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Samantha Kym Fitch

Abstract

Information-sharing in health care presents opportunities for efficient and effective patient care based on the exchange of high quality information, improved decision making, and increased collaboration and coordination of care across the system. However, it also presents concerns around the control of information and maintaining trust in the privacy, confidentiality and security of information. These concerns reflect the difficulty in balancing how to share information in ways that protect the interests of the individual and any overriding interests of the public. This thesis reports on research exploring trust and information-sharing between patients and General Practitioners (GPs) in New Zealand using a multi-method, empirical-ethics approach. This combines a critical realist theoretical perspective with critical applied ethics. The findings from two empirical studies outline expectations that GPs ensure patient privacy and confidentiality, only sharing information as necessary or appropriate. While levels of trust in health professionals and organisations are high, patient knowledge and awareness of the rules and practices around information-sharing are low. Further these matters are not often discussed between GPs and patients, and patients are not concerned by this. Patients showed little concern about information being shared within the health system or with health professionals, but had concerns about the potential implications of third-party sharing. While some actions may disrupt or breach trust there are ways that GPs can seek to rebuild trust with patients. The findings confirm the importance of trust for the GP–patient relationship and suggests that patients’ trust GPs to use and share information when necessary and for their benefit. In an ethical analysis based on Beauchamp and Childress’ four principles, this thesis suggests that trust is best conceived as a foundational aspect of what it is to interact with patients in a way that fulfils GPs’ obligations. This thesis suggests that an orientation towards building and maintaining trusting GP–patient relationships provides a more robust and relationally focused way of balancing conflicting ethical obligations as exist around information-sharing.
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∗ ∗ ∗

“When eating an elephant take one bite at a time.” — Creighton Abrams

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Chapter 1
Introduction

1.1 Context and Research Problem

Information-sharing has been promoted as a solution in New Zealand to serious social issues (following Coronial Inquests into the death of vulnerable children) and as a way to improve the quality, efficiency and sustainability of the health system and public services more generally. However, a series of data breaches, particularly the Accident Compensation Corporation (ACC) breach in 2012, have created a counterweight to that view. These factors inform the context of this thesis, whereby protecting the interests of individuals to maintain the privacy and confidentiality of their information appears to conflict with other interests for the public good.

In primary care, discussions about patient-centered care and Electronic Health Records have highlighted the potential of information technology infrastructures to enable information-sharing, as well as the potential concerns about privacy, confidentiality and security. Strategy documents have continued to outline the importance of trust for health information since it is mostly collected in a situation of confidence and trust in the context of a professional–patient relationship (Health Information Strategy Steering Committee, 2005; King, 2000; Ministry of Health, 2016a).

Previous research has explored a number of ethical\(^1\), legal and professional issues around information- and data-sharing including:

- Privacy and confidentiality between patients and doctors including the impact of electronic health records (Johnson, 2015; Layman, 2008; Perera et al., 2011; Rothstein, 2010).
- The use of large-scale health data (often referred to as “Big Data”) (Kaplan, 2016; Poulin et al., 2016; Sterckx et al., 2015).

\(^1\)The terms ethical and moral will be used interchangeably in this thesis
• Sharing health information for research purposes including limits on the use of biobank data (tissue and genetic data) (Dove and Phillips, 2015; Ploug and Holm, 2016).

• Sharing health information with third parties (i.e. insurance companies, private organisations) (McSherry, 2004; Sterckx et al., 2015).

This literature has discussed the benefits of intra- and inter-organisational information-sharing for research, public health and other purposes while emphasising ongoing practical and ethical concerns including privacy, confidentiality, and security (Johnsson et al., 2013; Perera et al., 2011; van Panhuis et al., 2014). Despite the centrality of privacy and confidentiality to medical practice, the role of trust in practices associated with information-sharing has received little critical attention in research. While trust has been identified in some cases (Constant et al., 1994; Qiao et al., 2015; Stone et al., 2005; Yang and Maxwell, 2011) the function or role of trust in expectations of information-sharing in the GP–patient relationship has not been investigated. How do patients’ expectations impact upon our understanding of trust in general practice, and the obligations of GPs around appropriate ways for patient information to be shared?

Looking to the literature, there is a growing tradition of researchers highlighting the need for trust in health care, particularly between the patient and their primary care doctor, but also public, systems and organisational trust (Anderson and Dedrick, 1990; Calnan and Rowe, 2007; Gilson, 2003; Hall et al., 2001; Mainous et al., 2003; McKinstry et al., 2006; Murray and McCrone, 2015; Rowe and Calnan, 2006). Trust is a defining aspect of the relationship between doctor and patient (Bova et al., 2012; Calnan and Sanford, 2004; Miller, 2007) and more broadly between the medical profession and society (Gilson, 2006; Parsons, 1951; Pellegrino et al., 1991; Rogers and Ballantyne, 2008; Sass, 1991). Specific to health information, the confidential relationship between a patient and their doctor is predicated on “…maintain[ing] trust between clinician and patient in the interest of both social and public order as well as better care for each individual patient” (Kaplan, 2016, p. 315). Based on this understanding “both parties develop expectations about how information shared in the therapeutic setting will be used and protected” (Lea and Nicholls, 2016, p. 342). These expectations are derived
from professional conduct, legal and regulatory arrangements and interactions between a patient and their doctor. These expectations are imbued with ethical interests that need to be balanced. These include reasons to protect privacy and confidentiality, to seek consent, and protect patients from the harm of unwanted disclosures. There are also reasons to share information—to improve patient care, increase efficiency, to prevent harm to the patient or others, and aid in more equitable health care resourcing. Information-sharing is ethically relevant as it presents doctors, in this case, General Practitioners (GPs), with questions about how they ought to share information with other professionals or organisations in a way that maintains the trust-relationship between themselves and their patient/s.

Increasingly complex models of service provision and moves toward a more free flow of health information across the health system present a problem for expectations about who, beyond a single practitioner, will receive information:

The addition of all these individuals and entities into what was once a simple, two-party, physician–patient relationship has completely changed the original privacy “bargain” in the Oath of Hippocrates. Sharing medical secrets with one physician, known to and selected by the patient, is hardly the same thing as disclosing medical secrets to a physician or other health care provider with the reasonable expectation that the information will be disclosed to numerous unknown individuals and entities in the health care enterprise for a wide range of purposes (Rothstein, 2010, p. 8).

As such, information-sharing may jeopardise the trusting relationship between a doctor and patient. Ongoing innovation and the political will to establish a single electronic health record in New Zealand (Ministry of Health, 2016b), provide a rationale to explore patients’ existing expectations around the information shared in a health context with their provider or shared by a practitioner with others. Australia and the United Kingdom have faced implementation issues with information-sharing programmes where patients have been unaware of the programme or where the sharing is said to result in a breakdown of traditional expectations of GPs (Carter et al., 2015; Lehnbom et al., 2014). This thesis will explore expectations of information-sharing by focusing on one type of patient–practitioner relationship in primary care. This thesis will investigate the role of trust for patients in sharing information with their General Practitioner (GP) and for information their GP may share with others.
1.2 Definition and Scope of Information-Sharing in this Thesis

Information-sharing and data-sharing are often used interchangeably. The data-information-knowledge-wisdom hierarchy is a fundamental and widely acknowledged model in the information and knowledge literature and contextualises the terms data, information, knowledge and wisdom relative to each other and describes the process of transformation from one state to another (Rowley, 2007). In his seminal article, Ackoff (1989) defines each term and discusses these terms in relation to information systems:

Information is contained in descriptions, answers to questions that begin with such words as who, what, where, when, and how many. Information systems generate, store, retrieve, and process data. In many cases, their processing is statistical or arithmetical. In either case, information is inferred from data (Ackoff, 1989, p. 3).

For the purpose of this thesis, information is defined as meaningful, well-formed data, about an identifiable individual (Floridi, 2004). Data, on the other hand, is uninterpreted (Floridi, 2004). Information-sharing involves aspects of information-seeking and information-giving where information is communicated within a defined relationship (Ong et al., 1995). This highlights the role of agency or choice in what information is shared and with whom. For the purpose of this thesis, no distinction has been made between formal or informal information or the method of exchange. While health information technology enables information-sharing and has been fundamental in the success of the early and widespread adoption of electronic health records by GPs in New Zealand, this thesis is focused on the interpersonal or relationship-based aspects of information-sharing.

From an information science perspective, Yang and Maxwell (2011) distinguish between three levels of information-sharing—interpersonal, intra-organisational and inter-organisational. The interpersonal level is focused on how and why individuals share information within interpersonal relationships (Yang and Maxwell, 2011). This thesis focuses on information-sharing from the perspective of a patient who gives or provides information to their GP (an interpersonal relationship), who may then share information with others (a type of intra-organisational or inter-organisational sharing).
Using the language of the Privacy Act 1993 with the three levels mentioned above, information-sharing in this thesis is concerned with:

1. An individual sharing information with a GP, or,
2. A GP sharing information with another health professional or health organisation, or,
3. An agency sharing information with a third party agency (one who is outside of the organisation/system)

This includes information that is given by patient (which is about that individual) to a GP, and information shared by that GP with other professionals within the practice where necessary for the patient to benefit from treatment (McSherry, 2004). Or where a GP shares information with a health professional from outside the practice, for example, to get advice from a specialist. At both of these levels there may be ethical concerns about the privacy, confidentiality and security of a patient’s information, and concerns about respect for autonomy, consent and the distribution of benefits or risks for the individual. Where information is shared with a third party who is outside of the organisation/system (such as an insurance company, or government agency), there may be concerns about potential harms to the individual for instance if the information is used against them (McSherry, 2004).

1.3 Research Aim and Approach

The aim of this thesis is to explore the function of trust and information-sharing within the GP–patient relationship in a New Zealand context. This thesis will examine the role of trust as both an ethical and practical dimension.

This thesis contends that concerns about information-sharing (on the basis of legal and ethical concerns) are mitigated by trust between the patient and GP. That is, the patient has expectations that the GP will not disclose or share the patient’s personal information (including medical and other information) unless they have given consent, or if it is medically relevant or necessary.

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2Which defines an agency as, “any person or body of persons . . . in the public sector or the private sector; and, for the avoidance of doubt, includes a department”
This thesis seeks to answer the following research question:

What role does trust have in patients’ attitudes and expectations around information-sharing in primary care?

This research question has been operationalised as four research objectives:

1. Identify attitudes about trust (general, particular, and organisational) and information-sharing in health care settings.
2. Determine what patients expect when sharing information with their GP, or their GP shares information with others, and identify ways that patients think that breaches of trust can be remedied.
3. Outline some of the processes that GPs can or should undertake (as reported by GPs and patients) to build, maintain and restore trust.
4. Outline recommendations for GPs around how to be trustworthy with information and how to instil trust into information-sharing exchanges.

1.4 Presentation of the Thesis

This thesis is written and presented using the third person. Use of the third person is not intended to present an objective view of the research process, but as a way to allow the reader to engage with the ideas presented.

1.5 Outline of the Thesis

This thesis is organised into 15 chapters. Chapters 1–5 provide the background to the research and comprises five chapters. Chapter 1 (this chapter) introduces the study and provides a brief outline of the rationale for this thesis, the research question and objectives, and the thesis outline. Chapter 2 outlines the context of primary care in New Zealand and mechanisms for information-sharing. Chapter 3 positions this thesis within the trust literature, outlining how trust has been approached and providing a definition of trust and conceptual model (the Beitat model) that shape how trust is used in the remainder of the thesis. Chapter 4 outlines the place of ethical theory in general practice and discusses the ethical interests relevant to information-sharing using the four ethical principles discussed by Beauchamp and Childress (2013). This chapter
includes an initial discussion of how the principles apply to information-sharing, and GPs’ obligations to patients in this regard. Chapter 5 provides a review of studies of trust in primary care, highlighting minimal research looking at this topic.

Chapter 6 outlines the methodological framework of the thesis, positioning this thesis within a critical realist approach. This provides details of how empirical and ethical approaches will be used in this thesis and how the research design will help answer the research question.

Chapters 7–10 present the first study in this research: Survey-based Exploration of the Attitudes and Perceptions of Trust in the New Zealand Health System. Chapter 7 provides the rationale for study 1, that no substantial study of trust has been conducted in the New Zealand context. Chapter 8 describes the cross-sectional survey design employed in study 1, the creation of a questionnaire, multi-method data collection and analysis using statistical and qualitative procedures. Chapter 9 presents the results, identifying the factors that influence general, particular and organisational trust, and expectations around information-sharing. Chapter 10 contains a discussion of the findings and implications of the research.

Chapters 11–14 present the details of the second study in this research: A Vignette-based Study about Trust and Information-Sharing in Primary Care with Patients and General Practitioners in Auckland. Chapter 11 provides a rationale for study 2, based on the findings from study 1, and seeking a deeper understanding of the role of trust for patients and GPs. Chapter 12 describes the qualitative design, use and construction of two hypothetical vignettes for use in the interview guide, maximum variation sampling of patients and GPs, and thematic analysis. Chapter 13 presents the results of interviews from patient and GP perspectives. Chapter 14 contains a discussion of the findings and implications of the research.

The final chapter (Chapter 15) presents the overall discussion and conclusions for this thesis. This draws together the findings from both studies with the ethical literature and outlines the conclusions of this thesis.
Chapter 2
Primary Care and the Role of Information

The previous chapter described the context for this thesis and outlined the question and objectives that serve to orient this research. This chapter describes the organisation of the New Zealand health system with a focus on primary care and the typical types of information-sharing that occur within general practice. This includes a discussion of the broader context in which patients share information with their GPs.

2.1 New Zealand Health System

The New Zealand health system has experienced a number of structural and organisational changes with recent key reforms in 1993, 2001, and 2008. These have shaped the way health care is funded, organised and delivered (for a discussion of these reforms see Ashton et al., 2005; Gauld, 2008, 2012; McAvoy and Coster, 2005; Starke, 2010).

2.1.1 Financing

New Zealand’s health care system provides universal access to a broad range of health services (Cumming et al., 2014). It is predominately funded on a single-payer, tax-funded model where approximately 81% is publicly funded (Cumming et al., 2014; Gauld, 2012; Gauld et al., 2011). General taxes represent 88% of the public funding, with the remainder coming from the Accident Compensation Scheme (ACC) (11%) and local government (1%) (Gauld, 2012). The source of private funding includes private insurance, direct payment for services, and out-of-pocket co-payments (Cumming et al., 2014; Gauld, 2012).
2.1.2 Organisation and Governance

The New Zealand health system is often described as a “mixed” system, as services are provided by a mix of public and private providers (both for-profit and not-for-profit) (Ashton et al., 2005). The Ministry of Health (MOH) is the primary advisory body to the government on health activities, although other government agencies also contribute (Cumming et al., 2014). Twenty District Health Boards (DHBs) have the responsibility of planning and funding health services for those in their geographical areas (Cumming et al., 2014). Their “provider” arm provides hospital services as well as some community and public health services while the “funder” arm contracts with private and non-government providers in the provision of primary care and other services.

2.2 Primary Care

In New Zealand, the primary care provider is the first point of contact for a patient, acting as a “gatekeeper” to secondary or specialist care (Cumming et al., 2014). There are exceptions where those who present directly to a hospital emergency department bypass primary care. Patients have the choice of accessing publicly or privately funded secondary services as well as publicly funded primary health care and health promotion services where eligible (Cumming et al., 2014).

Primary health care is organised through 32 Primary Health Organisations (PHOs) and delivered by GPs, independent nurse practitioners, public health nurses and various allied health professionals including midwives, physiotherapists and others (Ashton et al., 2004; King, 2001; Ministry of Health, 2014). PHOs receive capitation or population-based funding for their enrolled populations (Cumming et al., 2014; King, 2001). Under current arrangements, patients may choose to enrol with a GP or practice, and the patient is then enrolled with the PHO to which the GP or practice belongs—94% or 3.4 million adults are currently enrolled with a PHO (Ministry of Health, 2015). Those enrolled in a PHO will have to pay a fee for the GP services they receive although this will vary depending on age and other factors. While there have been some changes to public funding to reduce the cost of accessing primary care services, the majority of patients are still required to pay an out-of-pocket co-payment.
for GP services (Cumming and Mays, 2011). In those practices who do not belong to a PHO, (often solo practitioners), patients will pay the full fee-for-service cost of the GP services they receive (Raymont and Cumming, 2009).

In some urban areas, Accident and Medical (A&M) clinics provide primary care services (Hider et al., 2005; Tenbensel et al., 2013). A&Ms provide walk-in GP services with extended opening hours and no appointment system (Hider et al., 2005; Tenbensel et al., 2013). While some are contracted by DHBs to provide services, most operate as fee-for-service (Tenbensel et al., 2013).

2.3 Health Information in NZ General Practice

Information is central to the delivery of health care. Increasing the flow, exchange or sharing of information has been a priority since the New Zealand Health Strategy (2000), where the continued development of information management and technology was seen as a key part of achieving the vision of the strategy:

The ability to exchange high-quality information between partners in health care processes will be vital for a health system focused on achieving better health outcomes. Better access to timely and relevant clinical information can improve clinical decision-making and, therefore, health outcomes for individual patients. Privacy and confidentiality of personal information must be maintained at all times in compliance with the Privacy Act 1993 and the Health Information Privacy Code 1994 (King, 2000, p. 29).

The Health Information Strategy for New Zealand (2005) recognised the importance of information management for the sector, identifying the need to maintain trust in the system by ensuring appropriate safeguards around privacy and confidentiality. This is because:

Most health information is collected in a situation of confidence and trust, often in the context of a health professional/patient relationship; maintaining this confidence and trust is critical (Health Information Strategy Steering Committee, 2005, p. 45)

In general practice, information is collected from patients, but is also stored in patient records, and used and shared or disclosed. As gatekeepers, GPs are responsible for enabling patients to access other parts of the health system. This places information-sharing as a core aspect of their role. A study of GP activities in 2001/2002 and found that the majority (88%) of visits were for medical conditions, 9.4% were Accident Compensation Corporation (ACC) related visits and 2.3% were for maternity (Ministry
of Health, 2004). Prescriptions were provided at 66.2% of visits and laboratory tests, and other investigations were ordered in 25% of visits (Ministry of Health, 2004). Over half (57.2%) of the patients were given a follow-up appointment within three months, while 15.8% were referred on (Ministry of Health, 2004). This study demonstrates how often GPs have to share information about a patient with someone else in the course of a patient’s care.

Information at the GP level is used in many ways. GPs are required to record information about the reason for a patient’s visit, details about any examination or assessment, as well as management, progress and outcome details (RNZCGP, 2016). Information collected from a patient (within a consultation) is stored in a patient’s electronic health record (using a patient management system i.e. Medtech). In some situations, the GP may be permitted or required to share information and may do so using electronic or other means, and share information using formal or informal channels. Third parties may also request information about a patient. These practices are situated within a context of legal and professional frameworks, discussed in Chapter 4, which seek to protect the privacy and confidentiality of the patient, while also protecting doctors by requiring that they record or report particular information.

A diagnostic situation (see Figure 2.1) of a patient presenting with cold-like symptoms can be used to demonstrate the types information-sharing that may occur. The patient describes their symptoms (a sore throat, headaches, runny nose) to their GP (Patient–GP sharing). The GP records this and additional information in the patient management system (PMS). The GP undertakes an examination of the patient—the GP takes the patient’s temperature, listens to their heart and lungs, checks the patient’s ears and throat and takes a throat swab to rule out strep throat. Based on the history the patient has shared the GP advises the patient take pain medication to alleviate the symptoms and rest. The GP writes a prescription for the pain medication (which is printed out for the patient, but also sent electronically) and tells the patient to call in two days for the result of the swab (which is sent to the lab for a microbiology culture). This simple example shows how information about a patient is shared with the GP and others. Information-sharing becomes more complex when more people or organisations are involved, or where the information about the patient is more removed.
from the original context in which it was collected.

2.3.1 Capacity for Sharing Information in General Practice

As outlined earlier, information-sharing is concerned with the communication of well-formed, meaningful data about an identifiable individual. This may include a patient sharing information with their GP (or their GP collecting information from the patient i.e. observations or examinations, tests or investigations), or information being shared by the GP with another person or agency. One way that information may be shared is through the use of electronic communication. New Zealand General Practices have achieved high levels of computerisation (Bowden and Coiera, 2013; Didham et al., 2004; Osborn et al., 2015; Protti et al., 2008; Schoen et al., 2012). In 2009 and 2012, 97% of GPs reported that they use electronic medical records (Schoen et al., 2012), and 100% in 2015 (Osborn et al., 2015). Patient management systems (PMS)\(^1\) allow providers to manage patients’ electronic health records (EHR) so that they remain up to date, accurate, accessible and safe (RNZCGP, 2016). These have the capability to monitor and follow-up with patients (e.g. sending reminders about screening); link to risk assessment tools and clinical decision-making support; facilitate

\(^{1}\)Those used in NZ include MedTech, MyPractice, Intrahealth and Houston (Patients First, 2016).
coordinated care (including sharing information across organisations), and support electronic transactions for funding (RNZCGP, 2016). They can also integrate with other systems including electronic referral (eReferral), secure messaging for prescribing and dispensing medications (ePrescriptions), retrieval of discharge summaries from DHBs (eDischarge), the transfer of health records (GP2GP), patient portals, and shared care records (RNZCGP, 2016).

2.3.2 Barriers and Enablers in Information-Sharing

A number of barriers to intra and inter-organisational information-sharing have been identified (Eden et al., 2016; van Panhuis et al., 2014) including:

- Technical barriers related to information system capabilities.
- Motivational barriers such as personal and organisational issues.
- Work-flow barriers—for example, separate logins and passwords that require too much time or too many clicks.
- Economic barriers include human and technical resources.
- Political and structural barriers—characteristics within systems which may present themselves as a lack of trust, restrictive policies or lack of guidelines.
- Legal and ethical barriers that restrict information-sharing—confidentiality and privacy protection, consent processes.
- Ethical barriers—such as fairness and the proportionality of risks and benefits of information-sharing.

In New Zealand, research suggests barriers to the free flow of information (accessing and sharing information electronically) include inadequate funding and resources, as well as privacy and security concerns (McKenna, 2010). The incompatibility of systems also presents an obstacle where systems are unable to communicate or exchange information with each other (McKenna, 2010). This is explained by information being put into systems at the point-of-care by professionals who work across settings, sectors, regions, and locations. Further, the tension between information-sharing across agencies and an individual’s right to privacy means that issues of privacy and confidentiality need to be addressed with changes to public service design or provision (Lips et al., 2011). Eden et al. (2016) suggest that robust training about privacy and security can be an
enabler for information-sharing, as can rethinking consent processes, and providing ongoing training about software systems.

Other enablers include technical aspects such as a single login and developing workflows that integrate information exchange (Eden et al., 2016). Lips et al. (2011) identified several enablers for information-sharing between New Zealand agencies including trust in individual relationships; the distinction professionals make between formal and informal information, the exchange of informal information, the use of information-sharing protocols, use of signed consent forms and co-location of collaborative partner organisations. Lack of trust can be a barrier to information-sharing where the information provider has concerns about how the information may be misinterpreted, misused or deliberately abused (van Panhuis et al., 2014). Trust as an enabling factor related to trust by the information sharer in the person receiving it, and trusting that person to treat it professionally and use it wisely (Lips et al., 2011). While trust has been identified as an enabler for all levels of sharing, it is not known how trust can be built, maintained or rebuilt in relation to information-sharing arrangements. There is also no information about how trust may function in information-sharing in a health care setting that involves all three levels of sharing. As such this thesis explores how information-sharing and trust function within the GP–patient relationship in general practice.

2.4 Conclusion

This chapter has outlined the structure of the New Zealand health system and primary care setting. This identifies the context within which expectations of information-sharing are formed. Given both the increasing technological capability for information to be shared, and the political will to establish a single electronic health record for all New Zealanders, this thesis looks at expectations around information-sharing between patients and GPs. A central part of the health IT plan focused on patients understanding, supporting and trusting how their health information is recorded, managed and accessed. This thesis interrogates patients’ understanding of how their information is managed by GPs, and how trust impacts upon aspects of information-sharing, and information-sharing upon trust.
Chapter 3

Trust

Trust, and the issues which surround it are foundational to the lives of individuals and wider society (Candlin and Crichton, 2013). A viable society relies on basic forms of cooperation (Gambetta, 2000). According to Annette Baier (1986, p. 232):

It seems fairly obvious that any form of cooperative activity, including the division of labor, requires the cooperators to trust one another to do their bit, or at the very least to trust the overseer with his whip to do his bit, where coercion is relied on.

People become aware of trust when it is problematic (Möllering et al., 2004). As such, the importance of trust is highlighted in situations where it is breached, tested, lost, questioned or contested as well as when it is first established or later reaffirmed.

Literature pertaining to ‘trust’ is spread across a range of disciplines (Arnott, 2007a,b; Meyer et al., 2012b; Rousseau et al., 1998; Seppänen et al., 2007; Sheppard and Sherman, 1998) including: psychology (Simpson, 2007), sociology (Lewis and Weigert, 1985; Luhmann, 2000; Möllering, 2001, 2006; Möllering et al., 2004; Powell and Owen, 2006), philosophy (Baier, 1986; Jones, 1996; Miller and Weijer, 2006; O’Neil, 2012; O’Neill, 2002a,b; Wanderer and Townsend, 2013), politics (Ahn and Esarey, 2008; Rothstein and Stolle, 2008), organisational behaviour, management and organisational studies (Abrams et al., 2003; Hosmer, 1995; Kramer, 1999; Li, 2007; McEvily et al., 2003; McEvily and Tortoriello, 2011; Möllering et al., 2004; Nguyen and Liem, 2013; Pirson and Malhotra, 2011; Rousseau et al., 1998; Seppänen et al., 2007), information systems (Rao and Lee, 2007; Schlichter and Rose, 2013) and health related disciplines (Abelson et al., 2009; Bova et al., 2012; Brownlie, 2008; Calnan and Sanford, 2004; Ding et al., 2013; Hall, 2006; Hardie and Critchley, 2008; Henaghan, 2012; Jones, 2012; Mechanic, 1998; Meyer et al., 2012b; O’Neill, 2004; Pilgrim, 2011; Rowe and Calnan, 2006; Skirbekk et al., 2011; Straten et al., 2002; Thom et al., 2004, 2002; White et al., 2011, among others). Due to the diversity of trust research, it is possible to overlook articles when searching in subject-specific databases with the term ‘trust’
or to return a high number of irrelevant articles (Arnott, 2007a).

The previous chapter provided an overview of the New Zealand health system with a focus on primary care. This included a discussion of how information is shared in general practice and highlighted barriers and enablers, including trust. The purpose of this chapter is to position this thesis within the trust literature by discussing current definitions, conceptions and approaches to trust. It also outlines the place of trust in health care, and the context of primary care. Ultimately, it outlines a definition of trust and a conceptual model of trust in primary care that shape trust as it is understood and discussed in the remainder of this thesis.

### 3.1 Defining Trust

Trust is “…a slippery word in more ways than one” (Horsburgh, 1961, p. 28). It is ambiguous (Goudge and Gilson, 2005), elusive (Kramer, 1999; Möllering, 2006; Zand, 2016), and difficult to define (Brownlie, 2008; Burt and Knez, 1995; Hosmer, 1995; Lewis and Weigert, 1985; Li, 2007, 2012; Misztal, 1996; Möllering et al., 2004; Morrone et al., 2009; Rousseau et al., 1998; Seppänen et al., 2007). This preoccupation with defining trust has led to the propagation of many definitions with different assumptions (Blomqvist, 1997; Gargiulo and Ertug, 2006; Lewicki and Brinsfield, 2012; Lewicki et al., 2006; Wright, 2010). One review, for example, identified 126 definitions of trust (Fink et al., 2010).

What trust is seen to mean, and how it is used, depends on the empirical context and theoretical backgrounds of those who study trust (Fink et al., 2010; Seppänen et al., 2007). Researchers continue to grapple with how best to conceptualise, define and operationalise trust: “Is trust vulnerability or reliability, confidence or predictability, calculus or affect, contractual or institutional, voluntary or coerced, cause or consequence?” (Zand, 2016, p. 63). Trust has been defined as “…a noun and a verb, as both a personality trait and a belief, and as both a social structure and a behavio[ur]al intention” (McKnight and Chervany, 2001, p. 28). While many adopt a psychological definition of trust as with Rousseau et al. (1998, p. 395) there are a growing number that argue for a behavioural (Li, 2012) or process definition (PytlíkZillig and Kimbrough, 2016).
3.1.1 Definitions and Explanations from the Literature

Trust research often starts out with a discussion of the number of ways that trust has been conceptualised, followed by a call for unity around a single definition. Li (2015) suggests these calls indicate a need for unity in the conceptualisation of trust while maintaining diversity in the various types/forms/levels of trust and the epistemological and methodological approaches used. While diversity in perspective may have some advantages, confusion or ambiguity around how best to conceptualise trust can result in misunderstandings (Fink et al., 2010; Li, 2012, 2015; PytlikZillig and Kimbrough, 2016). Some see the search for a single definition of trust as a futile endeavour (Fink et al., 2010). Blomqvist (1997) goes so far as to suggest that no universal definition of trust seems possible, in part due to the situational or context specific nature of trust and therefore the different requirements researchers have when operationalising a definition. Some argue that trust researchers would benefit more by understanding trust as a set of related concepts (McEvily and Tortoriello, 2011) or a family of constructs (Lewis and Weigert, 2012) or as a process (Flores and Solomon, 1997; Möllering, 2006). These views embrace the complexity of the trust literature and seek to reconcile the use of the word trust in everyday use and across a range of research domains (PytlikZillig and Kimbrough, 2016). It recognises that all the different conceptualisations have the potential to increase our understanding of trust (Fink et al., 2010; Möllering, 2006).

Not only is trust defined in different ways, but the bases, levels, antecedents and outcomes of trust are variably described within the literature. For example, typologies of trust reference the way trust is built or produced. These include: disposition-based, history-based, category-based, role-based, rule-based (Kramer, 1999), process-based, characteristic-based, institutional-based, cognition-based, affect-based, calculus-based, knowledge-based, and identification-based trust (Candlin and Crichton, 2013; Möllering, 2001).

The common approaches in the trust literature (psychology, sociology, economics, and management and organisation studies) are discussed subsequently. The contribution of philosophy, while not as prolific, is also included. These disciplinary approaches provide different ways of conceiving of trust. Each places certain concerns or elements in the foreground, and others in the background depending on the context and focus.
of trust in their approach. Table 3.1 displays commonly cited definitions of trust from the literature.

**Psychology**

The psychological approach seeks to understand the intra-personal states associated with trust—expectations, affect, intentions, and dispositions (Blomqvist, 1997; Lewicki et al., 2006; Mayer et al., 1995; Rousseau et al., 1998). This views trust as a behaviour or disposition which implies potential vulnerability to another person while possessing some knowledge of the person that is said to inspire or provide the basis of trust (Blomqvist, 1997). The widely supported definition given by Rousseau et al. (1998, p. 395) can also be used as a starting point where trust is seen as a “psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behavior of another”. This comprises two aspects: willingness to accept vulnerability because of our dependency on another person, and a positive expectation about the intentions, motivations and behaviour of another (Lewicki et al., 2006). However, a dispositional approach such as this does not usually recognise the importance of macro-level factors like an institution or organisation in the development of the relationship (Bachmann, 2011). Empirical research looking at trust from a psychological perspective has included survey approaches (e.g. Rotter, 1967) and trust games (Fareri et al., 2015), while neuro-psychologists have employed techniques to measure trustworthiness (Freeman et al., 2014).

**Sociology**

From a sociological perspective, trust exists in a social system; it is a collective notion that goes beyond an individual’s psychological state (Lewis and Weigert, 1985). While an extended discussion is not possible here, Misztal (1996) provides a thorough discussion of the concepts employed by some of the great sociologists—Durkheim, Simmel, Parsons, Toennies, Weber and others—that help us understand social order and notions of trust. Sociologists have been concerned with trust as a base of social order or social capital (Barber, 1983; Garfinkel, 1967; Luhmann, 1979; Misztal, 1996; Parsons, 1951). This is not based on rational self-interest but rather the idea that social order is constituted by cooperative relations (Misztal, 1996; Parsons, 1951). For Simmel, trust functions as a “hypothesis certain enough to serve as a basis for
practical conduct” (Simmel, 1950, p. 318 as cited in Misztal, 1996) and may “rest upon particular reasons but is not explained by them” (Simmel 1990, p. 179 as cited in Möllering, 2001, p. 412).

Trust can be seen to reduce the complexity of social life. Luhmann (1979, p. 93) says that trust:

\[ \ldots \text{reduces social complexity by going beyond the information available and generalising expectations of behaviour in that it replaces missing information with an internally guaranteed security.} \]

Luhmann (1979) and Garfinkel (1967) outline trust as an expectation about the persistence of the moral social order. This links to the psychological literature that outlines trust as a positive belief in the actions of another—trust is believing (hoping, expecting, anticipating) that something will be favourably resolved (i.e. that someone will fulfil their role, act in the way you expect, or do what you asked). To show that this type of trust existed, Garfinkel conducted experiments which sought to manipulate or breach the social order to show how people react—they are made uncomfortable, angry, anxious and confused by breaches of trust. Drawing on this work, Barber (1983) defines trust in two ways:

1. Trust as an expectation of “technically competent role performance”.
2. Trust as “fiduciary obligation”, a social mechanism that makes the just use of knowledge and power possible, and that resists abuses of power.

Notions of competence and knowledge are prominent in work about the sociology of professions, where trust and professionalism are linked (Evetts, 2006). Traditionally this discussed the role of doctors, lawyers and members of the clergy who were trusted to provide advice to citizens (Evetts, 2006).

**Economics**

In economic terms, trust is about rational choice (Banerjee et al., 2006; Bottom et al., 2002; Tonkiss, 2009), and the assumption that individuals will act rationally and efficiently, making choices to maximise utility (Kramer, 1999; Misztal, 1996). This is sometimes outlined as a calculative approach, where trust decreases risk and helps develop expectations of, or predict, future behaviour (Seppänen et al., 2007). This approach draws on sociological, economic and political theory and is influential in the
organisational trust literature (Kramer, 1999). An approach to trust which looks at
reason makes several assumptions. Firstly, trust is selective (we do not trust everyone,
we trust certain people) (Möllering et al., 2004, p. 13). Secondly, trust is reasonable,
meaning we look for reasons to trust someone and assess their trustworthiness before
we trust them (Möllering et al., 2004). Thirdly, trust is decisive, we trust by taking
a particular step in one direction, reaching a state of expectation and performing the
actions which fit with that (Möllering et al., 2004). This is echoed in the definition
proposed by Gambetta (2000, p. 217) as:

a particular level of the subjective probability with which an agent assesses that another
agent or group of agents will perform a particular action, both before he can monitor
such action (or independently of his capacity ever to be able to monitor it) and in a
context in which it affects his own action. When we say we trust someone or that
someone is trustworthy, we implicitly mean that the probability that he will perform
an action that is beneficial or at least not detrimental to us is high enough for us to
consider engaging in some form of cooperation with him.

This definition encapsulates the idea of trust as a threshold point of more general
expectations (where the point can have a value between complete distrust (0) and
complete trust (1)), that trust is important where there is uncertainty or ignorance
about the actions of a third party, and it excludes those situations where trust bears
no influence on the decision we make (Gambetta, 2000). Rational choice approaches
have often used prisoner’s dilemma scenarios or other trust games that have been
modified to take into account different incentives.

**Philosophy**

Philosophical studies of trust draw on an understanding of trust (and trustworthiness)
as moral notions (Baier, 1986; Holton, 1994; Hosmer, 1995; Jones, 1996; Tschannen-
Moran and Hoy, 2000). Typically they follow Baier (1986) who outlines trust as
more than reliance or cooperation: “When I trust another, I depend on her good
will toward me” (Baier, 1986, p.234). Jones (1996, p. 6), following Baier, says “At the
center of trust is an attitude of optimism about the other person’s goodwill”. In this
construction, Jones (1996) outlines trust as being comprised of an affective attitude
which is an attitude of optimism about the goodwill and competence of another person,
and an expectation that the person trusted will be moved by the thought that you trust
them. In either position, trust is considered to be betrayed/violated where the trustor
perceives that the trustee is acting contrary to his or her expectations (Elangovan et al.,
Holton (1994) takes issue with the requirement of goodwill, pointing out that a conman may rely on the goodwill of a victim, but not trust them. Holton (1994) outlines a “participant stance” as what differentiates trust from cases of reliance—this is an attitude which the trustor adopts in relation to or towards the trustee (Holton, 1994; Wright, 2010). Wright (2010) explains this using an example of a refrigerator to say that we rely on things (the refrigerator) to work, while when we trust someone, we prepare ourselves to be either betrayed (should they fail to act as we have trusted them to) or to be gratified (if they have acted as we have trusted them to). This is to say that we do not have a participant stance in relation to the refrigerator (or a car, as in Holton’s example). Although it may fail when we are out and may ruin our produce, we feel disappointment or perhaps anger as opposed to betrayal (Holton, 1994; Wright, 2010). If one is trustworthy it implies an interest in considering the interests of the trustor (Jones, 2012). In order to maintain an ongoing relationship, the expectations of the other party must be met (Jones, 2012). It can be difficult to convey trustworthiness: “‘Trust me!’ is for most of us an invitation which we cannot accept at will—either we do already trust the one who says it...or it is properly responded to with, ‘Why should I and how can I until I have cause to?’” (Baier, 1986, p. 244).

While individuals, professions and institutions need trust, O’Neill (2002a) starts from the presumption that we cannot have guarantees that everyone will keep trust. There has to be a point at which we just trust—trust is needed because guarantees are incomplete (O’Neill, 2002a). Trust is sometimes misplaced, meaning that “others let us down and we let others down” and, when this happens, relationships based on trust are damaged (O’Neill, 2002a, p. 6).

**Management and Organisational Studies**

The management and organisational literature sees trust as necessary for cooperative relations (Mayer et al., 1995; Möllering, 2006; Pirson and Malhotra, 2011; Seppänen et al., 2007; Tyler, 2003) within and between organisations, between individuals, and in team and group dynamics (Boss, 1978; McEvily et al., 2003; Zand, 1972). This literature has explored trust in diverse ways, drawing on psychology, economics and sociology. In many ways, this literature attempts to reconcile theoretical and empirical
approaches to trust.

Möllering (2001, p. 356) defines trust in terms of expectation, interpretation and suspension as seen in Table 3.1. This multidimensional approach to trust reconciles the different strands of the trust literature which argues trust is either a belief, choice or action. It views trust within a context where “rules, roles and routines are bases for trust in so far as they represent taken-for-granted expectations that give meaning to, but cannot guarantee, their fulfilment in action” (Möllering, 2006, p. 70). Trust involves gradualness or a process of building and maintaining trust as opposed to being an all or nothing phenomenon. Additionally, a suspension or leap of faith is necessary for trust to be at play (Möllering, 2006). Möllering (2006) provides a way to consider and study trust that is inclusive and coherent from the initial concepts through to methodological implications.
Table 3.1: Definitions of Trust

<table>
<thead>
<tr>
<th>Definition</th>
<th>Discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...a hypothesis certain enough to serve as a basis for practical conduct” (Simmel, 1950, p. 318 as cited in Misztal, 1996)</td>
<td>Sociology</td>
</tr>
<tr>
<td>“...an expectancy held by an individual or a group that the word, promise, verbal or written statement of another individual or group can be relied upon.” (Rotter, 1967, p. 651)</td>
<td>Psychology</td>
</tr>
<tr>
<td>“...the conscious regulation of one’s dependence on another&quot; (Zand, 1972, p. 230)</td>
<td>Management and Organisation Studies</td>
</tr>
<tr>
<td>“...undertaking of a risky course of action on the confident expectation that all persons involved in the action will act competently and dutifully” (Lewis and Weigert, 1985, p. 971)</td>
<td>Sociology</td>
</tr>
<tr>
<td>“...reliance on others’ competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care.” (Baier, 1986, p. 259)</td>
<td>Philosophy</td>
</tr>
<tr>
<td>“...the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party” (Mayer et al., 1995, p. 712)</td>
<td>Management and Organisation Studies</td>
</tr>
<tr>
<td>“an attitude of optimism that the goodwill and competence of another will extend to cover the domain of our interaction with her, together with the expectation that the one trusted will be directly and favorably moved by the thought that we are counting on her” (Jones, 1996, p. 4)</td>
<td>Philosophy</td>
</tr>
<tr>
<td>“...a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behavior of another” (Rousseau et al., 1998, p. 395)</td>
<td>Management and Organisation Studies</td>
</tr>
<tr>
<td>“...a reflexive process of building on reason, routine and reflexivity, suspending irreducible social vulnerability and uncertainty as if they were favourably resolved, and maintaining a state of favourable expectation towards the actions and intentions of more or less specific others” (Möllering, 2006, p. 356)</td>
<td>Management and Organisation Studies</td>
</tr>
</tbody>
</table>
3.1.2 Key Themes in the Trust Literature

The literature on trust is unanimous in outlining vulnerability or risk and interdependence as components of trust (Banerjee et al., 2006; Blomqvist, 1997; Hall et al., 2001; Mayer et al., 1995; PytlikZillig and Kimbrough, 2016; Rousseau et al., 1998; Tschannen-Moran and Hoy, 2000). Vulnerability entails that one party to the trust relationship is at the mercy of the actions or behaviours of another (Banerjee et al., 2006). Løgstrup (1997, p. 14) says that in trusting another “we deliver ourselves over to the hand of another”. Agents may fail to meet our expectations—the possibility of “exit, betrayal, defection” makes trust relevant (Gambetta, 2000, p.218-219). Further, trust involves interdependence, that is, at least one party is dependent on another to accomplish or achieve something (Banerjee et al., 2006). The “carrier of trust” has expectations, a trustor expects positive intentions on the part of the other, the trustee (Möllering, 2006). Trust is present when an individual “self-surrenders” in relation to an expectation (Løgstrup, 1997). Where there is no vulnerability or risk there is no need for trust (Lewis and Weigert, 1985; Rousseau et al., 1998) as to trust means to leave or lay oneself open and that is why we react as we do when our trust is abused or betrayed (Baier, 1986; Holton, 1994; Løgstrup, 1997). The result of this vulnerability is risk: “the greater the risk, the greater the potential for either trust or distrust” (Hall et al., 2001, p. 615). The risk or vulnerability can come from many different places: one of these sources is information. Blomqvist (1997) outlines that some, but not perfect, information is needed for trust to occur. If the actor had perfect information, there would be no vulnerability, it would not be trust but a matter of rational calculation, and where there was no information it would be a matter of faith or a gamble (Blomqvist, 1997).

3.1.3 Definition and Scope of Trust in this Thesis

Given the centrality of interdependence, vulnerability and expectations in the trust literature, an adequate definition of trust should include each of these aspects, or at least not exclude them. This thesis adopts a multi-dimensional, multi-level, multi-disciplinary, process-oriented definition of trust as outlined by Möllering (2001, 2006).
Table 3.2: Definition of Trust Adopted

Trust is “...a reflexive process of building on reason, routine and reflexivity, suspending irreducible social vulnerability and uncertainty as if they were favourably resolved, and maintaining a state of favourable expectation towards the actions and intentions of more or less specific others” (Möllering, 2006, p. 356).

There has been some discussion about who (or what) can be a party in a trust interaction. Is trust dyadic (between two persons), or can trust extend to non-natural agents such as organisations and governments, or to objects such as information systems, or machinery? The organisational trust literature has sought to outline how a person can trust an organisation, or how organisations can trust one another (Möllering et al., 2004). Janowicz and Noorderhaven (2006) assume the trustor is always an individual but a trustee can be an individual or an organisation. Whether non-natural agents such as organisations can take the place of the trustor cannot be settled here.

In this thesis trust is conceived as a three-place relation (Baier, 1986; Holton, 1994; Jones, 2015). This takes the form:

\[
\text{A trusts B with respect to Z}
\]

This recognises several aspects of trust:

1. Trust is not all or nothing: you can trust the outcome of a certain expectation or a certain domain (Z) but not others (Jones, 2015). For example, one might trust their neighbour to collect their mail, but not to look after their child. Or one might trust their doctor with their health but not their money.

2. It provides the possibility of trust being built gradually, as the range of actions (Z) is extended (Jones, 2015; Möllering, 2006).

3. B may be occupied by persons or non-natural agents and non-human entities (Jones, 2015) such as information systems or things such as machinery or rope. Whether non-natural agents such as organisations can take the place of A (the trustor) cannot be settled here, although it has parallels with literature about group agency.
3.2 Trust and Health

Trust is “essential” (Bova et al., 2012, p. 397) to health care relationships, such as that between a patient and a health professional (Anderson and Dedrick, 1990; Hall et al., 2001; Mainous et al., 2003; McKinstry et al., 2006; Mechanic, 1998; Miller, 2007; Rowe and Calnan, 2006; Skirbekk et al., 2011; Thom et al., 2004; Tofan et al., 2013; White et al., 2011). Trust “…is the core, defining characteristic that gives the doctor–patient relationship meaning, importance, and substance—the way that love or friendship defines the quality of an intimate relationship” (Hall et al., 2001, p. 613). The importance of public trust in health care more generally has also been outlined (Calnan and Sanford, 2004; Hardie and Critchley, 2008; McKinstry et al., 2006; Mechanic, 2004; Straten et al., 2002) as it can influence interpersonal trust (Straten et al., 2002). As a result, preserving, maintaining, building and justifying trust has been a key goal in medical ethics (Hall et al., 2001; Miller, 2007) and has generated important objectives for health law and public policy (Connell and Mannion, 2006; Hall et al., 2001; Morrone et al., 2009). The literature on trust in health care refers to general (public), interpersonal (particular), and organisational trust (Abelson et al., 2009; Brownlie, 2008; Calnan and Sanford, 2004; Gilson, 2006).

3.2.1 General or Public Trust

At a macro level, trust matters in health because of the socio-political nature of health care (Brownlie, 2008). Essentially, health care contributes to wider social values and norms which form the basis for ethical considerations which is why maintaining public trust in health care organisations, institutions and the overall system remains important (Brownlie, 2008; Gilson, 2006). Interest in public trust in health is driven by a range of factors including widely publicised medical scandals, an emphasis on patient safety and concerns about efficient and equitable use of resources (Abelson et al., 2009).

High profile cases of individual and system failure can be perceived as eroding the public’s trust in medicine (Calnan and Sanford, 2004; Guthrie, 2008; O’Neill, 2002a). In the United Kingdom (UK), scandals around medical competence have contributed to shaking public trust, particularly in light of enquiries into paediatric cardiac surgery in Bristol, the conviction of Dr Harold Shipman (who falsified the death certificates of the
patients he murdered) and the retention of organs from children that had been removed without consent at Alder Hey Hospital (Calnan and Sanford, 2004; O’Neill, 2002a). Other scandals also highlight untrustworthy behaviour—for example Willowbrook Hospital in the USA where children were infected with hepatitis deliberately, or Tuskegee where black Americans with syphilis were not given treatment so as to study the untreated disease (O’Neill, 2002a). In New Zealand, the Cartwright Inquiry 1988 shed light on the “unfortunate experiment” at National Women’s Hospital in Auckland concerning the cervical cancer research conducted by Dr Green (Rogers and Ballantyne, 2008). The inquiry found that doctors failed to adequately treat cervical cancer in a number of patients, as well as failures in ethical practices. More recently a series of high-profile data breaches by government departments, agencies and crown enterprises (most notably by ACC in 2012 which triggered an inquiry) raised questions of trust concerning the protection of citizens’ information. These extreme cases are important due to their potential impact on public perception of the medical profession (Rogers and Ballantyne, 2008). They can also trigger reform which impacts the regulation of the doctor–patient relationship (Rogers and Ballantyne, 2008). This can be seen in New Zealand with the Cartwright Inquiry which triggered the development and adoption of the Patients’ Code of Rights.

Continuing pressures on health systems which can undermine trustworthiness (recession, budget constraints, growing populations) reaffirm the ongoing need to consider the role of trust in ensuring equity and justice in health systems and to seek actions that create a safe space where trust can grow (Gilson, 2006). O’Neill (2002b) suggests that a loss of trust may be a cliché of our time as patients no longer trust doctors, hospitals or hospital consultants, while Beauchamp and Childress (2013, p. 41) point to the number of malpractice suits and the “adversarial relations” between health professionals and the public (in the US) as evidence that the climate of trust is endangered. Many authors outline a decline in trust as justifying the need to look at trust in health care (Calnan and Sanford, 2004; Hardie and Critchley, 2008; Rowe and Calnan, 2006; Straten et al., 2002; White et al., 2011). The crisis of trust in medicine is perceived as a problem for patients trusting their health care providers (Miller, 2007; Thom et al., 2004) as well as a perceived decline in public trust of health care institutions more generally (Calnan and Sanford, 2004; Mechanic, 1998; Straten et al., 2002; White et al., 2011).
3.2.2 Interpersonal or Particular Trust

At the interpersonal level, trust in health care seems to be important because of the element of risk with regards to the competence and intentions of the health professional as well as a vulnerability of the patient (Brownlie, 2008; Calnan and Sanford, 2004; Miller, 2007). This is attributable to the nature of illness, injury and disease (Rowe and Calnan, 2006; Skirbekk et al., 2011) and not being able to meet one’s own needs (Dinc and Gastmans, 2012; Thomasma, 1983), as well as information asymmetry and power imbalances (Rowe and Calnan, 2006; Tofan et al., 2013), uncertainties about health issues (Brownlie, 2008; Rowe and Calnan, 2006), and the competency and intentions of the professional/s they rely on (Rowe and Calnan, 2006).

Various devices, strategies and mechanisms can be instituted to prevent abuses of trust or as an alternative to trust. These may include the use of advance directives and informed consent documents (Miller, 2007); processes around education, certification and accreditation; or ensuring quality and control through auditing, performance targets and reporting, to ensure accountability and transparency (Mechanic, 1998; O’Neill, 2002a). The law, organisational and professional codes of conduct, contracts, and auditors can deter those who might break/breach trust (O’Neill, 2002a). These processes and mechanisms seek to avoid the possible consequences that a breach of trust may entail: disciplinary action, lawsuits, bad publicity and loss of reputation (Miller, 2007). O’Neill (2002b) suggests that this shifts our preoccupation and can result in rather perverse incentives. These mechanisms seek to decrease uncertainty or reduce vulnerability (Heimer, 2001) so that instead of trusting a particular individual or organisation:

Many rely on the trustees or guardians of trust, a supporting social-control framework of procedural norms, organizational forms, and social-control specialists, which institutionalize distrust (Shapiro, 1987, p. 635).

Hall et al. (2001, p. 164) calls this a sceptical approach to trust whereby:

...trust is diminished and cannot be effectively maintained, and therefore looks for substitute means to maintain medical relationships...In one sense, these regulations might be thought of as restoring a measure of trust, but this is a more guarded form of confidence of the sort popularized by the Cold War slogan “trust but verify.”
If this analysis of trust is correct, many of the procedures and mechanisms designed to incorporate trust into the system function under an assumption that the health system, organisation or provider cannot be trusted. Instead, where we need to rebuild trust, it is suggested that we seek good governance instead of accountability, and think less about transparency and seek ways of limiting deception (O’Neill, 2002b).

3.3 Conceptual Model of Trust in Primary Care

A number of models or frameworks of trust have been developed (Beitat, 2015; Beitat et al., 2013; Hoffman et al., 2006; Kelton et al., 2008; Mayer et al., 1995; Möllering, 2006; Zand, 1972, among others). These models vary in complexity; some focus on conceptualising the dimensions of trust (Beitat, 2015; Hall et al., 2001; Hoffman et al., 2006; Möllering, 2006) and others integrating dimensions of trust with processes of trust (Kelton et al., 2008; Mayer et al., 1995). They also vary in the context to which trust is applied—including organisational trust (Mayer et al., 1995; Möllering, 2006) and trust in teams (Zand, 1972), trust in digital information (Kelton et al., 2008) or computer systems (Hoffman et al., 2006) and health care encounters (Beitat, 2015; Beitat et al., 2013). As this thesis has adopted a multi-dimensional, process-based definition of trust (page 27), only process-based models are considered here.

A commonly cited model of trust, in the organisational trust literature, is the spiral reinforcement model of trust (Zand, 1972), seen in Figure 3.1. This model conceptualises trust in terms of behaviour which is trusting (or mistrusting) through information, influence and control (Zand, 1972). He suggests that the person who does not trust others will act so as to withhold, conceal or distort information, resist attempts by others to influence them (being unreceptive to proposed goals, methods of achieving goals or evaluating criteria), and evade attempts by others to control behaviour (Zand, 1972). In the same way, trust will lead to increased information disclosure, acceptance of influence and reduced control which will result in reinforced trust, and so the spiral continues (Möllering, 2006; Zand, 1972).

Beitat et al. (2013) and Beitat (2015) outline a dynamic process model of trust based on health care encounters between patients and clinicians in primary and secondary health care settings (Beitat model) shown in Figure 3.2. This model has the same trust
spiral aspect as Zand (1972), but places patient–clinician communication at the centre. Beitat et al. (2013) suggest trust is a dynamic relational process where communication is a core component of the interaction between agents. While trust is important in all health care settings, patient experience in hospital settings is quite different from that of primary care, where patients maintain a level of control and independence in relation to managing their health (Beitat et al., 2013).
Common to both the models developed by Zand (1972) and Beitat (2015) is the focus on expectations (which Zand talks about as an initial level of trust) and information or knowledge as dimensions of trust. The focus on expectations can be attributed to the psychological tradition of trust which attempts to understand the complexity of trust in terms of interpersonal states such as expectations, intentions, affect and dispositions (Lewicki et al., 2006). When expectations of trust are not confirmed, trust declines (Lewicki et al., 2006). The presence of information and knowledge as a dimension of trust is due to the claim that trust grows with a positive relationship history and as knowledge of the other party increases (Lewicki et al., 2006). This increases predictability and decreases vulnerability. Initial expectations of trust affect subsequent information-sharing between individuals (Zand, 1972). Information-sharing tends to reinforce the initial expectations of trust and consequent trust further enhances information-sharing (Butler, 1999). Butler (1999, p. 219-220) refers to this as a “mutually reinforcing dynamic spiral of trust and information-sharing within the
This spiral necessitates that trust involves information-sharing, but also that information-sharing involves trust. Möllering (2006) has also drawn on the concept of trust as a reinforcing spiral; he outlines trust as comprising i) reason, ii) routine, iii) reflexivity and iv) suspension (also referred to as a leap of faith).

Zand (1972) does not use the term outcomes. Instead, he describes control and influence as being consequences (outcomes) of a person’s expectations of trust. The outcome or action resulting from trust at one point in time affects the trustees perceptions (Mayer et al., 1995). Outcomes inform expectations (Beitat, 2015) and also determine whether trust in a relationship is going to evolve over time (Mayer et al., 1995). This is consistent with Möllering (2006) who positions trust as involving gradualness or a process of building and maintaining trust as opposed to being an all or nothing phenomenon. While the Beitat model does not diverge from Zand—it captures the key elements—it was specifically designed for a health care context.

3.3.1 The Dynamic Process Model of Trust (Beitat model)

This thesis adopts the Beitat model of trust. The model has four parts, which are explained in more detail in this section. Within primary care, a patient’s orientation to trust will be shaped by their expectations and personal preferences (Beitat et al., 2013). The outer circle in the model denotes that trust is based on prior information and experiences which can be said to (prefigure) expectations, actions and attitudes towards information and knowledge (Beitat et al., 2013). Trust is maintained unless there is a change at the core, in which case trust is at risk (Beitat et al., 2013).

Communication

The dynamic model of trust shows a core of trust between the professional and patient which is a process of ongoing interaction (indicated by solid arrows) and is actualized or achieved through communication (Beitat et al., 2013). Where or when there is a breakdown of communication the relationship may enter crisis which may negatively impact the other aspects of interaction which include expectations, information/knowledge and actions/outcomes (Beitat et al., 2013). Communication is seen to influence the information and knowledge levels of patient and doctor (Beitat, 2015). Where communication is open and responsive each party can attempt to
understand each other and together build knowledge from where medical decisions can be made (Beitat, 2015).

**Knowledge/Information**

Information may come from within the doctor–patient relationship (i.e. information shared by the patient with the doctor or vice versa) (Beitat, 2015). It may also come from prior knowledge or external sources such as the internet, family and friends or other health providers (Beitat, 2015). Open communication allows for information gaps or inconsistencies to be addressed (Beitat, 2015).

**Expectations**

Expectations are formed based on the information and knowledge that a person has, as well as previous experience (Beitat, 2015). Where patients do not have experience with a practitioner, communication is important in developing the trust relationship (Beitat, 2015; Thom et al., 2004). Further expectations may be made known through communication, and where there is a mismatch in expectations, these may be identified and addressed through appropriate communication (Beitat, 2015). Problems at this point may mean that there is conflict at the action/outcome stage.

**Actions/Outcomes**

Actions and outcomes of a health care encounter are evaluated against expectations; where they match trust is re-enforced and where they do not this may impact upon the doctor–patient relationship (Beitat, 2015). This evaluation becomes new information that shapes expectations (Beitat, 2015).

**3.3.2 Conceptual Model of Trust in this Thesis**

The Beitat model draws on a holistic or multidimensional understanding of trust as multi-level and comprising both cognitive or rational and affective elements that is consistent with the approach of this thesis outlined earlier. This provides a theoretical approach to trust that can be used for the basis of the empirical work in this thesis. In approaching the study of trust empirically within the domain of primary care the domains of the trust model are:
1. Information/Knowledge
2. Expectations
3. Action/Outcome
4. Communication

While the empirical work looking at trust after medical incidents in Beitat (2015) has provided evidence for the inclusion of competence, care and communication as influencing factors, the model does not specify what types of expectations, knowledge/information/experience or actions and outcomes affect trust in primary care.

3.4 Conclusion

As demonstrated in this chapter, the trust literature is vast and disparate. Further, the theoretical questions about trust and the debates about how it is best conceptualised are not yet resolved. This chapter has discussed the conceptual debates within the trust literature and adopted a multi-dimensional, process-based definition of trust (Möllering, 2001, 2006) and the dynamic process model of trust (Beitat et al., 2013) as a conceptual model applicable to primary care interactions for use in this thesis. A narrative review of trust in primary care relationships in Chapter 5 will discuss key factors have been found to influence trust based on empirical research. The next chapter discusses the ethical considerations around information-sharing.
Chapter 4

Ethics and Information-Sharing

There is a large body of literature dedicated to the development of moral concepts, principles and theory and their use in biomedical ethics (the depth and breadth of the literature is demonstrated in Chadwick et al., 2011; Kuhse et al., 2015; Kuhse and Singer, 2010; Rhodes et al., 2008; Steinbock et al., 2003, and others). This chapter presents an account of the ethical considerations surrounding information-sharing using Beauchamp and Childress’ principle-based approach as outlined in *Principles of Biomedical Ethics (PBE)*, first published in 1979 with the seventh edition published in 2013. Their approach outlines four prima facie principles (Beauchamp and DeGrazia, 2004):

- Respect for autonomy—this concerns claims based on the decision-making capacities of autonomous persons.
- Nonmaleficence—that we should not cause harm to others.
- Beneficence—obligations about preventing harm, providing benefits and balancing the costs and benefits.
- Justice—this concerns the fair distribution of benefits, risks and costs.

These are a cluster of middle-level principles or norms consistent with a number of ethical theories and derived from the consideration of medical traditions and common morality (Steinbock et al., 2003). As a mid-level approach, Beauchamp and Childress provide a theoretically modest analytic framework for use in applied ethics that draws on universal moral norms. Besides being fairly enduring, their approach is arguably the “best-known approach to bioethical reasoning that appeals to principles” (O’Neill, 2001, p. 15).

This thesis draws on Beauchamp and Childress’ approach as “a sound and useful way of analysing moral dilemmas” (Macklin, 2003, p. 275) and “doing good medical ethics” (Gillon, 2015, p. 111). Given the aim of this thesis to inform practice through
the consideration of information-sharing as an ethical or moral problem there is good reason to use an approach that is widely recognised in medical practice, and is grounded in how people reason about ethical issues. Besides being well established in the bioethical literature, the four principles are reflected in New Zealand’s legal and regulatory environment and broader health and social policies.

This chapter has two main aims:

1. To explain Beauchamp and Childress’ principle-based approach for ethical deliberation and defend its use in this thesis.
2. To outline how the principles apply to information-sharing practices in primary care with reference to legal and professional regulation.

The connection between the role of ethical theory (discussed here) and empirical methods in this thesis is outlined on page 87.

4.1 Beauchamp and Childress’ Framework

Tom Beauchamp and James Childress outline a framework of basic principles\(^1\) for moral decision-making about problems, policies and practices in biomedical ethics (Beauchamp, 2016; Beauchamp and Childress, 2013). Their approach, as described in *PBE*, outlines four categories or clusters of principles—these are abstract moral statements of obligation that form “the basis of moral reasoning” (Beauchamp, 2007, p. 3). Specific rules and judgements for health care may be formulated through reference to these principles. Overall, the principles serve as a form of “distilled morality” providing a useful and “serviceable” set of norms for analysing moral problems (Beauchamp, 2007, p. 3). This section will discuss the key attributes of Beauchamp and Childress’ approach, specifically:

1. The origin of the principles and the parallels with the *Belmont Report*.
2. The mid-level theoretical approach.
3. The connection or grounding of the principles in common morality.

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\(^1\) Childress (2010) notes that while some proponents or defenders of their approach refer to it as the “four principles approach” (Gillon, 2015; Macklin, 2003). Critics often refer to it as ‘principlism’ (Clouser, 1995; Harris, 2003; Holm, 1995). Overtime ‘principlism’ has become a more neutral label for the approach (Paulo, 2016).
4. The framework of moral norms. This includes the method of ethical justification, which combines specification and balancing with reflective equilibrium seeking coherence between principles, rules, judgements and the common morality.

The content of the principles themselves will be discussed in the next section. While principle-based approaches have faced a number of criticisms,\(^2\) Beauchamp and Childress have demonstrated the adaptiveness of their approach by responding to their critics in subsequent editions of *PBE* (Arras, 1994; Steinbock et al., 2003).

### 4.1.1 Principles of Biomedical Ethics and The Belmont Report

The use of principles in medical ethics has a short history, coming to prominence in the 1970s (Beauchamp, 2016). Although Beauchamp and Childress’ approach is not the only principle-based articulation (Ross, 2002; Veatch, 2007), it is the most widely known. *PBE* was written at the same time as the *Belmont Report* of the United States National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research which also articulates a framework of basic principles (Beauchamp, 2016; Beauchamp and DeGrazia, 2004; Paulo, 2016). Both outline abstract principles grounded in common morality; however the *Belmont Report* presented principles to govern research ethics in light of a number of biomedical research scandals, while *PBE* sought to provide a set of principles for general use in biomedical ethics (Beauchamp, 2016; Beauchamp and DeGrazia, 2004).

### 4.1.2 A Mid-level Approach

The role of theory has presented tension in bioethics—particularly the extent to which principles function in ethical deliberation and decision-making (for further discussion of this issue see Arras, 1991, 1994; Beauchamp, 2007; Childress, 2010; Jonsen, 2007; O’Neill, 2001; Steinbock et al., 2003; Sunstein, 1996; ten Have, 2011; Veatch, 2007). Beauchamp and Childress’ approach is described as a mid-level approach—this references the use of principles that express general ethical statements to be considered to guide action in a particular situation (Espinoza and Peterson, 2012). This mid-level approach is contrasted with high-level normative theories, such as consequentialism.

\(^2\)For further discussion of the general criticisms of Beauchamp and Childress, and how one might respond see Lustig (1992) and Huxtable (2013).
deontology, and virtue ethics that seek to provide a justification for what one ought to do in every situation (Espinoza and Peterson, 2012). Their approach is also contrasted with anti-theorists, particularists and casuists who argue for the centrality of cases in bioethical deliberations (Dancy, 2004; Jonsen and Toulmin, 1988; Jonsen, 2007).

Beauchamp and Childress’ “theoretically modest” approach centred on the development of a small set of mid-level principles has proved popular (Arras, 1994, p. 986). This was due to compatibility of the principles with high-level theories while being grounded in their usefulness for decision-making (Espinoza and Peterson, 2012). This mid-level approach does not make a stand about which high-level theory is correct or should be endorsed, thus avoiding the theoretical disagreement facing those applying high-level theory:

Without having to bother with the Sisyphusian task of grounding their ethical judgments in ultimate theoretical norms, clinicians could pronounce them justified by appealing to such objective and universal principles as autonomy, beneficence, and justice (Arras, 1994, p. 991).

Beauchamp and Childress’ mid-level approach places ethical decision-making and action-guidance at the fore. Further, the principles and cases are positioned in a “dialectical relationship” where the “principles both shape and are shaped by the responses to particular cases” (Arras, 1991, p. 986). As such, their approach leaves room for judgement for particular cases (ten Have, 2011) through specification and balancing that seeks coherence with the common morality (Paulo, 2016). This means ethical deliberation is oriented towards clinicians and others, as opposed to use solely by philosophers and other theoreticians. This does not lay aside theory, instead, it seeks to engage with theory through evaluation, reflection and argument with applied situations in mind. This mid-level theoretical approach is appropriate in this thesis due to the focus on providing recommendations for information-sharing in general practice, and because it “seek[s] to construct theory in the light of experience” (Frith, 2012, p. 205).

4.1.3 Common Morality

Beauchamp and Childress’ four principles are grounded in or derived from common morality. The common morality refers to a universal set of moral norms that all persons are committed to—they are not relative to different groups, cultures, individuals
or time (Beauchamp and Childress, 2013). It includes standards of action or rules of obligation (e.g. do not kill, do not steal, keep your promises), moral character traits or virtues (e.g. honesty, integrity, trustworthiness, kindness), rights and moral ideals (e.g. charity) (Beauchamp and Childress, 2013). The four principles do not constitute the entire universal set of norms, but rather have been selected from the common morality for the purpose of constructing a normative framework for biomedical ethics (Beauchamp, 2016). Beauchamp and Childress do not think they are imposing the four principles but rather that the principles reflect the common morality and aspects of medical and professional tradition. The cluster of principles (respect for autonomy, beneficence, nonmaleficence and justice) build on the tradition of health professionals’ obligations being conceived as professional commitments to provide care and in doing so protect patients from harm, to provide benefits (Beauchamp, 1995). This is an attractive approach on the basis that the:

...four principles are already embedded in public morality and are presupposed in the formulation of public and institutional policies. In truth, these principles do not deviate from what every morally serious person already knows as a matter of general knowledge. Every moral person believes that a moral way of life requires that we respect persons, take account of their well-being, and treat them fairly (Beauchamp and DeGrazia, 2004, p. 58).

As such, the four principles are viewed as valid moral norms that fit with people’s convictions and provide a “widely agreed moral basis for the many more specific principles rules and laws that govern medical practice” (Gillon, 2012, p. 197). This is corroborated by Byrd and Winkelstein (2014) who identified the principles as core moral norms in eight ethical codes. The principles are presupposed or specified in the New Zealand Medical Association Code of Ethics which outlines the health and wellbeing as a doctor’s first priority (NZMA, 2014). The code outlines 11 additional principles which include: respecting patient rights, autonomy and freedom; avoiding exploitation; accepting responsibility to assist in protecting and improving the health of the community; and advocating for adequate resourcing of, and equitable access to medical services (NZMA, 2014). Each of the NZMA principles reflects moral norms about medical practice and are further specified in responsibilities to patients. These place emphasis on professional obligations to provide care and in doing so avoid harm, provide benefits, respect autonomy and uphold justice. This is not to say that the four principles are valid merely because they appear in codes of professional conduct, as
the principles as well as those in the Belmont report shaped the content of codes of research ethics and subsequently professional codes of ethics around the world.

