Who rules the centre of care? An institutional ethnography exploring patient experiences within the New Zealand primary care setting

A thesis presented in fulfilment of the requirements for the degree of

Doctor of Philosophy

in

Nursing

Massey University

Manawatū

New Zealand

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2022

Abstract

Improving 'patient experience' is at the forefront of international quality improvement agendas and is prioritised by dominant frameworks such as the Institute for Healthcare Improvement's 'Triple Aim.' To gather knowledge of this priority measure, New Zealand developed a set of 'system level measures' to benchmark and compare data between local, national and international health systems. The primary care patient experience survey, introduced as a system level measure, is purported to measure 'patient experience.' The survey produces official reports of a person/patient-centred primary care system. However, the findings in this report differ from what I learned talking with patients about their actual experience.

This project uses the tools of institutional ethnography to begin an inquiry from the accounts of patients. To generate these accounts, I asked people about their experience of being a patient (N = 10). The intention is to learn about what patients say, know and do. I then asked seven clinicians (general practitioners, nurse practitioners, and registered nurses) about their experience, again focusing on what they say, know and do.

The analysis reveals that some frontline patients and clinicians reported care practices that explicitly challenge their ability to be at or put patients at the centre of care. In some instances, practices purported to enhance person-centred care instead appear to place the person at an even greater distance from the centre, generating new work for patients without a clear benefit for the patient doing such work. Examples investigated include 'GP triage' and 'team-based practice.'

From these findings, I followed what patients and clinicians say, know and do into the institution of primary care. At this level I talked with other key stakeholders of primary care and patient experience; people in management and governance, practice owners, strategy writers, survey writers, and primary care researchers (N = 11). I asked people in these positions about what they say and know, with the intention of using this knowledge to make sense of what can be said and done at the frontline of primary care.

I found that standardising practices (e.g. 15 minute appointments, consultations limited to one issue per appointment, fee for service) constrain the clinician (and by proxy the patient) to what can be said and done during an episode of primary care. These practices are powerfully controlled by the private business model of primary care despite significant public funding. I found that patients and clinicians undertake significant workarounds to support care priorities such as continuity of care and timely access to care. Yet, the measurement of the "person-centredness" of primary care (the survey), renders invisible these actions of both patients and clinicians.

The implications of these findings suggest that primary care, as it is presently organised, reorganised and protected by its principle protagonists, shifts the work of person-centred practices onto the frontline of primary care. The frontline of primary care is, at present, invisibly attempting to save this system from failure through their best efforts at addressing patient need.

Acknowledgements

First and foremost, I must express my deepest and sincerest gratitude to my supervisory team. Professor Jenny Carryer has guided me through this journey with patience and poise, always ready with just the right words at just the right time. Your contribution academically and personally has profoundly shaped the way I have and will continue to look at, question and challenge the world around me. Dr Sue Adams has complemented and completed this supervisory team. Sue, your knack for asking the right questions to elicit the spark and the confidence to take the next steps in this process has been greatly appreciated. Together, Jenny and Sue, your unfaltering confidence that a thesis would emerge out of the rubble gave me hope, and somehow that belief has come true.

I want to thank Dr Nicola Waters for her methodological support, most significantly, for showing me how to open doors into the social world. Your guidance showed me a path through the data that I could not see. To my critical companion Dr Rhonda McKelvie, I treasure our "strolls around the estate" to solve all manner of problems. You inspire me more than you may ever know. To the brilliant researchers with whom I have shared an office, you have each made a unique contribution to the researcher I am today. Notably, Dr(!!) Akisi Ravono. I do not think I will ever meet a more kind and gentle soul. Thank you for being the office mate I never knew I needed. You make me a better person. To the "imposters corner," Camille and Max, I credit my sanity to you in the final stretch. I also acknowledge the many others in the School of Nursing who gently encouraged me in the corridors, the doorways, and across the coffee or lunch table; you all have a place in this PhD journey.

My family, and friends who are family, you have supported me unconditionally. Alice, Amanda, Ash, Corinne, Hannah, Kathryn, Kellie, Nicole and Sara, thank you for making space in our relationships for this season of study, growth, and hard work. Thank you for providing the companionship, the laughs, the coffee, the wine, and the hope for a life beyond doctoral research.

Mum. The strongest woman I know. You have shown me how to navigate difficult spaces with grace and purpose. You inspire me. Thank you for being my champion. And Dad, who always believed in my ability to succeed in this space, but passed away before I reached the finish line. It is bittersweet finishing this without you.

To my husband, Josh, I am eternally grateful for the safe harbour you have provided for this long journey. I think you always knew I would finish, but neither of us quite knew what it would take to get there. Thank you for never giving up. And to my daughters, Beatrice and baby Pippa. You have made me stronger, better, and more fulfilled than you may ever know.

Finally, a special thank you to the many participants. Thank you for the generous gift of your time and stories. Health care is for you. This research is for you. 'He aha te mea nui o te ao? Māku e kī atu, he tangata, he tangata, he tangata.' *What is the most important thing in this world? It is people, it is people, it is people.*

Funding

I am grateful for the Massey University, College of Health, Doctoral Scholarship awarded to this research project.

Notes to the Reader

Dorothy E Smith is the prominent author of methodology resources cited in this thesis. For enhanced readability, all references to Smith pertain to Dorothy E Smith, unless otherwise indicated by alternative author initial.

In the absence of a glossary, key terms of institutional ethnography (the research methodology applied within this thesis) are attended to as they enter the research discussions. In doing so, the term is located in reader context, thus explained in a meaningful (contextual) way. Below is an index of key terms as they arise alongside meaningful or contextual explanation.

Work	4
Healthwork	85
Disjuncture	16
Problematic	4
Standpoint	5
Social organisation	4
Ruling relation	20
Texts	7
Ideology	83
Discourse	84
Shell terms	85
Ideological circuit	86

Table of Contents

List of Figures

List of Tables

Abbreviations

ACC	Accident Compensation Corporation
CEO	chief executive officer
DHB	District Health Board
GP	general practitioner
HQSC	Health Quality and Safety Commission New Zealand
IFHC	integrated family health centre
IHI	Institute of Healthcare Improvement
IoM	Institute of Medicine
OECD	Organisation for Economic Co-operation and Development
NHC	National Health Committee
NP	nurse practitioner
NPM	new public management
NZ	New Zealand
NZBMA	New Zealand branch of the British Medical Association
PCC	person-centred care
PHCS	Primary health care strategy
PHO	Primary Health Organisation
RN	registered nurse
WHO	World Health Organisation

Chapter One - Beginning in the experiences of people

"The New Zealand Health Strategy… emphasises a health system that is based on co-operation, a system that puts people at the heart of health care" (Minister of Health, 2000, p. iii)

"National wants more personalised healthcare. This requires a patient-centred health system where individuals are active partners with health professionals in the management of their own treatment and care."

(National Party health spokesperson, 2007, p.23)

"The people-powered theme [of the refreshed Health Strategy] reflects the Government's priority of delivering 'better public services' and the opportunity to achieve this through taking more people-centred approaches to providing health services." (Minister of Health, 2016b, p. 5)

Introduction

Being a patient, participating in the world of primary care[1] is a familiar experience for many people. Less familiar, though, are the institutional and political foundations of the system within which patients participate. When a patient enters into the system of primary care they are often entirely oblivious to the many layers of bureaucracy playing out behind the scenes. These layers organise the distribution of resources, models of funding allocation, workforce development, purported population needs and system designs. For patients, the opacity of these layers they are 'gearing into'[2] is not a routinely acknowledged problem, yet is endemic to the routine itself. However, when

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[1] There is an important distinction to be made between primary care and primary health care. The two terms are not synonymous. To be clear, primary care refers to general medical services provided as the first point of contact in the community. General Practitioners (GPs) are the dominant providers of primary care in New Zealand, with an emerging uptake of Nurse Practitioners (NPs) (Adams et al., 2020). Primary health care covers a broad range of out-of-hospital services which address the wider determinants of health, including public health, population health, health promotion, prevention, education, and treatment, of which one aspect is primary care.

[2] 'Gearing into' is used in this research project to describe purposive actions or activities that people do at a specific social interface, that 'gear [them] into' the complex workings of an institution, for example patients' actions within the interface with primary care processes. "Viewed in this way, work happens at (gears into) the interface between the individual, embodied subject and the physical and social worlds…" (McCoy 2006, p. 111). Note that McCoy has taken up the phrase gearing into from the work of phenomenologist Alfred Schutz.

the everyday experience is troubling for patients, this warrants examination of the institutional processes *organising* what is happening.

Shaping the research problem

Increasingly, there are reports that primary care services are not meeting the needs of some sectors of the New Zealand population. In 2018, nearly a third (30.4%) of the New Zealand adult population reported via national survey at least one instance in the past year of unmet need within primary care (Ministry of Health, 2019a). Comparatively, this figure increased to 41.4 per cent for Māori[3] (Ministry of Health, 2019a). Unmet needs (as defined by the Ministry of Health survey) include care not accessed due to cost, unmet need for after-hours care, inability to get an appointment within 24 hours, and lack of transport or childcare to attend an appointment (Ministry of Health, 2019a). While these concepts of unmet need represent the Ministry of Health's assumptions and agenda (not the patient's), and the abstraction of such data is problematic, as I will show later, there are further examples of people raising concerns about their experience with primary care.

Recent research voiced the concerns of Māori people in their experience of receiving health care in New Zealand (Simmonds et al., 2020). Participants said, for instance, "they [general practitioners] take time to read the notes, then speak for two minutes to ask what I was there for, then write a prescription" (p. 45). Others described that care was impersonal and rushed, and said they felt like they were on a "conveyor belt" (p. 45).

Throughout the duration of this study, I have observed and reflected upon primary care in New Zealand. I have observed a care setting that is undergoing constant review and revision but little change to its fundamental mode of operation. I see rapid changes in the physical and digital

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[3] Māori are the indigenous people of New Zealand. New Zealand is theoretically a bicultural country, founded on Te Tiriti o Waitangi, a treaty agreement between the colonizing British settlers (Pākehā) and Māori. Te Tiriti outlines the expectation that both groups should benefit and prosper equally, yet Māori health status is persistently demonstrably poorer than non-Māori (Ministry of Health, 2019; Palmer et al., 2019; Sheridan et al., 2011).

environment with new buildings and apps, becoming ever more complex to navigate physically and digitally. I have noticed increasing wait times, up to several weeks for a routine consultation in some settings. I have felt hurried in face-to-face encounters. I have listened to the distress and frustration of friends, family, and other health care users, who report increasing difficulty in accessing, attending, and following up with primary care services.

