) warned that it can be difficult to achieve a balance between a positivist testing of a hypothesis and the phenomenological expectation of the researcher as a blank slate, because if researchers relinquish all control over the conversation, the data needed to address the research questions will likely not be gathered. On the other hand, the constraints of preconceived assumptions, categories and perceptions mean that interviews have the potential to become quantitative surveys (Petrie, 2005). Josselson (2013) argues that the best semi-structured interviews are "co-constructed" (p. 8), as the production and analysis of the material, is influenced by both the participant and the researcher, but regardless of the interviewer's skill and good intentions, there is always a power imbalance (Kvale, 2006). Interviews, by their nature, are encounters in which one person is attempting to obtain information for a particular purpose, and the interviewer inevitably not only assumes control, but also approaches the interviewee with an assumption that this is the natural order of the process (Kvale, 2006). As such, perhaps unsurprisingly, analysts have raised concern of interviewers using relationships of empathy and trust to elicit unguarded confidences and exploitatively gain ‘interesting’ material (e.g., Kvale, 2006; Duncombe & Jessop, 2012).

It would also be naïve to pretend that the researcher's and interviewee's status, race, culture, and gender do not influence what can be said, how it is said, and what can be written about (Nunkoosing, 2005). This becomes particularly significant when informed researchers are conducting interviews among patients and healthcare providers, as there is the potential for an asymmetrical knowledge and power imbalance. In my own case, as I have worked as a health practitioner, patients could perceive a conflict of interest, thinking that I am "on the side" of the medical establishment. With these challenges, defining the role of the researcher is not easy. According to Oakley (2003), research textbooks frequently typify the interviewer as either a recording system and a reporter, or alternatively, a psychoanalyst. Yet the way the interview is conducted is of significance, because the quality of the data gathered is the product of the interview (Nunkoosing, 2005) and the interviewer becomes "a tool of an instrument" (Goode & Hatt, 1952, p. 185). Data gathered from interviews cannot be viewed as providing absolute "truths" about meaning but need to be read as the constructed and reported realities which individual participants experience and interpret at that particular time and in the context of the interview situation.

I carried out my interviews in the second half of 2015. During them, I was transparent with the participants about my background and the purpose of the research before I commenced gathering. I guided the discussion with a list of open-ended questions, allowing participants to veer off when they wanted. This meant that the interview lengths varied from 20 minutes to over an hour and twenty minutes, although on average they were about 40 minutes long. The interviews were undertaken at locations where the participants felt comfortable, which included office meeting rooms and cafes, as well as over the phone with some of the doctors, where they were limited in time and travel would be difficult.

### *Data saturation*

In accordance with inductive analysis, this approach, I undertook gathering of primary data until I reached data saturation, and I deliberately avoided setting “number targets” for a certain number of participants. The concept of data saturation was introduced by Glaser and Strauss (1967) and it refers to the point in data collection when no additional data would develop further aspects of a conceptual theory. There is no agreed method of establishing when data saturation is met, although this has been explored by some researchers. Guest, Bunce and Johnson (2006) for instance, took an empirical approach using a set of 60 interviews and concluded that saturation occurred within the first 12 interviews, although the broad themes were apparent in the first 6 interviews. Francis et al. (2010) employed a similar approach and found that data saturation was achieved at the higher number of 17 interviews. Data saturation, then, is a vexed question, and seems to be very much in the eye of individual researchers. What it means is that sample sizes will vary to suit the complexity of different studies and the range and distribution of experiences or views of interest, rather than statistical parameters like those used in quantitative research (Francis et al., 2010).

I found that I had reached data saturation after ten interviews with the doctors, but although broad themes were definitely emerging in the patient data after my five interviews, I am not prepared to claim that data saturation occurred.

### *Data analysis*

After each interview, I transcribed the raw data in order to work with the whole data set. My transcriptions noted laughter and other spontaneous reactions, because I sought to understand my participants’ “perceptions”, and perception is not a purely cerebral response. For the analysis of my interview datasets I used a form of thematic analysis, influenced by the works of Boyatzis (1998), Braun and Clarke (2006) and Braun et al. (2015). This is a tool which examines “repeated patterns of meaning” (Braun & Clarke, 2006, p. 86), to find, analyse and report themes within datasets (Boyatzis, 1998). A strength

of thematic analysis is its flexibility. It is not tied with any particular theory or methodology and it can be used with quantitative and qualitative research, and both inductive and deductive approaches (Boyatzis, 1998; Braun & Clarke, 2006; Braun et al., 2015). This varies from other approaches to qualitative analysis, which are underpinned by specified and predetermined ontological and epistemological frameworks (Braun et al., 2015).

There have been some criticisms about the strength of thematic analysis in providing high quality data (Vaismoradi, Turunen, & Bondas, 2013). Dixon-Woods et al. (2005) argued that “there is lack of clarity about exactly what thematic analysis involves and the processes by which it can be achieved” (p. 47). The truth of this statement may depend on the form of thematic analysis. Boyatzis (1998), Braun and Clarke (2006), and Braun et al. (2015) provide a step-by-step guide for analysis which have guided my interpretation and as Braun and Clarke (2006), argue, even in an inductive approach, discursive themes or codes do not simply ‘emerge’, but rather, they must actively be sought out.

Braun et al. (2015) identified six steps for successful analysis. The first involves researchers becoming familiar with the data by reading and re-reading the entire dataset, following which codes covering key ideas are derived from the dataset. The next phase involves searching for themes, which identifies a broader level of meaning than a code, and it typically involves clustering codes together. Following this process, the researcher needs to review the themes alongside the original dataset to ensure that it effectively reflects the dataset and that the coding has not missed crucial data. Finally, the themes need to be defined and named, before being written up. Boyatzis (1998) outlined a similar process. He suggested three phases of inquiry: first, to observe the data in order to understand, second, to recognise important facets in the data in order to encode it; and third, to interpret the significance of the theme.

As mentioned, I interviewed ten doctors and five patients in the latter half of 2015. I took notes during the interviews of topics to probe or follow-up on and the interviews

were recorded with the participants' consent. While the process was time-consuming, I chose to transcribe the recordings myself, rather than outsourcing this to a professional transcription service (Kuniavsky, 2003) because it helped me to become intimately familiar with my datasets. I used the complete verbatim method (E. Jensen & Laurie, 2016), which meant that the transcriptions were identical to participants' words. I found having both transcriptions and audio recordings useful because I could listen to the audio recording to check that my transcription was correct and check the emotional context of nonverbal cues such as the tone and speed.

Having assembled the transcripts, I began my analysis by further familiarising myself with the datasets. After reading and rereading the datasets, and listening again to the audio recordings, I wrote notes about initial codes that covered key ideas covered within and across the interviews. I took these initial codes back to the datasets, noting anything I may have missed. The reoccurrence of a code across the dataset indicated possible coherent theme, but I also coded for repetition and intensity, that is any signals of emotion such as frustration or enthusiasm. I then manually made coding sheets (provided in Appendix E on page 323), which contained descriptions of each code and key words that occurred in each code. This helped me to group together similar codes, as I could see which encompassed similar concepts. For example, I ended up combining an initial code from the interviews with the doctors which concerned financial cost, with the key words 'money', 'financial', 'pay', 'charge', and 'free', with another initial code which concerned the concept of time, with the key words 'time' and 'efficiency'. Through constant comparison and cross checking, the codes were developed into broader themes. I arrived at this analysis method as a process of trial and error. My decision to transcribe the interview transcripts was an instinctual one but it worked to develop a deep familiarity with the interviews, which, in its own way, aided the process of analysis. I used an iterative process of coding as I did not want to arrive at a confirmation bias. As I have discussed, I am conscious that research is not value free, but with this process it was as much as possible.



Finally, in the writing up, I set out to present the participants' voices as accurately and in as lively a way as possible. In his essay on the interpretation of cultures, Geertz (1973, p. 23) talks of producing "thick description", the sort of ethnographic data that captures the sense of being present in a situation. Although I did not approach my write up with quite this ideal in mind, I was always aware that the portals engendered mixed and deep reactions among my participants and presented the data as much as possible as it was spoken to me, so as to show the depth of feeling that the portals provoke. However, as with any research, the extraction, collation, interpretation and presentation of data is naturally, prone to the researcher's interpretation, and intrinsically to their subjective position. I tried to lessen this, or at least provide clarity in my assessments, by giving each theme a label, definition and a description for its identification as recommended by Boyatzis (1998). What I tried to achieve in my presentation of the themes was a description of the qualities in the data, as opposed to simply providing a collection of numbers. This involved examining both the repetition and the emphasis of subjects within and across the data sets. Using this approach, I ended up with some themes being prominent in all the interviews, while others were present in a small number.

#### **5.4. SUMMARY**

Having explored prior theories and literature to contextualise my research, the purpose of this chapter was to outline my methodology and method. This chapter started by contextualising the time in which the research was undertaken. The rest of this chapter was divided into two parts, the methodological framing, and the method and operationalisation – that is my approach to the research, and the procedures that I undertook. Critical theory, which was discussed in section 5.1.1, was the research paradigm which guided my doctoral research. Aligning to this paradigm, my research is qualitative as discussed in section 5.1.2. I used a qualitative approach to my research because I felt that it was appropriate for gaining a rich, in-depth analysis of patients' and doctors'

perspectives. In section 5.2.1., I explored Dyzek's (1997) discourse analysis, which involved analysing the entities recognised and constructed, assumptions about natural relationships, the agents of the discourse and their motives, and finally, the metaphors and any other rhetorical devices. Section 5.2.2. stated my participant recruitment, interview conduction, and interview analysis. I used purposeful and snowball sampling to recruit participants, and I conducted semi-structured interviews which were analysed with an inductive approach to thematic analysis. Now that I have outlined the methodology and method, in the next three chapters I will present the findings from my primary research gathering.

**THE ANALYSIS MATERIALS<sup>17</sup>**

*This content has been removed by the author due to copyright issues.*

Figure 6.1: The Discourse Analysis Materials

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<sup>17</sup> The analysis materials are provided in a larger size in Appendix B on page 311

## **6: PATIENT PORTAL PROMOTION: A DISCOURSE ANALYSIS**

The purpose of this research is to examine patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand and an understanding of these perspectives is enriched if they are 'read' against the promotional communication that was developed to sell particular hopes and expectations. To this end, therefore, chapter 6 provides an analysis of selected promotional texts which were directed at patients and doctors. The analysis shows the basis of the discourses that are operant in the texts: the entities that are constructed or recognised, the assumptions that are made about the relationships between and among the stakeholders in the adoption of patient portals, the motivation of the agents of the discourses and finally, the rhetorical devices that were deployed in the attempt to create the portals as a social reality (Dryzek, 1997).

The screenshots on page 137 show the seven advertisements and two brochures I analysed. Texts 1-7 in the upper two rows are advertisements produced by the NHITB

and texts 8 and 9 are advertisements produced by Medtech for the ManageMyHealth patient portal. As outlined in chapter five, these advertisements were publicly available from the NHITB and Medtech websites. I chose to analyse the NHITB advertisements because it was the first time that they used paid advertising for the portals and included patients in its target audiences. I chose to analyse the Medtech advertisements to see whether the same promises and ideologies were in play in a private company, and Medtech provides ManageMyHealth, which is the most common portal in New Zealand (R. Brown, 2017).

Texts 1-3 and 8 targeted doctors, and texts 4-7 and 9 targeted patients. The targeting is clear within the advertisements. They address the target audience directly with phrases like “your practice”, and the images in the doctor-targeted advertisements are set in healthcare clinics, while those in the patient-targeted advertisements appear to be set in patients’ homes. Additionally, the choice of colour in the advertisements signals the target audience. For instance, the light blue of the scrubs and the clean white of the rooms are synonymous with medical practices and hospitals and the familiarity of the scenes depicted would allow doctors to develop instant identification. Likewise, patients are likely to feel comfortable with the diverse colours and “typical” styles in the texts aimed at them. Both sets of texts are designed, through the comfort of unchallenging and familiar scenes, to create common ground with their diverse audiences (Cheney, 1983). Texts 8 and 9 in the bottom row are brochures that were produced by Medtech for the ManageMyHealth patient portal. Again, the targeting is clear, with the doctor-targeted brochure on the left also referencing “your practice” and the patient-targeted brochure on the right referring to managing “your health”.

My method of analysis was influenced by Dryzek (1997). I did not follow his method of discourse analysis in a strictly linear way, but instead, I used his four principles to guide the examination of the texts. As discussed in chapter five, Dryzek’s

method examines what is seen in a discourse and its underpinning assumptions, judgments, and contentions. More specifically, it investigates the entities recognised and constructed, the assumptions about natural relationships, the rhetorical devices, and agents and their motives. From my analysis two sub-discourses were detected: the caring and concern discourse which constructed healthcare in terms of physical and emotional connection, and the business of healthcare discourse, which constructed healthcare as a commercial product.

There are two agents (Dryzek, 1997) who are invisible in the discourses, but have a strong impact on the implementation of patient portals. These are the producers of the texts, who occupy little space on the advertisements and brochures. In texts 1-7, the NHITB has a logo in the top right corner of the advertisements and Orion Health has a logo on the bottom right hand corner of text 8 and is unnamed in text 9. The aim of both agents is to persuade patients to ask their doctors about patient portals to increase the uptake in the implementation of the technology, although their motivations for doing so are different. The ultimate aim of Orion Health is to maximise profit by selling as many *ManageMyHealth* packages as possible. It is likely that they did not mention their company name in the advertisements to distance the *ManageMyHealth* patient portal from being a commercial product. The NHITB represents the Ministry of Health and seeks to effect behavioural changes in patients to bring about improvements in their health costs in the health sector.

### **6.1. THE CARING & CONCERN DISCOURSE**

The texts all, one way or another, show examples of care in action: doctors regarding their patients with focused concern; a mother cuddling her child; the invisible system allowing a young couple in a park to access information at their own convenience, which is, in its own way, an expression of care. Thus, I contend that *caring*

*and concern* is one of the entities constructed (Dryzek, 1997) in the promotional discourses of patient portals, and is heavily present in all the advertisements and brochures. This is expressed through the images which depict intimacy and closeness between the characters, most notably, perhaps, in the obvious visual metaphors in the patient-centred advertisements showing medical professionals emerging from technological devices. Here, the suggestion is that medical support is always close at hand whenever it is needed. This differs from the reality of patient portal use, as while information is available at the patient's convenience, clinicians are unlikely to answer queries outside of office hours.

Additionally, some of the images are redolent with standard tropes associated with caring: as I have already said, among the images in the patient-targeted texts, there is a mother holding her sleeping child (text 4), and the implication is that a patient portal means that medical expertise and care is close at hand to alleviate parental worry. The image in text 6 showing two adults sitting arm to arm with their coffee on a table in front of them suggests that receiving medical care can be as informal, comfortable and chatty as two friends having coffee. Text 9 is not so straightforward to interpret, because the written text emphasises the security of information in the portal and the picture depicts smiling Māori elders standing in front of a traditional carving which is possibly part of a *wharenui*<sup>18</sup>. The connection of the verbal message to the picture is not immediately obvious, but perhaps intends to reassure readers by referencing the old saying that something is “as safe as houses”. Alternatively, the peaceful smiles could be intended to carry the message of security, and the fact that the models are Māori is either an agreeable irrelevance or an effort to build a bi-cultural aspect into the brochure.

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<sup>18</sup> A *wharenui* is a traditional Māori meeting house, which is often decorated with carvings, rafter paintings and panels.

Whatever the interpretation, the images of smiling, relaxed people dominate the texts. For instance, the advertisements targeting patients (texts 4-7) are completely covered by pictures, and the advertisements directed towards doctors (texts 1-3) are about two-thirds picture. The images texts 1-3 construct a notable, and sometimes reciprocal closeness between patients and healthcare practitioners: facial expressions and eye contact depict friendliness and warmth. For example, text 2 shows a mother and child sitting in a waiting room, smiling at an approaching healthcare practitioner.

As well as showing an idealised closeness between practitioners and patients, these images construct simultaneous but somewhat conflicting views of patients. On the one hand, they are shown in charge, availing themselves of the convenient technology (text 9), but also as vulnerable and dependent on their doctors for help, reassurance and support. Vulnerability is signalled in the advertisements by featuring children and elderly people, and by showing body language of concentrated attention on the practitioner (text 5), in which an older man is bent towards the doctor, clearly listening attentively, and text 4, in which a child is shown cuddled curled up on her mother, clearly seeking comfort. At the same time, the patient portals apparently encourage vulnerable patients to hope for good outcomes, because their body language suggests optimism, as though the affordances of the patient portals offers a certain peace of mind. It is fair to say, however, that these patients do not appear acutely unwell, so perhaps the ultimate message is “care and concern *everyday*”: the portals would have no appropriate place in acute or emergency situations.

The intimacy and closeness between the characters shows a recognition of the psychological components of healthcare, which contrasts with the biomedical viewpoint (Nettleton, 2006a). Healthcare is here constructed as more than just the delivery of medicine or the mending of physical ailments: it is also shown as a tool of reassurance, where the act of medical care is delivered through compassion and the simulation of



physical touch. The new technology, therefore, promotes its distant service in terms of the most established form of medical practice, the face-to-face contact, and in this respect, maintains the convention that doctors control the encounter and are central to the patients' well-being. Thus, the healthcare professionals are constructed as the binary opposites of the patients: they are presented as experts, and their expertise is represented by their confident body language and reinforced by various symbols of the medical profession, including a nurse's uniform (text 2), scrubs (text 3), a lab coat (text 1), and a stethoscope around a doctor's neck (text 1 and 4-7). It is not a coincidence that these symbols have been included in the texts, because they not only identify the roles of the different 'characters' in the texts, but also represent and perpetuate the power of the medical profession, as expertise is the surest way that doctors can exert power over patients in the context of healthcare delivery, even if they do it unconsciously or with the best of intentions.

The asymmetry of the patient-doctor relationship is perhaps demonstrated in text 8, where a doctor's hand passes an apple to a patient. The apple in this text refers to the old proverb "An apple a day keeps the doctor away", and here symbolises health as a commodity which the doctor can dispense, and the patient will receive passively at the doctor's hand. Although this text may be well-intentioned, it nevertheless constructs doctors as the gatekeepers or providers of good health, though oddly, the reference to the old adage seems to contradict the dominant message. The construction inevitably emphasises doctors as the gatekeepers and providers of good health which tends to work against any development of patient independence and informed decision-making. Here, the reference to the old adage seems to contradict and work against the dominant message of the portals as enablers. Here too, instead of giving the variety of apple and its source, the sticker on the apple states the source of better health: the

ManageMyHealth brand. This patient portal is positioned, therefore, as the way for doctors to become the provider of health.