Some have questioned the appeal to common morality, charging the approach with failing to recognise the multiplicity of views (Huxtable, 2013). This critiques the approach for being imperialist, Western and explicitly American (Holm, 1995; Huxtable, 2013). This has led to some empirical exploration to determine the importance or relevance of the four principles (Christen et al., 2014; Ebbesen and Pedersen, 2007; Henning et al., 2016). In the New Zealand context, Henning et al. (2016) demonstrated that 73% of the qualitative responses about the resolution of ethical dilemmas, in a survey of medical and pharmacy students, could be coded as one of the four principles while 14% of responses indicated an overlap between principles. Not only does this reflect the pedagogical importance of the principles within the pharmacy and medicine curriculum at the University of Auckland, but it also demonstrates the way that students draw on the principles to resolve ethical dilemmas. This presents an opportunity for this thesis to explore how Beauchamp and Childress’ four principles are relevant or important for ethical deliberation about information-sharing issues in general practice.

Another concern with Beauchamp and Childress’ approach is that it is not theoretical enough, or fails to offer a systematic account of the principles (Green et al., 1993; Lee, 2010) Green (1990, p. 190) claims:

…that moral analysis cannot be confined to a process of identifying and applying moral principles, however sophisticated this process might be, when the essential work of deriving the basis, meaning, and scope of these principles is left undone.

However, Beauchamp and Childress caution:

…against expecting too much from ethical theories in the way of systematic tidiness and action guidance…no available ethical theory will eliminate the importance of specification, balancing, and reaching for reflective equilibrium as aids in practical reasoning (Beauchamp and Childress, 2013, p. 423)

This underscores the connection between their method of specification and reflective equilibrium as a model of justification that supports some specifications, but not others (i.e. those that are not coherent with justified beliefs and considered judgements from common morality) (Beauchamp and Childress, 2013).
4.1.4 Framework of Moral Norms

The framework of moral norms outlined by Beauchamp and Childress includes principles, rules, obligations and rights. Rules are specified from the principles—rules are an obligation that is “more specific in content and restricted in scope” (Beauchamp and Childress, 2013, p. 14). Determining what an agent should do in a particular situation requires that the principles be specified and balanced.

Prima Facie Principles

Unlike other approaches, the principles outlined by Beauchamp and Childress have no priority or weighting—they are said to be equal. Beauchamp and Childress follow W.D. Ross (1930) in outlining the principles as prima facie duties, meaning:

The principles of autonomy, nonmaleficence, beneficence, and justice create obligations that are always incumbent on the moral agent. We always have a duty to respect the autonomy of another and to be beneficent to him. Nevertheless, these are prima facie obligations because it is not always possible to carry them out. When these duties conflict, we cannot always fulfill all of them. To respect a patient’s autonomy may infringe upon our duty to medically benefit him or her (Kuczewski, 1998, p. 516).

Unlike other approaches that employ a single principle (e.g. utilitarianism, where the moral duty is to maximise consequences) or some form of ranking or lexical ordering (Veatch, 1995), the idea of four equal principles gives rise to the criticism that Beauchamp and Childress do not provide a defensible framework for resolving conflicts between principles (Arras, 1994; Clouser, 1995; Green et al., 1993; Lustig, 1992). Beauchamp and Childress (2013) resolve conflict through the generation of sub-rules and considerations of weighing and balancing. Specification reduces the “indeterminacy” of norms by generating action-guiding rules (Beauchamp and Childress, 2013, p. 17).

Whether the principles are equal has been a point of contention within the literature. Some have construed Beauchamp and Childress’ approach as a “one note theory with a few underlying supportive melodies” due to the focus on autonomy (Callahan, 2003, p. 289). Beauchamp and Childress have always outlined the principles as equal and respond to this criticism by saying the “order of our chapters does not imply that this principle [respect for autonomy] has priority over other principles” (2013, p. 101). Responding to Callahan, Gillon (2003) argues that respect for autonomy should be the
“first among equals” of the four principles because it is a necessary component of the other three and autonomy is a special or important aspect of moral life. However,

If we allow the existence of a First Principle we run the risk of resurrecting just those problems we sought to escape from by turning to the idea of prima facie duties. We should do better to acknowledge the importance of respect for autonomy, remind ourselves of the importance of the other principles too, and accept that there is no way of saying, at the theoretical level, which principle matters most (Dawson and Garrard, 2006, p. 201).

To make judgements about particular cases the principles provide a structure from which we can specify rules for certain contexts (Dawson and Garrard, 2006) (i.e. about the confidentiality of health information as a specification of respect for autonomy), and determine how they may apply in our particular circumstances.

**Specification**

Beachamp and Childress argue prima facie norms can only be applied through balancing and specification, not deduction (Paulo, 2016). This responds to those who take a case-driven approach who have attacked principlism for being mechanistic and deductive (Arras, 1991, 1994; Steinbock et al., 2003). This is a concern for uncritical and mechanistic applications of the principles (Huxtable, 2013). However, as O’Neill points out:

> The ethical principles that have received most attention are highly indeterminate rather than quasi-algorithmic. They may constrain but do not regiment action; they are more likely to recommend types of action, policy, and attitude than to offer detailed instructions for living (O’Neill, 2001, p. 18).

Further, “additional interpretation, specification, and balancing of the principles is needed in order to formulate policies and decide about cases” (Beauchamp, 1995, p. 182). More recently the “din of clashing moral methodologies” has been replaced by convergence on the role of reflective equilibrium (Arras, 2009, p. 47). Over time there has been a shift within the field, but also in subsequent editions of *PBE* which demonstrate a move from deductive to coherentist approaches. For instance, Beauchamp and Childress now draw on reflective equilibrium as an integrated approach to ethical justification. This seeks coherence between the principles, rules and judgements with beliefs and theories as discussed on page 48.

The four principles require specification to make them suitable for analysing a context, case or policy. Specification “provide[s] increased action-guiding capacity, while
retaining the moral commitments in the original norm” (Beauchamp, 2003, p. 269). For example, when a patient discloses information to their GP, it may be difficult to know what moral obligations apply—how exactly do respect for autonomy, beneficence, nonmaleficence and justice apply?

Beauchamp and Childress (2013) present and defend three types of rules—substantive rules, authority rules and procedural rules. Substantive rules provide guidance for action that is more specific than the four principles (Beauchamp and Childress, 2013, p. 14). Authority rules relate to who can and cannot make decisions and perform certain acts while procedural rules establish procedures (Beauchamp and Childress, 2013).

Beauchamp and Childress draw on the idea of specification as defined by Richardson (1990, p. 295–296):

“Norm p is a specification of norm q in and only if

(a) norms p and q are of the same normative type;
(b) every possible instance of the absolute counterpart of p would count as an instance of the absolute counterpart of q (in other words, any act that satisfies p’s absolute counterpart also satisfies q’s counterpart);
(c) p qualifies q by substantive means (and not just by converting universal qualifiers into existential ones) by adding clauses indicating what, where, when, why, how, by what means, by who, or to whom the action is to be, is not to be or may be done or the action is to be described, or the end is to be pursued and conceived; and
(d) none of these added clauses in p is irrelevant to q.”

Specification requires extensional narrowing as stipulated in (a) and (b)—that is so that the initial norm may be “brought to bear” on the more specific norm (Richardson, 2000, p. 289). Further, it also requires glossing of the determinables as outlined in (c) this adds clauses that spell out or qualify the action to be done or avoided (Richardson, 2000). The example used by Beauchamp and Childress (2013, p. 17) outline “respect the autonomy of competent patients by following their advance directives when they become incompetent” as an example of how respect for autonomy is specified in the context of advance directives.

See below the attempt to specify respect for autonomy in the context of protecting confidential information. Specification requires narrowing (i.e. a rule is more targeted or particular than a principle) and stipulating clauses that outline what action is to be done or avoided. Richardson (2000) argues that a rule should also invoke the
norm/principle so that it is clear that the rule and the principle are connected. The rule ‘protect confidential information’ as a specification of respect for autonomy narrows but it does not add clauses or connect clearly to the principle, while ‘respect the autonomy of patients by protecting confidential information’ connects to the principle but does not provide further clauses. The addition of clauses that indicate when, why, how, by who, and by what means the action should or should not be done adds content to the specification, as well as making it a more determined obligation—it provides action-guidance. Such a rule for confidentiality might be: ‘respect the autonomy of patients by not sharing confidential information unless the patient gives permission for information to be shared’. This is likely one of many rules that could be generated through specification.

There is a concern that Beauchamp and Childress’ approach cannot provide definitive answers and that without a unified foundation the principles can be used to produce whatever outcome we desire (Clouser, 1995; Harris, 2003; Holm, 1995; Lee, 2010). This is a critique of the ethical justification or moral reasoning employed by Beauchamp and Childress and questioning the role of principles in this process. Harris (2003, p. 303) argues that:

…much of bioethics is not concerned with identifying the principles or values appropriate to a particular issue, but rather involves analysing the arguments that are so often already in play and which present themselves as offering solutions in one direction or another…the principles allow massive scope in interpretation and are, frankly, not wonderful as a means of detecting errors and inconsistencies in argument.

However, there is no reason to think that the principles are not entailed within the “arguments that are so often already in play”. For example, with information-sharing, bioethics has focused on arguments about the role, value and limits of privacy and confidentiality. This can be seen as an argument that balances concern for the autonomy of the patient the information is about, with arguments about the benefit of sharing information for the patient’s care, research, or education or preventing serious harm to the patient or others, or for the equitable allocation of resources. Harris agrees that the principles “are bound to figure in any adequate discussion of the ethics of any issue” but thinks that using only these principles may be inappropriate in many cases (Harris, 2003, p. 303).
Huxtable (2013) suggests the strengths and weaknesses of Beauchamp and Childress’ approach lie in the readiness of the principles to be applied or used in varied contexts by diverse agents; however, they are only the start of the moral work. This requires a more exhaustive approach that draws on the four principles as well as other considerations. This fits with the model of reflective equilibrium that Beauchamp and Childress discuss. For this reason, this thesis considers not only the application of the principles but also how empirical data provides details to help in the application and specification of the principles and to highlight tension or conflict between norms that need to be balanced. This is congruent with a critical realist approach (discussed in Section 6.3) that interrogates current theory and alternatives to find the best explanation of the phenomena. This will entail an analysis of the arguments for and against information-sharing in primary care that goes beyond the four principles.

**Balancing**

Specification of moral norms sufficient for all actions or circumstances would require “potentially hundreds, thousands or millions of rules, each suited to a narrow range of conduct” (Beauchamp and Childress, 2013, p. 22). As such, moral judgement is required to determine which norms apply. Balancing considers the weights and strengths as to which moral norms should be used in a particular case. This considers the wider framework of moral norms, balancing obligations (principles and rules) with character traits or virtues, rights and moral ideals.

For information-sharing which moral norms have more weight? How are respect for autonomy and nonmaleficence balanced with beneficence and justice? How can specifications requiring that doctors protect patient information and uphold privacy and confidentiality be balanced against obligations to prevent harm, or to pursue the best interests of a patient? How do other values, virtues or rights fit in? In a routine encounter with a GP, (as outlined in Figure 2.1) a patient is likely to be happy for information about them to be documented and shared with the pharmacy and lab tests. Not only will sharing information help the patient (by finding out what is wrong, and providing treatment), but the harm associated with documenting or sharing information about the patient’s cold symptoms is likely to be very low, and is unlikely to infringe upon future medical decision-making. In different circumstances,
the relevant principles and the decision will be different.

Veatch (1995, p. 209) has concerns with balancing because it “is nothing more than an elaborate rationale for letting pre-conceived prejudices rise to the surface”. Balancing theories or approaches have also been associated with intuitionism (Veatch, 1995). In response to the concern with balancing relying on intuition, partiality and arbitrariness, Beauchamp and Childress (2013, p. 23) propose six conditions that must be met to justify infringing one norm to abide by another:

1. Good reasons can be offered to act on the overriding norm rather than on the infringed norm.
2. The moral objective justifying the infringement has realistic prospect of achievement.
3. No morally preferable alternative actions are available.
4. The lowest level of infringement, commensurate with achieving the primary goal of the action, has been selected.
5. All negative effects of the infringement have been minimized.
6. All affected parties have been treated impartially.

These criteria outline the importance of providing reasons or argument for a particular course of action.

**Reflective Equilibrium**

A number of different and conceivably incompatible solutions may be determined when specifying the principles (Beauchamp, 2016; Richardson, 1990). Further, in balancing moral obligations that apply in a particular context it may be unclear which moral norms are morally salient, or which judgements best fit the case at hand. This is a question of moral justification—“how claims that particular actions or practices are right or wrong, permissible or impermissible may be confirmed or disconfirmed” (Jaggar, 2000, p. 225). Theory may be applied in a top-down or deductive fashion where general norms (principles or rules) are applied to particular cases (Beauchamp and Childress, 2013)—some refer to this as moral generalism. Moral judgements can also be justified inductively drawing on the particularities of cases, this is a stance called moral particularism and is discussed by Jonsen and Toulmin (1988) and Dancy (2004). Beauchamp and Childress have adopted reflective equilibrium as their model of justification. This seeks to overcome the pitfalls of both top-down (deductive) and bottom up (inductive) approaches of justification by seeking coherence (Beauchamp and Childress, 2013). Reflective equilibrium (Arras, 2009, p. 47)
is the:

project of justifying ethical beliefs [which] ideally involves the attempt to bring our
most confident ethical judgments, our ethical principles, and our background social,
psychological, and philosophical theories into a state of harmony or equilibrium (Arras,

This is a dialectical approach whereby:

a specification is justified...if and only if it is consistent with the norms of common
morality and maximises the coherence of the overall set of relevant, justified beliefs
of the party doing the specification...these beliefs could include empirically justified
beliefs, justified moral beliefs and previously justified specification (Beauchamp, 2016,
p. 11).

While the principles are acceptable without argumentative support, the process of
achieving equilibrium requires the deliberation and reflection of judgements and beliefs,
adjusting and specifying so that all are coherent (Beauchamp, 2016). Achieving this
reflective equilibrium is by no means straightforward, and will remain an ongoing
project as beliefs and judgements change and incoherent aspects emerge (Beauchamp,
2016).

4.2 The Four Principles

This section provides a discussion of the four principles as outlined by Beauchamp and
Childress. This includes some consideration of the source of tension or controversy
in the conceptual and theoretical literature about each principle. Nonmaleficence and
beneficence have traditionally played important roles in medical ethics, while respect
for autonomy and justice have become more prominent in recent times (Beauchamp,
2016). As outlined earlier these principles form the basis of the framework described
by Beauchamp and Childress. However, they must be further specified for particular
context and circumstances.

4.2.1 Respect for Autonomy

Respect for autonomy is a principle based on liberty and self-determination, or
rather, of “personal autonomy as self-rule free of the controlling influence of oth-
ers” (Beauchamp, 2016, p. 5). Individual rights and autonomy have become central
themes in bioethics making them dominant in topics from genetic testing to psychiatry
to end of life and medical innovations (O’Neill, 2002a).
The core of personal autonomy relates to self-government (Christman, 1988; Christman and Anderson, 2005; Mackenzie and Stoljar, 2000a) and the idea:

...of being one’s own person, directed by considerations, desires, conditions, and characteristics that are not simply imposed externally on one, but are part of what can somehow be considered one’s authentic self (Christman and Anderson, 2005, p. 5).

Positive conceptions of autonomy focus on the active self-direction of an agent, while negative conceptions suggest a person is autonomous when free from controlling influences (Christman, 1988).

There are many theories of autonomy including hierarchical or split level theories, (as discussed in Christman, 1988) as well as relational theories (Mackenzie, 2008; Mackenzie and Stoljar, 2000a). Debates about the role of authenticity and competency play into these theories (Christman and Anderson, 2005), as well as the role of social relationships. Authenticity focuses on the capacity to reflect on your desires and values, while competency specifies requirements or capacities for rational thought and self-control free from external or internal coercion (Christman and Anderson, 2005). The most influential model of autonomy is that developed by Gerald Dworkin and Harry Frankfurt (Christman, 1988; Christman and Anderson, 2005). In this theory, autonomy is constituted by lower and higher order desires (Christman, 1988). Autonomy involves:

...second-order identification with first-order desires under conditions of “procedural independence”—that is, conditions under which the higher-order identification was not influenced by processes that subvert reflective and critical capacities (Christman and Anderson, 2005, p. 9).

Beauchamp and Childress (2013) find this hierarchical theory problematic, instead outlining a three condition theory of autonomy comprising:

1. Intentionality: Actions are intentional—meaning that the person has a conceptualisation of planned action, although the planned outcome may not come about.
2. Understanding: An agent has adequate understanding of an action, sufficient for decision-making.
3. Noncontrol: An agent is free from external sources of coercion or internal influences or states that undermine self-rule.

This model focuses on autonomous choice as being free from non-ideal conditions.
Beauchamp and Childress (2013) identify a number of issues related to autonomy: autonomous choice, competence and informed consent. Ensuring rights and autonomy are upheld is often associated with medical practice that seeks informed consent for patients and participants for all medical treatment, medical research and disclosure of information (O’Neill, 2002a). While autonomy is often equated to informed consent (Kukla, 2005; Mackenzie and Stoljar, 2000a), it is not the only consideration. Dodds (2000) argues that the narrow focus on consent constrains the debate of autonomy in bioethics and health care to matters of voluntary choice and self-determination as opposed to considering the wider competencies required for autonomy—such as self-discovery, self-direction and self-definition that are supported by equitable access to health care, and socialisation (Dodds, 2000; Mackenzie and Stoljar, 2000b).

As a positive obligation, the principle requires actions that support autonomous decision-making (Beauchamp and Childress, 2013). As a negative obligation, the principle requires that the actions of autonomous agents not be subjected to controlling influences or constraints by others (Beauchamp and Childress, 2013). For information-sharing, this would see positive autonomy as the self-direction of the patient to choose what, how and with whom information is shared. Negative autonomy would be concerned with ensuring that a patient was free from coercive or other influences when sharing or consenting to share information. This places an obligation on professionals to disclose information to patients, ensure understanding and voluntariness and foster decision-making (Beauchamp and Childress, 2013). In relation to information-sharing, this places an obligation on GPs to ensure patients know who will receive/have access to their information, how it will be stored, and the purposes for which it can be used. These positive and negative aspects support many rules—Beauchamp and Childress (2013, p. 107) offer several examples including:

1. Tell the truth.
2. Respect the privacy of others.
3. Protect confidential information.
4. Obtain consent for interventions with patients.
5. When asked, help others make important decisions.

How the principle of respect for autonomy should be specified for information-sharing
in general practice will depend on considered judgements including empirical evidence. As such these specifications will be impacted by what patients expect of their GPs when sharing information as well as their knowledge and understanding of information-sharing.

4.2.2 Nonmaleficence

The principle of nonmaleficence relates to the maxim “Above all [or first] do no harm”, and requires that individuals “ought not to inflict evil or harm” (Beauchamp and Childress, 2013, p. 150–152). As such health professionals have a negative obligation to make sure their actions will not inflict harm (Beauchamp, 2016). Following Feinberg, Beauchamp and Childress (2013, p. 153) talk about harm as:

... thwarting, defeating, or setting back of some party’s interests, but a harmful action is not always wrong or unjustified.

Some setbacks to interests may be justified—as with the amputation of a patient’s leg to save their life (Beauchamp and Childress, 2013). These setbacks or harms require justification either by showing that the action does not infringe obligations of nonmaleficence or that other principles or rules outweigh those considerations (Beauchamp and Childress, 2013). Rules that specify the principle of nonmaleficence include the following examples (Beauchamp and Childress, 2013, p. 154):

1. Do not kill.
2. Do not cause pain or suffering.
3. Do not incapacitate.

Given the personal and sensitive nature of health information, patients may be harmed by the disclosure of information about them to others or if pertinent health information about them is not shared with others (for example not disclosing medications that may be contraindicated).

4.2.3 Beneficence

Beneficence has long been established in health care as part of the Hippocratic tradition and medical professionalism. Beneficence is about acting to benefit others (Beauchamp and Childress, 2013). This implies a duty for doctors to “act for the good of their
patients” (Rogers and Braunack-Mayer, 2009, p. 70). The principle of beneficence generates positive requirements for action to prevent evil or harm, remove evil or harm, and to do or promote good Beauchamp and Childress (2013, p. 152). Rules supported by beneficence include (Beauchamp and Childress, 2013, p. 204):

1. Protect and defend the rights of others.
2. Prevent harm from occurring to others.
3. Remove conditions that will cause harm to others.
5. Rescue persons in danger.

One concern about beneficence is found in discussions of paternalism—the intentional overriding of another’s preferences and actions justified by an appeal to the action providing benefits to the person or mitigating or preventing harm (Beauchamp and Childress, 2013). In paternalistic models the doctor (as expert) acts in the best interests of the vulnerable patient while maintaining physician autonomy (Beisecker and Beisecker, 1993; Childress and Siegler, 1984; Emanuel and Emanuel, 1992; Rogers and Braunack-Mayer, 2009; Roter, 2000). This prototype is characterised by high doctor power and low patient power, where the goals and agenda of the exchange are set by the doctor, the patient’s values are assumed, and the doctor acts as a guardian (Roter, 2000). In this type of relationship, the doctor demands the patient to trust them, their competence and their decisions about treatment meaning that trust is not reciprocal (Rogers and Braunack-Mayer, 2009).

On the other end, consumerist models highlight the needs of the patient and emphasises or implies patient autonomy (Beisecker and Beisecker, 1993; Childress and Siegler, 1984; Roter, 2000) In this model the patient, while ill, seeks help and is willing to cooperate (Szasz and Hollender, 1956). This prototype is characterised by low doctor power and high patient power, where the goals and agenda of the exchange are set by the patient, and the doctor acts as a technical consultant (Roter, 2000). In many ways, this type of relationship excludes trust (Rogers and Braunack-Mayer, 2009).

Over time, there has been a move from doctor–centred approaches to patient–centred approaches. These patient–centred approaches emphasise joint or shared decision-making within a relationship based on mutual cooperation (Emanuel and Emanuel,
Alternatives to paternalism and autonomy are presented in collaborative models. For instance, Emanuel and Emanuel (1992) outline an interpretive model which, while similar to consumer model, views the doctor in a more caring role, as a counsellor or advisor helping the patient to understand their own values and make a decision about the information given. Other collaborative models include negotiated or patient/person-centred models that highlight the mutual nature of the doctor-patient relationship where both parties have approximately equal power, need one another (they are mutually interdependent), and engage in activity satisfying to both (Childress and Siegler, 1984; Szasz and Hollender, 1956). Collaborative models represent a balance between beneficence and respect for autonomy where trust, empathy, communication, listening and sharing information are key aspects of the doctor-patient relationship (Hoff and Collinson, 2016).

Information-sharing is framed in terms of the benefits to individual patient’s, community and wider society. Some of these benefits come from improved treatment or care, while others come from the benefits of secondary used of information as in medical and genetic research.

4.2.4 Justice

Rules of justice define the terms of interaction between people in society (Beauchamp, 2016). Social justice is concerned with human well-being—particularly in securing and maintaining social conditions necessary for a sufficient level of wellbeing for everyone (Powers and Faden, 2006). The essential dimensions of wellbeing have been variously stated in the literature (Nussbaum and Sen, 1993; Powers and Faden, 2006). For instance Faden and Powers (2011) outline health, personal security, reasoning, respect, attachment and self-determination as six dimensions that help shed light on requirements of justice in public health and health policy.

Inequalities of access to health care and health status lead to the question: what does justice require in health care situations? Justice relates to the distribution of
benefits and burdens in society. Justice is of concern in health care situations to ensure that patients are not discriminated against, and that vulnerable groups are not exploited (Beauchamp and Childress, 2013). Further, there is some consideration about access to health care, and the efficient and just allocation of health care resources as well as priority setting and rationing (Beauchamp and Childress, 2013). Beauchamp and Childress (2013) outline various conceptions of justice including egalitarian and utilitarian approaches and the way they reconcile the distribution of benefits, risks and costs. Beauchamp and Childress (2013) argue that no single theory of justice is sufficient for use in the reflection on health policies—for this reason, policies that reflect or emphasise some aspects of these theories over others is to be expected. This is reflected in the assertion that:

> Explicating the demands of justice in allocating public health resources and in setting priorities for public health policies, or in determining whom they should target, remains among the most daunting challenges in public health ethics (Childress et al., 2002, p. 172).

For information-sharing, considerations of justice are bound in ensuring that information-sharing does not exploit individuals or groups, and in the way, that information can be used to improve the quality and efficiency of health care services.

### 4.3 Ethical Considerations around Information-Sharing

Information-sharing outside the bounds of the GP–patient relationship centres on how to balance the interests in protecting or withholding information against those for sharing or disclosure. While the benefits of health information provide opportunities to improve health and health care they also raise concerns about invasions or loss of privacy and confidentiality (Dove and Phillips, 2015; Kaplan, 2016; Rothstein, 2010). This section discusses the ethical arguments and legal and professional regulation of information-sharing in relation to the four principles.

#### 4.3.1 Professional Obligations of New Zealand Doctors to Protect Patient Information

In New Zealand, doctors’ obligations to protect patient information are specified as legal rules and professional responsibilities. They are found in the Privacy Act 1993 and associated Health Information Privacy Code (1994), official information legislation,
law of equity, contract and professional negligence, law of civil and criminal procedure, law of evidence, and legislation that allow (require or permit) or prohibit certain disclosures (Dawson, 2015). These legal rules relate to obligations that include:

1. The duty of health professionals to maintain privacy and confidentiality of health information. This includes a duty to collect, store and use information in appropriate ways.
2. Exceptions where those who hold health information have a duty or discretion to disclose information to a third party on the basis of the public interest.
3. Avenues for making complaints and seeking remedies where individuals feel their privacy or confidentiality has been breached.
4. The right of individuals to access health information about them, that is held by others.
5. Powers of the courts and litigants to get access to health information relevant to legal proceedings—including powers to order disclosures by health professionals and to order compulsory medical exams.
6. Evidentiary privilege where confidential information may be withheld from court or legal proceedings, or where a witness may be directed not to produce evidence. (Dawson, 2015).

This thesis is concerned with the interplay of 1–4 focusing on the protection of privacy and confidentiality balanced with reasons for disclosure and the role of trust.

The Privacy Act 1993 takes a principle-based approach to privacy. The Health Information Privacy Code 1994 (HIP code) extends the scope of the privacy principles as they apply to health information. Overall, information can be shared/disclosed if it is within the purpose for which it was collected, if consent is obtained to use it for a different purpose, or if there is a compelling reason (i.e. there is an exception that requires or permits disclosure). The first two reasons are justified on the basis that the patient is aware of how the information is being used and can consent to its use for a different purpose. This is worded as “that the disclosure is authorised by the

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3 The 12 principles can be found in Part 2 of the Act, "Information Privacy Principles".
4 The HIP code commenced the 30th July 1994 and applies to all agencies that provide health and disability services as well as to Crown Health Enterprises, other licensed hospitals, ambulance services, and homes for elderly people (Health Information Privacy Code, 1994)
individual concerned” under Principle 11(c) of the Privacy Act 1993. The requirement of consent presents the opportunity for individuals to make decisions about who their information is shared with or disclosed to (respect for autonomy). However, it also recognises that privacy is not absolute and that there may be good reasons to disclose information to prevent harm, or for the public good (beneficence and nonmaleficence).

Professional bodies, including the New Zealand Medical Association (NZMA), Medical Council of New Zealand (MCNZ) and The Royal NZ College of General Practitioners (RNZCGP) guide appropriate conduct concerning patient information (NZMA, 2014; Stevens, 2013). The NZMA Code of Ethics states that medical practitioners will: “Protect the patient’s private information throughout his/her lifetime and following death, unless there are overriding considerations in terms of public interest or patient safety” (NZMA, 2014, p. 4). This shows the way that respect for autonomy is balanced with beneficence. Numbers 9–14 and 25 within the responsibilities to the patient section of the code relate to patient information. These represent ways that rules of privacy and confidentiality are specified and balanced in relation to patient information:

9. Doctors should access patient health records only when there is an appropriate reason.
10. Doctors should ensure that information is recorded in an accurate and timely manner.
11. Doctors have an obligation to guard against unauthorised access to any health information they have collected pertaining to identifiable patients, including when transferring data.
12. Doctors should keep in confidence information derived from a patient, or from a colleague regarding a patient, and divulge it only with the permission of the patient or in those unusual circumstances when it is clearly in the patient’s best interests or there is an overriding public good, including the risk of serious harm to another person. If there is any doubt, doctors should seek guidance from colleagues or an appropriate ethics committee.
13. When appropriate, doctors should communicate with colleagues who are involved in the care of the same patient. This communication should respect patient confidentiality and be confined to necessary information. Patients should be made aware of this information-sharing, which enables the delivery of good quality medical care. Where a patient expressly limits possession of particular information to one practitioner, this must ordinarily be respected. Patients should be made aware in advance, if possible, where there are limits to the confidentiality that can be provided.
14. When it is necessary to divulge confidential patient information without patient consent, this must be done only to the proper authorities, and a record kept of when reporting occurred and its significance. Whenever possible, the patient should be informed this has occurred.
25. Doctors must be aware of statutory provisions and the codes of the Privacy Commissioner, the Human Rights Commissioner and the Health and Disability Commissioner, and the requirements of the Medical Council of New Zealand. (NZMA, 2014, p. 5–7).
These obligations outline the importance of respect for patient autonomy by protecting patient information, but also highlight the tension between respect for autonomy and beneficence, nonmaleficence and justice. The importance of trust is alluded to in this list, separate from the four principles, in the way that patients should be made aware of information-sharing wherever possible, even where the patient has no control over it. While this duty does not serve the four principles directly, it constitutes fairness and honesty around information and signals trustworthiness.

4.3.2 Respect for Autonomy

Health information in the New Zealand context is defined within the Health Information Privacy Code 1994 as:

- information about the health of an individual including medical history; information about any disabilities an individual has, or has had; information about any health or disability services that are or have been provided to an individual; information provided by the individual in relation to the donation of any body part or bodily substance derived from the testing or examination of any body part or bodily substance of the individual; information that is collected before or in the course of (which is incidental to) the provision of any health or disability service to an individual. (Health Information Privacy Code, 1994, s4(1)).

Legal and professional regulation around health information is oriented to respect patient autonomy by protecting privacy and confidentiality unless it is outweighed by other considerations.

Expectations of privacy and confidentiality are grounded in the relationship between health professionals and society and the ethical standards they abide by (Anthony and Stablein, 2016). Warren and Brandeis (1890, p. 195) argue for the recognition of a right to privacy to protect private life and prevent “what is whispered in the closet ... be[ing] proclaimed from the house-tops.” Marmor (2015, p. 4) outlines privacy as protecting people’s interest in having “a reasonable measure of control over the ways in which they can present themselves (and what is theirs) to others”. Control based definitions of privacy are justified on the basis of autonomy and so form a parallel with informed consent. However, privacy is also justified for instrumental reasons—privacy is necessary for personal development, social relationships, personal freedom, as well as aspects such as love, friendship and trust (Gavison, 1980; Rachels, 1975). Confidentiality can be seen as a subset of privacy—it is an interest in the release of personal information to another person with imposed limits and conditions about future
disclosure of that information (Smith et al., 2011). This means that confidentiality involves information being entrusted to someone as with a patient with their GP.

4.3.2.1 Are Privacy and Confidentiality Justified by Respect for Autonomy or Trust?

Privacy and confidentiality have been justified on the basis that professionals can only practice with full information and unless patients’ confidentiality is assured they will withhold information (Montgomery, 2003). Another argument points out that “patients convey information on the understanding that it will remain secret and that a failure to keep it so is a breach of a tacit agreement between professional and client” (Montgomery, 2003, p. 253). Philosophers have discussed the duties and responsibilities of medical professionals in relation to patient information. Ethical accounts related to information-sharing are often concerned with confidentiality and privacy (with rationales considering the rights of individuals to these things) alongside aspects of trust. This includes issues of concealment and revelation (Bok, 1989), truth-telling and secret keeping (Jackson, 2001), trust and informed consent (O’Neill, 2002a,b). Trust for instance is vital not only to individuals and the public, in trusting the organisations or individuals to whom they have provided information, but also between organisations to support shared responsibility and collaboration (Lips et al., 2011). Doctors need their patients to disclose or divulge information about themselves, and patients must trust their doctors to keep this information secret (Rhodes, 2001):

...trust provides a direct justification of the importance of confidentiality that ranks confidentiality as one of the most essential moral commitments of the profession. This perspective makes it clear that individual violations of confidentiality put the public’s general trust of medicine in jeopardy and shows that confidentiality has significant moral weight for medicine as a profession. (Rhodes, 2001, p. 498)

While some accounts of confidentiality derive its importance from respect for autonomy or privacy, trust explains why information shared between a patient and their doctor (where patients share information under the assumption they can trust their GP not to share it) is different from information shared in the private sphere about (using Rhodes’ example) how much a neighbour paid for their house where confidentiality requires making a promise. While trust has been explored in philosophy in relation to social order and cooperative relations, discussed on page 22, its use in medical ethics and determining how one ought to act, has been limited. In the empirical sphere, Culnan
and Armstrong (1999) and Miltgen and Smith (2015) outline how trust is associated with privacy concerns. When an individual develops trust with an individual or entity, their levels of privacy risk concern reduce because the likelihood of a negative outcome is reduced (Culnan and Armstrong, 1999; Miltgen and Smith, 2015). Based on trust as a reason to protect confidentiality, and in light of trust being both a barrier and enabler of information-sharing this thesis seeks to understand how the role of trust in patient’s expectation and attitudes toward information-sharing in primary care settings.

**Harms of Disclosure**

Gavison (1980) says that a loss of privacy may occur in the loss of any one of three elements: secrecy, anonymity and solitude. That is, “the extent to which an individual is known, the extent to which an individual is the subject of attention, and the extent to which others have physical access to an individual” (Gavison, 1980, p. 433–434). However, not all losses of privacy are harmful; patients surrender some privacy when they share information with their doctor, or grant the doctor access to their information (Allen, 2007). Health disclosures make it possible for a patient to be cared for, to receive appropriate medical treatment and services or benefits they are entitled to (Allen, 2007).

Research has sought to understand patient perspectives and expectations about how information is collected, used and shared. Most patients acknowledge that doctors need to share information with each other (Sankar et al., 2003). However, patient opinions about when confidentiality can be broken vary by patient population, the content of the information and depending on who the information would be given to (Sankar et al., 2003). Factors that influence an individual’s decision for their information to be shared/used include the perceived sensitivity of the information (Hunter et al., 2014; Powell et al., 2006; Riordan et al., 2015; Whiddett et al., 2016), how informed individuals are about how their information will be used (Lehnbom et al., 2014; Riordan et al., 2015) and the purpose of the information being shared or to whom it will be shared (Hunter et al., 2009; Whiddett et al., 2006; Willison et al., 2009).

Patients may have concerns about sharing information, particularly where it is of a more personal or sensitive nature (Sankar and Jones, 2005; Whiddett et al., 2006, 2016). Patients may deliberate over whether to share sensitive information with their
doctor (Sankar and Jones, 2005) and may not want information from their primary care records to be shared with others (Lehnbom et al., 2014; Powell et al., 2006; Riordan et al., 2015). Sensitive information may include mental health issues, personal problems, sexual health issues, drug use and other medical issues (Powell et al., 2006; Sankar and Jones, 2005). The sensitivity of information invokes the notion that some information would cause more harm to an individual if it were shared or accessed without authorisation, and that such disclosure should be prevented.

Disclosure of sensitive private information may harm the patient socially or financially meaning that patients may want to prevent the disclosure of embarrassing facts or avoid being presented in a false light (Bansal et al., 2016). Solove (2006) outlines violations of privacy that concern information, including:

- The aggregation or linking of information about a person. This can reveal new facts about an individual that the individual did not expect would be known.
- Unwarranted disclosure of information due to insecurity. This includes security glitches, lapses, abuses and illicit or malicious uses of personal information.
- Use of information for secondary purposes without consent as individuals may not have expected or desire secondary use.
- Breach of confidentiality, this recognises the harm of disclosure and violation of trust.
- Public disclosure of private facts that are “highly offensive to a reasonable person” and “not of legitimate concern to the public”. This is harmful as it can have an impact on their future, making a person a prisoner of their past.
- Exposure of physical and emotional attributes about a person that may create embarrassment and humiliation.
- Blackmail.
- The appropriation of the name or likeness of another.
- Defamation, libel and slander.

These invasions, losses, violations or infringements of a patient’s privacy are considered wrongful and associated with harm or injury to the individual concerned. Therefore, in order to prevent these invasions and violations we can respect patient autonomy by ensuring that information is only used or shared within the purpose for which it was
collected and respect privacy and confidentiality where it applies, and allow patients access to their own information.

**Protecting Autonomy Through Consent**

Beauchamp and Childress (2013, p. 107) outline “respect the privacy of others” and “protect confidential information” as rules supported by the principle of respect for autonomy. Informed consent is a large part of the way in which information is disclosed/shared for secondary purposes (Ploug and Holm, 2016). Consent is seen as a way to respect the autonomy of the patient by allowing them to decide who should have access to their information (McSherry, 2004). Kluge (2004) takes an extreme position in arguing that access to patient information without their consent is analogous to assault. A more moderate position is to say that patient information should not be used or accessed without consent or authorisation as doing so violates the understandings of privacy and confidentiality that patients have.

There has been some effort to develop consent protocols which would allow researchers to access patient information, including biobank data (Buckley et al., 2010; Ploug and Holm, 2016). These approaches seek alternative forms of consent for information-sharing beyond specific informed consent that recognise the changing nature of information-sharing capabilities and the benefits that may be derived from sharing health information. However, patients may have varying views on the extent to which consent is required.

Central to informed consent is that the patient is aware or has an understanding of an action to an adequate level for decision-making. Studies have shown that patients have little knowledge or awareness about information-sharing projects (Bratan et al., 2010; Lehnbom et al., 2014) or what information is collected and held in patient records (Hunter et al., 2014; Stone et al., 2005; Whiddett et al., 2006). An Australian study looking at the uptake of the Personally Controlled Electronic Health Record (PCEHR) found that patients had little knowledge or awareness about the PCEHR, although over 62% of respondents believed it would enable healthcare professionals to provide better care (Lehnbom et al., 2014). Stone et al. (2005) found that patients had an inadequate understanding of the type of information in their GP records or how this information could be shared.
New Zealand studies suggest that patients do not know how their information is shared, or about mechanisms used to enhance privacy protection—as with the use of a unique patient identifiers such as the National Health Identifier (NHI) in New Zealand (Hunter et al., 2014; Whiddett et al., 2006). Whiddett et al. (2006) suggest that patients are poorly informed about the use of their information, with 90% of respondents having incomplete or no knowledge of how their information is shared, and 79% having no knowledge of their NHI. Studies have also reported that patients may sign consent forms that release information because they believe they have no choice, or without realising what they had signed (Sankar et al., 2003). This presents an opportunity for this thesis to explore patient’s knowledge of information-sharing and the extent to which this may impact upon expectations of GPs. This may provide valuable insight into the ways that patients and GPs specify the four principles when thinking about routine information-sharing in primary care and how consent plays into what actions are deemed appropriate and inappropriate.

Protecting Autonomy through De-identification

The definition of “personal information” within the Privacy Act 1993 centres on it being information about an identifiable individual (Privacy Act, 1993). Identifiable information is information where a specific individual can be identified. Identifiers can include an individual’s name, image, date of birth, address and so on (Australian Law Reform Commission, 2008). De-identified information has had personal identifiers removed (Australian Law Reform Commission, 2008). Re-identifiable data/information is information where the identifiers have been removed but it is still possible to re-identify a specific individual through linking data sets and other means (Australian Law Reform Commission, 2008).

Sharing de-identified information reduces the potential harm to patients while securing benefits for the public. This balances the concerns about respect for autonomy while allowing information to be used in ways that will benefit the public. The Privacy Act 1993 cites that an agency that holds personal information shall not disclose it unless they believe that it:

(i) is to be used in a form in which the individual concerned is not identified; or (ii) is to be used for statistical or research purposes and will not be published in a form that could reasonably be expected to identify the individual concerned; (Privacy Act 1993,
Information can also be disclosed under Principle 11, where the source of the information is publicly available, or where the disclosure is to the individual to whom the information is about. Non-identifiable information may be disclosed for statistical purposes. However, information for health research purposes requires approval (Medical Council of New Zealand, 2016). This recognises that non-identifiable information can be used for beneficial purposes and does not infringe on the autonomy of an individual. One key way that this is used in general practice is through the presentation of de-identified or anonymous case studies for education purposes.

Patients are more willing for deidentified information to be shared (Hunter et al., 2009; Whiddett et al., 2006) and less willing to share information that is of a more identifiable, personal or sensitive nature (Whiddett et al., 2006, 2016). Hunter et al. (2014) explored patient attitudes towards information-sharing in sexual health services in a New Zealand hospital which identified that confidentiality was a significant concern. In this context, routine sharing of patient information was found to be a barrier to attendance for some patients (Hunter et al., 2014). They suggest that the need for confidentiality may be due to a lack of knowledge around the benefits and risks of information-sharing (Hunter et al., 2014). In a study of UK patients’ views of sharing primary care record data for research, Buckley et al. (2010) found that 83% of participants were willing to let their GP decide when to provide anonymous information to researchers without informing them, while only 38% said they would be willing for this to happen with identifiable information. For identifiable information 71% of participants reported they would like to be asked before that type of information was provided to anyone else outside the practice (Buckley et al., 2010). Riordan et al. (2015) found that 91% of respondents expected to be asked for consent for their identifiable records to be accessed for health provision, research or planning. Where records were de-identified 49% did not expect to be asked for consent before they were accessed (Riordan et al., 2015).
4.3.3 Beneficence and Justice

In health care, there are good reasons to share information based on the benefits to patients, professionals and society. One of the unique aspects of the doctor–patient relationship is that it allows two people to engage with a certain level of intimacy, the type that if developed, may allow the patient to reveal personal and private concerns within a safe environment (Kaba, 2007). Conversations about records or other repositories of patient information presuppose that patients will share information with their doctors. In the medical interview, data is gathered, “...diagnoses and plans are made, compliance is accomplished, and healing, patient activation, and support are provided” (Goold and Lipkin, 1999, p. S26). Information is central to health care and is used:

...not only to deliver necessary healthcare directly to individuals—secondary uses of medical data to broaden scientific knowledge, for both public and private benefit, are also myriad and increasing. Data have long been used for invaluable secondary purposes that benefit society as a whole, such as population health monitoring, healthcare quality improvement, and biomedical research (Dove and Phillips, 2015, p. 640).

There are benefits to information-sharing in terms of improved service delivery and patient care and preventing harm (beneficence and nonmaleficence), and improving the quality and efficiency (justice) of the system. Current arrangements in New Zealand seek to protect health information unless there is a good reason to share it. This places the patient’s control over the dissemination of their information as prime and requires health professionals to seek consent from the patient to share/disclose information if it falls outside the purpose for which it was collected.

Information-sharing between a patient and health care provider can improve the accuracy of diagnosis, increase patient education and promote self care (Perera et al., 2011). Health information can be used to find patterns in access and utilisation, determine the effectiveness and safety of treatments, as well as generating knowledge from biomedical and epidemiological investigations (Johnsson et al., 2013; Perera et al., 2011). When shared, public health information can be used to monitor population health, target interventions, allocate resources, prioritise funding and plan provision of services, provide estimates of disease burden, measure progress in achieving health targets or other indicators, and identify trends at local, national and global levels (van
Panhuis et al., 2014). These present good reasons for sharing information based on the benefits to individuals and society promoting the principles of beneficence and justice.

Information-sharing is an issue of beneficence where sharing information is in the best interests of the patient and their health outcomes. Information-sharing is a justice issue where information can be shared to increase the efficiency of a health service or the health system (given that there are finite resources), as well as in measuring and tracking inequalities and inequities, or to aid in more equitable resource allocation.

### 4.3.4 Nonmaleficence

It has long been accepted that there may be good reasons to disclose information to prevent harm. Nonmaleficence and beneficence may outweigh granular control over one’s own health information as patient’s may be harmed if providers cannot access important information (Meslin and Schwartz, 2015, p. S4):

A patient, for example, might decide not to give a cardiologist access to information in the health record that shows that the patient is being treated for depression. If this means that the cardiologist prescribes a medication that has a dangerous interaction with the one that the patient is taking for depression, then it seems that something has gone horribly wrong.

Exemptions in the Privacy Act may allow for information-sharing to occur, or it may be overridden by other legislation for particular reasons. In this case, other statutes may specify when or what information can—or can not—be shared. Under the Privacy Act 1993 and HIPC 1994, personal information may be used and disclosed to prevent or lessen a serious threat to public health or public safety, or to the life or health of the person concerned or another person, for issues of law enforcement, for the delivery of public services (under an Approved Information Sharing Agreement) and for the public interest. A serious threat is:

a threat that an agency responsibly believes to be a serious threat having regard to all of the following: (a) the likelihood of the threat being realised; and (b) the severity of the consequences if the threat is realised; and (c) the time at which the threat may be realised (Privacy Act 1993, Amendment to s2(1)).

Other legislation provides specific provisions where public safety overrides respect for autonomy. For example, the Land Transport Act requires medical professionals to notify the New Zealand Transport Agency (NZTA) if they think a patient should not be driving or should have limits on their driving due to public safety. Other examples
include the Tuberculosis Act 1948, section 3, and the Children, Young Persons and their Families Act 1989, sections 15–16.

### 4.3.5 Application of the Four Principles to Information Sharing

Given the discussion of how the four principles apply to information sharing given legal, professional and other arguments, the specification of the principles may be summarised in Table 4.1. This table contains rules or specifications of respect for autonomy, beneficence, nonmaleficence and justice that relate to information sharing.

<table>
<thead>
<tr>
<th>Respect for Autonomy</th>
<th>Beneficence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only use and share information for the purpose it was collected.</td>
<td>Share information where it is in the best interests of the patient (e.g. More accurate diagnoses, improved health outcomes, better quality of care, to facilitate self care).</td>
</tr>
<tr>
<td>Respect patient privacy and confidentiality.</td>
<td></td>
</tr>
<tr>
<td>Do not access or share information without patient consent/authorisation.</td>
<td></td>
</tr>
<tr>
<td>Provide patient’s access to their own information.</td>
<td></td>
</tr>
<tr>
<td>Remove personal identifiers from information where appropriate before sharing information.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nonmaleficence</th>
<th>Justice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Share information when necessary to prevent harm to the patient or another person.</td>
<td>Share information to increase efficiency of system.</td>
</tr>
<tr>
<td>Share information when necessary to prevent or lessen a serious threat to public health or safety.</td>
<td>Share information to measure and track inequalities and inequities.</td>
</tr>
<tr>
<td></td>
<td>Share information to aid in more equitable resource allocation by determining utilisation and cost-effectiveness of services.</td>
</tr>
</tbody>
</table>
4.4 Conclusion

The first part of this chapter discussed the principle-based framework of moral norms of Beauchamp and Childress, as developed for thinking about biomedical ethical issues. This approach is characterised by a set of moral principles (respect for autonomy, beneficence, nonmaleficence, justice), that may be specified as rules for particular contexts. This thesis has adopted this approach due to its ongoing relevance to medical ethics, modest theoretical approach, and focus on specifying and balancing rules that guide action. The second part of this chapter has outlined how the protection of information and information-sharing may be justified based on an appeal to the four principles. Beyond the four principles, patients’ expectations around how their information is collected, used and shared, as well as expectations of trust in the GP–patient relationship inform consequence-based justifications for the limits of privacy and confidentiality. This highlights the opportunity for empirical evidence to aid in the specification and balancing of moral norms for information-sharing between patients and GPs in New Zealand. In moving towards this aim, the empirical aspects of trust are discussed in the next chapter.
Chapter 5
A Narrative Review of Trust in Primary Care Relationships

Trust between primary care providers and patients (referred to as doctor–patient, clinician–patient, professional–patient, patient–provider or GP–patient trust) has been linked to better health outcomes (Beitat et al., 2013; Bova et al., 2012; Rowe and Calnan, 2006). It is associated with important health behaviours, particularly patient compliance (Beitat et al., 2013), such as adherence to medication and glycemic control in adults with diabetes (Bova et al., 2012). It is also considered an indicator of quality as it results in higher levels of patient satisfaction (Beitat et al., 2013; Rowe and Calnan, 2006; Skirbekk et al., 2011). Despite the high correlation between trust and patient satisfaction it is believed to be a separate construct (Rowe and Calnan, 2006). This is framed on the basis that trust is forward looking (it is an attitude relating to an ongoing or future relationship), whereas patient satisfaction is reflective as it calls on past experience to assess the performance of a practitioner (Rowe and Calnan, 2006). Low levels of trust, on the other hand, have been related to negative consequences including greater depression or leaving the hospital against medical advice (Bova et al., 2012). Well-placed trust can result in good outcomes where patients seek care or advice when trouble first arises, reveal and communicate important information about their condition, and accept and comply with medical recommendations (Calnan and Rowe, 2008; Miller, 2007; Rowe and Calnan, 2006).

Most of the research in this area has focused on the trust that a patient has in their doctor/physician (Anderson and Dedrick, 1990; Bova et al., 2012; Cook et al., 2004; McKinstry et al., 2006; Skirbekk et al., 2011; White et al., 2011) whereas we know little about physicians’ trust in their patients (Cook et al., 2004). Research has focused more on quantitative studies that seek to measure trust in doctor–patient relationships, and
less on general or organisational trust (Calnan and Rowe, 2008). There has been some consideration of the moral and ethical aspects of doctors trusting patients (Miller, 2007; Rogers, 2002), but little empirical research conducted in this area (Cook et al., 2004).

This chapter reviews empirical studies of trust between a patient and their primary care doctor. While the previous chapter discussed the application of ethical concepts to information-sharing, this chapter is restricted to empirical (qualitative and quantitative) literature on patient trust in primary care doctors. The methodological (Müller et al., 2014; Ozawa and Sripad, 2013) and conceptual literature (Hall et al., 2002a) has been reviewed elsewhere. While trust in the patient–provider relationship has been reviewed (Brennan et al., 2013; McKinstry et al., 2006; Murray and McCrone, 2015) these have focused on all types of health care providers. The review involves the analysis of the current research and the identification of gaps in the literature.

5.1 Data Collection and Analysis

An article search was conducted in three international databases (SCOPUS, Proquest Central, and ABI inform) using the following search string:

“trust AND health profession* OR patient OR doctor OR physician AND theor* OR measure OR buil* OR restored AND primary care”

A supplementary search of Google Scholar was also conducted. This yielded an initial return of over 1000 items. While no date or journal restrictions were applied, items were excluded based upon the following criteria:

1. Limited to English language
2. Limited to peer-reviewed journal articles
3. Exclude items including the terms insurance, managers, hospitals, surgery

Articles that did not refer to primary care were excluded. Additionally, articles that involved health professionals other than a general practitioner (GP), primary care doctor or primary care physician were excluded (i.e. nurses, physiotherapists, specialists). After reading the abstracts, and removing those which were not relevant, a total of 31 sources were read in full. Sixteen of these were excluded as they were not empirical. Thirteen of the articles looked at the primary care doctor–patient relationship and trust. Three of the articles identified talked about the role of trust
related to information, with two of them focusing on primary care.

During the process of extraction and analysis the relevant information was put into a spreadsheet. This included the bibliographic details, study design, sample size (where relevant), methodological issues/limitations and results. The findings of the review are discussed thematically below.

## 5.2 Factors Related to Trust

Thirteen of the articles identified factors that affect patient trust in a primary care setting. The literature matrix of these studies can be seen from page 293. Prominent themes were identified during the review including continuity, partnership communication and interpersonal skills, and competence. Many of these themes are congruent with the Beitat model outlined on page 33.

### 5.2.1 Continuity

The attributes that contribute to a patient’s trust in a primary care doctor vary according to whether it is a first or one-off encounter or a relationship characterised by repeated interactions. Tarrant et al. (2010) found that when seeing a doctor for the first and possibly only time, patients rely on social or institutional (general) trust—this includes trust in the health system, the medical profession or institutions and organisations. This type of trust is functional, whereby patients rely on the competence and skills of the doctor (based on the belief that they are suitably qualified) in seeking advice or treatment (Tarrant et al., 2010). In this type of interaction, patients draw on cues about the trustworthiness of the doctor based on group membership and reputation (Tarrant et al., 2010). The act of “showing up” can be viewed as giving a doctor a “mandate of trust” (Skirbekk et al., 2011).

Continuity of care is associated with higher levels of trust (Skirbekk et al., 2011; Tarrant et al., 2008, 2010, 2003). Relationships between a patient and doctor based on repeated interactions or continuity support the development of trust as it provides an opportunity to “amass cumulative experiences of trustworthy behavior and establish norms of cooperation and reciprocity” (Tarrant et al., 2010, p. 443). Butterworth and Campbell (2014) found continuity of care facilitated older patients’ preference for
and involvement in decisions about their care, as well as nurturing trust. On the other hand, models of care that prioritise access and choice in primary care at the expense of continuity of care may undermine patient trust (Tarrant et al., 2008). This means that the provision of care through alternative services (such as walk-in clinics and polyclinics) may mean that the opportunity for committed partnerships between patient’s and their GP is lost (Tarrant et al., 2008).

It is unclear whether the duration or length of the relationship is related to trust. Tarrant et al. (2003) found that the duration of the GP–patient relationship and the number of visits were not independently associated with trust, while Leisen and Hyman (2004) found there was a positive correlation of relationship length with trust. However, Tarrant et al. (2008) found that patients who saw their usual GP had higher trust scores than those who did not. Platonova et al. (2008) suggests that patients who have a trusting relationship with their doctor are more likely to recommend their doctor to others and to keep seeing that doctor.

### 5.2.2 Partnership

Several of the studies were focused on patient–centred care—the hypothesis being that the more patient–centred a doctor–patient relationship, the more the patient is likely to trust the doctor due to belief congruence (Krupat et al., 2001). Krupat et al. (2001) found that physicians who were patient–centred were more likely to be trusted by patients. Van Den Assem and Dulewicz (2014) found that patients who are satisfied with their doctors perceive them as being more trustworthy and have a greater preference for shared decision making. Finding common ground (Mainous et al., 2003), feeling that you are being taken seriously by the doctor (Croker et al., 2013), and being united against a common adversary (such as the illness, or other professionals or parts of the health and social system) (Skirbekk et al., 2011) help build trust. This is indicative of trust relationships being unproblematic where doctors meet the expectations of the patient. Skirbekk et al. (2011) found that patient’s trust in their physician was always limited (i.e. it was never blind faith); patients trusted the intentions of the physician, but patients restricted the relationship if they were unsure.
5.2.3 Communication and Interpersonal Skills

Tarrant et al. (2010) found that in a first encounter patients assess their doctor’s communication skills and whether they have found a common understanding. This then allows swift trust to develop in a first or initial encounter (Tarrant et al., 2010). This is consistent with Tarrant et al. (2003) who found that GP–patient communication, interpersonal care and a GP’s knowledge of the patient were important predictors of trust. Platonova et al. (2008) also found that good interpersonal relationships with a primary care physician are a predictor of patient satisfaction and loyalty. Relationships with more open mandates of trust can be more resilient to challenges but may also be more vulnerable to betrayals than those based on limited mandates of trust (Skirbekk et al., 2011).

5.2.4 Competence

Competence is significantly related to trust (Berry et al., 2008; Leisen and Hyman, 2004; Tarrant et al., 2010). Patients report higher levels of satisfaction with their doctor where they believe their doctor is benevolent and technically competent (Leisen and Hyman, 2004). The perception of poor quality care is perceived by doctors as a barrier to building trust (Mainous et al., 2003). However, doctors are unsure whether patients can recognise quality care, meaning that, while the relationship between a patient and doctor might be good, the doctor may not be delivering good care (Mainous et al., 2003). Communicating that advice or treatment was in line with clinical practice guidelines was also seen as a way to pro-actively build trust (Mainous et al., 2003).

5.3 Information, Primary Care and Trust

Two articles were focused on information and trust in primary care as summarised on page 300. Stone et al. (2005) used a qualitative approach to explore knowledge and attitudes of patients and professionals about data sharing in primary care. Due to limited knowledge about what information is on or in the record and what is shared Stone et al. (2005) found no suggestion that concern about information-sharing negatively affects patient trust or patients sharing information with their provider. In a quantitative study, Qiao et al. (2015) found that 87% of participants trusted the
electronic health record. Respondents who believed their records to be accurate and secure were significantly more likely to trust the EHR used in primary care (Qiao et al., 2015). As such, patient trust in EHRs can be enhanced by providing patients with access to their records to verify access.

5.4 The Impact of Patient Attributes on Trust

Several of the studies looked at attributes of patients that had a positive or negative impact on trust (Bova et al., 2012; Croker et al., 2013; Krupat et al., 2001). Krupat et al. (2001) found that the belief that power and information should be shared between the patient and doctor was associated with younger age, being female, white ethnicity, more education and higher income. However, Bova et al. (2012) did not find any significance based on gender, chronic health status, or level of education. Both Tarrant et al. (2003) and Bova et al. (2012) found differences based on ethnicity and age. Croker et al. (2013) found that levels of definite trust in a doctor were more commonly reported by patients who were older, from white ethnic backgrounds, who reported good health, those who lived outside inner-city areas, and those who lived in areas of low deprivation. This may suggest that demographic factors that influence trust may vary depending on the country as well as national and local factors. However, it could also suggest that trust is a complex phenomenon that cannot be explained by reference to demographic factors alone.

5.5 Future Research and Opportunities for this Thesis

This review shows there has been minimal research into the factors that impact patient trust in their primary care providers, as well as how to measure patient trust in a provider.

These 13 articles do not provide conclusive evidence for the contribution of demographic factors to levels of trust. While four of the articles used statistical techniques to determine the impact of patient attributes (including demographic factors) that influenced trust, the findings were not consistent. However, there is some indication that age and ethnicity may have an impact. Asking participants a range of demographic questions would enable an analysis of how these attributes contribute to levels of trust.
There is limited research looking at trust in primary care in countries outside the US and UK. This review included studies mainly from the USA (4) and UK (6) with one each from Norway and Sweden and one cross-national study of the USA and New Zealand. This may reflect the choice of key words and databases used in the review. However, as identified in the reviews by Murray and McCrone (2015) and Brennan et al. (2013), the majority of trust studies are US based.

Ten of the studies were quantitative, and three qualitative. One of the qualitative studies utilised multiple methods (interviews and videotaped consultations). Of the quantitative studies, the most common analysis technique was statistical regression analysis of survey items. This is consistent with other reviews that suggest quantitative studies of patient trust are more common (Müller et al., 2014; Ozawa and Sripad, 2013).

This review identified two papers that talked about information-sharing or use of patient records in primary care and the impact on patient–provider trust; one which used a survey and the other which utilised interviews. This suggests that further studies using quantitative and qualitative approaches exploring trust and information-sharing in primary care are needed.

Overall, this review suggests there are opportunities for a New Zealand based study. More qualitative, mixed or multi-method studies could also be used to further develop an understanding of trust in primary care.

5.6 Conclusion

This chapter has identified the importance of continuity, competence, partnership, communication and interpersonal skills for patient trust in primary care doctors. However, there remains very little research into patient trust in primary care. This chapter has identified the opportunity for studies that consider qualitative and quantitative aspects of patient trust, and studies which look at the role of trust in information-sharing and disclosure. The next chapter provides an introduction to the methodological framework for this thesis.
Chapter 6
Methodology

This chapter restates the research questions and outlines the philosophical and methodological approach. This includes the theoretical perspective, methodology, research design and methods used in this thesis.

6.1 Restatement of Research Question and Objectives

This thesis explores current expectations, perceptions and experiences of trust and information-sharing between patients and GPs in primary care, in New Zealand. This thesis seeks to answer the following research question:

What role does trust have in patients’ attitudes and expectations around information-sharing in primary care?

This research question has been operationalised as four research objectives:

1. Identify attitudes about trust (general, particular and organisational) and information-sharing in health care settings.
2. Determine what patients expect when sharing information with their GP, or their GP shares information with others, and identify ways that patients think that breaches of trust can be remedied.
3. Outline some of the processes that GPs can or should undertake (as reported by GPs and patients) to build, maintain and restore trust.
4. Outline recommendations for GPs about how to be trustworthy with information and how to instil trust into information-sharing exchanges.

This research sees trust as a key part of the context of information-sharing between patients and GPs. This research draws on the Beitat model of trust, and the multidimensional definition of trust proposed by Möllering (2006) to explain the theoretical considerations around trust in primary care. The definition and model
conceive of trust as multidimensional and multilevel, and highlight domains which are part of the trust process. This means that trust has multiple meanings. The wider context includes legal and regulatory frameworks, professional guidelines, the experience and expectations of both the patient and the GP, and the use of communication discussed in Chapters 2–5.

This context necessitates an interdisciplinary approach to the topic as it spans a range of theoretical and disciplinary backgrounds including ethics, law, psychology, sociology, and health research. The aim of the research is to develop an understanding of trust as an ethical and practice concept in the context of information-sharing in primary care.

6.2 Methodological Framework

One way to think about the process of research is to consider the assumptions made about reality, knowledge, values, and the practice of research. There are multiple layers of theory in this thesis. Due to the intricacies in combining moral theory and empirical observations, this thesis reconciles the different levels of theory at the epistemological and ontological level, and at the methodological level. Assumptions about the process of knowing and creating knowledge and how we view the world provide justification for how we approach research. These assumptions relate to the nature of reality (ontology), how we know what we know (epistemology), the role of values (axiology), the language of research (rhetoric), and the methods used in the research process (methodology) (Creswell, 2007, p. 17). Crotty (1998) presents these as four components: the theoretical perspective, methodology, research design and methods.

Within this thesis, the ontological and epistemological assumptions are encapsulated in a critical realist world view (theoretical perspective) discussed in Section 6.3. Methodologically, this thesis is positioned as a piece of empirical ethics research combining social science empirical methods with philosophical theory using a critical realist approach, outlined in Section 6.4. It uses a multi-method research design incorporating a survey of the general public, semi-structured interviews, and ethical analysis as described in Figure 6.1. The methods are described in Chapters 8 and 12.
6.3 Theoretical Perspective

In this thesis the theoretical perspective (critical realism) combines particular epistemological and ontological assumptions that underpin the research inquiry. The purpose of this section is to discuss the theoretical background of critical realism and outline the implications of a critical realist approach to social scientific and ethical inquiry as appropriate for this thesis.

6.3.1 What is Critical Realism?

The genesis of critical realism (CR) can be traced to the 1960’s and 70’s with the work of Roy Bhaskar. Critical realism has been expanded and developed by other critical realists including Sayer (1992), Archer (1995), Collier (1994), Danermark et al. (2002), and Maxwell (2012). There are a number of versions of CR in circulation which means it is far from a homogeneous movement (Danermark et al., 2002; Elder-Vass, 2007). This thesis draws on the critical realist approach to social science as first outlined by Bhaskar (pre-dialectical and pre-transcendental) and not his later work\(^1\). CR is not a paradigmatic approach in the traditional sense. It may be more aptly referred to as a theoretical perspective or as providing a general methodological framework for research that is not associated with particular methods (Elder-Vass, 2007; Fletcher, 2016).

Certain aspects are common to all critical realist approaches. A critical realist perspective is said to retain an ontological realism (that the world exists independently

\(^1\)Bhaskar’s later work is known as dialectical critical realism and transcendental dialectical critical realism which have had less of an impact (Cruickshank, 2003a)
of its perception) combined with epistemological relativism or constructivism (that knowledge is partial and constructed) (Maxwell and Mittapalli, 2010). This perspective enables the researcher to separate epistemology and ontology, recognising that while our knowledge or understanding of phenomena changes, the things themselves are relatively unchanging.

CR was developed as an alternative to positivism and constructivism (Cruickshank, 2003a; Danermark et al., 2002; Fletcher, 2016). In *A Realist Theory of Science* (1978), and *Possibility of Naturalism: A Philosophical Critique of the Contemporary Human Sciences* (1979), Bhaskar challenges notions around the nature of knowledge and the scientific endeavour. Bhaskar (1998) critiqued positivism for reducing reality to what can be found or known empirically—this is called the epistemic fallacy. (Collier, 1994; Fletcher, 2016). Likewise, he critiqued constructivism in so far as it views reality as entirely constructed (Bhaskar, 1998; Elder-Vass, 2007; Fletcher, 2016). In many ways, critical realists accuse positivism and constructivism as being too superficial (Alvesson and Skoldberg, 2009; Elder-Vass, 2007). Critical realists reject positivism (and the notion of a single objective reality), but they hold onto the idea of knowledge being “positively applied to assist technical and medical progress” (Cruickshank, 2012, p. 71). They believe that, while the world exists independently of our knowledge of it (sometimes called mind-independence), our knowledge of the world is theory-laden and fallible (Sayer, 1992, p. 5). Social constructionists also reject positivism, but in doing so promote a relativist rejection of notions of truth (Cruickshank, 2012). However, realists see the world as an open system where unobservable causal laws interact in ways that produce change in observable events (Christ, 2013).

Bhaskar (1978, 1998) argued an adequate account of the philosophy of science should reconcile the process of science (which creates theories, facts, models, paradigms, methods, and techniques created in the scientific process), with knowledge about things (things that do not depend on human activity, such as the gravity of an element). CR turns the focus of philosophy to issues of ontology, by claiming that human knowledge only captures part of a deeper reality (Elder-Vass, 2007; Fletcher, 2016; Norrie, 2010). As such, we can attempt to access or understand reality through philosophical and social scientific methods, where some knowledge can present a better depiction of reality.
than other knowledge (Cruickshank, 2003a; Fletcher, 2016).

6.3.1.1 Depth Realism

CR is based on the premise that different levels of reality exist (Christ, 2013; Fletcher, 2016; McKeown, 2015). This may be referred to as depth realism or ontological stratification. Bhaskar (1978) outlines three domains or levels of reality (the real, the actual, and the empirical), and three types of knowledge (generative mechanisms, events, and experiences)\(^2\) (Bhaskar, 1978; Lipscomb, 2008). These layers of reality have come to be referred to as depth realism (Collier, 1994; Norrie, 2010), and present three ways or levels of interpretation:

1. The **empirical** domain which contains the things we *experience* directly or indirectly (Danermark et al., 2002). This is the level where events, experiences or objects can be measured empirically, though they are mediated through human experience and interpretation (Fletcher, 2016).

2. The **actual** domain, where *events* happen regardless of whether we experience them or not (Danermark et al., 2002; Fletcher, 2016). This is where our explanations about the world operate—those things we have inferred from data collection and analysis (Christ, 2013).

3. The **real** domain, where structures and *mechanisms* produce/cause/generate events or phenomena (Danermark et al., 2002; McEvoy and Richards, 2006).

The goal of CR is to explain social events by reference to the causal structures and mechanisms (in the real domain) and the effects they can have in the actual and empirical domains of reality (Fletcher, 2016).

In reference to these domains, there is a key ontological difference between the reality of the social world (intransitive realm) and our knowledge of those worlds (transitive realm) (DeForge and Shaw, 2012). That is, there are entities that cannot be observed or measured but are still very real. Ultimately, phenomena emerge as a product of events that are generated or caused by underlying structures and mechanisms (DeForge and Shaw, 2012; Zachariadis et al., 2013). But they are real:

\(^2\)As Bhaskar’s work became more dialectic and transcendental, this approach became more complex. This thesis is limited to the three original levels.
Concepts, meanings and intentions are as real as rocks; they are just not as accessible to observation and description as rocks. In this way they are like quarks, black holes, the meteor impact that supposedly killed the dinosaurs...we have no way of directly observing them, and our claims about them are based on a variety of sorts of indirect evidence (Maxwell, 2012, p. 18).