Locating the tension – a door into the research problem

These observations and experiences sit in tension with the way policymakers, health workforce educators and primary care governance talk, teach and write about primary care. In particular, there is a sharp contrast with the frequently referenced concept "person-centred care" seen in such talk and text. Person-centred care is a concept based on the idea that the needs, values and preferences of individuals seeking health care will be the focus of service delivery rather than those of the organisation (Mead & Bower, 2000; Phillips & Scheffmann-Petersen, 2020; World Health Organization, 2015b).

The idea that people (patients) are at the centre of primary care is repeatedly referenced in numerous high-level health care policies, frameworks, models and planning documents.[4] Additionally, person-centred care is taught as a fundamental concept of nursing and medical education (see for example; compulsory course texts; Crisp et al., 2016; Medical Council of New Zealand, 2017), and embedded in legal documents like the nurse practitioner scope of practice (Nursing Council of New Zealand, 2020). Conceptually, documents intended to govern primary care coupled with forward-facing patient education documents develop, define and suggest that primary care *is* person-centred (Health Quality & Safety Commission New Zealand, 2016c). Yet I

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[4] There are many key strategies and supporting documents in New Zealand, which demonstrate either a clear or conceptual relationship or commitment to person-centred care. As appropriate, this thesis draws from these texts both individually, and as a collective representation of national health care policy and planning documents. For a summary of these texts see Appendix A.

discovered, and will further explicate,[5] that, contrary to the talk and text about person-centredness, some frontline patients and clinicians reported care practices that explicitly challenge their ability to be at or put patients at the centre of care. In some instances, practices purported to enhance person-centred care instead appear to place the person at an even greater distance from the 'centre' generating new 'work'[6] for patients without a clear benefit for the patient doing such work. In these cases, the familiar experience of participating in primary care is troubling for patients.

Research aim

This thesis is an institutional ethnographic study (Smith, 2005b, 2006b), which takes as its problematic[7] the troubling, conflicting and frustrating experiences of patients in the everyday world of New Zealand primary care. The aim of this study is to explore *how* the social organisation of primary care coordinates the everyday work of people at the frontline (patients and clinicians). The primary question is "how do national strategies, policy directives, and governing activities organise the interface between patients and those on the other side of primary care institutional practices?"

Standpoint

As the researcher, I adopt a standpoint alongside patients, paying close attention to what patients know and how they talk about their everyday experiences of utilising primary care services. From the standpoint of patients, I can explore primary care as it happens for them - from their perspective (not from preconceived theory). To do so, I talk with patients, listening to their experiences before, during and after their encounters with the primary care setting. I listen for the moments when their needs were not met, when they were not in control, for contradictions and frustrations. These moments indicate that *something* is organising their experience that displaces

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[5] To *explicate* is an often-used analytical term in institutional ethnography, meaning to go beyond the data/experiential knowledge to understand what is missing/invisible or hidden, from their situated understanding of how things happen (Campbell & Gregor, 2004).

[6] The concept of work is used *generously* in institutional ethnography. Work describes "anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about" (Smith, 2005b).

[7] A problematic is in similar vein to a research question, with a distinct focus on the explication of the everyday world as such experiences come to be seen as troubling (Smith, 1987).

them from the centre of care. Through following these moments of 'something,' I can find clues which begin to unravel assumptions about, and practices undertaken, which may or may not deliver person-centred care.

At times in this research project, I talk about *people at the frontline of primary care* - both patients and clinicians. Combining patients and clinicians to formulate a single *frontline* is appropriate for some discussions, as I learned that both patients and clinicians are drawn into many of the same orchestrated institutional experiences in the provision of primary care. Importantly though, I remain committed to patients as the standpoint of this inquiry. This decision is discussed further in this chapter.

Location of the study

This study takes place in the setting of primary care in New Zealand. Primary care in New Zealand refers to the general medical services provided primarily by general practitioners (GPs), a growing number of nurse practitioners (NPs), and practice nurses (registered nurses) in the community (Adams et al., 2020; Ministry of Health, 2018e).

Primary care versus primary health care

Primary care is a significant aspect of primary health care. Primary care denotes the first level health services attending to presenting problems and responding with diagnosis and management, long-term condition management and further disease prevention (Downs, 2017; Moore, 2019). In contrast, primary health care is described by the Alma-Ata declaration, as universally accessible health care addressing (among other things) population health, health promotion, prevention, education, maternal and child care such as family planning and immunisation, promotion of food supply, food safety, healthy nutrition, supply of safe water, basic sanitation, prevention and control of local disease, and the provision of pharmaceuticals (World Health Organization, 1978).

Primary care in New Zealand

Primary care is generally the first point of contact for people accessing medical services. People access these services either in person at a primary care centre, or more recently via electronic communication systems and virtual consultations (Almeida & Montayre, 2019; Carryer & Kooienga, 2017; Ministry of Health, 2018e). Primary care has historically practiced according to a western model of care and informed largely by an English model of governance and public sector management (Atmore, 2017; Bailly, 2016; Duncan & Chapman, 2010; Goodyear-Smith, 2015; New Zealand Nurses Organisation, ND).

Primary care in practice

All New Zealand citizens and permanent residents are eligible for publicly funded health services (Downs, 2017). Government funding (via Vote Health) subsidises a significant portion of primary care costs, with patients paying a fee-for-service (dependent on social and geographical need, as well as frequency of access) to the general practices (Downs, 2017; Greatbanks et al., 2017). To access this funding, people must enrol with a general practice. General practices are typically privately owned, although some are owned by community groups, trusts, some DHBs, iwi,[8] and growing corporate ownership (Crampton et al., 2004; Gauld et al., 2019). General practitioners have historically been self-employed small business practice owners but are becoming increasingly corporatised (Atmore, 2017).

Reading notes

To support the reading of this thesis, and indeed the early data encountered in this chapter, I foreground reader instructions. Firstly, read this thesis with the theoretical and analytical assumption that knowledge is socially constructed through a social practice undertaken by people. Therefore, social life is not chaotic but instead organised to happen as it does (Campbell & Gregor,

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[8] Iwi as used here represents Māori tribal organisations. Iwi, as independent organisations, provide Māori centred primary health and primary care services to their population (Malcolm & Barnett, 1994).

2004). Hence this study posits that the practices occurring at the frontline of primary care are designed and coordinated to occur within a framework of socially constructed institutional rules, funding structures, and layers of governance. It is my work to demonstrate how this happens.

Secondly, and significant to the first assumption; socially organised knowledge is spread, controlled and changed by texts (Smith, 2006a). This infers that texts are located and used in the primary care setting to coordinate (spread, control, and change) the activities of people. The term 'texts' is used here to represent words or images (something with definite material form) that is replicable (Smith, 2005b). I ask the reader to pay attention to texts as they appear in the everyday activities of the people whose experiences are a part this thesis.

I approach this thesis as a registered nurse, a 'well' user of primary health care services, and frequently called upon navigator and translator of health services for friends and family. I have listened to the frustrations voiced by people who feel lost in the enormity of their health problems, uncertain of what, from whom, or where to get help. I hear the worries voiced by clinicians who feel unable to meet patient needs due to increasing demands on their time and attention. Appropriately, the knowledge I hold from each position informs elements of this research. I am not independent of this thesis, nor should I be. Indeed, troubling experiences expressed by people I encountered in these many locations served as a research catalyst, leading me into this line of inquiry.

Orientating the project and reader

Below are two summaries derived from my interviews with people (patients and clinicians) regarding their experiences within primary care. The accounts below exemplify the problematic of this study. The first from a patient, 'Jan,' identifies the contradiction between primary care as intended, and primary care as experienced. The second, from a nurse practitioner, 'Alex,' introduces the tension for clinicians at the intersection of intended and actual care delivery. I refer to their combined location within the health care system as the "frontline" of primary care. These accounts are intended to orientate the reader to the way institutional ethnography has been employed to investigate the research concerns addressed within this thesis. Jan and Alex draw the reader into the everyday experiences of people undertaking practices associated with the provision of primary care in New Zealand. Their experiences hold clues that hint towards many of the institutional relations that organise the practices of frontline primary care. I demonstrate how accounts such as Jan and Alex's are used to begin an institutional ethnography, by opening "doors through which the ethnographer may go" (Smith, 2005b, p. 151) into the social world of primary care, to unravel the institutional practices that organise people's frontline experience.

The social world

Before going any further, it is necessary to articulate what is meant here when talking about the social world – a foundational concept of institutional ethnography. Smith, and subsequently, institutional ethnographers, believe the world is invariably social (Campbell & Gregor, 2004) and what people know, enact and experience does not happen in isolation but is organised within a complex network of connections to others that constitutes *the social*. Thus, institutional ethnographers approach inquiry with a theorised interest of the social world. With this in mind, institutional ethnographers aim to know through investigation "the social as people actually bring it into being… [through] the actual ongoing ways in which people's activities are coordinated… that connect up multiple and various sites of experience, … ordinarily inaccessible to people" (Smith, 1999, p. 129).

Making the social world visible requires thorough explication of the social relations that coordinate the knowledge and practice of people's everyday work within that landscape. In practice, opening these doors to further resources of knowledge entails talking with people, identifying the texts they use or mention (for example, a document involved in a consultation – a computer programme, a clinical guideline, a referral) and following the texts to see how they link the frontline or standpoint informants to others through textual coordination.

Textual coordination

As mentioned earlier, socially organised knowledge is spread, controlled and changed by texts (Smith, 2006a). Texts are located and used in the primary care setting to coordinate the activities of people. Both patients and clinicians produce and communicate through texts such as lists, patient management software, and prescriptions. Even the slip of paper given to patients by reception staff communicates institutional knowledge of appointment organisation, which I can begin to see as organising the way people interact with appointment times. The institutional ethnographer's purpose is to show how people at the frontline activate the 'authorised' knowledge carried within the texts; how what they know and are able to do is coordinated, often without their knowledge, by decisions made by others, elsewhere. The complete account of this process is in Chapter 3; the section below (following the accounts of Jan and Alex) sets out the basic principles required to come to see the world as socially organised.

Jan

Jan is retired and describes herself as "old, but not *that* old." She lives at home with her husband, whom she terms as "actively retired." Jan and her husband have worked hard but lived a simple life, and now rely on superannuation from the government. Jan has type two diabetes,[9] for which she takes insulin multiple times a day. Further, Jan's vision is affected by glaucoma.[10] She has "other pills" too, but she says, "no big deal, I take them the same time every day, and yeah, I carry on."