Texts 4-9, which target the patients, feature doctors rising ghost-like from digital devices that represent the patient portal. The representation of the portals is not direct, but it is difficult to depict an intangible product, and the assumption that underpins the depiction is that a strong, positive relationship exists between patients and technology. Significantly, the assumption is mostly implied, because only two images actually feature technology at all. Text 9 shows a young, healthy-looking couple sitting closely together, smiling as they presumably access a patient portal. The main focus of this image, and all the other images, is not technology, but rather, people which is not to say that the texts do not construct the product which they are promoting, for they do. However, what is constructed seems overwhelmingly fantasy version of a patient portal, suggesting friendly, caring interpersonal relationships (as opposed to solitary access of an impersonal medical record) arising from trouble-free technology.

The entities recognised and constructed in the texts (Dryzek, 1997) can be deciphered from the written text as well as the images in the texts, which all (except for text 9) feature verbal messages superimposed directly on images that are likely to be familiar to the target audiences. This familiarity, together with the use of the second person pronouns, relates to, and draws in the viewer who is addressed as “you”. Fairclough (1992) speaks of forms of synthetic politeness created by the use of personal pronouns in otherwise impersonal contexts, and I contend that here they are used to build synthetic politeness. The written messages are woven into the structure of the pictorial fantasy, contributing pithy ‘bumper sticker’ ideas that build and reinforce meaning. For example, text 2 shows the image of a doctor smiling at two patients. The image is accompanied by the words, “Because the highlight of your team’s day is seldom admin”, which suggests two things: first, that the interaction with patients, and perhaps

that helping others in need, is the real highlight of the medical profession, and second, that a caring leader of a team would do whatever it takes to reduce the “admin” load by providing staff with a patient portal. This may reflect the growing administration that is being placed on staff in general practice, that has been documented in scholarship for over a decade (e.g., McAvoy & Coster, 2005; McMurray & Clendon, 2015).

Nevertheless, taken together, the image and the written message evoke the notion that medicine is more than just a job, and that delivering care is a higher calling that serves the greater good. Similarly, the verbal message in text 8 claims that a “Clinical and Patient Portal” is part of “Enhancing Patient Care”, constructing the entities of empathy, friendship, and other elements often considered fundamental to ‘patient care’.

The NHITB advertisements (texts 1-3), which are directed towards doctors, contain four sentences claiming that a patient portal should be implemented because it will give, “...more time to spend with the patients you [the doctor] really need to see”. The last five words of this tagline are particularly telling, because they highlight the value placed on face-to-face interaction, and it positions patients as being in need of the doctor’s aid, although it simultaneously suggests that some patients are not ones the doctor “really needs to see”. As with the other texts, the use of the second-person pronoun “you” appeals directly to the target audience and builds identification with product. Part of the identification under construction here occurs because of the separation of “you” from “they” - the patients - who are referred to in the third person. This lexical separation suggests that the makers of the patient portals have an intimate and sympathetic understanding of the problems of doctors’ work, and want to help solve this particular problem, the burdensome and time-consuming patient who does not “really” need to be seen. This advertisement stands in marked contrast to the personal identification established with “your team” in text 2. The doctors and the

doctors' team are personalised, while the patients are not, another signal that the relationship between patients and healthcare providers is unequal.

The nature of relationships varies in the texts. In the patient-targeted texts, intimacy and closeness is depicted between patients and their loved ones outside of the medical establishment, demonstrating a separation and a relationship shift that is constructed by the patient portal, in which the doctor is repositioned from the carer to the expert, and the patients' loved ones become the providers of support and care. For example, all of the patients are depicted outside of the medical facility, and the Medtech brochure (text 9) emphasises how a patient portal can allow healthcare to be managed "anywhere, anytime". Conversely, most of the images in the doctor-targeted texts show a closeness between patients and healthcare practitioners, and texts 1-3 state, "Enhance your relationship with your patients". Thus, the doctors are constructed for the two different audiences as both experts providing medical knowledge and patients' carers and sources of support, and both constructions occur through the medium and mediation of the patient portal: the doctor-targeted texts claim that it a portal will give doctors more time with their patients, while the patient-targeted texts claim that it will allows patients' healthcare to be managed in the home, with the care and love of family.

There are two instances where the use of a homographic pun exemplifies the caring and concern discourse. Broadly, both puns refer to the patient portal as enhancing relationships while simultaneously lessening the physical proximity between patients and doctors. The first pun occurs in the word "closer", in the tagline "Your GP has never been closer" which is used in texts 4-7, the advertisements targeted at patients, and the second is in text 1<sup>19</sup>, in the word "connected", as in the phrase, "Stay more connected with your patients". The puns may have been unintentional but

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<sup>19</sup> The word "closer" in the first sentence could refer to a more intimate relationship or to a shorted proximity through a digital device between patients and doctors. The word "connected" in the second sentence could refer to doctors being electronically or psychologically linked with their patients.

considering the benefits that patient portals are meant to offer both sides of the doctor-patient relationship, it is unlikely that the straightforward denotative meaning of either words was intended. Reading the taglines in the context against the purpose of the advertisements, it becomes clear that the portals are desirable for patients because they make medical care accessible from a distance, which in real terms, is the opposite of “closer”, although the idea is reinforced by the images which depict doctors emerging from electronic devices. Conversely, the advertisements directed towards doctors place value on the way the portals can improve the psychological connection between doctors and patients, as it shows a doctor caring for a frail man.

These two taglines are significant for a number of reasons. First of all, both are part of the largest, most dominant written text in the advertisements, and they are placed and coloured in such a way that they inevitably catch the reader’s attention. Therefore, it is likely that much thought was put into the meanings and connotations associated with the phrases. Furthermore, the way that the two puns bring the viewers’ interpretation to the different meanings show the conflicted nature of the caring and concern discourse: on the one hand, the care it expresses is occupied with eliminating all but “the patients you really need to see” from the doctors’ day, but on the other, it brings the doctors “closer” to the patients than ever before. Significantly, the two goals are contradictory and incompatible.

The taglines also demonstrate the different technological functions of the portals, redefine concepts of closeness and care in the patient-doctor relationship, and notably, that this concept is not a negotiated one, but rather, is technologically determined. Choice exists (at least for the time being), for patients to accept or reject the use of portals, but if they do accept them, then, as suggested in the advertisements, this is a new model of “closeness” to which they must acquiesce. In the case of the advertisements targeted at doctors, the focus of the discourse of “care and concern”

rather concentrates on the way the portals can assist and preserve the traditional patient-provider relationship where the doctors are the holder of the power, or, as text 8 suggests, the apple of good health.

One of the entities constructed in the discourse of Care and Concern is *technological safety*, and this entity is developed and substantiated in two ways. The first method of bringing technological safety into being is to de-emphasise technology altogether and to emphasise, people instead: people interacting with others – family, doctors, patients – looking relaxed, happy, and confident in their different situations. Thus, through the safety and convenience of this new technology, the discourse of patient portals constructs enhanced interpersonal relationships, surely to circumvent uncertainties and doubts about the online safety of personal health information. An abundance of studies has shown that patients' worry about the privacy of information in healthcare ICTs (Fischer et al., 2014; Peek et al., 2014), and here the Medtech brochure reassures its audience by likening patient portals to the security and familiarity of internet banking. The entity of technological safety, therefore, runs parallel with assumption about the medical safety of the portals: the discourse of care and concern cannot function as a representation of social reality unless it is predicated on a sense that patients are in virtual hands that are as safe as human hands. Despite the reassurances offered about the safety and convenience of patient portals, on balance, the texts directed at patients contain fewer images of the patients using the technology. One reason for this might be that not all the target audience are digital natives and some people might either not have access to the technology or might have been frustrated by online programs in the past. Usability issues have been shown as a barrier to the successful uptake of healthcare technologies among patients (Fischer et al., 2014; Peek et al., 2014).

## 6.2. THE BUSINESS OF HEALTHCARE DISCOURSE

Although the discourse of the Business of Healthcare is less overt than the Caring and Concern discourse, it is present, deeply embedded within the advertisements. The discourse of caring and concern dominates the images in the advertisements, but the Business of Healthcare discourse becomes evident when the verbal component of the texts is examined. For instance, the “blurb” in text 8 is full of terms such as “efficiency”, “effectiveness”, “reduces costs” and “generates revenue” and I contend that all these are noticeable examples of medical practice being colonised by the discourses of business and managerialism. On the surface, the Business of Healthcare discourse seems even less explicit in the advertisements that are directed at patients, but such images as those in texts 4-7, of a doctor ghosting out of a digital device, accompanied by written suggestions that patients can manage more of their healthcare for themselves, are subtle examples of this discourse in practice. Much has been written elsewhere of the colonisation of private life by the service of capital<sup>20</sup>, and the same principle is in operation here. The advertisements emphasise the business side of doctors’ practices. The business terms quoted above construct doctors not only as experts, but also as business owners possessed of a business mentality, and, therefore, concerned with efficiency, profit margins and revenue generation. It is doctors-as-business-people, rather than as healers, that the doctor-targeted advertisements address directly. For example, texts 1 and 2 state, “A patient portal can reduce your general practice team’s administrative burden and improve workflow, giving you more time to spend with the patients you really need to see”. In this sentence, the doctor’s employees, the “team”, are presented as being inefficient or at least not as efficient as they would be if a patient portal were implemented, improving “workflow” and

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<sup>20</sup> See, for example, the discussion of “free labour” in Lazzarato (1996) and Beverungen, Böhm and Land (2015).

streamlining the manner in which the medical practice is run. The language here sounds more reminiscent of factory organisation and operations management than the people-oriented functions of traditional health care. Furthermore, the use of the word “burden” suggests that healthcare practitioners are overworked because of an excessive amount of administration, which hinders their time with patients. The words “patients you really need to see” imply that delivering care and concern is still a priority in the medical profession, but taken with the business terms, this indicates that caring must also return a profit.

For some time, public discourse has been full of expressions like “encourage efficiency, flexibility and innovation in the delivery of health care to the community” (Upton, 1991, p. 3), and there is a sense in which these advertisements reflect this thinking. Business thinking, as an entity constructed in the discourse, is demonstrated in other ways. For example, in text 8, the Medtech brochure states, “Connecting doctors with patients online to enhance practice efficiency and effectiveness”, and it claims that a patient portal is, “A secure online solution that extends the capabilities of your practice”. The idea of “enhancing practice efficiency and effectiveness” is surely appealing, as is the notion of extending the “capabilities of your practice”. However, here the discourse is long on claims and short on detail: these business “buzz words” are, on one level, impossible to oppose, because what sensible person would not want to be more efficient and effective? However, as I have already pointed out, the claim is predicated on the idea that present systems need improvement, and that medical practice is readily conceived of as a throughput. The verbal message in text 3 states: “because the 30 hour day is unlikely to eventuate”, and this supports the suggestion to practitioners that they are overworked from administration and this can be lessened by streamlining services with a patient portal.



Aligning with the idea that patient portals commodify healthcare, the advertisements directed at patients show them as consumers who have the ability and the resources to make free and informed decisions about the portal services available to them. At this point, the focus in the advertisements shifts towards patient wellness, as something that can be managed with the help of the patient portals, and away from any sense of patients' illness. In other words, the discourses of business embedded in the advertisements construct an entity of patients as motivated and informed consumers rather than people suffering illness. The constructed entity of health consumption dominates the written message. This construction dominates the written message of text 9, which pushes "The freedom to manage your health and wellness online" and urges people to "Stay on top of your health and wellness". Here, the patient portal is positioned as a tool for patients to take control of their healthcare, health conditions, and, significantly, their overall health status, as opposed to their sickness. For example, the Medtech brochure emphasises individual control, stating "You're in control" and "Take control of your health and join today", and promising that "You will also be able to improve your health and track your progress online". The NHITB advertisements in texts 3-7 similarly state, "A patient portal is a fast, safe and convenient way for you to manage more of your own health care". Thus, the patient portals present an idealised view of patients, not as sufferers of sickness, but as pro-active purchasers of health.

In constructing the claim that portals put patients in control of their healthcare, the advertisements make a series of assertions about what that means. According to the NHITB advertisements in texts 3-7, control means to "Book appointments with your GP, request a repeat prescription, check lab results, see your health information and communicate more easily with your practice". Similar services are listed in text 9, the Medtech brochure. Thus, in this realm, control means to overcome the barriers of time and location, because "You can log in to your patient portal and manage it in your own

time – 24 hours a day, seven days a week – from wherever you happen to be”. The images depict caring and concern, but healthcare is constructed as a series of purchasable services delivered by healthcare practitioners.

In addition, the texts define what it means to manage one’s health and further, to be healthy. Text 9 states, “You will also be able to improve your health and track your progress online”. Here, the advertisement is offering the portal as an external device for motivating self-management and accepting responsibility for improving health. This is particularly evident in text 8, which depicts a doctor passing an apple to a patient, above the phrase “technology for health”. Again, the claim is large: the details of how the technology delivers health are absent. This point is also demonstrated in the advertisements directed toward patients by the avoidance of terms for ‘illness’ and ‘disease’ and advocacy for managing health, a framing which is significant, given that portals are likely to be most beneficial to individuals receiving medical treatment for illness.

Thus, illness and disease are rendered invisible and instead, what is constructed are many shades of managed health, and no one is outside of the boundaries of requiring self-management. This could be an example of healthism (i.e., Crawford, 1980) and healthicisation (i.e., Conrad, 1987), where health is moralised and presented as a result of individual choices. It could also be part of a broader trend, as analysts as far back as 2000, have discussed how patients are being expected to take more responsibility for managing their healthcare in New Zealand (e.g., Barnett, 2000; Fitzgerald, 2004). Although this might seem economically desirable, as Rose (2013) explained, responsibility is a “double edged sword” (p. 349); patients have more information and decision-making, but they are also obliged to take on this role and to accept some of the consequences of their decisions.

The doctor-targeted advertisements do not construct the patient portals as an important intervention in the delivery of healthcare, but rather considered as a tool to reduce administrative burden and increase time for face-to-face care. The following quote features in texts 1-3, all of which are directed at doctors: “A portal can reduce your general practice team’s administrative burden and improve workflow, giving you more time to spend with the patients you really need to see”. Furthermore, none of these advertisements depict patients using portals, which is a noticeable absence, given that one of the most important functions of all portals is the ability to give patients access to their health records and to contact their healthcare practices electronically. Correspondingly, the written messages in the NHITB advertisements do not mention the portal functions that serve patients, and although text 8, the Medtech brochure, does mention them, it does so in a way that downplays patient control and up-plays benefits to doctors: “Connecting doctors with patients online to enhance practice efficiency and effectiveness” and “patient self-service”.

Taken as a whole, then, the patient-doctor relationship constructed in the Business of Healthcare discourse is one in which doctors are the providers of a business service and the patients are the discerning consumers of this service. Each of these agents is constructed as possessing personal motivations: the consumers as wanting control of their healthcare, and the doctors as wanting to streamline their services and maximise efficiency and profit. The two sets of texts show curiously little awareness of the other audience: the doctor-targeted advertisements are one-dimensional in their focus, showing little acknowledgement of the needs of patients, and, although the patient-targeted texts recognise the doctors as with providers of healthcare, they, equally, pay no concern to the efficiency of medical practices. Like the discourse of Caring and Concern, the discourse of business presents patient portals as capable of delivering both of these goals.

Table 6.1: Summary of Key Results

	The Caring and Concern Discourse	The Business of Healthcare Discourse
Ontology	<ul style="list-style-type: none"> <li>- Care is delivered through compassion and physical touch.</li> <li>- Patients are vulnerable and dependent.</li> <li>- Healthcare practitioners are experts.</li> </ul>	<ul style="list-style-type: none"> <li>- Healthcare is a commodity which can be bought and sold.</li> <li>- In the patient-targeted texts, patients are constructed as consumers who have the ability and the resources to make free and informed decisions.</li> <li>- Doctors are providers of a service.</li> <li>- In the doctor-targeted texts healthcare practitioners are overworked and less effective than they might be due to excessive administration.</li> </ul>
Assumptions about Natural Relationships	<ul style="list-style-type: none"> <li>- In the patient-targeted texts, doctors are experts to consult and the patients' loved ones are the providers of support and care.</li> <li>- In the doctor-targeted texts, doctors are both experts providing medical knowledge and patients' carers and source of support.</li> <li>- There is a strong relationship between people and technology that is positive.</li> </ul>	<ul style="list-style-type: none"> <li>- Doctors are business owners and providers of a service.</li> <li>- Patients are the discerning consumers of this service.</li> </ul>
Agents and their Motives	<ul style="list-style-type: none"> <li>- In the patient-targeted texts, patients seek doctors for information.</li> <li>- In the doctor-targeted texts, doctors want to spend more time with patients who are in need.</li> <li>- People can and want to use technology.</li> </ul>	<ul style="list-style-type: none"> <li>- Patients want control of their healthcare independent to the medical facility.</li> <li>- Doctors want to streamline their services to be more efficient and profitable.</li> </ul>
Key Examples of Rhetorical Devices	<ul style="list-style-type: none"> <li>- Homographic puns in the phrases: "Your GP has never been <u>closer</u>" (texts 4-7) and "Stay more <u>connected</u> with your patients" (text 1).</li> </ul>	<ul style="list-style-type: none"> <li>- Homographic pun in the phrase: "let a patient portal <u>work</u> for you" (texts 1-3).</li> <li>- The switch to the first-person pronoun in the brands "managemyhealth" and "its <u>my</u> health" (text 9).</li> </ul>

### 6.3. SUMMARY & DISCUSSION

This chapter analysed seven advertisements and two brochures promoting patient portals to two separate audiences in New Zealand, following Dryzek's (1997) four principles for discourse analysis. Within the overarching discourses of medical technology in general, and patient portals in particular, two sub-discourses were detected<sup>21</sup>. In the first, the discourse of care and concern, healthcare is constructed in terms of physical and emotional connection, presenting patients as vulnerable and dependent, and doctors as experts. In the second, the discourse of health as business, constructed healthcare as a commercial product, provided by doctors to consumers, in which efficiency is paramount.

Although both discourses stress the benefits of patient portals and appear to be motivated by strong, socially-oriented altruism, they are essentially promotional, and primarily serve the companies selling patient portals in the medical marketplace. Finding the appearance of altruism and concern in the texts was not entirely unexpected. As Cheney (1983) argues, in attempting to convince message recipients of the value of a social artefact (in this case, patient portals), rhetoricians can express concern for individuals to engender favourable attitudes and desired changes in the target audience. Here, the push to appear concerned for the well-being of patients might lead to their adoption of the portals as part of their way of life, overcoming any initial uncertainty that might exist about the technology.