Because of this, knowledge produced using a critical realist perspective cannot be, or is not, identical to what exists—it is a representation (Christ, 2013).

### 6.3.1.2 Knowledge as Partial

Critical realists believe that knowledge is a human product—constructed and situated within a social and historical context (Cruickshank, 2003b; Lipscomb, 2008). This differs from a positivist perspective that sees knowledge as empirically derived (Cruickshank, 2012), and from the social constructionist position which conflates epistemology and ontology in claiming that there are separate and distinct realities constructed by the socio-cultural location of the self (Cruickshank, 2003b; McKeown, 2015). Critical realists seek to understand social events by exploring the causal structures and mechanisms which underlie phenomena. It is not that we have direct access to the truth, but rather that we can access reality through a lens of fallible theories (Cruickshank, 2003b). Critical realists think “the world is the way it is”, but that there is more than one way of understanding reality in conceptual terms (Maxwell, 2012, p. 5). This view asserts that there is an objective reality, and that over time knowledge claims will better reflect this reality (Cruickshank, 2003b).

CR accepts that knowledge claims are fallible while expecting that our claims about or interpretations of reality will improve over time (Cruickshank, 2003a)—they are revisable (McKeown, 2015). This means that social scientific inquiry need not find a finished truth or absolute knowledge about a phenomenon (Cruickshank, 2003a) but can be used to study other peoples’ experiences and interpretations of the social world and explore the mechanisms and events that cause them.

### 6.3.1.3 Abduction and Retroduction

Critical realists formulate conceptualisations of phenomena by constructing and interpreting subjective and objective data through two processes called abduction and retroduction (Blom and Morén, 2011; Christ, 2013; Cruickshank, 2003b; Danermark et al., 2002; Fletcher, 2016; McEvoy and Richards, 2006; Meyer and Lunnay, 2013).
These are tools of analysis which may be used within a methodological process to analyse generative mechanisms (Blom and Morén, 2011; Danermark et al., 2002; Fletcher, 2016; Meyer and Lunnay, 2013; Zachariadis et al., 2013).

Deductive inference entails going from general principles or theory to the more specific: from particular premises to a logical conclusion (Danermark et al., 2002). Inductive inference entails the opposite, going from specific observations to general principles and theory (Danermark et al., 2002). Abduction is a different kind of inference. It has been described as occupying the middle ground between induction and deduction:

...Unlike induction, abduction accepts existing theory, which might improve the theoretical strength of case analysis. Abduction also allows for a less theory-driven research process than deduction, thereby enabling data-driven theory generation (Järvensivu, T., & Törnroos, J. (2010), p. 102 as cited in McKeown, 2015, p. 10).

It is perhaps most usefully framed as redescription and recontextualisation (Danermark et al., 2002). This combination (of knowledge that is deductively and inductively generated) seeks the best explanation for empirical results or a characterisation justified by those results (McKeown, 2015).

Retroduction involves moving between observations or lived experiences (the empirical data), and making inferences about underlying structures and mechanisms (McEvoy and Richards, 2006). Retroduction creates knowledge across the three levels of ontological stratification (Christ, 2013). This starts with the empirical or observable and may involve determining how variables relate to one another. In the actual domain, the analysis of data and the use of explanations enable a more complete understanding of the phenomenon. Finally, knowledge emerges that provides a representation of the structures and mechanisms operating in the real domain (Christ, 2013). This is an analytical approach that moves “from a concrete context within which causal mechanisms are abstracted and analysed and then back to the concrete context to understand how these causal mechanisms operate” (Roberts, 2014, p. 5). This is an iterative process that involves asking: what caused this, what does this indicate, and why have things happened this way? (McEvoy and Richards, 2006; Meyer and Lunnay, 2013). Such explanations are open to revision, particularly if alternative theories better explain phenomena (McEvoy and Richards, 2006).
6.3.2 Critical Realism and Moral Reasoning

This thesis is centred on a practical ethical issue meaning this thesis must contend with how moral facts and claims function in the world. This section briefly defines the naturalistic moral realist position. A defence of this position, or the discussion of alternative moral realist stances, or other moral metaphysical and epistemological positions is beyond the scope of this thesis.

Congruent with a moral realist approach this thesis holds that there are real moral facts. Moral realists claim that there are objective facts or truths about moral things independent of the specific moral beliefs and attitudes of moral agents/appraisers (Brink, 2001; DeLapp, 2013; Railton, 1986). Like critical realism, moral realism holds a mind-independent view of reality, but in this case, it relates to moral values (DeLapp, 2013). Critical realism is consistent with a moral realist position in that it also accepts that we can not always know what the moral facts are. Instead of reducing ethical claims to a mere matter of opinion, CR implies an account of moral realism that is naturalistic, yet conditional (McKeown, 2015). This is consistent with the approach of those who defend moral realism and ethical naturalism, like Railton (1986) or the Cornell realists (Rubin, 2015) including Brink (2001) and Boyd (1988). This type of moral realism holds that:

1. Moral statements are or express something that is true or false. These can also be approximately true or largely false (Boyd, 1988).
2. The truth (or falsity) of moral statements is for the most part independent of our moral opinions and theories—i.e. they are independent of the appraiser (Boyd, 1988; Brink, 2001; Rubin, 2015).
3. “Ordinary canons of moral reasoning—together with ordinary canons of scientific and everyday factual reasoning—constitute, under many circumstances at least, a reliable method for obtaining and improving (approximate) moral knowledge” (Boyd, 1988, p. 306).

Naturalistic moral realism as with critical realism relies on the assumption that our theories and methodologies approximate the truth and develop over time to more closely reflect reality. If we accept that moral properties, as with natural and social
scientific properties, relate to a mind-independent reality, then we endorse a naturalistic moral realism consistent with critical realism. As such this thesis proceeds on the basis that ethical aspects under inquiry, like the social scientific aspects (experiences, events, structures and powers) can be approached using a critical realist explanatory approach.

### 6.3.3 Implications for Thesis Topic and Questions

Given the ontological and epistemological positioning of this thesis (from a social scientific and moral standpoint), trust exists not only in the mind but in the objective world. Trust functions as a social and ethical phenomenon, meaning that trust is also morally real. The theoretical approach to trust used within this thesis is positioned as an initial theory that “facilitates a deeper analysis that can support, elaborate or deny that theory to help build a new and more accurate explanation of reality” (Fletcher, 2016, p. 4). Some theories may be more correct than others which means we should “avoid any commitment to the content of specific theories and recognise the conditional nature of all its results” (Bhaskar, 1998, p. 6).

It is the contention of this thesis that trust is a real causal mechanism (in the real domain of reality) that explains how information-sharing between patients and GPs is the way it is. However, our knowledge of this phenomenon is limited by the ontological stratification of reality (the empirical, actual and real domains). This means that trust and the information practices central to this thesis are situated within a historical and social context. As such our understanding of trust is partial, and accessible only through the use of research methods that capture the things we experience within the empirical domain. Our attempts to infer, theorise or explain the function of trust for information-sharing in primary care takes place within the actual domain as we attempt to express the reality of trust as precisely as possible.

### 6.3.4 Implications for Methodology and Methods

A critical realist perspective seeks to provide a basis for the use of empirically driven methods and methods that capture human experience to contribute to our understanding of a phenomenon. No matter what method is used, the central tenet is that the foundation of knowledge generation is found in the empirical domain (Zachariadis et al., 2013).
Quantitative or extensive methods can be used to describe the phenomena being studied (McEvoy and Richards, 2006; Zachariadis et al., 2013). They may also be used to identify patterns and associations or test theories about underlying structures and mechanisms in a particular context (McEvoy and Richards, 2006). The results of quantitative analysis (namely quantitative summaries or correlations between variables) cannot uncover evidence about the underlying structures and mechanisms alone (Zachariadis et al., 2013). This is where a retroductive approach comes into play moving from the data to theorising and seeking explanations that reflect underlying causes and mechanisms.

Qualitative methods allow for description but also identify complex relationships between mechanisms and structures (Zachariadis et al., 2013). Critical realists “see the meanings, beliefs, values and intentions held by participants in a study as just as real as physical phenomena, and as playing a causal role in individual and social phenomena” (Maxwell, 2012, p. 40). The implication of this is that critical realists can take a multi-dimensional approach to thinking about research—moving past the quantitative-qualitative divide because mental and physical phenomena are seen as equally real.

Critical realism is consistent with the empirical-ethics and multi-method aspects of this thesis. CR supports the view that quantitative and qualitative research can work together to address each other’s limitations (Shannon-Baker, 2015). CR is often drawn upon in multi- and mixed-methods studies as the theoretical approach that overcomes the qualitative-quantitative divide (Shannon-Baker, 2015). CR can be used to justify the combination of empirical research and moral reasoning (McKeown, 2015; Owens and Cribb, 2011). However, McKeown (2015) concludes that because a CR approach entails that knowledge (and moral development) is dynamic and open, it may require the revision of one’s position in light of new information. The naturalistic approach provides a provisional account of how the world is and what one ought to do because there is always more that could be known empirically about a situation (McKeown, 2015). Ultimately, the account of a phenomenon that more accurately or usefully explains reality is going to be preferred over one that does not (Danermark et al., 2002).
The version of CR used in this thesis asserts that:

1. Both mental and physical phenomena are real (ontological realism). Consistent with this, moral judgements are real (moral realism).

2. Different levels of reality and truth exist. Our knowledge of the world is interpretive and provisional (epistemological constructivism). This means that theories can be revised in light of new information. The account that is preferred is one that best explains reality given the available information.

3. If the research process is seen as real, then researchers need to be reflexive, and understand their influence on the research process (axiology).

4. The research process is interactive. It involves more than just the way the researcher thinks about what they are doing. It is about real interactions with people in their context (rhetorical).

5. There are different (valid/correct) ways of understanding reality. Critical realism takes a multi-dimensional view of methods which overcomes the traditional quantitative-qualitative divide. Different methods can be used together to help understand the underlying mechanisms, events and experiences of a phenomenon (methodological pluralism).

All of this means that a critical realist approach can inform a range of research designs, strategies, methods and analytical approaches.

### 6.4 Methodology and Research Design

The purpose of this section is to outline the methodological approach of the thesis—namely an empirical-ethics approach informed by critical realism within a multi-method research design.

#### 6.4.1 Empirical Ethics

The role of empirical research alongside ethical analysis within bioethics is a matter of on-going discussion (see: Ashcroft, 2003; Borry et al., 2005; Davies et al., 2015; Dunn and Ives, 2009; Dunn et al., 2012; Frith, 2012; Haines, 2002; Hedgecoe, 2004; Ives, 2014; Ives and Draper, 2009, and others). While the field of bioethics has a long tradition of interdisciplinary collaboration (Borry et al., 2005), the increasing interest in using empirical methods in ethical research sees researchers from a range of backgrounds
joining the conversation (Leget et al., 2009). The label ‘empirical ethics’ serves to express the relationship between the different fields that contribute to bioethics (Ives, 2014).

The way that Kon (2009) and others categorise the interaction between empirical research and ethical analysis assumes a fact/value distinction which implies that empirical ‘facts’ are real. Dunn and Ives (2009) urge us to consider the role of epistemology and methodology for the project of empirical ethics, to avoid “…a naive and over-simplistic account of empirical research” which could hinder the development of empirical ethics. In connecting social science methodologies and normative ethics approaches, they encourage researchers to think more broadly about the implications of their decisions (Dunn and Ives, 2009).

Ives and Draper (2009) make a distinction between two approaches to bioethics based on their aims: ‘philosophical bioethics’, that draws on philosophical theory and principles using logical argument, and ‘policy or practice-based bioethics’, that draws on empirical methodologies as well as moral theory and logical argument (Ives and Draper, 2009). This thesis fits the latter approach as it uses multiple empirical methods, with moral theory and argument to address the research question and generate normative guidance.

Empirical ethics integrates empirical data into traditional philosophical analysis (McK-eown, 2015). It is not a methodology, but perhaps a methodological attitude to using empirical findings in ethical reflection and decision making (De Vries and Gordijn, 2009). The argument for empirical ethics is that ethical analysis which has been informed by empirical research is more relevant to clinical practice than the abstract philosophical approach as it is more grounded and context specific (Ives et al., 2012). Of course, there are those who are more sceptical about the use of empirical research. This attitude may stem from the perceived incompatibility of empirical approaches which attempt to describe the world, ‘as it is’, whereas normative approaches seek to describe the world as it should or ‘ought to be’ (Leget et al., 2009, p. 228). Instead, the conversation needs to move beyond this separation and towards the discussion about the necessary relationship between (or contribution of) empirical approaches to bioethics. Birnbacher (2016) sees the consideration of empirical data/facts as necessary
for two reasons, firstly, as a way to assess the impact of ethical principles on in real situations and secondly, in adapting practice rules to the norms and attitudes in the context they are being applied.

Some writers are explicit in the way that they address the gap between social science and philosophical bioethics. These approaches include integrated (Molewijk et al., 2004), mixed methods (Brodwin, 2008), symbiotic (Frith, 2012), philosophical (Davies et al., 2015) and policy-oriented approaches (Ives and Draper, 2009) among others. Molewijk et al. (2004) and Leget et al. (2009) propose a way of combining empirical data with ethical theory where each is equal. Molewijk et al. (2004, p. 56) describes critical applied ethics, which applies the “critical function of ethics to empirical data and simultaneously lets the moral theory be criticized by empirical data”. Neither moral theory or social practice have the authority—empirical data and moral theory interact (Molewijk et al., 2004). Leget et al. (2009, p. 231) develop critical applied ethics as a five stage process (a) the determination of the problem, (b) the description of the problem, (c) the study of effects and alternatives, (d) normative weighing and (e) the evaluation of the effects.

However, this approach requires a methodology that can clearly explain and support this level of interaction (Leget et al., 2009; Molewijk et al., 2004). McKeown (2015) claims that the methodological approaches in empirical ethics used to date are deficient because they either a) entail critical realist assumptions without realising or are b) theoretically underdeveloped. Responding to this criticism, this thesis draws together critical applied ethics with critical realism to provide a step by step approach to the combination of empirical data with ethical theory described in Section 6.4.2. The use of CR as the theoretical perspective provides “an account of reality which excavates and makes explicit the connection between the validity of deductive reasoning in philosophical and ethical analysis, and the inductively apprehended social phenomena in the world to which we are applying this analysis” (McKeown, 2015, p. 5).

This thesis contends that the social science methods can contribute meaningfully to our understanding of ethics by describing patterns of trust and information-sharing in primary care (empirical work) which help develop our conceptualisations of trust and information-sharing practices (theoretical work) and provide ways of specifying how
ethical principles work in the context of information-sharing in primary care (ethical analysis).

### 6.4.2 A Methodological Process

This section outlines a step by step process for answering the research question, given the critical realist and ethical aims of this thesis. The stages in a critical realist analysis have been described by Danermark et al. (2002), Blom and Morén (2011), Meyer and Lunnay (2013), Zachariadis et al. (2013) and Fletcher (2016). This thesis draws on the six stages of explanatory research based on critical realism as outlined by Danermark et al. (2002, see p. 109–11), which influences many of the others. These are: description, analytical resolution, abduction, retroduction, comparison between different theories and abstractions, concretisation and contextualisation (Danermark et al., 2002). The approach outlined in Danermark et al. (2002) was developed in response to Bhaskar’s four-phase model of how natural and social sciences proceed ³. The six stages described in Danermark et al. (2002) and five steps in critical applied ethics described by Leget et al. (2009) have been combined in the following four steps.

**Step 1: Observation and Description**

The first step is to identify and describe the problem. “...empirical research, whether done using qualitative or quantitative methods, contributes to the identification of ethical issues and to the accurate description of the processes used for dealing with these issues” (Leget et al., 2009, p. 232). Observation and description is common to both processes, where it is vital to describe the situation or practice at hand. This includes a description of the context and actors (Blom and Morén, 2011) or the who, what, where, when, and how of the practice or situation (Leget et al., 2009). This step takes place in Study 1 and 2, in seeking to describe the context of information-sharing in primary care by identifying variables that may predict levels of trust, and describing the expectations of patients and GPs.

³These are presented in Bhaskar’s (1978, 1998) earlier work and discussed in more detail by Collier (1994).
Step 2: Theoretical Redescription

This step combines abduction and retroduction outlined earlier. In practice, abduction and retroduction often occur together when beginning to explain concepts (Blom and Morén, 2011; Danermark et al., 2002). The focus is theoretical redescription whereby different theoretical interpretations and explanations of a particular phenomenon or event are explored (Danermark et al., 2002). This interpretive exercise (Blom and Morén, 2011) involves redescribing empirical data using theoretical concepts (Fletcher, 2016). Blom and Morén (2011, p. 69) outline an example of abduction where “the single occurrence that a person anxiously and suspiciously turns around when meeting people in the street can theoretically be described and reinterpreted as the ‘general’ phenomenon of paranoia”. In this thesis the Beitat model of trust, and wider literature, are used as the theoretical basis for the redescription of empirical data in study 1 and 2.

Step 3: Normative Weighing and Theory Comparison

This step combines study of effects and alternatives with normative weighing, and the comparison between different theories and abstractions. By this stage assumptions about the mechanisms that help explain information-sharing behaviours will have been formulated (Blom and Morén, 2011). This step is where more explicit attention is given to ethical theory and its application to the ethical problem/situation. This thesis draws on four ethical principles discussed in Chapter 4. This step involves thinking about the implications of using the four principles and how the empirical findings may impact upon the principles and how the principles may change our understanding of the empirical situation. This involves further consideration about the appropriateness of the ethical theory or principles, and how these ethical principles apply to information-sharing.

Step 4: Concretisation and Contextualisation

This final step involves “examining how different structures and mechanisms manifest themselves in concrete situations” (Danermark et al., 2002, p. 110). This involves explaining the events and processes in specific situations and showing how the mechanisms are expressed (Blom and Morén, 2011). This can be done by demonstrating
how the mechanism relates to a concrete example from the empirical material or in new or different contexts (Blom and Morén, 2011; Danermark et al., 2002). Concretisation and contextualisation is analogous to the specifying and operationalisation of ethical principles to particular contexts. Musschenga (2005, p. 473) says “Ethicists should not limit themselves to formulating abstract and general principles. They have to specify and operationalize principles for particular contexts”. This is where the action-guiding recommendations are specified by taking general principles and translating them into practice rules—or put another way, applying theoretical principles to a situation via middle-range principles or rules for practice.

6.4.3 Research Design

This research utilises a multi-method, sequential research design, comprising a quantitative study and a qualitative study within a critical realist, empirical ethics methodology. The rationale for using multiple methods for this research relates to the complex nature of the topic and that very little research has been conducted on trust in health or information-sharing in New Zealand. Möllering (2006) states that the empirical work in trust research should be:

...highly ambitious in its methodological strategy. It requires a process perspective, obtaining a rich (typically qualitative) picture of actual trust experiences, understanding the embeddedness of the relationships under investigation (Möllering, 2006, p. 152).

The multi-method approach seeks to measure and identify factors that influence trust (Study 1) and explore the complexity of information-sharing and trust in the GP–patient relationship (Study 2). These methods are used as forms of evidence to explain and be explained by existing social science and ethical theory using the four-step process described earlier.

Study 1

Using a quantitative approach, Study 1 informs the research question by examining patterns of responses to gain an understanding of attitudes and expectations about trust and information-sharing in primary care. It also examines the influence of demographic, health service utilisation and experiential factors on levels of general, particular and organisational trust. This study uses a self-administered, mixed-mode survey instrument to collect information from members of the New Zealand public.
Study 2
The qualitative approach in Study 2 explores patient and GP expectations of trust and information-sharing. Study 2 uses constructed vignettes and follow-up questions within semi-structured interviews with patient and GP participants from across Auckland.

Use of Social Science and Ethical Theory
The data from these empirical studies provides an understanding of patients’ attitudes and expectations of GPs about information-sharing in primary care. These expectations impact upon perceptions of trust (Beitat et al., 2013) and further indicate patients’ attitudes and beliefs about the ethical obligations of GPs in relation to information—such as confidentiality, privacy and professional conduct. This provides a basis for understanding the way patients’ use ethical theory when making judgements about the actions of GPs and others in primary care and considering the normative force that patient expectations have upon the practice of GPs. This moves the thesis from merely documenting and describing the state of patients’ expectations of trust and information-sharing, to the generation of action-guiding recommendations for clinical practice.

6.4.4 Methodological Appropriateness
In seeking to produce good quality research, both quantitative and qualitative, researchers have resorted to checklists and criteria. Liamputtong (2013) draws links between the four qualitative criteria proposed by Guba & Lincoln (1985, 1989) and their quantitative counterparts: credibility and authenticity (comparable to internal validity), transferability or applicability (comparable to external validity), dependability (comparable to reliability), and confirmability (comparable to objectivity or neutrality). It has been common for qualitative researchers to reject the notion of there being a set of criteria to determine the quality of qualitative research because of the number of methodological approaches (Caelli et al., 2003; Liamputtong, 2013). Notions of what makes ‘good’ research go beyond the methodological approach of quantitative versus qualitative. It relates to the whole research process—the questions asked, theoretical and methodological approach taken, and how data is collected, analysed, interpreted and presented.
Patton (2015, p. 92) suggests that:

...operating narrowly within any singular paradigm ...can be quite limiting...
Being practical and flexible allows one to eschew methodological orthodoxy for
methodological appropriateness as the primary criterion for judging methodological
quality, recognizing that different methods are appropriate for different situations.

Instead of orthodoxy, this thesis draws on a practical stance seeking methodological
appropriateness to answer the research questions (Patton, 2015). This reorientation
requires an evaluation of the entire research process including the purpose, procedures,
results and the audience, and not just the methodology chosen (Patton, 2015). The
evaluation of methodological appropriateness can also be framed as a concern with
rigour. This makes issues of quality more about the congruence of each part of the
research process as opposed to achieving criteria from a prescribed list. This thesis
has sought to ensure congruence across the research process through the use of one
model of trust in the construction of the tools in Study 1 and 2, and careful attention
to the implications of a critical realist perspective on the methodology, methods and
the application and interpretation of empirical data in light of theoretical concepts.

6.5 Conclusion

This chapter has discussed the philosophical and methodological approach of this thesis.
This thesis does not prioritise the authority of the social science methods and theory
over the use of ethical theory: they are considered equal. Overall, the empirical studies
within this thesis can be seen as making two distinct moves. Study 1 draws on social
science theory in order to collect information about the attitudes and expectations
of individuals related to information-sharing, trust and health (objectives 1 and 2).
It draws attention to the nature of the context. This move describes expectations
of trust—it draws attention to the relations between actors by describing general,
particular and organisational trust. Study 2 draws on moral and social science theory
in order to engage with individuals about the practice of information-sharing and the
role of trust (objectives 2 and 3). The interpretation of these empirical studies involves
the use of social science and ethical theory.
STUDY 1: Survey-based Exploration of the Attitudes and Perceptions of Trust in the New Zealand Health System
Chapter 7
Introduction to Study 1

This chapter introduces the first study in this thesis. In the first section, the rationale for this survey-based study is discussed. This is followed by a discussion of measures of trust from the literature as well as those used in the New Zealand context. The aims and approach of the study are stated in the final section.

7.1 Rationale

As discussed in Chapter 5 there has been very little research that has explored the role of trust as it relates to information-sharing in primary care. Of the two studies identified in the review, one was quantitative; however, it focused on trust in electronic health records (EHRs) (Qiao et al., 2015). The factors associated with patient trust in EHRs included patient trust in their primary care physician, recognition of the characteristics of EHRs and perception of how the physician uses EHRs (Qiao et al., 2015). This study found that patient trust in their primary care physician was high (94% said they had complete trust in their doctor) however it did not explore what factors were associated with patient trust in the primary care physician (Qiao et al., 2015). This suggests that further research into the factors that influence trust is warranted.

7.2 Measuring Trust

Public trust can indicate where there is support for the system and for where change is needed (Abelson et al., 2009; Straten et al., 2002). The central question asked of people in determining levels of public trust is whether they have confidence in their health system (Straten et al., 2002). The confidence or public perception of health systems in various countries have been investigated, including but not limited to Australia (Hardie and Critchley, 2008), Cambodia (Ozawa and Walker, 2011) Canada (Abelson et al., 2009), the Netherlands (Straten et al., 2002), Turkey (Dinç et al., 2013), the United
States (Egede and Ellis, 2008) and the United Kingdom (Calnan and Sanford, 2004). The findings from these studies have been largely limited in their application as they are bound within the health and wider socio-political context of each country. Cross-country comparisons, while not common, have been made possible in some instances (Bjørnskov, 2007; Delhey and Newton, 2005; van der Schee et al., 2007). Both van der Schee et al. (2007) and Saarinen et al. (2016) demonstrate that the method of health system funding (taxation versus social-insurance) has some influence on cross-national comparisons of trust.

It has only been recently that more research has attempted to analyse and measure interpersonal or particularised trust in health care. Some of the contexts in which patient trust in doctors have been studied include: the impact of information about previous decisions (White et al., 2011), managed care (Goold and Klipp, 2002), ongoing interactions during pregnancy (Ahmad et al., 2013), trust after medical incidents (Beitat et al., 2013) and quality of care (Thom et al., 2004). The methods commonly include the development and testing of general surveys of patient trust in doctors (Anderson and Dedrick, 1990; Bova et al., 2012; Calnan and Sanford, 2004; Hall et al., 2002b; Kao et al., 1998a,b), and the use of qualitative methods to explore the nature of the trust relationship between patient and doctor (Beitat et al., 2013; Cook et al., 2004; Skirbekk et al., 2011). Less common is the use of experimental methods (White et al., 2011) which are more common to the management setting, or the study of interventions which aim to improve patient trust (McKinstry et al., 2006).

### 7.2.1 Surveys

While multi-item scales have been developed to measure trust in primary care doctors, insurers, hospitals and the health system internationally (Currall and Judge, 1995; Egede and Ellis, 2008; Hall et al., 2001; McEvily and Tortoriello, 2011; McKinstry et al., 2006) no such measure has been used in, or developed for, the New Zealand context. Often cited measures of trust include the Role Boundary Persons Trust Instrument (Currall and Judge, 1995), Multidimensional Trust in Health Care Systems Scale (Egede and Ellis, 2008), Trust in Physician Scale (Rotter, 1967), Wake Forest Physician Trust Scale (Hall et al., 2002b) and the Health Care Relationship Scale Revised (Bova et al., 2012). In a review of measures Müller et al. (2014) show that the
methodological quality of psychometric properties in studies of patient trust are not satisfactory. This may be due to a lack of information about these aspects (particularly validity, reliability, responsiveness and floor and ceiling effects) (Müller et al., 2014).

### 7.2.2 Existing Trust Research in the New Zealand Context

In New Zealand, no substantial survey measuring general, particularised or organisational trust in primary care, or the health system has been conducted. Studies of trust in the New Zealand context have been limited to those asking about trust in general terms, or the trustworthiness of professional groups or of government. In the World Values Survey 2011, 55.3% of New Zealanders, responding to the question ‘Generally speaking, would you say that most people can be trusted or that you need to be very careful in dealing with people?’ said that most people can be trusted (World Values Survey, 2016). The 2014 Privacy Commission survey reported 92% of participants said health service providers including doctors, hospitals and pharmacists were highly or somewhat trustworthy (OPC, 2014). A 2016 report suggests that medical practitioners and the Police are the most trusted groups, while bloggers and Ministers of Parliament (MPs) are the least (Institute for Governance and Policy Studies, 2016). Further, 26% the respondents reported trusting medical practitioners a little or a lot more over the last three years (Institute for Governance and Policy Studies, 2016). However, these studies have grouped health service providers and medical practitioners together. There is also no indication about the trustworthiness of GPs in comparison to other health professionals. It follows that a study exploring trust in health care in a New Zealand setting would seek to measure levels of trust in these different professionals to see if there is any difference. This would also provide a context for how trusted GPs are from a general standpoint before exploring the particular and organisational trust aspects.

In relation to interpersonal or particular trust, a question about trust and confidence is included in the New Zealand Health Survey. According to the 2014/2015 New Zealand Health Survey (NZ Health Survey) 80% percent of adults who had visited a GP in the last three months reported having confidence and trust in their GP; this is slightly lower than 2011/2012 where the rate was 84% (Ministry of Health, 2015). Those over 65 were more likely to have confidence and trust in the GP they visited than
those aged 25–44 years but there was little or no difference by sex, ethnicity or level of deprivation (Ministry of Health, 2015). Admittedly, as this is a single-item in a larger survey, it is difficult to determine the extent that this item is solely measuring trust in the GP, or whether it is linked to patient satisfaction or general trust. Given the dearth of literature about trust in the New Zealand context, this study explores the impact of demographic, utilisation and experiential variables on general, particular and organisational trust in the health system.

### 7.2.3 Potential Factors that Influence Trust

The literature has explored the role of a number of factors that are theorised to influence trust. For the purpose of this study these are broadly categorised as:

- **Demographic factors**—this has included gender, age, ethnicity, language, race, income, education, and geographical location.
- **Health Utilisation factors**—this has included number of visits, continuity of care, whether the doctor is the usual provider, length of relationship, number of health conditions, and health status.
- **Experiential factors**—these are related to the most recent visit and include aspects like patient satisfaction, perceived quality of the visit, communication, and involvement in decision-making.

Except for age (Castle et al., 2012; Croker et al., 2013; Dittrich, 2015; Hall et al., 2001; Li and Fung, 2013; Tarrant et al., 2003; Van den Brink-Muinen and Rijken, 2006), studies show inconsistent relationships between demographic variables and trust (Bulloch, 2013; Gabay, 2015; Giordano and Lindström, 2015; Meyer et al., 2012b; Murray and McCrone, 2015; Qiao et al., 2015). Age has a positive relationship with trust, which may reflect a generational effect and greater contact with doctors (Hall et al., 2001). Several studies have indicated that ethnicity influences trust (Croker et al., 2013; Egede and Ellis, 2008; Stepanikova et al., 2006; Tarrant et al., 2003), however, the concepts of ethnicity and race are inconsistently applied. Stepanikova et al. (2006), who looked at race, ethnicity, language and trust, suggest that racial and ethnic differences vary depending on the measure of trust. Due to the inconsistency of the reported influence of demographic factors, this study will include a range of
demographic questions to explore whether they have any impact on trust in a New Zealand context.

Other factors, like continuity of care and other aspects of the physician-patient relationship, appear to have a greater impact on trust than ethnicity, education, income or health status (Croker et al., 2013; Gabay, 2015; Hall et al., 2001). This study explores health utilisation and experiential factors as financial, cultural and geographic barriers to access to primary health care have been shown to affect New Zealanders (Jatrana and Crampton, 2009). According to the latest New Zealand Health Survey (2014–2015), 80% of adults had visited a GP in the last 12 months, with an average of 3.1 visits (Ministry of Health, 2015). However, 27% experienced unmet need for primary care in the last 12 months (Ministry of Health, 2015). Unmet need referred to the experience of the following barriers to primary care: cost of GP or after-hours services, lack of transport to GP or after-hours care, or the inability to get an appointment at their usual GP within 24 hours. Women, older people, Māori and those living in the most socio-economically deprived areas experienced barriers to access (Ministry of Health, 2015). These barriers to access mean that some patients present to an Emergency Department (ED) instead of primary care, which may have an impact on trust. Of those adults who had seen a GP in the last 12 months, 90% reported that their GP was very good or good at explaining their health conditions and treatments (92%), and at involving them in decisions about their care (90%) (Ministry of Health, 2015). These two questions are used as experiential factors.

### 7.3 Aims and Approach

Study 1 is a cross-sectional survey of New Zealanders’ attitudes about trust and information-sharing in the context of health care. The data was collected using a self-administered, mixed-mode questionnaire developed from the literature.
Study 1 answers the research question by addressing the first two objectives of this thesis:

1. Identify attitudes about trust (general, particular, and organisational) and information-sharing in health care settings.
2. Determine what patients expect when sharing information with their GP, or their GP shares information with others, and identify ways that patients think that breaches of trust can be remedied.

The survey outlines the context of information-sharing by describing the attitudes and expectations within the sample that responded. This study uses multiple sequential regression analysis to determine which variables (demographic, health utilisation and experiential) predict levels of trust. It also provides respondents with the option to provide qualitative responses about their expectations.

### 7.4 Conclusion

Given that there have been no studies in New Zealand that have looked at trust in the health system, this study explores general trust in professional groups and organisations, particular trust in the primary care provider, and organisational trust. A cross-sectional survey was used for this study as a way to identify attitudes about general, particular and organisational trust and determine the influence of demographic, health utilisation and experiential factors. The design and survey items have been developed for the New Zealand context drawing on existing New Zealand questions, and measures of trust from the trust literature, as discussed in the next chapter.
Chapter 8

Methods

This study used a survey instrument to collect information from members of the general public in order to determine the attitudes and expectations of individuals in relation to trust in the New Zealand health system. This chapter outlines the study design, sampling, tools, and the procedures for data collection and analysis.

8.1 Design

Study 1 used a cross-sectional research study design, with data obtained at one point in time with the aim of collecting quantifiable data about two or more variables to determine patterns of association (Bowling, 2014; Bryman, 2012). This study was also mixed-mode with the self-administered questionnaire sent via mail or accessed online.

8.2 Sample

The target population for the study was ‘Adults who live in New Zealand’. A power calculation showed that for the intended analysis with the largest sample size requirements (linear regression), a total sample size of 400 would achieve 90% power to detect a relatively small effect size of $f^2 = 0.05$ with 12 predictors and an alpha level of .05. The sampling strategy used random and purposive sampling to ensure a sample of this size.

Phase 1: Random Sample

The first phase of sampling involved the random selection of 1000 people from the New Zealand Electoral Roll obtained from the Electoral Commission in March 2015. Potential participants were invited to participate via the postal address listed on the roll.
Phase 2: Purposive Sample

Initial descriptive statistics performed on Phase 1 returns showed 60%, of the respondents, were over 54, with 20% over 75. Research suggests there may be a relationship between age and trust (Castle et al., 2012; Dittrich, 2015; Li and Fung, 2013), which provided a rationale for purposively sampling adults aged 18–54. A social media advertisement on Facebook (see page 312) was used to target male and female individuals between the ages of 18 and 54 in New Zealand.

8.3 Tools

A 62-item self-administered questionnaire was constructed for use in this study. It sought to include items that informed the four domains of the Beitat model in Figure 3.2. Using the Beitat model, items from existing scales and newly generated items were included to ensure coverage of all four domains. The questions, source and the dimension/domain they cover are described in Table 8.1, of which:

- Nine questions focused on expectations
- Five on actions/outcomes
- Three on knowledge/information
- Four on communication, and,
- Four which were about both knowledge/information and expectations.

The questionnaire comprised six sections, and are described below.

Section 1: General Trust

The first section sought to measure general trust in health professionals and organisations. This comprised two questions and 16 items—about the trustworthiness of eight health professionals (Q1.1) and eight organisations (Q1.2).

Section 2: Utilisation of Health Services

Section 2 asked three questions about participants use of health services based on questions from the 2013/2014 New Zealand Health Survey (NZHS) (Ministry of Health, 2015). These questions asked whether the respondent had a GP that they saw regularly, and the number of times they had been to a GP in the last 12 months.
Section 3: Trust in GP (experiential factors)

Section 3 was about participants’ last visit to their GP. Three of the questions asked about how much the participant agreed or disagreed with statements about their GP, including whether the GP involved them in decision making, how good they were at providing information to the patient, and their trust and confidence in the GP. These questions provided information about the interpersonal or experiential aspects of the GP–patient relationship. One open-ended question asked about participants’ expectations of GPs regarding their personal information.

Section 4: Trust in Primary Health Provider you see Most Regularly

Section 4 sought to measure particularised trust in a respondent’s primary health provider. This section included 16 items. They were able to specify the type of health provider that they saw most regularly in question 4.1. Question 4.2 asked about how much the participant agreed or disagreed with statements about their regular Primary Health Provider. Ten of the items were originally from the Multidimensional Trust in Health Care Systems Scale (MTHCSS) (Egede and Ellis, 2008), and four were from the paper by Currall and Judge (1995) which aimed to determine how individuals behave with their health care provider. Item 14 in Section 4.1 was developed from a similar question asked in the Privacy Commission Survey. The items were mixed up to reduce response bias.

Section 5: Organisational Trust in Health Care Institutions and the Health Profession

Section 5 sought to measure organisational trust in health care institutions. This section contained three questions and a total of 12 items. Question 5.1 contained ten items that asked about how much the participant agreed or disagreed with statements about health care institutions related to their motives, actions and the extent to which the participants thought they were trustworthy. Questions 5.2 and 5.3 invited participants to detail their expectations of health organisations concerning personal information, and how health professionals and organisations could rebuild trust when it is compromised or lost.
Section 6: Demographic Questions

The final section asked ten demographic questions. As a way to ensure that these were appropriate for the New Zealand context, the demographic questions about gender, age, ethnicity, country of birth, education level and occupation from the 2013 Census were used. The questionnaire also asked about the type of area and region of New Zealand the participants occupied, their relationship status and current work situation.

8.3.1 Rating Scales or Response Categories

The questionnaire used a combination of 7-point Likert scales, multi-choice and open-ended questions. Likert-scales are used to measure attitudes—opinions, preferences, and dispositions (Gob et al., 2007). Likert scales, (for example a 5 point scale where 1= ‘strongly disagree’ and 5=‘strongly agree’) can be used to measure the intensity (agree vs. disagree, strongly vs. moderately) of a person’s attitude towards an item/object (Liu et al., 2015; Weijters et al., 2010). A concern about Likert scales in the agree/disagree format is acquiescent response bias where respondents choose ‘agree’ more often than other options (Liu et al., 2015). Research indicates that having seven response categories is more reliable than less than that (Preston and Colman, 2000). Labelling of scales also varies with the use of unipolar and bipolar methods (Cabooter et al., 2016). Scales can have positive only, or positive and negative labels. The unipolar format is easy to construct, as it comprises a statement to which respondents rate their level of agreement (Cabooter et al., 2016). It also looks at just one pole of the underlying construct (Cabooter et al., 2016). Including ‘no opinion’ or ‘don’t know’ response options is not advised (Furr, 2011). A unipolar, positive, seven-point scale was used for all Likert scale-items. All of the seven-point response scales were labelled $1=\text{strongly disagree}$ to $7=\text{strongly agree}$, as shown in Figure 8.1.

![Figure 8.1: Response Scale Used in the Questionnaire](image-url)
Table 8.1: Survey Items, Source of Item, and Construct or Dimension being Measured

<table>
<thead>
<tr>
<th>General Trust</th>
<th>Source</th>
<th>Construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 How much do you agree or disagree about the trustworthiness of the following health professionals in New Zealand?</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think GPs (General Practitioners) are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Hospital based doctors are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Nurses are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Pharmacists are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Physiotherapists are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Psychologists are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Counsellors are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Midwives are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>1.2 How much do you agree or disagree about the trustworthiness of the following health organisations and government departments in New Zealand?</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think GP practices or clinics are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think hospitals are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think District Health Boards (DHBs) are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think St Johns Ambulance is trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think ACC is trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think The Ministry of Health is trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think Government departments, in general, are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
<tr>
<td>I think private health insurance providers are trustworthy</td>
<td>New: Adapted OPC Survey 2014</td>
<td>Measure of General Trust</td>
</tr>
</tbody>
</table>

| Health Service Utilisation                                                     |                                |                                          |
|-------------------------------------------------------------------------------|                                |                                          |
| 2.1 Do you have a GP clinic or medical centre that you usually go to when you are feeling unwell or injured? | A2.01 from 2013/2014 NZHS       | Measure of Health Service Utilisation    |
| 2.2 In the past 12 months, have you seen a GP or been visited by a GP about your own health? | A2.12 from 2013/2014 NZHS       | Measure of Health Service Utilisation    |
| 2.3 How many times did you see a GP in the past 12 months?                     | A2.13 from 2013/2014 NZHS       | Measure of Health Service Utilisation    |

| Trust in Your GP                                                              |                                |                                          |
|-------------------------------------------------------------------------------|                                |                                          |
| 3.1 How good was the GP at explaining your health conditions and treatments in a way that you could understand | A2.22 from 2013/2014 NZHS       | Measure of experiential aspects of Patient-Professional relationship |
| 3.2 How good was the GP at involving you in decisions about your care, such as discussing different treatment options? | A2.23 from 2013/2014 NZHS       | Measure of Particular Trust             |
| 3.3 Did you have confidence and trust in the GP you saw?                      | A2.28 from 2013/2014 NZHS       | New                                     |
| 3.4 What do you expect of your GP when you provide him/her with your personal information? | New                            |                                          |

Continued on next page
<table>
<thead>
<tr>
<th>Trust in the Primary Health Provider you see most regularly</th>
<th>Source</th>
<th>Construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 What type of health provider do you see most regularly?</td>
<td>New</td>
<td></td>
</tr>
<tr>
<td>4.2 How much do you agree or disagree with the following statements about the health provider that you see most regularly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My health care provider is usually considerate of my needs and puts them first</td>
<td>MTHCSS</td>
<td>A</td>
</tr>
<tr>
<td>I give my health provider all known and relevant information about important issues</td>
<td>Curall &amp; Judge (1995)</td>
<td>C</td>
</tr>
<tr>
<td>I have so much trust in my health provider that I always try to follow his/her advice</td>
<td>MTHCSS</td>
<td>A</td>
</tr>
<tr>
<td>I trust my health provider so much that I believe everything they tell me</td>
<td>MTHCSS</td>
<td>A</td>
</tr>
<tr>
<td>Sometimes, I do not trust my health provider's opinion and feel I need to see another provider</td>
<td>MTHCSS</td>
<td>A</td>
</tr>
<tr>
<td>I can trust my health provider's judgments concerning my medical care</td>
<td>MTHCSS</td>
<td>K/E</td>
</tr>
<tr>
<td>I deliberately withhold some information when communicating with my health care provider</td>
<td>Curall &amp; Judge (1995)</td>
<td>C</td>
</tr>
<tr>
<td>My health provider will do whatever it takes to give me the medical care that I need</td>
<td>MTHCSS</td>
<td>K/E</td>
</tr>
<tr>
<td>Because my health provider is an expert, he/she is able to treat medical problems like mine</td>
<td>MTHCSS</td>
<td>K/E</td>
</tr>
<tr>
<td>I minimise the information I give to my health provider</td>
<td>Curall &amp; Judge (1995)</td>
<td>C</td>
</tr>
<tr>
<td>I can trust my health provider's decisions on which medical treatments are best for me</td>
<td>MTHCSS</td>
<td>K/E</td>
</tr>
<tr>
<td>I think carefully before telling my health provider my opinions</td>
<td>Curall &amp; Judge (1995)</td>
<td>C</td>
</tr>
<tr>
<td>My health provider offers me the highest quality medical care</td>
<td>MTHCSS</td>
<td>A</td>
</tr>
<tr>
<td>I am concerned about my GP sharing my health information with others without telling me</td>
<td>New: Adapted OPC Survey 2014</td>
<td>E</td>
</tr>
<tr>
<td>I completely trust my health provider</td>
<td>MTHCSS (reworded)</td>
<td>Measure of Particular Trust</td>
</tr>
</tbody>
</table>

| Trust in Health Care Organisations and Institutions | | |
|-------------------------------------------------------|--------|
| 5.1 How strongly do you agree or disagree with the following statements about health care organisations? | | |
| Health care organisations only care about keeping medical costs down, and not what is needed for my health | MTHCSS | E         |
| Health care organisations provide the highest quality medical care | MTHCSS | E         |
| When treating my medical problems, health care organisations put my medical needs above all other considerations, including costs | MTHCSS | A         |
| I am concerned about organisations in the health sector sharing information about my health with other organisations in the health sector without telling me | New: Adapted OPC Survey 2014 | E         |
| Even if I don't like the way government agencies use and protect my personal information I am often forced to deal with them anyway to get the things I need | New: Adapted OPC Survey 2014 | A         |
| I feel in control of the way government agencies use and protect my personal information | New: Adapted OPC Survey 2014 | K         |
| I feel in control of the way health care organisations use and protect my personal information | New: Adapted OPC Survey 2014 | K         |

Continued on next page
Table 8.1 - continued from previous page

<table>
<thead>
<tr>
<th>Trust in Health Care Organisations and Institutions</th>
<th>Source</th>
<th>Construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel there should be more sharing of information between health professionals and health organisations</td>
<td>New: Adapted OPC Survey 2014</td>
<td>E</td>
</tr>
<tr>
<td>I am concerned about data breaches which may involve the compromise or loss of my personal health information</td>
<td>New: Adapted OPC Survey 2014</td>
<td>K</td>
</tr>
<tr>
<td>I trust that the doctors will only share information about me that is relevant to my care</td>
<td>New: Adapted OPC Survey 2014</td>
<td>E</td>
</tr>
<tr>
<td>I trust that the doctors will keep my personal information confidential no matter what</td>
<td>New: Adapted OPC Survey 2014</td>
<td>E</td>
</tr>
<tr>
<td>5.2 What do you expect of health organisations when you give them your personal information?</td>
<td>New</td>
<td>E</td>
</tr>
<tr>
<td>5.3 How do you think health professionals (like GPs) and organisations can rebuild trust when it has been compromised or lost?</td>
<td>New</td>
<td>E</td>
</tr>
</tbody>
</table>

**Demographic questions**

Gender  
Age  
Ethnicity  
Education  
Country of Birth  
Relationship Status  
Area of Residence  
Region of Residence  
Education  
Current Work Situation  
Occupation

Note: From the Beitat model: E = Expectations, A = Actions/Outcomes, C = Communication
8.3.2 Format

The mail questionnaire was compiled using SDAPS (an open source optical mark recognition program) (Berg, 2015, Version 1.19) and \LaTeX. The web instrument used the same questions and response categories as the paper questionnaire. The online questionnaire was formatted or compiled using Qualtrics (Qualtrics, Provo, UT), a web-based research suite for designing and distributing surveys.

8.3.3 Testing

The completed survey was piloted among colleagues. They were asked to think critically about the survey and to check specifically for typographical errors, the flow of the questions and sections, and the language used. They were asked to highlight any perceived barriers or difficulties that participants might have. This serves as a type of face validity (Litwin, 1995). Some typographical errors and order of items were altered based on feedback from pilot testing.

8.4 Data Collection Procedures

For the first phase of sampling (random sample), survey packs were posted to 1000 individuals on the 11th March 2015 with the web survey going live the same day. Response rates to surveys can be increased by using incentives, personalised communication/contact, postage paid envelopes and follow-up (De Vaus, 2014; Edwards et al., 2002; Millar and Dillman, 2011). Questionnaires originating from a university are also more likely to be returned than those from other sources or organisations (Edwards et al., 2002). These techniques were all employed. As an incentive to encourage people to respond (Millar and Dillman, 2011), participants could complete the form shown on page 312 for the chance to win a $50 supermarket voucher. The follow-up postcard (page 311) was sent 11th May 2015.

For the second phase of sampling (purposive sample) and an advertisement was placed on Facebook for two weeks commencing 3rd July 2016. Those who clicked on the advertisement were directed to the survey on the Qualtrics website (Qualtrics, Provo, UT). Participants were offered the same incentive (as phase 1) and redirected to a separate form at the completion of their survey. An additional screening question was
included to ensure that participants would have the same characteristics as those on
the electoral—being a New Zealand Citizen or Permanent Resident.

8.5 Data Analysis Procedures

The procedures for analysing the survey results are described in this section. Analysis
of the questionnaire data involved analysis of univariate statistics to describe the nature
of the data and sample, Principle Component Analysis (PCA) and internal consistency
measures to assess the reliability and validity of the measures, and hierarchical
multiple regression analysis to address the research objectives. Statistical analyses were
completed using SPSS Statistics version 23, and the open-ended questions analysed
using QSR International Nvivo version 11.

8.5.1 Preparing Data for Analysis

From the first phase of sampling, 175 paper questionnaires and 11 web surveys were
returned. Six were ineligible—returned blank. Twelve were returned as ‘Gone no
address’ or ‘Return to sender’ and categorised as unreachable. From the second phase
of sampling, 372 partial and completed questionnaires were received. Of these, 47
entries did not fit the criteria, and 7 were blank, all 54 entries were excluded and
deleted from the data file; 318 entries remained. These entries were compiled with
those from phase 1 giving a total of 504 responses (186 from phase 1, and 318 from
phase 2). The data file was checked for accuracy. Univariate statistics were checked
to ensure that values were in the appropriate range, and the means and standard
deviations were plausible. When the scale-items were tested for reliability, the internal
consistency (inter-item correlations) table was used to check the items.

Demographic Classification

Demographic items were transformed into numbers. Ethnicity was coded using
prioritised and total response methods outlined in the ethnicity data protocols for
the health and disability sector (Ministry of Health, 2004). Using the priority system
respondents were allocated as follows:

1. If Māori was recorded the participant was assigned to ‘Māori’.
2. If any Pacific Island ethnicities were recorded the participant was assigned to ‘Pacific Island’.
3. If any Asian ethnicities were recorded the participant was assigned to ‘Asian’.
4. If any other ethnic group except NZ European was recorded the participant was assigned to ‘other ethnic group’.
5. Remaining participants were assigned ‘NZ European’.

**Missing Data**

Missing data can be a serious problem for data analysis (Tabachnick and Fidell, 2001). When deciding on a method of addressing missing data De Vaus (2014) suggests finding a solution that minimises data loss and avoids distorting sample variation and correlations. The pattern in the missing data is often more important than how much is missing, with missing values scattered through the data being less problematic (Tabachnick and Fidell, 2001). There were no patterns in the missing data. However, some entries were missing large amounts of data. The following criteria were applied:

1. Cases with 70–100% of the data (43 or more items) would be included.
2. Cases with 0–70% of the data (20 items or more missing) would be excluded (deleted).

Any missing data that remained was assumed to be random.

**8.5.2 Univariate Statistics**

To describe the nature of the sample and the data, the demographic, health service utilisation and experiential questions were analysed. The distribution of the variables were analysed including central tendency (mean, median) and dispersion (maximum and minimum values, standard deviation).

**8.5.3 Scale Construction and Principle Component Analysis**

As discussed in Chapter 7, the survey sought to measure three aspects of trust:

1. General trust in health professionals and organisations.
2. Particularised or interpersonal trust in primary health care provider.
3. Organisational trust in health institutions and the health profession.
To be able to determine which dependent variables influenced trust, scales were developed based on the Likert-response items. Scale building captures the complexity of a concept by drawing on multiple indicators instead of just one (De Vaus, 2014). Multiple indicators help develop more valid measures, increase reliability, and allow for greater precision (De Vaus, 2014).

In scale composition, all items must be scored in the same direction (De Vaus, 2014). For this reason, negatively rated items were reverse coded. The internal consistency of each scale (general, particular, and organisational trust) was tested to ensure the items related to the same underlying dimension. If a scale is reliable, an individual will get the same scale score two different times (De Vaus, 2014). Alternatively, we look at the internal consistency of an individual’s response across different items. Cronbach’s Alpha Coefficient ($\alpha$) is the statistic that describes item-item internal consistency; this ranges between 0 and 1—the higher the Cronbach’s alpha ($\alpha$), the more reliable the scale (De Vaus, 2014).

The final step in confirming the scales was to perform Principal Component Analysis (PCA), a statistical technique that reduces a large set of variables to a smaller set of underlying variables (Tabachnick and Fidell, 2001). PCA was used to see if the measures of trust (general, particular and organisational trust) with lots of items, measured a single dimension or whether there were underlying sub-scales or dimensions (Foster et al., 2006).

**Assumptions of PCA**

Performing PCA requires interval-level data, where respondents scores vary, have linear correlations and are normally distributed (Foster et al., 2006). The scores should have linear correlations between items (Foster et al., 2006; Tabachnick and Fidell, 2001) as when linearity fails, the solution is degraded (Tabachnick and Fidell, 2001). Most of the correlations in the correlation matrix should be above 0.30 (Foster et al., 2006). Variables with very low correlations should be excluded as they will not contribute to a component, and those with very high correlations (above 0.9) excluded as they are redundant (Foster et al., 2006). Bartlett’s test of sphericity is used to test the null hypothesis (that the variables in the population are uncorrelated) if it fails to reject the null-hypothesis (where $p > .05$), PCA should not be performed (Foster et al.,
For PCA, multicollinearity is not a problem, but extreme multicollinearity and singularity can be (Field, 2009; Tabachnick and Fidell, 2001). 

While normality can enhance the solution in PCA if it fails the solution may still be valuable (Foster et al., 2006; Tabachnick and Fidell, 2001). Normality can be tested by plotting the distribution and examining whether it looks more or less like a normal distribution (Foster et al., 2006). The shape of the distribution can be evaluated based on skewness (is the peak of the curve in the centre) and kurtosis (the high of the tails of the curve)—statistical indices of skewness and kurtosis should be close to zero (Foster et al., 2006).

The sample size recommendations for PCA vary with Tabachnick and Fidell (2001) suggesting that 300 cases are advisable because correlation coefficients can be less reliable in smaller samples. Some researchers suggest 10–15 cases per variable, or even ten times the number of participants as variables (Field, 2009). The Kaiser-Meyer-Olkin (KMO) measure assesses the sampling adequacy of the items (Foster et al., 2006). The KMO statistic varies between 0 and 1 with a score of 1 suggesting that patterns of correlations are compact which means PCA should result in distinct and reliable components (Field, 2009). Values should be 0.6 or above (Foster et al., 2006), “. . . values above 0.9 are superb” (Field, 2009, p. 647).

Rotation Method

Rotating factors aims to achieve a simple structure, where items load highly on one component and low on others, so it is easier to interpret (Foster et al., 2006). Oblique rotations should be used when expecting variables to be correlated, while orthogonal rotations assume variables are not correlated (Field, 2009). SPSS has three options for orthogonal rotation (varimax, quartimax and equamax), and two for oblique rotation (direct oblim and promax) (Field, 2009; Tabachnick and Fidell, 2001).

Extracting Components

There are two ways of deciding how many components to extract in PCA (Field, 2009; Foster et al., 2006). The first is to use the eigenvalues and retain factors above 1 (Kaiser’s criterion) (Field, 2009). The other way is to examine the scree-plot where the eigenvalue is plotted against the component number—the number of components
extracted is indicated by how many are above the elbow in the line (Foster et al., 2006). Further, the combination of components should explain 70–80% of the variance (Timm, 2002). Pattern matrices were examined to identify which items belonged to each component, which was indicated by a high loading on one of the components. These items were then considered in terms of theoretical explanations to give the sub-scale a name.

8.5.4 Hierarchical Multiple Regression

Regression analysis is a statistical method for investigating relationships between variables (Yan, 2009). Hierarchical multiple linear regression determines the variance in the dependent variable (DV) that is explained by the regression model, and the importance of the independent variables (IV) to the solution (Tabachnick and Fidell, 2001). In this method, the independent variables are entered into the regression in the order specified by the researcher instead of all at once (Tabachnick and Fidell, 2001). They can be entered one-at-a-time, or in blocks and often depends on theoretical considerations (Tabachnick and Fidell, 2001).

Assumptions of Multiple Linear Regression

For linear regression models, predictor/independent variables should be quantitative or categorical, and the outcome/dependent variables should be quantitative and continuous (Field, 2009). Categorical predictor variable can be dummy-coded as binary for inclusion in a regression model (Field, 2009). The 7-point Likert scales in the questionnaire are ordinal scales as the values “agree” and “moderately agree” do not represent equal intervals between them. The scale data was initially discrete, not continuous but has been transformed into continuous data through PCA.

The simplest rule of thumb when testing predictors is to ensure that sample size is \( N \geq 104 + m \), where \( m \) is the number of IVs (Tabachnick and Fidell, 2001).

To check that there were not any overly influential cases in the regression model the test statistics for Mahalanobis Distance and Cooks Distance can be checked via case summary (Field, 2009). Cooks Distance test statistic values should be below 1, while the Mahalanobis Distance test score \( x^2 \) for 9 IVs, is critical at \( \alpha = .001 = 27.827 \) for 9df.
The errors or residuals should be uncorrelated or independent (Field, 2009). The Durbin-Watson test looks for serial correlations between errors, a test statistic close to 2 indicates no correlation (Field, 2009). In evaluating multicollinearity, a correlation matrix of all of the predictor variables was scanned to determine if there were any that were highly correlated. Collinearity diagnostics report the variance inflation factor (VIF) and associated tolerance which indicates if a predictor variable has a strong linear relationship with any other predictor variable. Researchers should be concerned if the value of the VIF statistic is 10 or above, or if the average VIF is significantly greater than 1 (Field, 2009; Tabachnick and Fidell, 2001). For tolerance (which is $\frac{1}{VIF}$), values below 0.2 may suggest cause for concern, and below 0.1 serious problems (Field, 2009).

Multiple regression assumes that the scores of variables are normally distributed, linear and homoscedastic (Foster et al., 2006). It is assumed that the residuals or errors in the regression model are random, normally distributed variables that have a mean of 0 (Field, 2009). Scatter plots of the Regression Standardised Residuals versus the Regression Standardised Predicted Value, can be looked at to evaluate heteroscedasticity (unequal variance of residuals) and linearity. P-Plots of the residuals can be evaluated, if all of the points are on or very close to the line, then linearity can be assumed (Field, 2009).

**Hierarchical Method**

Based on the literature, each measure of trust (general, particular and organisational) was thought to be explained first by demographic variables (age, gender, ethnicity and level of education), so these were given priority and entered into the model at **step 1**. Gender was coded as male (0) versus female (1). Age was coded as ordinal (18–24=1, 25–34=2, 35–44=3, 45–54=4, 55–64=5, 65–74=6 and 75+=8). Ethnicity was dummy coded for Māori, Pacific, Asian and other (1) versus NZ European (0). The level of Education was recoded as University Qualification (1) and High school level or lower (0). Three health service utilisation variables, having a regular GP (yes=1, no=2), visiting a GP in the last 12 months (yes=1, no=2) and the number of visits in the last 12 months (ordinal between 0 and 30), were entered as **step 2** to see if there is a significant increase in $R^2$ when they are added to the model. Lastly, in **step 3**, two
experiential variables, about how good the GP was at involving the patient in their care and explaining health conditions and treatments in a way the patient could understand were included in the third step (very good=1, good=2, neither good or bad=3, poor=4, very poor=5), were added to the regression model to see if these influenced measures of trust after controlling for demographic and health service utilisation variables.

Interpreting Regression Statistics

In hierarchical multiple regression two values can be used to determine how much the IVs predict the DV. First is the proportion of variance in the dependent variable explained by the predictor/independent variables, $R^2$ (Field, 2009; Foster et al., 2006). When another IV is entered $R^2$ is recalculated and the difference between the first and second is the change in $R^2$ (Foster et al., 2006). The output provides a series of $R^2$ values and shows the change at each step (Foster et al., 2006). Secondly, the standardised beta coefficients $\beta$ for each predictor or IV can be examined to determine their significance within the regression model while B tells you the direction and magnitude of the relationship given an increase in the DV by one unit (Field, 2009).

8.5.5 Qualitative Description

The open-ended questions (3.4, 5.3 and 5.4) were analysed using a descriptive qualitative approach. Thematic and qualitative content analysis differ from quantitative analysis where predetermined codes are applied. The codes in qualitative content analysis are “data-derived...generated from the data themselves...by searching for overarching themes” (Sandelowski, 2000, p. 338). The responses were read several times before initial codes were developed using a descriptive coding process (Saldaña, 2011). This involves choosing nouns that summarise the topic of a particular piece of data (Saldaña, 2011). Overarching patterns within the codes were grouped together as themes and described with supporting quotes.

8.6 Ethics Approval

Ethical approval for study 1 was obtained from the University of Auckland Human Participants Ethics Committee on 18th December 2014 for three years (reference number 013396). Two amendments were approved, the first for the follow-up postcard,
and the second for the purposive sampling phase using Facebook to advertise the survey and administered online. Ethics approval addressed some of the key ethical considerations that arise from this research including consent, anonymity, use of incentives (two prize draws), privacy and confidentiality, participants’ ability to withdraw from the research and the storage and protection of data.
Chapter 9

Results

This chapter presents the results from the first study in four sections. The first
section reports the response rate. The second section describes the sample. Section
three presents the descriptive results outlining expectations of general, particular
and organisational trust in the health system. The fourth section presents results
determining which factors influence trust based on principle component analysis
and hierarchical multiple regression. The final section presents the results from
the open-ended questions. These outline respondents expectations of GPs and
health organisations concerning their information and how health professionals and
organisations might rebuild trust when it has been compromised or lost.

9.1 Response

A total sample of 400 was required for this study. The response rate after the first
phase of sampling was low (19%), so an additional 214 responses were required. The
second phase of sampling resulted in 318 eligible responses. Fifty-five entries (11%),
were deleted following the criteria for missing data outlined in Section 8.5.1. This was
deemed a simple and acceptable method of dealing with data, particularly as it resulted
in a loss of less than 15% of cases (Tabachnick and Fidell, 2001). After data cleaning
and addressing missing data, 449 entries remained.

9.2 Sample Characteristics

The demographic characteristics of the survey sample are summarised in Table 9.1
and 9.2. Nearly two-thirds of the respondents were female. The percentage in each of
the age groups are all above those reported by Statistics NZ for resident population
age in 2014. Sixty-nine percent of the sample were NZ European. The majority of
respondents, have some form of tertiary education, and over a third of the respondents
work full-time. Further, the majority of respondents were born in New Zealand. Nearly two thirds live in a city, and a majority live in the Auckland region. Responses to the occupation question varied greatly and included the areas of accounting, advertising, engineering, banking, company ownership, public service, teaching (early childhood, primary, secondary and tertiary), tertiary study, health (doctors, registered nurses, physiotherapists, personal trainers and alternative medicine), customer service, communications, agriculture, forestry and the trades.

Nearly eighty percent of respondents indicated that the provider they saw most regularly was their GP, as shown in Table 9.3. Nearly all respondents had a regular GP clinic, and over eighty percent had seen a GP in the last 12 months. In the last 12 months, respondents had been to see a GP between zero and thirty times, with an average of three visits (Mean = 3.45, Median = 3.0, SD = 3.297).

The survey asked four questions about trust in the respondents’ GP, asking them to recall their most recent visit. As shown in Table 9.3 the majority of respondents reported that their GP was good or very good at explaining their health conditions and treatments in a way they understood. When asked how good the GP was at involving them in decisions about care, such as discussing different treatments, the majority reported their GP was good or very good. Despite around 20% of respondents rating their GP poorly on these questions, these first two questions, when asked if they had confidence and trust in the GP they saw only 5.8% said ‘no, not at all’.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>309</td>
<td>68.8</td>
</tr>
<tr>
<td>Male</td>
<td>131</td>
<td>29.2</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–24</td>
<td>85</td>
<td>18.9</td>
</tr>
<tr>
<td>25–34</td>
<td>81</td>
<td>18.0</td>
</tr>
<tr>
<td>35–44</td>
<td>64</td>
<td>14.3</td>
</tr>
<tr>
<td>45–54</td>
<td>77</td>
<td>17.1</td>
</tr>
<tr>
<td>55–64</td>
<td>49</td>
<td>10.9</td>
</tr>
<tr>
<td>65–74</td>
<td>47</td>
<td>10.5</td>
</tr>
<tr>
<td>75+</td>
<td>41</td>
<td>9.1</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NZ European</td>
<td>310 (340)</td>
<td>69.0 (70.8)</td>
</tr>
<tr>
<td>Māori</td>
<td>41  (41)</td>
<td>9.1 (8.5)</td>
</tr>
<tr>
<td>Pacific Island</td>
<td>21  (22)</td>
<td>4.7 (4.6)</td>
</tr>
<tr>
<td>Asian</td>
<td>29  (29)</td>
<td>6.5 (6.0)</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>42  (42)</td>
<td>9.4 (8.8)</td>
</tr>
<tr>
<td>Refused</td>
<td>6   (6)</td>
<td>1.3 (1.3)</td>
</tr>
</tbody>
</table>

**Highest level of Education**

- No qualifications, pre-primary, primary or lower education | 37 | 8.2 |
- NCEA Level 1 or equivalent | 28 | 6.2 |
- NCEA Level 2 or equivalent | 21 | 4.7 |
- NCEA Level 3 or equivalent | 48 | 10.7 |
- Tertiary certificate, diploma or undergraduate degree | 201 | 44.8 |
- Postgraduate Degree | 104 | 23.2 |

**Work Situation**

- Full Time (30+ hours/week) | 166 | 37.0 |
- Part Time (8–30 hours/week) | 45  | 10.0 |
- Self employed                | 38  | 8.5  |
- Carer                        | 27  | 6.0  |
- Student                      | 75  | 16.7 |
- Retired                      | 67  | 14.9 |
- Other                        | 30  | 6.7  |

*Note. α. Ethnicity coded using prioritised output, total response output shown in brackets.*
Table 9.2: Geographic and Relationship Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of Birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td>322</td>
<td>71.7</td>
</tr>
<tr>
<td>Country other than NZ</td>
<td>123</td>
<td>27.4</td>
</tr>
<tr>
<td>Area Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>City (50,000 people or more)</td>
<td>310</td>
<td>69.0</td>
</tr>
<tr>
<td>Town (10,000 to 49,000)</td>
<td>56</td>
<td>12.5</td>
</tr>
<tr>
<td>Small Urban Town (1000 to 9000)</td>
<td>43</td>
<td>9.6</td>
</tr>
<tr>
<td>Rural Centre/Town (300 to 999)</td>
<td>14</td>
<td>3.1</td>
</tr>
<tr>
<td>Rural or Remote (less than 300 people)</td>
<td>20</td>
<td>4.5</td>
</tr>
<tr>
<td>Region of New Zealand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northland</td>
<td>10</td>
<td>2.2</td>
</tr>
<tr>
<td>Auckland</td>
<td>226</td>
<td>50.3</td>
</tr>
<tr>
<td>Waikato</td>
<td>36</td>
<td>8</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>22</td>
<td>4.9</td>
</tr>
<tr>
<td>Gisborne</td>
<td>4</td>
<td>0.9</td>
</tr>
<tr>
<td>Hawkes Bay</td>
<td>11</td>
<td>2.4</td>
</tr>
<tr>
<td>Taranaki</td>
<td>6</td>
<td>1.3</td>
</tr>
<tr>
<td>Manuwatu–Whanganui</td>
<td>24</td>
<td>5.3</td>
</tr>
<tr>
<td>Wellington</td>
<td>30</td>
<td>6.7</td>
</tr>
<tr>
<td>Tasman</td>
<td>4</td>
<td>0.9</td>
</tr>
<tr>
<td>Nelson</td>
<td>11</td>
<td>2.4</td>
</tr>
<tr>
<td>Marlborough</td>
<td>2</td>
<td>0.4</td>
</tr>
<tr>
<td>West Coast</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Canterbury</td>
<td>32</td>
<td>7.1</td>
</tr>
<tr>
<td>Otago</td>
<td>22</td>
<td>4.9</td>
</tr>
<tr>
<td>Southland</td>
<td>7</td>
<td>4.6</td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>119</td>
<td>26.5</td>
</tr>
<tr>
<td>Legally Married</td>
<td>206</td>
<td>45.9</td>
</tr>
<tr>
<td>De facto Relationship</td>
<td>67</td>
<td>14.9</td>
</tr>
<tr>
<td>Separated or Divorced</td>
<td>26</td>
<td>5.8</td>
</tr>
<tr>
<td>Widow/Widower</td>
<td>23</td>
<td>5.1</td>
</tr>
</tbody>
</table>
Table 9.3: Health Care Utilisation and Most Recent Visit to GP

<table>
<thead>
<tr>
<th>Utilisation dimension</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provider seen most regularly</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>348</td>
<td>78.2</td>
</tr>
<tr>
<td>Nurse</td>
<td>22</td>
<td>4.9</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>8</td>
<td>1.8</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Counsellor</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Midwife</td>
<td>16</td>
<td>3.6</td>
</tr>
<tr>
<td>Other</td>
<td>33</td>
<td>7.4</td>
</tr>
<tr>
<td><strong>Has regular GP clinic</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>432</td>
<td>96.2</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Seen a GP in last 12 months</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>397</td>
<td>88.4</td>
</tr>
<tr>
<td>No</td>
<td>52</td>
<td>11.6</td>
</tr>
<tr>
<td><strong>Visits to GP in last 12 months</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>54</td>
<td>12.0</td>
</tr>
<tr>
<td>1</td>
<td>68</td>
<td>15.1</td>
</tr>
<tr>
<td>2</td>
<td>81</td>
<td>18.0</td>
</tr>
<tr>
<td>3</td>
<td>71</td>
<td>15.8</td>
</tr>
<tr>
<td>4</td>
<td>72</td>
<td>16.0</td>
</tr>
<tr>
<td>5-9</td>
<td>75</td>
<td>16.7</td>
</tr>
<tr>
<td>10+</td>
<td>26</td>
<td>5.8</td>
</tr>
<tr>
<td><strong>At your most recent visit, how good was the GP at explaining your health conditions and treatments in a way you understood?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Good</td>
<td>249</td>
<td>55.5</td>
</tr>
<tr>
<td>Good</td>
<td>67</td>
<td>14.9</td>
</tr>
<tr>
<td>Neither good or bad</td>
<td>12</td>
<td>2.7</td>
</tr>
<tr>
<td>Poor</td>
<td>94</td>
<td>20.9</td>
</tr>
<tr>
<td>Very Poor</td>
<td>16</td>
<td>3.6</td>
</tr>
<tr>
<td>Does not apply</td>
<td>10</td>
<td>2.2</td>
</tr>
<tr>
<td><strong>At your most recent visit, how good was the GP at involving you in decisions about your care, such as discussing different treatment options?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Good</td>
<td>203</td>
<td>45.2</td>
</tr>
<tr>
<td>Good</td>
<td>80</td>
<td>17.8</td>
</tr>
<tr>
<td>Neither good or bad</td>
<td>21</td>
<td>4.7</td>
</tr>
<tr>
<td>Poor</td>
<td>103</td>
<td>22.9</td>
</tr>
<tr>
<td>Very Poor</td>
<td>31</td>
<td>6.9</td>
</tr>
<tr>
<td>Does not apply</td>
<td>10</td>
<td>2.2</td>
</tr>
<tr>
<td><strong>Thinking about your most recent visit, did you have confidence and trust in the GP you saw?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, Definitely</td>
<td>286</td>
<td>63.7</td>
</tr>
<tr>
<td>Yes, To some extent</td>
<td>133</td>
<td>29.6</td>
</tr>
<tr>
<td>No, Not at all</td>
<td>26</td>
<td>5.8</td>
</tr>
</tbody>
</table>

123
9.3 General, Particular and Organisational Trust

This section describes responses about general, particular and organisational trust. The percentage tables may be seen on page 314, 315 and 316.