Jan sees a GP for support with managing her long-term conditions and for help with other health concerns that may arise. Jan has been seeing the same GP, Doctor M, for many years. She first started seeing Doctor M, whom Jan refers to by his first name, at a small practice located close to her home. Over many years Doctor M got to know Jan well. She says "I've been with him for a long time now, I'm happy with him. He's very good." Jan elaborates, telling me about the

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[9] A chronic condition affecting the way the body processes sugar (glucose) in the blood.

[10] A chronic condition of the eyes causing gradual loss of vision.

relationship she has with him, and how she has full trust in the care he provides to her. Jan describes how he listens to her, and that she feels he genuinely tries to do the best for her. Most of all, Jan appreciates feeling that he knows her well. Jan likes how Doctor M asks after her husband, that he remembers important events in Jan's life, and will say "hello" when they bump into each other in town.

Recently, Doctor M closed his small practice and moved into a large new conglomerate health centre (Integrated Family Healthcare Centre – IFHC). In doing so, the patients enrolled with his practice transitioned to the centre as well. Jan had reservations about Doctor M moving, including difficulties in getting to the new location, changes in costs, and changes in the care she received from him. Doctor M explained to her the reason for moving, and assured her the care would be the same, just in a new building. "He did tell me… he wants to retire in so many years, and what if nobody buys that practice? See, nobody will buy one practice, but in that there [an IFHC] somebody will buy to come into the practice, so you can see his point of view, but it's not a good idea." Despite her reservations, Jan elected to stay with 'her GP' and move to an IFHC.

Since moving to the new practice, Jan describes increasing difficulties obtaining an appointment with Doctor M when she has needed one. When she phones the centre reception to request an appointment, she is often told there are no appointments available with Doctor M. Instead, Jan is offered an appointment with a different clinician at the centre. The centre explained to Jan how the clinicians work in teams and how they tried to "convince" her that this new team approach would work well for her. Jan knows that she can access the other clinicians in her health care team, but she enrolled with the centre specifically to stay with Doctor M. In her desire to see only Doctor M, Jan does what she describes as "pushing" for him. When I asked her what she meant by this, Jan told me "I particularly say, 'I want to see Doctor M. I won't see anybody else.' Unless I'm dying, then I'd have to." Jan tells me that so far, this approach is effective in securing an appointment with Doctor M, as the receptionists eventually "find" an appointment. However, Jan has additional concerns about the centre.

Jan has noticed that her relationship with the staff at the new centre is different.

> You haven't got the same relationship. In the little practice, you walk up to the reception; "Hey Jan!" see? There [Jan's IFHC], you line up and wait and there might be three girls and you don't know any of them, you know, whereas in the smaller practice you knew them all, they say "Hi" to you. You just go there [Jan's IFHC], all the different girls are there, they say "next," and you get served, and you go around the corner and sit, whereas before you could even talk to the other reception girls if you want… But these ones, no, they just give you the bit of paper and around the corner you go and sit.

Further, on describing the physical centre, Jan summarises, "Yes, it's less personal being bigger, and you notice too when you go there, it's a big room, the waiting room… you would call it impersonal, a lot more impersonal."

Jan's other concerns centre around increasing costs for patients; "every time you go, it's [patient co-payment for the consultation] gone up; dearer. It's gone up far more than what the average person on a pension can afford." She told me that she now "thinks twice" before going to the doctor or nurse and worries about the financial burden as she ages with her long-term conditions. Additionally, Jan is not impressed by the incidental costs that she is charged at the new centre, for activities such as phone calls and faxes. Jan speculates these costs are the result of patients "paying for the new building."

I asked Jan if there were any benefits to her from the move to the new centre, she tells me "no, no, no. No extra benefits, no. Nothing new, like that you'd think, oh that's nice, we didn't have that before, no, there's nothing like that." On further probing, Jan was aware of some of the services at her IFHC. For example, an acute care walk-in clinic ("I've never bothered with it, I just see Doctor M"); a pharmacy (she would rather support her local one); on-site diagnostic services (Jan had an ECG performed at the centre, and recounted "that's about the only thing that's been better"). Despite the lack of perceived benefits and Jan's concerns with the IFHC, she remains content with the care Doctor M provides her "once I make it in!" In one of her final sentences of our interview, Jan said to me gravely, "I'll hate for the day to come when he retires."

Alex

Alex is a nurse practitioner (NP), who works at an IFHC. Previously, they worked in a "smaller practice." Alex sees patients who are enrolled at the centre. Alex is familiar with some of the patients they see (their 'regular' patients). Other times they are patients who require an appointment with the next available clinician and are subsequently booked into one of Alex's unfilled appointments. Alex's appointments are 20 minutes long. General practitioners at the centre are allocated 15-minute appointments.

To initiate a routine consultation, Alex first checks the booking system on the computer to see who is booked for the next appointment. If available, Alex locates the patient's digital notes, briefly scanning their history, recent test results, and "flags"[11] in their notes. Alex then walks from the office out to the waiting room, "calls the patient in" scheduled for the next consultation (some of whom Alex says "you don't know them from a bar of soap"). Alex then walks them to the consultation room, introduces themself, and if required, briefly informs the patient of the role of an NP.

When talking with me about their actions within the consultation, Alex is quick to identify aspects which are troubling. In particular, Alex shared examples where tension is present in the

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[11] "Flags" are concerns identified by the patient management software, relating to national health screening agendas. For example, a person recorded as "current smoker" would raise a flag to prompt the clinician to offer brief smoking cessation advice. Cervical screening and immunisation status similarly trigger a flag.

consultation. In one such case, Alex talks about a perceived constraint as a clinician when providing care for a person with more than one health concern that day:

> I've got a patient sitting in front of me with five issues today, because they've waited until they've got $42, so that they can come and *see* their health care provider with their five issues that should have been addressed two years ago, now they're coming in because they've got their $42, and what is the system doing? Our practice… and this has been forced down the throat of all our junior clinical staff; we are *only* allowed to… we are supposed to ask the patient "what is your most important concern for today?" and we will address that, and you need to make [another] appointment for the others. How scary is it that that patient had to build up the financial resources to come and see you with their five problems, and today, sit in front of you, only for you to go, "sorry, you need to pick one of them."

Alex spoke of further discomfort felt, recounting times of asking patients to return for a follow-up appointment. Alex's discomfort centred around the cost incurred for the patient. Saying; "I've got to tell them, 'Well, we're not 100 per cent sure what is going on with you today, I would like to see you again in two weeks' time. And… you need to pay *another* $42 next week or the week after.'" Alex expressed concern for both the patient's ability to afford this followup cost and with the centre's lack of alternative options. Alex says it "does not sit well with me because we do not have a follow-up appointment cost. We just have one cost, and that's for all." When I asked why they were so uncomfortable charging patients for follow-up visits, Alex linked their concerns to their values that they see as informed by their nursing background:

> I'm quite adamant I'm staying true to nursing, to what we do as nurses and our nursing model of care - I do not know - if a patient is sitting in front of you, and they cannot afford that money, they need to choose, between food, and seeing you, does that justify asking them for forty-two dollars?

Alex speculates what they believe is driving this change, and the need for patients to pay the full amount, regardless of the service provided or the clinicians' judgement.

> When we were in a smaller practice, the clinicians had the authority to make that decision, does that patient pay full, follow-up cost, or nothing at all today? Now we are in a big organisation, we're moving to this massive integrated family health centre that's being run by managers and non-clinical people, and they go, "You will ask the full amount because you're worth it."

Alex is critical of this position but believes they are powerless to make a change. Alex acknowledged:

> Yes, we are worth it, but we are shooting ourselves in the foot. We're not giving those patients the opportunity to access health care. We, ourselves, as the health care providers, are actually putting barriers up for patients to access health care.

Alex shared with me additional work undertaken to overcome what they perceive as shortfalls of the IFHC consultation processes:

> So how I've gone around the system is, I've cut up my paper time and break time into 15 minute intervals and 10 minute intervals, and fit them in between that patients' appointments, which is not great, but it means if I go over time, the next person is not waiting 20 minutes for me. So, yes, it is stressful, yes, I'm not doing myself a favour by not having tea breaks, or actually sitting down and going through the results, I do that on my own time, because that does not *fit* into that consult time. I take shorter lunch breaks. I stay later. It's a bit… if you count the minutes you use per patient, it's more than half an hour, and it's definitely not 15 minutes.

Alex clearly knows this workaround is not sustainable but continues to push the one resource they have control over (their allocated breaks) to work around the edges of the rules. Alex is clear with me regarding their nursing model and conceptual view of 'good care.' However, Alex is also uncomfortably aware of the need to be a good employee. I saw Alex again about a year after our first interview, concerned about them, I asked if they were still working in this way. Alex reported "no change" to this invisible patchwork system.

Jan and Alex show various points of tension, contradiction and frustration – these are the places for this study to begin. Like a pin placed on hiking map of complex and interwinding trails, this study stands, right now, with Jan and Alex figuratively representing "you are here" on the map, with vast trails leading off from this point.

You are here

Institutional ethnographers frequently invoke metaphors of maps, trails, and doors to tangibly describe the connections between people's accounts, their everyday work, texts and technologies, and the sequences of actions which connect each aspect together (Smith, 2003, 2005b). Smith says we "might think of [aspects] of people's experiential accounts of their work as doors through which the ethnographer may go to open up further resources of knowledge from those at work on the other side of a particular story" (2005b, p. 151). This quote usefully depicts the researcher process of institutional ethnography.

Accounts of frontline work include details of actions undertaken by people which can be described figuratively as points on a map. These points are *local sites* of people's experiences and actions. In isolation, the points on the map are meaningless; the reader cannot see how to get there, what is contributing to that point, what happens beyond there, or why that point is there in the first place. However, institutional ethnography tells us that people's local sites of experience are "connected into the extended social relations of ruling and economy" (Smith, 2005b, p. 29). Therefore, each point on the map is a place for further potential exploration of the institutional environment (the extended social relations). The ethnographer must find the trails or sequence of actions that connect the points to make sense of the map. These connections are considered as discoverable by explicating how the work of people located at different points is connected textually to those at other points. To do so, the ethnographer must find out what people know and how they are connected to others by asking, where can I see doors into the extended social organisation of what is happening here?