In giving the impression of serving two quite different audiences, the discourses of the patient portal seem somewhat contradictory, but the unifying element in each is the concept of care, albeit a form of care plotted along two quite different axes. In texts 1-3 and in text 8, my analysis has shown that profit and the delivery of care go hand-in-hand. This finding is significant in that, within the context of patient portals, care is removed from being straightforwardly a natural human reaction that characterises the relationships

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<sup>21</sup> A summary of some of the key points of each discourse is provided on the facing page.

in the medical profession, and is, instead, conflated with profit and success in business, rather than success in simply helping people get through illness.

Although this chapter is ordered into two clear-cut discourses, my analysis showed that there is variability between the patient and doctor targeted texts. For example, in the Care and Concern discourse, the provider of support and care is the patient's loved ones in the patient-targeted texts, but it is the doctors in doctor-targeted texts. The same discrepancy is present in the discourse of the Business of Healthcare, as the notion of a discerning consumer is not present in the texts targeted at doctors, even though healthcare is formulated in business terms such as "efficiency", "reduces costs" and "generates revenue" (text 8). Furthermore, the representation of patient portals varies so significantly between the patient and doctor targeted texts, that they appear to have a completely different purpose. In the patient-targeted texts, the patient portal "gives" (text 10) consumers a way to manage their healthcare in the home with digital devices, but in the doctor-targeted texts, it "works" (texts 1-3) for doctors by reducing administrations and streamlining services. Whichever purpose is uppermost in the readers' minds, the texts show evidence of what Cheney (1983, p. 152) calls the "advocacy of benefits and activities". In other words, regardless of audience, patient portals are 'sold' as advantageous additions to their lives. Again, the texts must be said to covertly serve the manufacturers, not medicine, although the overt messages are quite the opposite of this interpretation.

Both sets of texts depict a commodified version of healthcare that perhaps reflects in part the growing financial pressures in the healthcare sector. This in turn alters conceptualisation of closeness. In the doctors' texts, closeness is depicted between patients and healthcare practitioners, which constructs a relationship of a paternalistic nature (see, for instance, Emanuel & Emanuel, 1992), where doctors provide physical care for patients. Simultaneously, the discourse of the Business of Healthcare constructs healthcare as a business in which doctors are sellers of a service, and closeness is commodified as a part of

the product. In the patients' texts, closeness occurs not in a clinic, but within the home, and not with doctors, but with family. Communication with healthcare professionals occurs at a distance via the patient portal. This resembles Emanuel and Emanuel's (1992) consumer model, where patients make decisions about their healthcare, and doctors provide the required information.

I believe that this shift in focus is important to note, because even if the outcomes of patient portals are entirely benign (and that is not the question here), healthcare has changed -- or perhaps more truly, *will* change -- as a result of technology that by its nature, cannot help but reconfigure the traditional relationships between health professionals and their patients. The technological determinism (Marx & Smith, 1994) of the portals is altering the conventions of closeness, in the senses of both physical proximity and emotional connection, and at the same time shifting some of the responsibilities and stresses of clinical administration onto patients. The presumption of new closeness – the doctor is always *in* (the device) – makes no mention of any new stresses that might adhere to the new technology, nor to the fact that the work of organisations has been shifted to citizens-as-patients, in much the same way as has happened with on-line banking, travel and entertainment bookings, and a whole raft of other areas of social life. This shift has not been overtly framed in the texts in terms of neo-liberal ideology, but what appears to be functioning in the discourse is a naturalised acceptance that what technology makes possible should, *ipso facto*, become part of the institution of health care. The conclusion that can be drawn is that the patient portal technology serves a wider social purpose than simply making life more convenient for doctors and patients. The 'wider social purpose' I allude to here may in fact be a technologically-determined move to reduce the costs of health care by shifting some of 'health work' onto patients.

I can see in the texts that closeness is being changed, and I wonder whether the changes will undermine the trust that patients need to feel in their health care professionals, or whether it will lead to a different kind of trust from the past. By "a different kind of

trust”, I mean that trust might come to be based on the technological virtuosity of the portal itself, rather than on the interpersonal and medical skills of doctors. Text 1 argues that the digital relationships can be deep: the image shows a doctor looking deeply and empathetically into the eyes of an elderly man, using touch by way of a hand on the shoulder, to convey reassurance and comfort. This is in no sense a new form of connection, although it might be a little more intimate and idealised than is typical of busy doctors in their daily work, and the image may in fact undermine the portals’ message of ‘24/7’ technological availability because it is so clearly situated in traditional notions. The scholarship on hyperpersonal communication (Walther, 1996) posits that computer-mediated communication can exceed face-to-face communication in terms of impression-generating and achieving relational goals. Certainly, the image in text 1 suggests that the patient portal offers a high level of interaction and involvement which implies that it may be difficult to achieve the same level of satisfaction in traditional patient-doctor consultations. The trust that is depicted in this image is trust deriving from a web-experience that seems to promise all the time in the world for the doctor to be caring and warm, rather than efficient and brisk, and it is trust based on the image of caring rather than an experience of sound diagnosis and correct treatment. At the same time, however, what is portrayed is a traditional person-to-person trust. Like closeness, trust will change, as well as what is trusted.

The discourse of the Business of Healthcare raises the issue of whether efficiency equates to effectiveness in the context of healthcare. The NHITB doctor-targeted advertisements (texts 1-3) claim that the patient portal lessens the administrative burden practices have to carry giving doctors more time to spend with their patients, and thus increasing the effectiveness of a consultation. However, the inevitable equations in a business model are that less administration equals fewer staff or more consultations. Reduced costs and increased income are pertinent matters in relation to patient portals, as clinics must cover implementation costs and on-going operating fees. In the hard light of



the bottom line, it seems unlikely, therefore, that patient portals will enable doctors to spend more time with their patients.

The images in texts 1-3 of doctors ghosting out of digital devices persuasively - but contestably - suggest that patient portals could replace traditional face-to-face consultations. Some research has determined that patients are reluctant to select an intervention that appears to undermine physical person-to-person contact (e.g., Loh et al., 2009; Milligan et al., 2011; Walsh & Callan, 2011). Nonetheless, should such a shift occur, this begs the question of the impact that this would have on the nature of healthcare delivery, and further, as Martin (2014) queried, on what it means to care and be cared for. Oudshoorn (2001) argued that technologies (such as patient portals) involve a transformation in the order of care, where patients are expected to perform tasks which were once the province of healthcare practitioners. When I consider this point in relation to the image in text 1, of the elderly man and the doctor, I cannot help but return to my critique of the paternalistic and consumer models of healthcare (Emanuel & Emanuel, 1992) in chapter two: that understanding medical facts is not the same as understanding patients' needs and concerns. If the purpose of medical care is to deliver care and support, then changing doctors to providers of medical knowledge and patients to decision-makers alters the implicit relationship between doctors and patients and inevitably alters the purpose of medicine.

The consumer model (Emanuel & Emanuel, 1992) does have potential advantages for patients. For instance, it could level patient-doctor power relations and allow patients to make informed decisions. Yet it is hard to neglect the weaknesses in positioning patients as consumers, that can and want to use technology. Such assumptions contradict the work that shows that patients need to feel known and understood (e.g., Burton et al., 2010; Engel, 1988; Levinson et al. 2005; Stiggelbout & Kiebert, 1997). It also assumes that patients want to be consumers and make decisions about their healthcare. This assumption conflicts with literature which has shown that patients more often prefer

doctors to play the primary role in decision making (e.g., Burton et al., 2010; Levinson et al. 2005). Of further significance is that the consumer model assumes that patients have the ability, resources, and, as was constructed in the discourse of Care and Concern, the support networks who are able and willing to provide care, which again, is not always the case.

The texts aimed at patients show another consequence from commodifying healthcare, which is that it constructs a particular view of health. The notion that individuals can “improve” (text 9) their health from the use of an online medium, separates the state of being healthy into a spectrum of various shades which means that no one is outside of the boundaries of requiring health management. This broad re-definition of health supports arguments in favour of patient portals, placing obligations on individuals to ensure that they manage and maintain themselves. This notion is reminiscent of Conrad’s (1987) ‘healthicisation’ and Crawford’s (1980) ‘healthism’, and has the potential to moralise health, framing sick people as the responsible for, and perhaps even the cause of their condition. It also encourages medical interventions, as managing health is defined in texts 3-7 as being able to “book appointments with your GP, request a repeat prescription, check lab results, see your health information and communicate more easily with your practice”.

A (perhaps extreme) extension of this argument might produce claims that if society does not grant permission to be ill in the absence of a diagnosed disease (Glenton, 2003; Nettleton, 2006b), equally, it will not grant permission to be healthy without medical intervention. Carrying this argument to its logic extremes would inevitably have financial ramifications for patients, because if the added cost of consulting professionals to be told that they are maintaining their health. It would also have implications for the way that health and ‘being healthy’ is viewed and practised. Perhaps the most disturbing element however would be patients’ loss of agency over their own bodies, which aligns with a kind of healthism (i.e., Crawford, 1980) and healthicisation (i.e., Conrad, 1987) where medicine

is further entrenched into daily life. It could also impact the nature of the healthcare professional, to focus further on the maintenance of health, as opposed to the treatment of illness.

A weakness of my analysis is the risk that the discourses I have identified exist only in the texts I have studied and analysed. I cannot dispute that this risk exists, although I can say, as I prepare to write up my interview data, that the discourses overlap with my findings from the interviews. My discussion of the discourses has highlighted some scepticism about changing patients to consumers, but I would argue that what I have found is neither completely positive or nor completely negative, but instead reflect a change that is defined by and expressed in new language. Recently, I spoke to a German man who said that the English language is humorous the way everything is “a glass half full” with regard to healthcare. He said that in Germany “you don’t buy health insurance; you buy sickness insurance. You don’t receive healthcare; you receive sickness care. And, a nurse is translated to a ‘sister of sickness’”. The point that this man made, which is worth making here too, is that the language used in health (or sickness) demonstrates a sanitisation of healthcare which wraps ‘sickness’ up in an optimistic bow of ‘health’. Correspondingly, the characters in the texts appear optimistic and do not seem acutely unwell, which differs from my experiences at healthcare practices. Furthermore, what my analysis has also shown is that the use of the terms like ‘health’ reinforce changing social obligations on the healthy, what it means to deliver care and healthcare, and who is included within the reach of the healthcare establishment.

## 7: THE DOCTORS' PERSPECTIVES

The discourses of the patient portals are strongly promotional: they see benefits to two separate audiences, using two quite different constructs to do so. One of these constructs is patient portals are promoted to doctors on the basis of liberating them from administration so that time can be re-directed to more worthwhile tasks, and this 'liberation' is depicted in terms of care and compassion for patients. It is against this background of these constructs that I now place the data gathered from the interviews I conducted with doctors. The ten doctors whom I interviewed worked at different healthcare practices in Auckland, Wellington, Manawatu, Northland, Waikato and Marlborough. At the time of the interviews, eight of them were using a patient portal at their workplace, and another was in the process of implementing a portal.

The ten interviews produced more than fifty-thousand words of raw data which constituted a bulk of material requiring a form of analysis that would allow main ideas to be made transparent. I, therefore, analysed the interviews thematically (Boyatzis, 1998; Braun & Clarke, 2006; Braun et al., 2015) and determined four themes existed in the data from the doctors. These themes are of the bulk of this chapter. I chose to use thematic analysis because it is a way of inductively finding, analysing and reporting "repeated patterns of meaning" (Braun & Clarke, 2006, p. 86) in datasets. As I discussed in chapter five, the

analysis involved: transcribing the interview recordings verbatim; reading and re-reading the transcripts and listening to the recordings; developing initial codes covering key ideas derived from the dataset; searching for themes, which identifies a broader level of meaning; reviewing the themes alongside the original dataset; and finally defining, naming, and writing up the themes.

Analysis revealed four themes in the data. I have captured the sense and qualities of the themes, beginning each with the key words that coalesced into a pattern and thereby showed the theme, together with a brief definition of the overall ‘aspect’ of the theme. This was recommended by Boyatzis (1998). The first theme is “Uptake” and it shows the doctors’ awareness of the difficulties connected with the adoption of the new technology, especially in terms of enrolment in and use of the patient portals by patients, doctors and healthcare practices. The second theme describes the cost of patient portals in money and staff time. The third theme explores the doctors’ hopes for the portals, showing their awareness of the qualities and the functions of the technology. Finally, the fourth theme examines patients’ information seeking behaviours, the communication between patients and healthcare providers, and the overall impact of the technology on relationships. Following Braun et al. (2015), I have kept the four themes distinctive and have not allowed them to overlap, but I have showed where they relate to one another. The chapter closes with a summary and discussion of the key concepts in the themes.

### **7.1. THEME 1: UPTAKE**

Keywords: uptake, enrolment, use, inequality, promotion

Definition: doctors describe the enrolment and use of the patient portal services by patients, doctors and healthcare practices.

‘Uptake’ was not the biggest theme in the sense of the number of times its key words occurred in the data, but it was nevertheless something that the doctors were clearly aware of and even concerned about. Some of my participants brought the matter up only in

response to my direct questions, yet their answers were so emphatic sometimes even strained, that “uptake” must be considered as a noteworthy theme because it is a window into patient portals in the ‘real’ world. The elements in this theme are, as I have listed in the text box, uptake, enrolment, use, inequality, and promotion, and different aspects of these elements are throughout this theme.

I started the interviews by asking the doctors when they first heard about, or implemented the service, which elicited answers about the struggles of implementation, both technically (although patient portals have evolved) and also in adapting their clinical and administrative processes. Since the doctors using the portals were working in large practices, there were a lot of people to ‘get on board’, to ensure their sufficient uptake and use. Most the doctors I spoke to were advocating patient portals within their practices, and the promotion keyword was used to describe their role within healthcare practices. For instance, some doctors spoke about how they initially needed to “convince” their co-workers that installing a portal was the right decision. Doctor 2 described how he “sold it” to his practice by discussing the potential efficiency gains, stating, “Look, imagine in five years’ time, a third of our regular patients who phone up [use a patient portal]... It would cut down a huge amount of churn.”

This theme revealed an uneven uptake among doctors within practices: for example, Doctor 9, a prominent pioneer in the development of patient portals in New Zealand who had been using the technology for several years, said that approximately seventy percent of his own patients were enrolled in the service, but that overall, only twenty percent of the patients in his practice were enrolled. Doctor 10, who implemented the service five years earlier, revealed that fewer than five percent of his practice’s patients were enrolled. All the doctors in his practice were using the portal, “to varying degrees”. These doctors, then, are promoting the portals, despite the uneven uptake within their own practices. Doctor 8 more cautiously stated, “No one’s not on board. That’s not to say all of them are up to

speed with it. Ugh, but, but having said that, you know... it's a slowly growing thing, which is going to accelerate".

Although factors such as the introduction of a Smartphone app and changes to the charging structure had some influence over patient enrolment, the doctor's promotion and attitude toward the portals was the most important determinant in patient enrolment. Therefore, the keyword promotion related both to staff within healthcare practices as well as patients. Doctor 6 alluded to the importance of having a "champion inside the practice who drives the progression and tells everybody it's going to be all right", and he attributed his practice's low uptake to his being on several months of sick leave. Correspondingly, Doctor 5 whose practice had a forty percent patient uptake said that the reason for this was:

Because we've really embraced it. Like it's a whole team approach. So, not just one doctor, all of the doctors are asking everybody to enrol, or enrolling people themselves. If they're getting a blood test, we say 'we're doing a test, this is where you will find your results. We'll call you if they're abnormal. But this is where you'll find your normal stuff'. So every time anyone has a test, they're enrolled in by the GP. Anytime anyone registers in the front desk, they're enrolled by the receptionist.

While this promotion and encouragement clearly results in a higher number of enrolments, this statement does raise a question about how meaningful patients' engagement and use of the portals is: that is, whether the enrolled patients are using the technology to its greatest benefit, or whether the enrolment was simply a 'tick in the box'. Other doctors who regularly used a patient portal had a less than twenty-five percent patient enrolment in their practice and the tone in which they discussed take up indicated that it was a sensitive topic. Some of the doctors said that they had tried other promotion methods, although they acknowledged that more needed to be done. For instance, Doctor 8 said: "We've stuck some A4 posters up, in a few places in reception... So at least it's there with a blur of other stuff. They're curling up a bit now". Two doctors said that they had sent out newsletters which discussed the patient portal as a means of promoting the service and another said that they had mentioned it on their practice website.

I asked the doctors if enrolled patients had specific characteristics in common. Many of the doctors said that they could offer only anecdotal evidence because they did not have any hard data. Doctor 6 answered that he did not know but that this should be monitored, implying a concern toward potential uptake inequalities. He also added, "That's very much, on... the practice, and who they, who they tell, and who they make an effort to enrol", again alluding to influence of the doctors' promotion on the patients' uptake. Others said a range of patients were enrolling and that they had not noticed any particular characteristics, or that there did not seem to be a noticeable uptake inequality. Doctor 2 said, "Some people who actually have great internet access, smart phones, and two phones in their purse still prefer to ring. Rather talk more than go online". However, some doctors had noticed elderly patients or those with chronic health conditions were more likely to enrol. The statement below was typical of the experience of some of the participants:

So, the majority of users for us will be, or certainly have been, between the ages of sixty and ninety-six... They have been mostly older people with potentially more chronic health conditions, or more reason to visit the doctor more regularly, who are on prescriptions. Cos actually to be honest, there's probably not much point in someone who's not on a prescription regularly, who doesn't see the doctor from one year to another... (Doctor 8)

It was clear from the doctors' descriptions that the use of patient portals by both healthcare practitioners and patients was considerably affected by the functions each practice selects for installation, and in fact, the choice of functions is interesting data in its own right. For example, the Open Notes function, which allows patients to view their own medical records, is not available in all the doctors' practices. Doctor 6 who offered this function said that it was the reason that he decided to implement a patient portal and that he did not understand why it is not more prominently promoted. He stated:

If there's one single reason I'd have a patient portal in my practice it's Open My Notes. The rest of it... You know, making an appointment, or making... Repeat prescriptions, well I just think it's all secondary to the power of having, you know, that open relationship with your patient, where they can read what you have to say about them. (Doctor 6)



Two doctors who were not using Open Notes said that they hoped that they would offer the function soon, although the idea of making records available to patients had met with some resistance from other doctors in their practices. This was also the case with another function (sometimes known as ‘e-consult’) which allows patients to contact clinics electronically. In Doctor 9’s practice, only some of the doctors had signed up, which meant that only some of the clinic’s patients could use the function.