General Trust

The survey asked respondents to indicate how much they agreed with a statement about the trustworthiness of eight professions (GPs, nurses, hospital-based doctors, pharmacists, physiotherapists, psychologists, counsellors, and midwives) and eight organisations (GP practices or clinics, hospitals, District Health Boards, St Johns Ambulance, ACC, Ministry of Health, government departments, and private health insurance providers). The respondents, on average, agreed that all of these professions and organisations were trustworthy, (68% of participants slightly, moderately or strongly agreeing). The means varied between 4.04 for government departments, and 5.88 for St Johns Ambulance. The means were higher for the professions than for the organisations. Of the professions, GPs had the highest mean score (Mean = 5.84) with 87% of respondents agreeing with the statement “I think GPs are trustworthy” as seen in Figure 9.1. Of the organisations St John’s Ambulance had the highest mean score (Mean = 5.88) with 86% of respondents agreeing with the statement “I think St John’s Ambulance is trustworthy” as shown in Figure 9.2. The majority of respondents selected slightly agree or above for all of these items indicating high levels of trust in these professions and organisations.

\[^{1}\text{This includes slightly, moderately and strongly agree}\]
Figure 9.1: Mean Scores of Trust in Health Care Professionals

Figure 9.2: Mean Scores of Trust in Health Care and Other Organisations
**Particular Trust in Health Care Provider**

In response to questions about the trustworthiness of the health care provider participants see most regularly, 77% agreed with the statement “All things considered, I completely trust my health care provider”. Additionally 91% of participants said that they gave their health care provider all known and relevant information about important issues.

**Organisational Trust**

In response to statements about health care institutions and organisations, 80.6% agreed with the statement “I trust that doctors will only share information about me that is relevant to my care” and 70.4% of respondents agreed with the statement “I trust that doctors keep my personal information confidential no matter what”. When asked about whether there should be more sharing of information between health professionals and health organisations, 51.3% agreed, 30.1% neither agreed nor disagreed, and the remaining 18.6% disagreed.

**9.4 Factors Influencing Trust**

Principle component analysis and hierarchical multiple regression were used to determine which factors influenced or predicted trust in the sample who responded. This section presents the results of these analyses according to the three measures of trust—general, particular and organisational trust. The independent and dependent variables are outlined in Table 9.4. A table for each regression model/solution reports the standardised $\beta$ coefficients, the $R^2$ and change in $R^2$ at each step. The significance of the predictors, $R^2$ and change in $R^2$ are indicated by stars (*).

**9.4.1 Evaluating Assumptions**

**Evaluating Assumptions for PCA**

With 42 variables and 449 cases, sample size was adequate for PCA. The distributions of the 42 items were examined to test the assumption of normality. After looking at skewness and kurtosis values, it was evident that the items were negatively skewed (skewness values between -2.358 and 0.177) and showed a mix of positive and
Table 9.4: Variables in Hierarchical Multiple Regression

**Predictor/Independent Variables (12 IVs)**

*Demographic Variables*
- Gender
- Age
- Ethnicity
  - Māori
  - Pacific
  - Asian
  - Other ethnic group
- Education

*Health Service Utilisation Variables*
- Has a regular GP
- Been to a GP in last 12 months
- Number of visits to GP in last 12 months

*Experiential Variables*
- How good was the GP at explaining your health conditions in a way that you could understand?
- How good was the GP at involving you in decisions about your care such as discussing different treatment options?

**Dependent Variables/Measures of Trust (12 DVs)**

**Major Scale: General Trust in Health Professionals and Organisations**
- General Trust Subscale: Medical Professionals and Organisations
- General Trust Subscale: Organisations
- General Trust Subscale: Allied Health Professionals

**Major Scale: Particular Trust in Primary Health Provider**
- Particular Trust Subscale: Care Aspects of Health Provider Relationship
- Particular Trust Subscale: Information Aspects of the Health Provider Relationship
- Particular Trust Subscale: Distrust in/of Health Provider

**Major Scale: Organisational Trust**
- Organisational Trust Subscale: Organisations Act in Patient’s Best Interest
- Organisational Trust Subscale: Distrust in/of Organisations
- Organisational Trust Subscale: Control of Information Given to Institutions
negative kurtosis (-1.380 and 5.681) meaning that some of the items have heavy-tailed distributions while others have light tails. This suggests that the normality assumption may not be satisfied, however, the solution may still be valid (Tabachnick and Fidell, 2001). As such no transformations were performed. Upon inspecting the correlation matrix of all the variables there was evidence of one or two high correlations (above 0.8), but there were no instances of perfect correlation—based on this, the assumption that all scores have linear correlations between (.30 and .90) was satisfied so all items were retained.

The correlation matrices and scree plots were used to determine the number of components to be extracted as seen on page 325. Since we cannot assume independence of factors, the obliquely rotated solution is more meaningful. The use of an oblique rotation is supported by the component correlation matrices that show correlation coefficients above 0. As promax is designed for use with very large data sets, direct oblim was the rotation used and the pattern matrices interpreted (Field, 2009). The pattern matrices are reported (see Tables 9.5, 9.10 and 9.15) as is standard for oblique rotated solutions. The loadings highlighted in bold indicate which items have been attributed to each component.

**Evaluating Assumptions for Hierarchical Multiple Regression**

As a first step, each of the scales were checked for signs of skewness and kurtosis. This information was put together with histograms (page 317) of each of the scales which showed some evidence of censoring, suggesting that values may have occurred outside the range of the 7-point Likert scale. Upon checking cases and looking at the scatter plots, there were no obvious outliers. Checking for any overly influential cases using case summary, the test statistics for Cooks’ distance were all below 1. Upon inspecting case wise summaries of these statistics, no cases had a Mahalanobis test score above 27.827 (where $x^2$ is critical at $\alpha = .001 = 27.827$ for 9df). However, this is not surprising as the range of the Likert scales in the initial questionnaire ranged from 1 to 7. Residuals were used to evaluate a number of assumptions including independence, and multicollinearity. For each of the models, the Durbin-Watson test statistic was close to 2 indicating no correlation. As a crude check for multicollinearity, the correlation matrix of all predictor variables was scanned to ensure none were highly correlated—they were
not. All of the VIF statistics were below 10, and the average close to 1 with tolerance values above 0.2. Scatter plots of the Regression Standardised Residuals versus the Regression Standardised Predicted Value, did not show any immediate concerns with heteroscedasticity or violation of the linearity assumption (see page 323). P-Plots of the residuals, on page 321, were evaluated and did not indicate any serious violation of this assumption, as the points were all on or very close to the line.

9.4.2 General Trust in Health Professionals and Organisations

The items from section 1 (shown in Table 9.5) of the survey sought to measure General Trust in Health Professionals and Organisations.

Data Quality

Eleven percent (n = 50) of the data was excluded as it was missing. The means for these items are all quite high (tending towards moderately agree and strongly agree). Given that the scale was 1–7, and that there are several means close to 6 (moderately agree), there is little room for variability.

Internal Consistency

The Cronbach’s alpha (α) for these items (1–16) was .932 indicating high internal consistency. The item-total statistics show that the corrected item-total correlations for these items ranged between .545 and .769, indicating that all items were likely to be measuring the same construct and so all items were retained.

Analysis of Scale Structure

The data was shown to be adequate for conducting the principal component analysis to look for sub-scales within this main scale. These items were shown to have a KMO score of .919 which verifies the sampling adequacy. The Bartlett’s test of sphericity was significant (p = .00) at $\chi^2(120) = 4696.609$, indicating that correlations between items are sufficient for PCA. The communalities table showed that the extraction values for all the items were high (range .466 to .809). Three components had eigenvalues above 1 and in combination explained 70.83% of the variance. The scree plot (Figure B.9) was somewhat ambiguous as to whether three or four components should be retained. Upon extracting four components, the fourth component did not fit as well as three did.
because the extra component only included one item which fitted better (theoretically and statistically) within the first component. Given this, along with the convergence of the scree plot and Kaisers criterion three components were retained in the final analysis.

The pattern matrix in Table 9.5 was used to identify which items belonged to each component. Component 1 corresponds to general trust in medical professions and organisations. As GPs, hospital-based doctors, nurses, pharmacists, GP practices, hospitals, and St Johns Ambulance are all traditionally “medical professionals”. This subscale was named General Trust in Medical Professionals. Component 2 represents trust in higher level organisations (trust in DHBs, ACC, Ministry of Health, government departments, private health insurance companies). This subscale was named General Trust in Organisations. Component 3 represents trust in allied health professionals (trust in physiotherapists, psychologists, counsellors and midwives). This subscale was named General Trust in Allied Health Professionals. Overall three more subscales were created by generating a new variable from the average (mean) of the items in the subscales indicated by the PCA. The results of the hierarchical multiple regression analysis follow with the overall scale first, followed by the three subscales.
Table 9.5: Pattern Matrix for Items Measuring General Trust in Health Professionals and Organisations

<table>
<thead>
<tr>
<th>Item</th>
<th>Component 1</th>
<th>Component 2</th>
<th>Component 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think GPs (General Practitioners) are trustworthy</td>
<td>.898</td>
<td>-.059</td>
<td>.025</td>
</tr>
<tr>
<td>I think hospital based doctors are trustworthy</td>
<td>.903</td>
<td>-.003</td>
<td>-.060</td>
</tr>
<tr>
<td>I think Nurses are trustworthy</td>
<td>.795</td>
<td>-.119</td>
<td>.169</td>
</tr>
<tr>
<td>I think Pharmacists are trustworthy</td>
<td>.623</td>
<td>.006</td>
<td>.272</td>
</tr>
<tr>
<td>I think Physiotherapists are trustworthy</td>
<td>.273</td>
<td>-.063</td>
<td>.676</td>
</tr>
<tr>
<td>I think Psychologists are trustworthy</td>
<td>-.007</td>
<td>.076</td>
<td>.830</td>
</tr>
<tr>
<td>I think Counsellors are trustworthy</td>
<td>-.079</td>
<td>.112</td>
<td>.866</td>
</tr>
<tr>
<td>I think Midwives are trustworthy</td>
<td>.251</td>
<td>.088</td>
<td>.523</td>
</tr>
<tr>
<td>I think GP practices or clinics are trustworthy</td>
<td>.842</td>
<td>.086</td>
<td>.031</td>
</tr>
<tr>
<td>I think hospitals are trustworthy</td>
<td>.823</td>
<td>.262</td>
<td>-.172</td>
</tr>
<tr>
<td>I think District Health Boards (DHBs) are trustworthy</td>
<td>.213</td>
<td>.680</td>
<td>.063</td>
</tr>
<tr>
<td>I think St Johns Ambulance is trustworthy</td>
<td>.546</td>
<td>.114</td>
<td>.127</td>
</tr>
<tr>
<td>I think ACC is trustworthy</td>
<td>.006</td>
<td>.858</td>
<td>-.017</td>
</tr>
<tr>
<td>I think the Ministry of Health is trustworthy</td>
<td>.064</td>
<td>.878</td>
<td>.010</td>
</tr>
<tr>
<td>I think government departments, in general, are trustworthy</td>
<td>.039</td>
<td>.906</td>
<td>-.058</td>
</tr>
<tr>
<td>I think private health insurance providers are trustworthy</td>
<td>-.132</td>
<td>.739</td>
<td>.182</td>
</tr>
</tbody>
</table>

Note: Extraction method: Principal Component Analysis, Rotation method: Oblimin with Kaiser Normalization, Rotation converged in 6 iterations

9.4.2.1 Major Scale: General Trust

The demographic predictors contributed significantly to the regression model, ($R^2=.037, F(7,418)=2.274, p < .05$) and accounted for 3.7% of the variation. Those belonging to a Pacific ethnic group are predicted to have slightly lower levels of general trust than NZ Europeans ($B=-.678, \beta=-.144$). Controlling for demographic factors the health service utilisation variables explained an additional 2.8% of the variation ($R^2=.065, F(3,415)=4.170, p < .01$). Here, those belonging to the Pacific ethnic group are predicted to have slightly lower levels of general trust than NZ Europeans ($B=-.678, \beta=-.144$), and those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of general trust than those who had ($B=-.350, \beta=-.112$). Controlling for demographic and health service utilisation factors the experiential variables explained an additional 5.2% of the variation and this change in $R^2$ was significant ($R^2=.116, F(2,413)=12.058, p < .001$). As in the previous steps, those belonging to the Pacific ethnic group are predicted to have slightly lower levels of general trust than NZ Europeans ($B=-.533, \beta=-.113$). If respondents score on how
good the GP was at explaining health conditions went up by 1 (e.g. from ‘Very Good’ to ‘Good’ or from ‘Poor’ to ‘Very Poor’), general trust is predicted to go down (B=-.107, β=-.156), and if the score for how good the GP was at involving the patient in decisions about care went up by 1, general trust is predicted to go down (B=-.078, β=-.119).

Together the twelve independent variables accounted for 11.6% of the variance in General Trust in Health Professionals and Organisations ($R^2=.116$, $F(12, 413)=4.095$, $p < .001$).

### Table 9.6: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of General Trust in Health Professionals and Organisations

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 β</th>
<th>Step 2 β</th>
<th>Step 3 β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.009</td>
<td>-.005</td>
<td>.001</td>
</tr>
<tr>
<td>Age</td>
<td>.053</td>
<td>.037</td>
<td>-.035</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.040</td>
<td>-.027</td>
<td>-.023</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.144**</td>
<td>-.129**</td>
<td>-.113*</td>
</tr>
<tr>
<td>Asian</td>
<td>.047</td>
<td>.067</td>
<td>.061</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.084</td>
<td>-.086</td>
<td>.062</td>
</tr>
<tr>
<td>Education</td>
<td>-.045</td>
<td>-.044</td>
<td>-.047</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td></td>
<td>-.156**</td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td></td>
<td>-.119*</td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained) and $\Delta R^2$

<table>
<thead>
<tr>
<th>$R^2$ (Variance Explained)</th>
<th>.037*</th>
<th>.065**</th>
<th>.116***</th>
</tr>
</thead>
<tbody>
<tr>
<td>$\Delta R^2$</td>
<td>.028**</td>
<td>.052***</td>
<td></td>
</tr>
</tbody>
</table>

Note. N = 425. *$p < .05$ **$p < .01$ ***$p < .001$

#### 9.4.2.2 General Trust Subscale: Medical Professionals and Organisations

The demographic predictors contributed significantly to the regression model ($R^2=.061$, $F(7,418)=3.892$, $p < .001$) and accounted for 6.1% of the variation. As in the major scale, those belonging to a Pacific ethnic group are predicted to have lower levels of general trust in medical professionals and organisations than NZ Europeans (B=-.828, β=-.163). Controlling for demographic factors the health service utilisation variables explained an additional 2.8% of the variation ($R^2=.089$, $F(3,415)=4.196$, $p < .001$).
At this step ethnicity (Pacific) and having been to a GP in last 12 months were significant. Those belonging to a Pacific ethnic group are predicted to have lower levels of general trust than NZ Europeans ($B=-.745, \beta=-.147$) and those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of general trust than those who had ($B=-.420, \beta=-.125$). Controlling for demographic and health service utilisation factors the experiential variables explained an additional 5.6% of the variation ($R^2=.145$, $F(2, 413)=13.472$, $p < .001$). Pacific ethnicity, and both experiential variables were significant in this step. Those belonging to a Pacific ethnic group are predicted to have lower levels of general trust in medical professionals and organisations than NZ Europeans ($B=-.665, \beta=-.131$). If respondents score on how good the GP was at explaining health conditions went up by 1, general trust is predicted to go down ($B=-.107, \beta=-.145$), and if the score for how good the GP was at involving the patient in decisions about care went up by 1, general trust is predicted to go down ($B=-.101, \beta=-.141$). Together the twelve independent variables accounted for 14.5% of the variance in General Trust in Medical Professionals and Organisations ($R^2=.145$, $F(12, 425)=5.819$, $p < .001$).
### 9.4.2.3 General Trust Subscale: Organisations

Both the demographic predictors in step 1 and health service utilisation variables in step 2, did not contribute significantly to the regression model. However, ethnicity (Asian) was a significant predictor in step 2, with those belonging to an Asian ethnic group predicted to have slightly higher levels of general trust in health organisations and institutions than NZ Europeans ($B=-.561, \beta=-.100$). This was the only significant predictor in the regression model. Together the twelve independent variables accounted for 5.9% of the variance in General Trust in Health Organisations and Institutions, however none of the predictors were significant ($R^2=.059$, $F(9, 416)=2.216$, $p < .05$).
### Table 9.8: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of General Trust Subscale: Organisations

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.052</td>
<td>.044</td>
<td>.047</td>
</tr>
<tr>
<td>Age</td>
<td>.036</td>
<td>.025</td>
<td>-.019</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.057</td>
<td>-.047</td>
<td>-.044</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.064</td>
<td>-.051</td>
<td>-.041</td>
</tr>
<tr>
<td>Asian</td>
<td>.082</td>
<td>.100*</td>
<td>.094</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.051</td>
<td>-.053</td>
<td>-.037</td>
</tr>
<tr>
<td>Education</td>
<td>-.045</td>
<td>-.037</td>
<td>-.036</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.079</td>
<td>-.069</td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td></td>
<td>-.092</td>
<td>-.071</td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td></td>
<td>-.083</td>
<td>-.077</td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td>-.119</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td>-.049</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained)                               | .020           | .039           | .059*          |
$\Delta R^2$                                             |                | .020           | .020*          |

Note. N = 426.  
*p < .05  **p < .01  ***p < .001

### 9.4.2.4 General Trust Subscale: Allied Health Professionals

Analysis revealed that the demographic predictors in step 1, and health service utilisation variables in step 2, did not contribute significantly to the regression model. Controlling for demographic and health service utilisation factors the experiential variables explained an additional 3.2% of the variation in the measure of trust and this change in $R^2$ was significant ($R^2 = .072, F(2, 396) = 6.913, p < .01$). Ethnicity was significant in all three steps with those belonging to a Pacific ethnic group predicted to have lower levels of general trust in allied health professionals than NZ Europeans ($B = -.649, \beta = -.119$). Together the twelve independent variables accounted for 7.2% of the variance in General Trust in Allied Health Professionals ($R^2 = .072, F(12, 408) = 2.563, p < .01$).
Table 9.9: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of General Trust Subscale: Allied Health Professionals

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.072</td>
<td>.072</td>
<td>.078</td>
</tr>
<tr>
<td>Age</td>
<td>-.011</td>
<td>-.014</td>
<td>-.074</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>.010</td>
<td>.017</td>
<td>.017</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.141*</td>
<td>-.133*</td>
<td>-.119*</td>
</tr>
<tr>
<td>Asian</td>
<td>.040</td>
<td>.052</td>
<td>.046</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.065</td>
<td>-.066</td>
<td>-.046</td>
</tr>
<tr>
<td>Education</td>
<td>-.002</td>
<td>-.008</td>
<td>-.010</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.062</td>
<td>-.049</td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td></td>
<td>-.052</td>
<td>-.020</td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td></td>
<td>-.090</td>
<td>-.080</td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td>-.119</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td>-.102</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained) .027 .040 .072**
$\Delta R^2$ .012 .032**

Note. N = 409. *$p < .05$ **$p < .01$ ***$p < .001$

9.4.3 Particular Trust in Primary Health Provider

The items from section 4 (seen in Table 9.10) sought to measure Particularised Trust in Primary Health Provider—this is the major scale.

Data Quality

Five percent (n = 25) of the data was excluded as it was missing. The means ranged between 4.3 and 6.

Internal Consistency

The Cronbach’s alpha ($\alpha$) for these items was .918 indicating high internal consistency. The item-total statistics show that the corrected item-total correlations for these items ranged between .308 and .854, indicating that all items were likely to be measuring the same construct and so all items were retained.
Analysis of Scale Structure

The data was shown to be adequate for conducting the principal component analysis to look for sub-scales within this main scale. These items were shown to have a KMO score of .935 which verifies the sampling adequacy. The Bartlett’s test of sphericity was significant ($p = .00$) at $\chi^2 (105) = 5231.350$, indicating that correlations between items are sufficient for PCA. The communalities table showed that the extraction values for all the items were high (range .455 to .849). Three components had eigenvalues above 1 and in combination explained 73.11% of the variance. The scree plot (Figure B.10) also justified retaining three components in the final analysis.

The pattern matrix in Table 9.10 was used to identify which items belonged to each component. Component 1 corresponds to the caring abilities of the provider, including the perception that the health provider provides good care, makes good decisions, will do whatever it takes, and is a considerate provider that the patient can trust and does trust completely. This subscale was called: Care Aspects. Component 2 relates to informational or communication aspects of the doctor–patient relationship where the patient may withhold, minimise or think carefully about the information they share with their provider. This subscale was named: Information Aspects. Component 3 represents distrust in the provider, where the patient may be concerned that the provider shares their information without telling them, and may not always trust their GP and wants a second opinion. This subscale was called: Distrust of/in Provider Scale. Overall three more subscales were created by generating a new variable from the average (mean) of the items in the subscales indicated by the PCA. The results of the hierarchical multiple regression analysis follow with the overall scale first, followed by the three subscales.

9.4.3.1 Major Scale: Particular Trust in Primary Health Provider

Analysis of the major scale measuring Particular Trust in Primary Health Provider showed that in step 1, demographic predictors contributed significantly to the regression model ($R^2=0.075$, $F(7,417)=4.831$, $p < .001$), and accounted for 7.5% of the variation, with gender and ethnicity (Pacific and other ethnic group) being significant. Females are predicted to have lower levels of particularised trust in primary provider than males ($B=-.255, \beta=-.098$). Those belonging to a Pacific ($B=-.974, \beta=-.174$) and other
Table 9.10: Pattern Matrix* for Items Measuring Particular Trust in Primary Health Provider

<table>
<thead>
<tr>
<th>Item</th>
<th>Component 1</th>
<th>Component 2</th>
<th>Component 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>My health care provider is usually considerate of my needs and puts them first</td>
<td><strong>.848</strong></td>
<td><strong>.074</strong></td>
<td><strong>-.096</strong></td>
</tr>
<tr>
<td>I give my health provider all known and relevant information about important issues</td>
<td><strong>.590</strong></td>
<td><strong>.363</strong></td>
<td><strong>-.485</strong></td>
</tr>
<tr>
<td>I have so much trust in my health care provider that I always try to follow his/her advice</td>
<td><strong>.894</strong></td>
<td><strong>.048</strong></td>
<td><strong>-.134</strong></td>
</tr>
<tr>
<td>I trust my health care provider so much that I believe everything they tell me</td>
<td><strong>.820</strong></td>
<td><strong>-.038</strong></td>
<td><strong>.064</strong></td>
</tr>
<tr>
<td>I can trust my health provider’s judgments concerning my medical care</td>
<td><strong>.903</strong></td>
<td><strong>.032</strong></td>
<td><strong>.010</strong></td>
</tr>
<tr>
<td>My health care provider will do whatever it takes to give me the medical care that I need.</td>
<td><strong>.889</strong></td>
<td><strong>-.026</strong></td>
<td><strong>.036</strong></td>
</tr>
<tr>
<td>Because my health care provider is an expert, he/she is able to treat medical problems like mine</td>
<td><strong>.832</strong></td>
<td><strong>-.121</strong></td>
<td><strong>.139</strong></td>
</tr>
<tr>
<td>I can trust my health provider’s decisions on which medical treatments are best for me</td>
<td><strong>.912</strong></td>
<td><strong>-.013</strong></td>
<td><strong>.038</strong></td>
</tr>
<tr>
<td>My health care provider offers me the highest quality medical care</td>
<td><strong>.915</strong></td>
<td><strong>-.053</strong></td>
<td><strong>.028</strong></td>
</tr>
<tr>
<td>All things considered, I completely trust my health care provider</td>
<td><strong>.891</strong></td>
<td><strong>.032</strong></td>
<td><strong>.105</strong></td>
</tr>
<tr>
<td>I do not withhold information when communicating with my provider</td>
<td><strong>-.005</strong></td>
<td><strong>.879</strong></td>
<td><strong>.036</strong></td>
</tr>
<tr>
<td>I do not minimise the information I give to my provider</td>
<td><strong>.015</strong></td>
<td><strong>.881</strong></td>
<td><strong>-.054</strong></td>
</tr>
<tr>
<td>I do not think carefully before telling my provider my opinions</td>
<td><strong>-.057</strong></td>
<td><strong>.652</strong></td>
<td><strong>.152</strong></td>
</tr>
<tr>
<td>I am not concerned about my GP sharing health information with others without telling me</td>
<td><strong>.053</strong></td>
<td><strong>.277</strong></td>
<td><strong>.615</strong></td>
</tr>
<tr>
<td>I trust my GP and do not see the need to get a second opinion</td>
<td><strong>.369</strong></td>
<td><strong>.106</strong></td>
<td><strong>.627</strong></td>
</tr>
</tbody>
</table>

ethnic group (B=-.417, β=-.104) are predicted to have lower levels of particularised trust in their provider than NZ Europeans. Controlling for demographic factors, the health service utilisation variables explained an additional 3% of variation and this change in $R^2$ was significant ($R^2=.105, F(3,414)=4.607, p<.01$). At this step gender, ethnicity (Pacific and other ethnic group) and having a regular GP were significant predictors. Females are predicted to have lower levels of particularised trust in primary provider than males (B=-.312, β=-.121). Those belonging to a Pacific (B=-.901, β=-.161) and other ethnic group (B=-.433, β=-.109) are predicted to have lower levels of particularised trust in their provider than NZ Europeans. Those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of particularised trust than those who had (B=-.714, β=-.108). Controlling for demographic and health service utilisation factors the experiential variables explained an additional 9.1% of the variation in the measure of trust and this change in $R^2$ was significant ($R^2=.195, F(2, 412)=23.201, p < .001$). The significant predictors after step 3 were gender, ethnicity (Pacific), how good the GP was at explaining their health condition in a way they could understand, and how good the GP was at involving them in decisions about their care, such as discussing different options. Females are predicted to have lower levels of particularised trust in primary provider than males (B=-.288, β=-.111). Those belonging to a Pacific ethnic group are predicted to have lower levels of general trust in medical professionals and organisations than NZ Europeans (B=-.789, β=-.141). If respondents score on how good the GP was at explaining health conditions went up by 1, particularised trust is predicted to go down (B=-.146, β=-.178), and if the score for how good the GP was at involving the patient in decisions about care went up by 1, general trust is predicted to go down (B=-.146, β=-.186). Together the twelve independent variables accounted for 19.5% of the variance in the measure of Trust in Health Provider ($R^2=.195, F(12, 412)=8.343, p < .001$).
Table 9.11: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Particularised Trust in Primary Provider

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-.098*</td>
<td>-.121*</td>
<td>-.111*</td>
</tr>
<tr>
<td>Age</td>
<td>.090</td>
<td>.066</td>
<td>-.029</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.083</td>
<td>-.069</td>
<td>-.063</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.174***</td>
<td>-.161***</td>
<td>-.141***</td>
</tr>
<tr>
<td>Asian</td>
<td>-.023</td>
<td>-.015</td>
<td>-.019</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.104*</td>
<td>-.108*</td>
<td>-.078</td>
</tr>
<tr>
<td>Education</td>
<td>-.024</td>
<td>-.019</td>
<td>-.020</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.104*</td>
<td>-.086</td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td>-.090</td>
<td>-.044</td>
<td></td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td></td>
<td>.041</td>
<td>.054</td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td></td>
<td>-1.78**</td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td></td>
<td>-1.86***</td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained)      | .075***        | .105***        | .195***        |
$\Delta R^2$                    | .030**         | .091***        |

Note. N = 425. *$p < .05$   **$p < .01$   ***$p < .001$

9.4.3.2 Particular Trust Subscale: Care Aspects

Analysis revealed in the first step that demographic predictors contributed significantly to the regression model, ($R^2 = .093, F(7, 417)=6.142, p < .001$) and accounted for 9.3% of the variation, with both age and ethnicity (Pacific and other ethnic group) being significant. Going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go up slightly (B=.100, $\beta$=-.143). Those belonging to a Pacific (B=-1.031, $\beta$=-.164) and those belonging to other ethnic group (B=-.594, $\beta$=-.132) are predicted to have lower levels of particularised trust than NZ Europeans. The B indicates that a Pacific participant is predicted to have a trust score 1.031 lower than that of a NZ European participant on a scale of 1–7. Controlling for demographic factors the health service utilisation variables explained an additional 3.2% of variation in Trust in Health Provider and this change in $R^2$ was significant, ($R^2=.122, F(3,414)=4.442, p < .01$). At this step gender, age, ethnicity (Pacific and other ethnic group) and having a regular GP were significant predictors. Females are predicted to have lower levels of particularised trust in primary provider than males.
(B=-.326, \( \beta = -.112 \)), and going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go up slightly (B=.084, \( \beta = -.119 \)). Those belonging to a Pacific (B=-.961, \( \beta = -.153 \)) and other ethnic group (B=-.614, \( \beta = -.136 \)) are predicted to have lower levels of particularised trust in their provider than NZ Europeans. Those who did not have a regular GP are predicted to have slightly lower levels of particularised trust than those who had (B=-.813, \( \beta = -.105 \)). Controlling for both demographic and health service utilisation factors the experiential variables explained an additional 8.4% of the variation in the measure of trust and this change in \( R^2 \) was significant (\( R^2=.202, F(2, 412)=20.635, p < .001 \)). Gender, ethnicity (Pacific) and both experiential variables were significant. Females are predicted to have lower levels of particularised trust in primary provider than males (B=-.300, \( \beta = -.103 \)). Those belonging to a Pacific (B=-.842, \( \beta = -.134 \)) and other ethnic group (B=-.485, \( \beta = -.107 \)) are predicted to have lower levels of trust than NZ Europeans. If respondents score on how good the GP was at explaining health conditions went up by 1, general trust is predicted to go down (B=-.159, \( \beta = -.172 \)), and if the score for how good the GP was at involving the patient in decisions about care went up by 1, general trust is predicted to go down (B=-.151, \( \beta = -.170 \)). Together the twelve independent variables accounted for 20.2% of the variance in the measure of Care aspects of Trust in Health Care Provider (\( R^2=.202, F(12, 412)=8.675, p < .001 \)).
Table 9.12: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Particular Trust Subscale: Care Aspects

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-.090</td>
<td>-.112*</td>
<td>-.103*</td>
</tr>
<tr>
<td>Age</td>
<td>.143**</td>
<td>.119*</td>
<td>.030</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.079</td>
<td>-.066</td>
<td>-.061</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.164***</td>
<td>-.153***</td>
<td>-.134**</td>
</tr>
<tr>
<td>Asian</td>
<td>-.002</td>
<td>.002</td>
<td>.003</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.132**</td>
<td>-.136**</td>
<td>-.107*</td>
</tr>
<tr>
<td>Education</td>
<td>-.036</td>
<td>-.031</td>
<td>-.031</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.105*</td>
<td>.088</td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td>-.074</td>
<td>-.030</td>
<td></td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td>.057</td>
<td>.069</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td>-.172**</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td>-.170**</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained) | .093*** | .122*** | .202***
$\Delta R^2$                  | .028**  | .080*** |

Note. N = 425. *$p < .05$  **$p < .01$  ***$p < .001$

9.4.3.3 Particular Trust Subscale: Information Aspects

Analysis revealed in the first step that demographic predictors contributed significantly to the regression model ($R^2=.034$, $F(7,414)=2.050$, $p < .05$) and accounted for 3.4% of the variation, with both gender and ethnicity (Māori) being significant. Females are predicted to have lower levels of particularised trust in primary provider than males ($B=-.431, \beta=-.124$). Also, Māori respondents are predicted to have lower levels of particularised trust than NZ Europeans ($B=-.534, \beta=-.097$) Controlling for the demographic factors the health service utilisation variables explained an additional 1.1% of the variation. While gender was a significant predictor, this step did not contribute significantly to the model. Controlling for both demographic and health service utilisation factors the experiential variables explained an additional 2.6% of the variation in the measure of trust and this change in $R^2$ was significant, ($R^2=.070$, $F(2, 409)=5.712$, $p < .01$). Females are predicted to have lower levels of particularised trust in primary provider than males ($B=-.462, \beta=-.133$). Together the twelve independent variables accounted for 7% of the variance in the measure of Information Aspects of
the Health Provider Relationship. \( R^2 = .070, F(12, 409) = 2.565, p < .01 \).

### Table 9.13: Standardised Betas, \( R^2 \) and Change in \( R^2 \) for the Prediction of Particular Trust Subscale: Information Aspects

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 ( \beta )</th>
<th>Step 2 ( \beta )</th>
<th>Step 3 ( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-.124*</td>
<td>-.137**</td>
<td>-.133**</td>
</tr>
<tr>
<td>Age</td>
<td>-.018</td>
<td>-.033</td>
<td>.083</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.097*</td>
<td>-.090</td>
<td>-.087</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.085</td>
<td>-.075</td>
<td>-.067</td>
</tr>
<tr>
<td>Asian</td>
<td>-.069</td>
<td>-.062</td>
<td>-.063</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.012</td>
<td>-.012</td>
<td>.001</td>
</tr>
<tr>
<td>Education</td>
<td>.040</td>
<td>.042</td>
<td>.042</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.036</td>
<td>-.024</td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td></td>
<td>-.074</td>
<td>-.047</td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td></td>
<td>.028</td>
<td>.035</td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td>-.076</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td></td>
<td>-.118</td>
</tr>
</tbody>
</table>

\( R^2 \) (Variance Explained) \( .034^* \) \( .044^* \) \( .070^{**} \)

\( \Delta R^2 \) \( .011 \) \( .026^{**} \)

**Note.** N = 425. *p < .05  **p < .01  ***p < .001

#### 9.4.3.4 Particular Trust Subscale: Distrust in/of Health Provider

Analysis revealed in the first step that demographic predictors contributed significantly to the regression model \( R^2 = .046, F(7, 414) = 2.870, p < .01 \) and accounted for 4.6% of the variation. Age was a significant predictor meaning that going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go down slightly (\( B = -.146, \beta = -.168 \)). Controlling for demographic factors the health service utilisation variables explained an additional 2.8% of variation in Trust in Health Provider and this change in \( R^2 \) was significant, \( R^2 = .074, F(3,411) = 4.138, p < .01 \). In this step a number of variables were significant including age, having been to the GP in the last 12 months, and the number of visits to the GP in the last 12 months were significant. Going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go down slightly (\( B = -.152, \beta = -.175 \)). Those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of particularised trust than those
who had (B=-.849, β=-.166). If the reported number of visits to the GP in the last 12 months increased by 1 particularised trust is predicted to go down slightly (B=-.068, β=-.137). Controlling for both demographic and health service utilisation factors the experiential variables explained an additional 2.0% of the variation in the measure of trust and this change in $R^2$ was significant ($R^2=.094, F(2, 409)=4.427, p < .05$). The significant predictors after step 3 were age, having been to the GP in the last 12 months, and the number of visits to the GP in the last 12 months. Going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go down slightly (B=-.190, β=-.218). Those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of particularised trust than those who had (B=-.735, β=-.144). If the reported number of visits to the GP in the last 12 months increased by 1 particularised trust is predicted to go down slightly (B=-.065, β=-.132).

Together the twelve independent variables accounted for 9.4% of the variance in the measure of distrust in/of provider ($R^2=.094, F(12, 409)=3.530, p < .001$).

### Table 9.14: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Particular Trust Subscale: Distrust in/of Health Provider

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 β</th>
<th>Step 2 β</th>
<th>Step 3 β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.075</td>
<td>.069</td>
<td>.074</td>
</tr>
<tr>
<td>Age</td>
<td>-.168***</td>
<td>-.175***</td>
<td>-.218***</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.045</td>
<td>-.038</td>
<td>-.036</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.074</td>
<td>-.054</td>
<td>-.045</td>
</tr>
<tr>
<td>Asian</td>
<td>-.088</td>
<td>-.056</td>
<td>-.056</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.036</td>
<td>-.031</td>
<td>-.018</td>
</tr>
<tr>
<td>Education</td>
<td>-.064</td>
<td>-.073</td>
<td>-.074</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td></td>
<td>.007</td>
<td>.016</td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td></td>
<td>-.166**</td>
<td>-.144*</td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td>-.137**</td>
<td>-.132*</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td></td>
<td>-.067</td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td></td>
<td>-.102</td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained)  
$ΔR^2$  

<table>
<thead>
<tr>
<th></th>
<th>.046**</th>
<th>.074***</th>
<th>.094***</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>.028**</td>
<td>.020**</td>
<td></td>
</tr>
</tbody>
</table>

Note. N = 425.  
*p < .05  
**p < .01  
***p < .001
9.4.4 Organisational Trust

Items 40–50 from section 5 (seen in Table 9.15) sought to measure Organisational Trust in Health Institutions and the Health Profession—this is the major scale.

Data Quality

Nine percent (n = 40) of the data was excluded as it was missing. The means ranged between 3.7 and 5.4.

Internal Consistency

The Cronbach’s alpha (α) for these items was .818 indicating high internal consistency. The item-total statistics show that the corrected item-total correlations for these items ranged between .373 and .655, indicating that all items were likely to be measuring the same construct and so all items were retained.

Analysis of Scale Structure

The data was shown to be adequate for conducting the principal component analysis to look for sub-scales within this main scale. These items were shown to have a KMO score of .986 which verifies the sampling adequacy. The Bartlett’s test of sphericity was significant (p = .00) at \( \chi^2 (55) = 1588.97 \), indicating that correlations between items are sufficient for PCA. The communalities table showed that the extraction values for all the items were high (range .307 to .896). Three components had eigenvalues above 1 and in combination explained 60.70% of the variance. The scree plot (Figure B.11) also justified retaining three components, or possibly even two components in the final analysis.

The pattern matrix in Table 9.15 was used to identify which items belonged to each component. Component 1 corresponds to trust in the actions of institutions to act in the best interests of patients. This includes that health organisations and the medical profession as an institution will act to provide the best care for the patient and look after/use patient information appropriately. This subscale was named: Organisations Act in Patients Best Interests. Component 2 represents distrust in the actions of institutions and the concern that patients have about health care institutions sharing information, data breaches, and needing to share information to get the things you
need, and that they may be motivated by cost and not just a patient’s health needs. This subscale was named: *Control of information* Component 3 relates to control over information. These two items express the extent to which respondents feel in control about how government agencies and health care organisations use and protect personal information. This subscale was called: *Distrust of/in organisations*. The results of the hierarchical multiple regression analysis follow with the overall scale first, followed by the three subscales.

**Table 9.15: Pattern Matrix\(^a\) for Items Measuring Organisational Trust**

<table>
<thead>
<tr>
<th>Item</th>
<th>Component 1</th>
<th>Component 2</th>
<th>Component 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care institutions provide the highest quality in medical care</td>
<td>.782</td>
<td>.059</td>
<td>.037</td>
</tr>
<tr>
<td>When treating my medical problems, health care institutions put my medical needs above all other considerations, including costs</td>
<td>.661</td>
<td>-.092</td>
<td>-.186</td>
</tr>
<tr>
<td>I feel in control of the way government agencies used and protect my personal information</td>
<td>.105</td>
<td>.058</td>
<td>-.890</td>
</tr>
<tr>
<td>I feel in control of the way health care organisations used and protect my personal information</td>
<td>.204</td>
<td>.094</td>
<td>-.808</td>
</tr>
<tr>
<td>I feel that there should be more sharing of information between health professionals and health organisations</td>
<td>.389</td>
<td>.145</td>
<td>-.200</td>
</tr>
<tr>
<td>I trust that doctors will only share information about me that is relevant to my care</td>
<td>.813</td>
<td>.098</td>
<td>.066</td>
</tr>
<tr>
<td>I trust that doctors keep my personal information confidential no matter what</td>
<td>.742</td>
<td>-.109</td>
<td>-.074</td>
</tr>
<tr>
<td>Health care institutions care about my health and not just keeping medical costs down</td>
<td>.223</td>
<td>.650</td>
<td>.236</td>
</tr>
<tr>
<td>I am not concerned by organisations in the health sector sharing information about my health with other organisations in the health sector without telling me</td>
<td>.039</td>
<td>.796</td>
<td>-.016</td>
</tr>
<tr>
<td>I am not concerned about data breaches which may involve the compromise or loss of my personal health information</td>
<td>-.128</td>
<td>.754</td>
<td>-.108</td>
</tr>
<tr>
<td>If I don’t like the way that government agencies use and protect my information I am able to get the things I need without dealing with them</td>
<td>-.079</td>
<td>.619</td>
<td>-.290</td>
</tr>
</tbody>
</table>


**9.4.4.1 Major Scale: Organisational Trust**

Analysis of the major scale revealed in the first step that demographic predictors did not contribute significantly to the regression model. Controlling for demographic factors the health service utilisation variables explained an additional 2.6% of variation in
General Trust in Health Professionals and Organisations and this change in $R^2$ was significant ($R^2=.056, F(3, 414)=3.777, p < .05$). Ethnicity (other ethnic group), having been to a GP in the last 12 months and the number of visits in last 12 months were significant at this step of the model. Those belonging to the other ethnic group are predicted to have lower levels of organisational trust in health care institutions than NZ Europeans ($B=-.414, \beta=-.120$). Those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of particularised trust than those who had ($B=-.437, \beta=-.137$). If the reported number of visits to the GP in the last 12 months increased by 1 particularised trust is predicted to go down slightly ($B=-.033, \beta=-.106$).

Controlling for demographic and health service utilisation factors the experiential variables explained an additional 5.3% of the variation in the measure of trust and this change in $R^2$ was significant ($R^2=.108, F(2, 412)=12.133, p < .001$). Those belonging to the other ethnic group are predicted to have lower levels of organisational trust in health care institutions than NZ Europeans ($B=-.332, \beta=-.096$). If respondents score on how good the GP was at explaining health conditions went up by 1, general trust is predicted to go down ($B=-.107, \beta=-.152$), and if the score for how good the GP was at involving the patient in decisions about care went up by 1, general trust is predicted to go down ($B=-.085, \beta=-.125$). Together the twelve independent variables accounted for 10.8% of the variance in Trust in Organisations and Institutions ($R^2=.108, F(12, 412)=4.168, p < .001$).
Table 9.16: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Organisational Trust

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-.023</td>
<td>-.034</td>
<td>-.027</td>
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<tr>
<td>Age</td>
<td>.008</td>
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<td>-.077</td>
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<td>Ethnicity</td>
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<tr>
<td>Māori</td>
<td>-.078</td>
<td>-.068</td>
<td>-.064</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.079</td>
<td>-.062</td>
<td>-.046</td>
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<tr>
<td>Asian</td>
<td>-.014</td>
<td>.011</td>
<td>.005</td>
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<tr>
<td>Other ethnic group</td>
<td>-.120*</td>
<td>-.120*</td>
<td>-.096*</td>
</tr>
<tr>
<td>Education</td>
<td>-.063</td>
<td>-.069</td>
<td>-.069</td>
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<td>Has a regular GP</td>
<td></td>
<td>-.055</td>
<td>-.039</td>
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<tr>
<td>Been to a GP in last 12 months</td>
<td>-1.37*</td>
<td>-.101</td>
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<tr>
<td>Number of visits to GP in last 12 months</td>
<td>-.106*</td>
<td>-.095</td>
<td></td>
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<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
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<td>-.152*</td>
<td></td>
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<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td>-.125*</td>
<td></td>
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</tbody>
</table>

$R^2$ (Variance Explained) | .030 | .056** | .108***
$\Delta R^2$ | .026* | .053***

Note. $N = 425$.  *$p < .05$  **$p < .01$  ***$p < .001$

9.4.4.2 Organisational Trust Subscale: Organisations Act in Patients Best Interests

Analysis revealed in the first step that the demographic predictors contributed significantly to the regression model, ($R^2=.059$, $F(7, 417)=3.755$, $p < .001$ and accounted for 5.9% of the variation, with age and ethnicity (Pacific and other ethnic group) being significant. Going up an age group (e.g. from 35–44 to 45–54) organisational trust is predicted to go up slightly ($B=.067$, $\beta=-.112$). Those belonging to a Pacific ($B=-.525, \beta=-.098$) and other ethnic group ($B=-.494, \beta=-.129$) are predicted to have lower levels of particularised trust in their provider than NZ Europeans. Controlling for demographic factors, the health service utilisation variables explained an additional 2.4% of variation in Trust in Health Provider and this change in $R^2$ was significant, ($R^2=.084$, $F(3,414)=3.651$, $p < .05$). At this step ethnicity (other ethnic group), and having been to the GP in the last 12 months were significant. Those in the other ethnic group ($B=-.494, \beta=-.129$) are predicted to have lower levels of particularised trust in their provider than NZ Europeans, while those who had not been
to a GP in the last 12 months are predicted to have slightly lower levels of particularised trust than those who had (B=-.492, $\beta=-.139$). Controlling for demographic and health service utilisation factors, the experiential variables explained an additional 5.6% of the variation in the measure of trust and this change in $R^2$ was significant ($R=.140$, $F(2, 412)=13.501$, $p < .001$). The other ethnic group and both experiential variables were significant predictors in step 3. Those in the other ethnic group (B=-.398, $\beta=-.104$) are predicted to have lower levels of particularised trust in their provider than NZ Europeans. If respondents score on how good the GP was at explaining health conditions went up by 1, general trust is predicted to go down (B=-.128, $\beta=-.164$), and if the score for how good the GP was at involving the patient in decisions about care went up by 1, general trust is predicted to go down (B=-.092, $\beta=-.123$). Together the twelve independent variables accounted for 14.0% of the variance in the measure of care aspects mediated by information given to institutions ($R^2=.140$, $F(12, 412)=5.585$, $p < .001$).

Table 9.17: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Organisational Trust Subscale: Organisations Act in Patient’s Best Interest

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
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<tr>
<td>Gender</td>
<td>-.082</td>
<td>-.098</td>
<td>-.092</td>
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<tr>
<td>Age</td>
<td>.112*</td>
<td>.094</td>
<td>.020</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>-.029</td>
<td>-.018</td>
<td>-.014</td>
</tr>
<tr>
<td>Pacific</td>
<td>-.098*</td>
<td>-.062</td>
<td>-.065</td>
</tr>
<tr>
<td>Asian</td>
<td>-.023</td>
<td>.045</td>
<td>.038</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>-.129**</td>
<td>-.129**</td>
<td>-.104*</td>
</tr>
<tr>
<td>Education</td>
<td>-.031</td>
<td>-.035</td>
<td>-.034</td>
</tr>
<tr>
<td>Has a regular GP</td>
<td>-.057</td>
<td>-.040</td>
<td></td>
</tr>
<tr>
<td>Been to a GP in last 12 months</td>
<td>-.139*</td>
<td>-.102</td>
<td></td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td>-.064</td>
<td>-.053</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at explaining health conditions in a way that you could understand?</td>
<td></td>
<td></td>
<td>-.164**</td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td></td>
<td>-.123*</td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained): .059**, .084*, .140***
$\Delta R^2$: .024*, .056***

Note. N = 425. *$p < .05$ **$p < .01$ ***$p < .001$
9.4.4.3 Organisational Trust Subscale: Distrust in/of Organisations

Analysis revealed in the first step that demographic predictors contributed significantly to the regression model ($R^2 = .050$, $F(7, 416) = 3.133$, $p < .01$) and accounted for 5% of the variation, with age and ethnicity (Asian) being significant. Going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go down slightly ($B = -.118$, $\beta = -.167$). Those belonging to an Asian ethnic group ($B = -.524$, $\beta = -.096$) are predicted to have lower levels of organisational trust than NZ Europeans. Controlling for demographic factors, the health service utilisation variables explained an additional 2% of variation in Trust in Health Provider and this change in $R^2$ was significant ($R^2 = .070$, $F(3, 413) = 2.888$, $p < .05$). At this step, a number of variables were significant including age, having been to the GP in the last 12 months, and the number of visits to GP in last 12 months. Going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go down slightly ($B = -.121$, $\beta = -.171$). Those who had not been to a GP in the last 12 months are predicted to have slightly lower levels of particularised trust than those who had ($B = -.470$, $\beta = -.112$). If the reported number of visits to the GP in the last 12 months increased by 1 particularised trust is predicted to go down slightly ($B = -.052$, $\beta = -.128$). Controlling for demographic and health service utilisation factors the experiential factors explained an additional 1.9% of the variation in the measure of trust and this change in $R^2$ was significant ($R^2 = .089$, $F(2, 411) = 4.432$, $p < .05$). The significant predictors after step 3 were age and the number of visits to GP in the last 12 months. Going up an age group (e.g. from 35–44 to 45–54) particularised trust is predicted to go down slightly ($B = -.152$, $\beta = -.215$). If the reported number of visits to the GP in the last 12 months increased by 1 particularised trust is predicted to go down slightly ($B = -.049$, $\beta = -.122$). Together the twelve independent variables accounted for 8.9% of the variance in the measure of distrust in/of organisations ($R^2 = .089$, $F(12, 411) = 3.342$, $p < .001$).
Table 9.18: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Distrust in/of Organisations

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.045</td>
<td>.043</td>
<td>.047</td>
</tr>
<tr>
<td>Age</td>
<td>.167***</td>
<td>-.171***</td>
<td>-.215***</td>
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<td>Ethnicity</td>
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<td>-.075</td>
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<td>Pacific</td>
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<td>-.063</td>
</tr>
<tr>
<td>Asian</td>
<td>-.096*</td>
<td>-.072</td>
<td>-.073</td>
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<td>Other ethnic group</td>
<td>-.066</td>
<td>-.064</td>
<td>-.051</td>
</tr>
<tr>
<td>Education</td>
<td>-.074</td>
<td>-.084</td>
<td>-.084</td>
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<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.022</td>
<td>-.012</td>
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<tr>
<td>Been to a GP in last 12 months</td>
<td>-.112*</td>
<td>-.090</td>
<td></td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td>-.128*</td>
<td>-.122*</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td></td>
<td>-.071</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td>-.097</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained)                    | .050**         | .070*          | .089*          |
$\Delta R^2$                                   | .020*          | .019*          |

Note. N = 424.  *p < .05  **p < .01  ***p < .001

9.4.4.4 Organisational Trust Subscale: Control of Information

Step 1 and 2 of the model explained 2.7% of the variation, but did not result in a significant $R^2$. Controlling for both demographic and health service utilisation factors, adding the experiential factors to the regression model explained an additional 2.5% of the variation in the measure of trust and this change in $R^2$ was significant, ($R^2=.052$, $F(2, 406)=5.368$, $p < .01$). In step 3, how good the GP was at explaining health conditions in a way that you could understand was significant. If respondents score on how good the GP was at explaining health conditions went up by 1, general trust is predicted to go down ($B=-.148$, $\beta=-.135$). Together the twelve independent variables accounted for 5.2% of the variance in the measure of organisational trust that was concerned with the control of information ($R^2=.052$, $F(12, 406)=1.864$, $p = .05$).
Table 9.19: Standardised Betas, $R^2$ and Change in $R^2$ for the Prediction of Organisational Trust Subscale: Control of Information

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>Step 1 $\beta$</th>
<th>Step 2 $\beta$</th>
<th>Step 3 $\beta$</th>
</tr>
</thead>
<tbody>
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<td>Gender</td>
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<td>-.001</td>
<td>.003</td>
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<tr>
<td>Age</td>
<td>.059</td>
<td>.053</td>
<td>.004</td>
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<td>Ethnicity</td>
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<td>Māori</td>
<td>-.074</td>
<td>-.068</td>
<td>-.065</td>
</tr>
<tr>
<td>Pacific</td>
<td>.038</td>
<td>.044</td>
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<td>Asian</td>
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<td>Education</td>
<td>-.050</td>
<td>-.052</td>
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<tr>
<td>Has a regular GP</td>
<td></td>
<td>-.060</td>
<td>-.048</td>
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<tr>
<td>Been to a GP in last 12 months</td>
<td>-.037</td>
<td>-.013</td>
<td></td>
</tr>
<tr>
<td>Number of visits to GP in last 12 months</td>
<td>-.041</td>
<td>-.033</td>
<td></td>
</tr>
<tr>
<td>How good was the GP at explaining your health</td>
<td></td>
<td></td>
<td>-.135*</td>
</tr>
<tr>
<td>conditions in a way that you could understand?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td></td>
<td></td>
<td>-.051</td>
</tr>
</tbody>
</table>

$R^2$ (Variance Explained)                      | .021           | .027           | .052*          |
$\Delta R^2$                                      | .007           | .025**         |

Note. N = 419.  *$p < .05$  **$p < .01$  ***$p < .001$

9.4.5 Significant Predictors of Trust

Overall, the results of the Hierarchical Regression Analysis suggest that some demographic, health service utilisation and experiential variables have some influence on the levels of trust as measured in the 12 constructed scales. All twelve variables accounted for between 5.2% and 20.2% of the variance in the measures of trust. This indicates that variables not captured in the survey contribute to or explain these measures of trust. The significant predictors for each step in the regression model for the major scales and each subscale can be seen in Table 9.20. The experiential variables were significant in all three major scales/measures of trust—general trust, particular trust in primary health provider, and organisational trust. Overall, the analysis suggests gender, age, ethnicity and the health service utilisation variables have a small influence on levels of trust. In general, levels of trust are predicted to be lower for those who are female, older, those who identify as Pacific or other (that is non-Māori, non-Pacific, non-Asian and non-NZ European) as their ethnicity, as well as
those who do not have a regular GP, have not been to the GP in the last 12 months, go
to the GP more frequently, and score their GP more poorly for experiential variables.
These aspects will be discussed in the next chapter.
### Table 9.20: Significance of Predictors at Each Step for General, Particular and Organisational Trust and all Subscales

<table>
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</tr>
<tr>
<td>Gender</td>
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<td>2 3</td>
<td>1 2 3</td>
<td>1 2 3</td>
<td>1 2 3</td>
<td>1</td>
<td>2 3</td>
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<td>1 2 3</td>
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<tr>
<td>Has a regular GP</td>
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</tr>
<tr>
<td>Been to a GP in last 12 months</td>
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<td>2</td>
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<td></td>
<td></td>
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<tr>
<td>Number of visits to GP in last 12 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>How good was the GP at explaining your health conditions in a way that you could understand?</td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How good was the GP at involving you in decisions about your care such as discussing different treatment options?</td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: 1 = Significant at step 1, 2 = Significant at step 2, 3 = Significant at step 3
9.5  Expectations Around Use of Personal Information by GPs and Health Organisations and How to Rebuild Trust

This section outlines respondents’ expectations of about personal information use, and how trust can be rebuilt. The response rate of each question is shown in Table 9.21.

Table 9.21: Responses to Free-Text Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage (%)</th>
<th>n</th>
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</thead>
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<tr>
<td>Q 3.4</td>
<td>88.9</td>
<td>399</td>
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<tr>
<td>Q 5.3</td>
<td>80.8</td>
<td>363</td>
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<td>Q 5.4</td>
<td>75.9</td>
<td>341</td>
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<td>N = 449</td>
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</tbody>
</table>

9.5.1  Expectations of GPs

Question 3.4 asked ‘What do you expect of your GP when you provide him/her with your personal information?’ Responses indicate expectations around confidentiality and privacy as well as particular attributes of a GP. The range of verbs used to describe respondents’ expectations point to a requirement for GPs to ‘do’. This includes keeping information private and confidential but also that they: access, assist, communicate, complete, disclose, discuss, get, give, help, hide, hold, inform, keep, know, make, move, pass, prescribe, protect, provide, retain, secure, see, share, support, take, tell, think, and treat.

Confidentiality, Privacy, Disclosure

The overwhelming response from participants about their expectations of GPs, when they give them personal information, concerns confidentiality and privacy. Confidentiality\(^2\) was the most frequently used term in response to this question (176 participants). A smaller number identified privacy as an expectation (55 participants). Nine respondents identified physical and environmental aspects in protecting the privacy and security of information.

\(^2\)And associated words like confidence and confide
The limits of confidentiality and privacy were outlined by many respondents in describing when or how information could be shared. The range of responses suggested that there was a spectrum of sharing where some respondents seem to imply absolute confidentiality and privacy while others wanted every health professional they saw to have all of their information. Sixty-five participants outlined that information could be shared ‘as appropriate’ or ‘when necessary’.

Record it accurately, hold the information securely, discuss it with colleagues confidentially if has concerns, allow it to be shared with other treatment providers if appropriate (e.g. within the practice—consented when enrolled, for referrals—consented during appointments), don’t gossip or share identifiable information when not appropriate.

Thirty-three said GPs should seek consent to share information.

That this will remain confidential, shared only with other health providers (and only the relevant information to that provider shared) for the purposes of providing health care to me, and only with my knowledge and consent. The only exception to this would be if my GP had imminent and serious concerns about my safety or that of others - and I would set the bar for judging ‘imminent and serious’ very high, and expect the GP to be able to unequivocally justify such a disclosure.

Twenty participants said that information could be shared if it would benefit them. Specific examples of when information could be shared/disclosed included:

- Referral to another provider, service or organisation.
- Where it will benefit the patient.
- If it is required in the course of the patient’s care.
- If it will prevent harm.
- When consent or permission has been sought.

A small number of respondents outlined that information could be shared with family (2) or research purposes (3).

**GPs’ Attributes**

Expectations of GP’s extend to specific attributes. Based on the information patients share with their GPs, a third of patients (106) said they expected their GPs to use or act on that information to provide good care:

To listen to me. To examine me and my situation (consider the environment we live in). To investigate information available on the issues. To inform and explain his/her understanding of my health concern. To discuss options to manage my concerns. Arrange further tests or refer to another health professional. Provide follow-up if necessary and contact people available if appropriate.
Smaller numbers of participants responded that their GP should be respectful (22), honest (15), professional (13), and listen to them (5). In many ways, GPs are expected to protect patients’ information. Thirteen participants said they expected GPs to be trustworthy with the information they (patients) disclose which included: following the rules, using information wisely and professionally, working within any rules or laws (like the Privacy Act), and using appropriate security measures to keep information safe and secure.

For it [information] to only be shared within the agreement I signed upon enrolling (i.e. some info such as blood tests and X-rays available to other health organisations such as hospitals) and for the clinics records to be password protected, timed out with no activity (in case of a room being unattended so others can’t wander in and access my records) and to only be visible to other medical professionals and myself (i.e. records closed before next patient enters room).

9.5.2 Expectations of Health Organisations

Question 5.3 asked ‘What do you expect of health organisations when you give them your personal information?’ The responses to this question are best captured by the respondent who expects health organisations “To treat it as they would their own information”.

Privacy and Confidentiality

Participants expect their personal information to be kept within organisational boundaries unless there is a good reason to share. A third of respondents mentioned confidentiality (125) as an expectation of health organisations and a quarter identified privacy (90). Some stated ‘privacy’ or ‘confidentiality’ without any further qualification or explanation. Several respondents included personal stories, describing practices they endorsed or condoned. Some outlined that organisations should make sure they do not compromise the accuracy, integrity or privacy of the information.

That they [organisations] don’t use it inappropriately and or lose it and or accidentally (or whatever) leak it out.

Purpose

Fifty-seven respondents said that they expect health organisations to use their personal information for its intended purpose:

Use it for intended purpose. Don’t breach my privacy. Share only relevant information with other agencies as required
To stick to the law regarding security, storage, access and privacy and use the highest standard of integrity regarding what/when to share data of relevance.

This means that organisations, and the people that work within them, should adhere to organisational policies, guidelines, and regulations about how information is to be kept, used, shared, accessed. Thirteen respondents identified legal requirements that organisations should adhere to—like the Privacy Act 1993 which was identified by three respondents.

**Consent**

Where information was going to be shared, 45 respondents expressed an expectation for health organisations to seek permission or consent, or to notify them first:

- That they are not made available to all and sundry without my knowledge and permission. They should keep info secure so unauthorised people cannot gain access.
- That it remains confidential to them. That it is secure. That it will not be shared with third parties without my consent. That I will be notified of any request to share with third parties or of any breaches in patient/my data security or confidentiality.

**Use to Benefit ‘Me’ or Others**

Sixty-five respondents expressed the expectation that personal information given to health organisations be used to benefit the patient, or in the course of their care:

- Keep it safe & confidential. Share relevant information between organisations if it is for the best interests of the individual—e.g. domestic abuse concerns, mental health concerns.

While some participants alluded to particular concerns which would necessitate that information be shared, others outlined certain purposes that information could be shared for—like research (9 respondents).

**9.5.3 Rebuilding Trust**

Question 5.4 asked respondents’ ‘How do you think health professionals (like GPs) and organisations can rebuild trust when it has been compromised or lost?’ Responses indicated that respondents’ see communication and change as central to rebuilding trust.
**You Cannot Rebuild Trust**

Of those that responded, 49 said trust could not be rebuilt or repaired—many responding with ‘they can’t’. Other participants reflected that trust was very hard to rebuild once broken or lost—so professionals and organisations should not break or breach trust in the first place:

I think it would be hard to rebuild trust in a doctor/health professionals if they have lost your trust, you expect 100% trust when seeing them so for me once the trust has gone it’s gone forever.

Moving to another GP or health professional was also seen as a response to a breach of trust:

...most people in losing trust would search for alternative options or avoid medical organisations entirely. Someone may return to a service but this would most likely be out of necessity, e.g. visit to the hospital.

**Communicate, be Honest and Apologise**

Thirty percent of respondents (104) emphasised the importance of communication in rebuilding trust; this included openness and honesty (40), apologising (38) and talking about what happened or what they will do to remedy the situation (31):

Talk to you in person and explain the reasons why they did whatever they did to lose to persons trust, and what they are doing to rectify it.

Own their own mistakes or failings and apologise; Learn from past mistakes and failings; Be more open and honest

Some respondents said that the person or organisation needed to ‘own up’ about what happened. Rebuilding trust was seen as being something that could only be achieved if it was talked about and something changed.

**Transparency and Accountability**

Another way that honesty and openness was described was through the appeal to accountability and transparency, as identified by 87 participants. After all, as one participant says:

All organisations will face a breach which compromises trust—so it is imperative that they have policies and procedures in place to be able to adequately manage (and reverse) potentially trust-damaging incidents.

Most of these participants (55) identified the need for policies around information use that would prevent the wrongful disclosure, compromise or loss of information. Others
oulined the need to put things right, or to do something to remedy the situation (28 respondents), with 9 respondents saying that an official investigation or inquiry should be held. Organisations should:

Outline processes that they will go through to ensure it doesn’t happen again and what that organisation will change or look at to ensure it does not happen again.

**9.5.4 Summary of Key Themes**

Overall, the analysis of the open-ended questions suggests there are common expectations across the sample around how GPs and health organisations should use personal information and how they can seek to rebuild trust where it has been compromised or lost. Confidentiality and privacy were core themes around the use of information by GPs and health organisations. These were balanced by reasons for disclosure including where consent is given, where it would benefit the patient or others, or prevent harm. Rebuilding trust was seen to hinge on communication and change, where health professionals and/or organisations are seen to make the effort to communicate clearly about what has happened (gone wrong) and sought to remedy it.
Chapter 10
Discussion

This chapter discusses the results of study 1 in relation to the Beitat model and existing literature. While Chapter 9 reported and described the results in line with step 1 of the methodological process, this chapter explores theoretical explanations for the results and considers the underlying structures that explain trust. This chapter also discusses the strengths and limitations of this study and outlines recommendations for future research.

10.1 Answering the Research Question

The research question is: What role does trust have in patient’s attitudes and expectations around information-sharing in primary care? Study 1 helps to answer this question by addressing objectives one and two:

1. Identify attitudes about trust (generalised and particularised) and information-sharing in health care settings.
2. Determine what patients expect when sharing information with their GP, or their GP shares information with others, and identify ways that patients think that breaches of trust can be remedied.

Attitudes about trust and information-sharing were identified through the descriptive analysis of the survey data and the use of multiple sequential regression to determine which personal and experiential variables significantly predict trust. Expectations of GPs and health organisations in relation to health information, and how to remedy a breach of trust have been identified through the thematic analysis of the free-text questions.
10.2 Levels of General, Particularised and Organisational Trust are High

The findings from Study 1 suggest participants have high levels of general, particular and organisational trust in health professionals and organisations. Trust in all eight health professions (GPs, hospital doctors, nurses, pharmacists, physiotherapists, psychologists, counsellors and midwives) were high. This is consistent with other New Zealand surveys where trust in the medical professional is high (Institute for Governance and Policy Studies, 2016; OPC, 2014). Countries where health care is funded by taxation have been shown to have higher levels of trust in doctors (Saarinen et al., 2016; van der Schee et al., 2007). The existence of the gate-keeping role in New Zealand may also explain why GPs were considered the most trustworthy. van der Schee et al. (2007) found that patients in the UK and the Netherlands, where family physicians act as gatekeepers to secondary care, had higher levels of trust in family physicians (GPs) than Germany where there is no gatekeeping, and the choice of physician is larger. The high levels of trust may also reflect New Zealanders’ high levels of trust in people more generally (Morrone et al., 2009).