Jan and Alex, in describing their work, give clues for the researcher to follow that will begin to build a picture of how their experiences are organised by powerful factors of which they are not aware. These clues open doors to the social world allowing the ethnographer to see the moments of their experience in which tension resides. Moments of tension or contradiction are known as disjunctures (Smith, 2005b). Disjunctures indicate a difference between ways of knowing, "between the artificial realities of the institutions and the actualities that people live" (Smith, 2005b, p. 187). The purpose of locating disjunctures is to find the clues to follow (explicate) beyond the person's experience and way of knowing, thus moving into the map of the social world.

Like the pin on a map saying, "you are here," the accounts of Jan and Alex are the signpost of this thesis. "Here" (with Jan and Alex) is where this thesis begins. In what follows, I describe what I can see from here, attending to the moments which appear at odds. Such moments open the doors into the social, guiding where this thesis may progress the inquiry. This section is a glimpse into the analytical thinking of institutional ethnography; Chapter 4 includes a detailed account of data collection and analytical decision making.

Locating Jan and Alex on the map through texts and work processes

Jan has a well-established relationship with a GP with whom she reports feeling respected and safe. She is content with this relationship and the familiar processes required of her to maintain this relationship. Historically, Jan's familiar sequence of actions resulted in the expected outcome of an appointment with her GP and, therefore, maintenance of care continuity. When Jan's GP moved to an IFHC, the familiar actions no longer worked as expected; the actions alone were not sufficient for her to secure an appointment with her GP. Here Jan orientates our view to come to see appointment bookings as troublesome work. In response, Jan undertook new actions to ensure she continued to see only her GP rather than accepting care from a different GP within her new health care team. The actions undertaken by Jan introduce a new type of patient work apparently required to maintain 'patient-clinician relationship'[12] and 'continuity of care' under the new circumstances of an IFHC model of primary care. Had Jan not undertaken these new actions (pushing for Doctor M), it appears a different outcome would result from the appointment booking process – the appointment would be made with a different clinician. Jan's story introduces the concrete features of what health care literature ideologically recognises as patient-clinician relationships and continuity of care. She has a relationship with a clinician whom she trusts and has received continuous care (across multiple visits and health needs) from the same trusted, familiar clinician.

From here, doors to the social open. In this example, Jan's new actions, which she describes as "push[ing]," are of particular interest. Her desire to see only her GP aligns with the politically promoted concept of continuity of care, where care is in theory provided by the same health care provider (Jatrana et al., 2011). From here, I can look into continuity of care as talked about through diffuse texts at different layers of the social to begin to make sense of this intention. I can also investigate appointment booking systems (another trail on the map) to explore how Jan is caught up in these arrangements. From these locations, I can make visible the institutional processes that organise how this is happening for Jan. As I will go on to show, the shifting of work to maintain continuity of care from practice to patient conflicts with the intent of the primary health care strategy and the New Zealand Health Strategy (Downs, 2017; King, 2001).

A second work process identified from the two accounts is that of *enrolling* with a primary care centre. Jan mentions that she is "enrolled with Doctor M." For Jan, under the condition of

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[12] Conceptual terms such as patient-clinical relationship is introduced here in inverted commas, as while theoretically familiar to health care professionals, at this point of the research project they are considered empty terms unless filled with real activity. See 'shell terms' (Chapter 4) for thorough explanation.

enrolment, she moved from one physical location to another to remain enrolled with her chosen doctor. Jan's understanding of being enrolled with Doctor M seems to differ to the way the IFHC implements enrolment. Alex describes patients as "enrolled at the centre," with an additional division between "regular" patients, and those he "[did not know] from a bar of soap." This suggests there is a text orchestrating enrolment that I can follow, which can lead me into the social organisation of the formal patient-clinician relationship. The enrolment text is another door to the social.

A third tension visible from Jan and Alex's accounts is Alex's description of discomfort arising from the enforcement of standardised consultation practices. Alex is aware of the restrictions and rules imposed on both them and the patient during the consultation; in particular, the limit of 20 minutes per consultation, the cost of 42 dollars per consultation, and the onus to address only one issue per consultation. Alex undertakes significant additional work to resist the rules and put patients at the centre of the consultation (which Alex refers to as the "episode of care"). For example, Alex uses personal time to extend the consultation time, thus enabling the patient to discuss more than one issue, or deal with their concern in greater depth. Tensions experienced by Alex open the door to explore how the textual rules of the consultation link clinicians to their employers in ways that organise and constrain what they can do in each appointment.

In the course of this thesis, I travel beyond the experiential world of Jan and Alex to show how the tensions arising for them (and others) at the frontline are organised by decisions made elsewhere. As Diamond (2006) suggests, "we always want to be able to hold on to them [experiential stories], to be able to return back to them, to the "you are here" point on the map from which we began" (p. 62). Thus, Jan and Alex's descriptions of their work, knowledge and actions are not an end in itself; instead, they are a point from which to begin the inquiry, as well as a place to return to as the analysis departs from, yet remains grounded in, their stories. This means that as the research moves beyond the social location of patient and clinician into the institution[13] - professional work sites, bureaucratic layers, government agencies and so on - the research site moves, but the standpoint remains that of people at the frontline of primary care.

My approach to the inquiry

Canadian feminist and sociologist Dorothy E. Smith's *institutional ethnography* guides this investigation. Developed in the 1980s (Smith, 1983, 1987, 1990b), and refined by international scholars (notably; Campbell & Gregor, 2004; Diamond, 1992; Griffith & Smith, 2014; Rankin & Campbell, 2006), institutional ethnography has matured into a mode of inquiry which enables researchers to explore the social organisation of knowledge and its consequences in contemporary society. The ontology of institutional ethnography, that knowledge is socially constructed (Smith, 1996a, 2003, 2006b), underpins all aspects of the investigation. Smith contends that the construction of knowledge is a social practice, and further, is something that organises (and sometimes) controls people's everyday activities within different institutional settings to "happen as it does" (Smith, 2006b).

Smith asserts that the social is discoverable as a series of sequences of actions, known as social relations. Such sequences of actions come about, often invisibly, through broader sites of administration and governance. The mechanisms of coordination as used by these sites are understood as the ruling relations[14] and are the focus of the inquiry. Ruling relations are a fundamental concept of institutional ethnography, based upon the notion that experience and the social world are constructed and coordinated by levels of power authorised by texts, often resulting

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[13] The term institution as used here and throughout this project, relates to a state function (e.g., health care, education, immigration, marriage), not a particular type of organisation, or a community versus institutional divide (DeVault & McCoy, 2006). Further, institution as a concept draws attention to the complexes of coordinated social relations that accomplish health care as an institutional function (see Mykhalovskiy & McCoy, 2002). In particular, institution, in its usage here, draws attention to work practices occurring at multiple sites which may be geographically and theoretically diverse, yet occur and intersect within the institution of primary care as identified by the researcher.

[14] Ruling relations are a fundamental concept of institutional ethnography, based upon the notion that experience and the social world are constructed and coordinated by levels of power authorised by texts, and often a result of ingrained conceptual practices (Smith, 2006b).

from ingrained conceptual practices (Smith, 2006b; Stanley, 2018). Discovering, tracing, and connecting the social and ruling relations honours the ethnographic nature of institutional ethnography. Meanwhile, institution reflects the complexes of coordination that produce a state function such as health care.

Social organisation

Examining the activities of Jan and Alex reveals traces of sequences of actions that we can begin to see as social organisation. For example, Jan's interactions with the appointment booking system, from a phone call, to "pushing," to appointment attendance, illustrates a textually coordinated sequence of actions, which begin to show the organisation of what is happening. Social organisation is used in this thesis to indicate "things being put together systematically, but more or less mysteriously and outside a person's knowledge, and for purposes that may not be theirs" (Campbell & Gregor, 2004, p. 18). Based on this definition, I take up social organisation to mean that social life is not chaotic; rather, it is purposefully organised to happen. I can begin to see that the appointment booking system plays a part in organising Jan's access to Doctor M, her frustration with how this happens is a moment of disjuncture that gives a clue that what is happening is being socially organised.

The actions that Jan and Alex participate in are seemingly obvious, but the complex network of ruling relations into which they are linked through their participation in these processes is often just out of view or consciousness. Institutional ethnographer Liza McCoy shares a useful description of familiar examples of our everyday participation in invisible relations. She reveals; "You get out of bed, turn on the tap, make coffee, read the newspaper you collected from your front step – and you are participating in institutional relations (municipal water systems, international trade, the mass media)" (McCoy, 2006, p. 111). These are everyday interactions, familiar to us all, yet the complex relations organising these interactions are less familiar. Similarly, patients and clinicians, such as Jan, Alex, and indeed the entire frontline of primary care, participate every day in the familiar processes of primary care and less familiar institutional (social) relations.

Considering my awareness of social relations prior to commencing the research, I identified the following. I knew that patients and clinicians at the frontline of primary care participated in health care consultations thus participating in evidence-based practice and clinical guidelines. I knew that patients pay a co-payment for health care services thus participating in crown health funding, private business, and social welfare. In addition, I knew that theoretically, a range of high-level texts drive the system of primary care with several national strategies intended to shape the delivery of care through regional and national government. From this understanding, it seems that the conceptual underpinnings of these high-level texts, about, for example, person-centred care and multidisciplinary health care team models, are intended to have an effect in organising social relations and processes.

What is not immediately apparent *is how* these social processes enter and organise the experience of people at the frontline of primary care as it happens. It troubles me that the social relations, as I understood them at the outset of this research project, appear at odds with what the frontline are describing as actually happening. For example, Alex describes consultation experiences that are at odds with how I know of and read about clinical guidelines and person-centred care. Alex talks about the instruction from their employer to address only one issue per person per consultation. Yet, Alex also knows through their nurse practitioner training and experience that the prevalence of multimorbidity is rising, and that the New Zealand population often requires more than one issue addressed per consultation. To be person-centred in the consultation, focussing on the unique care needs of the person, Alex must overrule the instruction from their employer and address multiple issues for the person if required. This conflict is a clue to follow, a door to open. These moments of disconnect between what people or texts say they are doing and what they are actually doing provide the place to start from to begin to see the social relations and further, are clues that lead to discovering the social organisation.

(Re)orientating to the social

Jan and Alex's stories offer the 'self' through which to look "beyond the everyday to discover how it came to happen as it does" (Smith, 2006b, p. 3). For example, Jan's experience of securing a primary care consultation with her GP re-orientates our view to come to see appointment bookings as troublesome work. Jan's expert knowledge of this experience differs from the way appointment bookings and resource allocation are known about and planned for at an operational level. By beginning from and staying grounded in the activities of people like Jan, this thesis maintains re-orientation. Importantly, this re-orientation focuses the analytical gaze at explicating empirically how the social systems that make up the primary care setting work, as opposed to a more traditional theoretical approach of criticising the organisations and people providing care for failing to meet conceptual practices.