Doctors promotion also undoubtedly influenced patients’ use of the functions that were available. It is not surprising that one impediment to uptake is concern that patients would excessively message their providers through portals but many of the doctors using the services strongly emphasised that patients do not over-use the messaging capability and in fact, one doctor said that staff kept forgetting to check the function, partly because messages were so infrequent. It seems, therefore, that the messaging function was not being used to potential. Doctor 5 explained that the practice received messages only rarely because of the way the portal has been promoted. Generally, the doctors found that the most common uses of patient portals were booking appointments, checking test results, and renewing prescriptions. These functions do not facilitate as much patient engagement as Open Notes or eConsult.

Some of the doctors seemed defensive when they discussed the low uptake of the patient portals by healthcare practices, and they certainly saw impediments to the wide adoption of portals, as sections 7.2 and 7.3 (below) show. Notably, the doctors who were the most favourable towards the portals argued that New Zealand was about to reach a “tipping point” (Doctor 6), when enough practices start offering the technology that there would be “Demand from the grass roots” (Doctor 9) pressuring other practices to use the services. Doctor 6 stated, “I’m hearing anecdotal stories... of people walking in going ‘when can you bring a portal in?’... My GP hasn’t got one. Every time I see him, [I ask] ‘can you put the portal in?’” A couple of the doctors used a similar argument regarding the low patient uptake within their own practice. Most of the participants were people with a

higher than average interest in the technology and so were not only promoting the technology within their own practices, but also promoting it to other practices.

## 7.2. THEME 2: COST

Keywords: time, money, financial, pay, charge, free, efficiency

Definition: doctors describe the cost of patient portals regarding financial payments and staff time.

In terms of coding 'hits', cost was a theme that clearly occupied the doctors a great deal, and covered cost in the sense of both financial outlay and time. The elements, time, money, financial, pay, charge, free, and efficiency were dominant in most of the interviews. Many of the doctors discussed the matter of the cost of healthcare in general and patient portals in particular in strong terms, exhibiting immense passion, and brought up the issue in many of their answers. At times, I would try to steer my participants away from the subject by asking follow-up questions beginning with "Aside from the cost and the time...", only to find that they brought their answer back to cost and time anyway. For example, Doctor 3 said that a detrimental aspect of portals is the "add on programs" which require more money and time. This is not to say that the doctors often narrow focus on cost militated against their desire to do their best for patients: instead, the cost of portals came across as a hindrance which they confronted on a day-to-day basis. They seemed to be caught in a multi-faceted conflict of trying to give enough time to their patients while coping with the time constraints in the healthcare sector; between providing the best medical care while trying to run a business; between their Hippocratic Oath while facing the reality of working in such a demanding field.

The key words, cost and time, frequently overlapped and were sometimes used synonymously, but they were also, at times, distinctive. For instance, Doctor 1 kept referring to the amount of time that it would take to use the patient portals, but when he did mention the financial cost, he indicated that the two are closely related. He stated,

“Talking about the charging is just forcing the time to check that, and to apply that”.

Another doctor was asked if patient portals are cost effective, and she replied that it saved reception time. The cost of portals is not only in wages. Many doctors pointed out the ongoing expense of maintenance, and Doctor 2 said:

I’m up to one-thousand-five-hundred dollars, for my base infrastructure, per month, there’s another six hundred dollars for the licence fee for the software every month... Plus another three-hundred dollars for IT stuff like to connect to healthlink and all the rest.

Cost preoccupied the doctors, and not only in relation to the portals: it was often mentioned in relation to the broader institution of medicine. For instance, Doctor 3 spent a lot of time vehemently discussing the financial cut backs that general practitioners have faced, but when he was asked if this would turn doctors toward specialisation, his answer made it clear that he would not change his job. Another, Doctor 1, discussed the difficulty he often encountered with patients coming to consultations with a list of multiple health problems. Although doctors are meant to give patients one fifteen-minute consultation for each medical problem, he found it hard to tell patients to make another appointment if they had multiple problems, so he would, he said, “...try to deal with them all at the same time if I can... It’s really, allowing the time to answer the question” (Doctor 1).

The issue of cost filtered through into doctors’ views of the patient portals, and most felt that patient portals would increase practice costs, and that projections of savings were not validated. Correspondingly, when they were asked about any possible negative aspects of the portals, cost was the most common answer and for some doctors it was their only answer. Doctor 2, who was already using a patient portal, showed his empathy for other practices when he said: “It’s, you know, pay for something to make your life a lot harder”. He drew an analogy of tenants having to pay for lawn mowing at their rented accommodation. Likewise, Doctor 3 discussed how difficult it is for smaller practices like his to afford the ongoing expenses of portals, because the calculation of the fees charged

for the technology often does not consider the number of patients enrolled in a practice.

He stated:

The difference is that I'm in a single practice and most practitioners are moving towards groups. The cost... doesn't run in parallel with the amount of patients you've got registered so that's what's put a lot of it off for smaller practices... [referring to large practices] they just say 'oh yes, we should have this' and get it in and... Which is fine, which is probably just how it works in a group system is... but it's difficult if you have to be just one doctor. (Doctor 3)

However, the added cost did not always stop the doctors from implementing the service. When I asked Doctor 3 from the single practice if he would consider implementing a patient portal, he answered that he was already in the process of tidying up his website so that it could be put in. Similarly, while another talked about how difficult a patient portal could make his workload, he said that he would like it in the practice where he was employed because "I would want that ability to open my... tests when I need to as well" (Doctor 1). From the doctors' account, the implementation of patient portals involved the practice taking the costs, for the benefit of their patients. Doctor 2 described this as a "value add, rather than a straight dollar add". He discussed how he decided to implement a patient portal to increase the engagement and the health literacy of his patients. However, as his practice was in a low socioeconomic area, his patients could not afford to pay for the service, and so eventually he absorbed the costs and made it free.

This was at a big financial burden to his practice. He stated:

... That fell over. They couldn't pay. It didn't work... So we made it, um, free and we absorbed the cost, um and, and made it a point of difference... And, I really, you know, it's really aggravating to have so many forced costs put on you to join the public system...

Interestingly, Doctor 5, who worked in a high socioeconomic area similarly found that when they first implemented the service with a fee for the users, "Nobody picked it up. Well, it was only one or two people who used it", but when the clinic made access free, there was a much larger uptake. However, Doctor 5 was the only participant who found that the patient portal is cost effective in her clinic, claiming that they saved on text billing,

as well as nurse and reception time. When I probed further about this, she answered, “I mean we’re just beginning to, um you know, we’re beginning to see these things tick in”. It was the next sentence of her answer that was particularly telling, when she said: “you really have to get to about forty percent to actually start seeing the difference”. Their practice had only recently reached a forty percent uptake, which at the time of the interview, was the highest in the country.

Taken as a whole, the cost of patient portals was a contentious issue for doctors. This point was strongly expressed by the doctor from the single practice who said that, “The government ministers all decided that this wonderful thing, is... Everyone should be using it. It would be wonderful for every person in New Zealand to be able to access this stuff, which is partly true...” (Doctor 3). His point was that no matter how much the portals work in theory and rhetoric, in practice they present difficulties in the context of the pressures of the medical profession. He commented, “We’re doubling up our appointments. How do you expect us to fit in all this time in answering emails to patients and queries about their blood tests?” He said that the reason that many practices have not implemented a portal has not been because they are ideologically opposed to the technology but rather because, “... a lot of the resistance has been sort of, from the fact that we’re already overloaded”.

### **7.3. THEME 3: INCREASING ACCESS**

Keywords: information, health literacy, access, transparency, e-consults, Google, internet.

Definition: doctors describe the qualities and functions of the patient portals.

This theme deals with the choice some doctors made to implement a patient portal especially in light of the fact that most of the doctors maintained that patient portals are a significant financial burden for a practice. The theme, effectively, deals with doctors’ altruistic desire to increase patient engagement and health literacy, improve clinic

accessibility, and make records more transparent. However, though altruism was important to doctors, it was tempered by practical considerations: increased accessibility, for instance, overlapped with cost, and many doctors opposed patients gaining access to their health records. The elements in this theme are information, health literacy, access, transparency, e-consults, Google, and internet.

Interestingly, doctors' drive towards altruism matches the underpinning purpose of the patient portals, which is to increase some form of information access. For instance, e-prescription makes information available for renewing patients' prescriptions, e-consults gives patients and providers a direct communication channel, and online test results and medical records allow patients easy access to their own information, which could potentially assist them in improving their health literacy. However, the way in which doctors discussed the access functions of portals, and whether each function was seen as an advantage or a disadvantage, a hindrance or an assistance, often came down to doctors' own philosophical positions about the degree of access patients should have to information.

Doctor 5 in fact accounted for the disparity in the views regarding patient access and the uptake of patient portals by pointing out the difference in the underpinning philosophies of different practices. She said that her practice had implemented a patient portal because it aligned with their philosophy of increasing convenience and access for their patients and argued that this attitude differs from some other practices who will not use the portals. From this doctor's account, the access functions patient portals offer might be an even greater impediment to uptake than cost. Her experience was that giving patients easier and increased access to their information motivated them, which has been valuable for chronic illness sufferers because they could self-monitor "numbers to actually make change" (Doctor 5). Her descriptions drew close parallels to those of two other doctors who said that making medical information available online made the relationship transparent and gave their patients a better understanding of their conditions, which led to

improved patient compliance (Doctor 2 and 9). One of them also maintained that by implementing patient portals, they were positioning themselves in the bigger healthcare system, where patients could have long term continuity of care.

Some doctors expressed an active aversion to patients accessing their practices' medical records. This may be a widespread viewpoint. One doctor stated strongly, "Most doctors, having heard from almost everyone, ninety-nine percent plus, do not want patients looking at what we write!" (Doctor 3). Another doctor expanded on this more placidly, stating, "It's not saying, [that] we say a lot of bad things about patients...But, ugh, you do have some impression [that you] write down... If the patient... comes across [as being] very anxious, or... for drug seeking" (Doctor 1). These two comments show the complexity of the argument about how much access patients should have to information. On the one hand, the records may contain comments that could help other doctors but offend patients. There is also the possibility that patients might not understand the medical jargon in the notes, which could require even more doctor time to interpret. Furthermore, the function may simply be misunderstood. The amount of information which a patient can view is determined by the particular set up of the portal, doctors using the technology did not seem fully aware of the level of control they could exercise. For these reasons, then, doctors often opposed the portal technology, but on the other hand, patients have the right to view their medical records.

Doctors also related some of the access functions of portals to improvements in providing safer, higher-quality health care. For example, Doctor 5 said of her experience with e-prescription:

It's much better for me. Instead of being given the piece of paper in the corridor by the nurse... 'Oh can you just sign this thing you did yesterday?' I am now able to pick up on my task, I'm able to click in and see if it would be appropriate or not before I sign it, or... get pressured to sign it. So it's um, it's much, much easier.

The participant quoted above sees the benefits of faster access to patient information. She could access the same information before the implementation of the

portal, but time constraints meant there was a higher potential for short cuts and checks not carried out. Another doctor whose practice was trialling a patient portal believed it could assist in collecting correct patient details because there could be required fields in online forms. He said that when patients leave voice messages, they often do not provide enough information, which can waste nurses' time in return calls. In medicine, insufficient or wrong information can have drastic consequences, such as when "We try to ring back and it's the wrong number, or it's been disconnected. Especially those patients [who] say they have chest pain [needing urgent attention]" (Doctor 1).

Of all the access functions offered by portal technology, e-Consult came across as the doctors' least popular. The two participants who had not implemented a portal expressed concern about this function, especially in regard to its resulting cost. Doctor 2, who seemed the most optimistic about e-Consult said, "Very few will ask questions or forward things through the consults... All it's really done is open up a separate communication channel", pointing out that doctors still charge for their time. However, charging for e-Consult was not so simple, according to Doctor 5. This participant said, "We don't really like the e-consults [because] they [patients] ask a question then expect not to be billed", adding, "Most of my colleagues fail miserably to try to charge for their time with e-consults". She also claimed that half the questions result in the patients needing to make medical appointments because the queries cannot be dealt with satisfactorily in an online medium. She also said that her medical centre receives a large proportion of its messages from "... one patient with mental health issues" (Doctor 5), but despite these drawbacks, she would not disable the function as it can be useful for follow-ups.

#### **7.4. THEME 4: THE CHANGING CONSULTATION**

Keywords: information seeking, communication, trust, relationships

Definition: doctors describe patients' information seeking behaviours, the communication between patients and healthcare providers, and the impact that this has on relationships.



At one point in all the interviews, I asked the doctors whether they thought that the communication between patients and their healthcare providers is changing. This theme, therefore, includes the doctors' descriptions of patients' information seeking behaviours, the communication between patients and healthcare providers, and the impact of both on relationships. It is centred on the elements: information seeking, communication, trust, and relationships. The theme shows that in some cases, portals have begun to move the relationship between patients and some healthcare providers away from a traditional, paternalistic model. For instance, Doctor 2 talked about how he "Googled" health subjects with his patients, and I could not help but think that this behaviour represents a significant 'loosening' of the expert/non-expert positioning of the parties that typified the traditional model of medical consultation.

An idea that was strongly expressed was that patients are information seeking – they want and actively seek out information about health. Doctor 5 explained it as, "... [patients] like to be involved in their care. You know, might be seen as being a bit pushy. They just really do want information". I asked my participants what they thought about patients searching the internet for information about their symptoms or health conditions, and generally, the doctors thought that it could be constructive for the patients' care. Although some doctors mentioned instances when "Dr Google" led to unnecessary anxiety, they could also see a number of advantages, such as the likelihood that patients will feel sufficient concern about their symptoms that they will book a consultation and the possibility that they will become more health literate. Some doctors commented that they even assist their patients in their information seeking, by locating reliable information sources. Doctor 2 said:

I encourage it. Cos I give people information sheets... The Dr Google gives information sheets... you know telling people what the plan was, whether they accept that they know enough of what you're worried about, what you are trying to rule out, what are the reasons for the blood test are. You know it sort of merges into

Dr Google cos what you're trying to do is get people to watch and record things which don't go the way you expect.

This is not to say that patients are always successful in their information seeking endeavours, because the internet provides information of variable quality. As Doctor 6 pointed out, "It's very hard to find good health information of high quality that you can trust. So people are, you know, doing their best efforts, like trying to learn stuff". The experiences related by my participants indicated that they thought the increased access to information did not diminish their patients' perception of the importance of the medical consultation and patient-doctor communication. In fact, Doctor 2 went so far as to state the contrary view:

I've always had the attitude, you think, 'oh my god everyone's going to rush and go and Dr Google everything'... What I've found, is that it's made people realise how complex things are, and how judgement calls as much as science behind things, where they thought it was more scientific maybe... in a funny way you think, they actually value someone's time more because you're saving hours and hours of time and days and days of anxiety maybe, hours and hours of time researching something.

This quote is significant, as it shows the doctor's belief that the internet increases patients' value placed on medical consultations, and indicates that even when patients can access information, doctors are still positioned as experts. It also alludes to the anxiety that can be created by the vast array of information on the internet, and further, that despite having access to information, patients still trust doctors and feel that they need to consult doctors for guidance and reassurance. Other doctors saw the increased information-seeking behaviours of patients as a reflection of current society. Doctor 7 remarked, "People just don't want to wait. ... They want instant sort of answers, instant access to everything. Whether it's their banking, or their health". What they seemed to be alluding to was that patients searching for health information does not reflect a deficit in medicine, but rather, a change in the way that individuals now lead their lives.

The change in patients' behaviour in information seeking has had some effect on the nature of communication between doctors and patients. Some of the doctors considered

the communication facility of portals to be a way of connecting with patients in another medium and focused on the convenience of being able to complete tasks efficiently at a distance, allowing patients to fit it in with their often-busy schedules. For example, Doctor 8 said that patients can find it hard to find time to come in for a consultation. He said, “It’s a real pain in the arse to take time out of their work to try to see you, to wait twenty-five minutes cos you’re running late... to see you for five minutes” (Doctor 8). He said that he finds it difficult getting to his own general practitioner to get his blood pressure medication and so patient portals could be a way of renewing his prescriptions, which he might otherwise delay. Doctor 7 expressed the idea that the internet can be used to connect with patients in modern terms:

I think healthcare needs to be responsive to that as well. So I think it’s just another way of finding a way to interact with your patients. Many people still prefer the face-to-face approach. but then again there’s a lot of people you never see... So it’s changing where they can engage with you through a different forum.

Doctor 7 also said, “The communication is changing, and will continue to change. I think that’s a positive thing. I think that’ll help break down barriers. And I think it helps to have ongoing conformation, to share information in a more meaningful way”. This statement certainly demonstrates that the communication between patients and doctors is moving away from a paternalistic model, especially in the light of a subsequent comment: “It might help to address the sort of power imbalance in the doctor-patient relationship”.

Despite the obvious changes, however, a core component of the doctor-patient relationship will remain the same. Doctor 7 commented that “...but ultimately, the doctor will still be, or the nurse I guess, will ultimately be still taking responsibility for that person’s healthcare”, and this thought resonates with the idea discussed at the beginning of this theme, which indicated that while patients have more access to information, the doctor is still valued as an expert for consultation. The same notion of the core component of the patient-provider relationship remaining unchanged was discussed more directly by Doctor 8, who stated:

People will always have a sort of, similar relationship with their doctor because they trust them to convey information to them ... It's something that we respect, and they appreciate. So I think the core relationship will be the same, but I think that some of the stuff round the edges will make it more efficient when there's a place for it... But we will still use the face-to-face when it's needed. Which is clearly important for a huge bunch of our stuff.

This is an ideal quote to explore in closing, as it demonstrates many of the main ideas that emerged in this theme. What this participant is alluding to is that electronic communication provides a vehicle to connect with patients and it can be used to preserve the patient-provider relationship in modern terms. However, it does not interfere with the traditional act of providing and receiving care: the doctor still gives guidance and reassurance and is positioned as the respected expert.

## **7.5. SUMMARY**

My participants believed patient portals could offer a range of advantages, including helping patients to increase their engagement and health literacy and delivering services in a way that can cope with increasing demands. On the whole, however, the descriptions of their actual use of the patient portals indicated that the functions of the portals were not being engaged effectively, which was demonstrated by the low patient uptake, and, to a lesser extent, by the low use of some portal functions. Significantly, many of the doctors acknowledged themselves or their colleagues as contributors to the underuse of the patient portals in their practices. They claimed that the main reason for the low patient uptake was that it was not sufficiently promoted by the practices and the treating doctors. For example, Doctor 6 stated the patients who enrol in the portal depends "... very much, on... the practice, and who they, who they tell, and who they make an effort to enrol".