Reported trust in health organisations were lower than those of the professionals with the exception of St John’s Ambulance. This may reflect the characteristics of the Order of St John as a charitable organisation that provides ambulatory/emergency medical services across New Zealand. Government departments, private health insurance companies and ACC had the lowest means. This may reflect a number of factors including the data breach by ACC in 2012 having a significant impact on trust, restructuring of government departments, and the profit-driven priorities of many private insurers. Gillespie and Dietz (2009) conceptualise organisational trustworthiness as being formed by six aspects: the leader’s conduct and decisions, strategy, culture, the systems and processes, external governance and public reputation. In the wake of the ACC data breach, and breaches in government departments, the culture around privacy has been identified as an issue (Office of the Privacy Commissioner, 2012) and public reputation has taken a hit. In a speech at the 2015 Government Information Systems Forum, the Hon. Peter Dunne spoke about
information, technology and trust as it applied to public services for citizens and for
good government acknowledging that:

Every realised risk to security and privacy undermines trust. Every delay in addressing
the issues arising from realised risks, undermines trust. (Dunne, 2015).

The difference between trust in professionals and levels of trust in institutions or
organisations has also been demonstrated by van der Schee et al. (2007). The lower
levels of trust in organisations may also be explained by participants being unfamiliar
with some of the organisations and therefore being unsure of whether they trust them
or not (Meyer et al., 2012b).

The high levels of trust in GPs and GP practices in this part of the survey may be
reflective of high levels of trust in participants’ health provider, as attitudes about
the general trustworthiness of professionals are dependent on experiences with a
particular professional (Hall et al., 2002a). This is consistent with analyses of trust that
stress that familiarity or seeing a usual provider over a number of encounters builds
trust (Platonova et al., 2008; Stone et al., 2005; Tarrant et al., 2008, 2010). However,
this may also depend on questions asked about general and particular trust in health
professionals (Hall, 2006; Saarinen et al., 2016).

10.3 Factors that Influence General, Particular and
Organisational Trust

The trust literature reiterates that: “We do not all trust in the same way or to
the same degree: trust varies according to many different factors, not least our age,
gender, ethnicity and socioeconomic status.” (Brownlie, 2008, p. 28–29). This study
investigated general, particular and organisational trust of New Zealand adults and
the influence of demographic, health service utilisation and experiential factors. As
reported in the previous chapter, and shown in Table 9.20, the following variables
were significant: gender, age, ethnicity, having a regular GP, a visit to a GP in the
last 12 months, the number of visits to a GP, how good the GP was at explaining
health conditions and how good the GP was at involving the patient in decisions. The
significance, direction and possible explanations of why these factors influence trust
are discussed in subsections that follow.
10.3.1 Demographic factors

The demographic predictors significant in the regression analysis were age, gender and ethnicity. Overall, the demographic factors explained a maximum of 9.3% of the variation in the measure of particular trust for the care aspects subscale. For the general, particular and scales the demographic variables explained 3.7% and 7.5% of the variation respectively. Demographic factors did not contribute significantly to the regression model for the organisational trust scale. These findings are congruent with other studies which have found the contribution of demographic variables to trust is low (Bulloch, 2013; Gabay, 2015; Meyer et al., 2012b; Murray and McCrone, 2015).

Gender

Females were found to have lower levels of particular trust in their primary health provider in comparison to males but not for the other measures of trust. This was also true for two subscales—the care aspects and information aspects of particular trust in primary health providers. This finding has not previously been documented, with several studies indicating that gender is not a significant predictor of patient trust (Gabay, 2015; Hall et al., 2001; Peck and Denney, 2012). A possible explanation for this relates to differences in health care utilisation between men and women based on health status and levels of morbidity. It could also reflect differences in the importance of relational aspects of trust like interdependence which differ between men and women (Maddux and Brewer, 2005).

Age

While age was not significant the three main scales, it was significant in two of the particular trust subscales (care aspects and distrust), and two of the organisational trust subscales (organisations act in patient’s best interest and distrust in/of organisations). This suggests an age component with older participants showing higher levels of trust in comparison to younger participants. Studies of trust in primary care have identified age as a predictor of trust (Bova et al., 2012; Croker et al., 2013; Tarrant et al., 2003) where by older people are more likely to trust. This is seen to be a generational effect and may reflect greater contact with doctors (Hall et al., 2001).
Ethnicity was a significant predictor for general, particular and organisational trust including seven of the nine subscales. The regression model compared four ethnic groups (Māori, Pacific, Asian and Other) using NZ European as the comparator. Pacific participants showed lower levels of trust in comparison to NZ Europeans in the measure of general trust and particular trust. Those belonging to the ‘other’ ethnic group reported decreased levels of trust in comparison to NZ Europeans for organisational trust. On five occasions one of the ethnic groups was significant at step 1 or 2 but was no longer significant in step 3. For example, Māori showed lower levels of trust in comparison to NZ European group for the information aspects subscale of particular trust in primary care provider, but this was only significant in step 1. This suggests that variables in step 2 and 3 predict the measure of trust better than in the role of ethnicity and the other demographic variables in the first step of the model.

This study suggests that those belonging to the Pacific ethnic group had lower levels of trust in comparison to the NZ European group for general and particular trust. In relation to trust in health organisations those in the ‘other’ ethnic group had decreased levels. These differences may be explained by structural, cultural or other barriers (such as racism and discrimination) which have been shown to influence health inequalities and unmet need for health care services (Harris et al., 2012; Ministry of Health, 2015). The literature shows mixed evidence about the impact of ethnicity on trust. This is partially due to the use of different measures including ethnicity, race, and language (Stepanikova et al., 2006). Peck and Denney (2012) found that there were no reported differences in trust or satisfaction by patients based on race. This was unexpected, as previous research had indicated that in race and gender concordant encounters between patients and doctors, patients were more satisfied (Peck and Denney, 2012). As this is the first study to identify the influence of ethnicity on trust in a New Zealand context, exploring the possible reasons for these differences, and replicating these findings would be useful.
10.3.2 Health Service Utilisation Factors

Beyond that of the demographic factors, the health service utilisation factors explained a maximum of 3.2% of the variation in the particular trust scale, 2.8% for general trust and 2.6% for organisational trust. As seen in Table 9.20, no health service utilisation variables were significant at step 3 for these major scales. Those who reported that they did not have a regular GP had lower levels of particular trust that those who did. Having been to a GP in the last 12 months was significant in the general trust scale, medical professionals and organisations subscale, distrust of health provider subscale, and three out of four of the organisational trust scales. The number of visits to a GP was significant for the distrust in health provider subscale, organisational trust and distrust in organisations subscale.

The role of continuity of care has been highlighted as by those who do not have a regular GP having lower particular trust in their health provider than those who have a regular GP. Further, both those participants who had not been to their GP in the last 12 months, and those who saw their GP more often, had lower levels of organisational trust. While continuity of care is associated with high levels of trust (Skirbekk et al., 2011; Tarrant et al., 2008, 2010, 2003), it is unclear whether the duration of the relationship or number of visits is associated with trust (Leisen and Hyman, 2004; Tarrant et al., 2003). Uijen et al. (2012, p. 266) suggests that achieving continuity as “the patient’s experience of a coordinated and smooth progression of care” requires “excellent information transfer, effective communication, flexibility, relational continuity and care from as few professionals as possible”. Given that none of the health utilisation variables are significant at step 3, this suggests that the experiential factors explained the variance. This may suggest that the health service utilisation variables are confounding variables.

10.3.3 Experiential Factors

Beyond the demographic and health service utilisation variables the experiential factors explained an additional 1.9–9.1% of the variation in the trust measures. For the general, particular and organisational trust scales the experiential variables explained an additional 5.2%, 9.1% and 5.3% of the variation respectively. Both factors, how
good the GP was at explaining their health conditions in a way the patient understood and involving the patient in decisions about their care, were significant at step 3 for all three major scales. This predicts that a patient scoring their GP higher on the scale (where 1=very good and 5=poor), will have lower levels of trust. This indicates that those who thought their GP was poor at explaining their health conditions, or at involving them in decisions about their care in their last visit had decreased levels of trust compared to those who did not.

This has captured two interpersonal dimensions of the GP–patient relationship. This is congruent with the trust literature which has linked aspects of interpersonal care to levels of patient trust (Tarrant et al., 2003). It is also consistent with the Beitat model of trust in that actions and outcomes (as with the last visit to the GP) are seen to have an impact on levels of trust going forward. Explaining health conditions and involving the patient in decision-making are central to measures of patient–centred care and have been previously associated with patient trust (Butterworth and Campbell, 2014; Chu-Weininger and Balkrishnan, 2006; Thom, 2001). The extent to which patients are involved in decision-making has an impact on trust (Calnan and Rowe, 2006; Fiscella et al., 2004; Thom, 2001). This may be due to the way that involvement in decision-making indicates to patients that they are being taken seriously and given enough attention (Calnan and Rowe, 2006). However, this study is unable to indicate whether trust influences decision-making or decision-making influences trust. Van Den Assem and Dulewicz (2014) and Trachtenberg et al. (2005) have demonstrated that those who are more satisfied with their doctors are more likely to say that they are trustworthy and have a greater preference for shared decision-making. The rating of these dimensions can also be said to reflect the extent to which the patient was satisfied with their GP. It may reflect an endorsement of the GP which has been linked to higher patient trust (Krupat et al., 2001; Van Den Assem and Dulewicz, 2014).

This study suggests that patient trust and confidence in their GP is high—while the dimensions explaining and involvement in decision-making can be seen to relate to these, there was a discrepancy between those who reported that their GP was poor or very poor in relation to these aspects and those who said they did not trust their GP. This could suggest a disconnect between the actions of GPs and levels of confidence.
and trust in that GP. However, it could also indicate that there are interpersonal and other factors that influenced participants’ propensity to reports that they trusted their GP. For instance perceived competence or professional expertise (Berry et al., 2008; Calnan and Rowe, 2006; Leisen and Hyman, 2004), continuity of care (Tarrant et al., 2010, 2003), and communication (Platonova et al., 2008; Skirbekk et al., 2011; Tarrant et al., 2010) have been associated with higher levels of patient trust.

10.3.4 Connection of Findings to the Beitat Model

Despite overall levels of trust being high, it appears that women, older people, those of pacific or other ethnic group, those who did not have a regular GP, had not been to a GP in the last 12 months, had been to the GP more frequently, and who rated their last experience with their GP more poorly, have lower levels of trust. Drawing on the conceptual model that has shaped this thesis (page 33), one explanation for why some groups have lower levels of trust despite levels of general trust tending to be high is because of how patient expectations change over time. Initial levels of trust may be high indicating high expectations of health professionals and organisations at a level of abstraction or generality (i.e. GPs in general, as opposed to a particular GP). However, the differences in levels of trust may indicate that real life experience, and repeated interactions with the health system, including GPs, adjust these patients expectations and therefore levels of trust. This may be indicative of breakdowns in the doctor–patient relationship, or there is not a stable relationship—for those who report they do not have a regular GP, have not been to the GP in the last 12 months, or have been a number of times. It could also indicate that particular actions or outcomes have had a negative impact on levels of trust and expectations going forward.

This suggests that expectations in health professionals and organisations are high, but that particular or interpersonal trust is shaped by ongoing interactions between patients and GPs where these expectations may be enforced or adjusted accordingly. Tarrant et al. (2010) found that patients often rely on general trust when seeing a doctor for the first time. This relies on mechanisms that may be seen as increasing interpersonal trust through safety and credentialism where patients rely on indicators of trustworthiness based on group membership and reputation Pilgrim (2011); Tarrant et al. (2010). However, ongoing interactions allow patients to establish norms and expectations.
for the GP–patient relationship where communication, interpersonal care and a GP's knowledge of their patient are important predictors of trust (Tarrant et al., 2010, 2003). Given that the experiential factors were significant in the overall measures of general, particular and organisational trust, this points to the importance of the interpersonal aspects of care for levels of trust. Establishing whether this explanation has any merit requires further research and alternative methods that capture experiences of trust over repeated interactions.

10.4 Expectations of Health Professionals and Organisations and Patient Information

The free-text questions asked participants to outline their expectations. While these questions were directed at identifying the expectations component of the Beitat model (page 33), they provided a wider understanding of how particular communication aspects and actions and outcomes could undermine or build trust in relation to information and trust.

10.4.1 Privacy and Confidentiality

Confidentiality and privacy were the most commonly reported expectation. Many stated ‘privacy’ or ‘confidentiality’ without any further qualification or explanation. This is perhaps indicative of the language used around health care being steeped in concerns around privacy and confidentiality that many people would say they expect this, even if they cannot exactly explain what it requires. Some respondents indicated an expectation of absolute confidentiality and others indicated complete disclosure and participants’ responses showed an understanding that there were limits or exclusions to confidentiality and privacy. The presence of a subset of patients who have serious concern has been demonstrated in other studies (Kim et al., 2015; Shaw et al., 2011). Participants outlined a number of situations where information could or should be shared including in the course of care (i.e. referral to another provider, service or organisation), where it is in the benefit of the patient or will prevent harm, or where consent is sought.

Many of the respondents said that they expect the information they provide to
organisations to be used only for the purpose that it was collected or used appropriately or when necessary. This means that consent is sought when needed, that patients are made aware when their information is going to be shared, and that information is shared with only those who require it. This reflects the desire for individual control over when information is accessed or shared and knowing who has access and for what purpose (Kim et al., 2015). It is also congruent with other New Zealand studies which have found patients are willing for their information to be shared or the purpose of providing care (Hunter et al., 2014, 2009; Whiddett et al., 2006). This is also in line with the requirements of the Privacy Act 1993 where information should be collected with a clear purpose and only used for that purpose. While the language of the Privacy Act was used to describe expectations of information holding agencies it is impossible to speculate whether this indicates knowledge of the act, particularly given studies that have found knowledge and awareness of information storage, use and disclosure to be low (Hunter et al., 2014; Stone et al., 2005; Whiddett et al., 2006). Future research could explore patient knowledge of legal or professional regulation around information-sharing and of what GPs can and cannot do with their information using a qualitative approach.

10.4.2 Care and Competence

Participants reported expectations around information that related to the care and competence displayed by GP. While these are not expressly about the information, this highlights the complexity of a medical consultation and the connection between interpersonal aspects of the doctor–patient relationship and trust (Hall et al., 2002a). By its very nature an interaction with a GP requires the exchange of information for care to take place (Fung and Paynter, 2008; Shibl et al., 2008). Patients expect GPs to use or act on the information they provide to provide good care. However, there are factors that make patients more willing to divulge/disclose information—participants identified attributes including respect, professionalism, honesty and listening. These underscore the relevance of patient-centred care as well as interpersonal attributes which patients perceive as signalling that the doctor is trustworthy (Epstein et al., 2005; Hall et al., 2002a). Participants also identified competence and technical knowledge which has been linked to trust (Berry et al., 2008; Leisen and Hyman, 2004; Tarrant
et al., 2010). For example, Leisen and Hyman (2004) found that patients who believe their doctor is benevolent and technically competent show higher levels of satisfaction and trust.

10.4.3 Rebuilding Trust Through Openness

Data breaches are not the only way that trust can be lost. However, it does reach to the heart of the concerns expressed about information-sharing with GPs and organisations—that information should not get “out there” to people who do not have a reason to access it. A data breach also represents unfulfilled expectations about the confidentiality and privacy as identified by patients. Where expectations are not confirmed, trust declines (Beitat, 2015; Lewicki et al., 2006). Participants identified actions that may restore trust including maintaining open and honest communication, apologising, and making changes. These all reflect the need for the ‘violator’ to respond in some way (Gillespie and Dietz, 2009). Studies of trust repair have found that apologies and simple explanations can help ameliorate trust, although substantive amends have more positive effects (Bottom et al., 2002). However, depending on the severity of the outcome and the timing of the violation, apologies are not always sufficient (Kim et al., 2006; Lount et al., 2008; Tomlinson, 2011). Participants also outlined the need for transparency and accountability. Transparency can help repair trust, and it also promotes accountability, collaboration, cooperation and commitment (Jahansoozi, 2006). If an organisation’s decision-making and operational processes are transparent, accountability is possible as internal and external stakeholders can determine where the responsibility lies (Jahansoozi, 2006). Future research could look at how trust can be repaired between patients and GPs.

10.5 Strengths and Limitations

There were a number of strengths and limitations associated with this study. Firstly, was the exploratory nature of this study. As there had been no previous research measuring patient trust in New Zealand’s health system, this study looked at general and particularised trust. This included questions about the trustworthiness of health professionals and organisations as well as questions to measure trust in the health provider the participant sees most regularly. This has enabled the comparison of levels
of trust in GPs and GP practices to other professional groups and organisations.

Second, was the development of the survey tool and the use of the Beitat model as the conceptual model in the development of the survey instrument/tool. While this ensured that trust was operationalised based on actions/outcomes, expectations, information/knowledge and communication, the survey tool had not been previously validated although some individual items had. Based on the model outlined in Beitat (2015); Beitat et al. (2013) existing scales and new items were included in the survey tool. Although the items showed high internal consistency or reliability, the external validity of the survey has not been determined. It may be that the model should have been operationalised into dependent variables to test the meaningfulness of the model to the underlying construct of trust, instead of ensuring that the items relating to trust mapped onto the model. The inclusion of qualitative or open-ended items enabled the collection of a broad range of responses about expectations of health professionals and organisations about patient information.

Thirdly was the scope or focus of the survey instrument. This survey did not ask participants how they felt about specific instances of sharing. A previous study (Hunter et al., 2009) asked about access to information by particular people for particular uses, whereas the focus of this study was to understand the broad attitudes of general and particularised trust in health professionals and organisations as opposed to the support for particular acts of sharing. The research question is focused on trust and information-sharing between GPs and patients to which this study gives considerable context about the influence of demographic, health service utilisation and experiential variables as well as indicating that levels of general, particular and organisational trust are high. However, as is common, surveys on patient trust in their doctor/physician are restricted to eliciting responses from one party, which makes their view of the doctor–patient relationship incomplete (Cook et al., 2004). This study elicited responses from the general public and not dyads. Exploring GP–patient dydads could be an area for future research.

Finally, non-response bias may have been introduced by low response rates in the first phase of sampling (Shih and Fan, 2007). Singer and Ye (2013) suggests framing non-response in light of the sharp decline in responses to surveys. Groves (2006)
suggests we move away from the focus on non-response rates and towards non-response error. Reasons for the low response in phase 1 may be attributable to the use of a mixed-mode approach (concurrent web and mail survey). The literature has shown that internet/web survey methods have lower response rates than mail surveys (Börkan, 2010; Kaplowitz et al., 2004; Millar and Dillman, 2011; Sinclair et al., 2012). Using web and mail options concurrently also reduces the response rate (Medway and Fulton, 2012). Potential reasons for this include an increase in the complexity of decision-making presented by offering a web and mail option, or participants may open the mailed questionnaire and decide to do it online, but that does not happen due to a break in the response process (Medway and Fulton, 2012). Further, there are technical issues that may mean that an attempt to complete the web option remains incomplete due to frustration with the instrument or because of connectivity issues (Dillman and Bowker, 2001; Medway and Fulton, 2012). It is recognised that the use of postal contact for a web-based survey can be burdensome (Millar and Dillman, 2011). Further, the use of a complex URL and its distribution within a letter may have made completing the survey online undesirable. A URL shortening (as offered by URL shortening service providers such as tinyurl.com or bit.ly) could have been used, so the URL was more user-friendly to type in. However, URL shortening services can expose individuals to potential privacy issues through the ability to track a user. The low response rates were addressed through the use of a mixed sampling approach. Initially, the survey was sent to a random sample of 1000 people from the electoral roll. However, given the low response rate, a second sampling approach was used to increase the number of responses. This used a social media advertisement to encourage participants to click through to the web survey. This presents bias from non-response and self-selection. This is evident in the demographic profile of the sample which shows the sample to be predominantly female, NZ European, and Auckland-based. However, the large sample size is a strength. It allowed for the inclusion of a larger number of predictors in the analysis and the ability to detect smaller effect sizes. Overall this reduced the chances of missing something that exists in the population. Using a second sampling strategy allowed for greater variation in the sample across the age groups.
10.5.1 Unintended Consequences

In communicating with participants the University of Auckland image was used as a way to convey trustworthiness. The participant information sheets for the mail survey clearly stated that the participants had been randomly selected from the Electoral Roll. Several notes were found in the returned envelopes that expressed concern about the way their details had been obtained. Another person phoned and asked to be taken off ‘the list’. There appeared to be some concern that personal information had been taken from another University of Auckland research project, or that contact details had been sold or otherwise given without their permission. This was an unintended outcome of the sampling and recruitment process.

10.6 Implications and Areas for Further Research

This study has provided information about the attitudes of New Zealand adults surrounding trust and information-sharing in the health system. It has provided insights about generalised and particularised trust in health professionals, as well as patient expectations of GPs and health organisations.

Overall, the descriptive statistics from Study 1 show that levels of general and particularised trust were high in the study sample of 449 New Zealand adults. While Institute for Governance and Policy Studies (2016) and OPC (2014) have asked questions about the trustworthiness of organisations and professions this has been limited to the comparison of health professionals to other professions—such as the police, schools and colleges, ministers, members of parliament. This is the first study in New Zealand to measure levels of trust across health professionals and organisations. This study contributes to the trust research into health professionals.

The multiple sequential regression indicated that the demographic, health service utilisation and experiential factors were limited in predicting levels of trust as they were only able to explain up to 20% of the variation. Further, demographic factors varied in their influence over general, particularised and organisational trust—this is worth further investigation. The findings suggest that the experiential or interpersonal aspects of the GP–patient interaction is a predictor of trust, as has been demonstrated.
in other contexts (Butterworth and Campbell, 2014; Tarrant et al., 2003; Thom, 2001; Trachtenberg et al., 2005; Van Den Assem and Dulewicz, 2014). While gender, age, ethnicity, health utilisation and last visit to GP may have some predictive power, this study has failed to explain what the other predictors of trust may be. Additional factors not assessed in this study may also be determinants of trust. Further research is required to explore the unique factors that influence or predict trust. This could include further investigation into the role of the GPs characteristics or behaviours, measures of continuity and patient-centred care that have been explored in other settings (Fiscella et al., 2004; Tarrant et al., 2008; Thom, 2001) as well as health status (Giordano and Lindström, 2015; Meyer et al., 2012b) and socioeconomic status (Meyer et al., 2012a).

The causal mechanisms that explain trust are in some way indicated by the significant predictors of trust. The role of expectations and actions/outcomes are addressed. However, this study has not outlined the impact of communication or knowledge/information on the building of and breakdown of trust as outlined in Beitat et al. (2013) and Beitat (2015). This presents an opportunity for these aspects (communication and knowledge/information) to be explored in more detail.

This study has identified patient expectations around how professionals and organisations treat their information. The implications of these expectations on the ethical aspects of information-sharing will be discussed in Chapter 15. Analysis of the open-ended questions underscores the importance of confidentiality and privacy of information held by health professionals and organisations. Specific to information-sharing, the study participants indicated a willingness for information to be shared. Further participants reflected on concepts such as consent, purpose and benefit when outlining when information could or should be shared. This indicates that the reasons for sharing or disclosure are important. Further exploration of how expectations and information/knowledge interact, as well as the impact of actions and outcomes on trust, is needed. For GPs and GP practices, this study serves to reinforce the importance of confidentiality as an expectation around information, and the centrality of communication and openness to issues of trust, particularly where it needs to be rebuilt.
10.7 Conclusion

Overall, this chapter has discussed findings of study 1. In response to the research question—What role does trust have in patient’s attitudes and expectations around information-sharing in primary care?—Study 1 concludes that trust is predicted by aspects of the interaction between patient and GP (i.e. experiential factors) and to a lesser extent, demographic and health service utilisation variables. This study has demonstrated that levels of trust in GPs and GP practices are high. Further, confidence in the way that GPs and organisations use information is positive. The findings suggest the opportunity to explore the interpersonal aspects of trust as they relate to information-sharing using an in-depth qualitative approach. This will allow for the discussion of issues of trust and information-sharing that goes beyond the descriptive nature of this study.
STUDY 2: A Vignette-based Study of Expectations About Trust and Information-Sharing in Primary Care with Patients and GPs in Auckland
Chapter 11

Introduction to Study 2

This chapter introduces the second study in this thesis. In the first section, the rationale for this vignette-based study is discussed. The aims and approach of the study are stated in the final section.

11.1 Rationale

The first study in this thesis investigated the attitudes and expectations of New Zealanders’ with respect to trust in the health system and aspects of information-sharing. It identified factors that influence levels of general, particularised and organisational trust. The experiential factors were significant across all three measures, indicating the importance of communication and interpersonal relationships on trust. It also identified expectations of GPs around the use of information. However, it is unclear how expectations of the GP–patient relationship and information-sharing influence trust or expectations of trust may influence information-sharing. This provides a rationale for a more in-depth exploration of patient and GP expectations of information-sharing and trust which has not been captured by the quantitative approach of study 1.

As discussed in Chapter 5 there has been very little research that has explored the role of trust as it relates to information-sharing in primary care. Of the two studies identified, one used a qualitative approach. Stone et al. (2005) used a grounded theory approach to explore knowledge and attitudes of patients and members in a primary health care team about sharing primary care record data. Their study demonstrated that patients had limited knowledge of the type of information in their records, or how it was shared (Stone et al., 2005). However, there was no suggestion that concern about information-sharing negatively affected patient trust or lead to patients withholding information (Stone et al., 2005). Attitudes about the accessibility of health information held in electronic health records have been previously studied in New Zealand. Hunter...
et al. (2009) found that the role of the person accessing the information, the content of
the medical information, the level of identification, and reason or purpose for accessing
the information have an effect on patient attitudes. Whiddett et al. (2006) and Hunter
et al. (2014) have also highlighted that knowledge and awareness of information storage,
use and disclosure are low. While study 1 asked about expectations of GPs and health
organisations around personal information, the impact of knowledge about the legal or
professional regulation around information-sharing and of what GPs can and cannot
do with personal information was not explored. This is, however, addressed in study
2.

Qualitative approaches allow researchers to understand processes to build trust, and
explore local notions of trust (Goudge and Gilson, 2005). Qualitative studies of
trust mostly use semi-structured interviews and focus groups, although ethnographic
methods have been used (Ozawa and Sripad, 2013). Cook et al. (2004) highlighted
the reciprocal nature of trust between patient and physician by interviewing both
parties. These methods allow patients to explain their relationship with their health
care provider and elaborate on factors that have an impact on trust (such as previous
trust researchers to “...get away from measuring predefined variables and get closer
to the respondents’ idiosyncratic experiences and interpretations”. “Trust cannot,
therefore, be boiled down to a single opinion/poll measure: there is a need to explore the
different dimensions qualitatively as well as quantitatively” (Brownlie, 2008, p. 10). In
response, this study explores patients’ and GPs’ experiences, expectations, knowledge
and understanding of trust and information-sharing using a qualitative approach. This
provides a way of testing the Beitat model of trust (page 33), which was not possible
using the survey design in study 1. It also allows for the exploration of patients’
and GPs’ understandings of the importance and function of trust as it relates to
information-sharing within and outside of the GP-patient relationship.

11.2 Aims and Approach

Study 2 is a cross-sectional, interview-based qualitative study of patients and GPs from
across the Auckland region. It examines the “everyday routine making and keeping of
promises and commitments” (Solomon (2000) p. 239 cited in Brownlie, 2008, p. 11) of
patients and GPs in primary care. This study seeks to answer the research question by addressing objectives two and three:

2. Determine what patients expect when sharing information with their GP, or their GP shares information with others, and identify ways that patients think that breaches of trust can be remedied.
3. Outline some of the processes that GPs can or should undertake (as reported by GPs and patients) to build, maintain and restore trust.

The data was collected using constructed vignettes within semi-structured interviews to explore the issues of trust, information-sharing and the patient-GP relationship. This study uses thematic analysis to identify patterns across the data set to establish the expectations that patients and GPs related to information-sharing. The study also identifies the way that patients and GP think about trust in primary care and how trust can be built, maintained and restored if it is compromised or lost.

11.3 Conclusion

Following on from study 1, and the minimal research conducted around trust in primary care, this study will explore trust and information-sharing using a qualitative approach. This will involve interviews with patients and GPs from across the Auckland region. The design of the interview guide and vignettes, drawing on the Beitat model of trust and findings from study 1 will need to be developed. This will be discussed in the next chapter.
Chapter 12
Methods

The second study incorporated vignettes and follow-up questions into a semi-structured interview guide to collect qualitative information from patients and GPs based in Auckland about expectations of trust and information-sharing. This chapter outlines the study design, sample, tools, and the procedures for data collection and analysis used in Study 2.

12.1 Design

Study 2 comprised a cross-sectional or one-point-in-time qualitative research design (Patton, 2015). This involved semi-structured interviews with patients and GPs living in Auckland. The interviews sought to explore patients’ and GPs’ ideas about trust and expectations of information-sharing in primary care.

12.2 Sample and Recruitment

Maximum variation sampling, a non-probability, purposeful sampling approach was used. This seeks to capture and describe themes from a heterogeneous group (Patton, 2015, p. 283). By sampling a wide variation of people, common patterns across the group serve to highlight core dimensions of the phenomenon being studied (Patton, 2015). Maximising variation involves identifying diverse characteristics for the sample (Patton, 2015). The aim is not to generate a random or representative sample, but instead to engage with individuals across the range to which the phenomena apply (Maykut and Morehouse, 1996). The minimum number of participants to allow for variation across age, gender and ethnicity was determined to be sixteen patients and seven GPs. Recruitment of both groups was continued until “no new analytical insights . . . [were] forthcoming” (Bowling, 2014, p. 396). This is sampling to the point of redundancy, meaning that when the same issues or topics are being talked about
then a sufficient sample size has been obtained (Bowling, 2014; Patton, 2015). To gauge redundancy, data collection and preliminary data analysis occurred simultaneously.

12.2.1 Patients

This study sought to engage with a diverse range of patient perspectives. Apart from age, it is not clear how patient characteristics predict trust. Study 1 demonstrated some influence of gender, age, and ethnicity across the measures of trust—this was used as the basis for sampling patients for maximum variation across these three dimensions. The study sought to recruit at minimum one NZ European and non-NZ European participant of each gender in four age bands (18–24, 25–44, 45–64, 65+). At the end of the interview, participants were asked to complete several demographic questions including gender, age, ethnicity, whether they had a regular GP, and how they rated their health. This information was used to keep track of the variation of the sample.

Recruitment of patient participants involved distributing information about the study to over 55 organisations across the Auckland region—businesses, clubs and groups, gyms, cafés, union organisations, non-profit and religious organisations, and the University of Auckland. Organisations were contacted by email and asked if they would circulate the information to their network, or where appropriate flyers were dropped off.

12.2.2 General Practitioners

This study also sought to engage with GP perspectives. It is unclear what characteristics of GPs contribute to trust. Ideally, the sample would include GPs who worked with different populations across Auckland who were in varying phases of their careers, and a mix of gender, age and ethnicity. In total, 30 organisations were contacted, including three PHOs and 27 individual practices across Auckland. All GPs who responded were asked to participate. GPs were asked to complete the same demographic questions as the patients, as well as a question asking how many years they had been working in general practice, and their working status.
12.3 Tools

Study 2 used semi-structured interviews to engage with individuals about the role of trust in information-sharing. An interview involves two people engaging in a process of exchanges that create ‘the interview’ (Fontana and Frey, 2005). This means that interviewing is more than the exchange of questions and answers. Instead, an interview is a “contextually bound and mutually created story” (Fontana and Frey, 2005, p. 696).

Preceding each interview, the researcher and participant engaged in a brief explanation of the research and a discussion of the information sheet, consent form, the koha (gift), and recording of the interview. During this time patients were asked to think about a pseudonym and to complete several demographic questions. An interview guide was used which is described in section 12.3.1. Upon starting the interview, the participant was presented with a first vignette (about trust and expectations of a patient–GP interaction) and asked follow-up questions. The second section of the interview asked questions about information-sharing. The third section of the interview presented the second vignette (about a data breach) and asked follow-up questions. As the interview drew to a close, participants were asked two reflective questions.

12.3.1 The Interview Guide

The interviews were oriented around testing the model of trust and its application to information-sharing in primary care. The interview guides have been included on pages 330 and 335. Two vignettes were used as a way to orient participants to the topic of trust and information-sharing. The vignettes and questions have been developed from the literature, specifically the Beitat model of trust between patients and clinicians previously outlined on page 33. The questions for both patients and GPs have been mapped onto these domains as seen in Tables 12.1 and 12.2.
### Table 12.1: Patient Interview Questions as They Map Onto the Trust Domains

#### Expectations

1. If Sabrina trusted Dr Jones, do you think this would change anything? What if she doesn’t trust Dr Jones at all? [What do you think the GP could do to be more trustworthy or to develop trust with Sabrina? Is there anything that Sabrina could or should have done to build trust with the GP? What if you had heard things from a friend about this Doctor, would this have an impact? If you think about your own doctor, do you trust them because they’re a Doctor, and that’s their job, or because of something else?]
2. What do you expect of your GP when you share information with him/her about you and your health?
3. If this, or something similar happened, what would you expect Dr Jones, or the organisation to do? [How might Dr Jones rebuild trust with you? How might your own GP rebuild trust with you? What if the trust couldn’t be repaired?]

#### Action/Outcomes

1. If something like this happened and your information was on the hard drive, would it change how you feel about Dr Jones, or your own GP? [What about if the data on the hard-drive is encrypted? What if the data is not encrypted? What about if it is stored securely inside Dr Jones house? What if the hard drive is in a locked box or briefcase? What if you knew that this was the procedure and then this happened? Would you feel any differently if it was the Doctors/Dr Jones’ fault? If Dr Jones lost the hard drive or caused the information to get out?, What about if it were a systems or technical issue?]  

#### Knowledge/Information

1. What do you know what GPs can or cannot do with your personal information? [Any legal or professional limits? Do you know these things based on your experience? Your own research/reading/talking with people? Information your GP has given you, or talked to you about?]
2. What concerns do you have about sharing information with your GP, or with your GP sharing information about you with others?
3. Where do you think your attitudes and ideas about what GPs should and should not do with your personal information come from?

#### All three

1. What do you think GPs can or should do to make sure they are trustworthy with information? [What kinds of information sharing do you expect your GP talk to you about? Are there certain people or organisations that you would expect or not expect your GP to share information with? Have you ever had a conversation with your GP (initiated by yourself or them) about when information sharing is necessary or appropriate?]

*Note: Prompts shown in square brackets*
Table 12.2: GP Interview Questions as They Map Onto the Trust Domains

<table>
<thead>
<tr>
<th>Expectations</th>
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<tbody>
<tr>
<td>1. If Sabrina trusted Dr Jones, do you think this would change things? What</td>
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<td>if she doesn’t trust Dr Jones at all? [What do you think the GP could do</td>
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<tr>
<td>to be more trustworthy or to develop trust with Sabrina? Is there anything</td>
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<td>that Sabrina could or should have done to build trust with the GP? What if</td>
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<td>Sabrina had heard things from a friend about this Doctor, would this have an</td>
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<tr>
<td>impact? If you think about your own practice, do you think your patients</td>
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<tr>
<td>trust you because they’re a Doctor, and that’s your job, or because of</td>
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<tr>
<td>something else?]</td>
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<tr>
<td>2. What do you expect of your Patients when you are communicating with them</td>
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<tr>
<td>you expect them to treat you in certain ways? To do or be certain things?</td>
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<tr>
<td>To ask certain things? To know certain things, or to help you further</td>
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<tr>
<td>understand things? To follow through with the treatment or clinical decisions</td>
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<td>that have been made?]</td>
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<tr>
<td>3. Where do you think patients expectations of GPs, and about information</td>
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<td>sharing come from?</td>
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<table>
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<tr>
<th>Action/Outcomes</th>
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<tr>
<td>1. If you were</td>
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<td>in Dr Jones’</td>
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<td>shoes, what</td>
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<td>would you do?</td>
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<td>Do you think it</td>
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<td>would affect the</td>
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<td>trust that your</td>
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<td>patients have in</td>
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<td>you? [What about</td>
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<td>the data on the</td>
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<td>hard-drive is</td>
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<td>encrypted? What</td>
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<td>if the data is</td>
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<td>not encrypted?</td>
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<td>What about if it</td>
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<td>is stored securely</td>
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<td>inside Dr Jones</td>
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<td>house? What if</td>
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<td>the hard drive</td>
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<td>is in a locked</td>
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<td>box or briefcase?</td>
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<td>What if you</td>
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<td>knew that this</td>
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<td>was the procedure</td>
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<td>and then this</td>
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<td>happened? Would</td>
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<td>you feel any</td>
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<td>differently if</td>
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<tr>
<td>it was the Doctors/Dr Jones’ fault? If Dr Jones lost the hard drive or caused</td>
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<td>the information to get out? What about if it were a systems or technical</td>
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<td>issue?]</td>
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<tr>
<td>2. If this, or</td>
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<td>something similar</td>
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<tr>
<td>happened, what</td>
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<td>would you do? How</td>
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<tr>
<td>might you seek to</td>
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<td>rebuild trust with any affected patients?</td>
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<th>Knowledge/Information</th>
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<tbody>
<tr>
<td>1. What do you think</td>
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<tr>
<td>Patients know about</td>
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<tr>
<td>what they can or cannot do with their personal information? [Any legal or</td>
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<td>professional limits?</td>
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<tr>
<td>Do you think this is</td>
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<td>based on their experience, research/reading/talking with people or information</td>
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<td>you have given them or talked with them about?]</td>
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<tr>
<td>2. What concerns do</td>
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<tr>
<td>you have about sharing</td>
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<td>patient information with other professionals or organisations?</td>
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<th>All three</th>
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<tr>
<td>1. What do you think GPs can or should do to make sure they are trustworthy</td>
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<td>with information? [What kinds of information sharing do you talk to your</td>
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<tr>
<td>patients about? Are there certain types of information sharing that you</td>
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<tr>
<td>assume patients are okay with? What happens if a patient refuses to let you</td>
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<tr>
<td>share information?]</td>
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</table>

Note: Prompts shown in square brackets
12.3.2 Vignettes

Vignettes, scenarios or paper people can be used to simulate experience (Bradbury-Jones et al., 2014; Hughes and Huby, 2002; Schoenberg and Ravdal, 2000; Wilson et al., 1998) using stories about hypothetical characters and circumstances that the participant responds to (Finch, 1987). Using vignettes as a methodological tool involves creating:

a short, descriptive sketch of an incident and then presenting it to informants to elicit their opinions and reactions to its contents. The vignette or scenario is carefully designed to depict a circumstance or represent a germane issue and to elicit rich but focused responses from informants (Schoenberg and Ravdal, 2000, p. 63).

Vignettes have been used in the study of health care topics including patient–provider communication (Bradbury-Jones et al., 2014; Hillen et al., 2013; Lapatin et al., 2012; Sastre et al., 2011) and studies looking at information-sharing, disclosure or use (Bunting et al., 2010; Hunter et al., 2009; Sastre et al., 2011). Vignettes have also been used in trust research in mixed and multi-method studies (Addison, 2015; Barrera et al., 2015). The use of vignettes to explore perceptions, beliefs, attitudes and behaviours makes them suitable for researching trust (Addison, 2015).

Vignettes have been used in both qualitative and quantitative research designs as the method or tool for collecting data (Wilks, 2004), and presented as written text, images or other mediums (Hughes and Huby, 2002; Ulrich and Ratcliffe, 2007). Asking about concrete situations (using vignettes) distances the issues from the participant—making the questions less threatening (Finch, 1987). Vignettes can be incorporated as an icebreaker at the beginning of an interview (Barter and Renold, 1999) or used at the close of an interview to broaden the focus of the responses (Barter and Renold, 1999). No matter when they are used, participants are generally invited to respond to questions about a vignette after being presented with it (Schoenberg and Ravdal, 2000). They do not necessarily require participants have in depth or expert knowledge about the topic (Hughes and Huby, 2002), and can be used to encourage participants to reflect on their role and the role of others in the vignette (Wilson et al., 1998).
12.3.2.1 Constructing Vignettes

The construction of the two vignettes and the questions surrounding them are described in the following sections. Constructing vignettes can be challenging as the characters and storyline need to be believable (Finch, 1987) and while they may simulate aspects of experience, they cannot completely mirror the reality of people’s lives (Hughes and Huby, 2002). Spalding and Phillips (2007, p. 961) says:

I have come to realize that one of the endearing features of vignettes is that they seem to declare themselves as fictions. Through their constructedness they can signal to the reader that they are a version, an interpretation . . . What has become apparent is the practical worth of vignettes not as truths but as representations that can stimulate reflection and improve action.

Static (as opposed to staged or developmental) vignettes were used in this study to focus the interviews and break away from the limitations of personal experience (Finch, 1987; Jenkins et al., 2010).

Vignette 1: Sabrina

The first vignette, shown in Vignette 12.1, depicts the interaction between a patient, Sabrina, and a doctor she is visiting for the first time.

Vignette 12.1: ‘Sabrina’

Sabrina is a 24-year old woman. She has just moved to a new part of town and is visiting a new GP practice. She is seeing Dr Jones for the first time. When she arrives, Sabrina is asked to complete an enrolment form. This includes a section which asks if she wants to transfer her patient notes from her former GP to the new practice. When Sabrina enters Dr Jones’ office she is nervous about talking to a strange doctor about her symptoms. She worries that Dr Jones won’t believe what she is saying. She is also wary of whether Dr Jones is a good doctor. Sabrina feels like Dr Jones is typing furiously as she describes her symptoms, barely looking at her. Sabrina is curious as to what Dr Jones is writing about her, but is too scared to ask. Dr Jones prints out a referral letter for a specialist and a list of blood tests—Sabrina isn’t sure what they’re all for, but nods as Dr Jones says what they are. Dr Jones seems busy—set on getting Sabrina out of the door as soon as possible.

The trust literature outlines risk and vulnerability as key dimensions of trust—as such the vignette portrays Sabrina as nervous, wary and scared. The Sabrina vignette was constructed to encourage the participant to think about five aspects that connect the model of trust between doctors and patients with information-sharing:
1. *Expectations* of a new GP (new part of town and visiting a new GP practice, wary of whether Dr Jones is a good doctor).

2. *Information-sharing* (via the enrolment form and transferring patient notes, Sabrina describing her symptoms and Dr Jones recording them, a referral letter and list of blood tests).

3. *Communication* aspects of the interaction (Sabrina feeling nervous, Dr Jones barely looking at her, Sabrina is not sure what the tests are for but nods, Dr Jones seems set on getting her out the door as soon as possible).

4. *Actions and outcomes* of the consultation (namely the specialist letter and blood test form, and recording of notes).

5. *Knowledge and information* that the patient may or may not have (Nervous about seeing a new doctor, worries that doctor will not believe what she is saying, not knowing what the blood tests are for).

The follow-up questions ask about the role of trust and what patients and GPs can do to build trust as well as knowledge and expectations of trust and information-sharing in primary care. This includes an exploration of whether trust is based on the role of the GP (as a doctor) or as a person. One of the questions asks participants about what GPs can and cannot do with personal information. This tests the knowledge/information aspect of the model and draws on the results of Study 1 where participants used words such as purpose and necessary, which is also terminology used in the Privacy Act 1993. This separates what it is that patients may expect of GPs, from what they have knowledge about. GPs are asked similar questions based on their perception of their patient’s expectations and knowledge of them.

**Information-Sharing Questions**

The information-sharing questions ask participants to reflect on their expectations—what concerns do they have about information-sharing and how can GPs be trustworthy with information? In asking what GPs should do to be trustworthy with information, participants will draw on all three aspects of the model—their expectations of GPs, their knowledge of information practices and how they feel about particular actions/outcomes. This acknowledges that participants’ may have action or outcome-oriented expectations and knowledge or information-oriented expectations. GPs are
asked about the concerns they have with information-sharing practices, and how they can be trustworthy with information. In this section participants’ were asked how they felt about information being shared—with professionals, with organisations, with third parties such as an insurance company or ACC, or about sensitive information being shared.

**Vignette 2: Dr Jones**

The second vignette, shown in Vignette 12.2, was constructed to ask about how trust might be rebuilt when it is lost. The vignette describes a daily backup procedure with off-site storage. While these two things are in line with good data management procedures, the vignette shows that Dr Jones takes the hard-drive (a physical backup) home, which puts the information at risk both to and from, and when stored in the study of a Dr Jones’ residence.

![Vignette 12.2: ‘Dr Jones’](image)

At the GP Practice where Dr Jones works, all patient notes are kept electronically. The notes are stored on a server, held on the premises in a locked server closet. They also keep a backup of files on a hard-drive that one of the staff takes home at the end of the day. As the last person to leave work one night Dr Jones takes the backup hard drive home. Dr Jones takes the hard drive into the house before going out for the evening. When Dr Jones gets home, the house has been ransacked and items have been taken. Dr Jones races through to the study, but the hard drive is gone.

The Dr Jones vignette was constructed to encourage participants to think about five aspects:

1. **Expectations** related to the privacy and security of personal health information and the scope or reach of a GPs responsibilities.
2. **Knowledge and information** about what procedures or processes may or may not ensure the security of patient information (including GPs knowledge of their own systems/processes).
3. How different **actions/outcomes** may impact trust (the role of encryption or who is to blame/at fault—loss versus deliberate disclosure).
4. The role of **communication** in ameliorating a data breach situation or rebuilding trust.
5. The implications for **trust** between a patient and GP or more widely, and what
GPs and practices can do to rebuild trust.

The follow-up questions ask participants to think about the role of different contextual factors that may reinforce or undermine trust. This includes whether this situation would change how the participant feels about Dr Jones or their own GP. For this reason, the vignette is purposefully vague. Prompts to this question allow the details of the vignette to be altered based on procedural and person related facts. It also enables the exploration of attribution of fault based on system versus individual action, and between human error and deliberate acts. The other follow up question asks how the situation can be ameliorated, and trust restored or rebuilt. GPs are asked to respond as the GP in this situation and to reflect on what they would do as a GP to rebuild trust.

In closing the interview patients were asked to reflect on where their expectations of GPs and information-sharing might come from. GPs were asked to reflect on where they thought patient expectations came from. Finally, participants were asked to define trust using their own words.

12.3.2.2 Testing and Piloting

It is common to check the congruence of the vignettes with experts or potential participants. Wilson and While (1998, p. 82) tested their vignettes by showing them to a nurse and social worker involved in their study to make sure they “simulated reality”. The vignettes were shown to three GPs (including two GP researchers), to ensure that they would make sense to a GP. The interview guide was tested with one patient and one GP, and the feedback used to further refine the interview guide.

12.4 Data Analysis Procedures

This section describes the data analysis procedures including transcription, data management, coding, and thematic analysis.

12.4.1 Thematic Analysis

Thematic analysis is a process or method used to identify patterns within qualitative data (Boyatzis, 1998; Braun and Clarke, 2006). It can be seen as a foundational method
for qualitative research analysis due to its flexibility or compatibility with realist and
constructionist approaches (Braun and Clarke, 2006). Thematic analysis according
to Boyatzis (1998, p. 1) is a “way of seeing” and a process of encoding qualitative
information. A theme is “...a pattern found in the information that at minimum
describes and organizes the possible observations and at maximum interprets aspects
of the phenomenon” (Boyatzis, 1998, p. 4). Themes may be generated from prior
research (deductively) or from the data (inductively). However, the language of themes
emerging:

...can be misinterpreted to mean that themes “reside” in the data, and if we just
look hard enough they will ‘emerge’ like Venus on the half shell. If themes ‘reside’
anywhere, they reside in our heads from our thinking about our data and creating links
as we understand them (Ely, 1997, p. 205–206).

The research questions and previous literature were used to generate initial codes.
Additional codes were identified or constructed from the data itself. As such the
thematic analysis approach used in this thesis is both theory and data driven (Boyatzis,
1998). The process of conducting the thematic analysis is described in the following
sections: familiarising, coding, and refining themes.

12.4.2 Becoming Familiar with the Data

Familiarising yourself with your data is a key step in thematic analysis (Boyatzis,
1998; Braun and Clarke, 2006). While it can be tempting to skip this step because it
is time-consuming, it is a “bedrock” for the analysis (Braun and Clarke, 2006, p. 87).
Becoming familiar with the data involved transcribing the audio files, reading the text,
and writing a brief summary of each interview.

Transcribing

The process of transforming the audiotape into a text format is a complex process of
determining the best way to interpret what is conveyed in an interview and displaying
that in text. Following Powers and Faden (2006) and Saldaña (2011), the approach to
transcription was dictated by the purpose of the transcripts as necessary for analysis.
Poland (1995) outlines the importance of transcripts as being trustworthy accounts of
what is said by participants. If care is not taken in transcribing audiotapes meaning
can be changed or lost because:
...transcripts are translations, and like all translations they cannot exactly reproduce the original. But like many translations they can be well-crafted forms of the original that allow for further appreciation, insights or analysis (Powers, 2005, p. 3).

The interviews were transcribed first and foremost as a way to become familiar with the data (Saldaña, 2011) but secondly to avoid the ethical concerns associated with hiring professional transcribers, as this would require sharing information beyond the research team. The interviews were transcribed verbatim with a focus on accurately reproducing the recorded speech. Punctuation was used to indicate pauses and aid in reading. En dashes were used to indicate repetition of a word, and periods were used to indicate where a sentence ended (Powers, 2005). Every word was transcribed including false starts, broken sentences, repetitions, filler words and non-verbal sounds. A systematic syntax for conveying emotional context (intonation, silence, long pauses, sighs, or laughter) was not used as it was deemed unnecessary for the method of analysis (Saldaña, 2011).

12.4.3 Coding

Interviews were analysed using QSR Nvivo version 11. Deductive codes were generated from the research question, objectives and interview guide. Additional codes were identified inductively by reading and coding six of the patient interviews. Consistent with Boyatzis (1998) each code has been labelled, defined and described, along with at least one quote as an example. Together these two sets of codes were developed into a coding matrix (see page 337).

The remaining transcripts were coded using the coding matrix. From there the data assigned to each code was scanned for themes in an inductive fashion, this added additional codes. In the process of naming and reviewing themes a number of memos were written and conceptual diagrams drawn (Boyatzis, 1998; Saldaña, 2011). This process was invaluable in refining and defining the themes.

12.4.4 Refining Themes and Presenting Findings

The process of coding themes involved moving through the data looking for patterns and themes. Ely (1997, p. 206) describes this as:

...a process of sorting through the fabric of the whole for our understanding of the threads or patterns that run throughout and lifting them out—as a seamstress lifts
threads with a needle—to make a general statement about them.

However, this process extends only to the identification of themes and not to the condensing and refining of them—this requires interpretation and categorisation of basic themes into a more complex structure. To determine the boundaries of a basic theme each was:

... moulded and worked to accommodate new text segments, as well as old ones; each theme has to be specific enough to pertain to one idea, but broad enough to find incarnations in various text segments (Attride-Stirling, 2001, p. 392).

Basic themes are the lowest-order theme, in essence they are simple premises derived from the data (Attride-Stirling, 2001). Organising themes are a middle-order theme that organises the basic themes into similar issues by summarising the main assumptions (Attride-Stirling, 2001). The grouping of organising themes gives rise to global themes that “encompass the principal metaphors in the data as a whole” (Attride-Stirling, 2001, p. 389). Global themes make final or concluding claims about the data to present a position about the reality of a given issue (Attride-Stirling, 2001). The themes generated from the analysis from the patient and GP interviews were combined and condensed to form layers of basic, organising and global themes.

12.5 Ethics Approval

Ethical approval for study 2 was obtained from the University of Auckland Human Participants Ethics Committee on 11th March 2015 for three years (reference number 013917). This addressed some of the key ethical considerations that arise from this research including consent, anonymity/pseudonymity, use of incentives ($30 koha/gift), privacy and confidentiality, participants’ ability to withdraw from the research, data storage and protection of data, and the opportunity to review the transcripts.
Chapter 13

Results

The results of Study 2 are presented in four sections. The first section describes the sample characteristics. Section two describes patients’ perspectives followed by GP perspectives in section three. The fourth section compares the patient and GP perspectives. The results are organised under themes identified using thematic analysis as discussed in Section 12.4.1. Textual support for these themes is provided through quotes from participants. The names included with the quotes are pseudonyms (chosen by the participant or allocated by the researcher); these distinguish between participants without identifying the participant.

13.1 Sample Characteristics

In total, 52 interviews were conducted between February and April 2016—40 with patients, and 12 with GPs. The characteristics of the patient and GP participants are described in Table 13.1. All of the participants were recruited from, and interviews conducted in, Auckland, New Zealand. The patient interviews and lasted an average of 32 minutes (mean=32.02, median=31, range=18–52). On average the GP interviews lasted 38 minutes (mean=38, median=35, range=23–75).
### Table 13.1: Characteristics of Interview Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients (N=40)</th>
<th></th>
<th>GPs (N=12)</th>
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<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
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<td><strong>Gender</strong></td>
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</tr>
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<td></td>
</tr>
<tr>
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<td>17.5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
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<td>25</td>
<td>3</td>
<td>25</td>
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<td>8</td>
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<td>25</td>
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<td>55–64</td>
<td>5</td>
<td>12.5</td>
<td>4</td>
<td>33.3</td>
</tr>
<tr>
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<td>4</td>
<td>10</td>
<td>-</td>
<td>-</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>20 (25)</td>
<td>50 (52.1)</td>
<td>6 (6)</td>
<td>50 (50)</td>
</tr>
<tr>
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<td>4 (4)</td>
<td>10 (8.3)</td>
<td>-</td>
<td>-</td>
</tr>
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<td>Pacific Island</td>
<td>4 (5)</td>
<td>10 (10.4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asian</td>
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<td>20 (20.8)</td>
<td>5 (5)</td>
<td>41.7 (41.7)</td>
</tr>
<tr>
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<tr>
<td>Refused</td>
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<td>-</td>
<td>1 (1)</td>
<td>8.3 (8.3)</td>
</tr>
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<td></td>
<td></td>
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<tr>
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<td>5</td>
<td>12.5</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td><strong>How do you rate your health?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>28</td>
<td>70</td>
<td>12</td>
<td>100</td>
</tr>
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<td>12</td>
<td>30</td>
<td>-</td>
<td>-</td>
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<td>Poor</td>
<td>-</td>
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</table>

<sup>a</sup> Ethnicity coded using prioritised output, total response output shown in brackets.
**Table 13.2: Characteristics of Patients**

<table>
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<tr>
<td>Anna</td>
<td>F</td>
<td>18–24</td>
<td>NZ European</td>
</tr>
<tr>
<td>Anton</td>
<td>M</td>
<td>18–24</td>
<td>Other</td>
</tr>
<tr>
<td>Bibi</td>
<td>F</td>
<td>45–54</td>
<td>Asian</td>
</tr>
<tr>
<td>Bob</td>
<td>M</td>
<td>35–44</td>
<td>Asian</td>
</tr>
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<td>Daisy</td>
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<td>NZ European</td>
</tr>
<tr>
<td>Dan</td>
<td>M</td>
<td>35–44</td>
<td>Pacific</td>
</tr>
<tr>
<td>Dee</td>
<td>F</td>
<td>35–44</td>
<td>Maori</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>F</td>
<td>75+</td>
<td>NZ European</td>
</tr>
<tr>
<td>Gerard</td>
<td>M</td>
<td>25–34</td>
<td>Other</td>
</tr>
<tr>
<td>Harvey</td>
<td>M</td>
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<td>Asian</td>
</tr>
<tr>
<td>Jason</td>
<td>M</td>
<td>75+</td>
<td>NZ European</td>
</tr>
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<td>18–24</td>
<td>NZ European</td>
</tr>
<tr>
<td>Joanna</td>
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</tr>
<tr>
<td>Joe</td>
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<td>Pacific</td>
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<tr>
<td>Joy</td>
<td>F</td>
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</tr>
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</tr>
<tr>
<td>Kara</td>
<td>F</td>
<td>35–44</td>
<td>Pacific</td>
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<tr>
<td>Khaleesi</td>
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<td>Pacific</td>
</tr>
<tr>
<td>Mr Purple</td>
<td>M</td>
<td>35–44</td>
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</tr>
<tr>
<td>Nat</td>
<td>F</td>
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<td>Nicole</td>
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<td>25–34</td>
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<td>F</td>
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<td>NZ European</td>
</tr>
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<td>F</td>
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<td>Maori</td>
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<td>F</td>
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</tr>
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<td>25–34</td>
<td>NZ European</td>
</tr>
<tr>
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<td>M</td>
<td>55–64</td>
<td>NZ European</td>
</tr>
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<td>Sophia</td>
<td>F</td>
<td>18–24</td>
<td>NZ European</td>
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<td>F</td>
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</tr>
<tr>
<td>Tama</td>
<td>M</td>
<td>25–34</td>
<td>Maori</td>
</tr>
</tbody>
</table>

*Note: a Ethnicity coded using prioritised output.*
13.2 Patient Perspectives

This section presents patient perspectives on the issues of information-sharing and trust in primary care based on thematic analysis of 40 patient interviews. Table 13.2 describes the characteristics of each patient participant—including their pseudonym, gender, age group and ethnicity.

13.2.1 Trust

Patient participants were asked questions about trust in response to the Sabrina vignette outlined on page 189. In the conversations that followed, participants articulated what they thought trust does and requires, as well as delineating between role-based and interpersonal trust before attempting a definition of trust.

Patient participants could relate to the Sabrina vignette with all of the participants identifying that the relationship depicted in the vignette was not ideal. Some participants expressed that they had experienced this or a similar situation before, while others related to the vulnerability of being unwell and unsure of what was going on. One participant (Louise) exclaimed that if Dr Jones actually did what Sabrina thought then “…he should be shot”. This demonstrated an outrage at the actions of Dr Jones who Sabrina perceived as busy, typing furiously and trying to get her out the door as soon as possible. Many participants questioned how ‘good’ Dr Jones was in terms of his communication and patient skills.

13.2.1.1 What Trust Does

Patient participants were asked whether Sabrina trusting the doctor would change anything. Patients, on the whole, said that it would change things (37 participants out of 40); trust was seen to encourage openness, change feelings, and have an impact on outcomes and could potentially explain the situation.

Encourages Openness

Nine participants said trust would allow Sabrina to be more open and comfortable in disclosing information and asking questions. Trust between Sabrina and Dr Jones would, according to eight participants, make Sabrina more comfortable to disclose information about her symptoms. Otherwise, she might:
Kind of hold back on symptoms if she feels like she is being judged a bit
— Anton

Sabrina could or would ask questions if she trusted Dr Jones (13 participants).

Yes she wouldn’t be so nervous um and she would probably ask questions that you
don’t when you’re nervous.—Daisy

Impact on Outcomes

Five participants also identified that trust could have an impact on the way that Dr
Jones approaches Sabrina’s symptoms and the treatment plan or further investigations:

yeah but if you don’t let the doctor know what happening for you, for example, you
don’t trust them, and you hide a certain information they won’t be able to find out the
correct problem with you, so I think it’s very important.—Nat

It could also have an impact on Sabrina’s health, according to three participants. One
patient recalled:

...I always remember one of the research that went on that was if you believe your
doctor believes in you, it is, it’s, it is, more likely that you will not recover but last
longer for want of a better word so therefore the trust and the belief that you believe
your doctor believes you’ll do well means a huge amount.—Susan

Changes Feelings

Trust would or could change how Sabrina feels. Seven participants said Sabrina would
be less anxious, nervous or worried in a trusted GP–patient relationship. Two indicated
that it would increase Sabrina’s confidence in Dr Jones.

Might Explain the Situation

A previous relationship was seen as the basis for trust, with eight participants
explaining that it would be unlikely for Sabrina to trust Dr Jones at this first visit.
Five participants thought trust in the GP might explain Sabrina’s actions or make the
doctor’s behaviour okay, particularly if she had previous experience with Dr Jones and
knew his/her way of approaching things.

Yes, I think if she had history with the doctor and she knew that Dr Jones was writing
extensive notes and then there would be a follow-up with the specialists and the blood
tests then she’d be happier because this could have been just part of a longer journey.—
Sally
13.2.1.2 What Trust Requires

Patients were asked what Dr Jones could do to develop trust with Sabrina. Patients identified aspects they thought trust between a patient and GP required. This included a mutual relationship, the demonstration of care and time, and are reported as follows. Several contextual factors that could affect the development of trust were also highlighted.

A Mutual Relationship

Trust between a GP and patient requires a mutual relationship characterised by clear communication, openness and reciprocity. Ten participants expressly used the word relationship to describe what the GP needed to do.

There needs to be a personal relationship of some kind, and the way he um would look at her as he speaks to her would listen to her without necessarily writing every word down it’s the personal relationship thing that would have helped her to be relaxed.—Elizabeth

Others described the GP–patient relationship as two-way, implying reciprocity or engagement between doctor and patient. This included or required two-way communication, which would encourage openness and vulnerability.

...it makes a big impact on me when they really engage with me and they sort of ask me questions and um, when they ask things like “How do you feel about that?” or “How does that make you feel?” or “What do you think about this?” ...like a give and take kind of thing, instead of a this is what is wrong and this is how you fix it sort of thing.—Khaleesi

For the most part the onus was placed on Dr Jones to develop trust with Sabrina. This was conveyed concerning specific things the doctor should have done—communicate more, use body language (e.g. more eye contact), listen, make Sabrina feel comfortable. It could be as simple as:

...a smile or as simple as eye-to-eye, face-to-face contact I mean over here when Dr Jones is typing very fast obviously it’s as if he’s saying okay I don’t have time for you I want to see the next patient so of course you won’t build that trust because he doesn’t want you there.—Mary

Patients also described ways that the doctor’s behaviour could be mitigated, as with typing furiously:

I think, it says that the doctor is typing away like crazy, my doctor has done that many times but she talks what she’s saying, like “right now I’m typing notes, this is for... we want to do a blood test because you could have this or this could be this...” so you’re
Many of the participants said that Sabrina needed to ask more questions or be more confident to ask questions. Two suggested an advocate or support person could have been helpful to Sabrina. Overall, participants reinforced notions of trust requiring a relationship or connection, some form of reciprocity that demonstrated vulnerability and care. One participant did not think that the situation was about trust but more about the characteristics and behaviour of the GP:

"Yeah, you see I don’t know, I don’t know if it’s to do with being trustworthy, I think it’s got to do with probably his demeanour, his communication skills, you can be trusting but still behave like that, which sort of comes across like a little bit of a fairly cold really, and, and I don’t know if it’s all to do with trust."—Alan

**Demonstration of Care**

The reciprocity and openness of the relationship provided opportunities where the GP could demonstrate that they were interested in and cared for the patient. Five patients said GPs could engage by being understanding and demonstrating they care for the patient and their interests. This could be as simple as asking something personal:

"...it’s that ability to connect with the understanding...and remembering it so next time they come in they ask you about it so my previous GP I mean obviously he made notes about it but before it he read the notes so he wasn’t reading it and then ask me about it it was just a quick thing like oh you know Bob’s dog was sick last time, you know how is your dog? Did he get through that? Oh that’s cool and stuff like that so yeah I think it’s very it’s like oh you know me, you remember me, cool."—Bob

Showing interest or developing this relationship meant that participants would not feel like “just a number” or “just a patient” which was mentioned by a number of participants:

"...you’re treated as a number or a ticket, punch the ticket you’re done and you’re through there is really no personal interaction with the GP and that’s what I’ve found with other friends and family saying that “this is what you’ve got this is the medicine you need to take see you later and if you get any worse come back and we’ll see what we can do”.—Dan

This makes trust about relationships as opposed to a patient merely receiving care. One participant talked about the pressure put on GPs which pushed them away from relationship-based practice:

"You know I think...the scenario on the front [Sabrina vignette] is quite common because there is a lot of pressure on GPs to have to get through a significant amount of paper work and we have this system...that pushes doctors into a transactional mode away
from a relational kind of way of being and actually GP a big part of I imagine what many doctors get into medicine for is the relationship, supporting people. We’ve got a medical system that is focused on transactions to help people not be sick you know it’s really pushed down a very transactional route you know I think that actually if we want people to be well then we need to focus on the relationship.—Roberto

Another participant talked about how she would like to see a relational approach to general practice result in a holistic approach to health:

I’d like to see the doctors instead of curing people so called “curing people” actually promoting uh ways in which people can be healthier so you know the what is it the ambulance at the top of the cliff as opposed to the bottom...Like when I take my car to the garage, because I’ve been with him for 40 years he will say to me look Susan I think you know your cam belt really needs to be changed you can leave it but if you change it now you’ve got another 100kms but if you leave it and it cranks out it will make your engine blow up and it will cost a lot of money, it’s the same thing why don’t doctors do things like this instead of just saying here’s a pill.—Susan

Time

Trust, of an interpersonal nature, requires time to develop. Eight participants mentioned that having trust in the doctor when meeting them for the first time would be difficult—more than one interaction is required.

I think trust for me, comes from a relationship, and I guess you can’t build a relationship if you see someone once a year...that’s not on them and I guess it’s not on me because I don’t want to go visit them all the time just to have a good relationship because if I’m not sick, I’m not sick so it’s probably hard...even if it’s your first time to see a doctor, if you don’t see them for another year then there probably isn’t going to be a good relationship there.—Nicole

While the first consultation may provide a basis of trust to see them again, trust was seen to require time to build up.

13.2.1.3 Initial Impressions and Contextual Factors

Participants highlighted the way that initial impressions and contextual factors could positively or negatively affect the relationship and the potential to develop trust. This includes things such as the power dynamic between the doctor and patient (15), and the vulnerability of the patient who is unwell (11).

Power

Power was seen to impede the patient’s ability to initiate or build trust:

I think it, because of the power dynamic with the doctor being on such of a on a pedestal, it is really hard I reckon for a patient to try and initiate that trust, I think it
does need to, well it doesn’t have to, but in this sort of situation it has to come down from the doctor down.—Anna

This power stemmed from the doctor holding knowledge and being the one you go to for help:

Um she should have spoken up but I–ah again it might not it might feel like the doctor has the power and you’re sort of not but it seems a bit she should speak up but I do understand that there is people that are quite nervous out there and you sort of go to them [doctors] as the knowledgeable one and they’re helping you so you sort of I don’t want to say anything I don’t want to step on toes um so you just sort of get your referral letter and go okay um.—Nicole

Time Pressure

Another factor that participants identified was the time pressure of a 15-minute consultation which was exacerbated if GPs appeared to be under time pressure:

the doctor seems very busy and stressed so maybe he has a lot of patients to do during the day, more than he can cope, but yeah.—Rosa

Many participants said they understood that GPs were under pressure and could not have a “leisurely conversation”; they indicated that sometimes there is not enough time to establish a connection or rapport, let alone start to build trust in 15 minutes. This indicates that each interaction is important, and presents the opportunity for trust to be built or for it to decline.