Connecting to the social from a small hero

Smith (2006, Fig. 1.1, p. 3) developed a diagram to display and connect the ruling relations (of the social) to her standpoint (social position), whom she refers to as the "small hero" (p. 3). Below is my small hero, who I have adapted. The experiences of Jan, and the many other patient informants of this research inform the view of and from the small hero. This study examines the conditions that establish the tensions, contradictions, and frustrations for patients by following the empirical links from the small hero into the social. The complex relations beyond her view are informed by the analysis made in the upcoming chapters. By preluding my small hero, I am enabling you, as the reader, to 'look up' through the complex, to see how this thesis takes up different aspects of the patient experience, beginning where the small hero stands. I will return to the small hero(es) again later in this thesis.

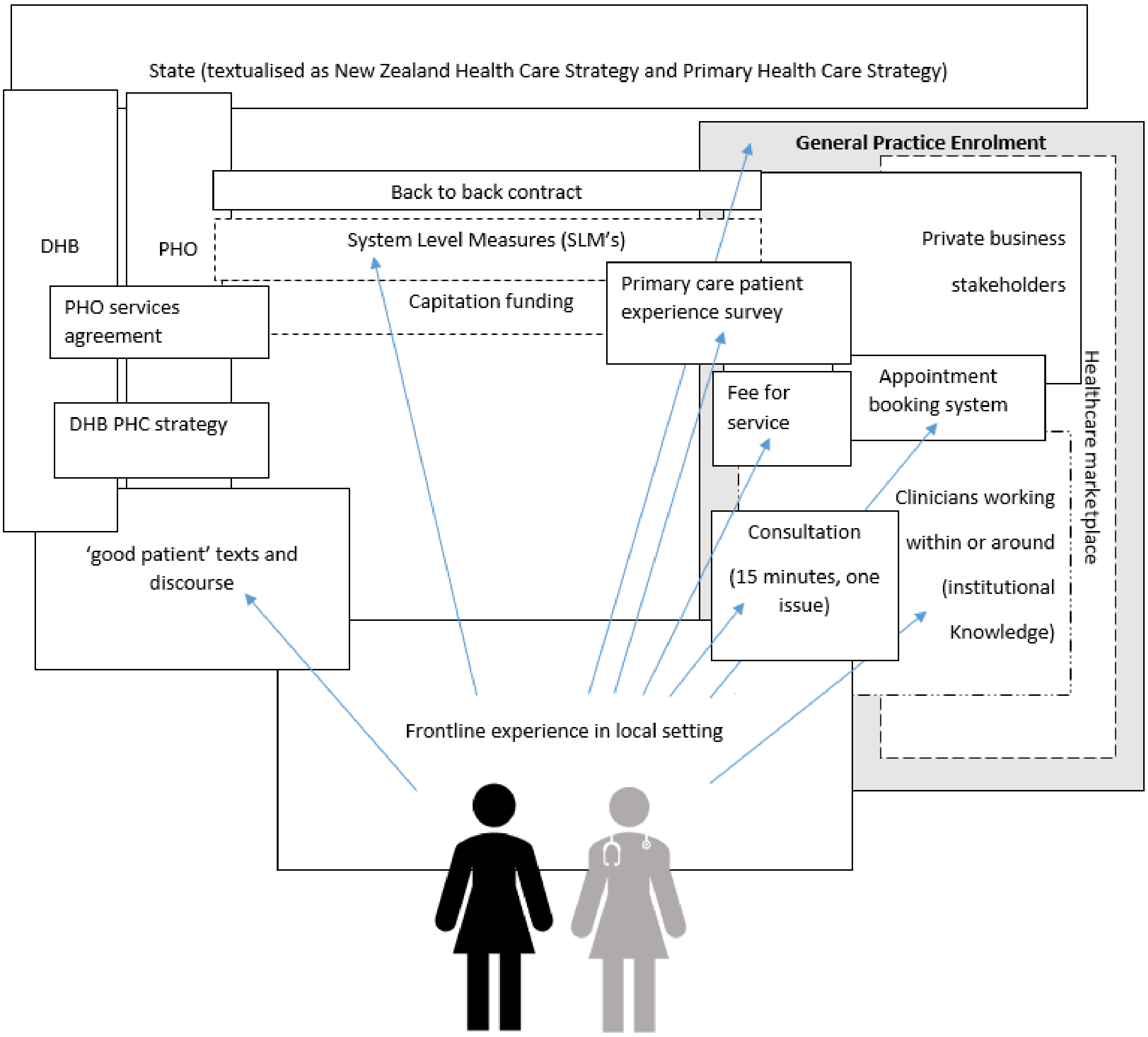

Figure 1. Small hero

The patient, standing beneath the vast complex of socially organised knowledge is joined by the clinician. Both patient and clinician are *subject to* the ruling relations, whether or not they are aware of them. While other institutional ethnographic researchers such as Cupit (2018) and Waters (2016) acknowledge the important and significant power differential between patient and clinician, this project adopts a different position. The approach taken in this thesis conceives that the particular ruling relations of the institution of primary care as seen above in the small hero figure organise what can be said and done by all people at the frontline of primary care. Patients and clinicians stand on the same side of (most of) the institutional processes I follow in this thesis. While there are intricacies in accountability that separate how this happens for both patient and clinician, as I will show in this thesis, the institutional power organising what can be said and done is problematic for the social position of both patient and clinician, and neither's interests are being served. Where appropriate, the outcomes for both patients and clinicians are explored, with priority given to patient outcomes when necessary. At times when patient and clinician fall on opposing sides of an institutional process, I acknowledge this, and endeavour to remain committed to the standpoint of the patient.

As well as considering the social position of patient and clinician at the frontline, I also account for the dynamic environment in which these informants participate. Primary care is a terrain in constant motion, over time the names may change, the texts may be 'refreshed', and entities may come and go. The small hero, however, remains subject to the relations, though shifting and changing on the surface, ingrained in deep-seated conceptual practices. The following chapters move beyond these entry points into the socially and textually organised ruling relations of primary care.

Research decisions, doors opened, and doors left closed

Dorothy Smith often compares the decision-making conundrums for the institutional ethnographic researcher to the hiker, choosing which walking trail to follow. As shown above, through the small hero looking up into the ruling relations, there are various doors to open and potentially vast trails to follow into the social organisation of primary care. My exploration follows a deliberate selection of trails which begin from the greatest and most troubling aspects of informant experiences as I perceived them and those that are directly connected to the frontline experience, in preference to those that lead beyond frontline. For example, I follow the data from Jan shifting from small general practice to a large IFHC into further exploration of the institutional environment of primary care strategic planning, as this shift brought about many troubling experiences. In contrast, I did not follow (in its entirety) the data into the institutional environment of Alex's employment, or Doctor M's role as stakeholder, with IFHC practices. While this does appear to bring about troubling experiences for Alex and Doctor M, this is occurring away from the immediate frontline activities. I do, however, pull small threads that relate to employment at times when there is a clear intersection with the disjuncture under investigation. Where appropriate, I gesture towards these trails/paths not followed and locate intersections where decisions of research economy were made.

Overview of chapters and thesis structure

Writing up an institutional ethnographic thesis is by no means a pre-scripted path. There is no formula. This thesis, like others before, see Cupit (2018) and McKelvie (2019) for examples, gently pushes and deviates from the boundaries of academic convention. For example, as outlined in chapter two, the conventional notion of exploring a gap in the literature is not useful, nor is it the point of institutional ethnography. Appropriately though, this thesis embraces a tremendous number of literary conversations. A literature review exploring the current status of primary care from a theoretical perspective is deliberately replaced with a condensed snapshot of the history of the New Zealand health care system. For lucidity, some literature discussions that relate to the significant history, events, and current organisation of the health care system are presented early in this thesis, while additional literature discussions will sit alongside the aspect of the thesis they are supporting.

Chapter two evolves the problematic, through attention to tensions in people's everyday activities. Beginning in the actualities of people's lives, doors into the social world are opened, providing a snapshot of the complex terrain in which this research takes place. The context from these snapshots provides insight into the structural, political, and discursive landscape of the research terrain. Concepts of institutional ethnography are briefly discussed as they relate to the social world.

Chapter three attempts to provide some clarity to the methodology of institutional ethnography. This chapter extends the overview of institutional ethnography which began in chapter one, paying close attention to the specific aspects taken up in this research.

Chapter four examines the practical application of institutional ethnography, detailing data collection and analytical processes. This chapter also attends to the challenges of researching within an institutional ethnographic lens.

Chapter five is the first in the series of analysis chapters drawing on ethnographical fieldwork. Beginning in the experience of people at the frontline of primary care, this chapter considers the troubling aspects of accessing primary care. From these entry points, activities of accessing care are considered via institutional ethnography's textual mediation to show how ruling relations regulate some of the work of patients and clinicians when accessing care.

Chapter six proceeds further into the everyday practices of primary care, explicating tensions for patients and clinicians as they arise within the primary care consultation. It explores patient and clinician involvement in the institutional processes that purportedly organise and produce care that is person-centred.

Chapter seven explores how a national survey frames the understanding of patient experiences and problems. The analysis shows how a patient's lived experience is constructed into an authorised form of knowledge via a survey. The sequences of actions arising from the survey are mapped to facilitate the analytical tracing of authorised decision-making back into the everyday world as patients and clinicians experience it.

Chapter eight concludes this thesis. By asking the question, so what? This chapter returns analytical discussions to the everyday world and current landscape of health care in New Zealand. Most significantly, this chapter questions the value of feeding the rhetoric of person-centred care, in the absence of systems or resources that are truly able to put people at the centre of their care.

Conclusion

Jan and Alex have been introduced as actors in the social landscape and to introduce the problem researched in this study. The experience and discomfort felt by both patient and clinician begin to unravel the contextual site of this research project, while gradually introducing relevant aspects of institutional ethnography for the reader. Most importantly, Jan and Alex position this research amongst people doing work at the frontline of primary health care in New Zealand. As seen through the early accounts in this chapter, the frontline of primary health care appears to be organised by rules and practices that organise what can be said and done. As will be further revealed the rules and practices organising the experiences of people at the frontline intersect with powerful ideologies, in particular new public management. The next chapter picks up from Jan and Alex, to open the doors into the social landscape of primary care, and the wider context of this study.