Cost in time and money was the most common negative aspect of the portals, which aligns to international findings (e.g., Lester et al., 2016; D. Miller et al., 2016). However, while the cost was a hindrance that the medical business faced, it was not an impediment to the medical practice, as doctors wanted to do the best for their patients. On this point,

some participants had implemented a portal for the good of their patients, even though it operated at a financial loss, which corresponds almost exactly with Vydra et al.'s (2015) findings. The only doctor who said that the portal is cost-effective in her practice said that this requires a 40 percent patient uptake overall, and at the time of the interview her practice was the only one in the country to have this (Doctor 5). In fact, the rest of the doctors who had implemented the technology had a less than twenty percent patient uptake, which is consistent with the average patient uptake per practice nationally (NHITB, 2016) and experiences overseas (e.g., Irizarry et al., 2015; Otte-Trojel et al., 2016). This is not economical from a financial sense<sup>22</sup>, and it would mean that many of the doctors' anticipated benefits for implementing the patient portals would not reach most of their practices' patients.

From my analysis, I am also unsure of whether the use of the patient portal is meaningful for both the patients and doctors enrolled. The doctors generally claimed that the patient portal was most commonly used for booking appointments, checking test results, followed by renewing prescriptions, which arguably directly facilitates less patient engagement, when compared to other functions such as electronically contacting doctors or viewing health records, which were not available in some of the doctors' practices. This could be because functions like booking appointments, checking test results, and renewing prescriptions, have a more visible impact on administrative financial savings (Otte-Trojel et al., 2015), although I suspect that there are various contributing factors to this, which I hope will be explored further in the patients' interviews.

Notably, the doctor working at the practice with the highest patient uptake, said that the reasoning was because her practice employed "a whole team approach" (Doctor 5). This suggests that unlike other practices, there was organisational readiness for the technology. However, she also stated that "Anytime anyone registers in the front desk,

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<sup>22</sup> The only modelling in New Zealand that has shown a net gain to a practice from patient portals was by Sapere Research Group (2015) and it was based on a 20%, 40% and 80% patient uptake different co-payment options and varying amounts of clinical queries through the patient portals.

they're enrolled by the receptionist" (Doctor 5). This is important, as just giving patients access to a technology is not enough in itself to see any benefit. This was demonstrated in a study by Wagner et al. (2012) which examined the health outcomes from giving 453 patients access to a patient portal and found that few patients used it with any frequency. Furthermore, international literature has determined that many patients do not have sufficient knowledge and training to fully engage with patient portals (Czaja et al., 2015; Zieth et al., 2014), and a lack of familiarity of the technology has been widely reported as an impediment to its use (e.g., Gagnon et al., 2016; Nazi, 2013; Vydra et al., 2015).

It is likely that the first two themes intertwine by their causality. That is, a low patient uptake can hinder the cost effectiveness of portals and, to a lesser degree, the cost of promoting and being trained in using the patient portals can hinder its uptake. This is contributed to by practices often not charging patients for asking doctors questions through the patient portal. Despite the doctors' altruistic reasoning for implementing a patient portal, they did not seem to have a sound plan for its promotion or employment. Many of their descriptions about their actual usage did not align with their altruistic reasoning for implementing the patient portals for the good of their patients, or as Doctor 2 explained, for the "value add, rather than a straight dollar add". From my dataset, I cannot definitively state why this was that case, although several deductions can be made. It is likely that their colleagues in their practices had varying enthusiasm about the patient portals, as they had different proportions of patients enrolled. A few of the doctors also claimed that the patient portals were not being promoted effectively partly because of time constraints, which is somewhat counterproductive given its potential benefits. This indicates that they did not have organisational conditions to successfully implement the technology, the importance of which has been emphasised by various analysts (e.g., Greenhalgh et al., 2008; Nazi, 2013; Otte-Trojel et al., 2015). There is also, as one doctor described, the dilemma that if a patient portal reduces consultation appointments, then this could be detrimental for a practice, although it was not raised by the other participants.

The last theme may provide some insight into the reasoning for the doctors' utilisation of the patient portals. This theme included discussions about the changing communication in healthcare delivery, which was frequently related to patient portals. The doctors interviewed were open-minded about the digital communication in healthcare, although this is arguably unsurprising given their interest in patient portals. They discussed how digital communication could help to "... break down barriers" (Doctor 7) and to connect with patients in modern terms. Yet significantly, while the doctors were largely progressive in terms of technology, many were resistant to state that the relationship between patients and their healthcare providers has changed, although some acknowledged that patient portals could lessen paternalism. There was a strongly-held opinion that the patient and doctor roles were unchanged, and that the healthcare provider will "ultimately be still taking responsibility for that person's healthcare" (Doctor 7), which could be indicative of a resistance to change. The doctors seemed to highly value their current relationship with their patients, and while they seemed progressive, they did not seem to want to transition to Emanuel and Emanuel's (1992) informative or consumer model, where patients are in control as the ultimate decision-makers and the doctors' role is to inform them of the relevant medical information. This made me wonder if this contributed as a hindrance for themselves or their colleagues in the effective use of the technology.

Many of the interview findings mirror overseas experiences. This is in terms of their concerns about cost and time (e.g., Lester et al., 2016; D. Miller et al., 2016; Vydra et al., 2015) and about giving patients access to medical records (e.g., Grünloh et al., 2016; D. Miller et al., 2016). While these issues are somewhat predictable, what I was surprised by was the low uptake of the portals by patients, and, to a lesser degree, by the low utilisation of some functions. Although this is consistent with international literature (e.g., Irizarry et al., 2015; Otte-Trojel et al., 2016; Zieth et al., 2014), I viewed New Zealand as being receptive to ICTs because of the high uptake of electronic health records in the past

(Schoen & Osborn, 2009), and the cost of the technology. Nevertheless, I can say that my doctor interviews help to confirm the documented complexity of implementing portals into organisations (e.g., Otte-Trojel et al., 2015; Prey et al., 2016).



## 8: THE PATIENTS' PERSPECTIVES

The interviews with the doctors yielded valuable insights into their perspectives about the implementation and function of patient portals in a number of healthcare practices. However, these interviews, satisfying though they were on one level, could not account for the users on the other side of this communication equation: that is, the patients. The purpose of this chapter, then, is to unpack the themes that I found in the data I gathered from interviews with patients. All but one of the participants in this second group of interviewees were patients that had used a portal as part of receiving medical care, and the remaining participant had expressed a strong interest in patient portals (both to myself and her healthcare practice) and regularly emailed her practice nurse regarding her healthcare.

Like the analysis of the interviews with the doctors, I thematically analysed the interviews with the patients using Boyatzis (1998), Braun and Clarke (2006) Braun et al. (2015). I found this method to be a way of representing main ideas presents in tens of thousands of words of raw data. In this chapter, I present the themes uncovered from the analysis of the interviews with patients. The first theme sets out the communication between patients and healthcare providers related to the introduction of the portals, and the second theme describes patients' concerns about around the electronic storage of, and

access to, personal health information. The last theme outlines the participants' expectations for portals and similar technologies in the future.

### **8.1. BRIDGING THE TWO FACES OF MEDICINE**

Keywords: relationship, communication, consultation, partnership, power, imbalance.

Definition: participants discuss the nature of communication between patients and healthcare providers and how this has or could be impacted by patient portals.

In scholarship dealing with medicine as a social institution, it is not uncommon to find that a distinction is drawn between two “faces”: between, technology and humaneness, between cure and care, and between the science and the art of medicine (Putnam, Stiles, Jacob, & James, 1985). In a similar vein, Engel (1988) established a binary differentiation between patients' need to know and understand, and their need to feel known and understood. For some of the participants in my research, it seems that the patient portal bridges these two faces: they could, for instance, retrieve their medical histories, which allowed them to know and understand, and seek to be known and understood in communication with their doctors at times outside of regular face-to-face consultations. Portals, therefore, have the potential to enhance relationships between patients and doctors, yet, some of my participants felt that the portals pose the risk of depersonalising healthcare, leading to a “call centre approach” (Patient 3) to medicine. The “call centre” view was, perhaps oddly, expressed more strongly by the participants who were consumer representatives (Patient 3 and 4) for patient portals than by those who were simply portal users (Patients 2 and 5): the consumer representatives tended to be warier of the technology. In this theme, the elements are, as I have listed in the text box, relationship, communication, consultation, partnership, and power imbalance.

My participants were divided between these two positions and this theme provides an account of the way that patients situated themselves in relation to the portals. Because the “Two Faces” theme deals with matters of power relations and the struggle to find an

effective point of cooperation between the two faces of medicine, it seems fitting to start this theme with the patients' descriptions of their relationships with their health providers. It was the inadequacy in these relationships, along with the attitudes and the 'incompetence' of the medical profession which originally led Patient 1 to pursue access to a patient portal and to keep digital records of her medical information. In her many years receiving medical care for her multiple health conditions, she frequently challenged medical professionals and encouraged others to question the treatments they were offered. At the time of the interview, she described how her regular interaction with her practice nurse by email has helped her to forge a good relationship with this individual. However, she considered her relationship with her general practitioner to be inadequate and one reason she gave for that is that he refuses to even take a phone call.

The other patients were satisfied with their relationships with their health providers. As one patient said, "I have a very good relationship with my GP. And the admin staff there. I mean, very constructive you know, quite respectful. For me, more of a partnership" (Patient 3). This portrayal of a patient-provider "partnership" was consistent with other descriptions. For example, Patient 2 said that he has a high degree of collaboration with his general practitioner in making decisions about treatment options, and that his general practitioner is always open to suggestions. He described how he has undertaken research about his health condition because "...doctors don't know everything. And sometimes you can sort of say, well 'what about this?', or 'could this be a possibility?'" (Patient 2). This notion that patients can contribute knowledge to the medical consultation contrasts with traditional paternalistic models of healthcare communication. It also indicates that the patient public's perceptions of doctors could be changing, because, as this participant said, "doctors aren't held up as gods like they used to be... People are taking more responsibility for their own health" (Patient 2).

However, while most of the participants were satisfied with their relationships with their healthcare providers, they were well aware of the time constraints operating in the

health sector. For instance, Patient 2 thought that his current general practitioner is the best that he has had for some time, but found the limited time was noticeable. He said, “When you do have an appointment, the GP doesn’t really have the time to sit down and talk” (Patient 2). He said that the lack of time poses the risk that underlying causes of health conditions will be missed and that “... we don’t wanna get to a point where everything’s being rushed through just for convenience sake” (Patient 2). Patient 1 who had multiple health conditions expressed her dismay about the shortening of the consultation time down to fifteen minutes. Her tone made it clear that this change had a substantial impact on her, both financially and emotionally, and in regard to her visits, she stated passionately, “What do you think I do when I go there? I go there with a list!” (Patient 1).

When the participants were asked about the potential or current benefits of patient portals, answers commonly centred on speed and convenience, not only for themselves, but also for the clinics they attended. They said that this is not only for the patients using patient portals, but also for their healthcare providers. For example, Patient 2 saw advantages to the clinic if patients used the portal to book appointments, because a phone call took up the receptionist’s or nurse’s time, and sometimes the doctor’s as well. Other participants held similar opinions (Patient 3 and 5). They thought that the use of portals could result in less time wasted in consultations on matters that could be resolved through electronic communication. They recognised the constraints in the healthcare sector and considered that the portal could usefully save their doctors’ time.

Further, Patient 2 maintained that the easy communication permitted by patient portals made patients more likely to ask questions, whereas in the past they might have felt like they would be a bother, both to their healthcare providers and themselves. This participant said that since he started using a patient portal, his communication with his healthcare provider has improved markedly, and he feels more satisfied and secure. He is managing a chronic illness, and he described how, “sometimes you get overloaded with

information...and you just want to clarify something so, I just send him a quick email and he replies quite quickly” (Patient 2). This participant was certain that clarification and answers to questions helps not only patients’ physical care, but also their psychological well-being, because they feel more reassured and less vulnerable outside of their consultations. He thought that patient portals could help patients receive emotional support and said that it would have been beneficial when he had cancer in his younger years. He stated:

I had cancer when I was in my twenties. And, you know, it’s a bit of a freak out... My doctor, for a few years, a lot of the time was just spent [offering] reassurance because you were a bit traumatised... [A patient portal] would’ve been a good thing. To be able to, send a quick thing off, saying, you know, ‘feeling a bit freaked out at the moment’. Like I said, it just makes you feel like you’re doing something towards things. (Patient 2).

The participants who regularly used electronic healthcare communication (Patients 1, 2 and 5) did not think that there was any concern that the portals could in some way damage their relationships with their health providers, and in fact their accounts tended to suggest that the portals had improved their relationships. For example, Patient 1’s description of her email correspondence with her practice nurse revealed that the emails made her feel acknowledged in a way that she had previously struggled to gain from the medical profession. An even stronger response was that the portals allow patients to obtain information and thus be more in control of their healthcare and judged this as crucial to improving patients’ physical and mental wellbeing. Again, they saw this as advantageous to both patients and their healthcare providers. As one Patient 3 stated:

When you think about the potential for, for people with long term conditions, that they could be actively participating in their care through this portal... but without it being direct face-to-face... you know it might take time to start with, but it will reduce time and the dividends... it’s mutually beneficial I would’ve thought.

However, there were voices of dissent, and interestingly - perhaps significantly - they were the voices of two participants who had previously been consumer representatives for the portals (Patients 3 and 4). These two participants challenged the idea that portals give

patients more control. They disagreed with the promotional material for patient portals, and saw the primary benefits accruing to the healthcare providers, because it is the providers who decide how the portals will be implemented and managed. For instance, Patient 3 pointed out that because the public is largely uninformed about the portals, there is the possibility that information will be uploaded without patients' consent or even knowledge. Furthermore, they felt that the power-imbalance implicit in the doctor-patient relationship meant that patients may feel under pressure to comply with the doctors, and as she explained, "... if I say 'right, that's not going up'... they'll say 'Oh but we think it should go up, it's really important'" (Patient 3). Of further concern was that Patients 3 and 5 knew of doctors who decided to choose which patients would be allowed access to their patient portals. Patient 3 found this "dumbfounding", the other found it "controlling" and "outright disrespectful", stating:

It's like "I like you and I know you'll behave" ... And it's like, okay, we know that some people don't understand a lot about their health... I suspect that they might be the ones ... knocked off the list. But you know... it's kind of counterproductive, it's disrespectful. Yeah, it is. It's absolutely disrespectful. If you're going to offer portals then it's [for] everyone who wishes to take it.

Additionally, the idea that the portals might replace telephone calls or consultations left some participants concerned about increased isolation and disengagement. One participant thought that this is a particular risk among the elderly, or those without a strong social support network (Patient 4). Another said that patient portals could make healthcare overly efficient and productive which she did not see as "the recipe for success" (Patient 3). While the idea of healthcare being too productive might seem nonsensical, she explained that the reduction of tasks which once required interpersonal communication into online processes might increase efficiency, but it could also take the humanity out of healthcare, which she did not consider was a practical way to engage a population. She also emphasised that "there's some stuff that simply can't be communicated in the virtual world" (Patient 3).

Generally, the concerns raised about patient portals were underpinned by the need to uphold patient-provider relationships, to keep the patient informed, and ultimately, to balance the two faces of medicine. The contentious issue raised by the patient participants is the degree to which healthcare communication can or should be fostered through electronic media, and on this point, views diverged quite widely. Some participants favoured the portals for both their own and their providers' convenience, but at the other end of the continuum, others were doubtful about the efficacy of the technology. The two participants who had been consumer representatives voiced the strongest doubts, but were not entirely opposed to the technology, provided that they were developed and implemented in conjunction with effective communication and strong interpersonal relationships. All of the participants using electronic media to contact their healthcare providers stressed that many aspects of healthcare communication simply do not need to be discussed in person or over the telephone.

## 8.2. SCRUTINISING THE BLACK BOX

Keywords: information, storage, access, confidentiality, consent

Definition: patients discuss issues around the storage and electronic access of personal health information.

The term 'black box' connotes mystery and ambiguity. It is commonly used to describe the systems which collect data in airline accidents, but it more broadly denotes a device, object, or system with unknown inner workings. For some of the participants, portals were a form of this broad definition, in that they understood that healthcare providers generally input data which patients could retrieve, but the rest of the operations of the portals remained in the category of "black box". Subjects in the "unknown" category, for instance, included who has jurisdiction over the data that is stored, who has access, what aspects of patient data are uploaded, and the processes around informed consent. Thus, the patient participants perceived that there were benefits to the electronic

storage of data, they also perceived problems and raised a number of concerns. This theme comprises the discussions about access to, and storage of, personal health data. The elements in this theme are information, storage, access, confidentiality, and consent.

Notwithstanding this association with mystery, people did feel that there were advantages to the electronic storage of information. It was not difficult for the participants who used patient portals (Patients 2 and 5) regularly to identify the benefits of having access to their personal health data. Neither participant had experienced difficulties or detriments and they both said the portal was simple to use without instruction. They clearly found the fast access to information valuable. Patient 5 said, “Any information, whether it be a visit to the GP, face-to-face or over the phone, that’s recorded straight away and I get a message... it’s absolutely brilliant”. The other participant using a patient portal regularly (Patient 2) described his use more pragmatically, stating, “If you just wanna talk to your GP, you just do it... Instead of paying \$48 to go and see her you just type it in. It’s as simple as that”. Neither of them experienced negative aspects of using a patient portal and they felt that portals could and should benefit more of the wider public.

For these participants, it was not just the added convenience that made the patient portal advantageous, but also the increase in available information which would otherwise have been challenging to find or navigate. For instance, Patient 2 explained that he found it useful being able to compare the timing of his flu vaccinations with the number of times he visits the doctor for the flu. In this example, the patient portal provided the participant with a clearer picture of his healthcare journey so that he could make informed decisions for his future care.

The patients using electronic healthcare communication (Patients 1, 2 and 5) were adamant that it would lead, or has already led, to safer, higher quality healthcare. Patient 5 discussed an experience she had when she was waiting for an operation and discovered that her hardcopy notes had been lost. She exclaimed, “It’s going to stop all of that from happening!” Patient 1 listed the medical mishaps that she has experienced due to



miscommunication and described how she requested a copy of her notes after an operation, only to find that she had not been told about her recommended post-operative care. Now that she uses electronic communication to receive her prescriptions, she has found that the pharmacy is less likely to make mistakes than they were when they received hand-written request forms.