Cultural Appropriateness

The worldview of a GP (real or perceived) can also present barriers to developing trust, particularly where assumptions are made about your cultural or ethnic background. Three of the four Pacific participants raised cultural appropriateness as important. Judgements on the basis of ethnicity were seen as problematic and a barrier to developing a trusting relationship with a GP:

So it’s based not only on your looks but also on if they automatically assume I’m Pacific and I’m walking in of course they will treat me differently I think if I was a non-Pacific say European…So when they come from that lens and they speak to you from that you almost feel like um you almost feel like you’ve been judged then and then and so you you’re not being given the care that you have a right to you’re not getting the care that you deserve and so that questions also my trust in that doctor because they’re not doing their job and I feel they have to be they have to be able to be open minded and understand us as a people especially being Pacific and so that would make me feel uneasy.—Mary
Two patients who talked about growing up in a different country described their negative experiences with GPs in New Zealand. Lucy, a 25–34-year-old female who identified as Chinese, describes her experience with a “Kiwi doctor”:

I think for the first time I met her and we talked about some kind of test oh the name is cervical smear... to be honest in my country I had never heard about that test before and she asked me she said “have you ever attended this kind of test before” and I said no I had no idea about that and she said “Oh you have to do that and you also need to pay that” and I think that’s okay I would like to pay for that and then she said “because you don’t belong to here”, what I don’t belong to here yeah I don’t belong to here but you don’t need to mention it you don’t need to advertise that so I feel a little bit like look down upon yeah looked down upon... but I don’t think that would happen with the Chinese speaking doctors but they would say you need to pay for that type of test but you don’t they wouldn’t say “you don’t belong to here” maybe in our culture it is not so polite.—Lucy

This participant later described her current GP, who is Chinese speaking and understands her background as a doctor she trusted. Cultural aspects were not mentioned as barriers by any NZ European participants. However one NZ European talked about cultural background as something GPs should consider when building trust:

...right from the start find out about their patients about who they are where they come from because you can tell a lot it’s that holistic thing again because sometimes what when someone is ill it’s not just the physical thing, it’s their environment they’re in, it can be the food they eat, it can be the culture they come from, or there is a whole range of different the whànau the family background so it’s there are a whole range of things that can give you a view as to why a person’s wellbeing is not has been compromised whatever.—Joanna

13.2.1.4 Types of Trust

Participants identified trust between a patient and GP as being about the interpersonal relationship and the role of ‘doctor’. This was also characterised in terms of the initial trust one might have when seeing a doctor for the first time, as opposed to the type of trust built over time.

13.2.1.5 General or Inherent Trust in Doctors

Participants were asked what they inherently trusted about doctors. The reasons given included the position or title of ‘doctor’ and how it was respected or regarded within society, and the knowledge or competence of the doctor.
Position in Society

Six participants referred to the position of a doctor within society and the respect and trust that engenders.

Well I think that when someone says they’re a doctor you inherently trust them anyway because obviously you hold doctors up here, lawyers maybe not, you know there are certain professions where you presumably trust those people.—Joe

Five participants, who were NZ European and over 50, identified that many in their generation or older put doctors on a pedestal and viewed them as ‘Gods’ to be obeyed not questioned. However, these participants said that they were more critical, and did not regard doctors in this way.

Knowledge, Experience and Expertise

The key aspect surrounded the training and qualifications of doctors as well as their knowledge, expertise and experience. They have medical knowledge that patients do not have, or they know how to access that information and have been trained to know what to do in response. This was described by one participant as inherent trust in the process that doctors go through:

Um, the process, that they’ve the knowledge, the learning, the experience, the coaching, someone mentoring them, the supervision, so therefore I trust that they know their stuff and that they are going to be able to ah lead me down the pathway to good health. If they don’t have the answers I trust that they are able to access knowledge.—Kaha

Participants described how becoming a doctor reflects a dedication to years of medical training. After all, says Joy “...med school is really hard and really long (laughs) and really expensive so whoever wants whoever is a doctor has put in a lot of commitment”. GPs’ reasons for becoming a doctor were also a factor, including altruism and wanting to act in the best interests of their patients.

I trust that the majority are in or have decided to do that profession for altruistic reasons it’s a bloody hard profession, and so I trust that they’re in it for good generally good reasons.—Roberto

13.2.1.6 Initial Trust

General trust can have an impact on initial trust as can role-based trust. Many participants noted it would be hard for Sabrina (from the vignette) to trust the GP since it was the first time that they had met. Others implied that other things could influence initial trust such as research or the recommendations of others.
Research

Initial levels of trust in a doctor could be influenced by research a patient may have done. Seven participants highlighted the importance of choosing “the right” GP for you. This could include the GP being someone you relate to; someone of the same age, gender or ethnicity as you; someone who has a good reputation; or someone who has a particular skill set or knowledge base that is important to you. Joe talked about how he tries to find the right fit by asking lots of questions:

I think people will automatically think they can trust the doctor, I’m a little bit different I actually ask them a lot of questions that’s just because of how I am I want to find out whether this doctor is the right fit for myself in terms of simple example the sport I do the ethnicity that I am cos sometimes it is a bit hard for a doctor say they’re of Asian descent to relate to a Polynesian because of you know the food we eat and our body structure and things I think it’s just those little things like for me I always ask my doctor a lot of questions to make sure they know and for them to be upfront if they don’t know... —Joe

Related to this, five participants talked about finding out information about a GP to increase their confidence or trust in the GP they were seeing. This could include information from people you know, looking at the website of the GP practice, or social media.

...although I still think that um it is hard to trust someone that you haven’t met before you know some you can find some information or–or about them either through friends or online which might give you some level of trust but the importance of that relationship, of first impressions, or establishing you know like an initial rapport is really important.—Roberto

Recommendations

Initial trust was further explored with participants in considering the impact of recommendations or the opinions of others on what they thought of a GP. Twenty-eight participants said the opinion of someone else would influence what they thought of a GP because “...if your friend kind of trusts them you feel like you could trust them.” (Jim). This largely related to trust in the person that they talked to or got a recommendation from and what they say:

Yes, obviously if you trust the person that is telling you about the doctor certainly it will influence your view and you will be either more confident and more trusting or less so depending on what you’ve heard.—Jason

For some of these participants, word-of-mouth or the recommendation from someone they knew served as a way to reduce risk associated with visiting a new GP. Mark said:
I think it’s like anything, like if someone recommends a good real estate rather than you just choosing one out of the phone book is someone say’s hey da da da’s good then you have more confidence in that person that they are good as opposed to going in blind so yeah definitely.—Mark

A recommendation could also save you from wasting time and money and the risk of poor treatment. A minority said it would depend on what was said, and they would make their own conclusions. Three participants mentioned that if something negative had been said about the GP they had been seeing for a short time, they would wait and see how things turned out. One participant said hearing something negative was unlikely to impact upon her view of her current GP:

I’m fully aware that people make mistakes and it is the relationship, your personal relationship with that GP so everybody’s relationship is different or–so I don’t unless it’s something really, really bad I don’t really take a lot of it, I mean I’ll listen but I don’t really um let it kind of bother my judgement because I think it’s a it’s such a personal thing um so yeah I definitely do listen and if it’s something like I say real bad I do consider it but overall I don’t think it would really phase me especially with my personal GP.—Penny

13.2.1.7 Role-based vs. Interpersonal Trust

Participants were asked to think about their current GP or GPs they had seen think about the reasons they trusted them (if they did). For instance, did they trust them because they were a doctor and that was their job, or because of something else? One participant described two types of trust:

there is the “I’m assuming and hoping you know what you’re doing because this is your job”, and then there is the “I see you every month, we’re quite close, I like your personality, I like how you’ve treated me so I have a trust in you as both as a doctor and as a human”—Nicole

Four responses emerged as the reason for participants trust in their GP:

1. Trust because they are a doctor and that is their role
2. Trust them because of something else
3. Combination of 2 and 3
4. None of the above/Did not trust GP for either reason

There were no patterns across age, gender or ethnicity for these responses.
Did Not Trust GP for Either Reason

Four participants said that they did not trust their GP for either reason. One said GPs were just a portal to specialists; another stated that they only went to that GP because they held their medical record, another said that GPs are too general and another referred to their GP as they were “a bit crap”.

Trust GP Because They Are a Doctor and That Is Their Role

Eight participants said they trusted their GPs because of their role as doctors. One participant talked about the knowledge of a doctor compared to a teacher:

I would certainly say that I trust them because that is their job. That is their job. So, um, it’s it’s funny because, as a teacher I always found that...education, it’s the only job where someone can walk in and tell you what to do because they have been to school, they have experience of learning themselves. But I can’t walk into a Doctors thing and profess to know, just because I’ve had a knee surgery that I could tell them what it takes to fix a knee, I don’t think I could ever do that, so, it’s specialist in my opinion, so yeah, I do trust, I do have to trust in them.—Tama

Other participants talked about the particular context of their GP practice as a factor in trusting GPs because of their role:

...cause I’m at the X doctors and they are a little bit useless, so I don’t have the same person each time or anything. So the reason I trust them is because they’re a doctor, not because they know my background or anything.—Anna

Trust GP Because of Something Else

Fourteen participants said they trusted their GP because of something else. The ‘something else’ could be related to the type of person they were, their personality or the interpersonal relationship that had built over time (through repeated interactions).

Um I trust them because I’ve built up a relationship with them they basically know everything about me so yeah I just feel they’re really professional and I feel I have complete trust and if there is anything I don’t mind opening up to them I’ll talk about anything...—Penny

Three participants indicated that while they now trusted their GP based on their relationship this had not always been the case. While going to the GP had been about seeing a doctor for their skills and expertise, they could now see the benefit of a relational-based encounter with their GP. All three of these participants were in the 35–44 age group, had a regular GP and reflected that the relationship had become more important over time. As one them said:
I think that’s probably changed as I’ve gotten older though, like in my twenties I was going to the A&E so I didn’t care about any relationship at all I just wanted the most knowledgeable doctor and if he was as cold or unfriendly as hell it didn’t worry me because I wanted the knowledge, now I’m more about someone that cares for me I don’t mind you misdiagnosing me once or twice because with a GP you know it’s not life threatening they will quickly hand me over if it is life threatening.—Bob

**Trust GP Because of Their Role and Other Factors**

Thirteen participants said they trusted their GP because of their role as a doctor and because of something else. These participants recognised the importance of the doctor role in the way they trust/ed their GP as well as the interpersonal nature of trust:

> It’s a combination it’s because they’re a doctor and it’s their job and also because I’ve built–because I’ve gone to my present doctor for fifteen years now so I’ve built up that relationship with them and I know I can trust them because they’ve proven that they can be trusted I’ll put it that way, they’ve followed through on what they say they’re going to follow through on.—Joanna

**13.2.1.8 What Trust Is**

Each participant was asked to define trust. This produced 40 different definitions. The key elements, as described below, include a feeling or belief, a mutual or negotiated understanding, reliance in someone else and the assurance in their actions, and having your best interests in mind. Nine participants described two of these dimensions in their definitions, while 31 described one of these dimensions.

**Reliance on Another’s Actions**

Trust involves reliance on someone else and the assurance that they will do something. Half of the patients (20) referred to trust as knowing that someone (or a doctor) will do something. Nearly all of the male participants included this dimension in their definition (11 out of 14) in comparison to only a third of the females (9 out of 26). This reliance was described as knowing, being sure, or security. Four participants used the term expectation—that the person will do what you expect. Trust as reliance on another person and assurance in their actions is described as:

> …being prepared to let someone else take responsibility for you rather than yourself taking responsibility for you—Anton

> …when someone says something to you, makes a statement that they will follow through on that statement and complete it um and they won’t they won’t promise things that is beyond their beyond their power or beyond their ability—Bob
Two participants described this reliance as a willingness to be vulnerable to the other party. One participant talked about trust concerning his expectation of a GP to keep confidences, and to be knowledgeable, competent and put the patient’s interests first:

> I think there is the trust about the confidentiality aspect, there is the trust about the competency of the GP, can you trust the competency of this doctor? I think there is the trust about, I trust that he’s got my interests at heart before his own interests, um, and the trust that he’s doing the best he possibly can with the knowledge that he has for my benefit.—Alan

### Feeling or Belief

A third of the patients (13) defined trust as a feeling or belief about a person—twelve of whom were female. Seven participants used the word confidence.

> Trust is a belief of one person in another to treat each other kindly and sensitively and that they share information and experiences positively—Kaha

> I think trust is the feeling you get when you establish a respectful relationship with someone that is defined by limits and boundaries.—Khaleesi

### Mutual Understanding

Ten patients defined trust as a negotiated, mutual or shared understanding. This involves some form of interaction or communication. Two participants described trust by saying:

> . . . open communication um the desire to work towards a common understanding—Roberto

> . . . An understanding between the two parties.—Anna

### Best Interests

Eight patients talked about trust as someone having your best interests in mind or that they will do their best for you. One participant defines trust as best interests and reliance on another:

> . . . knowing that the other person has your best interests at heart um and knowing—knowing without knowing that they are going to do their best to do right by you, just that expectation that um that they’re going to do the right thing by you, and uh just being able to believe what they say.—Kara

#### 13.2.2 Patient Information

Patients were asked what they knew about what GPs could and could not do with their personal information. Half identified that the information shared with a GP was
confidential or that confidentiality applied to the GP-Patient relationship. A third of patients conveyed that they did not know, were assuming, suspecting, or guessing about these things. The following quotes show an attempt to express what they know. Some of them do this by detailing what they think the limits would be:

I probably don’t know a lot, but I think that there is a measure of confidentiality, I accept that the doctor will possibly talk about my condition to colleagues, I expect it to be done professionally, and I expect that they might even publish something but then again it is confidentially. I expect that they will pass my information to another specialist if need be. And I just, yeah, I just trust that in all of the steps that they will treat my information professionally. I don’t expect it to be out anywhere that it isn’t supposed to be. Does that sound naïve?—Kaha

I would suspect that it would, that they would have to keep everything confidential and private. Um, I would also suspect that they have to keep their records in, for an X amount of time, I wouldn’t know what that period would be, I guess they would have to share information should I walk in with some sort of, small pox or something, maybe something life threatening to human life as we know it, but I would, I would hope that everything has to remain as confidential as possible.—Tama

Two patients mentioned privacy as an aspect of what could and could not be shared. On the other end of the spectrum, two patients said that all their information would be available across the health system:

I assume that there is a whole bank of information that the public health system can come into and get, so a GP will be able to get like with again with anything medical, if I’m doing breast screening which I just did there should be a two way process with these two as far as the breast screening people are concerned, of course they are not going to ask anything else hopefully... Because my GP would be my go to person, my first contact kind of thing, so that they would be able to know what is happening with me.—Bibi

13.2.2.1 Legal and Professional Limits

Thirty-four of the patient participants were asked whether they knew about legal or professional limits to what GPs can and cannot share.1 Over half of these participants (19) responded no to this question. Several of those who said they did not know explained why they did not know, or why they did not care to know. Two participants said it was about trust:

Nah. And again, because I have one hundred percent faith in these people, I don’t actually care, I trust that they know what they are doing. I have a bit of a belief to let them get on with their job, let me get on with my job, and if we have a problem then we’ll discuss it.—Louise

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1Six of the patients were not asked this question as they had been clear that they knew nothing about what GPs could or could not do with information in the previous question.
Fifteen patients gave an answer about what they did know of legal and professional limits for GPs and personal information—four patients talked about consent, and one mentioned a code of ethics that GPs would have, confidentiality was raised by two patients, and privacy by three. In terms of legislation, one patient cited the Privacy Act, and one the Official Information Act, both explaining that these provided guidance on what could be disclosed.

Well I know that there will be limitations on what they’re able to disclose and things about particular well presuming things about my health and also my personal details like my date of birth and my address and all of that information.—Dee

Four respondents outlined various reasons that information could be legally disclosed. These included public health reasons (e.g. notifiable diseases), in the course of a murder inquiry, psychiatric situations, or where there is a real threat of danger to someone.

13.2.2.2 How Patients Know

Patients were asked to think about how they knew about what GPs can and cannot do with their information, and whether this was from their experience, reading, research, talking with other people, or information from their GP. Over-half (22) attributed their knowledge to their experience, while a quarter said it was based on their own reading or research or talking with other people. Seven participants referred to media coverage of these issues, one citing the coverage of privacy issues in the media, one the media more generally, and the other five referring to things they had seen in movies and on television programmes.

Probably movies and television just like culture of you know seeing on movies that shrinks can’t you know divulge everyone’s secrets unless maybe it was like some intense murder case so I just presume it is the same with doctors.—Angelina

The five patients who referenced television or movies were all under 35, while the two who cited the media were older.

Five said that it was because of their experience of how information is treated within their job/profession—this included public service, finance, education, and allied health. Five patients said that they had talked with their GP about this, while several other participants said that they had never received such information from their GP. One participant reflected that her GP had never talked to her about this in the way that other practitioners had but that this may be because confidentiality is implied:
...I don’t think I’ve ever been told anything about confidentiality with a GP like ever, it’s really good with other clinicians but not with GPs and that might be because it is 15 minutes and it’s kind of implied. Anyway, I’ve found out through my own research and I work for a DHB so I know that side of stuff, as well as talking to people and stuff in the media as well.—Rey

Overall, six patients referred to this knowledge being implied or part of the general knowledge of what it is to interact with a GP.

### 13.2.3 Expectations of GP

Patients were asked about their expectations when sharing information about themselves and their health with their GP. Participants spoke more to general expectations about visiting a GP than to information-specific expectations. This demonstrated how information-sharing is difficult to separate from considerations of the GP–patient interaction more generally. Additionally, participants were asked if they expected the GP to treat them in certain ways, or to get particular outcomes. There were no patterns attributable to gender, age or ethnicity across these expectations.

#### 13.2.3.1 Care

Patients’ expectations of GPs centred largely on the provision of ‘good’ care—this was seen as involving good communication, professionalism, and knowledge. Patients expect to be cared for by their GP as expressed by 32 patients, with 11 patients saying the GP should be thinking about the patient’s interests.

I’d expect them to to care for me to the best of their ability where my interests are prime.— Alan

Patients expect the information that they provide their GP to be used to help them:

That they will use it for the betterment of my health they won’t share it with others beyond that. So the intent of me sharing is to get healthier and that is the purpose for them sharing with others so that is the only reason they will do that.—Roberto

Eleven participants talked about the expectation of confidentiality:

...that they keep it confidential or if they need to use that information for some reason then they—they seek my advice or seek my permission first.—Mark

### Application of Knowledge

Related to care is the expectation that GPs are knowledgeable, and that they apply their knowledge to the situation. This was identified by 11 patients.
...I just expect them to read over or to just identify uh an issue or identify what the issue is or what the possible issues are and then go through the whole diagnosis process or if they don’t know what the problem is or they know someone who could deal with it better to refer me on...—Harvey

Another 9 patients expressed that GPs should make good decisions about what is going on and what to do about it. This may include a diagnosis, treatment, further investigations, information or advice, or referral to someone who can help.

I expect him to, him or her to um give me the best advice and treatment that they know of and if they don’t know what’s wrong or if they don’t know how to help I expect them to be able to refer me to someone who can um I expect them to do their best to find out if it’s not something that they can pinpoint I expect them to do their best to try and find out what’s wrong and how they can help.—Kara

Outcomes or Results

Many of the care and communication aspects, as outlined earlier, come back to a general expectation that GPs should address a patient’s problem or symptoms. This is an expectation about the GP getting certain outcomes or results for patients. This was expressed by two participants as an expectation to “make me better”:

Just yeah I do so if I go in there and I’m sick I want them to make me feel better that’s the outcome yeah and I think that’s what we all expect of doctors don’t we? Make me better.—Mark

Other participants said that they expected the GP to address their problem in some way:

Um I do kinda I guess I do have an expectation that they will be able to help me with my problem but I I also know that it is each to their own so I know they won’t be able to fix everything but I do expect them to to to do it for the most part.—Rose

Several participants expressed that they recognised that GPs were human, and there was only so much they could do.

...because they’re human as well and they can only do what they can with the tools they’ve got.—Penny

One participant questioned the role of GPs and their ability to get results:

...it’s made me wonder on many times I’m sort of going like what is your purpose I feel like they’re the middleman like when you need tenants for your home they’re like the property manager so they just sit there and sort of listen to you um and usually they sort of figure let’s send you to the blood people or we’ll refer you to a specialist.—Nicole
13.2.3.2 Communication

Twenty-seven patients referred to communication as an expectation. This includes: listening and believing what the patient is saying (14 patients), being curious or interested and asking more questions (7 patients), and putting the patient at ease (4 patients). Patients also expect their GP to talk to the patient about what might be going on and explaining things clearly (19 patients), and making good decisions based on the information they have (9 patients).

...if they find out something that would affect my health then I would expect that they would instigate the communication or would contact me um as far as treating I think as long as they’re friendly and polite you know and respect you I don’t think there is any problem there I think these the best thing they can do is just tell you what is going on if you look at any issues, not with GPs with anyone, 9 times out of 10 it’s with communication and people haven’t communicated what they’re doing or what they’re trying to say effectively or properly and that’s where all—all problems start and finish really.—Mark

13.2.3.3 Professionalism

Thirty-nine patients expressed the need for GPs to treat or approach patients in a professional manner—this includes being respectful, friendly and approachable and maintaining confidentiality.

Respect

Respect was mentioned by 15 patients—including GPs treating patients with respect, and respecting patient decisions. An aspect of respect includes believing what the patient is saying, and communicating in a way that is respectful:

Um I will expect him to approach me and treat me with respect um that’s the main think because as long as they’re communicating to me about what’s happening and the way things are going to be done I’m pretty much okay with most things but if they do it in a manner that feel offensive or undignified then I’ll take issue with it.—Dee

Friendly and approachable

Twelve patients described expectations relating to the interpersonal skills of the GP. This related to the GP being friendly, approachable, open and honest. One patient describes this as an expectation that the GP will treat her with “...just sort of general personable niceness” (Angelina). GPs should treat patients as more than just a number:

I expect them to treat me at the time like I’m their only patient, they shouldn’t cut any corners with me just because I’m one of 200 or 500 of however many. I feel like I deserve their attention for that 15 minutes or whatever it is.—Anna
Several participants described this as being friendly and approachable while maintaining professional boundaries in the relationship.

Yeah I expect them to be friendly but professional, not my best friend um tell me like it is um but still with empathy and sympathy and listen, no hear, because they can always listen but to hear what I have to say.—Sally

**Confidentiality**

Eleven patients talked about confidentiality as an expectation when sharing information about themselves or their health.

Well number 1, with whoever, I don’t think that it’s the case of feeling nervous about the confidentiality aspect I think it’s really just whether you actually relate with the person or not and whether you feel comfortable with um, telling them all. I think the confidentiality thing, you know I think that’s a total expectation, I mean, I presume.—Alan

Several of the patients talked about confidentiality as an expectation, and also underscored the importance of professionals working together which would require information-sharing via referral and other means:

Um I expect that they will respect the information that is being given to them um and that there would be confidentiality within that um but the also that they would work in a network as opposed to as individuals so like if it needs to happen there would be like referrals for certain things and that sort of the doctor works in the community as well yeah.—Joy

Participants’ thoughts about information-sharing are outlined in Section 13.2.5.

**13.2.4 Genesis of Expectations**

Patients’ were asked where they thought their expectations of GPs and information-sharing came from. Participants cited their interactions or experience with GPs, family and friends, work or education, media, and common-sense or general knowledge.

**Interactions or Experience with GPs**

Eleven participants said that their expectations were informed by their experience with GPs. One participant said that her positive experiences had set her expectations:

...like my experiences like I’ve had quite positive experiences with a lot of health practices that I’ve come across with so yeah I guess I just expect to be like the person that I saw prior—Rose
**Family and Friends**

Fifteen participants said that their expectations came from talking with family and friends. This included the expectations of their parents as they were growing up and stories about the medical profession. Eight out of the 11 who said that family influenced their expectations were NZ European, with the other three being Māori or Pacific. There were no age or gender patterns.

> I suppose partly my upbringing my—what I’ve been taught by my parents and family, and my professional training, and partly my experience.—Jason (Male, 75+)

> A lot from just conversations with family and friends and what my, especially from what my parents expect from their GP, I reckon that influences how I treat my interactions with my data and with my GP.—Anna (Female, 18–24)

Three participants said their expectations had been influenced by close family members and friends who were GPs or in another medical field.

**Work or Education**

Fifteen participants said that their education or work provided the basis for their expectations. Those who mentioned their education were all aged 18–34, while those who mentioned work were 35 and older. Eleven patients referred to their experience or interaction with GPs providing the basis for their expectations. One participant described how experiences reinforce your expectations of what is or is not right:

> I think just growing up signing forms about confidentiality and I think um, just in general experience and respect and I think you go through a lot of, you see a lot of doctors and go through experiences where you have sat there passively and nodded your head and let them intimidate you or whatever and with hindsight as you’ve grown up you realise that’s not right.—Sarah

**Media**

Seven participants talked about the role of the media—news, television, movies and books—in setting expectations.

> Movies (laughs), um yeah I mean there is lots of media, movies, and conversations um your own personal beliefs um yeah, yeah—Mr Purple

Another participant talks about the role of children’s books in setting expectations:

> It like it’s probably really deeply ingrained in like little kid books and stuff that you read you see in like kids’ books a doctor with a clip board and there is an element of privacy because they are writing and you don’t know what they’re writing down and then I guess going to the everything about going to a doctor feels very professional
and clinical and that’s kind of connected to my head to being ethical and holding confidentiality so yeah I think it’s like being a doctor and confidentiality are quite like integrated ideas.—Joy

**Commonsense or General Knowledge**

This idea of expectations of doctors being deeply ingrained is talked about by six participants as a type of general knowledge or coming from common-sense:

I don’t think I’ve ever been in anywhere where they’ve told me that this is what they do with the information, or I don’t see it written on the wall anywhere so I just think whether it’s um GP or Lawyer or Accountant or any professional like that I just it’s just common-sense really what they do with their information.—Mark

**Culture**

It is unclear whether expectations have a cultural component. Four participants compared the New Zealand system to another country: two of them said they had developed new expectations of New Zealand, while the other two said that their home country might have impacted the way they view GPs. These four participants described the way previous expectations can have a positive or negative impact on your experience of GPs.

I have had to change that mind set because things are done so differently you know, so what happens in Singapore where you assume there is that level, I’ve had to get rid of that assumption…—Bibi

**13.2.5 Information-Sharing**

Participants were asked several questions about how they felt about information-sharing including disclosure to a GP; a GP sharing with other medical professionals, organisations or third parties; and conversations about information-sharing and how GPs can be trustworthy with information.

**13.2.5.1 Concerns with Information-Sharing**

Participants were asked if they had any concerns about sharing information with their GP or their GP sharing information about them with someone else. Patients described their concerns in relation to the potential exposure of their medical history or the perception that they had nothing interesting or of concern.
Exposure of Private Information

For some patients (7), there was a fear of exposure in relation to information-sharing. This came from not knowing what would be shared or who it might be shared with. What patients share with their GP are private details about themselves. Patients do not want these details exposed to “just anyone”:

Um, I guess all these things are very private, I don’t want, it is just a privacy issue, I don’t want my innards to be open for everybody to see, you know, I open it to my doctor for a reason because I want the doctor to be able to take the best care of my health and the more open I am with a doctor I think the more information I give a doctor then they will be able to help me better. But if it is nobody else’s business they shouldn’t have it at all, why should they?—Bibi

Loss of control over information was a concern:

Yeah, yeah, yeah cause um if the information is spread out to too many people it can be interpreted in multiple ways.—Dan

Sensitive Information or Issues

Patients were asked whether they had concerns about information-sharing about sensitive details or issues. Twenty patients expressed some concern. For five patients this concern was balanced by the need to share, or the ability of, that information to help them:

Oh, and again I think…it’s with the goal of better care or better result for me um share all the all the sensitive information you want really gosh you know you know because there is information that is sort of embarrassing or something I’d rather people know that about me but then I get a better a more accurate diagnosis of me that gives me better care that’s going to get me better or enable me to manage my health better through my life you know much more rewarding you know.—Bob

Three participants referred to the professional conduct of GPs, and the role of consent in sharing sensitive information:

So I think that if the GP shares that for professional issues then I have no problem if I have given consent. He should respect me as an individual and ask me if I can let him do, then I am all good.—Nat

Five mentioned that sharing sensitive information with your GP was about being comfortable with them:

No, not from a like whether not from a privacy point of view but from a comfortable to share those things I think that comes back to like I prefer trying to find someone that I can relate to more and therefore a woman doctor and so yeah I find it more comfortable to talk about sensitive issues in that way but yeah but otherwise not too much.—Angelina
Uninteresting Medical History

Fifteen participants said they did not have any concerns. Ten of these expressed that they did not have anything that they would be concerned about getting out with some using the term “boring” to describe the ways in which they thought their medical history would not be of interest to someone looking at it.

None, No, I’m not that complicated, I don’t have anything that particularly embarrasses me or anything along those lines, and and I’m pretty trustful that if information is shared it is shared for a reason, so I don’t have any concerns around that.—Gerard

Several participants said that while they have nothing to worry about they could understand people who would:

...if I was patient “B” and they just gave my case file to anybody I wouldn’t actually care to be honest I probably wouldn’t care if they gave my case file and it had my name because there’s not much there. I would care less even if it went to the media ever, I’d be like so what, but that’s cause that’s for me I can imagine many other people that I know who have a big history with doctors and medical files and there is no way in hell that would be okay—Nicole

13.2.5.2 Share When Necessary and Appropriate

The majority of patients (34) expressed that information should be shared only where necessary or appropriate. This was related to sharing information in the course of a patient’s care, with other health professionals, for testing or other investigations or where it would be of benefit to the patient.

I wouldn’t want my you know medical history to be shared with anybody apart from my GP and any other doctor who I’ve been referred to but any other organisation why I don’t see any need.—Laura

To Benefit the Patient

There was widespread support for information-sharing within the health profession. This was conveyed as participants having little or no concerns about sharing with their GP:

I don’t have concerns in sharing with the doctor and I would hope they wouldn’t be sharing it with anybody else unless it was a medical person for a medical outcome.—Daisy

Another participant talked about the benefit of sharing information with others so that the patient is treated by someone who has more knowledge and expertise:

I’ve had that with this mole on my neck where the GP looked at it and said look I’m not that good on moles do you mind if I get another GP in to look at it—I’m hardly
going to say no to that kind of thing. So yeah I expect them to do that even–even if they say you know “I–I know a specialist do you mind if I talk to them?” I can’t imagine the patient that says “Oh no I won’t let you, only you, you have to solve it” well I’m telling you I know someone who’s better at this, you know so I think yeah I think I expect them to do it.—Bob

Complete information was also perceived as better for patient care as the more the GP knows, the better equipped they are to do their job.

**Share Non-identifiable Information**

Seven patients mentioned that the use of pseudonyms or making the information non-identifiable would mean the sharing of information was of less concern. Three believed that their information would not be shared unless it had been anonymised:

> I’m not particularly concerned, I think I have a lot of faith that if they share anything about me they probably wouldn’t associate my name with it and therefore there is anonymity anyway, so for me it’s kind of a non-issue.—Angelina

Three patients said that information might be shared for research purposes but that this should be non-identifiable. One patient mentioned sharing statistical data, particularly in relation to Māori health outcomes.

**Where Legally Mandated or to Prevent Harm**

Eight patients highlighted circumstances where they would expect information to be shared. Most of these related to a criminal, legal or mental health situations, to protect individuals from harm. For example:

> Um, I would expect them to with the hospital so that they are aware of what is going on if I have to go in for an emergency. If I need to go to the Physio and for some reason there is something that they need to know, I would expect that I would be able to enable so that they can find out what they need to know. Apart from that, no not really.—Anna

> Um I would expect them to work with like other government agencies so things like CYFs even the Police maybe which they don’t but um I would sort of expect them so if a woman comes into them and has been heavily beaten and she discloses that she has been ah beaten up by her husband really I think there should be a duty bound thing for them to inform the police um and even if it’s in a way of so the police might not be able to go and arrest the person and take that sort of action because we don’t have statements and things like that but it makes the police aware or if there is a child that comes in that has been abused then they can notify CYFs so it’s really for the end wellbeing for that person not necessarily for you know prosecution or–or a witch hunt kind of thing.—Bob

One patient mentioned notifiable diseases and defrauding public funds and another highlighted that there may be situations with adolescents where information needs to
be shared.

13.2.5.3 Third Parties

Patients were asked how they felt about information being shared with a third party such as an insurance company or other organisations. Patients wanted to know why the third party wanted the information:

Yeah, like if I was applying for a job or, I, yeah I would expect that if the employer rang my GP that my GP wouldn’t say a whole lot of things, um, but I would probably expect that they shared it with other, like maybe the police if it was a situation, like a mental health situation, um or kind of those other trustworthy organisations um, yeah, I guess with insurance and ACC again, it’s depends why are they, what are they looking for and yeah, so I’d like, they shouldn’t really, if, if insurance company just rang a GP, the GP should be like “what is this about, what is this for? I need to talk to my client about this”.—Sarah

The types of third-parties mentioned varied across the 40 participants. As one patient observed:

…it depends on the individual I guess who yeah I suppose everybody has places they don’t want their information given to.—Mr Purple

Seven patients mentioned that they would not want information shared with marketing companies or companies that would make money from the information:

Ah commercial organisations so outside of the health industry so if there is no good reason for them to share the information to support your health and improving your health then they shouldn’t share it.—Roberto

Other third-parties mentioned included ACC, IRD, Police, schools, and employers. Some expected that information would be shared with these third parties in particular circumstances while others were specific about saying that they would not want information shared with particular agencies. One patient outlined her discomfort when asked about her medical details by an insurance receptionist. This was someone she did not perceive as “need to know” even though she had given permission (by signing the consent form) for the insurance company to have these details.

13.2.5.4 Seek Consent

Nearly half of the patients (19) talked about the need for GPs to get consent or permission before sharing information, particularly with third parties. The majority of patients expressed a desire for their GP to seek consent or permission so that they knew what information was being shared:
Well put it this way I would not expect him to share it with anyone that I had not
given consent for him to do so.—Jason

Um, I think permission should be asked, I’m not comfortable for them just to find out
because also that there could be some unscrupulous people out there that just ask and
they don’t know what the right hand doesn’t know what the left hand is doing kind
of thing so I do want to know that this is happening then so that I can agree to that
happening so that my GP has got the okay directly from me.—Bibi

Talking about consent, several participants outlined that this applied to people outside
the medical profession:

Well it depends, for people, like for example other medical people whether it be
communicating with a specialist or anything like that then it’s a given of course, but
for anyone else, yeah I reckon, anyone else. Yeah, I think that, I think that’s number
one really, and I guess, I guess now you know, that I’ve spoken with you for this period
of time I guess I start to get an understanding of what trust is about and I think
the element of trust is really about that confidentiality is setting right at the heart of
trust.—Alan

I would expect them to mention particularly if something was to go outside the medical
professional. In my experience here he tends to tell me whatever he’s writing to a
medical consultation or whatever anyway so I have a clear idea of what information
he’s passing on.—Saul

13.2.6 How GPs can be Trustworthy with Information

Patients were asked what GPs could or should do to be trustworthy with patient
information. The overarching themes were transparency around the use of information
and ensuring adequate information security. Three participants were unsure of how
they would know what information was shared unless it got back to them:

Um wow yeah you know I don’t even really know because they could share my
information with anyone and I don’t even know if I would find out sort of thing um
I’m trying to think of a way that they would share it and it would get back to me that
I hold on how do you know that about me you know specifically?—Bob

13.2.6.1 Transparency and Openness with Patients

Over half of the patients (25) talked about the need for clear communication about
what was done with the information or that there was openness and transparency
about it. Patients want to know, or be able to know where their information is, and
why it is being shared. Nearly half of the patients (18) talked about the need for GPs
to talk with their patients about how information is stored and when it will be shared.
One patient outlined the way that openness could increase trust:

I’ve never been told in any GP consultation what they’re going to do with my personal
information you know you get the um what’s wrong with you blah blah blah and you
see them typing into the computer but you don’t know um you don’t know where your information is going and you don’t know whether it’s going to be kept on that computer... if it’s going to be kept on a record or what so I’ve never been actually told by a GP person cause that would make me more trust–trusting of them if they tell me um what’s happening with my information—Mary

This openness by GPs is about making sure that patients are aware of what is being done with their information and their rights around information:

  Mmm I think they should always disclose to the patient when they are giving that information away no matter who it is and I think they do for the most part, I’m not sure that they let people know when insurance companies ask them for more information about stuff so I think there has to be some sort of etiquette or protocol around disclosing when that information is—when that information is going to another party.—Dee

Six patients talked about using a consent form or agreement that the patient (and possibly GP) signs as a way to ensure trustworthiness. Two patients mentioned written information in the form of a poster or notice displayed in their GP practice. The remaining participants said that this information could be talked about in a consultation. This could include talking about what gets recorded, what will be done with the information they collect, limits of confidentiality, who else might see the information, and any rights they might have to access the information.

13.2.6.2 Information Privacy and Data Security

Fourteen patients mentioned things that GPs could or should do to ensure the privacy and security of information that they hold.

Policies and Protocols

Seven patients talked about the wider practice environment concerning what other staff members do with patient information. Patients expect their GPs to treat their information privately, safely and sensitively. While the majority of this relates to the information in an electronic form, GPs also need to think about the physical environment where information is shared and used. Practices such as closing doors, locking computers or clearing screens, and using quiet voices help ensure privacy. One patient recalled that:

  ... in a GP office I went one time and the receptionist was really loud about what I’d done oh with what I’d been seen with and I was like “lady... come on”—Rose
There is an expectation that all staff in a GP practice are trained appropriately and are considerate of patient information.

**Audit**

Five patients mentioned the use of auditing or an audit trail. Three referred to auditing to ensure that protocol or procedures around information were up to date and in line with their legal and other responsibilities:

> Um outside auditors um internal auditing and making sure that new staff know the procedures... That there is a standard that is being kept that everyone is doing the same thing—Sally

Two patients talked about an audit trail, to keep track of who has accessed patient information.

**Data Security**

Patients were aware of the need to keep patient information secure with 14 patients discussing the security or safety of information in paper and electronic records. Patients outlined the need to have good passwords, encryption, and backups for computer records. For paper records, patients described locked cabinets, building security, and appropriate methods of destroying copies.

**13.2.7 Information Breach and Rebuilding**

In relation to the Dr Jones vignette, patients were asked about the impact of loss of data on how they felt about their GP/Dr Jones. They were also asked whether that would change if it were Dr Jones’ fault, what they would expect the GP and practice to do in response and how the GP might rebuild/repair trust following such an incident.

**13.2.7.1 Initial impressions**

Patient responses to the Dr Jones vignette were mixed. While many saw this scenario as problematic for a range of reasons, several participants thought the procedure for handling the data was acceptable. All of the participants felt that it was unfortunate that this had happened. Initial responses to this vignette ranged from “Bugger um well it is clearly a weak point in the security practice of the GP’s office” (Roberto) and “…far out why do you take something like that home?” (Rose) to “Dr Jones is
trying really hard and... his... GP practice are trying really hard to keep things safe but burglars have intervened” (Noelle). One participant outlined her initial impressions as a series of questions:

This is a straight out burglary or is it someone that believes there is some interesting information on Dr Jones’ files therefore is it for blackmail? Is it for publicity? Is it a famous patient? Is it for a reporter? File on a hard drive, now the thing is here is the problem like this even though only Dr Jones has taken it home if he it is customary to back things up, if he backed it up into the cloud could it be hacked? Could his stuff be hacked anyway?... Looking at that I would say that everybody is vulnerable uh to information being accessed and I’m not sure that there is any safe completely safe way of storing information cause as I said a hacker could get in very easily, he doesn’t need to steal.—Susan

These questions relate to the motivations behind the burglary, the nature of the information on the hard-drive, the properties of a backup (hard drive vs. cloud), the form of the information (electronic or paper/manual), and the security mechanisms (e.g. can he be hacked?).

13.2.7.2 Impact on Trust

The majority of patients (29) indicated that if something similar to the Dr Jones vignette were to happen to them, it would change the way they feel about Dr Jones. Eleven said that it would not change the way they feel about Dr Jones, with six patients saying it would not have an impact because it was not his fault that his house was burgled/ransacked:

...initially I would be frustrated that my data has potentially gotten into someone else’s hands but, after a while I think I would have to justify it to myself that it wasn’t actually Dr Jones who purposely went out of his way to distribute my health records. So I’d be annoyed but I’m not sure if it would change my view of them in the long run.—Anna

Several participants (3) distinguished between the procedure of the practice and the medical competence of the doctor. A poor procedure at the organisational or practice level is a separate issue from the competence and trustworthiness of Dr Jones, or how “good” a doctor he is:

Definitely about the surgery the whole practice and their security systems um because sometimes they could still be quite a good doctor they obviously the way they’ve chosen to be secure their information isn’t so good—Joanna

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The Procedure

Twenty-two patients identified the procedure (taking a hard drive home) as problematic:

Um accidents happen you know in this situation I think it’s a practice issue and you’ve got a flawed process that introduces the potential for human error which could be eliminated with good or decent thinking so I think I’d be more critical of the practice as a whole than the doctor.—Roberto

The procedure was seen to be problematic for three key reasons:

1. Patient information being taken off premises.
2. Use of a physical backup over remote or cloud storage.
3. Hard drive being kept at a residential address (Dr Jones’ home).

For some, the key issue was the responsibility placed on Dr Jones (or any one staff member) to take the hard drive home. For others it was about the hard drive being kept off-site at a residential address with some thinking that it should be stored within the practice (e.g. in a safe) or that those who took it home should have better security:

Why did the data have to be removed from the GP practice in the first place? So why is it not in the cloud? Or why is it not all electronic? Why do we have to have a hard copy because I feel like something could go wrong like it has. And with, if it’s Dr Jones as the last person leaving, does that mean that anyone could be taking it home, like the receptionist or another nurse. I have a lot of why questions I want justification why is this happening, why don’t I know about this?—Anna

For some, it was about using a hard drive as a backup and physically removing it from the premises as opposed to other methods of backing up (e.g. cloud storage or use of a data security provider and off-site storage). Some patients were concerned that the information could be accessed by whoever had stolen the hard drive. Many patients relied on the idea that if such a device was accessed, that their information would be one of many and would not be of interest in comparison to the information in other people’s files.

I mean...the way I’m thinking about it is, it is obviously not the Doctor’s fault, but, yeah because he is not in control of anything being stolen but additionally now everybody’s information is out there, on the other hand the burglars are probably not interested in looking through people’s medical information “ha ha ha you have haemorrhoids”, you know what I mean. I mean, if anything they’re just going to delete everything and sell the hard drive, but yeah, if it was my information knowing that just like some criminal had it, some common thief had it, that would be pretty uncomfortable.—Khaleesi
Others said that they did not have anything that could be held against them:

...there is nothing on my files that, well if this was me, there is nothing on my files that could be used against me. Unless it was an insurance company guy stealing it.—Rey

Two participants thought that stealing a hard drive was unlikely:

I don’t think it’s for the for voyeuristic pleasure of going through patient notes in the evening sort of thing and I do believe that the—the information would be secured as in encrypted or such so that whoever stole it would not be able to get access into it so yeah they’ve just got a hunk of plastic so I think it’s very—very reasonable.—Bob

**Actions or Fault of the Individual**

Where the information breach was attributed to an action of Dr Jones, participants outlined several implications. One patient reacted by saying:

Oh god yes, I could never trust him and would change, no way...Because this doctor has not understood his scope of responsibility to patients, yep, um, and he has taken it very lightly, he is not a very responsible doctor. So if he cannot be responsible with information, I don’t know how he can be responsible with my health and to really take it seriously.—Bibi

Five patients found it unlikely that a doctor would deliberately act in a way that would disclose patient information—all of these patients had earlier indicated that the situation would not have an impact on what they thought of Dr Jones. Eight participants recognised that “we are all human and all make mistakes”, and the same would apply to Dr Jones:

Ahhhh, if it, errrrrr, if it was a first time that it happened, you know, mistakes happen, that wouldn’t bother me too much, but if there was a pattern of that in that surgery or with that particular doctor then yes, and I would probably if that, if it started to happen regularly if he lost data you would start to question whether or not ahhhh that information is going somewhere else.—Gerard

Where a breach was attributable to Dr Jones, patients said that this showed carelessness and was irresponsible. This reflected poorly on his professionalism and approach to information. Patient’s health information should be treated with the care and importance it is due:

Yeah if it if it came out that he was just careless and just left it all in his car or whatever yes it would I would be a bit rather cheessed off. It’s kind of a little bit disrespectful because it is something that is not something to be taken lightly it is something that’s um yeah you’d feel as though you’d been a little bit exposed...but at the same time everybody makes mistakes it’s not as if someone has passed away because of it.—Penny

Explaining the difference between the initial scenario and a deliberate action, one participant says:
Because that’s [if the Dr did something] kind of blame on that doctor where as in this situation [points to Dr Jones vignette] it’s kind of the process that they kind of had in place and this a process you can amend and fix where as if it’s an individual who has done something blatantly that is basically on that individual yeah.—Dan

13.2.7.3 Expectation about Actions to Remedy

Patients identified expectations about what the GP and practice should do after such an incident.

Notify Patients

Over half of the participants (26) said that the GP and/or practice should notify, contact or inform patients about what had happened. This could be via a letter, email, or phone call.

Um I think they would need to contact their patients and tell them there had been a breach in their data security and tell them what the potential implications are of it so a letter to their patients or some form of communication with their patients apologising and identifying what they are doing to remedy—Roberto

Notify us, and be honest, um I guess if they were honest about it and nothing really big really came out of it I guess I would be way more forgiving or whatever than if I found out some other way, I really don’t like cover ups.—Kara

Apologise and Take Action

Participants also expect an apology and for appropriate action to be taken to retrieve the information. Patients also expect GPs and practices to learn from their mistakes and to make changes to ensure that such an incident would not occur again. Twenty-two patients said that the practice’s policies and procedures for storing and backing up patient information would need to be changed or updated, and 11 expected an apology.

Well they would have to change their way of securing people’s information mmm. . . and certainly not take it home.—Daisy

I mean they would seriously have to look at how they would retrieve what has been lost and what was going to happen with that, we’d have to be reassured I suppose about that and then definitely putting a decent system in place or else you go elsewhere I suppose.—Joanna Call you, apologise profusely um and keep you in—let you know what they’re going to do—Nicole

13.2.7.4 Rebuilding Trust

Patients were asked what a GP could do to rebuild trust if it was lost.
Rebuilding Trust Takes Time

Rebuilding trust is difficult. Three patients said that trust could not be rebuilt and would find another GP.

Not sure that I’d give the doctor a chance like that. I mean if it is a small mistake again put it down to human factor and that, but if it is just a huge mistake like that.—Bibi

Twenty-two patients outlined the difficulty of rebuilding trust because it takes time and effort, and some people do not see a GP very often:

I think, I think with a doctor if you have an episode where um something’s happened um because you’re only seeing them at a sort of almost you don’t see them often enough for them to actually repair, I don’t think aye, once damage has been done it is difficult to actually mend that damage. And again, mainly because of you know, you just don’t have that sort of contact with them sufficiently to enable that repairing to be done really.—Alan

I think just generally through time you’d kind of give them, if you keep going back to them, I mean there is kind of a limited exposure to a doctor so it’s not like a friend making it up to you by you know making you some cookies or something and their job is just to treat you so they’re not really going to be doing anything else so yeah just time.—Anton

Reassurance

Rebuilding trust requires an apology and reassurance that the incident will not happen again:

Um, the first thing is addressing it, owning up you know “yeah, we really made a mistake here” so accepting what they have done and not trying to palm it off or trying to blame it on something else, sure it wasn’t their fault that they got robbed but the reality is that they put sensitive information in a situation to be robbed, so I would suggest that them taking the onus saying “Hey, hands up, we’re really sorry, this is what has happened, to prevent this in future cases in the future this is what we have put in place, we will be monitored” and you know putting in what could prevent that, that would certainly go some way to building the, or repairing that relationship certainly.—Tama

Reassurance could be demonstrated by updating policies and procedures or adopting a new system.
13.3 GP Perspectives

This section presents GP perspectives on the issues of information-sharing and trust in primary care based on 12 GP interviews. Table 13.3 describes the characteristics of each GP participant—including their pseudonym, gender, age group, ethnicity, years worked in general practice, and work situation.

Table 13.3: Characteristics of GPs

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Years as GP</th>
</tr>
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<tbody>
<tr>
<td>Dr Alice</td>
<td>F</td>
<td>55–64</td>
<td>Asian</td>
<td>25</td>
</tr>
<tr>
<td>Dr Blue</td>
<td>M</td>
<td>25–34</td>
<td>Asian</td>
<td>0.5</td>
</tr>
<tr>
<td>Dr Daughter</td>
<td>F</td>
<td>55–64</td>
<td>NZ European</td>
<td>16</td>
</tr>
<tr>
<td>Dr Green</td>
<td>F</td>
<td>25–34</td>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>Dr Grumpy</td>
<td>M</td>
<td>45–54</td>
<td>NZ European</td>
<td>30</td>
</tr>
<tr>
<td>Dr Holmes</td>
<td>F</td>
<td>45–54</td>
<td>NZ European</td>
<td>23</td>
</tr>
<tr>
<td>Dr Judd</td>
<td>M</td>
<td>55–64</td>
<td>NZ European</td>
<td>33</td>
</tr>
<tr>
<td>Dr Monkey</td>
<td>F</td>
<td>25–34</td>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>Dr Stevens</td>
<td>M</td>
<td>35–44</td>
<td>NZ European</td>
<td>6</td>
</tr>
<tr>
<td>Dr Teal</td>
<td>F</td>
<td>55–64</td>
<td>Did not specify</td>
<td>30</td>
</tr>
<tr>
<td>Dr Violet</td>
<td>F</td>
<td>44–54</td>
<td>Asian</td>
<td>12</td>
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<tr>
<td>Dr Whittaker</td>
<td>M</td>
<td>35–44</td>
<td>NZ European</td>
<td>7</td>
</tr>
</tbody>
</table>

Note. a Ethnicity coded using prioritised output.

13.3.1 Trust

GP participants were asked questions about trust in response to the Sabrina vignette.

13.3.1.1 Initial Responses to Sabrina Vignette

There were two different reactions to the Sabrina vignette from the GPs. Some of the GPs thought that the vignette was an accurate portrayal of the first visit to a new GP where there are pressures on both the patient and the GP. Half talked about Sabrina being a new patient.

So I felt that you know this patient’s new to this practice, she has a lot of you know unsure, uncertainty about who her new doctor is and it looks like you know there is a lot of barriers between them and ah also the doctor’s obviously the patient’s too shy to ask him a lot of questions so the doctor doesn’t seem very patient centred. So that’s my initial impression there is not a lot of communication or trust or relationship building here at all.—Dr Monkey

Over half of the GPs mentioned aspects of the GP’s behaviour—being busy, typing furiously, communication (or lack of it)—and outlined what they would do instead. A
GP who has been practising for 30 years said that Dr Jones could be part of the “new breed of doctors” who prioritise information gathering over relationship building in the first visit.

13.3.1.2 What Trust Does

The majority of the GPs (9) reported that if Sabrina trusted the GP, it would change things. The other three qualified that trust is important; however it would depend on the relationship going forward.

Encourages Openness

Four GPs said that trust would make Sabrina more comfortable with the GP, and in disclosing her symptoms and asking questions.

I would have thought so, I would have thought she would feel more comfortable asking questions and therefore getting more feedback about her concerns.—Dr Alice

Does Not Excuse Bad Practice

According to 6 GPs, even if Sabrina trusted the GP, it still would not be an ideal consultation.

Yeah, I think she’d probably needed–this is sort of chicken and egg, she’s not going to get good trust unless she gets good listening and it sounds as if she’s sort of a little bit worried–anxious for starters and then she’s feeling like she’s not being listened to so she’s not going to trust. But maybe if it was the other way around then she’d be more trusting.—Dr Stevens

Trust cannot excuse bad practice. One GP said:

I think doctor–patient relationship builds up over time and once the patient trust the doctor yes the patient might get used to the doctor’s ways of doing things but most of the things towards the end of the consultation is not ideal even if Sabrina trusted Dr Jones.—Dr Violet

Other

One GP outlined that trust would have an impact on Sabrina’s outcomes.

One, she’s actually more likely to actually understand why she’s going to the specialist, two, she’s more likely to go, three, she’s more likely to do her blood tests, and um cooperate with any treatment and understand why she’s having the treatment done. So yeah, it makes a huge difference.—Dr Holmes

While trust is good for the doctor–patient relationship, it can also be another thing that GPs have to do, making it a burden.
13.3.1.3 Trust Requires

GPs were asked what Dr Jones could do to be more trustworthy or develop trust with Sabrina. Following that, they were asked if there was anything that Sabrina could or should have done. The GPs placed more emphasis on their actions in building trust, with two GPs saying outright that the onus was on them to build trust with patients.

But I don’t want to put any real responsibility on her [Sabrina, the patient] the–the onus should very much be on the doctor to be picking up these cues and providing the opportunities for those things...I mean it’s a two-way interaction but the onus is very much on the doctor.—Dr Judd

A Mutual Relationship

Trust between a patient and their GP requires the development of a mutual relationship based on reciprocity, openness and honesty. GPs talked about trust as being two-way:

I think it is a, it’s a two-way, it’s a two-way street and one as a practitioner you trust the patient to be honest with you and accordingly you will be honest you know so it’s a mutual respect of what you both bring to a consultation.—Dr Daughter

The consultation process requires both parties to be involved and to communicate openly and honestly with one another. It is about more than gathering information about clinical symptoms. All 12 GPs talked about communication, with several outlining the importance of building rapport and communicating from the very first contact with a patient:

Ah for sure well it doesn’t say much clinically does it but good rapport is the basis for you know good communication so if the doctor started off by having a bit of a mihi [introduction], sharing a little bit about each other and getting some common ground then Sabrina would feel more relaxed and she would feel more able to uh talk about uh you know what was on her mind or things that she was worried about.—Dr Whittaker

This includes establishing a rapport by finding common ground, respecting the patient, listening to them and asking open-ended questions.

Uh I usually think that to build a trust you need to know a bit of background about a patient and probably read them, ask them how they are doing and give them mostly open ended questions so that you give them opportunities to talk, pay attention to them, um and that’s probably more important because when you when a patient feels that their GP is listening to them they will be more comfortable opening up to the doctor so you need to make sure that you are listening to them at least for those first couple of minutes.—Dr Green

One GP said that good communication is the:

...cornerstone of what general practice is and we’re probably the best at of all doctors, so all, most GPs are good at it.—Dr Whittaker
This was in contrast to another GP who said:

I know that GPs don’t listen very well, you know we have a reputation for not listening very well so you know that’s how do you, how do you build trust um you are open, perceptive, warm, empathetic, have a have you know an obvious care for people and an interest in them.—Dr Daughter

Five of the GPs said that patients could help build the trusting relationship by being open and honest with them. Three GPs mentioned that patients may be more likely to trust their GP if they have done some research about them and the practice either by looking at the website or talking with others. Two of the GPs who had been practising for over 20 years talked about trust in relation to patients they had seen for many years, meaning that trust has been build over a long period of time.

**Demonstration of Care**

One of the GPs said that trust could be immediate, depending on the circumstances:

Trust can be immediate if you’ve you know they’ve come in and let’s re-write this case a little bit let’s say that Dr Jones jumps at the door as he notices the gash in her leg and is instrumental in stopping everything going into the waiting room sorting the bandages out, stopping the bleeding, making sure she’s okay and sitting her down in the room with a cup of tea and then asking her back in later as he’s seen three more patients, ah and makes sure that the nurse is having a chat to her and–and sort of attending to her, showing compassion those sort of things and then comes back, that way you could ramp up the trust level quite quickly.—Dr Grumpy

For trust to develop, the patient needs to know that the GP is interested in them and will do all they can to care for them. This can be demonstrated in the way that a patient’s history is taken and recorded, the examination of the patient and talking about the next steps. Some of this is about explaining things to the patient, so they know what is going on.

**Time**

Five GPs identified the role of time in building trust—four GPs said that trust takes time to develop. One said that giving a patient more time in the consultation would help build trust.

Yes, but trust takes time to accumulate so as long as Dr Jones tries to sort of handle her–her–her persona and beliefs and continuity and is a little bit more laid back you know um I’m sure that um things will happen yep, so trust is an important thing, but often trust is often the hardest thing we get and sometimes we won’t have trust for two years down the track with a patient.—Dr Grumpy
13.3.1.4 Types of Trust

The GPs were asked whether they thought that patients trusted them because they are doctors and that is their job, or because of something else. The GPs acknowledged aspects of public or general trust in doctors as well as trust in them as a person. All of the GP participants outlined that patients would trust them because of their role and other factors. After all, “I mean everyone who comes in comes to you because you’re a doctor” (Dr Green), and “...patients do give us their trust just by coming to see us” (Dr Daughter). The role as a doctor is what “...opens the door, but I would say that my patients trust me because of my previous behaviour so in other words trust is built.” (Dr Holmes).

**Trust Because They are a Doctor and That is Their Role**

The GPs who had been practising for three years or less outlined the difficulty in earning a patient’s trust, meaning that they have to work hard to establish trust beyond just the having the doctor role.

Um I think they, initially find it a bit tricky because I’m a bit younger and I look young so you have to work quite hard to earn their trust you’ve got to be quite thorough. You’ve got to be that anyway but I really make a point of working very, very, hard to get their trust initially especially because I look a bit younger and so things to do that are to be thorough, to try and chase up each of the things that they want to ask about and have enough time. —Dr Stevens

**Combination of Role and Other Factors**

The other factors that were mentioned related to interpersonal skills, competence and time. Trust in the medical profession was seen as one component of the trust that patients place in their GPs. The relationship developed between a GP and patient over time, and the characteristics of the GP and what they do (e.g. good listening, giving good advice) were also identified.

I think patients trust me obviously because of our profession I think there is a component to it but not all of it. I think that um you know it’s all about relationship building and your you know how you make the patient feel that—that you’re a good listener but you also you know are very keen to help, willing to give you know really you know um good advice that—that you really care for their health.—Dr Monkey

One GP described how some patients refer to a GP almost possessively as being “my GP”. This same GP said that sometimes patients prioritise the GP–patient relationship
when seeking medical advice from someone else at an earlier date was an option. There is a sort of loyalty that goes with trust.

13.3.1.5 What Trust Is

The GPs were asked to define trust. One declined, and one read a definition from a framed piece of artwork. The GPs identified trust as being about reliance on another’s actions, a feeling or belief, a mutual or shared understanding or someone having your best interests.

Reliance on Another’s Actions

Five of the GPs talked about trust as reliance on the actions of another, with three talking about trust as meeting expectations.

Yeah, so, trust is, that nebulous a nebulous concept that involves time, continued reinforcement of an expectation—Dr Grumpy

Feeling or Belief

Three GPs talked about trust as a feeling or belief.

I guess it’s sort of having a feeling that the–your–the person like say with the doctor–patient that the person is really has absolutely has your best interests in the forefront of their you know their practice and their mind.—Dr Stevens

Mutual Understanding

Five GPs talked about trust as a relationship or a shared/mutual understanding. Two GPs talked about trust as respect.

Trust, um defining trust, well it is a it’s um I suppose it’s an understanding it’s I suppose it’s a feel–it’s something that’s I don’t suppose it’s really an emotion but you feel you do feel it because you certainly feel mistrust um so um it comes from I don’t know mutual respect and this understanding and rapport and knowing and sharing. I don’t think one, one party trusts the other if there isn’t some reciprocity of that so it’s a as I said before it’s two person, two it’s um you know or a group you know it’s a thing it’s a shared um it’s not a feeling um hmm that’s a goody. I trust you, what does that mean? It’s kind of more than a faith, it’s more concrete than a faith. There’s a sort of assurance about it, there’s a reassurance about it.—Dr Daughter

Best Interests

Five of the GPs talked about trust as someone having your best interests.

Um, a, a situation where each party feels confident that they know what the other person is um expecting from them, that the other person will act in their best interest, um and they’re acting in their best interest without malice it—I suppose that’s another important part. Uh, and that they will do the best for them I guess.—Dr Alice
13.3.2 Patient Information

GPs were asked what they thought that patients knew about what GPs can and cannot do with their information. Two GPs said patients would know very little. Three GPs said that it would be variable. One GP said that it would depend on the person, their assumptions and experience of general practice, and their motivation to find out.

I think it is very variable um some people have already made it their business to know, other people again trust that the GP will ensure that it’s implicit in–in the whole doctor–patient relationship. We do obviously have written information that we normally give to people on enrolment but I’m not certain how much of it gets absorbed or read.—Dr Alice

The majority of the GPs (9) said they thought patients would have some understanding or assumption of doctor–patient confidentiality, but might not know all of the details:

I think most patients have got a basic idea of a health privacy code they probably don’t know the details of it but I–it varies a lot. I think most patients would be aware that there is some expectation of preserving confidentiality although young people, teenagers often aren’t aware of that and people from other cultures, where I work there are a lot of people for whom English is a second language they come from overseas and maybe don’t have any of those concepts. Um, I–I would expect all patients would assume that doctors can freely share their information with other health professionals um whether they–whether people realise that we can’t share that information with their employers or not or agencies like Work and Income or ACC I don’t know whether I think patients probably don’t realise that they have to consent for that information to be passed on.—Dr Judd

13.3.3 Expectations of Patients

GPs were asked what they expected of their patients. The answers all stemmed from the need for patients to openly and clearly communicate about why they are visiting the GP:

Um, that they tell me what they’ve come for I think that’s really the main thing and that’s what they’ll usually do.—Dr Teal

Honesty

The majority of the GPs (9) expected their patients to be honest. This included being honest or truthful about what they are coming to see the doctor about (e.g. symptoms), what they think it is (and any research they may have done), and doing what they say they are going to (e.g. follow up, payment, referral, treatment adherence).

I expect them to tell me what the problem I do expect them to tell me if they have asked tell me if they have Googled the research, that is very important nowadays people I feel
sometimes patients come with the diagnosis in their head and they come and expect things, they either tell you I think this is what is going on, I do expect them to tell me the truth if there is any—something bothering them it is, it actually depends on why they come in.—Dr Green

Related to honesty, two GPs said they expect patients to respect them.

**Ask Questions or Seek Clarification**

Seven GPs talked about the importance of patients communicating with their GP if they don’t understand, or if they have questions or queries that have not been addressed.

But I yes I do expect generally when I say to patients have you got any further questions or are you happy with that I expect that they will be generally comfortable enough with me to say yes or no appropriately or to ask further questions if they do have questions.—Dr Judd

### 13.3.4 GPs’ Perceptions of Patient Expectations

GPs were asked what they thought patients expected of them. They identified general expectations of any GP, and the particular expectations a patient might have in a particular visit/consultation. Patient expectations are important for GPs to be able to identify because general practice is “…all about expectations management” (Dr Grumpy); however understanding a patient’s expectation of the consultation can be difficult. Another GP talked about the medical and non-medical (often relational) aspects to patient expectations. One GP references expectations directly saying that they try to work out what a patient is expecting of the consultation:

So that’s sort of the first thing I try to tease out when the patient comes in, you know “why are you here?” “what are you expecting?” um it’s a lot easier asking that sort of question initially if you’re not sure so that I can try help them and yeah some patients will have expectations that you either can’t fulfil or you don’t think are best for them so I always try tell them what my thoughts are and what I can do for them and again being collaborative…You know in medical school and in GP we have quite a—it’s going more towards a patient-centred approach um so yeah talking about their feelings, their you know fears, concerns, their expectations, we try to incorporate a lot of the time.—Dr Blue

**Care**

All of the GPs said they thought that patients would expect them to apply their medical knowledge and expertise to the situation in providing good care. Three GPs talked about expertise and one about competence.
they expect me to be well informed and have access to both further information and the health care system on their behalf, yeah, an appropriate gatekeeper, an appropriate advocate where that is relevant.—Dr Judd

**Outcomes or Results**

Seven GPs talked about the outcomes or results that patients may expect. Patients visit their GP for a reason, with an expectation that the GP can provide a solution:

...some patients expect you to solve problems then and there.—Dr Green

There may be pressure on a GP to provide something within the consultation that the patient can walk out with like antibiotics or some other type of prescription. Cure or relief of the problem that a patient presents with is not always a possible outcome so sometimes it is about seeking comfort.

**Communication**

Four of the GPs said that patients would expect them to listen to them:

Well to listen quite a, you know, to listen and to listen accurately.—Dr Stevens

Patients would also expect their GP to be professional (3), empathetic (3), and respectful (3).

Four of the GPs said they thought that their patients expected confidentiality.

So I guess they expect me to keep everything confidential so I’m not going to go home and tell my wife and family and stuff, which is really important for them to open up.—Dr Blue

**13.3.5 Genesis of Expectations**

The GPs were asked where they thought patient’s expectations of GPs and information-sharing came from. GPs identified several sources including interactions or experience with GPs, the media, and common-sense of general knowledge.

**Interactions or Experience with GPs**

Several GPs (3) identified previous experience with GPs as a way that patients form expectations.

you know experience of general practice from a young age that this is sort of their go-to person and that with their family and things this is, that fosters I would hope an ongoing um understanding and respect of what General Practice may offer them at any time of their life—Dr Daughter
Media

Half of the GPs referred to the media as a source of patients’ expectations including news media reporting medical incidents, breaches of confidentiality and privacy; as well as the portrayal of doctors in entertainment media.

Um newspaper, the internet, the internet newspapers um, and probably a bit of the television news and various TV shows that kind of give them stories of doctors stuffing things up or privacy breaches that—that is kind of heavily reported on now.—Dr Stevens

Common-sense or General Knowledge

Four GPs also identified general knowledge or implicit assumptions:

...there is an implicit sort of understanding that you know that the General Practitioner will look after what you disclose to them and act on it um you know in a timely way to achieve what you want to achieve which is you know that they’re well, that the patient feels well looked after and that the patient is actually well looked after and whatever the prognosis that it’s resolved to the best it can be.—Dr Daughter

Two GPs talked about general societal expectations of doctors and other professions about how a professional ought to behave.

13.3.6 Information-Sharing

The GPs were asked whether they had any concerns about sharing information with other professionals or organisations.

13.3.6.1 Share When Necessary and Appropriate

Overall, the GPs did not have many concerns with information-sharing, mainly because information has to be shared in the course of patient care, to receive access to services and to receive payment for services.

Sharing is actually part of resolving...the patient’s um dilemma or disease or you know um or where they are at.—Dr Daughter

...as far as the DHB itself well yeah, um, if we don’t share the information we don’t get the service...so basically we have to.—Dr Holmes

Referral

Five of the GPs said that information-sharing is often implied, particularly when referring a patient to another health professional or service.

...it’s usually implicit in the fact that we’re going to be referring or whatever, or I don’t know enough about this I need to talk to a specialist or a colleague.—Dr Alice
Sharing With Other Professionals

The majority of the GPs (11) did not have concerns with sharing information with health professionals. This was due to an assumption about the professional ethos of other health professionals to protect privacy and confidentiality:

I think you generally, the one's that you’re choosing to share your information with you have an expectation that they are providing professional sort of level care and with it sort of privacy and confidentiality and everything so I can’t say I really get concerned...sharing with a professional.—Dr Stevens

However, one GP said that not knowing about the professional ethics of others was a cause for concern.

Sharing With Other Organisations

Seven of the GPs expressed some concerns about sharing information with other organisations. These were based on being unsure about whether patients fully understand the implications of sharing information with an organisation (for instance when signing an ACC form), or what organisations actually do with the information they are given:

With other organisations it depends I do have some concerns as to I suppose I have to–I always feel that I’m taking on trust that when for example the PHO or Ministry of Health say they are only extracting data around a certain parameter that that is all they are going to do and I almost feel that that’s a vulnerability that we have.—Dr Alice

13.3.6.2 Third Parties

GPs were asked about any concerns they might have about sharing information with a third-party like an insurance company or ACC. All of the GPs outlined the role of consent in sharing information. Without a patient’s written consent the GPs would not share information with a third-party:

They–they have really good policy they normally send us a consent form from the patient so without the consent form we are not allowed to disclose any information so they usually have good policy like they will get patient to sign a consent form first and then when they request for the information usually they have got patient consented.—Dr Monkey

The concern that GPs had about sharing with third-parties was more about the implications for patients, for instance where a patient may not have read everything on the consent form:
Sometimes when there are sensitive things in their notes I do ring the patient and tell them and a couple of times when I have done that they have been surprised and said “oh will it go with the notes as well?” because they don’t realise it will when they are signing the consent form with the insurance company the company asks for the whole medical records for the last 5 years so it can include anything and everything, patients are not that aware of what they are signing for.—Dr Violet

One of the GPs noted that it interfered with the doctor–patient relationship, and yet they worried about the unintended consequences for a patient if they did not share the information they were asked to.