Chapter Two - How the social is known about: Opening doors to the contextual and literary conversations of this investigation

Introduction

The experiences of Jan and Alex from chapter 1 orientated the project towards the experiences of people at the frontline of practice. This chapter further sets the scene for the study, looking upwards into the institution of primary care, taking account of current knowledge (institutional, governmental, and academic) of the terrain. The first section explains how the experiences of Jan and Alex have been applied to see this social world. From there, the empirical links are traced into the institution of primary care. Essentially, this opens doors to the social, taking a quick snapshot from each doorway to reveal the enormity and complexity of this research terrain. A table is provided detailing several years of health reform to make some sense of the multiple interconnecting features of the New Zealand health care system. As this chapter proceeds and the analytical argument is framed, I foreground private ownership of general practice, enrolment in primary care services, access to care and the emergence of new models of general practice delivery such as IFHCs. This is because these features became a combined focus of my inquiry as I came to understand experiences like Jan's and Alex's are constructed.

Utilising institutional ethnography's concept of textually-mediated social organisation (Smith, 1990a) involves explication of the role of texts as they enter into the social world of primary care. This requires revealing and discussing links to texts (grey literature, research, strategic plans, audit tools, and so on) as they become visible or of interest in the actions of people at the frontline of practice. Therefore, this chapter is the beginning of textual analysis, considering how the texts organise the activities of people at the frontline of primary care. By opening the doors to the social and exploring texts such as literature in this way, it contributes to the formulation of the problematic. Note the problematic is in similar vein to a research question, with a distinct focus on the explication of the everyday world as such experiences come to be seen as troubling (Smith, 1987).

Finding the social

To travel from Jan and Alex into the social requires a return to their accounts, looking for points of disjuncture – that is, when their experience is at odds with the official (authorised) ways through which their experience might be described (Smith, 1990b). In Jan's account, the new rules encountered when she moved to an IFHC impede her ability to see the clinician she wants to see. In response to the new practices, Jan takes on more work to see her GP as she pushes to maintain continuity of care. This illuminates the first disjuncture; Jan's experience of care continuity places this work squarely on Jan, yet a premise of the IFHC model is patient-centred care, which includes promotion of continuity of care for those who want it (Lovelock et al., 2017). Meanwhile, Alex attempts to work around the rules of the IFHC, such as restricting consultations to a single issue. Alex extends the consultation into personal time to make room for the patient to discuss more than one issue. Alex's work knowledge that consultations are restricted, yet patients require more, conflicts with nurse practitioner education and expectation of an episode of care. These examples draw attention to a disconnect (point of disjuncture) between primary care, as described by documents underpinning primary care, new models of general practice, and the actual experience of patients and clinicians realising these models.

Highlighted by these points of disjuncture, the broader sites of administration and governance organising Jan and Alex's invisible work come to attention. This attention is what Smith refers to as looking up into the institution (Smith, 2006b). As a researcher, I can see there must be something beyond what Jan and Alex are telling me that is organising the way their experiences occur. These are the doors that Jan and Alex's experiences open into the institution of primary care. Their points of disjuncture can open up the institutional relations for analysis. In addition, there are other clues in their accounts that are also useful to set the context of their experience. These clues may not be troubling or problematic but still illuminate important contextual terrain.

Interrogating the data to find the social

When reviewing early data, asking questions about what is happening, seeking places to establish context and identifying where to look for further knowledge, the following data points and related questions were of use:

- Jan says her GP is closing his practice to move to a new IFHC. Jan suggests this is because he wants to retire soon, and "nobody would buy one practice." What is happening in primary care ownership and workforce to perpetuate this change?
- Jan's GP moves to a new IFHC. What are the reasons for the shift in general practice model at this location?
- Alex suggests the IFHC they work for is "run by managers and non-clinical people." What is driving this shift in management structure?
- Jan has to enrol with the new IFHC. What is achieved through patient enrolment?
- Appointment booking process has changed for Jan; she says it is difficult to see her GP. How do IFHCs manage appointment booking, and how do they support continuity of care?
- Jan and Alex talk about consultations. What takes place in the consultation? What texts inform the consultation? What texts are produced and used in the consultation?
- Alex mentions they can only address one issue per consultation. What is holding Alex accountable to this rule?
- Jan "thinks twice" about going to the doctor because of the cost. What are the arrangements for primary care funding in New Zealand? How is primary care funding organised?

These questions posed above are some of the many doors into the social. Entry to the social relations to learn more about these questions is, according to Campbell and Gregor (2004), "facilitated by careful attention to data" (p. 81) at each setting and level. These are the places I can start looking for more information to see what may be organising the everyday experiences, and further, how these aspects contribute to the emerging disjunctures. Importantly, the researcher is looking for texts which organise "what can be said and done," thus making the everyday experience "textually mediated" (DeVault & McCoy, 2006, p. 34). The next section below provides necessary reader logic for the interpretation of textual mediation and other concepts of institutional ethnography encountered in this chapter, to then show how informants use texts to bring the IFHC and other general practice strategies to the frontline – whether they know it or not.

Institutional ethnography and textually-mediated social organisation

Institutional ethnography maintains that knowledge is spread, controlled, and changed by the dissemination and activation of texts (Smith, 2001). Smith's (1990b) term "textually-mediated social organisation" recognises the materiality and activity of texts, locating texts analytically as a "means of access, a direct line into the relations it organises" (p. 4). Further, Smith (2001) conceives that knowledge embedded in texts distinct to an organisation or institution has "an extraordinary capacity to co-ordinate people's work activities to achieve [the] objectives" (p. 163) of the institution. Therefore, through activating texts, such as the appointment booking system, clinical guidelines, even a sign on the wall, people, unknowingly, accomplish the objectives of the institution. Moreover, according to Smith (2005b) specific characteristics of texts enable the coordination of what can be said and done: namely replicability and their ability to be shared/read/heard in identical form across time and place.

This can be demonstrated in the process by which a restaurant chain delivers a recognisable and standardised service simultaneously across multiple locations, languages and time. It is texts, documents, and artefacts of the organisation which provide this capacity for the transcending coordination of people and practices (for example the menu, the uniform, the customer service scripts, as well as less visible texts such as company rules and regulations). The texts, documents and artefacts, when taken up by people doing the work of service delivery, restaurant management, staff training and so on, accomplish the objectives of the institution. A primary goal of this research project is to map the ruling relations – the hidden and mysterious forms of organisation that coordinate the everyday activities of people, potentially accompanying the objectives of the organisation. Thus, critical interrogation of texts encountered at all stages of the institutional ethnographic inquiry is essential to both find the social and explore what is being accomplished, by whom, and in whose interest.

Filling in the social world

The following discussion begins to trace the social world as it is described, constructed and organised through texts. These aspects of the social world became visible through clues found in frontline accounts of primary care. To find the information to explore this landscape, I talked to people from various locations within the health sector, such as primary care leaders, PHO leaders, and primary health academics. I read a substantial amount of literature pertaining to the social world described by research informants, such as the history of New Zealand health care and reform (notable literature includes; Department of Health, 1974; Gauld, 2000, 2009; Health Quality & Safety Commission New Zealand, 2016a; Robb, 1947), health systems (such as; Downs, 2017; Fougere, 2001; Ministerial Review Committee, 2009; National Health Board, 2010; Smith, 2018a, 2018b) quality in health care (Chassin & Galvin, 1998; Institute of Medicine, 2001; Minister of Health, 2003) measurement of health care (Ashton, 2015; Collins, 2014; Hamblin et al., 2015; Institute of Medicine, 2011) as well as wide reading of person-centredness and its historical and conceptual underpinnings (Gerteis et al., 1993; Institute of Medicine, 2001; Mead & Bower, 2000; Stewart et al., 1995; World Health Organization, 2015a, 2016). In attending to this literature, I begin to apply institutional ethnography's concept of textual mediation, considering the social origins of the textual knowledge and the embedded objectives of the text.

Reading about the social through research, grey literature, and other published and unpublished works, was an iterative process. As informant accounts suggested areas for further enquiry, I executed numerous "deep dives" into the surrounding literature. It is, therefore, a difficult task to separate these contextual conversations from the analytical discussions in the following chapters. Fundamentally, this chapter would not exist in the absence of the frontline data that guided the trail into the social. These discussions are a snapshot of the vast amounts of literature reading and conversations which have guided me to look *here* on the hypothetical map as a place to enter the context of the social world.

You are here

As in chapter one, where Jan and Alex's experiences signpost the trails of this study, the following discussions begin from the social position of people at the frontline of primary care. Their accounts reveal what it is about the institutional setting this investigation should follow or map (Norstedt & Breimo, 2016). This section first helicopters up to the health care system, which frames this research terrain. Threads of national and international health care strategy and planning, most pertinent to the current arrangement within which people are working, are examined to question what these pieces achieve individually and collectively. The health reforms discussed are selected for their relevance to analysis which follows in later chapters. These chapters provide exploration down through the layers of the institution such as workforce planning, primary care models, primary care funding, capitation and enrolment, before returning to Jan and Alex and their everyday experiences.

Health and health care systems: What are they? What do these systems achieve?

The World Health Organization recognises a health system as a system comprising all organisations, institutions, and resources that produce actions whose primary purpose is to improve health. The health care system then refers to the institutions, people and resources involved in delivering health care to individuals (World Health Organization, 2000, 2003). New

Zealand's health and health care system is complex (Gauld, 2016), and fragmented (Goodyear-Smith & Ashton, 2019) which becomes relevant to the troubling experiences for people revealed at the frontline of practice. The system boasts "a complex network of organisations and people" (Ministry of Health, 2017d, para 1), some of which are shared now to reveal the research terrain before opening the doors into the social.

Overview of the health care system

Figure 2 below details the many crown entities and agents, non-governmental organisations and private providers of health care in New Zealand. The network is connected through various funding and accountability arrangements. These funding and accountability arrangements hint towards text mediated methods of accomplishing the objectives of the institution, some of which are explicated in later chapters. The magnifying glass identifies the primary location of this study.

It is pertinent to note that the health care system is undergoing widespread system reform at the time of publication. The reorganisation from PHO and DHB governance and funding structures to "locality networks" is a key feature of these reforms (Ministry of Health, 2021b, p. 8) The overview below gestures towards these changes, but all discussions relate to the structure in place as at time of publication.