However, most of the participants (Patients 2-5) felt that the electronic storage of sensitive health information was a contentious issue, particularly for people in vulnerable situations. For example, Patient 5 pointed out that medical reports could expose the fact that a woman may be experiencing domestic violence, potentially putting her in further danger. In a similar vein, Patient 4 believed that databases which highlight precautions needed for the care of certain patients, such as, for instance, if they are HIV positive, are unfair because it leads to practitioners classifying individuals by their health conditions. While this participant's discussion was initially focused on the electronic "pop-ups" that occur on some healthcare databases, it became clear that this was a concern that she held for the digitisation of all medical information. She stated:

You get labelled and all of that. And once it's on there, it gets stuck on there. I am told that all this stuff could be seen anyway in paper form, but you know, with the alerts and stuff like that, I think it just makes it much more. (Patient 4)

Overall, this contention stemmed from the notion that patients have less control of their information when it is digitised. One participant summarised the point of view by saying, "With hand held notes ... you actually feel like you've got more control ... you can decide who you share it with" (Patient 3). In general, the patient participants felt that it was a weakness of the portals that they can be accessed by health practitioners without patients' consent or even knowledge. In addition, Patient 3 was concerned that patients could share their login passwords, which could compromise the protection of their information. Notably, it was also felt that one of the reasons that doctors are hesitant

about adopting patient portals is that they might find their note keeping or comments exposed and that patients could question their notes.

There was another point of view, though. One participant using a patient portal took the “I have nothing to hide” stance (Patient 2). He understood that some people doubted the security of the electronic storage of their medical information, but as he did not have sensitive or embarrassing health conditions, he was unconcerned by the uploading of his information, and he did not care who viewed his records. Patient 5 pointed out that electronic databases have existed for some time and at least the information in patient portals is kept absolutely secure from the sinister motivations of individuals outside the healthcare practice. This participant thought that it was nonsensical for practices to avoid implementing a patient portal because of security concerns, especially if they use other electronic methods such as email to transfer information, which she described as “the most insecure system out” (Patient 5).

The patients’ concerns focused on whether unauthorised people in the clinics could access their personal data. However, portals can monitor access to electronic patient records and this facility was mentioned as a positive attribute by a few of the participants. However, one participant quickly expressed doubts about whether healthcare practices would ever provide information about breaches of procedure within the clinics. Another participant, following a similar train of thought, said that if health clinics want to be transparent and build patient-provider partnerships, they should notify patients every time someone views their records.

Perhaps unsurprisingly, the participants who were past consumer representatives for patient portals were concerned about informed consent (Patients 3 and 4). Patient 3 spoke of her unease about which country or jurisdiction the information would be stored, and the laws around this. She said that if her practice implemented a patient portal, she would need to tell her doctor what was to be uploaded, and she would need a record of who viewed her information before she could feel confidence in the system. These natural doubts were

compounded by the reluctance of some doctors to promote or even discuss the service with patients. Patient 5 discovered the existence of a portal at her clinic from a poster. She stated:

The way I found out it was there was from a poster on the wall. I didn't even get a letter! ... And so I had to actually ask the lady at reception that was there. I said, 'How many doctors have signed up for this?' And she said, 'As far as I know everyone but three'. I said is one of those [removed], and she said 'yes'. (Patient 5)

This patient's experience highlights issues in the ways that the portal is being promoted at her practice, and also the lack of information about its functions. The concern that this experience raises is that patients require solid information in order to make informed decisions about their use of portals. It also draws some close parallels to the doctors' accounts. Individuals' right to choose lies at the heart of this discussion: two participants raised the point that some patients do not want to be more informed about their healthcare and therefore would not want to use a patient portal.

Overall, this theme has shown that while patients see that the electronic storage of health information can offer many benefits, they are also concerned about informed consent and the control of information after it is uploaded. Additionally, because of inconsistent and sometimes inadequate dissemination of information about portals, some aspects of the technology leave patients confused or unsure. In this sense, then, the "black box" aspect of the patient portals persists.

### 8.3. LOOKING FORWARD

Keywords: future, uptake, change, progress

Definition: patients discuss their expectations for the future of patient portals and information technology in the New Zealand healthcare sector.

The theme 'Looking Forward' encompasses the patient participants' descriptions of their hopes and expectations for the future of patient portals and information technology in the New Zealand healthcare sector. For the two consumer representatives this topic

included the challenges they perceived in rolling out the portals throughout New Zealand. In many respects, this theme is a fitting end to this chapter, because as the patient participants expressed their views on the future, they also revealed more thoughts on the present. They ended up disclosing whether they think patient portals are a satisfactory technological advance, and the degree to which they accept or reject future digital developments. The elements in this theme are future, uptake, change, and progress.

The participants commented quite frequently that New Zealand is increasingly moving into a digital culture which will inevitably change social expectations of healthcare. The healthcare sector was commonly compared to banks, which have successfully moved most of their customer service functions online. The participants foresaw the same development in health, with similar stringent security. The participants thought that patients' hesitations about patient portals would diminish in time, as the internet becomes even more present in people's lives. Additionally, Patient 2 indicated that he thought the digital divide will soon decrease and no longer hinder the use of patient portals. He stated, "Times are changing... I'm sixty-two, there's not that many people my age that wouldn't have computers now. I mean there's not going to be that many more years before everyone's computer savvy" (Patient 2). These descriptions indicated that the participants considered patient portals to be a technology that would be progressively used in the future and that the public demand for it would grow.

The participants also discussed potential ICTs that they would like to see introduced into the healthcare sector. For instance, two participants thought that the introduction of telemedicine could solve some of the issues with patient portals potentially reducing face-to-face communication. Patient 2 discussed how it would be valuable for parents with young children or the elderly to be able to have online consultations through skype. He thought that patients might sometimes need to visit a clinic for deeper investigation of a problem, but that in many cases, needful advice could be given electronically, far less expensively. He went so far as to say, "I'd be surprised if most of the doctor-client stuff

wasn't done by computer before too much longer" (Patient 2) and he seemed to have little concern about this potential development. Two other participants (Patients 3 and 5) remarked that the portals offer opportunities to reach new audiences with health promotion messages. One said that an advantage of patient portals is that these messages could be specifically targeted or tailored. For instance, smokers could receive information regarding new treatments for giving up their habit.

Not unnaturally, the patient participants tended to focus on the benefits of portals to patients, with little consideration for the healthcare practices. However, the consumer representatives (Patients 3 and 4) provided some insight into the efforts within practices to implement portals. They acknowledged that the initial uptake by practices has been slow, although Patient 5 remained optimistic stating, "It hasn't gone out much more, but they will get there, they will get there... it's positive, it's still positive". Patient 3 said that she could not imagine that in the near future, the majority of practices in her region would implement a portal. In her opinion, practices will respond to the portal technology only if a degree of pressure is applied from outside, at government or health board level. She observed three groups of doctors: an enthusiastic but small group of eHealth ambassadors; a group with a marginal interest in portals; and a third group that is frankly sceptical of the technology. She thought the implementation of patient portals was hindered by a lack of leadership. The eHealth ambassadors cannot provide adequate leadership because they have large regions to cover, and the group of doctors that is only a little interested in portals is unlikely to promote them or initiate conversations with their patients about them until the technology is more widespread.

Patient 4, however, thought more practices would eventually implement patient portals. This participant shared the opinion of many of the doctors adopting the stance that once the uptake of the patient portals gained momentum, a tipping point would be reached, and practices would be pressured to implement the technology. She saw that there

will always be some resistant individuals, but they will ultimately be disadvantaged by their attitude. She said:

With the way things are going, you're always going to have those who go, "Well, I don't wanna do it that way". But the reality is, we're moving into a digital culture. There's no stopping that. And nothing's gunna wait because somebody chooses to do it the old fashioned way. Unfortunately, those that wanna stay in the old fashioned way are the ones that are gunna miss out. They won't be able to access the same data as everyone else is. That's just my general feeling about it. (Patient 4).

Regardless of the apprehension expressed in the other themes, the participants viewed the widespread development and dissemination of patient portals and other similar healthcare technologies as being inevitable, and even useful. This viewpoint seemed to have the most agreement by the five participants. In part, it was attributed to the internet being increasingly prevalent in New Zealand society. In addition, the participants all acknowledged that these technologies could bring about a number of opportunities, although this was expressed with varying enthusiasm.

#### **8.4. SUMMARY**

The interviews with the patient participants revealed two opposing perspectives deriving from exposure to and use of the technology. The participants who used a patient portal regularly viewed their experience of it overwhelmingly positively, while the others expressed more caution and apprehension. This finding aligns with overseas research (e.g., Haun et al., 2014; Kelly et al., 2016; Wade-Vuturo et al., 2013) which has linked portal use to patient satisfaction and is possibly caused by uneven exposure to portal technology in the population. Some of the patient participants certainly commented that their doctors did not promote the portals, or that the practices were inconsistent and even backward in implementing them. Failure to educate the "patient public" about portals seems to be the significant issue here: the technology exists and regular use of it seems to increase patients' confidence, but it seems to pass many people by. Promotion and education, therefore,

seem to be matters which medical practices should address with patients if the technology is to achieve its full usefulness.

The first theme dealt with the impact of portal technology on patient-provider communication. It was clear that most of my group of patient participants were not locked down into a paternalistic relationship with their health providers, but rather, that they were fully involved in their health care. Their descriptions of their behaviour indicated quite a high level of collaboration in decision-making with their healthcare providers, which is consistent with Charles et al.'s (1997) notions of shared decision making, and Emanuel and Emanuel's (1992) interpretive or deliberative models. They used terms like "partnership" to describe consultations with their doctors, and one participant discussed how he contributes his opinions about possible diagnoses in the medical consultation. Furthermore, two of the participants discussed how people are taking more responsibility for their health. This finding seems important to the future of portal development in New Zealand, because the technology has the ability to engage people with their own health conditions and it is clear that at least some patients wish to take responsibility for their health rather than suffering illness. For instance, one participant traced connections between his flu vaccinations and contracting the illness. Allowing people to see the correlations between behaviour and health outcomes raises the possibilities for sensible self-intervention in the population. This finding, taken in conjunction with the discussion above about the lack of wide-spread promotion of, and education about, patient portals, suggests that without portal technology, the public of New Zealand may be short-changed in available health care options, remaining dependent on providers. Again, the medical practices of New Zealand will need to actively adopt portal technologies, because as one patient participant said, the low uptake of patient portals is a missed opportunity.

The feeling among the patient participants that they did not want to be nuisance to their doctors can be somewhat alleviated by portals, especially for those participants who saw the portals as a means of facilitating a partnership rather than dependency on a

professional. This finding bears out research by Archer et al. (2011), Ozok et al. (2014), and Tang et al. (2006), as well as Day and Gu (2012) in the New Zealand context. The work of these scholars suggests that providing patients with access to their personal health records can increase their engagement in their care, which increases the likelihood of compliance with prescribed regimes. At the same time, as some researchers showed (e.g., Kelly et al., 2016; Kruse et al., 2015; Neuner et al., 2015), patient portals can enhance patient-provider communication. This finding is significant for the health of the nation: it seems to say that if people are treated as reasonable and reasoning adults in an open communication relationship, they will respond accordingly. This is not to say, of course, that traditional patient-doctor relationships are always paternalistic, and that effective communication is absent in them. Rather, the patient participants' data suggest that the portals enhance the good features that exist and allow good to develop if it was missing before. Again, medical practices that do not use the portal technology may be denying their patients a way of understanding illness and improving their health.

The second theme explored issues around the electronic storage and access of health information. The patient participants found that portals gave them fast, convenient access to information which could assist them in navigating their care. However, all the participants acknowledged that portals also contained potential for privacy breaches, which is a documented impediment to the uptake of healthcare ICTs (e.g., Gagnon et al., 2016; Thompson et al., 2016). The participants felt that there was less control of digitised health records, perhaps because the information becomes more transferrable, shareable, and therefore potentially more vulnerable. There were also concerns raised about who has access to the information and the processes around informed consent. It was brought up by two participants that doctors control who the portal is promoted to, and in some cases, who is allowed access. This makes me wonder how much patient empowerment the portals can foster. On the one hand, it can give patients more information about their health conditions to allow them to be more involved in their healthcare, yet on the other



hand, the doctors are ultimately in control as the decision-making regarding the portal functions that are available and to whom rests with them. It is therefore understandable, perhaps, that Archer et al. (2011) claimed that portals are often doctor-oriented and do not incorporate patient-oriented functionalities. Certainly, making certain portal functions available, and trusting patients to use the functions wisely, seems to be something that doctors have difficulty with, and changing their attitudes on this point may be as much a matter for education as the existence of portals is.

When I was analysing the interviews for this chapter, I became conscious that some of the topics discussed by the patients were similar to the doctors. While I was cautious to avoid the doctors' perspectives impacting upon my subsequent analysis of the patients' interviews, the Bridging the Two Faces of Medicine theme has some resemblance to The Changing Consultation theme described in section 6.7, and the Scrutinising the Black Box theme has a likeness to the Increasing Access theme outlined in section 7.3. Aspects of these themes concurred with one another. For example, the patients gave corresponding descriptions of their relationships with their healthcare providers which they valued. For those using the digital communication, this relationship was not eliminated but rather facilitated or even enhanced. Both the patients and the doctors expressed concern regarding the "unknown" aspects about the access of information, and two patients even confirmed the insufficient promotion of the patient portals by doctors. Overall, in fact, the issue of promoting the portals is the one that stands out in both data sets as significant. From the doctors' point of view, promoting the portals binds them into a technology that may be more expensive than it is useful, but from the patients' perspective, promotion would bring them knowledge of technology that enhances patient–doctor relationships by changing the basis on which they operate and which improves health by allowing access to personal information.

# 9: DISCUSSION & CONCLUDING COMMENTS

This research employed a critical approach within the broad field of communication studies. It examined patients' and doctors' perspectives of patient portals in New Zealand and the changes to healthcare associated with, or at least, implied by, the implementation of the technology. My enquiry focused specifically on the impacts of the new technology on the relationships, the spatial dimensions and the formally and informally assigned roles in healthcare delivery. Before conducting primary research, I reviewed and critiqued scholarship pertaining to how ICTs are changing the healthcare landscape and the implications of the changes for the governance of health information and the delivery of care beyond the walls of medical practices. I also explored the changes that technology has wrought on the fundamental ideals of healthcare and the influence of these changes on communication within the patient-doctor relationship, and the social constructions of health, illness and disease.

For my examination of the patient portals, I discursively analysed (Dryzek, 1997) advertisements and I conducted interviews with patients and doctors. This offered a degree of triangulation of my investigation of the patient portal initiative in New Zealand.

I examined the portals from different points of view using two methodologies, and this adds a degree of validation to the findings. As stated by Babbie (2015):

Because each research method has particular strengths and weaknesses, there is always a danger that research findings will reflect, at least in part, the method of inquiry. In the best of all worlds, your own research design should bring more than one research method to bear on the topic (p. 118)

The analysis of the advertisements for patient portals in New Zealand helped to contextualise the interviews. Seven of these advertisements were produced by the NHITB and the remaining two were produced by Medtech, the providers the ManageMyHealth patient portal, which is the most common portal in New Zealand (R. Brown, 2017). My analysis uncovered two sub-discourses present in the advertisements. In the Caring and Concern discourse, healthcare is constructed in terms of physical and emotional connection, where doctors are experts that care for their patients in need. This representation contrasts with the widespread association of caring and emotional labour being devalued and carried out by those 'lower' in the medical hierarchy (Nettleton, 2006). At the same time, the Business of Healthcare discourse made it clear that doctors must make a profit while doing so. Considering my literature review, it seems that this finding reflects changing ideals in healthcare, where there has been a shift to new managerialism, which, as Ryan, Patterson, and Carryer (2003) explained, exacerbated the theoretical split between caring and curing into another dichotomy of caring versus cost effectiveness.

There was a significant contradiction between the messaging in the patient-targeted and doctor-targeted advertisements which intrigued me. In the patient-targeted texts, the portals were constructed as a way for patients to 'improve' their health and be empowered as managers of their healthcare outside of the healthcare practice, while in the doctor-targeted texts, the portals were constructed as administrative aids that do not interfere in the delivery of healthcare. These contradicting constructions have opposing positions on what a patient portal does and what it means for patient-doctor relationships. This made me question: how could both realities exist? The advertisements seemed to present a

paradox of constructions, which further cemented my desire to seek perspectives of the portals and explore the actual impact they are having when used in frontline healthcare delivery. The analysis of these advertisements, in addition to my literature review, contextualised and provided a setting for the interviews conducted with patients and doctors in 2015.

The research question that shaped this research is, “What are patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand?” My analysis of the interviews with doctors showed that doctors generally believed that patient portals can increase patients' engagement and health literacy, but many of them also considered patient portals to be expensive and time consuming, which was often discussed with emphasise indicating that these are significant issues with the portals. Both time constraints and the cost of the technology have been widely reported in scholarship hindrances to the uptake of portals by healthcare practices (e.g., Lester et al., 2016; D. Miller et al., 2016; Vydra et al., 2015), and there have been calls for more incentives to encourage portal uptake by practices in New Zealand in 2013 (i.e., Castaneda, 2013). Considering these factors and the significance placed on these issues by the doctor participants, this may be one reason why cost-effectiveness was emphasised so strongly in the doctor-targeted advertisements analysed.

The patients' opinions coalesced around two viewpoints: there were those who favoured the portals because of increased access to information and improved relationships with their healthcare providers. Another group considered that the portals are a risk, because medicine may be depersonalised and take on a “call centre approach”. Patients who use portals regularly were more optimistic about the technology, which aligns with past studies that have associated patient portal use with enhanced patient-provider communication (e.g., Cochran et al., 2015; Kelly et al., 2016; Kruse et al., 2015) and patient satisfaction (e.g., Kelly et al., 2016; Woods et al., 2013).

Some patients were concerned about the protection of personal information in the patient portals, which is again common in the literature (e.g., Gagnon et al., 2016; Thompson et al., 2016; Tieu et al., 2015). To some extent this concern can be attributed to a distrust in the security of online storage and transferral of information, perhaps reflecting the various privacy breaches of health information that have attracted media attention in New Zealand (e.g., Devlin, 2015; Plumb, 2015; Ryan, 2016). However, ICTs have been adopted in various industries long before they were adapted for the healthcare sector (Aanesen et al., 2011; A. Norris et al., 2009) and some participants drew positive parallels between the sensitivity of banking and health information. Correspondingly, the ‘secure’ login and the ‘safety’ of the information was stressed the NHITB and Medtech patient-targeted advertisements analysed.