13.3.6.3 Sensitive Information or Issues

There was an assumption that patients would know that information shared with a GP would be confidential, but that information would be shared when necessary in the course of the patient’s care. This included sensitive information where 2 of the GPs said that they would not be concerned about sharing sensitive information with a professional involved in their care.

Again with someone directly involved in their care the information no I don’t have any concerns, but where [the person is] not, you know, then yes I would if the patient could be identified.—Dr Teal

GPs outlined several situations where information-sharing could be problematic, including:

1. With children’s medical information—for example sharing information with divorced parents, or requests from Child Youth and Family
2. Adolescents—ensuring confidentiality
3. Older people with driver’s licences

Four of the GPs said that sharing sensitive information was to be considered on a case by case basis. These situations require openness with the patient and an understanding of the legal or other requirements that GPs have to share information. These situations can be difficult for the GP, who may want or need to get advice about what to do. There can also be problems for the patient going forward, as withholding information, or lack of information-sharing may mean that the GP does not have all the clinically relevant information required for the patient’s care. One GP identified that some patients may choose to avoid publicly funded services in order to avoid information being shared, but could only recall one such patient.
13.3.7 How GPs can be Trustworthy with Information

The GPs were asked what they thought GPs could or should do to be trustworthy with information.

13.3.7.1 Transparency and Openness with Patients

All of the GPs said that being open and honest with patients was important. GPs were asked if there are times where they would not tell their patient that they were going to share information. GPs outlined a number of circumstances including:

- Where information is non-identifiable (identified by five GPs). This included sharing cases in peer groups which was mentioned by four GPs.
- When the patient might be at harm (e.g. mental health, non-accidental injury of a child) was identified by four GPs.
- When it was in the best interests of the patient (e.g. concern of not presenting to a referral appointment if given all of the information) was identified by two GPs.
- In an emergency situation where a patient’s consent could not be gained (e.g. comatose) as identified by one GP.
- Where legislation allows for the disclosure of information without a patient’s consent (e.g. Child, Youth and Family, the Police) as identified by three GPs.

Six of the GPs said that GPs should be clear with patients about when they are sharing information. This means reassuring the patient about the expectation of privacy and confidentiality.

...we need to be really explicit about what we can or can’t do um, and to be very clear that everything is kept electronically pretty much now that um we’re particularly vigilant about ensuring the safety of that electronic information and where it goes um, and for patients to be aware that we’re doing our best.—Dr Alice

With patient information I guess I mean we could probably remind patients more that things are confidential and that the expectation is confidentiality and professionalism because from my perspective I just assume that and that’s how I behave but I guess it would be useful to remind them of that.—Dr Stevens

One of the patients highlighted that the use of patient portals or similar may change expectations as patients may be able to access their own information.
13.3.7.2 Information Privacy and Data Security

Six GPs outlined that procedures around information privacy and data security would help with trustworthiness. Four of the GPs highlighted that privacy and confidentiality are important components of medical education (at medical school and in the GP training scheme) and in quality and accreditation programmes. Having secure systems is important for patients but also for GPs, to know that they can trust the way information is collected, used, stored and shared. Other factors include the things that patients can see or hear—including the physical surroundings of the practice, how sound/voices travel, and visibility of files or screens.

13.3.8 Information Breach and Rebuilding Trust

The GPs were presented with the Dr Jones vignette and asked questions where they could respond as Dr Jones or themselves (as a GP). The GPs were asked about the impact of the loss of data on patient trust in the GP, whether that would change if it were Dr Jones’ fault, what they would do in response and how they might rebuild/repair trust with their patients following such an incident.

13.3.8.1 Initial Impressions

GP responses to the Dr Jones vignette were mixed. All of the participants felt that it was unfortunate that this had happened. Seven of the GPs said that this was an inappropriate way to handle a backup of patient information. One of the GPs said:

I’m appalled. I am just appalled. Um okay appalled because first of all um I think in the days where when we actually did have everything on tape as backup, it was locked away, people taking it home just seems like why?—Dr Alice

One of the GPs explained that the risk of something like that happening was the reason they changed to a cloud-based backup. Three of the GPs said that the situation could occur because practices still used this system for their backups, with one outlining cost as the reason.

Well, relatively realistic um you know that could happen, that’s not an uncommon form of backup at the moment—Dr Grumpy
13.3.8.2 Information Privacy and Data Security Policies

The GPs were asked whether their practice had policies around information privacy and data security. The majority (10 out of 12) said that their practice had policies. Two GPs said they were not sure, with one saying that she trusted that the practice had good measures in place:

I think I automatically assume that patient privacy is very important and so they—they—they should have really good measures in place to protect that patient information. So I think I automatically trust the practice that that’s all being done.—Dr Monkey

Both of these GPs had been in general practice less than three years. One of the GPs suggested that the level of knowledge about the policies would depend on the role of the GP in the GP practice. As an associate (as opposed to a partner) in the practice where she worked she said:

And I think as associates we probably have a—a slightly less degree of specific information unless we are particularly interested but obviously it is really important to us and it is discussed regularly at our sort of practice meetings.—Dr Alice

Five of the GPs referred to the “Cornerstone Accreditation” as a process where these policies were checked, revised and updated in line with current recommendations—these GPs had all been practising for more than 15 years.

So that is part of the Cornerstone Accreditation programme, so one of the doctors and the practice manager they are in charge of that policy and so we renew that policy um yeah probably I don’t know how often and then we, yeah we kind of send it out to all the staff by email and then we are supposed to go through all of the policies.—Dr Violet

The GPs were asked if they had a dedicated person responsible for information privacy and data security to which all of the GPs responded that they did with four referring to a “privacy officer”. The GPs identified a number of different people in the practice who were responsible, including another GP (4), the nurse manager (1), office or clinic manager (5) and the receptionist (1), while three were unsure of who had this role.

13.3.8.3 Impact on Trust

The GPs were asked whether such an incident would have an impact on the trust that patients have in them—eleven of the GPs said it would. It may not always be a personal impact, said two of the GPs, but more about the systems:

Oh yeah, I should think so. Maybe not personally, but the practice as a whole, you know, personally as in day-to-day I’ve got a cold, please see me kind of thing.—Dr
Alice

Two GPs outlined that it may have an impact on what patients disclose going forward:

Um I think the vast majority of patients would be sympathetic that a burglary in the house could not be realistically foreseen or protected against but I think there would be some patients it would make them wary about—about what they say in the future mm. Yes I think it would put some patients it would be a trust issue.—Dr Judd

The impact could be devastating:

Well obviously devastating so I can think of a number of patients who only come and see me because they know I keep shtum [silent or quiet] and ah yeah, um, so it would totally erode trust in those instances. They would usually leave.—Dr Grumpy

However, it is hard to know how people will react. The reaction can be variable and unpredictable depending on the content of the information and how it is being used. One GP said no, it would not have an impact as long as you were taking the issue seriously and did not try to cover it up.

**Actions or Fault of the Individual**

The GPs were asked about the impact if the breach was Dr Jones’ fault. The GPs’ answers were variable. While the outcome may be the same, the process means that the doctor has more responsibility for what happened:

I think at the end the outcome is similar, but I think in the process if you know the doctor would have greater responsibility for the loss of the data if it’s his fault not securing it properly.—Dr Monkey

While it may be more serious, GPs, like everyone else, make mistakes:

….we don’t necessarily understand what the full circumstances of that was, if the Dr Jones was a you know sort of careless person you know well I you know um that would certainly make a difference but yeah no everybody makes mistakes and if you own up to them then it can be quite incredible sort of you know how much loyalty you continue to engender in fact so.—Dr Daughter

Three GPs said that if it were malicious or deliberate, this would be a breach of ethics. However, one GP said that no one would do this deliberately.

**13.3.8.4 Actions to Remedy**

The GPs were asked what they would do if this incident or something similar happened to them. Seven of the GPs said they would notify the police. Four of the GPs said that they would seek advice or notify someone else—either notify their clinic, escalate
to the PHO level, or seek legal advice (e.g. from the Medical Protection Society).

Um, I would discuss it with um professional bodies um and I guess initially it would be the medical protection society and they might they might advise to talk to the um the privacy commissioner about it as well um—Dr Judd

Half of the GPs (6) said that they would notify the patients involved, either individually or in the most appropriate way:

Well you’d have to tell the person who’s information you’d not kept um secure so I mean if it’s a whole server then it’s everyone so you probably need to let everyone know in some way, put a notice up on your website or in your clinic and let them know you’re doing everything you can to get that information back and you’re treating it as a serious matter and you’ve referred it to the police.—Dr Whittaker

Four of the GPs said they would then do what they could to make sure it would not happen again and being proactive about the situation. This could include reviewing procedures or ensuring that the backup is secured better in future:

... being really cautious I guess and just going through the practices um all they have security systems they have in place, making sure everything is up to date.—Dr Blue

13.3.8.5 Rebuilding Trust

The GPs were asked how they would seek to rebuild trust with any patients that were affected by a situation like that described in the Dr Jones vignette. All of the GPs indicated that they would communicate with the patient (notify, inform, apologise) and seek to demonstrate that they had remedied the situation and that it would not happen again. This means taking responsibility, clearly communicating about what has happened, apologising and reassuring the patient/s about what they have done to secure the information, and what systems or policies they had changed to prevent it from happening again.

Debriefing the patients, talking to them, or sending them a letter, apology might be something that may help because at the end it it’s—it’s a theft you don’t plan such a things so some people might understand, some may not, all you can do is try—Dr Green

13.4 Similarities and Differences

This chapter has described the findings of Study 2, outlining both patient and GP perspectives about trust and information-sharing. The similarities and differences between the two are described below.
13.4.1 Trust

The dimensions of trust as discussed by the patients and GPs can be seen in Figure 13.1 and 13.2. In terms of trust, patient and GP participants described what trust is and what it requires in similar ways. Trust requires a mutual relationship between a patient and GP, time, and a demonstration of care. The patients identified factors that could jeopardise trust formation including power, time pressure and cultural appropriateness; these were not mentioned by the GPs.

Patients and GPs also identified that trust encourages openness in the doctor–patient relationship and can have an impact on outcomes. However, while patients thought that trust in the doctor might explain the Sabrina vignette, the GPs said that a patient’s trust in a GP did not excuse bad practice.

The patients also identified different types of trust—inherent trust in doctors, as well as initial, role-based and interpersonal trust. However, the GPs identified inherent, role-based and interpersonal trust, with the majority saying that their patients trusted them due to a combination of these aspects.

13.4.2 Expectation of GPs

The patients outlined expectations of GPs, and the GPs were able to identify these for the most part when asked what they thought patients expected of them. Patients expect the GP to care, communicate and to be professional. These expectations come from their interactions or experience with GPs, from talking with family and friends, their work or education, the media, common sense or general knowledge and their culture. The GPs were asked where patients’ expectations might come from and they identified interactions or experience with GPs, the media and common sense or general knowledge.
Figure 13.1: Thematic Network Map showing dimensions of trust discussed by Patients
Figure 13.2: Thematic Network Map showing dimensions of trust discussed by GPs
13.4.3 Information-Sharing

What patients knew about what GPs can and cannot do with their information was mixed. While half mentioned confidentiality, a third of the participants said they did not know, were assuming or guessing. This is in line with the assumption from GPs that patients would know about confidentiality, but that they might not know the details.

The GPs did not have many concerns about sharing information with other health professionals or organisations on the assumption that it was necessary to share the information in the course of patient care. Patients had few concerns about information-sharing within the health profession, particularly where it would be for the patient’s benefit. However, patients said that information should only be shared when necessary or appropriate on a “need to know” basis. Both patients and GPs were apprehensive about sharing information with third parties, particularly insurance companies. The patients wanted to be told if information was going to be shared, and for consent to be sought. However, the GPs were concerned that patients may not realise what the consent form authorises.

When asked what GPs can or should do to be trustworthy with information both patients and GPs said that GPs should be open and transparent with patients and that they should have appropriate information privacy and data security practices in place.

13.4.4 Rebuilding Trust

Both patients and GPs found the data incident outlined in the Dr Jones vignette unfortunate, and the majority thought that it would have a negative impact on trust. The GPs suggested that patients’ reactions could be variable. This was seen in the patient responses as some indicated they would not be concerned because they have a boring medical history, while others thought that a breach of this nature was far more serious. Further, some of the patients said they would change GP, while others said they would stay. Patients distinguished between the procedure and the actions or fault of the individual. For both patients and GPs, where the incident was outlined as the “fault” of the GP, then this was more serious. Patients expected to be notified
about the incident, for the doctor to apologise and for action to be taken to remedy the situation and prevent it from happening again. Similarly, the GPs outlined that they would seek to remedy the situation by informing the patients involved and ensuring that it would not happen again.

Patients said that rebuilding trust takes time (and sometimes it could not be rebuilt), and reassurance that the incident would not happen again. The GPs indicated that they would communicate with the patients involved and reassure them that they had made changes so that it would not happen again.
Chapter 14
Discussion

This chapter discusses the results of study 2 in light of the Beitat model of trust and existing literature. This chapter explores theoretical explanations for the results and considers the underlying structures that explain trust in information-sharing between patient’s and GPs in primary care. This chapter also discusses the strengths and limitations of this study and outlines recommendations for future research.

14.1 Answering the Research Question

The research question is: What role does trust have in patient’s attitudes and expectations around information-sharing in primary care? Study 2 helps to answer this question by addressing objectives two and three:

2. Determine what patients expect when sharing information with their GP, or their GP shares information with others, and identify ways that patients think that breaches of trust can be remedied.
3. Outline some of the processes that GPs can or should undertake (as reported by GPs and patients) to build, maintain and restore trust.

By addressing these objectives, this study has helped to answer the research question by identifying patient and GP expectations about information-sharing, as well as their perspectives on how breaches of trust (through a data breach vignette) could be remedied. Both groups also outlined what GPs can or should do to be trustworthy with information. These expectations and perspectives have been identified through the thematic analysis of 40 patient and 12 GP interviews as described in Chapter 13. The findings are discussed in the sections that follow.
14.2 Redescription of Results in Light of Theory

Under the Beitat model (page 33), trust is positioned as a dynamic process where the patient–practitioner relationship is represented in the middle as negotiated through communication (Beitat, 2015). The outer circle represents a continuous flow of information and knowledge which shapes expectations (Beitat, 2015). Expectations are used to evaluate actual actions and outcomes—where outcomes are in line with expectations trust is reinforced, and where they do not, trust is challenged (Beitat, 2015). Where the outer circle is disrupted on repeated occasions, positive expectations may become negative giving rise to distrust instead of trust (Beitat et al., 2013).

14.2.1 Communication

In this study, both patients and GPs highlighted the importance of communication for trust. It was also discussed as an expectation of the doctor–patient relationship that the GP should build rapport, listen to the patient and explain things clearly. In a first encounter, trust is developed by assessing the doctor’s communication skills and whether a common understanding has been reached (Tarrant et al., 2010). GPs identified the need for patients to be honest in their communication, and to ask questions if they do not understand or their concerns have not been addressed. Roter (2000) groups communication into five categories:

1. Information giving;
2. Question asking;
3. Partnership building;
4. Rapport building, and;
5. Socioemotional talk.

GPs and patients talked about the GP–patient relationship as requiring more than just information giving and question asking. Patients described trust as requiring a mutual relationship characterised by clear communication, openness and reciprocity. Many of the patients described how their GPs made them feel comfortable or at ease. Rapport building and socioemotional talk were discussed by some patients. Asking something personal or showing interest indicates the GP views the patient as more than “just a number” or “just a patient”. These are markers of what Skirbekk et al. (2011) describe
as open mandates of trust whereby the doctor shows interest in the patient, is sensitive to their emotions, gives the relationship time, and steps outside role expectations for short periods. All of the GPs talked about the importance of communication from the very first contact with a patient. This includes techniques to build rapport, find common ground, and connect with the patient. These aspects reflect patient-centred communication (PCC) which includes:

1. Eliciting and understanding the patient’s perspective—concerns, ideas, expectations, needs, feelings and functioning.
2. Understanding the patient within his or her unique psychosocial context.
3. Reaching a shared understanding of the problem and its treatment with the patient that is concordant with the patient’s values. (Epstein et al., 2005, p. 1517).

Fiscella et al. (2004) and Epstein et al. (2005) have explored the importance of trust for patient-centred communication, however, the results suggest there may be a more dynamic relationship between PCC and trust—where trust influences PCC and PCC influences trust.

The exploration of communication in this study suggests that it is an important expectation of the GP–patient relationship, and is a key building block for trust. Overall, this is congruent with the Beitat model that where communication and interaction between a patient and practitioner is a key requirement for a trusting relationship to develop.

14.2.2 Information/Knowledge

Patients’ knowledge of what GPs could or could not do with their personal information was limited. Half of the patients mentioned confidentiality, while a third said that they did not know. The patients also had very little knowledge of legal or professional requirements. This is consistent with national and international studies that have found knowledge and awareness of what happens with health information is low (Bratan et al., 2010; Hunter et al., 2014; Lehnbom et al., 2014; Stone et al., 2005; Whiddett et al., 2006). There was no indication that this lack of awareness negatively affected patient trust, a finding congruent with Stone et al. (2005).

GPs thought patients would have an understanding of doctor–patient confidentiality, although it was likely that the level of knowledge of any one patient would vary depending on a range of factors. The GPs did not as a matter of routine talk to
their patients about their information, although some of the GPs reported using the “confidentiality spiel” to encourage patients to disclose. This may seem surprising given the centrality of confidentiality in medical practice, however, it might be accounted for by latent meanings or rules that both GPs and patients used but were so taken for granted that they were not talked about.

The interviews also explored how patients knew these things. Half identified that their knowledge was based on their experience or interactions in general practice. Other sources of knowledge included: the media (mainly television and movies), experience with job or work, talking with the GP, or common sense (implied). Beitat (2015) suggests that communication influences the information and knowledge levels of patient and doctor as both parties attempt to build shared knowledge for medical decision making. With information-sharing, this link between communication and information and knowledge appears to be limited. This is evidenced by the lack of understanding by patients of what can and cannot be done with their information, as well as the assumptions by GPs that patients understand confidentiality.

14.2.3 Expectations

Expectations are formed based on information and knowledge and as influenced by prior experience (Beitat, 2015). Where they do not have prior information about the practitioner (e.g. their competence, character, skills or knowledge), communication becomes the basis of the trust relationship (Beitat, 2015; Tarrant et al., 2010). While the findings are congruent with this assumption, patients and GPs also talked about initial trust being influenced by research about the GP or practice, as well as recommendations from others. This suggests that other sources are used as signals of trustworthiness (Jones, 2013, 2015).

While patients were asked about their expectations when sharing information about themselves and their health with their GP, patients explored expectations more generally. This may be indicative of the extent to which health information is difficult to think about outside the context of the GP–patient relationship. Beitat (2015) identified communication, competence and care as trust building elements related to medical incidents. These aspects (referred to in Section 13.2.3 as care, communication and
professionalism) were discussed by patients as expectations of GPs. The role of care, communication and competence have been highlighted in conceptual and empirical analyses of trust (Beitat, 2015; Berry et al., 2008; Hall et al., 2002a, 2001; Leisen and Hyman, 2004; Mainous et al., 2003). However, based on the interviews from Study 2 it would seem that these aspects form part of the model not as outside factors, but instead manifest themselves in different ways as expectations, outcomes and information/knowledge. For instance, a patient may have an expectation that the doctor communicates well. This may be manifest in a vast number of ways by the doctor, and if it matches the expectation reinforces trust and reaffirms or alters expectations for the next encounter.

14.2.4 Actions/Outcomes

A key action or outcome for interactions with a GP relates to the GP’s ability to address the problem that a patient is presenting with. The extent to which the GP can address a patient’s medical needs is likely to impact trust. This means that each interaction with a GP presents an opportunity for trust to grow or to decline (Calnan and Rowe, 2008). For information, these actions or outcomes entail information being shared with other medical professionals in the course of care where it will benefit the patient.

A Breach of Trust

The breakdown or breach of trust occurs based on expectations people have about the behaviour, motivations or intentions of others (Hall et al., 2001; Lount et al., 2008).

Unfulfilled positive expectations are then interpreted as a trust breach, resulting in negative outcomes that are both observable (e.g. monetary costs or lost time) and emotional (e.g. anger and resentment). (Lount et al., 2008, 1602).

Through the Dr Jones vignette, patients were presented with an unfulfilled expectation about the confidentiality and privacy of health information (data security breach), that entails negative (yet unspecified) outcomes. For some of the participants, this scenario would have an impact on their trust in their GP—this was indicated by patients who said they would change GPs. However, some said that such an incident would have little impact. Tomlinson and Mryer (2009, p. 89) argue that not every negative outcome will cause trust to decline, as “The trustor may conclude either
that another actor or that situational factors caused the negative outcome.” The level of dependence of the trustor on the trustee and the severity of the outcome affect how the outcome is attributed (negative or not) and predicts whether the trustor perceives the need to and difficulty of repairing trust (Tomlinson, 2011). Patients exhibited “cognitive sensemaking to determine the cause and the degree to which the trustor [Dr Jones] might be culpable” (Tomlinson, 2011, p. 144). Some of the patients said it would not impact their level of trust because their information was “boring”, mundane or uninteresting—they have nothing sensitive, embarrassing or illegal to conceal. Solove (2007, 2011) has discussed this “I’ve got nothing to hide” argument as a misunderstanding about privacy. In many ways, this may stem from a misunderstanding about the harm to individuals as a result of information dissemination including—breach of confidentiality, blackmail, appropriate, distortion, and exposure (Solove, 2007). This falsely assumes that privacy is about concealing “bad” things or “a particular kind of visceral harm, one where privacy is violated only when something deeply embarrassing or discrediting is revealed” (Solove, 2007, p. 769). Data breaches of patient information represent a breach of confidentiality which entails not only emotional distress but the violation of a trusted relationship (Solove, 2007).

Others outlined what the GP would need to do for them to stay (i.e. communicate with them about what happened, remedy the situation the best they were able, and prevent it from happening again). This reinforces the importance of the GP–patient relationship for how patients respond to breaches and how the “aftermath” is structured (Beitat et al., 2013, p. 74). Patients were able to identify both technical and human factors as risks in the hypothetical data security incident with many identifying technical products, processes or systems as a way to ensure that patient information was safe (Colwill, 2009). Patients do understand that accidents happen, but expect procedures to reduce the risk of malicious and accidental acts that may compromise patient information. This highlights the importance of the actions of the GP and the organisation as the ‘violator’ to respond (Gillespie and Dietz, 2009; Mayer et al., 1995). Where a breach is uncovered, the Office of the Privacy Commissioner (OPC, 2013, p. 4) has outlined four steps that organisations should undertake:

1. Contain the breach and assess.
2. Evaluate risks.

3. Notify those affected, if necessary.

4. Prevent it from happening again.

Patients identified all four of these aspects as expectations of what GPs should do post-incident, and for how they could rebuild trust with patients. The assumption that “it will never happen to us” (Williams and Hossack, 2013, p. 155) cannot be the way that general practice approaches these issues as patients think there is no excuse for poor data management.

**Expectations of Trust are Based on More Than Actions**

Upon analysis of the Beitat model, it is unclear whether expectations are solely about actions or more. Patients’ responses suggest that in such an incident the medical competence and perception of care (of the patient and their information) have an impact on interpersonal trust. It was not just about what Dr Jones did, but also about his intentions and motivation. This indicates that the action of Dr Jones (taking a hard drive home where it was and it being stolen in a burglary) is only one part of the equation. Further exploration of the Dr Jones vignette showed that some patients had expectations about:

1. The GPs attitude towards their, and others, personal information.
2. The GP’s intentions with respect to the information.
3. The GP’s actions and how they are perceived.
4. The mechanisms and policies that support 1 and 2.

For instance, some patients focused on the need for procedures and processes to prevent such an incident happening again, while others focused on the character of the GP (i.e. it was not his fault, he was trying to look after the information, he was following the policy).

Many did not think that Dr Jones was blameworthy for the outcomes described in the vignette. Patients were willing to forgive Dr Jones because it was not his fault, but also because Dr Jones did not intend for the hard drive to be stolen, and because he had the disposition of trying to keep it safe. However, if Doctor Jones intended information to be disclosed this would reflect either malicious motivations or a careless attitude and
be at fault or worthy of blame. Hall et al. (2001, p. 616) says:

Trustening attitudes are directed as much to motivations and intentions as to results ... those who trust also hope for or expect a good result, but trust has a different character when they believe that another person has their best interests at heart.

This indicates that patients view trust as more than a calculated expectation (Hall et al., 2001). As such it is possible to trust the caring doctor who has made a mistake, or to distrust a doctor who is aloof who makes no mistakes.

14.3 Findings Outside of the Beitat model

It is unclear the extent to which a deficit in one of the domains (information/knowledge, expectations or actions/outcomes) may be satisfied by one of the others. Beitat (2015) suggests that where a patient has inadequate knowledge of or experience with a GP that the communication aspect of trust becomes the most important. This suggests that information/knowledge is only important to the model in so far as it shapes expectations. However, the absence of knowledge/information does not mean that patients do not have expectations. As seen in Study 2, many of the patient’s admitted that they did not know what their GP could or could not do with their information but were able to describe their expectations—this was seen in the use of terms like think, assume and hope.

With information-sharing, interpersonal trust between a patient and their GP can also be seen to support ignorance on the part of the patient. This can be seen in relation to quality of care—Mainous et al. (2003) outlines the importance of quality of care for building trust while also noting that patients may be unable to judge quality care. In this example, the expectations and outcomes may be positively reinforced despite a GP providing poor quality care because patients do not have the knowledge or expertise to judge the competence of the doctor. Study 2 suggests that trust may support ignorance about what happens with their information. Some patients did not know what GPs could or could not do with their information, and some did not care to know because they trusted their GP. Indeed trust is predicated on a blending of knowledge and ignorance (Lewis and Weigert, 1985; Luhmann, 1979; Möllering, 2001). Möllering (2006) argues that a leap of faith, which he refers to as suspension, is an essential feature of trust. Trust, as “a hypothesis certain enough to serve as a basis
for practical conduct” implies that one can trust without perfect or full information as actors may instead make a leap (Möllering, 2006). This casts a different light on the lack of knowledge identified earlier. The use of qualifying statements such as “I assume” and “I hope” serve instead as a demonstration of suspension in action as patients approach information-sharing with as “trust-as if” attitude.

This is better explained by the Zand (1972) model of trust (shown in Figure 3.1), whereby those who trust feel less need to impose controls on others are more likely to accept the influence of others and disclose more relevant information. Those who do not trust feel they cannot rely on someone to abide by agreements and will try to impose controls on their behaviour (Zand, 1972). This may be reflected by the patients who expressed a desire to know every instance in which their information was being shared or accessed by a health professional (a desire for control). Further, some patients said that where they did not trust their GP, they would be reluctant to share certain symptoms—particularly if the patient perceived these to be more personal or sensitive. Meanwhile, patients with high levels of trust have little or no desire to impose controls; they accept the influence of the GPs and are more likely to disclose relevant information.

14.4 A Revised Model of Trust for Primary Care

Based on the findings of Study 2, a revised or simplified model of trust is presented below. Given that information and knowledge did not have as much of an impact on trust concerning information-sharing in the GP–patient relationship, it has been removed from the model. Instead, information and knowledge are positioned as one way that expectations are formed. Others include experience, the interaction between GP and patient, and other sources such as the professional status of doctors and a general understanding of professional–client relationships. To convey the notion that the patient will reduce control, accept influence and disclose more information these have been included in the inner circle as part of the doctor–patient relationship.

Trust is depicted as a mutual relationship between a doctor and patient defined and negotiated through interpersonal communication balancing information disclosure, the level of imposed control, and acceptance of influence. The patient may cede control
to the doctor because they have high trust in the doctor and do not need to impose controls to assure they act in a way that is consistent with a shared understanding of their role. They are also more likely to disclose relevant information to the doctor and allow themselves to be influenced by the doctor (e.g. listen to their advice or engage in shared decision making). This means that the relationship is defined by mutuality and interdependence as opposed to independence. Where there is low trust, a patient may resist the influence of the doctor and seek to impose controls over their behaviour (e.g. by requesting or demanding particular actions), they may also do this by controlling or limiting what information they disclose. This incorporates the balance between trust and distrust into the model whereby expectations may become negative, thereby increasing the patient’s desire to control the actions of the GP.

Communication remains central to the development of trust within the doctor–patient relationship. This relationship is influenced by a patient’s expectations about the doctor’s actions, intentions and attitudes, as well as mechanisms and policies around medical practice. It is also influenced by actions and outcomes which will be evaluated as positive or negative based upon prior expectations. These actions/outcomes serve to reinforce expectations and therefore trust. Conversely, where actions and outcomes do not meet expectations (unmet expectations) trust may be tested or breached.

This model also applies where trust has been breached and needs to be rebuilt or restored. In this scenario, the patient’s trust can be rebuilt where the actions of the doctor to remedy the situation match a patient’s expectations. Similarly, the patient may assert control, resist influence and limit disclosure when trust is tested.
14.5 Understanding of Trust

Beyond the revised model of trust, Study 1 has also identified two different types of trust related to information-sharing—trust in the person and trust in processes.

Patients and GPs talked about trust as an interpersonal concept. That is trust in the practitioner to whom the information is disclosed. This includes trust in the intentions of the GP to act in a way that is beneficial to the patient and will not harm current or future interests and trust in the GP’s attitudes about the importance of confidentiality of the information shared (which may vary depending on the expectations of the patient).

They also talked about trust in systems or processes. This focused on a type of trust in the mechanisms or processes associated with the collection, storage and sharing of information (e.g. data security or ensuring the accuracy and integrity of the data). For some, this will mean trust through verification (that the systems/processes meet the technical requirements they know to be necessary), and for others, this will mean
trust through ignorance (the assumption that data will be safeguarded, which is met by surprise if a breach should occur).

14.6 Strengths and Limitations

There were a number of strengths associated with this study. The first is the qualitative approach which allowed for a rich exploration of information-sharing and trust between patients and GPs. Second is the use of the Beitat-model in the development of the vignettes and interview guide. This allowed for the exploration of trust through the consideration of the impact of actions/outcomes, expectations, information/knowledge and communication. This has been used as a way to interrogate/test the model outlined in Beitat et al. (2013) and to revise the model presented in Figure 14.1. Third was the use of vignettes. The Sabrina and Dr Jones vignettes were very effective in eliciting information from participants. They allowed participants to respond based on the character, or from their personal experience or perspective (Hughes and Huby, 2002). The vignettes worked particularly well with the GPs, as the presentation of cases is familiar to them. Further, the vignettes explored a routine interaction between a patient and GP, and a data security incident. Lastly, was the sample. Using maximum variation sampling, and a relatively large sample for a qualitative study a broad range of patients and GPs were interviewed. This allowed for the analysis of cross-group patterns.

There are three key limitations. Firstly, there were limitations due to the characteristics of the participants. The sample size may not have been large enough to show all the relevant cross-group patterns, particularly in the GP sample. Over 50% of the participants in each sample identified as NZ European. Further, all of the participants over 55 were NZ European. The GP sample does not contain any GPs who identify as Maori, Pacific or as belonging to an ‘Other’ (meaning non-Maori, non-Pacific, non-Asian, non-NZ European) ethnic group. This limits the claims made on the basis of patterns by ethnicity. The sample of patients was also had good health—with 70% reporting that their health was good, and the remaining 30% as okay. Talking with patients who had poor health, chronic conditions or co-morbidities may have had an impact on the findings. Delgado et al. (2008) found that patients expectations varied based on the nature and severity of condition. Future research could look at the impact
on health conditions on trust within a New Zealand context. Additionally, the method of sampling using organisations as a way to recruit participants may present sampling biases. These are biases related to the types of individuals that may or may not be employed by organisations and those who may or may not choose to be members of clubs and groups.

Second is the exploratory nature of this research. There was a concern that patient participants may want to air their grievances around health issues, medical incidents or information breaches, etc. However, the patient participants, in general, had good experiences with GPs. Many admitted that they did not go to the doctor very often because of their good health, and many reflected that their medical history was boring. This means that participants were mainly drawing on their ideas of routine or “business as usual” relationships with a GP. Also, the use of vignettes may limit the applicability of the findings to real life situations, as vignettes are constructed hypothetical scenarios (Spalding and Phillips, 2007). Future research could seek to find critical case examples of patients who had experienced a loss of trust, or a breach of their information, as Beitat et al. (2013) did with medical incidents.

Third is the scope of the interview guide. The interview guide did not ask specific questions about different types of health information or secondary uses of health information. For instance, the interviews did not ask participants about their views on sharing genetic information, or about the use of primary care information for research purposes. However, the use of biobank and genetic data for research has received considerable attention by ethicists and others (Dheensa et al., 2016; Johnsson et al., 2013; Kaplan, 2016; King et al., 2012).

14.7 Contribution to Critical Realist Understandings

This study affirms the centrality of communication to the development, maintenance and restoration of trust in doctor–patient relationships. It also highlights the role of expectations and actions and outcomes as reinforcing trust. However, this study suggests that the role of information and knowledge may not be as vital to the process of trust as outlined in the Beitat model. Instead, the causal mechanisms that explain trust may be described by the revised model in Figure 14.1. This presents trust as a dynamic
process where expectations and actions and outcomes influence the doctor–patient relationship which is characterised by communication and negotiated levels of control, influence and information disclosure. This model is based upon the exploration of trust with patients and GPs in relation to information-sharing, reflecting on routine interactions as well as a data privacy incident.

### 14.8 Implications

This study has important implications for trust and information-sharing research. First, it provides insights into aspects of trust as they relate to information-sharing practices in the patient-GP relationship. This study contributes to the trust research into health professionals. This supports the Beitat et al. (2013) and Beitat (2015) dynamic model of trust.

Secondly, it provides insights into the nature of trust between patients’ and GPs in New Zealand. This contributes to the broad literature dedicated to patients’ trust in their primary care physician. It also contributes additional findings about the role of trust for information-sharing in primary care focused on the doctor–patient relationship. This has found that patient’s trust in their GP may serve to mask concerns about information-sharing, as patients’ place information in the care of their GP.

Third, the findings of study 1 have led to the revision of the Dynamic Process Model of Trust as presented by Beitat et al. (2013) and Beitat (2015) to incorporate elements of the model outlined by Zand (1972). This model has been revised based on findings in a primary care setting asking about information-sharing. The model is informed by patient and GP perspectives about routine interactions and post-incident (a data security incident).

This study also has important implications for practice. The findings suggest that patients’ knowledge and awareness of how their information can and cannot be used by their GP is limited. Given the direction of the New Zealand Health Strategy towards the implementation of a national electronic health record, this study suggests the need to engage with patients about how their information is going to be shared using this system. This study was unable to talk to the acceptability of a national EHR by patients. This is an area for future research. However, the findings also suggest
that a lack of information/knowledge about how their information is shared does not impact upon patient’s trust in their GP. Patient’s trust their GP to share information appropriately.

**14.9 Conclusion**

In response to the research question—what role does trust have in patient’s attitudes and expectations around information-sharing in primary care?—this study concludes that trust facilitates information-sharing between patients and GPs by encouraging disclosure and reducing patient concerns about information privacy and data security. Trust and trustworthiness require the development of a relationship whereby expectations are managed and where actions and outcomes reinforce or undermine trust. However, other aspects may signal to patients that they can trust the GP, including certification, accreditation, perceived competence, or word-of-mouth. While negative outcomes have a variable impact on trust between a patient and GP, in some cases trust may be rebuilt where GPs address the expectations of patients by dealing with the problem and clearly communicating with them about it. In relation to information, patients and GPs identified openness and transparency as key ways that GPs could be trustworthy with patient information, as well as the implementation of appropriate privacy and security measures. The findings of study 1 have contributed to the revision of the dynamic process model of trust (Beitat, 2015; Beitat et al., 2013) that more appropriately explains the data.
Chapter 15
Discussion and Conclusion: Drawing Together the Ethical and the Empirical

Up to this point in the thesis, two empirical studies have been introduced, the methods outlined, results presented and the findings discussed in light of the literature. However, the discussion to this point (Chapter 10 and 14) has been restricted to considerations of the trust literature, and the Beitat model. This Chapter departs from that by discussing both studies in light of the Beauchamp and Childress’ ethical principles and the initial discussion of how these may apply to information from Chapter 4.

15.1 Answering the Research Question

This chapter analyses the data from study 1 and 2 in terms of relevant theories concerning trust as an ethical and practical consideration. This draws together the literature around trust reviewed in Chapters 3 and 5, and Beauchamp and Childress’ four principles discussed in Chapter 4. This chapter helps to answer the research question by addressing objective 4:

4. Outline recommendations for GPs about how to be trustworthy with information and how to instil trust into information-sharing exchanges.

In doing so, this chapter will outline some ethical conclusions about the role of trust and make recommendations regarding information-sharing in General Practice. The conclusions and recommendations will be situated within the existing literature, while also being oriented by the contribution of the empirical data from study 1 and 2. Overall, this chapter seeks to improve our understanding of the role of trust in the GP–patient relationship as it relates to information-sharing.
15.2 Implications of Empirical Studies for Understanding Trust Between Patients and GPs

Given the empirical studies, what more do we know about trust? The section will address the implications of three main findings for our understanding of trust in GP–patient relationships, and the role of trust for information-sharing:

1. High levels of trust in Study 1 and those groups who have lower levels of trust.
2. Low levels of knowledge and understanding about information-sharing practices in primary care.
3. The ways that trust is formed, lost, and rebuilt.

Study 1 has demonstrated that participants had high levels of trust in health professionals and organisations. Study 1 reports that on average, 68% of participants agreed (including slightly, moderately and strongly agree) that health professionals and organisations were trustworthy while 87% agreed that GPs were trustworthy. In terms of particular trust, 77% of participants said that all things considered they completely trusted their GP.

The hierarchical regression analysis indicated that some groups had lower levels of trust. This included females, older people, Pacific, and those who did not have a regular GP, had not been to a GP in the last 12 months, had been to the GP more frequently, and who rated their last experience with their GP more poorly. One explanation of this, as explored in Chapter 10, is that initial levels of trust are high (indicating high expectations of trust in professionals and organisations), but that those who have repeated interactions with GPs and the wider health system adjust their level of trust based on their experiences and the extent to which particular actions or outcomes do or do not align with these expectations.

Study 2 explored the nature of trust, with an attempt to identify expectations of GPs and to determine how trust is built, maintained and repaired. Not having to establish trust can be an asset for the GP, who then works to maintain initial levels of trust that are engendered by the initial interaction with a patient and the perception that the GP is caring, competent, professional, and acts in the best interests of the patient (Beitat et al., 2013).
Exploring what trust is and requires in Study 2, both patients and GPs acknowledged that trust was multifaceted, comprising communication, a mutual relationship, and caring, as well as the competence, knowledge and skill of the doctor. This finding fits with theoretical and empirical approaches to trust in health care settings that emphasise the importance of competence, communication and care (Beitat, 2015; Hall et al., 2002b), as well as aspects around integrity, honesty and professionalism (Hall et al., 2002b; Pilgrim, 2014). Study 2 demonstrates that patients have low levels of knowledge, understanding or awareness of what GPs can and cannot do with patient information. Further, GPs know little about what patients know, and patients and GPs report that it is not routine to talk about these things in consultations. Trust in the GP allows patients to bridge the gap that is left by these unknowns (Beitat et al., 2013). In doing so, patients trusted that their GP would act appropriately, maintaining confidentiality unless it was necessary or appropriate to disclose information with others.

The patients almost universally accepted that GPs should share information with other professionals within the health system where it would benefit them. There were fewer voices who wanted more control over their information. (Möllering, 2006) points out that there is a complex relationship between trust and control. While a basic understanding may present control as equal to distrust and promote sayings such as “trust but verify” or ‘trust is good, control is better” (Möllering, 2005, p. 285). Instead Möllering (2005) argues that trust can produce control and control produce trust. These issues of agency, control and trust could be further explored.

Study 2 indicated patients had low levels of awareness or understanding about information-sharing practices. However, these patients still demonstrate high levels of trust in their GP and very few concerns about their information being shared with other professionals or organisations in the health sector. While it could be said that this indicates a type of “blind” trust, the patients were able to provide reasons for why they trusted their GP indicating that it is conditional or negotiated. Patients were able to point to aspects of the interpersonal relationship, professional competencies and more general trust in the medical profession as different bases or types of trust. This links to Hall et al. (2001) who outlines patient trust as constitutive of a number of...
dimensions, some that are broadly mechanisms to ensure trustworthiness while others are relational. This underscores the way that “Individuals are not isolated in their trust but deeply embedded in social networks, organizational structures and institutional frameworks” (Möllering, 2008, p. ix). According to Möllering (2006) blind trust is part of all trust in that suspension is required to take the leap to trust someone. While many of the patients were aware that they did not know a lot about how their information could be shared and expressed that they should know, patients continue to interact with GPs and act despite these uncertainties. This has been documented with parents making decisions about MMR (measles, mumps and rubella) vaccinations where patients have limited knowledge and yet still act (Brownlie and Howson, 2005). The way that suspension functions in primary care encounters is an area worthy of further research, particularly given the varied knowledge and levels of trust that patients have.

Study 1 and 2 captured expectations around rebuilding trust. Participants varied as to whether they thought trust could be rebuilt. For those who thought it could be rebuilt, a number of factors were important including an apology or other form of communication, as well as action to remedy the situation and prevent it from happening again. As established by Beitat et al. (2013), the patient–caregiver relationship plays a central role in determining what happens after a breach of trust. Rebuilding trust required professionals to recognise that something had gone wrong and to address it. In many ways, this reaffirmed the importance of communication, competence and care as core components of trust, and while a loss or breach of trust may come from a failure in one of these aspects, rebuilding trust could be achieved by revisiting them. A core message from patients in study 2 was that rebuilding a relationship with a GP can be difficult given the limited number of encounters. As such, GPs should recognise that since communication is a pivotal aspect of rebuilding trust, they may need to communicate with patients outside of a consultation setting. Participants in both studies also identified the role of mechanisms to ensure that a breach of trust did not occur again through accountability and transparency measures. However, control depends on trust, meaning that new control measures to ensure accountability and other performance-measures require trust in those who design and apply the measures (Möllering, 2008). In many ways, this shifts the trust problem—either down
Overall, the empirical studies reaffirm the importance of trust in health care and GP-patient relationships (Beitat et al., 2013; Bova et al., 2012; Calnan and Rowe, 2006; Skirbekk et al., 2011). Trust functions in interpersonal and organisational settings and allows patients to accept the risk, vulnerability and uncertainty that is inherent in health care settings. Trust is also foundational to the ethical relationship between a patient and GP, whereby a patient trusts that their GP will keep their information confidential (Rhodes, 2001). The role of trust in ethical theory and the four principles is discussed in the section that follows.

15.3 Trust, Ethical Theory and the Four Principles

The problem of information-sharing is characterised as a concern about confidentiality and is often couched in terms of autonomy, or in preventing harm of information disclosure. Trust can be challenged where patient expectations about information-sharing and confidentiality are at odds with practice. Instead of focusing on whether practitioners and organisations can defend violations of confidentiality that occur through disclosure or information-sharing, this thesis has sought to determine the expectations of patients and what happens when these are not met.

The findings from study 1 and study 2 raised a number of ethical considerations based on participants’ expectations around how health information is used and shared and attitudes and perceptions about trust, which relate to:

1. The expectation or desire for the information that patients share with a GP should be kept confidential and private, to a certain extent.
2. Knowing that there are, or can be, good reasons for sharing information without the consent of the patient—including to procure a benefit for the patient or others, or to prevent harm or where the information does not identify the individual.
3. That some patients want to know about or be able to have control in situations when information is shared by their GP with other professionals, organisations or third parties.

Each of these shed light on how patients balance the ethical concerns around information-sharing, acknowledging that the desires or wishes of the patient should
be considered, but that sometimes other values compete with this.

Information-sharing may be seen as rupturing traditional expectations of confidentiality in the doctor–patient relationship. The empirical studies suggest that the concern may be overstated or misplaced. Overall, as Pilgrim (2011, p. 22) suggests:

Patients can still reasonably expect though that their personal records are only shared on a genuine ‘need to know’ basis. That is, they are not shared carelessly or whimsically with others who do not need to know.

Also, this thesis has demonstrated that trust is a salient feature in information-sharing between patients and GPs. Trust serves or encapsulates many of the relational aspects of the doctor–patient relationship and allows patients to have positive expectations in the face of uncertainty. When a patient develops trust with a GP, their levels of concern around information-sharing reduce in the same way that concerns about privacy reduce (Culnan and Armstrong, 1999; Miltgen and Smith, 2015) because the likelihood of negative outcomes reduce.

15.3.1 Trust as External and Additional to the Four Principles or Internal and Foundational to the Four Principles

Based on the findings from Study 1 and 2, there is good reason to go back to the four principles to interrogate what function or work trust is doing either alongside or within each of the four principles. The first approach follows Rosamond Rhodes (2001) in arguing for the importance of trust as something that is not contained in principle-based approaches as foundational to the doctor–patient relationship and medical practice. This view argues that trust provides a direct justification of the importance of confidentiality whereby violations of confidentiality put the public’s trust in jeopardy. However, patients in study 2 readily drew upon the role of beneficence and autonomy and to a lesser extent non-maleficence and justice. The second approach is that trust is an integral part of each principle. This presents the principles and trust having a dialectical relationship. This approach is advocated in the remainder of this chapter and demonstrated by a discussion of each of the principles as to what they may require in terms of information-sharing, and what trust contributes to this understanding.
15.3.2 What Does Respect for Autonomy Require?

There are good reasons to protect health information and the interests of the individual the information is about. Part of the rationale is that: “Handwritten medical records and electronic health information systems contain many sacred stories—stories that must be protected on behalf of the individual patient and on behalf of the aggregate communities of patients that are served in the health care system” (Harman, 2006, p. xxiii). Some reasons appeal to autonomy, and the protection of privacy, arguing that consent is the only basis for sharing information outside the doctor–patient relationship.

Kluge (2004) argues that electronic patient records be treated as an equivalent to material access to the individual who the record is about. This means that unauthorised access is likened to voyeurism, and the alteration of information without consent is like non-consensual interference with the body (Kluge, 2004). However, participants in Study 2 seem conflicted about whether respecting autonomy requires patients to consent to each act of sharing.

Although several patients expressed the desire to access an audit trail showing exactly who had accessed their records and why, these patients were in the minority. Viewing autonomy and privacy in terms of control fails to recognise justified exclusions to privacy and confidentiality between patients and doctors. These exclusions recognise good reasons to share information to prevent serious harm to others, or to secure benefits provided that the potential harms of disclosure are reduced through de-identification.

GPs have mixed ideas about what they think patients know. Many of them said they assumed patients would have an understanding of confidentiality, and that information would be shared with other health professionals involved in their care. However, some of the GPs thought that patients might not know much at all. GPs acknowledged that talking about information-sharing was not routine, and the “confidentiality spiel” was usually reserved for adolescents or for patient’s who appeared to be withholding information. This presents some difficulty if GPs are acting under the assumption that patient’s know how their information is being kept and with whom and for what reasons it might be shared. It also presents difficulty for consent where there is an
assumption of the patient being informed.

Many of the GPs said they did not think that patients necessarily understood what they agreed to when they signed consent forms (i.e. PHO enrolment form, ACC forms, or consent forms signed with an insurance company). In New Zealand, PHO enrolment forms serve as a way of determining the eligibility of a patient to receive a subsidy (reduced fees), and GPs receive a benefit for services provided. However, they also seek broad consent for information-sharing related to the provision of services, asking patients to tick that they have read the health information privacy statement provided. This suggests that the implications of providing consent to the collection, storage, and use of health information when they first engage with a GP practice may not be fully recognised by patients. This is perhaps reflective of ‘routinisation’ of consent (Ploug and Holm, 2014, 2015), or that the information privacy aspects do not seem relevant in comparison to the immediate or impending need for help/services.

On the other hand, Beauchamp and Childress (2013, p. 102), in talking about autonomy, argue that an autonomous person signing a consent form without reading or understanding it could be described as the person placing trust in the doctor and as an act that authorises the doctor to proceed. The findings from Study 2 support this idea, based on patient’s interactions with doctors being focused on resolving the health issue at hand and not about the information itself. The information being shared with a GP, and shared by that GP with others serves to benefit the patient, and as such patients’ trust their information to be used in ways that will achieve that purpose.

If respect for autonomy in relation to information-sharing is reducible to informed consent, this suggests that patients need to be aware or informed about how their information is used, stored or shared. While many patients indicated a desire to know who had information or why it had been shared, patients had very little knowledge of what GPs could or could not do with their personal information. However, this did not prevent patients from expressing expectations of GPs or of how they would expect their information to be treated. If autonomy requires that patients be informed about how their information is shared, this thesis highlights the need to increase patients’ knowledge and awareness. However, despite a lack of knowledge and understanding about information-sharing and what GPs do, the participants in Study 2 talked about
how they trusted their GPs with information. Further, patients were able to articulate their expectations about what would be acceptable and unacceptable. This means that the expectations do the work as opposed to the knowledge. As mentioned earlier, these positive expectations about the GP allow patients to trust in the absence of knowledge—this is called suspension. Where trust exists, knowledge may be secondary to a patient’s expectations. This does not undermine autonomy, but rather means that respecting autonomy and promoting trust can be achieved in relational ways, seeking meaningful interaction (O’Neill, 2002b) where doctors understand their patient’s expectations well and orient their practice towards it.

For GPs to understand their patients’ expectations, and for patients’ expectations to be oriented in an appropriate way, there may be an obligation for GPs to be transparent with the way that information is collected and used within the practice, and for other purposes. Or for GPs to be able to articulate why information would be disclosed, or why it would be accessed by someone other than themselves:

- By spelling out clearly and in detail when the requirement of consent can be overridden, such a policy informs the individual in advance of the limits on the confidentiality of his/her medical records and communications. The effect of such a policy is not only to limit disclosure without consent, but to limit the patient’s uncertainty about where his/her medical information may travel. The patient is thereby enabled to make an informed choice about what to reveal to whom, what tests to undergo, and so forth. (Woodward, 2001, p. 344–345).

This might be realised as a list of purposes for which information will be used and shared. For example:

- Routine data is collected for planning and funding purposes, but this does not identify anyone.
- Your regular GP will have access to all of the health information contained in your record. Other members of the care team may access information about you in the course of your care, but this is restricted to information required for them to carry out their role and responsibilities including auditing.
- Non-clinical staff (e.g. a receptionist) will have access to your contact information and details required for scheduling appointments and payment/billing. They will not have access to clinical notes.
- If you are referred by your GP to another provider information relevant to the issue/purpose will be made available to that provider. This may also include
information about your medical history, current or past medical conditions, results of laboratory tests or other diagnostic tests or investigations and list of prescriptions.

- If your GP needs to share information with a third party (e.g. ACC) they will seek your written consent. You may also provide consent to a third party to allow for the release of information, as with an insurance company.
- To help with the training and education of medical students and GP registrars, you may be asked for permission for a student or registrar to access your notes or to sit in on your consultation.
- As part of ongoing professional education and development GPs may use information about your case in a GP peer group—however, no identifiable information will be included.
- In some circumstances, the GP may be required or permitted to disclose information without your consent. Where possible or appropriate the GP will tell you if this will occur.
- You may access the information that your GP holds about you. Depending on your GP practice you may be able to access information via an online patient portal. If you want to see the information your GP holds about you, or seek a correction, talk to them or request it in writing.

However, GPs as gatekeepers need to share information for patients to access other parts of the health system—this means that getting accurate and complete information from patients is crucial (Rogers and Braunack-Mayer, 2009). This requires that a patient trusts that the GP is not going to share this information with just anyone. Sharing information can be potentially damaging to the trust relationship between a patient and GP if patients do not expect that certain information will be shared. This may present several solutions:

1. Stop sharing information.
2. Seek consent each and every time that information is shared.
3. Tell patients the circumstances under which information will be shared with third parties so that expectations are more appropriately formed.
4. Tell patients what information will be shared and with whom and for what
Solution 1 is untenable based on a GPs role as a gatekeeper. Further, findings from study 1 and 2 suggest that patients trust their GPs judgement to share information when necessary and appropriate. This means that solution 2, a requirement to seek consent even in instances where patients have a reasonable expectation that information will be shared (e.g. when a throat swab gets sent to the lab or for a referral to a specialist) may be unnecessary. Solution 3 and 4 seek to reorient expectations about information-sharing (to support trust) and the limits of privacy and confidentiality.

It could be said that trust mediates the risks or uncertainty around information-sharing. A focus on respect for autonomy removes the need for trust (Pilgrim, 2011). However, Nys (2016) argues that trust and autonomy are dialectical. Trust in a patient’s GP, the practice, or doctors as a professional group serves as a way to reduce uncertainty and allow for the complexity that is part of medical practice. Heimer (2001) argues that trust is required due to the specialisation and division of labour whereby professional groups are guardians of specialist knowledge. After all, “we cannot check or monitor everything on pain of an infinite regress” (O’Neill, 2002a, p. 142). We have to decide whom we can trust, and with respect to what (O’Neill, 2002a). While the findings from study 1 suggest that participants trust GPs and GP practices, the findings from study 2 suggest that patients trust their GPs with their information as well as their health care.

For some patients, knowing where their information goes will not increase their levels of trust in their GP. Rather, trust in their GP will extend to other aspects in the GP’s purview like their personal information. In this way, GPs may be said to act as guardians, not only of the patient’s health but also of their information based on the expectation by patients that their GP is competent, benevolent and trustworthy. However, this does not mean that doctors act without considering a patient’s desires or concerns about their information nor that they should seek consent for every information exchange. O’Neill (2002a) suggests that consent procedures that are based on seeking “genuine communication rather than legalistic form-filling” can help build trust. Such an approach places an obligation on GPs to inform their patients about how information is protected by them and how they will share it and to ensure
understanding around this. This connects with Beauchamp and Childress’ account of autonomy that places understanding and non-control as pivotal aspects. These ideas are reflected in the way that patients and GPs talked about how GPs could be trustworthy with information.

The two specifications that follow add content about how respect for autonomy can be enacted in relation to information when balanced or mediated by trust:

**Specification 1:** Respect the autonomy of patients, by being open about when and how a patient’s health information will be shared and talk to the patient about any preferences they might have around notification and consent.

**Specification 2:** Respect the autonomy of patients by providing mechanisms to increase patient awareness of how their health information is collected, stored, used and shared within and outside of the GP practice.

These specifications reflect the variation in opinion different consent approaches (Buckley et al., 2010) and the desire for more open engagement which builds trust (O’Neill, 2002a). While some patients outlined the need to be asked for consent or to be told about every instance of information-sharing, others indicated a broad consent for information-sharing within the health system, or that they might want consent sought in particular instances (e.g. for research purposes or where they were the information was identifiable). In many ways, these specifications are covered in the NZMA Code of Ethics that outline that “wherever possible the patient should be informed” when confidential information has been divulged, where information is shared with colleagues to enable the delivery of care. However, the code of ethics talks about these in relation to two particular types of information disclosure. This thesis suggests that tailored conversations early in the doctor–patient relationship may allow for patients and GPs to develop a clearer understandings of each others’ expectations around how information is collected, used and shared.

**15.3.3 What do Beneficence and Nonmaleficence Require?**

The principles of beneficence and nonmaleficence provide reasons for the protecting patient information to protect the interests of the patient and to prevent harm. 282
However, they also provide reasons to share information to provide better care. Patients and GPs in study 2 talked about the capacity to benefit from information-sharing. Patients wanted their information to be shared with other health professionals if it would benefit them as a patient. Several patients also mentioned that if their information would benefit anyone, then it could be shared (for instance if a GP saw another patient with similar symptoms and said that), or for research purposes. The benefits of information-sharing in a referral, for instance, potentially have a more direct and immediate benefit for the patient over other types of sharing. For example sharing information about health care utilisation may be beneficial for the allocation of services, or for an increase in services that a particular patient might use. However, it is difficult to conceive of this type of future and global benefit over the immediate and personal benefit.

Willison et al. (2009) found that there was permissive consent to use information for quality improvement, while using health information for marketing purposes resulted in the opposite response, with the majority saying that information should not be used for such a purpose. Patients are less willing for information to be shared with family, employers and insurance companies (Sankar et al., 2003). One study found that patients allowed their doctor to share information with an insurance company because they believed (falsely) that the doctor would withhold sensitive information (Lorge, 1989). New Zealand studies have found that patients are willing to share their information for the purpose of providing care particularly with GPs, hospital doctors and nurses (Hunter et al., 2014, 2009; Whiddett et al., 2006). Menkes et al. (2008) reports that patients may assume or have the expectation of confidentiality when talking about who can access personal health information. Patients are happy for their health information to be shared between health professionals; they were less willing or unwilling for it to be shared with administrators, researchers or government departments (Whiddett et al., 2006). This indicates that misuse of information and the breach or disclosure of information to people who are non-health professionals is a concern (Chhanabhai et al., 2006; Hunter et al., 2009; Maylor, 2010; Whiddett et al., 2006). These findings are supported by study 2.

Nonmaleficence requires that individuals not inflict harm on others. The disclosure
of identifiable information can set back the interests of a patient for future benefits or services, as well as cause pain and suffering. Restricting access to identifiable information, data anonymisation, and security measures may all ensure that patients can not be harmed. This may generate rules such as:

1. Do not share identifiable information with someone who is not involved in the provision of care of that patient without consent.
2. Protect the interests of a patient when sharing information with others.
3. Ensure that information is anonymous when sharing information with someone outside the care team.

The NZMA code of ethics already includes provisions that doctors should only access patient record when there is an appropriate reason, and that doctors have an obligation to guard against unauthorised access to information (NZMA, 2014). This thesis reaffirms the importance for doctors to know the content of these obligations to patients and patient information.

While patients wanted information to be shared for their benefit, the issue of nonmaleficence only arose concerning insurance companies or marketing companies. Patients did not want GPs to share information that might impact their ability to get insurance or that might affect their premiums. One participant expressed this in relation to not wanting her health information to adversely affect her in the future. GPs also raised this tension. Not only does third party sharing get in the way of the doctor–patient relationship but it also presents a tension where patients have signed a consent form allowing for the disclosure of certain information. The GPs said they were unsure whether patients understood what they were signing. Several GPs said that they would contact patients to let them know that something would be shared, sometimes to the horror of the patient. This suggests that patient and GP ideas about harms and benefits may differ. In many ways, more dialogue about these issues, may help doctors to have a better understanding of their expectations around the benefits and harms associated with different types of information and disclosures.
15.3.4 What Does Justice Require?

As outlined in chapter 4, justice is a complex principle. Beauchamp and Childress outline several approaches to justice incorporating distributive and procedural approaches. Overall, they see the principle of justice as the fair distribution of benefits and harm. This allows considerations of macro–justice, arrangements which affect justice beyond the level of the individual. However, justice at the interpersonal level can be conceived as fair dealing based on exchange frameworks of justice. In this approach, justice is an issue when two or more people exchange valued resources in a way that is mutually beneficial—this could include goods or services, money, love or affection (Cook and Hegtvedt, 1983). In this exchange framework:

...equity is typically defined as the equivalence of the outcome/input ratios of all parties involved in the exchange. When these ratios are not equal, inequity is said to exist” (Cook and Hegtvedt, 1983, p. 218).

Moving to considerations of allocation (a one-way distribution of resources), both distributive and procedural justice are highlighted—justice can be an issue where the distribution of resources is inequitable or unjust or where the procedures and rules around allocation are inequitable or unjust (Cook and Hegtvedt, 1983). If we consider both the exchange and allocation approaches for information-sharing, there is a need for interpersonal exchanges between doctor and patient to be fair and equitable. It seems fair that in providing information to a GP, there should be a type of reciprocity whereby the patients are told what will happen with their information, and the ways in which it could be used—i.e. in the delivery of care, to determine eligibility for other services, for statistical purposes, planning and funding. Beyond the mutually beneficial exchange of medical services (provided by the GP) in return for payment (provided in part by the patient), we can conceive of trust as a resource. In this scenario where the balance of trust is unequal or misguided, justice is an issue. For instance, several participants talked about the negative effects of GPs having or assuming certain information, such as ethnicity, and the impact this could have. This meant that GPs might treat them for example as “just another PT”, making assumptions based on ethnicity instead of the patient as a person. Imbalance at the level of exchange may also have negative impacts upon what GPs tell their patients and how GPs act in their gatekeeper role.
15.4 Strengths and Weaknesses and Areas for Future Research

Finally, as with any research, this thesis has raised further questions and areas for future research.

The scope of the study presents strengths and weaknesses. The purpose of this thesis was to explore the role or function of trust in information-sharing in primary care drawing on ethical and empirical considerations. The data that the ethical analysis (this chapter) is based upon has been derived from two studies. The multi-method approach allowed this thesis to investigate the factors that influence general, particular and organisational trust in health in the New Zealand setting, as well as exploring individuals perceptions, expectations and experiences of trust and information-sharing with patients and GPs in Auckland. However, the inclusion of two empirical studies has meant that the philosophical or ethical analysis has been limited. As such, there is scope for further exploration of the conceptual nature of trust from a philosophical perspective.

This thesis has contributed to the empirical ethics and trust literature by highlighting the importance of trust for information-sharing between GPs and patients in primary care and suggesting that trust acts to balance concerns around autonomy and control of information. This thesis has outlined tentative recommendations for how GPs ought to share information in primary care settings in ways that respect trust. However, it has not been possible, nor was it the aim of this thesis, to develop or defend a general theory about the role of trust in ethical theory. Additionally, this thesis has not fully realised the methodological process outlined in Chapter 6.4. More specifically, step 4 (p.91) which involves explaining how mechanisms are expressed in concrete situations remains incomplete due to difficulty in specifying the ethical principles into action-guiding rules for information-sharing in primary care.

As highlighted early in the thesis, there are differences between information-sharing and data-sharing. This thesis was confined to considerations of information-sharing rooted in the relationship between a patient and GP. This thesis did not explore perceived trustworthiness of the mechanisms of sharing (Patient Management Systems,
Patient Portals, Data Security systems, etc.), or the impact of other relationships or information (such as the impact of online health information) on trust in GPs. These areas could be explored in future research, particularly given the centrality of Health IT innovation as a solution to increase the efficiency and effectiveness of the health system and how much health information is now available online.

15.5 Implications of this Thesis

This thesis has explored the role of trust and information-sharing in general practice using a critical realist, empirical-ethics, multi-method approach. This brings together the concept of trust and the four bioethical principles (respect for autonomy, beneficence, nonmaleficence and justice), using social science and ethical theory to shed light on information-sharing in general practice. This approach shows that trust has an important role in the doctor–patient or GP–patient relationship in general terms and that it functions to allow patients to reduce the complexity and uncertainty involved in health care encounters. In relation to information-sharing, patients trust in their GP (and health professionals more widely) can be seen to reduce concerns about how information is shared, with the assumption that GPs are acting professionally and appropriately with patient information, sharing it when necessary and appropriate.

15.5.1 Implications for Research

The role of trust for information-sharing has received little attention in the literature. In many ways, this thesis has shown that those things that influence trust are constitutive of the broader GP–patient relationship. This thesis has explored the factors that influence trust. As other research has shown (Hall et al., 2001; Tarrant et al., 2008), the contribution of patient characteristics is limited, while the interpersonal or experiential aspects have more of an impact.

15.5.2 Methodological Reflections

Beauchamp and Childress outline specification and balancing in a method that takes the four principles and generates action-guiding rules. This thesis has sought to use two empirical studies from which content can be derived and applied to the four principles in relation to information-sharing between patients and GPs. However, in wrestling with
the method of specification it has been difficult to provide rules or recommendations that contain enough guidance for the situations that GPs may face. Drawing on the notion of trust as variable and multifaceted, it is possible that the recommendations or rules can only be made specific to a certain point. For recommendations to be aimed at GPs and General Practice in New Zealand, generality will always remain. In fulfilling their obligations to patients, GPs have the room or are required to take the principles and rules and specify them for a particular situation. This connects with the importance of a trusting GP–Patient relationship that is founded on a mutual relationship where GPs have knowledge about their patients and their expectations. This means they are ideally placed to specify and balance rules when making decisions within the context of the relationship, patient expectations and legal, professional and institutional requirements.

15.5.3 Recommendations or Implications for Practice

This thesis outlines important implications for the way that GPs and GP practices approach the issue of information-sharing. Firstly, this thesis has demonstrated that trust in GPs and GP practices is high. This reiterates the importance of trust in general practice. However, it has also shown that some groups of people have lower levels of trust suggesting more work may need to be done to build or maintain trust with some individuals. It also presents opportunities to further explore the impact of patient characteristics and relational, interpersonal or experiential factors. As demonstrated in this thesis, interpersonal factors are important in patient’s trust in their GP—GPs should recognise that each and every interaction with a patient presents an opportunity for trust to be built or for it to decline (Calnan and Rowe, 2008).

In relation to information-sharing, this study highlights the need for GPs to consider the expectations of patients regarding their information. It cannot be said that all patients will have the same expectations around how information is collected, stored or shared. This places the responsibility on GPs to talk with their patients about the role of information in their interactions and what patients can reasonably expect of them and their practice. GPs should engage in a tailored conversation with their patients early on in the GP–patient relationship about confidentiality and when and how a patient’s health information will be collected, used and shared within and outside
of the GP practice. This is about more than having a patient sign that they have read a health information privacy statement on an enrolment form, it is about providing real opportunities for patients to be informed, and to able to make decisions about how their information is shared.

This thesis has highlighted that patients understand that there are or can be good reasons for sharing information about the patient with others. There is an understanding that it is part of a GPs role to share information. Both patients and GPs highlighted some concern about information being shared with third-parties, particularly those who are outside of the health system.

This thesis has also indicated that rebuilding trust where it has been lost (in a data breach scenario) is possible for many people. While some patients may feel betrayed and look to change providers, many patients are open to rebuilding the trust relationship. Communication is central to this process of rebuilding or ameliorating trust. This places an onus on GPs and their practices to look at the ways that trust can be rebuilt by being open and honest about what has happened, apologising as is appropriate, instituting change, and showing that they are doing all they can to ensure it will not happen again. GP practices should think about how changes to processes or the introduction of new information technologies will change how GPs and patients interact, or how it may challenge reasonable expectations of patients, and respond accordingly.

15.6 Conclusion

This thesis set out to explore the role of trust for information-sharing between patients and general practitioners in New Zealand. The ethical dimensions of information-sharing and the role of trust as an ethical consideration were also investigated. The first study focused on understanding attitudes about trust and information-sharing in New Zealand’s health system. The second study focused on patients’ and GPs’ understandings and expectations around information-sharing and trust.

Study 1 established that levels of trust in health professionals and organisations are high. This included levels of trust in GPs and GP practices. The study also identified that participants were willing to share information, and trusted that their
health care provider would keep their information confidential. While the dependent variables (demographic, health care utilisation, and experiential factors) were limited in explaining the variation in levels of trust, there is evidence that they contribute. Participants expect GPs to ensure their information is kept private and confidential, although expect information to be shared when necessary or appropriate, particularly for their benefit or to prevent harm.