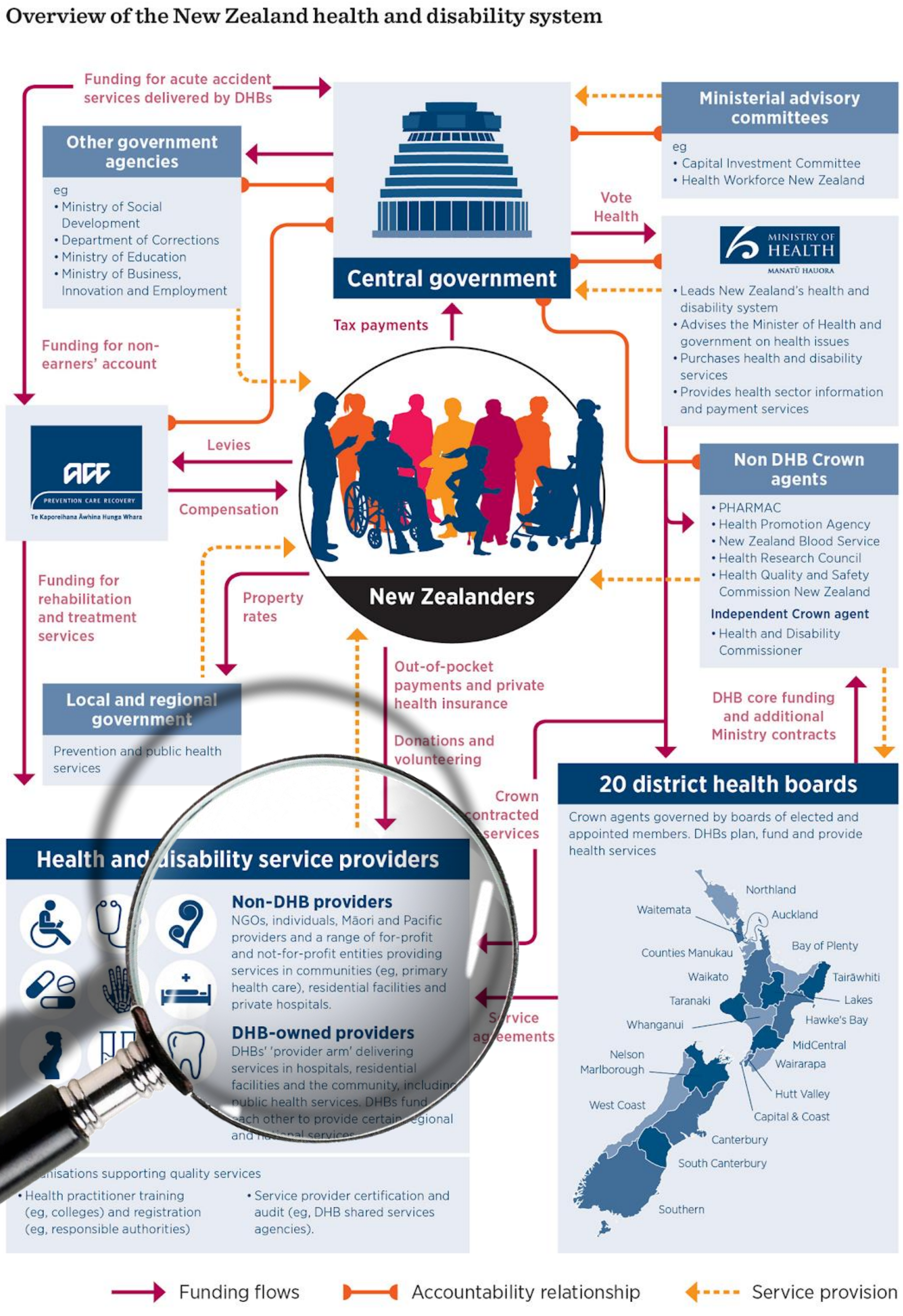

Figure 2. Overview of the New Zealand health and disability system (Minister of Health, 2016, p. 38)

As seen through the magnifying glass, the study location - primary care - sits amongst non-hospital providers, indicating a separate funding and provider arrangement that sits outside of Crown-owned DHBs, although PHOs sit financially and accountably within DHBs. The dark red lines reveal multiple streams of funding, flowing through service agreements, contracted services, ACC (accident compensation), donations, volunteering, and out-of-pocket payments as well as health insurance. Through Jan, it is known that patients pay a co-payment for primary care services. Through Alex, these co-payments come to be seen as a tension between (some) clinicians and employers. The other funding mechanisms are largely invisible to the people at the frontline of primary care, yet likely play an important role in the organisation of care provided, as is shown later in analysis chapters. The lack of an orange (accountability relationship) line connecting these services to central government or PHO is of interest, and is a possible site for further explication as the analysis proceeds.

The diagram below provides a visual understanding of the intricacies of primary health care funding within the New Zealand health care regime. A closer look at service funding hints towards some of the many relationships and contracts that may reveal what actually happens in the provision of primary care services. Funding streams and contractual agreements weave between financial accountability and care provision layers. Each funding stream between the funding provider and the service provider offers the possibility to carry the objectives of the funder into the everyday work of those providing the health services.

It is not possible to analytically attend to each arrangement, as these diagrams show the enormity and complexity of the total terrain. Instead, a deliberate selection from these many arrangements is pulled through into the analysis in subsequent chapters. In particular, those found to be most relevant to the people at the frontline of primary care, and to the troubling experiences they described were selected.

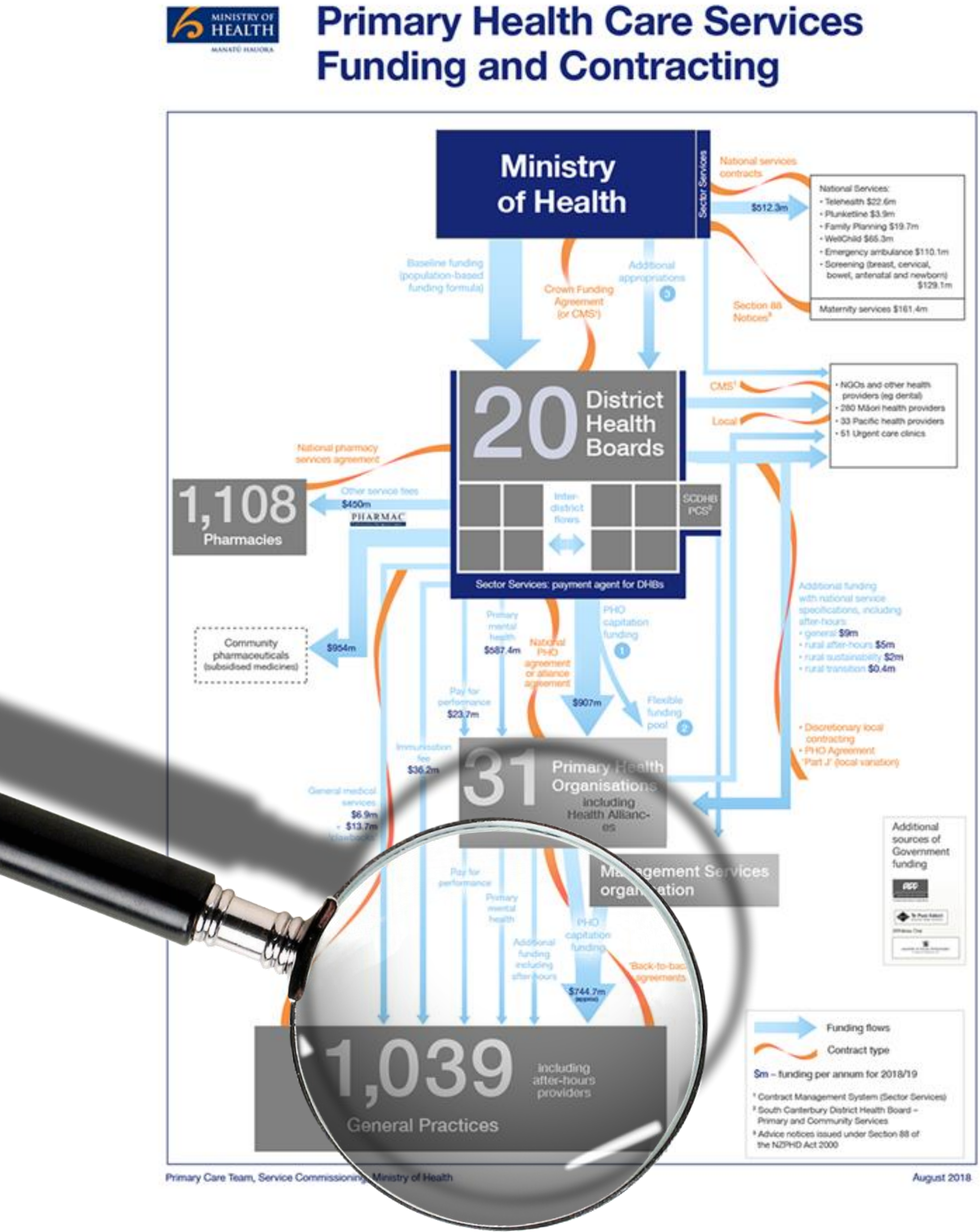

Figure 3. *Diagram of primary health care service funding and contracting in New Zealand. Retrieved from https://www.health.govt.nz/our-work/primary-health-care/primary-health-care-services-funding-and-contracting*

In Figure 3, multiple funding streams flowing into general practice begin to show the fragmentation of funding and delivery of care. General practice receives funding via the PHO for capitation, pay for performance, primary mental health services, and extras such as funding for after-hours services. Further funding is received via the DHB for immunisations and general medical services. A selection of these funding streams is explicated later as they come into view as a part of the problem for the people at the frontline of primary care. Later in this chapter, a further explanation of current finding mechanisms relevant to this inquiry is provided.

Returning to Figure 3, note in the top right corner, services such as family planning, WellChild (universal health services from birth to five years old) and screening services are funded outside DHB, PHO, and general practice contract arrangements. The segregation of funding (and contract/accountability) hints towards multiple agendas, stemming from various powerful organisers of health care, much of which cannot be seen from this helicopter view. While this project does not attend to many of these funding or contract arrangements, especially those that do not connect to primary care, where relevant I gesture to their presence in other conversations to keep in view the multiplexity of health care funding, contracting, delivery and accountability.

To further expand the view of the research terrain, Table 1 below presents a chronological list of significant reforms and legislation pertinent to this study, including the most relevant aims and intentions of the legislation, policy, or strategy. Such reforms have been well documented in multiple other theses and literary sources thus this is a condensed snapshot of the lengthy history surrounding health reform and health legislation in New Zealand. The table is provided to support and anchor this (and other) discussions of the social world of primary care. In the proceeding chapters, these key reforms, legislations, and outcomes are referred to as they intersect with the everyday experiences of people at the frontline of primary care.