The sharp divergence in patient opinions can be partly explained by the fact that patients are ignorant of many aspects of the portals. For instance, they do not seem to know where the data is stored, who has access to it, what is uploaded, nor the processes around informed consent. The concern expressed about the security of the portals revealed the significance and value of personal health information to patients, and probably originates in a deep awareness of the judgments and stigmatisation associated with certain health conditions. It may also reflect the complexity of issues of data ownership and governance when records are digitised. Rather than this being negotiated between practitioners and their patients in the case of hard copy notes, when records are digitised there is the potential for them to be viewed and controlled by various actors across multiple locations, and so it is perhaps no wonder that some patients expressed the potential for a loss of control of their information in portals.

The concern about the security of information makes me question whether fear of security breaches has contributed to the low patient uptake of the portals, although I cannot answer this with my limited sample. However, I am not the only researcher to wonder whether there is a connection to be made. For instance, a New Zealand study by

Hunter et al. (2014) showed that patients of sexual health clinics worried about the sharing of their attendance data and how such anxiety may inhibit people attending clinics. This would be detrimental for these individuals as well as the community as a whole, as it could exacerbate the spread of disease. This fear seems significant for both doctors and patients: obviously, patients foresee the embarrassment of having personal information reach the wrong hands, but doctors likewise face professional embarrassment if their notes were found to contain inappropriate comments or inadequate records.

While patient portals were for the most part an attractive idea for the doctors, their descriptions about their usage depicted a less attractive reality. All but one of the eight doctors using a patient portal reported that only 20 percent or less of their practices' patients were enrolled, and the functions which facilitate the most patient engagement were generally used less. Correspondingly, these functions which are more engaging for patients, such as allowing them to view their medical records or electronically contact doctors, were not mentioned in the NHITB advertisements that targeted doctors. While a low patient uptake in patient portals is not uncommon overseas (e.g., Irizarry et al., 2015; Otte-Trojel et al., 2016; Zieth et al., 2014) and it could be predicted from the NHITB's (2016) report on the number of patients registered trending over time, an unforeseen finding in this research was that the doctors themselves concluded that they and their colleagues were major contributors to the situation because they did not promote the portals enough. This indicates that patients are more likely to adopt a portal when encouraged by their doctors, and that engaging doctors in the portals could help to increase portal uptake by patients.

The doctors' opinion is somewhat borne out by the patient data: they might have been happier to use the portals more if they had sensed that their doctors were enthusiastic supporters of the technology and were pushing the benefits of enrolling. Although this finding is not dissimilar to past studies that associated doctor endorsement with patient uptake (e.g., Irizarry et al., 2015; Vydra et al., 2015), it was unexpected given that many of the doctors vehemently discussed the financial cost of patient portals for their practices.

The implications of cost being what they are for medical practices, it might have been reasonable to expect that doctors would recommend enrolment strongly to their patients, but that seems to have been a step too far for most of my doctor participants, whose discussions of patient uptake showed evidence of strain and discomfort.

This finding is significant. If patient portals are not being used effectively, then there is a real financial loss for medical practices, but more, there is a loss of potential both for doctors and for the public at large. A low patient uptake inevitably is detrimental for healthcare practices as the economic viability of patient portals is dependent on the patient uptake and use (Sapere Research Group, 2015). Patients suffer financially too: for instance, healthcare practices usually charge less for renewing a prescription through a portal, than they do for a visit to the practice. Then too, there are other advantages of portals which these practices would not fully appreciate: as the NHITB (2014b) has pointed out, workflow can be improved, administration can be managed better and more easily, and patients' convenience and their ability to manage their health conditions can also be enhanced. Another potential benefit of portals that, likewise, cannot be realised is that of patient engagement. Although the evidence on the impact of patient portals on health outcomes and quality of care is generally inconclusive (Kruse et al., 2015), providing patients with access to their personal health records does seem to increase their engagement and understanding of their health conditions (Archer et al., 2011; Ozok et al., 2014; Tang et al., 2006). As one doctor participant said, some of her patients who suffer with chronic illness are more involved and motivated in pursuing and persevering in health interventions now that they can monitor the numbers and see how it is directly impacting their results.

Significantly, my limited interviews with the patients who regularly used a patient portal indicated that when used effectively, patient portals can enhance the experience of receiving healthcare and can have crucial social and psychological benefits. As one of the patients using a patient portal said, patients can become "overloaded with information"

and so being able to message electronically doctors not only helps their physical care but can also make them feel reassured and less vulnerable outside of their consultations.

Another participant indicated that being able to electronically communicate with her health provider gave her a sense of acknowledgement which she had previously struggled to gain from the medical profession. The portals also gave the patients more information which could assist them in making informed decisions, a finding that corroborates research by Gu and Day (2013). Thus, as the doctors failed to promote and use the portals effectively, the loss of potential filtered down to many of their patients, with negative effects on their interpersonal relationships, their understanding and involvement in their healthcare and consequent social, psychological and physical outcomes.

This raises the question of why doctors were not promoting patient portals effectively when it was in their best interests to do so. Although one doctor mentioned that he displayed posters in his practice, which were “curling up a bit”, this led me to believe that the NHITB’s campaign to promote the portals to the public was having a limited impact. As I discussed in chapter seven, promotion may have been hindered by time constraints and lack of enthusiasm among their colleagues, but what seems to underpin all doctor decisions about portals is their views of the changes to the nature of healthcare associated with the technology. Both the patients and doctors thought that healthcare had evolved beyond the paternalistic model of delivery described by Emanuel and Emanuel (1992), where patients are passive recipients of expert advice from doctors and have limited participation. Rather, most of the patients described their relationships with their doctors these days as a form of “partnership” where decision-making requires “collaboration”, which gratified them. For instance, one patient stated that “... doctors don’t know everything. And sometimes you can sort of say, well ‘what about this?’, or ‘could this be a possibility?’” Additionally, the doctors said that they wanted to provide patients with information to allow them to be involved in decision-making and many of the



doctors were open to the idea of using electronic communication with their patients, even if they were not doing so through the portal.

Crucially, although many doctors were open to the notion of a partnership with their patients, there was also resistance among the doctors to make the transition to the other end of the spectrum, to what Emanuel and Emanuel (1992) described as the informative or consumer model, in which doctors inform patients of the relevant medical information and patients are in control as the ultimate decision-makers. This resistance was demonstrated in the way portals were implemented. For instance, while it was in doctors' best financial interests to promote the portal technology and charge for answering questions electronically, this facility was often not used perhaps because doctors preferred to focus on patients' wellbeing. It was also clear that the doctors did not see themselves as simply providers of a service, but rather, as expert holders of essential information and experience acquired through years of intensive training. They were unable to relinquish this view of themselves in their relationship with the patients, and they seemed to be quite protective of their existing patterns of interaction. A number of them emphasised that the roles in healthcare would not change because of the introduction of ICTs, with comments such as, "...the core relationship will be the same, but I think that some of the stuff round the edges will make it more efficient when there's a place for it" and "...the doctor will still be, or the nurse I guess, will ultimately be still taking responsibility for that person's healthcare".

The doctors' attitudes do not correspond with the way portals are promoted to the public. The promotional material targeting patients boosted the image of patient portals as a way for patients to be responsible for their own healthcare, which aligns with the e-health (electronic healthcare) discourse described by Henwood et al. (2008). Henwood et al. found that there is an underpinning assumption in the discourses about new technologies that they offer greater freedom to patients or consumers, and indeed that the new discourses of public health transfers agency from healthcare providers to consumers, who

are constructed as possessing the knowledge and capacity for independent decision-making. The notion of an informed and responsible patient public has advantages to governments and health boards that have to subsidise the cost of health care, but it also aligns to the ideological constructs of healthism (i.e., Crawford, 1980) and healthicisation (i.e., Conrad, 1987) where health and illness are framed as a result of individual actions and poses the risk of marginalising those who are unwell (Crawford, 2006).

This conflict felt by the doctors can be read as a philosophical struggle over the responsibility that an individual bears for their ill health and the amount of autonomy they should have for their health and healthcare options. Doctors talked as though giving patients more control over their healthcare was an attractive idea, but they did not act as though it was. I cannot definitively say why this struggle existed, especially among a group of doctors who were genuinely interested in patient portals. I surmise that there may be a generational factor at work: some of my participants appeared to be aged in the mid-forties to the sixties, and they have missed some of the social developments in medicine that have been occurring since the 1990s<sup>23</sup>. Another reason could be that their training, the culture of their practices, and more broadly the professional ethics of medicine, has socialised them into the view that they hold the place of experts who should determine what is best for their patients. The conflict I perceived has made me question whether doctors actually seek and support the movement toward empowering consumers to self-manage their healthcare, or whether it is some form of politically-driven “stunt” which has been pushed on them. According to A. Williams et al. (2011), the policy directives emphasising these ideas are usually developed and implemented independently of frontline healthcare providers.

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<sup>23</sup> Although the progression of the e-health discourse has been underway for some time, analysts have contended that in the 1990s medicalisation was increasingly being driven by the patient (e.g., Figert, 2011; Furedi, 2008) and it was during this era that strategies were encouraging the ‘individual’ or ‘consumer’ to self-manage their healthcare (Glass, 1996; Gabe, Olumide & Bury, 2004).

This conflict was not lost on the patient participants. While they were generally satisfied with their relationships with their doctors, they were concerned about control of portals, fearing access of their records without their consent or even knowledge. This finding revealed a conflict between the patients' and doctors' views about the control of health information. The patient participants felt that they own their personal health information and that have the right to decide how it is managed, protected and maintained, which is a strong and direct contrast statements made by some of the doctors. One doctor, for instance, said, "Most doctors, having heard from almost everyone, ninety-nine percent plus, do not want patients looking at what we write!" However, perhaps the best example of the conflict that doctors' experience in positioning themselves between the paternalistic and consumer models of relating to their patients was suggested by two of the patient participants, who pointed out some practices which had implemented a portal were not denying access to certain patients. This datum is certainly a strong indicator that access to portals is not equitable in New Zealand, even for patients attending practices using the technology. The doctor participants did not confirm this assertion directly, but on the NHITB website, Dr Dunning (2015) commented that her practice purposely excludes anxious patients from using patient portals.

At this practice at least, doctors were making judgments about who should have access to the portal, using unspecified and probably highly idiosyncratic criteria to determine whether patients are fit to understand and deal with information which is essentially about their own being. Furthermore, the NHITB indirectly endorsed this practice by publishing the article on their website as a solution to doctors' concerns, but what is not taken into account here is that doctors often see their patients at their most vulnerable, and judgments made on behaviour in the consulting room may be extremely unfair. This scenario shows that portals are being used counterproductively at times. For example, patients who are the most anxious about their health may be the very ones who

would have particular benefit from a portal, as the extra information and connections might ease their tensions rather than exacerbate them.

Individuals have a right to see their medical information<sup>24</sup>, and doctors should not make access more difficult for particular patients, aligns to the perpetuation of a paternalistic model of medical care and runs counter to both the messages in the promotional material and to the rationale offered by the NHITB for the development of the portal technology. It also depicts a doctor-centric view of portals: healthcare providers are in charge because they alone decide the way portals are implemented, what functions are activated and how information in them is managed. The actuality of the portal experience runs counter to the much-vaunted empowerment of patients. ‘Empowerment’, it seems, is allowed only if it fits the ethos of the medical profession. One of the patients saw this as being controlling and that the doctors were exerting their authority over patients, stating that “It’s like ‘I like you and I know you’ll behave’” ... It’s absolutely disrespectful”, a datum that resonates with Gruber and Trickett’s (1987) discussion that it is paradoxical for the state to seek to empower citizens to manage their healthcare, as the structure that puts one group in a position to empower another undermines the act of empowerment. This participant also commented that most of the promotion has been provider focused, and that while there are eHealth Ambassadors there is no patient equivalent.

Perhaps some of my results were predictable, given my analysis of the NHITB’s advertisements in chapter six. As I mentioned, the advertisements that the NHITB targeted at doctors did not mention the functions that serve - perhaps the correct word here is ‘empower’ - patients, such as allowing them to view their medical records or communicate with their healthcare providers but focused instead on how patient portals

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<sup>24</sup> The sixth principle of the Health Information Privacy Code 1994 gives patients the right of access to their information. The Code of Health and Disability Services Consumers’ Rights 1996 also states that patients have the right to be fully informed, including an explanation of their conditions and results from tests or procedures, as well as a written summary of the information provided on request. Similarly, the Health Act 1956 (section 22F) requires any person holding health information to disclose it to the individual about whom the information is held on request.

can reduce or ease administration. These messages were strengthened by statements by the eHealth ambassadors on the NHITB website (e.g., NHITB, 2014h) and in advertising brochures (e.g., NHITB, 2014b). Similarly, advertisements directed at patients emphasised the helpfulness of portals in managing more of their healthcare. I cannot say whether the NHITB had strong insight into patients' and doctors' viewpoints, or whether, perhaps, the style of promotion has acted as a form of self-fulfilling prophecy. In either case, I find it surprising that the NHITB did not try to change the viewpoints, because they seem to be strong indicators that the portals would be only partly successful.

### **9.1. CONCLUSION & AREAS FOR FURTHER ENQUIRY**

Like all research (Beins & Beins, 2012; Given, 2015), mine has limitations which I attribute in large part to the subject matter. I am fascinated by the portal technology, but it was hard to find participants willing to talk about matters that come so close to the privacy of their experience with their doctors and care providers. Thus, the scale of my primary data collection was only fifteen interviews, but within that small number, there were nevertheless real strengths. For instance, the ten doctors I interviewed were all from different practices which overall covered six different geographical regions in New Zealand. The limited number of patient participants that I was able to recruit could have been a reflection on my recruitment method, as well as the low patient uptake of portals, given that at the time of data gathering, only two patients in the consumer panel had access to a patient portal and only one was enrolled (S. Fletcher, Personal Communication, July 21, 2015). The data that I obtained at the time was from patients who had considerable knowledge about and experience of patient portals and their responses were therefore well informed and thoughtful. However, the sample was admittedly small, and at the time I wondered whether I should amend my original ethics application and undertaking mainstream advertising to recruit more patients using the portal technology. I decided against this course of action, partly because of time constraints, but also because I had so

much difficulty finding patients who were knowledgeable about the portals that I feared that widening my participant group would only put me in touch with people whose knowledge was superficial. When I started my research in 2015, only 69 practices had implemented patient portals and 0.3% of the general population was enrolled (NHITB, 2017). Since I began my research this has changed. In September 2017, long after my primary research was complete, the 509 practices offered patient portals and 472,894 patients were registered (NHITB, 2017).

Future research, then, should certainly take a wider scope than I was able to do within the time and financial limits of a doctoral investigation. The portal technology has potential benefits to both sides of the medical relationship, and it would be desirable to identify any take-up barriers so that they can be eliminated, in order that investment in the portal technology is not wasted. At the same time, research could be conducted into the best forms of public education about portals, so that patients are able to obtain the best possible healthcare. Another area that I feel could be examined in greater detail is the unequal access to patient portals and other ICTs used in healthcare, particularly among Māori and Pasifika, and the implications of this.

I chose to conduct semi-structured interviews because of the depth of the data it produces. I felt that this richness would be ideal for addressing my research questions as it allowed the participants to express their perceptions without being confined to a predetermined list of answers as is the case of quantitative survey research. This is not to say that quantitative research would not be useful for this topic, and with different research questions it could supplement or support the findings made and offer a degree of generalisability. My research offers insight for the future development and promotion of patient portal services in New Zealand. Yet patient portals are only one example of the many ICTs that are being introduced into the forefront of healthcare delivery in New Zealand and internationally. The discussions that my participants had about the patient portals and the findings uncovered can be applied to guide other technologies in the field.

There has been substantial research in the past about decision-making and doctor-patient relationships (e.g., Beisecker & Beisecker, 1990; Bensing et al., 2006; Charles et al., 1997; Emanuel & Emanuel, 1992; Roter & Hall, 2006) and one of my contributions is that this conflict exists in relation to patient portals. This conflict affects the way both sides view where autonomy and decision-making lie. My research showed that this conflict can be a hindrance to the successful adoption of the portals, as while some doctors want to use the technology, they still want fundamental elements of healthcare delivery to remain the same. This was deducted, in part, from a group of doctors who had an increased interest in the portals, and whose low patient uptake mirrored national figures (see: NHITB, 2016). This begs the question of whether the promotion and support of patient portals by the public sector is a pointless exercise, especially given that there has been a significantly lower uptake than anticipated (Johnathan Coleman, 2017). This makes me wonder if this is part of the reason why the portals are not currently one of the core components that the new Digital Advisory Board is focused on achieving (Ministry of Health, 2017b).

If it is not a pointless exercise, and the portals are still important to the Ministry of Health, then I have two recommendations going forward. First, for the patient portal to be an “easy, safe and convenient way for you to manage more of your own healthcare” (NHITB, 2015j, para. 1) as the National Health IT Board has claimed, then doctors’ attitudes need to change. By this I mean that doctors could be trained in a way which is more consistent with a consumer model of care (Emanuel & Emanuel, 1992). The interviews with doctors revealed that they were open to this in theory, but inefficient with this in practice, and so more training in this consumer model of care could change the adoption of patient portals to facilitate more patient engagement. Second, the messaging of promotional material for the portals for doctors should match the targeting to the public. I strongly recommend that future promotional material for the patient portals targeting doctors is not so strongly locked into existing more traditional healthcare delivery

models. This would help to ensure that expectations about the portals are more consistent and that portal functions are used closer to capacity.

When I began this research project for my doctorate, I knew what interested me, but had no idea what I would discover, and I was surprised by how much my findings resonated with previous research. I say I was surprised because New Zealand has had an early uptake of IT within a healthcare setting in the past (Didham et al., 2004; Jha et al., 2008; Schoen et al., 2009). Time and education may change that, but at the moment, patient portals seem to be one gateway that relatively few have walked through.

## **9.2. LAST WORD**

When a research question guides an enquiry along the lines of “What are the perceptions of a phenomenon?”, the answer to it is always going to be “many and varied”. What I have done in this research is capture some perceptions of the patient portals at a point in time, and I have contextualised those perceptions against the experiences in other countries. In doing so, I have given voice to the concerns of the different users. If I had to answer my research question in a single word, instead of the seventy-odd thousand that I have taken to this point, my answer would be simple. “What are the perceptions of patient portals?” “Hopeful.” “What are the associated changes?” “Profound.”