Study 2 confirmed trust plays an important role in information sharing, and in the GP-patient relationship more generally. Key aspects of patient trust include a positive belief or feeling; reliance on the actions, intentions, knowledge and competence of the GP; and that the GP has the patient’s best interests at heart. Trust is important for a patient to feel comfortable disclosing private or confidential information to a GP. This study suggested trust is constituted by ongoing communication between GP and patient, and the way that expectations are reinforced or undermined by subsequent actions and outcomes. The Beitat model of trust has been revised on the basis that information and knowledge are only one way that patient expectations were informed.

In response to the research question—What role does trust have in patients’ attitudes and expectations around information-sharing in primary care?—this thesis concludes that trust is central to information-sharing due to the need for trust between a patient and doctor. In the same way that health care both presupposes and requires trust, information-sharing presupposes and requires trust. However, it is also important due to the need of patients to trust doctors as information guardians or as their proxy in ensuring information is kept safe and secure and that confidentiality remains intact. The ethical analysis suggests that trust also acts in a dialectical way with autonomy, meaning that patients may rely on trust as the basis for a GP sharing information with others as opposed to demanding that they are made aware or must consent. However, patients may also demand accountability and other measures which respect autonomy as signals in determining the trustworthiness of the GP.
Appendix A

Trust Review Documents

Contained here are the documents relating to the Review of Trust outlined in Chapter A.1 including:

- Literature Matrix of Empirical Studies of Patient Trust in Primary Care Doctor
- Literature Matrix of Studies of Trust and Information in Primary Care
### Table A.1: Literature Matrix of Empirical Studies of Patient Trust in Primary Care Doctor

<table>
<thead>
<tr>
<th>Reference, Purpose, Location</th>
<th>Data Collection &amp; Analysis</th>
<th>Sample</th>
<th>Key Findings</th>
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</table>
| **Berry et al. (2008).** To assess relationship commitment and trust to patient-physician relationships. (USA) | Cross-sectional questionnaire including existing items circulated using waiting room sampling. Analysed using 3 stage least squares procedure. | 869 participants, from 4 clinics in central Texas, United States. | - Knowledge of the patient, competence and autonomy support were significantly related to trust.  
- The greater patients’ levels of adherence and trust the greater their commitment to the physician. |
| **Bova et al. (2012). To measure patient-provider trust in a primary care population. (USA)** | Prospective instrument design utilising three measures within a survey based study mailed to 1000 randomly selected patients. Analysed using principle components analysis and factor analysis. | 431 participants from a large adult primary care clinic in an urban area of Northeastern United States. | - Patient–provider trust scores did not vary significantly by gender, presence of chronic health or pain condition or education level.  
- Trust scores did differ significantly by ethnicity/race, provider type.  
- There was a weak correlation with participant’s age and their length of time with provider suggesting trust is associated with being older and having more time with a health provider, however it was not related to number of visits per year. |
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<tr>
<th>Reference, Purpose, Location</th>
<th>Data Collection &amp; Analysis</th>
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| *Butterworth and Campbell (2014).* To explore the trust of older patients in their general practitioners as well as perceptions of shared decision making. (UK) | Qualitative study. Open ended questions, semi-structured interviews. Analysed using constant comparative method | 20 participants, all over 65 years of age, registered with the GP surgery for at least 6 months from across 3 practices in Devon, United Kingdom. | - Factors that facilitate an older patients preference for and involvement in decisions about their care and nurture trust include the following patient factors: self-awareness and self-confidence, increasing healthcare and information requirements, vulnerability associated with ageing and increasing expectations of health care.  
- GP factors include characteristics including being patient-centred, caring, holistic, open and honest. Also GP communication skills including attentive listening, provision of an explanation, acknowledging the patient as an equal, providing choice, being willing to discuss GP expertise, offering an expert opinion and being willing to discuss uncertainties.  
- System factors include optimal access to a GP, optimal consultation duration, opportunities to find a match or congruence between patient and GP, and continuity of care with usual GP.  
- The status of GPs as perceived by society was also seen as a factor. |
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| *Croker et al. (2013).*  
To investigate the contribution of patient age, gender and ethnicity to any association between patients' ratings of interpersonal aspects of the consultation and confidence and trust in the doctor. (UK)  
Secondary analysis of data from the English GP Patient Survey (GPPS) undertaken in 2009. Analysed using binary logistic regression. | 2,163,456 patients aged 18 and over, registered with a GP in England for at least 6 months. | • Definite confidence and trust in the doctor were more commonly reported by older patients, patients from white ethnic backgrounds, patients living outside inner-city areas, those reporting excellent health, and those in areas of low deprivation.  
• Patient trust was similar for men and women.  
• Confidence and trust were most strongly associated with patients perception that their problems were being taken seriously by their doctor. |
| *Krupat et al. (2001).*  
To identify physician and patient characteristics that are associated with patient-centred beliefs about the sharing of information and power and to determine how these affect patient evaluations. (USA)  
Observational study of patients and physicians. Patients were surveyed before and after an outpatient visit. Physicians provided data before and after the same visits. Analysed using multi-variate statistical analyses including generalised estimating equations. | 909 patients, and 45 physicians (family physicians, general internal medicine specialists and cardiologists) from 2 major managed care systems in California, United States. | • Physicians who were patient-centred were marginally more likely to be trusted by patients than those who were not.  
• For patients, the belief that power and information should be shared was cultural where younger age, being female, white ethnicity, higher income and more education were associated with a desire for sharing.  
• The extent to which both patient and provider have similar orientations was a strong predictor for 2 out of 3 patient evaluation measures indicating that where patient's beliefs were congruent with their physician's the patient trusted them more. |
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| *Leisen and Hyman (2004).* To investigate the antecedents and consequences of patients' trust in their primary care physician. (USA) | Self-administered questionnaires using questions aimed at capturing both benevolence and technical competence. The questions used 7-point likert scales. Analysed using principle components analysis and structural equation modeling. | 214 patients from a service organisations in the South-western United States. | • Consumer satisfaction, benevolence and technical competence affect relationship outcomes positively.  
• Patients’ trust in their physician ws unrelated to wider patient choice in selecting their physician.  
• Satisfaction in previous interactions is requires for patients to believe that their doctor is benevolent and technically competent.  
• Relationship length correlates positively with trust. |
| *Mainous et al. (2003).* Identify strategies used by doctors that increase patient trust. (USA & New Zealand) | Cross-national study comprising in-depth, face-to-face, semi-structured interviews with primary care doctors. | 35 primary care doctors—15 from Charleston, South Carolina, United States and 20 from Auckland, New Zealand | • Trust is achieved by building a relationship, it begins with friendliness, rapport and non verbal cues.  
• Strategies to increase patient trust include: being professional, taking time (not being in a hurry), being willing to listen (because the patient expects to be listened to and understood), and trying to find common ground.  
• Time is important to the trust relationship as is continuity of care.  
• Barriers to trust included language and cultural differences between doctors and patients (identified by New Zealand doctors), and the perception of poor quality care. |
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| **Platonova et al. (2008).** Development and testing of a model to understand patient satisfaction, trust and loyalty to primary care physicians. (USA) | Cross-sectional survey using a 64-item instrument with measures of patient satisfaction, patient trust, commitment, intentions, and intentions to recommend. Analysed using a structural equation modeling approach. | 554 patients from two internal medicine outpatient clinics in the Southeastern United States. | • Trust and good interpersonal relationships with primary care physician are major predictors of patient satisfaction and loyalty to a physician.  
• Trusting relationships help develop or foster loyalty that leads to patients behaviours to recommend and to continue seeing the primary care physician. |
| **Skirbekk et al. (2011).** To examine the conditions for trust between patients and family physicians. (Norway) | Cross-sectional, mixed method qualitative study using video-taped consultations and in depth semi-structured qualitative interviews. Analysed using continuous comparison. | 8 family physicians and 16 patients (between 50 and 75 years of age), from urban and suburban areas in Norway. | • The trust relationship was relatively unproblematic where physicians were seen to meet the role expectations of the patient.  
• Elements associated with open mandates of trust include doctor showing early interest in the patient, doctor showing they were sensitive to the patient’s emotions, the doctor giving the patient and the relationship time; establishing alliances against a common adversary, and by stepping outside role expectations for short periods of time (e.g. showing sense of humour).  
• Conditions of trust varied by consultation, medical history, and the doctor–patient relationship. |
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<th>Reference, Purpose, Location</th>
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| **Tarrant et al. (2003).** To identify factors associated with patients’ overall trust in their general practitioner (GP). (UK) | Cross-sectional questionnaire survey of patients using the General Practice Assessment Survey (GPAS) that has one question asking about overall trust in GP. Analysed using multiple linear regression. | 1078 patients from ten practices in a primary care organisation in the East Midlands, United Kingdom. | • GP–patient communication, interpersonal care, GP’s knowledge of the patient, age and ethnic group explained 46% of the variation in trust scores.  
• Patient perceptions of the quality of their relationship with their GP is an important factor in their trust in the GP.  
• Reports of duration of the GP–patient relationship and number of visits to the usual GP were not independently associated with trust. |
| **Tarrant et al. (2008).** To test the association between aspects of continuity in the GP–patient relationship and patient trust, informed by game theory. (UK) | Cross-sectional survey using questions on aspects of continuity, interpersonal care, and trust. Analysed using multiple regression. | 279 patients from 3 general practices in Leicestershire, United Kingdom. | • The strongest predictor of trust in GP was patient’s rating of interpersonal care.  
• Patients who saw their usual GP had significantly higher trust scores than those who did not, however this was not an independent predictor of trust.  
• Other predictors of trust included good care from the GP in the past, belief that the GP knew or had checked whether the patient had followed the treatment or recommendations on past occasions, and the expectation that the GP would provide follow up care in the future.  
• Patients who reported that the GP asked them to come back and see him/her specifically in the future had higher trust scores than those who had not. |
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| **Tarrant et al. (2010)**. To explore the relationship between continuity of care and patient trust in primary care. (UK)** | Qualitative study. Open ended questions, semi-structured interviews. Analysed using constant comparative method | 20 general practice patients, Leicestershire, United Kingdom | - Repeated interactions support the development of trust.  
- Trust could be maintained and reinforced where the doctor seemed competent and acted in the best interests of the patient. It could be undermined by time pressures, appearing to be motivated by financial interests, or not caring for the patient.  
- Trust built over time was more robust and patients were willing to forgive mistakes or accept a GP’s limits without any long-term damage to their trust. |
| **Van Den Assem and Dulewicz (2014)**. To examine the doctor patient relationship and test hypothesised relationships between patient trust and satisfaction and continuity of care, doctor’s practice orientation and performance. (UK) | Questionnaire survey using closed-ended questions including a trustworthiness scale, doctors practice orientation scale, doctor’s performance scale and a patient satisfaction question. Analysed using t-test techniques to compare scores of high and low on the three scales. | 372 patients from seven self-selected GP surgeries in the East Midlands, United Kingdom. | - Those who are most satisfied with their doctors also perceive them to be more trustworthy, have a greater preference for shared decision making and rated their doctors performance higher on every item than the low satisfaction group.  
- Patients most satisfied with their doctor perceived their doctor as more trustworthy.  
- Patients who reported the highest levels of satisfaction with their doctor were much more likely to prefer a sharing decision making orientation with their doctor than those who were least satisfied. |
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<th>Data Collection &amp; Analysis</th>
<th>Sample</th>
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| **Stone et al. (2005).** To explore knowledge and attitudes of patients and members in a primary health care team about sharing data held in primary care records. (UK)** | Qualitative study using semi-structured interviews. Analysed using grounded theory. | 20 patients and 15 health care professionals from 5 general practices in Leicestershire, United Kingdom. | • Trust was viewed as being built through ongoing interactions (i.e. continuity) as opposed to respect for patient rights.  
• Patients had limited knowledge of the type of information in their records or the ways that they were shared.  
• In the climate of limited awareness there was no suggestion that concern about data/information sharing negatively affects patient trust or leads to patients withholding information from health care professionals. |
| **Qiao et al. (2015).** To identify factors associated with patient trust in electronic health records (EHR) used in primary care. (USA) | Cross-sectional study which gathered patients’ post-visit responses to a questionnaire using close-ended questions. Analysed using logistic regression. | 142 patients across 5 primary care clinics in the Midwestern United States. | • 87% of participants agreed that they trusted the EHR.  
• Patient trust in EHRs was associated with patient trust in their primary care physician, recognition of the characteristics of the EHR, and patient perception of how the physician uses the EHR.  
• The patient as the passive user of the technology develops trust in that technology (i.e. the EHR) by evaluating the active user (the physician), the characteristics of the technology and how the active user used the technology. |
Appendix B

Study 1 Documents

Contained here are the documents relating to study 1.

Survey documents:

- Letter to participants inviting them to take part in the survey.
- Participant information sheet for the survey.
- Copy of the mail questionnaire as sent out.
- The supermarket draw form.
- The postcard that was sent to participants as a follow up.
- Facebook advertisement and associated report.

Analysis output:

- Percentage of Responses to Survey Questions about General, Particular and Organisational Trust.
- Histograms of Scales with Normal Distribution Line Drawn.
- Histograms plotting Regression Standardized Residuals of Scales.
- Normal P-Plot of Regression Standardized Residuals for Scales.
- Scatter plots of Scales.
- Component Correlation Matrix and Screeplots for Three Large Scales.
<Date>

Dear <Name>,

My name is Samantha Fitch and I am a postgraduate (PhD) student at the University of Auckland. Privacy and information-sharing in health are important issues in New Zealand at the moment, so I am conducting research to explore the role of trust in Primary Health Care (i.e. with your GP).

I’d like to invite you to participate in a survey about your attitudes, opinions and expectations of trust in health professionals and health organisations as well as trust in information sharing. Your details were included in a random sample from the Electoral Roll, and that is why you have been invited to participate.

The survey will take you approximately 15 minutes to complete and can be completed online if you wish, or returned in the postage-paid envelope provided. The questions in this survey cover health service utilisation, trust in your regular doctor (or GP), and how you feel about certain types of information sharing.

For more information about what the survey involves, you can see the information sheet included. This survey is aiming to gather responses from a cross-section of New Zealanders and I would greatly appreciate it if you would consider participating.

Kind regards,

[Redacted]

Samantha Fitch
Project title: Information sharing within Primary Care: The role of trust as an ethical and practical consideration around the sharing of personal information.

Hello, my name is Samantha Fitch. I am a Doctoral Student in the Health Systems Department at the University of Auckland. I am conducting research to explore the role of trust as an ethical and practical consideration around the sharing of personal information in the health system. The focus is Primary Health Care.

I invite you to participate in a survey about your attitudes, opinions and expectations of trust in health professionals and health organisations as well as trust in information sharing. This survey gathers responses from a cross-section of the general public. Your details were included in a random sample of 1000 people from the Electoral Roll, and that is why you have been invited to participate. Privacy and information-sharing in health are important issues in New Zealand at the moment. The questions in this survey cover health service utilisation, trust in your regular doctor or general practitioner (sometimes referred to as a GP), and how you feel about certain types of information sharing.

By participating in this research, I am asking you to complete a survey. This survey will take you 10-20 minutes to complete. You can complete the paper format, or the electronic version, which may be accessed online at:

https://auckland.asia.qualtrics.com
Password: [redacted]

If you complete this online please do not return anything in the post.
There will be no way of identifying you from your completed survey. This also means that there will be no way of removing your survey from the sample. The barcode on the bottom of your survey document is for internal processing only and is no way connected to your details. We use the barcode to ensure that we know that all the pages belong to one survey, should any of the pages become separated.

The physical copies of the surveys will remain in a locked filing cabinet in the School of Population Health, The University of Auckland for six years. After this time, the written surveys will be destroyed by shredding and the electronic files will be destroyed by deleting the file. The electronic document containing the survey data will be accessible solely by the named researcher and supervisor in a password protected file.

You can enter the draw to win 1 of 6 Supermarket Vouchers valued at $50. You can do so by entering your details on the piece of paper included in your envelope and return it with the survey in the self-addressed envelope (or at the end of the online survey). If you do enter the draw these details will be kept separate from your survey when we receive it.

Thank you for considering this invitation. We appreciate your time.

If you should have any questions about this research or any ethical concerns, please do not hesitate to contact the following people:
Samantha Fitch (Doctoral Student), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [redacted] Email: [redacted]
Monique Jonas (Supervisor), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92015, Auckland. Telephone [redacted] Email: [redacted]
Dr. Tim Tenhaeff (HOD), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [redacted] Email: [redacted]

For any concerns regarding ethical issues you may contact: the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 87830/83761. Email: humanethics@auckland.ac.nz

The researcher was funded for the PhD degree by the Margaret Burdall Doctoral Scholarship.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 18/12/2014 FOR 3 YEARS, REFERENCE NUMBER [redacted]
Survey of Trust in Health and Information Sharing

Thank you for participating, we value your contribution. By completing this survey we take it that you consent to participating in the survey as outlined on your participant information sheet.

Please cross the box of the answer you want to select like this. If you change your mind about a response black out the box of the incorrect option like this, and cross the box the answer you want.

1 General Trust

These questions are about general trust. Please cross the box of the option that best applies for each statement on a scale from 1 to 7 as represented below.

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<tr>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>Moderately Disagree</td>
<td>Slightly Disagree</td>
<td>Neither agree nor disagree</td>
<td>Slightly Agree</td>
<td>Moderately Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

1.1 How much do you agree or disagree about the trustworthiness of the following health professionals in New Zealand?

- I think GPs (General Practitioners) are trustworthy
- I think Hospital based doctors are trustworthy
- I think Nurses are trustworthy
- I think Pharmacists are trustworthy
- I think Physiotherapists are trustworthy
- I think Psychologists are trustworthy
- I think Counsellors are trustworthy
- I think Midwives are trustworthy

1.2 How much do you agree or disagree about the trustworthiness of the following health organisations and government departments in New Zealand?

- I think GP practices or clinics are trustworthy
- I think hospitals are trustworthy
- I think District Health Boards (DHBs) are trustworthy
- I think St Johns Ambulance is trustworthy
- I think ACC is trustworthy
- I think The Ministry of Health is trustworthy
- I think Government departments, in general, are trustworthy
- I think private health insurance providers are trustworthy

2 Use of Health Services

These next questions are about seeing general practitioners (GPs) or family doctors. Cross the box of the most appropriate option.

2.1 Do you have a GP clinic or medical centre that you usually go to when you are feeling unwell or injured?

- Yes
- No
- Don’t know
Survey of Trust in Health and Information Sharing

2.2 In the past 12 months, have you seen a GP or been visited by a GP about your own health? By health we mean mental, emotional & physical health.

☐ Yes  ☐ No

2.3 How many times did you see a GP in the past 12 months?

Please state: _____________________________

3 Trust in your GP

For the following questions please think about your last visit to your GP. Cross the box ☒ of the most appropriate option.

3.1 How good was the GP at explaining your health conditions and treatments in a way that you could understand?

☐ Very Good  ☐ Good
☐ Neither good or bad  ☐ Poor
☐ Very Poor  ☐ Doesn’t apply

3.2 How good was the GP at involving you in decisions about your care, such as discussing different treatment options?

☐ Very Good  ☐ Good
☐ Neither good or bad  ☐ Poor
☐ Very Poor  ☐ Doesn’t apply

3.3 Did you have confidence and trust in the GP you saw?

☐ Yes, definitely  ☐ Yes, to some extent
☐ No, not at all

3.4 What do you expect of your GP when you provide him/her with your personal information?

4 Trust in the Primary Health Provider you see most regularly

4.1 What type of health provider do you see most regularly?

☐ Your GP  ☐ Nurse  ☐ Physiotherapist
☐ Pharmacist  ☐ Counsellor  ☐ Midwife

Other: ___________________________________
Survey of Trust in Health and Information Sharing

For the following questions keep thinking about the health provider that you have said you see most regularly in the question above. Please cross the box of the option that best applies for each statement on a scale from 1 to 7 as represented below.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Slightly Disagree</th>
<th>Neither agree nor disagree</th>
<th>Slightly Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
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</tbody>
</table>

4.2 How much do you agree or disagree with the following statements about the health provider that you see most regularly?

1. My health care provider is usually considerate of my needs and puts them first
   - 1 2 3 4 5 6 7

2. I give my health provider all known and relevant information about important issues
   - 1 2 3 4 5 6 7

3. I have so much trust in my health provider that I always try to follow his/her advice
   - 1 2 3 4 5 6 7

4. I trust my health provider so much that I believe everything they tell me
   - 1 2 3 4 5 6 7

5. Sometimes, I do not trust my health provider’s opinion and feel I need to see another provider
   - 1 2 3 4 5 6 7

6. I can trust my health provider’s judgments concerning my medical care
   - 1 2 3 4 5 6 7

7. I deliberately withhold some information when communicating with my health provider
   - 1 2 3 4 5 6 7

8. My health provider will do whatever it takes to give me the medical care that I need
   - 1 2 3 4 5 6 7

9. Because my health provider is an expert, he/she is able to treat medical problems like mine
   - 1 2 3 4 5 6 7

10. I minimise the information I give to my health provider
    - 1 2 3 4 5 6 7

11. I can trust my health provider’s decisions on which medical treatments are best for me
    - 1 2 3 4 5 6 7

12. I think carefully before telling my health provider my opinions
    - 1 2 3 4 5 6 7

13. My health provider offers me the highest quality medical care
    - 1 2 3 4 5 6 7

14. I am concerned about my GP sharing my health information with others without telling me
    - 1 2 3 4 5 6 7

15. I completely trust my health provider
    - 1 2 3 4 5 6 7
### Trust in Health Care Institutions

The following questions are about health care organisations including primary care providers, government organisations and non-government organisations (like a GP Office or Clinic, ACC, Labtests, Plunket etc). Please cross the box [X] of the option that best applies for each statement on a scale from 1 to 7 as represented below.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Slightly Disagree</th>
<th>Neither agree nor disagree</th>
<th>Slightly Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

5.1 How strongly do you **agree** or **disagree** with the following statements about health care organisations?

Health care organisations only care about keeping medical costs down, and not what is needed for my health

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
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<th>7</th>
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</thead>
</table>

Health care organisations provide the highest quality medical care

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

When treating my medical problems, health care organisations put my medical needs above all other considerations, including costs

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I am concerned about organisations in the health sector sharing information about my health with other organisations in the health sector without telling me

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

Even if I don’t like the way government agencies use and protect my personal information I am often forced to deal with them anyway to get the things I need

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I feel in control of the way government agencies use and protect my personal information

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I feel in control of the way health care organisations use and protect my personal information

<table>
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<tr>
<th>1</th>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I feel there should be more sharing of information between health professionals and health organisations

<table>
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<tr>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I am concerned about data breaches which may involve the compromise or loss of my personal health information

<table>
<thead>
<tr>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I trust that the doctors will only share information about me that is relevant to my care

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

I trust that the doctors will keep my personal information confidential no matter what

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
Survey of Trust in Health and Information Sharing

5.2 What do you expect of health organisations when you give them your personal information?

5.3 How do you think health professionals (like GPs) and organisations can rebuild trust when it has been compromised or lost?

6 Demographics

Lastly, we would like to ask you some questions about your personal background. Cross the box [X] of the most appropriate option.

6.1 Are you male or female?

☐ Male
☐ Female

6.2 Which of these age groups do you belong to?

☐ 18-19 years
☐ 20-24 years
☐ 25-34 years
☐ 35-44 years
☐ 45-54 years
☐ 55-64 years
☐ 65-74 years
☐ 75+ years

6.3 Which ethnic group do you belong to? - Cross all options that apply to you

☐ New Zealand European
☐ Maori
☐ Samoan
☐ Cook Island Maori
☐ Tongan
☐ Niuean
☐ Chinese
☐ Indian

Other such as DUTCH, JAPANESE, TOKELAUA. Please State: ________________________

6.4 Which Country were you born in?

☐ New Zealand
☐ Australia
☐ England
☐ China (People’s Republic of)
☐ India
☐ South Africa
☐ Samoa
☐ Cook Islands

Other (Please print the current name of the country): ________________________

6.5 What is your relationship status?

☐ Single
☐ Legally Married
☐ Divorced
☐ In a de facto relationship
☐ Widow/Widower
☐ Separated
Survey of Trust in Health and Information Sharing

6.6 In what type of area do you live?
- City (50,000 people or more)
- Small Urban Town (1,000 to 9,999 people)
- Rural or remote area (Less than 300 people)
- Town (10,000 to 49,999 people)
- Rural centre/town (300 to 999 people)

6.7 In which region of New Zealand do you live?
- Northland
- Auckland
- Waikato
- Bay of Plenty
- Gisborne
- Hawke’s Bay
- Taranaki
- Manuwatu-Whanganui
- Wellington
- Tasman
- Nelson
- Marlborough
- West Coast
- Canterbury
- Otago
- Southland

6.8 What is your highest level of Education?
- No qualifications, pre primary, primary or lower secondary education (includes kindergarten, play centre, Year 1 to 10, Primer 1 to Form 4)
- NZ School Certificate in one or more subjects, or National Certificate Level 1, or NCEA Level 1 (Year 11 or Form 5)
- NZ Sixth Form Certificate in one or more subjects, or National Certificate Level 2, or NZ UE before 1986 in one or more subjects, or NCEA Level 2 (Year 12 or Form 6)
- NZ Higher School Certificate or Higher Leaving Certificate or NZ University Bursary/Scholarship or National Certificate Level 3 or NCEA Level 3 or NZ Scholarship (Year 13 or Form 7)
- Post Secondary Education: Tertiary Certificate or Diploma
- Tertiary Education: Undergraduate Degree
- Tertiary Education: Honours, Masters, Doctoral or other Higher Degree

6.9 Which of these statements best describes your current work situation?
- Working full time (30+ hours per week)
- Working part-time (8-30 hours per week)
- Self employed
- Carer (of home, family etc)
- Full Time Student
- Temporarily unemployed, but actively seeking work
- Retired
- Other permanently unemployed (e.g. chronically sick, independent means)

6.10 What is your occupation?

Please state: ________________________________

Thank you for completing this survey! We really appreciate your time, and value the contribution you have made to this research by answering questions about trust and information sharing in the health system.
07 May 2015

Thank you for completing the “Survey of Trust in Health and Information Sharing”. We really appreciate the time and effort put into completing it. If you have sent in the survey or completed it online then you do not need to do anything.

If you have not completed the survey yet, we would value your input. You still have the chance to enter the draw to **Win 1 of 6 supermarket vouchers valued at $50** if completed online or returned by post by the 1st July.

If you would like to complete the survey there are 3 options:

1. You can complete the paper version of the survey sent to you in March and return it in the postage paid envelope.

2. If you would like to complete the paper version, but need a replacement sent out to you, then please contact me by phone on [redacted] or via email at [redacted].

3. Or, you can complete the survey online using this link: [https://auckland.asia.qualtrics.com](https://auckland.asia.qualtrics.com)  The password is: [redacted]

Thank you again for your time,
Kind regards,
Samantha Fitch

Follow up Post card
Be in to WIN!

By completing this form you enter the draw to **WIN 1 of 6 Supermarket Vouchers valued at $50 each.** The winners will be drawn at random, on the 1st July 2015, and contacted via your preferred method.

Name: ________________________________

Contact number: ______________________

Email address: ________________________

Please circle your preferred method of contact:   Email   or   Telephone

Supermarket Draw Form

---

Survey of Trust in Health & Information Sharing

By completing this survey you can enter the draw to win 1 of 6 supermarket vouchers valued at $50.

AUCKLAND.ASIA.QUALTRICS.COM

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Screenshot of the Advertisement placed on Facebook
Facebook Promoted Post / Report

Faculty/Department: School of Population Health  
Campaign Name: Survey of Trust in Health & Information Sharing  
Live date: 3-19 July 2015  
Objective: Clicks to survey (https://je.qualtrics.com)  
Total spend (NZD): $300.00  
Targeting: NZ 18-54

Screenshots of posts

Desktop

Mobile

Results

<table>
<thead>
<tr>
<th>Metric</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Reach (Unique Users)</td>
<td>40,464</td>
</tr>
<tr>
<td>Website Clicks</td>
<td>453</td>
</tr>
<tr>
<td>Cost Per Website Click (CPC)</td>
<td>$0.66</td>
</tr>
<tr>
<td>Post Likes</td>
<td>55</td>
</tr>
<tr>
<td>Post Comments</td>
<td>4</td>
</tr>
<tr>
<td>Post Shares</td>
<td>26</td>
</tr>
</tbody>
</table>

Please note: Website clicks, likes, comments and shares don't include engagements resulting from organic reach through people sharing the post. Thus actual numbers will be even higher than shown above.

Summary & Highlights

The promoted post targeting adults in NZ 18-54 years old worked very well, reaching over 40,000 users.

At a low cost per click of only $0.66 the promotion delivered 453 clicks to the survey. This doesn't include clicks from any of the post shares, so the actual number would be even slightly higher.
Table B.1: Percentage of Responses to Questions about General Trust in Professions and Organisations

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Slightly Disagree nor Disagree</th>
<th>Slightly Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I think GP's are trustworthy</td>
<td>1.8</td>
<td>1.8</td>
<td>2.9</td>
<td>6</td>
<td>11.1</td>
<td>41.9</td>
</tr>
<tr>
<td>2 I think Hospital based doctors are trustworthy</td>
<td>2</td>
<td>1.3</td>
<td>3.3</td>
<td>8</td>
<td>18.7</td>
<td>35.9</td>
</tr>
<tr>
<td>3 I think Nurses are trustworthy</td>
<td>1.1</td>
<td>1.1</td>
<td>3.1</td>
<td>7.8</td>
<td>15.8</td>
<td>39</td>
</tr>
<tr>
<td>4 I think Pharmacists are trustworthy</td>
<td>1.8</td>
<td>1.3</td>
<td>3.6</td>
<td>7.8</td>
<td>18</td>
<td>36.3</td>
</tr>
<tr>
<td>5 I think Physiotherapists are trustworthy</td>
<td>1.1</td>
<td>1.6</td>
<td>2.7</td>
<td>15.4</td>
<td>20</td>
<td>35.6</td>
</tr>
<tr>
<td>6 I think Psychologists are trustworthy</td>
<td>2.2</td>
<td>2.2</td>
<td>5.6</td>
<td>21.4</td>
<td>17.8</td>
<td>29</td>
</tr>
<tr>
<td>7 I think Counsellors are trustworthy</td>
<td>2.9</td>
<td>3.1</td>
<td>5.8</td>
<td>20.5</td>
<td>19.8</td>
<td>28.7</td>
</tr>
<tr>
<td>8 I think Midwives are trustworthy</td>
<td>2.4</td>
<td>2.4</td>
<td>6.2</td>
<td>21.8</td>
<td>15.1</td>
<td>28.3</td>
</tr>
<tr>
<td>9 I think GP practices or clinics are trustworthy</td>
<td>1.8</td>
<td>2.4</td>
<td>4.7</td>
<td>6.5</td>
<td>15.6</td>
<td>43</td>
</tr>
<tr>
<td>10 I think hospitals are trustworthy</td>
<td>2.2</td>
<td>1.8</td>
<td>5.6</td>
<td>10</td>
<td>22</td>
<td>35.9</td>
</tr>
<tr>
<td>11 I think DHBS are trustworthy</td>
<td>5.3</td>
<td>3.6</td>
<td>11.1</td>
<td>20.5</td>
<td>24.9</td>
<td>24.3</td>
</tr>
<tr>
<td>12 I think St Johns Ambulance is trustworthy</td>
<td>2.2</td>
<td>0.7</td>
<td>4</td>
<td>6.2</td>
<td>13.8</td>
<td>32.5</td>
</tr>
<tr>
<td>13 I think ACC is trustworthy</td>
<td>8.7</td>
<td>8.5</td>
<td>12.7</td>
<td>17.1</td>
<td>22.7</td>
<td>21.2</td>
</tr>
<tr>
<td>14 I think the Ministry of Health is trustworthy</td>
<td>6.9</td>
<td>7.6</td>
<td>12.2</td>
<td>23.4</td>
<td>19.8</td>
<td>20.9</td>
</tr>
<tr>
<td>15 I think Government departments, in general, are trustworthy</td>
<td>9.8</td>
<td>8.9</td>
<td>16.9</td>
<td>20</td>
<td>21.2</td>
<td>14.9</td>
</tr>
<tr>
<td>16 I think private health insurance providers are trustworthy</td>
<td>8.2</td>
<td>9.4</td>
<td>10.9</td>
<td>26.7</td>
<td>19.8</td>
<td>18.3</td>
</tr>
</tbody>
</table>
Table B.2: Percentage of Responses to Questions about Particularised Trust in Health Care Provider

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Slightly Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Slightly Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 My health care provider is usually considerate of my needs and puts them first</td>
<td>2.2</td>
<td>2</td>
<td>4</td>
<td>7.4</td>
<td>12.8</td>
<td>28.4</td>
<td>43</td>
</tr>
<tr>
<td>26 I give my health provider all known and relevant information about important issues</td>
<td>2.2</td>
<td>2</td>
<td>1.1</td>
<td>2.7</td>
<td>8.7</td>
<td>22.6</td>
<td>60.5</td>
</tr>
<tr>
<td>27 I have so much trust in my health care provider that I always try to follow his/her advice</td>
<td>3.1</td>
<td>2.9</td>
<td>4.5</td>
<td>9</td>
<td>17.1</td>
<td>32.8</td>
<td>30.6</td>
</tr>
<tr>
<td>28 I trust my health care provider so much that I believe everything they tell me</td>
<td>6</td>
<td>5.8</td>
<td>11.4</td>
<td>12.3</td>
<td>21.3</td>
<td>28.4</td>
<td>14.8</td>
</tr>
<tr>
<td>29 Sometimes, I do not trust my health care provider’s opinion and feel I need to see another provider</td>
<td>24.2</td>
<td>17.5</td>
<td>9</td>
<td>15.2</td>
<td>13.9</td>
<td>13.2</td>
<td>6.7</td>
</tr>
<tr>
<td>30 I can trust my health provider’s judgements concerning my medical care</td>
<td>1.8</td>
<td>3.4</td>
<td>4.3</td>
<td>6.8</td>
<td>18.6</td>
<td>36.3</td>
<td>28.8</td>
</tr>
<tr>
<td>31 I deliberately withhold some information when communicating with my health provider</td>
<td>52.2</td>
<td>16</td>
<td>5.9</td>
<td>7.7</td>
<td>5.6</td>
<td>6.8</td>
<td>5.4</td>
</tr>
<tr>
<td>32 My health care provider will do whatever it takes to give me the medical care that I need</td>
<td>2.9</td>
<td>4.1</td>
<td>4.5</td>
<td>13.4</td>
<td>20</td>
<td>25.6</td>
<td>29.5</td>
</tr>
<tr>
<td>33 Because my health care provider is an expert, he/she is able to treat medical problems like mine</td>
<td>3</td>
<td>4.3</td>
<td>6.2</td>
<td>10.9</td>
<td>19.1</td>
<td>30.3</td>
<td>26.2</td>
</tr>
<tr>
<td>34 I minimise the information I give to my health provider</td>
<td>47.7</td>
<td>19</td>
<td>10.4</td>
<td>7.7</td>
<td>5.9</td>
<td>5.9</td>
<td>3.4</td>
</tr>
<tr>
<td>35 I can trust my health provider’s decisions on which medical treatments are best for me</td>
<td>1.8</td>
<td>4.1</td>
<td>5.2</td>
<td>9.3</td>
<td>18.1</td>
<td>33.6</td>
<td>28</td>
</tr>
<tr>
<td>36 I think carefully before telling my health provider my opinions</td>
<td>24</td>
<td>16.1</td>
<td>8.1</td>
<td>14.3</td>
<td>13.1</td>
<td>16.3</td>
<td>8.1</td>
</tr>
<tr>
<td>37 My health care provider offers me the highest quality medical care</td>
<td>2.5</td>
<td>2.3</td>
<td>5.7</td>
<td>13.1</td>
<td>13.8</td>
<td>31.7</td>
<td>31</td>
</tr>
<tr>
<td>38 I am concerned about my GP sharing my health information with others without telling me</td>
<td>41.7</td>
<td>18</td>
<td>9.3</td>
<td>13.2</td>
<td>5.5</td>
<td>5.5</td>
<td>6.8</td>
</tr>
<tr>
<td>39 All things considered, I completely trust my health care provider</td>
<td>3.4</td>
<td>2.3</td>
<td>6.5</td>
<td>10.8</td>
<td>12.2</td>
<td>30.4</td>
<td>34.5</td>
</tr>
</tbody>
</table>
Table B.3: Percentage of Responses to Questions about Organisational Trust in Health Care Institutions and Organisations

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
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<th>Slightly Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Slightly Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 Health Care Institutions only care about keeping medical costs down, and not what is needed for my health</td>
<td>12.7</td>
<td>15.4</td>
<td>14.7</td>
<td>19.9</td>
<td>19</td>
<td>13.1</td>
<td>5.2</td>
</tr>
<tr>
<td>41 Health Care Institutions provide the highest quality in medical care</td>
<td>2.3</td>
<td>5.6</td>
<td>11.1</td>
<td>18.3</td>
<td>25.1</td>
<td>28.4</td>
<td>9.3</td>
</tr>
<tr>
<td>42 When treating my medical problems, health care institutions put my medical needs above all other considerations, including costs</td>
<td>6.6</td>
<td>8.8</td>
<td>19.5</td>
<td>20.6</td>
<td>19</td>
<td>20.9</td>
<td>4.5</td>
</tr>
<tr>
<td>43 I am concerned about organisations in the health sector sharing information about my health with other organisations in the health sector without telling me</td>
<td>21.1</td>
<td>20.1</td>
<td>11.7</td>
<td>15.1</td>
<td>13.5</td>
<td>10.3</td>
<td>8</td>
</tr>
<tr>
<td>44 Even if I don’t like the way government agencies use and protect my personal information I am often forced to deal with them anyway to get the things I need</td>
<td>12.9</td>
<td>10.3</td>
<td>6</td>
<td>31.7</td>
<td>15.6</td>
<td>11.7</td>
<td>11.7</td>
</tr>
<tr>
<td>45 I feel in control of the way government agencies use and protect my personal information</td>
<td>11.8</td>
<td>11.4</td>
<td>20.7</td>
<td>28.2</td>
<td>11.8</td>
<td>8.7</td>
<td>7.3</td>
</tr>
<tr>
<td>46 I feel in control of the way health care organisations use and protect my personal information</td>
<td>10.1</td>
<td>10.1</td>
<td>18.6</td>
<td>25</td>
<td>15.4</td>
<td>12.8</td>
<td>8</td>
</tr>
<tr>
<td>47 I feel that there should be more sharing of information between health professionals and health organisations</td>
<td>7.7</td>
<td>5.9</td>
<td>4.8</td>
<td>30.1</td>
<td>19.1</td>
<td>16.9</td>
<td>15.3</td>
</tr>
<tr>
<td>48 I am concerned about data breaches which may involve the compromise or loss of my personal health information</td>
<td>10.3</td>
<td>13.8</td>
<td>13.8</td>
<td>23.1</td>
<td>14.5</td>
<td>13.8</td>
<td>10.5</td>
</tr>
<tr>
<td>49 I trust that doctors will only share information about me that is relevant to my care</td>
<td>3.2</td>
<td>2.1</td>
<td>5.1</td>
<td>9</td>
<td>21</td>
<td>33.5</td>
<td>26.1</td>
</tr>
<tr>
<td>50 I trust that doctors keep my personal information confidential no matter what</td>
<td>4.2</td>
<td>3</td>
<td>7.6</td>
<td>14.8</td>
<td>17.4</td>
<td>30.3</td>
<td>22.7</td>
</tr>
</tbody>
</table>
Figure B.1: Histograms of Scales 1–6 with Normal Distribution Line Drawn
Figure B.2: Histograms of Scales 7–12 with Normal Distribution Line Drawn
Figure B.3: Histograms plotting Regression Standardized Residual of Scales 1–6
Figure B.4: Histograms plotting Regression Standardized Residual of Scales 7–12
Figure B.5: Normal P-Plot of Regression Standardized Residuals for Scales 1–6
Figure B.6: Normal P-Plot of Regression Standardized Residuals for Scales 7–12
Figure B.7: Scatter plots of Scales 1–6
Figure B.8: Scatter plots of Scales 7-12
Table B.4: Component Correlation Matrix for General Trust In Health Professionals and Organisations

<table>
<thead>
<tr>
<th>Component</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.000</td>
<td>.428</td>
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<td>2</td>
<td>.428</td>
<td>1.000</td>
<td>.419</td>
</tr>
<tr>
<td>3</td>
<td>.527</td>
<td>.419</td>
<td>1.000</td>
</tr>
</tbody>
</table>

Table B.5: Component Correlation Matrix for Particular Trust in Primary Care Provider

<table>
<thead>
<tr>
<th>Component</th>
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<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.000</td>
<td>.359</td>
<td>.121</td>
</tr>
<tr>
<td>2</td>
<td>.359</td>
<td>1.000</td>
<td>.161</td>
</tr>
<tr>
<td>3</td>
<td>.121</td>
<td>.161</td>
<td>1.000</td>
</tr>
</tbody>
</table>

Table B.6: Component Correlation Matrix for Organisational Trust in Health Institutions

<table>
<thead>
<tr>
<th>Component</th>
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<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.000</td>
<td>.274</td>
<td>-.318</td>
</tr>
<tr>
<td>2</td>
<td>.274</td>
<td>1.000</td>
<td>-.261</td>
</tr>
<tr>
<td>3</td>
<td>-.318</td>
<td>-.261</td>
<td>1.000</td>
</tr>
</tbody>
</table>

Figure B.9: Screeplot for General Trust In Health Professionals and Organisations

Figure B.10: Screeplot for Particular Trust in Primary Care Provider

Figure B.11: Screeplot for Organisational Trust in Health Institutions
Appendix C

Study 2 Documents

Contained here are the documents relating to the interviews.

Patient documents:

- Participant information sheet for patients.
- Consent form for patients.
- Interview schedule used for patients.

GP documents:

- Participant information sheet for GPs.
- Consent form for GPs.
- Interview schedule used for GPs.

Analysis documents:

- Coding matrix
PARTICIPANT INFORMATION SHEET
For Patient Interviews

Project title: Information sharing within Primary Care  Researcher: Samantha Fitch
The role of trust as an ethical and practical consideration around the sharing of personal information.

Hello, my name is Samantha Fitch. I am a Doctoral Student in the Health Systems Department at the University of Auckland. I am conducting research to explore the role of trust as an ethical and practical consideration around the sharing of personal information in the health system. The focus is Primary Health Care (GP’s).

I am interested in the views and experiences of a broad range of health service users. I invite you to participate in an interview about your attitudes, opinions and expectations of trust in health professionals and health organisations as well as trust in information sharing. Privacy and information-sharing in health are important issues in New Zealand at the moment. I would like to invite you to participate in an interview about the role of trust in information sharing in General Practice. Topics to be covered in this interview include the following: a discussion about your expectations and experiences around information sharing, your expectations of health professionals and health organisations, the importance of trust and your views on what may increase or decrease trust.

If you choose to be a participant, you will be asked to participate in a semi-structured interview that will be voice recorded (and recording can be stopped at any time). The interview will last approximately 30-60 minutes. Participation in the interview is completely voluntary and can be withdrawn at any time without penalty. You can also request that the information you provided can be withdrawn until 1st December 2016. Participants will receive a $30 supermarket voucher as thanks for their time and effort in participating.

A transcript of your interview will be completed by the researcher. You can request a copy of the transcript of your interview (which will be sent to you by email). You can request corrections to the transcript. You will have 2 weeks to let me know if there are any changes that you wish to make. Your name will be kept confidential and you will not be able to be identified in the publication of this research.

The transcribed interviews will be analysed using a software programme to assist analysis (Nvivo). The analysis will seek to further understand and generalise the opinions, expectations and attitudes of the sample. The results will be included in a doctoral thesis and may form the basis for academic papers.
The information from the interviews (voice recordings and transcriptions) will remain in a locked filing cabinet in the School of Population Health, The University of Auckland for six years. After this time, the written documents will be destroyed by shredding and the voice recordings will be destroyed by deleting the recording. The electronic document containing the interview data will be accessible solely by the named researcher and supervisor in a password protected file.

Thank you for considering this invitation. We appreciate your time. If you should have any questions about this research or any ethical concerns, please do not hesitate to contact the following people.

Samantha Fitch, (Doctoral Student), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [number] Email: [email]

Dr. Monique Jonas (Supervisor), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [number] Email: [email]

Dr. Tim Tenbensel (HOD), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [number]

For any concerns regarding ethical issues you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 extn. 87830/83761. Email: humanethics@auckland.ac.nz

The researcher was funded for the PhD degree by the Margaret Burland Doctoral Scholarship.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 11/03/2015 FOR 3 YEARS, REFERENCE NUMBER [number]
CONSENT FORM

For the Patient Interviews

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title: Information sharing within Primary Care: The role of trust as an ethical and practical consideration around the sharing of personal information.

Researcher: Samantha Fitch

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I understand that I am free to withdraw participation at any time, and to withdraw any data traceable to me up to 1st December 2016.
- I understand that the interview will last approximately 30-60 minutes.
- I understand that data will be kept for 6 years in a locked filing cabinet at the School of Population Health, The University of Auckland, and in a password-protected electronic file on a University of Auckland server, after which time they will be destroyed.
- I understand that if the information I provide is reported/published, this will be done in a way that does not identify me as its source.
- I understand that the information collected in the interview will be voice recorded (and recording can be stopped at any time) and later transcribed by the named researcher. I have the opportunity to review the information I have given. I will have 2 weeks in which to let the researcher know of any corrections I might have (see below).
- I understand that the information collected in the interview will be used for data analysis and presented in research outputs.

I wish to review the transcript of my interview. YES / NO

Name: ____________________________

Signature: _________________________ Date: ______________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 11th MARCH 2015 FOR 3 YEARS. REFERENCE NUMBER [Redacted]
PATIENT INTERVIEW SCHEDULE

1. Welcome. [Explain the purpose] I would like to talk to you about your experience as a patient or health service user. I would like to talk to you about the role of trust related to information sharing between yourself and your GP. [Timeline] The interview should take between 30-45 mins.

2. [Consent] I need to obtain your signed consent to conduct this interview. I have a copy of the participant information sheet here with me if you would like to read the details again (they will have received it by email). Do you have any questions about what the interview involves or what the information will be used for?

Content of interview

‘Sabrina’- Questions about trust and expectations when sharing information with a GP

Sabrina is a 24-year old woman. She has just moved to a new part of town and is visiting a new GP practice. She is seeing Dr Jones for the first time. When she arrives, Sabrina is asked to complete an enrolment form. This includes a section which asks if she wants to transfer her patient notes from her former GP to the new practice. When Sabrina enters Dr Jones’ office she is nervous about talking to a strange doctor about her symptoms. She worries that Dr Jones won’t believe what she is saying. She is also wary of whether Dr Jones is a good doctor. Sabrina feels like Dr Jones is typing furiously as she describes her symptoms, barely looking at her. Sabrina is curious as to what Dr Jones is writing about her, but is too scared to ask. Dr Jones prints out a referral letter for a specialist and a list of blood tests – Sabrina isn’t sure what they’re all for, but nods as Dr Jones says what they are. Dr Jones seems busy – set on getting Sabrina out of the door as soon as possible.

1. What are your initial impressions of what is going on in this scenario?

2. If Sabrina trusted Dr Jones, do you think this would change anything? What if she doesn’t trust Dr Jones at all?
   PROMPTS: What do you think the GP could do to be more trustworthy or to develop trust with Sabrina? Is there anything that Sabrina could or should have done to build trust with the GP? What if you had heard things from a friend about this Doctor, would this have an impact? If you think about your own doctor, do you trust them because they’re a Doctor, and that’s their job, or because of something else? [What is it about Doctors that you inherently trust?]

3. What do you know about what GPs can or cannot do with your personal information?
   PROMPTS: Any legal or professional limits? Do you know these things based on your experience? Your own research/reading/talking with people? Information your GP has given you, or talked to you about?

4. What do you expect of your GP when you share information with him/her about you and your health?
   PROMPTS: Do you expect them to treat you in certain ways? Your information? To do or be certain things? To get certain results or outcomes? To know certain things, or to help you further understand things?

Questions about trustworthy information sharing:

1. What concerns do you have about sharing information with your GP, or with your GP sharing information about you with others?
   PROMPTS: What about sensitive information or issues? What about third parties – like insurance companies or other organisations? [Imagine for instance that there was something in your notes that you had not thought relevant to disclose to your insurer…]

2. What do you think GPs can or should do to make sure they are trustworthy with information?
**PROMPTS:** What kinds of information sharing do you expect your GP talk to you about? Are there certain people or organisations that you would expect/not expect your GP to share information with? Have you ever had a conversation with your GP (initiated by yourself or them) about when information sharing is necessary or appropriate?

‘Dr Jones’ – Questions about losing and rebuilding trust related to information sharing.

At the GP Practice where Dr Jones works, all patient notes are kept electronically. The notes are stored on a server, held on the premises in a locked server closet. They also keep a backup of files on a hard-drive that one of the staff take home at the end of the day. As the last person to leave work one night Dr Jones takes the backup hard drive home. Dr Jones takes the hard drive into the house before going out for the evening. When Dr Jones gets home, the house has been ransacked and items have been taken. Dr Jones races through to the study, but the hard drive is gone.

1. What are your initial impressions of what is going on in this scenario? [Can follow up with: Let’s presume that this is a possible procedure]
2. If something like this happened and your information was on the hard drive, would it change how you feel about Dr Jones, or your own GP?
   **PROCEDURE RELATED PROMPTS:** What about if the data on the hard-drive is encrypted? What if the data is not encrypted? What about if it is stored securely inside Dr Jones house? What if the hard drive is in a locked box or briefcase? What if you knew that this was the procedure and then this happened?
   **PERSON RELATED PROMPTS:** Would you feel any differently if it was the Doctors/Dr Jones’ fault? If Dr Jones lost the hard drive or caused the information to get out? [Imagine Dr Jones is running late and goes to the supermarket on the way home, leaving the hard-drive in the car, on the front seat and it is stolen?]. What about if it were a systems or technical issue? [human error/accident versus deliberate]
3. If this, or something similar happened, what would you expect Dr Jones/ the organisation to do?
   **PROMPTS:** How might Dr Jones rebuild trust with you? How might your own GP rebuild trust with you? What if the trust couldn’t be repaired?

**Other questions:**

1. Where do you think your attitudes and ideas about what GPs should and should not do with your personal information come from?
2. [Do a little recap/reflection of the key points they have covered or emphasised] Is there anything else that you think is relevant to the discussion we’ve had?
3. Finally, based on everything we’ve discussed today, how would you define trust?

**Closing the interview:** Thank the participant for their involvement
PARTICIPANT INFORMATION SHEET
For Health Professional Interviews

Project title: Information sharing within Primary Care  Researcher: Samantha Fitch
The role of trust as an ethical and practical consideration around the sharing of personal information.

Hello, my name is Samantha Fitch. I am a Doctoral Student in the Health Systems Department at the University of Auckland. I am conducting research to explore the role of trust as an ethical and practical consideration around the sharing of personal information in the health system. The focus is Primary Health Care.

I am interested in the views and experiences of General Practitioners. I invite you to participate in an interview about your attitudes, opinions and expectations of trust as it relates to information sharing in the health system. Privacy and information-sharing in health are important issues in New Zealand at the moment. I would like to invite you to participate in an interview about the role of trust in information sharing, in light of your role as a health professional. Topics to be covered in this interview include the following: a discussion about your experience and expectations around information sharing (including expectations of patients), your expectations of health organisations or other health professionals that you work with, the importance of trust and your views on what may increase or decrease trust.

If you choose to be a participant, you will be asked to participate in a semi-structured interview that will be voice recorded (and recording can be stopped at any time). The interview will last approximately 30-45 minutes. Participation in the interview is completely voluntary and can be withdrawn at any time without penalty. You can also request that the information you provided can be withdrawn until 1st December 2016.

A transcript of your interview will be completed by the researcher. You can request a copy of the transcript of your interview (which will be sent to you by email). You can request corrections to the transcript. You will have 2 weeks to let me know if there are any changes that you wish to make. Your name will be kept confidential and you will not be able to be identified in the publication of this research.

The transcribed interviews will be analysed using a software programme to assist analysis (Nvivo). The analysis will seek to further understand and generalise the opinions, expectations and attitudes of the sample. The results will be included in a doctoral thesis and may form the basis for academic papers.
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Thank you for considering this invitation. We appreciate your time. If you should have any questions about this research or any ethical concerns, please do not hesitate to contact the following people.

Samantha Fitch, (Doctoral Student), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [redacted] Email: [redacted]

Dr. Monique Jonas (Supervisor), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [redacted] Email: [redacted]

Dr. Tim Tenbensel (HOD), Health Systems Section, School of Population Health, Tamaki Campus, The University of Auckland, Private Bag 92019, Auckland. Telephone [redacted]

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The researcher was funded for the PhD degree by the Margaret Burland Doctoral Scholarship.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 11/03/2015 FOR 3 YEARS, REFERENCE NUMBER [redacted]
CONSENT FORM

For the Health Professional Interviews

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

Project title:  Information sharing within Primary Care: The role of trust as an ethical and practical consideration around the sharing of personal information.

Researcher:  Samantha Fitch

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I understand that I am free to withdraw participation at any time, and to withdraw any data traceable to me up to 1st December 2016.
- I understand that the interview will last approximately 30-60 minutes.
- I understand that data will be kept for 6 years in a locked filing cabinet at the School of Population Health, The University of Auckland, and in a password-protected electronic file on a University of Auckland server, after which time they will be destroyed.
- I understand that if the information I provide is reported/published, this will be done in a way that does not identify me as its source.
- I understand that the information collected in the interview will be voice recorded (and recording can be stopped at any time) and later transcribed by the named researcher. I have the opportunity to review the information I have given. I will have 2 weeks in which to let the researcher know of any corrections I might have (see below).
- I understand that the information collected in the interview will be used for data analysis and presented in research outputs.

I wish to review the transcript of my interview.   YES / NO

Name: ________________________________  
Signature: ___________________________  Date: ________________

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 11th MARCH 2015 FOR 3 YEARS. REFERENCE NUMBER [REDACTED]
GP INTERVIEW QUESTIONS

‘Sabrina’ - Questions about trust and expectations when sharing information with a GP

Sabrina is a 24-year old woman. She has just moved to a new part of town and is visiting a new GP practice. She is seeing Dr Jones for the first time. When she arrives, Sabrina is asked to complete an enrolment form. This includes a section which asks if she wants to transfer her patient notes from her former GP to the new practice. When Sabrina enters Dr Jones’ office she is nervous about talking to a strange doctor about her symptoms. She worries that Dr Jones won’t believe what she is saying. She is also wary of whether Dr Jones is a good doctor. Sabrina feels like Dr Jones is typing furiously as she describes her symptoms, barely looking at her. Sabrina is curious as to what Dr Jones is writing about her, but is too scared to ask. Dr Jones prints out a referral letter for a specialist and a list of blood tests – Sabrina isn’t sure what they’re all for, but nods as Dr Jones says what they are. Dr Jones seems busy – set on getting Sabrina out of the door as soon as possible.

1. What are your initial impressions of what is going on in this scenario?

2. If Sabrina trusted Dr Jones, do you think this would change things? What if she doesn’t trust Dr Jones at all?

   i. What do you think the GP could do to be more trustworthy or to develop trust with Sabrina?

   ii. Is there anything that Sabrina could or should have done to build trust with the GP?

   iii. What if Sabrina had heard things from a friend about this Doctor, would this have an impact?

   iv. If you think about your own practice, do you think your patients trust you because they’re a Doctor, and that’s your job, or because of something else?

3. What do you think Patients know about what you can or cannot do with their personal information?

4. What do you expect of your Patients when you are communicating with them? What do you think they expect when they share information with you?

Questions about trustworthy information sharing:

1. What concerns do you have about sharing patient information with other professionals or organisations? (with colleagues, other health professionals, with third party organisations, government agencies)

2. What do you think GPs can or should do to make sure they are trustworthy with information?
Dr Jones - Questions about losing and rebuilding trust related to information sharing.

At the GP Practice where Dr Jones works, all patient notes are kept electronically. The notes are stored on a server, held on the premises in a locked server closet. They also keep a backup of files on a hard-drive that one of the staff take home at the end of the day. As the last person to leave work one night Dr Jones takes the backup hard drive home. Dr Jones takes the hard drive into the house before going out for the evening. When Dr Jones gets home, the house has been ransacked and items have been taken. Dr Jones races through to the study, but the hard drive is gone.

1. What are your initial impressions about this scenario?

2. Does your practice have policies or procedures around information privacy and data security?
   1. Do you have a dedicated person who is responsible for these matters?

3. If you were in Dr Jones' shoes, what would you do? Do you think it would affect the trust that your patients have in you?

4. Would you feel any differently if it was the Doctors/Dr Jones' fault? If Dr Jones lost the hard drive or caused the information to get out? [Imagine Dr Jones is running late and goes to the supermarket on the way home, leaving the hard-drive in the car, on the front seat and it is stolen?]. What about if it were a systems or technical issue?

5. If this, or something similar happened, what would you do? How might you seek to rebuild trust with any affected patients?

Other questions:

1. Where do you think patients expectations of GPs, and about information sharing come from?
2. If, for a moment, you think about your experience as a patient would you respond differently to any of the scenarios?
3. [Little recap] Is there anything else that you think is relevant to the discussion we've had?
4. Finally, based on everything we've discussed today, how would you define trust?
<table>
<thead>
<tr>
<th>Code name</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningful name of the code</td>
<td>A description of the code</td>
<td>Example of the code from the transcripts indicated as from the patient perspective</td>
</tr>
<tr>
<td><strong>Trust</strong></td>
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<td></td>
</tr>
<tr>
<td>Trust is</td>
<td>Definitions of trust given by participants</td>
<td>&quot;Trust is a belief of one person in another to treat each other kindly and sensitively and that they share information and experiences positively.&quot; - Kaha</td>
</tr>
<tr>
<td>Trust does</td>
<td>The things that trust does or does not do — the difference that trust makes to the Dr-Patient relationship and in information sharing practices.</td>
<td>&quot;...I don't think she'd be wary of-of sharing information because that's-that's going to give the GP a full picture of her condition. Um, I don't think she'd have so many anxieties if she had more trust in him/her, Dr Jones.&quot; - Kaha</td>
</tr>
<tr>
<td>Trust requires</td>
<td>What participants outline as factors or things that build or develop trust. This includes requirements of doctors and patients.</td>
<td>&quot;I mean if she had been seeing him for a while, she'd probably would feel differently going into it because she would know who he is and they would have established a repertoire (rapport??) and that sort of thing.&quot; - Khailees</td>
</tr>
<tr>
<td>Initial trust</td>
<td>Descriptions of trust based on first encounters</td>
<td>&quot;Ah probably...although I still think that um it is hard to trust someone that you haven't met before you know some you can find some information or or about them either through friends or online which might give you some level of trust but the importance of that relationship, of first impressions, or establishing you know like an initial rapport is really important.&quot; - Roberto</td>
</tr>
<tr>
<td>Role based trust</td>
<td>Descriptions of trust based on the role of a GP or professional. As a sub node — inherent trust.</td>
<td>&quot;I would certainly say that I trust them because that is their job. That is their job. So, um, it's it's funny because, as a teacher I always found that we're the only education, it's the only job where someone can walk in and tell you what to do because they have been to school, they have experience of learning themselves. But I can't walk into a Doctors thing and profess to know, just because I've had a knee surgery that I could tell them what it takes to fix a knee, I don't think I could ever do that, so, it's specialist in my opinion, so yeah, I do trust, I do have to trust in them.&quot; - Tama</td>
</tr>
<tr>
<td>Interpersonal trust</td>
<td>Descriptions of trust based on the interpersonal trust of a trustor in a trustee.</td>
<td>&quot;Who they are as a person, yeah. The lady I see is very, she is very person-centred, client-centred. I mean, I, I, to get a medical degree, I personally believe you need enough knowledge to get into medical school and then after that it is rote learning, and a lot more people that don't get into medical school could still become a doctor, personally I think the most important thing is what you do with those skills and that comes down to the person that you are.&quot; - Gerard</td>
</tr>
<tr>
<td>Vulnerability</td>
<td>Descriptions of the way that a patient or doctor may be vulnerable in the Dr-Patient relationship or in the health care setting.</td>
<td>&quot;Umm, because she is a bit on, like, some people have that stereotype that the GP is the expert, and um, so, she is on the back foot already and she is possibly...&quot;</td>
</tr>
<tr>
<td>Power</td>
<td>Perceived power dynamics between patients and doctors – e.g. GP/doctor as expert</td>
<td>“Um she could ask but she’s too scared to ask so she could say I’m keen to know what you’re asking, or I’d be keen to talk to you a bit before you start writing but it’s really difficult in my experience because there is a power imbalance between the patient and the doctor meaning it’s quite difficult to do that. When I was younger I was in quite a similar position and I found it really difficult to ask those types of questions.” - Roberto</td>
</tr>
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<td>---</td>
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</tr>
<tr>
<td>What others say</td>
<td>The impact of research into a GP, or recommendations or word-of-mouth.</td>
<td>“You trust that, if someone recommends someone then you go in with a level of trust and then you get to form your own opinions based on your own experience, I guess, but yeah.” - Tama</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Expectations</th>
<th></th>
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<tbody>
<tr>
<td>Verbal communication</td>
<td>Ways of verbally communicating between a patient and GP that are trust building, or positive and those that are not.</td>
</tr>
<tr>
<td>Non-verbal communication</td>
<td>Non-verbal cues and communication between a patient and GP that are trust building, or positive and those that are not.</td>
</tr>
<tr>
<td>Professionalism</td>
<td>Descriptions of the professional conduct of GPs. This includes actions around record keeping, approach to information, approach to patients etc.</td>
</tr>
<tr>
<td>Attributes of GPs</td>
<td>Descriptions of GP attributes that patients expect when sharing information about themselves</td>
</tr>
<tr>
<td>Outcomes</td>
<td>The outcomes or results that patients expect of GPs</td>
</tr>
</tbody>
</table>
| Genesis | Where patient expectations come from – as reported by patients and GPs | “I would expect, my expectations are built on like every child who generally grows up around the same doctor for quite a long time, like I said I had Dr X until I went to high school and he was always really lovely, so that builds your initial
<table>
<thead>
<tr>
<th>Best interests</th>
<th>The GP has the best interests of the patient.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information sharing</strong></td>
<td></td>
</tr>
<tr>
<td>Disclosure</td>
<td>Descriptions of when information can be shared</td>
</tr>
<tr>
<td></td>
<td>&quot;Ah, ah, I expect them to share information with people who I’ve, are, in the field of the condition that I might have. I would, insurance companies, I think is a fair and valid one, ACC.&quot; - Gerard</td>
</tr>
<tr>
<td>Nondisclosure</td>
<td>Descriptions of when information cannot be shared</td>
</tr>
<tr>
<td></td>
<td>&quot;Ah commercial organisations so outside of the health industry so if there is no good reason for them to share the information to support your health and improving your health then they shouldn’t share it.&quot;</td>
</tr>
<tr>
<td>Consent</td>
<td>The importance of consent, or the instances where consent may have been asked or required.</td>
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<td>&quot;I know that they are not allowed to share it with, well, anyone without my permission which includes my husband.&quot; - Louise</td>
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<tr>
<td>Third parties</td>
<td>Concerns that Patients and GPs raised about third party sharing – e.g. with insurance company or ACC</td>
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<td>&quot;I don’t have concerns sharing within the public sector what I do have concerns about is in private medical because we have private medical insurance and they can use anything you’ve said to your GP pretty much against you in terms of trying to avoid paying and to some extent I have concerns with ACC about that now because they have gone down quite an um interrogative route you know that they are really looking to avoid having to pay out if they can&quot; - Roberto</td>
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<td>Sensitive</td>
<td>Concerns that Patients and GPs raised about the sharing of sensitive information.</td>
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<td>&quot;...discussing something like, like sexual health, sometimes even going in to discuss those sort of things can be a bit personal and if you feel like your doctor isn’t judging you or that you sort of trust that they appreciate that you’ve come to them with sensitive information then you feel more comfortable that you’re not just treating this like I’ve got a cough and my tummy hurts, it’s a little more important than that.&quot; - Khaledesi</td>
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<tr>
<td>Purpose</td>
<td>The perceived purpose of information or information sharing. This describes where participants outlined that there needed to be a reason, need or purpose for information sharing.</td>
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<td>&quot;So the intent of me sharing is to get healthier and that is the purpose for them sharing with others so that is the only reason they will do that.&quot; - Roberto</td>
</tr>
<tr>
<td>Conversations about Information Sharing</td>
<td>Conversations between Patients and GPs that relate to information being shared</td>
</tr>
<tr>
<td>How to be trustworthy with information</td>
<td>What patients and GPs perceive as what GPs can or should do to be trustworthy with patient information. This includes processes or things that can be done as well as attitudes towards the patient information.</td>
</tr>
<tr>
<td>What patients know</td>
<td>What patients know about what GPs can and cannot do with information, and what GPs think patients know.</td>
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<tr>
<td>How they know</td>
<td>Source of knowledge about what can and cannot be done with patient information</td>
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### Information breach and rebuilding trust

<p>| Physical security measures | Description and perception of physical security measures – like the use of a fire proof safe or a lock box, shredding of materials, locking up in a room or cabinet | &quot;I'm sure or some recognition that that was pretty dumb, and I'd like to be told how it was, how it was going to be remedied, so &quot;in future we're going to buy a safe, a fire proof safe and lock it in there&quot; or something, so what has happened and what is going to happen in the future&quot; - Louise |
| Non-physical security measures | Description and perception of electronic security measures – like encryption or cloud based storage for back-ups, using secure email or remote access from home. | &quot;Well if it was encrypted it would be okay so it would depend what standards they have around that hard drive I'm assuming it would be encrypted because that would be relatively simple so then the best someone can do if they have stolen is wipe it and use it or sell it as a hard drive if it is not encrypted&quot; - Roberto |
| Fault or blame [procedure and person] | Who is to blame when data gets into the wrong hands? Is it focused on the procedure or process? Or on the person and their attitude towards information? | &quot;Erm, I don't see the necessity in taking the hard drive home... I ah, apart from that it's, it is to be a fairly safe way to keep the... it seems a fairly safe way to keep the notes to me, um, without me, like, I don't know the process or the legalities around how GPs are supposed to do that.&quot; – Gerard |
| Actions to remedy | What GPs and Practices can or should do to remedy a data breach. | &quot;Um I think they would need to contact their patients and tell them there had been a breach in their data security and tell them what the potential implications are of...&quot; - Khaa |</p>
<table>
<thead>
<tr>
<th>Impact on trust</th>
<th>The impact on trust of an information/data breach. This might include the reactions of patients to stay or leave the practice or how they might think about the GP after such an action.</th>
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<tbody>
<tr>
<td>Rebuilding trust</td>
<td>Descriptions of what a GP would need to do to rebuild or regain a patient’s trust. Can be coded more specifically like transparency, honesty, apology etc.</td>
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<td>“It would be huge, absolutely huge, especially if you were involved with a lot of government agencies, if there were a lot of people involved in your life, that would be dreadful.” - Louise</td>
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<td>“Um, the first thing is addressing it, owning up you know “yeah, we really made a mistake here” so accepting what they have done and not trying to palm it off or trying to blame it on something else, sure it wasn’t their fault that they got robbed but the reality is that they put sensitive information in a situation to be robbed, so I would suggest that them taking the onus saying “Hey, hands up, we’re really sorry, this is what has happened, to prevent this in future cases in the future this is what we have put in place, we will be monitored” and you know putting in what could prevent that, that would certainly go some way to building the, or repairing that relationship certainly.” - Tania</td>
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</table>
List of References


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