# **CODA: A CRITICAL SELF- REFLECTION ON MY DOCTORAL RESEARCH**

At the risk of being unconventional, I close this thesis with a self-reflection: of the approach I undertook, the methods I used, and the decisions I made during my doctoral study. To be consistent with my epistemological framing, I have tried to apply the same critical paradigm that shaped my lens toward the patient portal phenomenon. A critical self-reflection is: “defined as involving reason giving for decisions or events which takes account of the broader historical, social, and/or political contexts” (Hatton & Smith, 1995, p. 41). Its importance has been discussed in detail by scholars, particularly pertaining to education and learning (e.g., Ausubel, 1968; Dewey, 1933). As Boud (1999) asserted, the emergence of reflective practice is part of a broader change that acknowledges the need for students to think and act professionally as an integral part of learning. Self-reflection helps to make meaning from complex situations, and enables learning from experience (Mann, Gordon, & MacLeod, 2009). It assists professionals to become experts, by examining

problems faced, and tactics to overcome them (Schon, 1983, 1987). It has also been said that the researcher's self-understanding and self-reflection can strengthen the research (Herman, 2010).

But undertaking a critical and honest self-reflection can be difficult. Self-reflection can evoke feelings of vulnerability and self-blame for the perceived weaknesses uncovered (Hatton & Smith, 1995). I know that the inclusion of a self-reflection in this thesis is not only unconventional, but it also exposes me to potential criticism. Halton and Smith (1995) additionally asserted that self-reflection can be influenced by preconceptions and the social environment; matters which I explored in relation to my qualitative methodology in chapter five. Finally, there is an inherent bias in the process of recreating experiences to be reflected upon, as recall can be selective, where the individual avoids examining stressful situations (Newell, 1992).

I tried to overcome these difficulties by considering the context from which my research took place, and by actively embarking on discussions about my research. Since I commenced my doctoral research, I have been employed in a range of roles, spanning five different schools and two universities. This has meant that I have worked with people from varied ontological positions. I see this as a strength, as it assisted my development into an independent researcher, which has almost undoubtedly impacted my doctoral research. It also helped me to see the limitations and flaws in my research. Although I was transparent about these whenever possible, transparency on its own does not excuse shortcoming. The following section is a critical self-reflection of my doctoral research.

### **A PRODUCT OF ITS TIME**

My enrolment in a Doctor of Philosophy officially commenced on 30 April 2014, but my thoughts about the research topic started long before this date. I was working as a chief radiographer at the time, and I was eager to commence my doctoral study, as I had experienced much fulfilment while completing a master's degree. My research topic did

not stem from my master's dissertation (which involved analysing television commercials), but rather, it was actively sought out. I remember searching thesis and research repositories to try (in vain) to find inspiration, before I stumbled across a series of news articles about patient portals, one of which described them as a "game changer" (Newlove, 2014, para. 16) and another of which said: "The face of New Zealand healthcare will change before the year is out" (Carville, 2014, para. 1). I became intrigued by the patient portals, and I found myself thinking about my own patients and questioning why portals were being promoted and how they could impact relationships, as I searched for more information.

Doctoral research often starts by surveying and reviewing scholarship relating to the phenomenon at hand (Walshaw, 2012). In viewing the patient portals as an artefact of broader changes in healthcare, I wanted to position the portals alongside other ICTs used for healthcare purposes, as well as the macro-level social conditions that underpinned them. Unbeknown to me at this point in time, was the sheer volume of scholarship pertaining to these two areas. I became immersed in this scholarship, feeling myself and my research becoming torn between the fields of the technological and the social. I remember trying different systems to manage the information that I was retrieving, with my reference list extending beyond a hundred pages, and the document freezing because of the large size of the file.

Internalising and synthesising this information was one thing but presenting this in my thesis became a considerable challenge. I did not want scholarship to be reduced to single citations to support points without expansion, but, at the same time, I could not expand on every text while keeping to the subject at hand, and within the word limit of a doctoral thesis. I found that when I provided multiple citations within the parenthesis (consistent with APA referencing), this interrupted the flow of the writing, and the message was lost. I know that systematic review criteria could have transparently filtered the scholarship, but this would have introduced other challenges, as systematic reviews tend to

focus on quantitative studies, and miss the context and process (Mallett, Hagen-Zanker, Slater, & Duvendack, 2012). This meant that in deciding which scholarship to include and discard, judgment calls needed to be made. Further complicating the issue was that some scholarship quickly dated because the field was maturing so quickly. Much of the literature that I retrieved in my first year needed to be replaced, as it was no longer relevant by the time I submitted my doctoral thesis. I tried to constantly update my literature review, but I know that soon after this thesis is published, parts of the literature review will be obsolete.

After careful consideration of scholarship, I formulated the research question: "What are patients' and doctors' perspectives of patient portals and the associated changes the portals may bring to the nature of healthcare in New Zealand?" The two groups in focus, the 'patients' and 'doctors', were defined on page 3. My justification for these terms was to provide clarity and simplicity for the reader, perhaps reflecting my writing ethos. At the time, the division of the two groups was not something that I questioned - it seemed natural. The reasoning for this way of thinking is difficult to definitively pinpoint; being underpinned by assumptions, which, by their nature, go unexamined. I could have been influenced by the functions of patient portals, which differentiate between patient and doctor roles (e.g., Orion Health 2017a; Orion Health 2017b), the portal promotion which separately targeted patients and doctors (e.g., NHITB, 2015g; NHITB, 2015j), and by other studies that have this differentiation (e.g., Neuner et al., 2015; Sun et al., 2015). I also wonder if my employment in the healthcare sector influenced my construction of this patient-doctor dichotomy, as I viewed myself as being part of the medical establishment, and patients as the receivers of care. Another explanation is offered by Berger (2014) in the statement: "We search for binary or polar oppositions because meaning is based on the establishment of relationships, and the most important kind of relationship in the production of meaning in language is that of opposition" (p. 24).

Yet regardless of the reasoning, my thinking towards these labels has changed, and I am not sure if I would make the same decision to separate these groups today. I now

know that binary relations can be both damaging and inaccurate. For example, Gavigan stated that the binary opposition between patients and doctors is rooted in the male-female binary, “wherein the male term is privileged and the female term is marked...The doctor is constructed as rational, objective, and knowledgeable: all favourable (male) traits. Conversely, the patient is, general constructed as subjective, emotional and weak” (as cited by Bryan, 2011, p. 117). I should note that I would not have avoided the construction of binary oppositions if I had used the terms ‘consumers’ and ‘providers’, which reciprocally define each other in accordance to a business mentality. Today, I am also well aware that individuals can frequently move between labels; a doctor may use a portal at their workplace, then access their own information as a patient through a portal outside of their employment, and then access information about their child. Now when I consider my interviews, I cannot help but focus on the commonalities between the two groups.

Nevertheless, having formulated my research question while I was writing my literature review chapters, I found myself becoming frustrated at the deficiency in the scholarship pertaining to the patient portals in New Zealand. In contrast to other sections of my literature review, where the scholarship was deep and rich, I had not located any studies examining the portals in New Zealand at this stage, despite my extensive searching. This seemed to be both a blessing and a curse; my research could be an original contribution to knowledge, but I felt that I could not move forward without further grounding in the topic within the New Zealand context. Walshaw (2012) explained, “Engaging with past work will enable you to tune to an ongoing ‘conversation’ within your discipline that commenced long before you had given any consideration to doctoral work” (p. 29), and it was this conversation that I was missing - it felt a bit like I was shouting into the wind. There were, however, detailed reports that outlined the state of the ICTs used in the New Zealand healthcare sector at different points of time (i.e., Ministry of Health, 1991; Ministry of Health, 1996; WAVE Advisory Board, 2001; Controller and Auditor General, 2006; Ministerial Review Group, 2009), which I spent hours trying to condense

(see page 78 for the resulting table). This eventually led me to the realisation that the need for improved ICT in healthcare has frequently been documented, but progress is usually slow, which made me worry about the development of patient portals in New Zealand.

At this point in my reflection, I remember thinking that although the portal technology was successful, the social factors were less so. The deficit in the social context shaped my decisions about my primary data gathering and, consequentially, the findings of my research project. By this I mean that patient portals did not have the presence in New Zealand the way they do today. When I started my research, only 69 practices had implemented patient portals, and 153,000 patients were registered - 0.3% of the general population (NHITB, 2017). Aside from the news articles that initially sparked my interest in the topic, patient portals rarely featured in the media. In September 2017, long after my primary research was complete, the 509 practices offered patient portals and 472,894 patients were registered (NHITB, 2017).

However, back in 2013, the NHITB's national plan only mentioned the word 'portals' once, on page 50, in a bulleted list of initiatives that "the Plan supports" (p. 49). When I mentioned my research topic socially, the reaction that I received was mostly idol curiosity, superficial, and influenced by my description of the technology, because knowledge about portals in the community was so low. I think it was at this point that I decided to narrow my recruitment to doctors and patients who had a prior knowledge of the portals, so that I could obtain rich and contemplative responses, and I would be less likely to influence their views.

In late 2014, when I was feeling as though I was on a lone pursuit and was becoming tired of defining the patient portals in conversations, I searched profiles of academics who studied health informatics, and found that Dr Susan Wells was also researching the portals. We met one afternoon for coffee and chatted about the portals and the limited research being undertaken in New Zealand – it was pleasant. My discussion with led me to two conference proceedings by Day and Gu (2012) and Gu and Day (2013) which reported on

a study where ten patients were interviewed and observed using a patient portal. In 2015, after I began conducting primary research, Day and Wells' study was published in a conference proceeding, which involved semi-structured interviews about the governance of health information, including five patients, seven doctors (two of whom used patient portals at their workplace). These studies gave me insight into some stakeholders' views of the portals, but I still felt that I needed more contextualising information, including a background to the portals' promotion, the envisaged application, and the consequences of its implementation.

This was part my supervisor's reasoning for suggesting that I conduct a discourse analysis of a series of patient portal advertisements. At first, I resisted the idea, as I (like other researchers) considered a doctoral thesis to be a linear process where the data chapters must directly "answer" the research questions. Although Daymon and Holloway (2002) discussed how documents analyses can provide supplementary evidence that does not address the primary focus of the research, the inclusion of contextualising primary research is not commonplace in doctoral research (nor is a reflection, which is also a form of primary research). My decision to include the discourse analysis attracted some criticism, but I do not regret it. My analysis provided another, broader perspective of the portals by the point of view of the main promoters, and angle was not available in the scholarship current in the time. The findings were valuable in understanding the overall context of my research because the discourses defined relevant actors and their roles in relation to the technology and each other, and even foretold some of the findings from the interviews.

In 2015, I began interviewing patients and doctors. When I started contacting potential participants there was a delay in the responses which made me fear that the time that I had spent researching the portals would be in vain. It made me question if that was the very reason *why* there was so little research about the portals in New Zealand. But then the responses from doctors started arriving in a flurry. I remember a doctor calling me at

university out of the blue saying that he had heard about my research and would like to be involved. All the participants I interviewed were enthusiastic about talking to me, although this is not to say that they always viewed the portals positively. They were interested in my research and while many of them were very busy, this did not seem to impact the amount of time that they committed for their interviews.

The fifteen interviews I obtained gave me rich insights into people's experiences of and views about the patient portal phenomenon and, at least with the doctors, I felt I had reached data saturation. I cannot say the same for the interviews with my patient participants, whom I struggled to recruit. This may have been a reflection of the broader social context in which the portals were operating because when as at the time I was conducting my interviews, only two patients on the NHITB consumer panel had access to a patient portal and only one was enrolled (S. Fletcher, Personal Communication, July 21, 2015). At one point, I considered changing my research question to focus solely on doctors' perspectives and removing any mention of the patients' interviews to take away this limitation. In the end, I decided to keep the interviews with the patient, but to be transparent about its limitations, because I wanted to do justice for the patient participants that had given their time, and I felt that their insights were still valuable for my research.

However, I should point out that the number of participants in doctoral research varies significantly. Furthermore, J. Smith, Flowers and Larkin (2009) recommend a sample size for qualitative interviews to be between four to ten participants for doctoral-level study in order to provide a rich, in-depth analysis, while Tracy (2012) stated: "How many interviews are enough? The answer is an unabashedly ambiguous... I generally suggest five to eight interviews as pedagogically valuable – but this decision is tied to the course's specific goals and time constraints" (p. 138). I have not included this discussion to try to hide behind scholarship - that is to suggest that my participant number can be justified because it is recommended in a text, or because others had the same. Rather, I hope to illustrate Francis et al.'s (2010) claim that sample sizes should vary to suit the



complexity of different studies and the range and distribution of experiences or views of interest.

The analysis of the interview material was daunting but exciting. I decided against using analysis software because I thought it could take away my control of the analysis. I remember the highlighting that I used on the transcripts and the notes that I concurrently wrote. Incidentally, I have since used an analysis software for another project and found it useful for transparently organising and presenting the coding, which can be done manually. However, I do not regret my decision to avoid this software for my doctoral research. It was an organic experience. The write-up of my results and discussion and the final editing of my thesis was very enjoyable, and it was satisfying to see the different facets of my research come together.

As I close this reflection, one last observation that I can impart from my doctoral research is that it is an individual experience that can become close to the candidate. If I were to start the same research today, there are aspects that I would approach differently and so it seems that doctoral research is not just a product of its time in relation to the phenomenon being investigated but also to the candidate undertaking the investigation. Yet at the same time, I still feel that the research I produced was rich and in-depth and contributed to an area that had received little academic attention in New Zealand. Completing doctoral research is often described as a ‘journey’. I cannot say if this is the case for other candidates, but I can say that I am not the same person who searched repositories in 2014, hoping that the perfect research topic would emerge before me.

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# APPENDICES

## APPENDIX A: SCREENSHOTS OF THE PATIENT PORTALS IN NEW ZEALAND

*This content has been removed by the author due to copyright issues.*

The ConnectMed Patient Portal (ConnectMed, 2016).

*This content has been removed by the author due to copyright issues.*

The Intrahealth Patient Portal (Intrahealth, 2016).

*This content has been removed by the author due to copyright issues.*

The ManageMyHealth Patient Portal  
Retrieved from Medtech (2016).

*This content has been removed by the author due to copyright issues.*

The MyPractice Patient Portal (MyPractice, 2017).



## APPENDIX B: THE PATIENT PORTAL ADVERTISEMENTS

*This content has been removed by the author due to copyright issues.*

Stay more connected with your patients: Let a patient portal work for you [poster]  
(NHITB, 2015g).

*This content has been removed by the author due to copyright issues.*

Because the highlight of your team's day is seldom admin: Let a patient portal work for you [poster] (NHITB, 2015h).

*This content has been removed by the author due to copyright issues.*

Because the 30 hour day is unlikely to eventuate: Let a patient portal work for you [poster] (NHITB, 2015i).

*This content has been removed by the author due to copyright issues.*

Clinical and patient portal: Enhancing patient care [brochure] – Page 1 of 2  
(Medtech, 2014a).

*This content has been removed by the author due to copyright issues.*

Clinical and patient portal: Enhancing patient care [brochure] – Page 2 of 2  
(Medtech, 2014a).

*This content has been removed by the author due to copyright issues.*

Your GP has never been closer [poster] (NHITB, 2015j).

*This content has been removed by the author due to copyright issues.*

Your GP has never been closer [poster] (NHITB, 2015k).

*This content has been removed by the author due to copyright issues.*

Your GP has never been closer [poster] (NHITB, 2015l).



*This content has been removed by the author due to copyright issues.*

Your GP has never been closer [poster] (NHITB, 2015m).

*This content has been removed by the author due to copyright issues.*

The freedom to manage your health and wellness online [brochure] (Medtech, 2014b).

## APPENDIX C: AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE'S

### LETTER OF APPROVAL



A U T E C  
S E C R E T A R I A T

19 February 2015

Frances Nelson  
Faculty of Design and Creative Technologies

Dear Frances

Re Ethics Application: **15/20 e-Health Care: A case study of the patient portal initiative in New Zealand.**

Thank you for providing evidence as requested.

Your ethics application has been approved for three years until 18 February 2018.

As part of the ethics approval process, you are required to submit the following to AUTECH:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 18 February 2018;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 18 February 2018 or on completion of the project.

It is a condition of approval that AUTECH is notified of any adverse events or if the research does not commence. AUTECH approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

## **APPENDIX D: INDICATIVE INTERVIEW QUESTIONS**

Describe your knowledge/understanding/experiences of the patient portal services. [If it is a doctor from a practice that has implemented a portal, also ask to describe the implementation stage]

What are your perceived positives/negatives of this technology?

Do you think patient portals could/will change (1) the communication and (2) relationship with your patients? If so how?

How do you think (1) other doctors (2) other health practitioners and (3) patients, would consider the patient portals?

From your own experience, do you feel that the implementation of the patient portal services in New Zealand is beneficial?

[For doctors] Would you implement/recommend a patient portal at your practice?

[For patients] Would you use/recommend a patient portal at your practice?

Do you think the nature of communication between patients and their healthcare providers is changing? What are the positives/negatives of this?

## APPENDIX E: THEMATIC ANALYSIS CODING SHEETS

*Below are scanned copies of the last coding sheets that I formulated from the interviews.*

	UPTAKE Keywords: uptake, enrolment, use, inequality, promotion	COST Keywords: time, money, financial, pay, charge, free, efficiency	INCREASING ACCESS Keywords: information, health literacy, access, transparency, e-Consult, Google, internet	THE CHANGING CONSULTATION Keywords: information seeking, communication, trust, relationships
Doctor 1	✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓
Doctor 2	✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓
Doctor 3	✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓
Doctor 4	✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓
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Doctor 7	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓
Doctor 8	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓
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Doctor 10	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓	✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓✓

	BRIDGING THE TWO FACES OF MEDICINE  Keywords: relationships communication, consultation partnership, power imbalance	SCRUTINISING THE BLACK BOX  Keywords: information storage, access confidentiality, consent	LOOKING FORWARD  Keywords: future, updates progress, change
Patient 1	✓✓✓✓✓ ✓✓✓✓✓	✓✓✓✓	✓✓✓✓
Patient 2	✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓	✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓	✓✓✓✓✓
Patient 3	✓✓✓✓✓✓✓ ✓	✓✓✓✓✓✓✓ ✓✓	✓✓✓✓✓✓ ✓
Patient 4	✓✓✓✓✓✓✓ ✓✓	✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓	✓✓✓✓✓✓
Patient 5	✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓ ✓	✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓ ✓✓✓✓✓✓✓	✓✓✓✓✓✓✓