Date	**Key reforms and legislation**	**Relevant aims and intentions**
1938	Social Security Act, 1938 (SSA)	· Aspirations for a publicly funded, universal health care system · Universal health care system never fully achieved · Dual public/private system · **GPs reserved the right to charge a 'fee for service' for general practice consultations** · **GPs remain as private business owners**
1941	General medical services scheme	· Dual system of public and private payment established, with GPs receiving partial funding from the Social Security Fund via claim or refund, and **user co-payment approved as means to cover remaining cost**
1956	Health Act	· Established roles and responsibilities for high-level health governance roles such as the Minister of Health, the Director of Public Health, and other designated officers of health
1983	Area Health Boards (AHBs) established	· 14 Area Health Boards formed between 1983 and 1989 · Population based funding
1992-1993	Independent Practitioner Associations (IPA) formed	· Owned and controlled independently by general practitioners · Formed in response to undertones of health reform, diminishing union power, an introduction of general managerialism, and concern for professional representation · Formed to achieve better quality of health care, and improve health outcomes · Budget holding capability established, with intent to expand on this
1993	Regional Health Authorities (RHAs) established	· **Separation of purchasing and provision of health services** · RHAs set up to purchase all primary, secondary and tertiary health services · Separate arrangement for public health services (health education, health promotion and disease prevention)

1993	Crown Health Enterprises (CHEs) established	· AHBs reconfigured into CHEs · CHEs designed as independent business entities, **required to act as successful and efficient (for-profit) businesses** · **Public health services recentralised, contracted directly and indirectly between the Primary Health Commission and via CHEs**
1997	Coalition Agreement on Health	· Reformed structure of health system · Establishment of Health Funding Authority - a single national purchasing agency
2000	New Zealand Public Health and Disabilities Act 2000	· Health Funding Authority merged with MoH · 21 District Health Boards established · The Minister of Health must 'determine a strategy for health services… to provide a framework for the Government's overall direction of the health sector in improving the health of people and communities' · Sets the strategic direction and goals for New Zealand health and disability services
2000	New Zealand Health Strategy (Minister of Health, 2000)	· **Establishment of 21 district health boards (DHBs)** – responsible for regional planning and purchasing of services and delivery of secondary services · Population based funding · **13 population health objectives, a forerunner to national targets**
2001	Primary Health Care Strategy (King, 2001)	· Creation of primary health organisations (PHOs) – non-profit community based organisation responsible for the provision of primary health care services · **Public enrolment established** · **Universal publicly-funded capitation payments which subsidised primary care for all New Zealanders** · Increased accountability measures for primary care · Greater emphasis on the principles of Alma-Ata such as population health and the role of the community · Emphasis on health promotion and preventative care · **Acknowledged the need to involve a range of professionals in service delivery, and the expanded role of nursing** · **Attempt to shift away from NZs history with NPM, to return to social values**

2002	Primary Health Organisations (PHOs) established	· Funded by DHBs based on enrolled population · Provides primary health services either directly or through commissioned providers, such as general practices · Population health focus · Introduction of Nurse Practitioner role
2003	Health Practitioners Competency Assurance Act	· Legislation ensuring competency, controlling for practitioner scope of practice · Establishment of power to restrict activities to particular scopes and registrations of health professionals
2003	Improving Quality: A systems approach for the New Zealand health and disability sector (Minister of Health, 2003)	· Not intended to impose any new or additional regulatory or legislative requirements, however: · Strategy to encourage systems based continuous approach to quality improvement · Vision for a people-centred health and disability system · Encouraged the establishment of clinical auditing practices
2004	Crown Entities Act	· Provides the fundamental statutory framework for Crown entities
2004	Care Plus	· Funding stream for providers of primary care for supporting patients with long term conditions · Intended to support patient self-management
2008	Better, Sooner, More Convenient (Ryall, 2007)	· **Political proposal from then opposition centre right National party, notable not policy, but rapidly adopted:** · **Aimed to provide integrated, seamless, patient-centred care in the community** · **Promoted and supported the integration of multiple community health services under the working name 'Integrated Family Healthcare Centres' (IFHCs)**
2010	Establishment of Health Quality & Safety Commission (HQSC)	· **Expectation from the Government that HQSC would lead quality and safety improvements in the health sector**
2013	Health alliances	· All DHBs and PHOs required to form 'health alliances,' intending to advance local integration

2013	Integrated Performance and Incentive Management Framework	· Introduced **incentives (including financial) for primary care providers linked to performance measures** aimed to improve patient outcomes, efficiency, safety, and value for money.
2016	Refresh of New Zealand Health Care Strategy (Minister of Health, 2016a, 2016b)	· Introduced five strategic themes: o **People-powered** o Closer to home o Value and high performance o One team o Smart system · Introduced the **'triple aim'** as the goal for quality improvement · Current health system structure left in place
2016/17	System Level Measures	· **Introduction of six System Level Measures (SLMs)** · Aimed to re-orientate the accountabilities of health organisations to reflect the themes of the refreshed health strategy
2021	Dissolution of DHBs signalled (Ministry of Health, 2021b)	· Reform proposes: · Consolidation of DHBs into a new organisation – Health NZ and Māori Health Authority · Establishment of new Public Health Agency

Table 1. Chronological list of significant reforms and legislation relevant to this study

Table constructed from core documents as cited, alongside commentary from; (Ashton, 1996; Askerud et al., 2020; Doolan-Noble et al., 2015; Downs, 2017; Gauld, 2013; Malcolm & Powell, 1996; Wright-St Clair, 2001) For a more comprehensive account of New Zealand's socio-political health history, see prominent health policy researcher Robin Gauld (2009, 2016).

As noted, this is not an exhaustive table of all legislation and texts. The New Zealand health and disability system's statutory framework is made up of over 25 pieces of legislation (Ministry of Health, 2017c). The table above does not include all items of legislation, instead, only those that can be connected empirically to the experiences of people at the frontline of primary care, of which there are still many. The texts (policies, strategies, Acts and so on) shared above are considered analytically as part of the ruling apparatus (Smith, 1987) of primary care, with their distinct and traceable organising capabilities (Smith, 2001). From the texts shared above, the bold font acknowledges aims and intentions that I have empirically connected with or perceive to be relevant to this inquiry.

The following discussion draws from what I have learned of the social world of primary care, as connected to the everyday experiences from the research standpoint. Here, the foundations are laid for the connections between people's everyday work and the texts, accountabilities and service planning above, which govern or control the work they do, to support the analysis in subsequent chapters. That is, how the informants use texts to bring primary health care (and particularly IFHC) strategies to the frontline.

Primary care ownership

Primary care ownership emerged as a point of interest to this study through many of the accounts of frontline participants. Jan's GP owned a small general practice, prior to joining practices to form a large IFHC. This shift, from small practice to large IFHC, Jan speculates, brought about her troubling experiences. Alex, an NP, is an employee of a large IFHC, which Alex says is "owned by doctors." This information opens the door to general practice ownership in New Zealand, as a place to look into the institutional setting beginning with what is known about primary care ownership.

General practice, dating back to the late 19th century, long before public hospitals and government funded health care, was provided by doctors (with varying qualifications) who had their own practice in the community, and charged their patients a fee for their service (Wright-St Clair, 2003). Today, general practice ownership in New Zealand remains in the private sector, typically following an owner/operator model, with a more recent shift to larger multi-shareholder conglomerates (Crampton, 2005; Gauld et al., 2019). The lasting arrangement of primary care ownership is often related back to a historic political bargain struck between the Labour Government (centre left political party) of the time and the medical profession, during efforts to introduce the Social Security Act 1938 (Gauld, 2013; Wright-St Clair, 2001). The Act proposed the introduction of universal health insurance, financed via taxation, which would have removed the capacity for private billing for GP services, but many members of the medical profession strongly resisted the changes.

The medical profession was powerful within the negotiating space, owing largely to their representation through the New Zealand British Medical Association (NZBMA) (Gauld, 2013). The NZBMA's position on the proposed changes under the Act, was that patient charges drove accountability *to* the patient, thus, involving the Government would erode the doctor-patient relationship (Gauld et al., 2019). Further, fearing that doctors' incomes would suffer, and arguing that the profession could not adequately serve the people under a state medical service, the medical profession resisted the Act, consistently favouring a private business model with a fee-for-service mechanism, without capped fees (Wright-St Clair, 2001).

Within the resistance, GPs pushed to remain independent business owners in the private sector with the ability to charge patients for services, a point some suggest was an attempt to maintain their prestigious status as autonomous professionals (Croxson et al., 2009). The resistance from the GP negotiators forced the maintenance of a bifurcated health care system; hospital treatment was provided without patient fees by public employees at publicly owned institutions, while general practice remained in the private sector.

From the 2020 New Zealand GP workforce survey, 34% of GPs are practice owners or partners in a shared practice, and an estimated 80% of total general practices in New Zealand exist under the owner/operator model (Cassie, 2019). The remaining 20% of practices, made up of some of the largest practices in New Zealand, are owned by corporates, companies, PHOs and iwi (Cassie, 2019; Thomas, 2018). While GPs retain their independence as private sector providers of health, the trends within practice ownership, particularly the rise of corporate ownership, point towards emerging conflicts between funding, professional obligation, and accentuation of profitable business.

The funding structures which have evolved to support this arrangement (Figure 3) are discussed later in this chapter. Next, attention is turned to one aspect of primary care with an important connection to primary care ownership: workforce planning and the retirement of GPs.

Workforce planning

Doctor M shared with Jan that he plans to retire soon. The indication that many GPs intend to retire in the next decade places several stresses on current models of primary care, if current models are left unchanged. This includes delays to health care access nationally, deepening access concerns for the rural population, and increased reliance on locum GPs disrupting care continuity and costing considerable excess money for the sector (Adams & Carryer, 2019; Quin & Eggleton, 2018).

Latest data from the 2020 general practice workforce survey shows that 31% of GPs intend to retire over the next five years, and 49% within the next ten years (The Royal New Zealand College of General Practitioners, 2020a). Of those indicating they intend to retire in the next decade, 53% are currently owners or partners of general practice (The Royal New Zealand College of General Practitioners, 2020a). The ageing and shrinking workforce noted in the survey creates future succession issues, which Jan identified. Jan noted that Doctor M was motivated to move from his small practice to be a partner in a large IFHC, as "nobody will buy one practice," and that at an IFHC "somebody would come into [invest in] the practice." This suggestion from Jan aligns with national trends showing an increase in fully or partially corporate-owned large practices (RNZGP, 2019) and greater interest in larger practice investment from corporate investors (Thomas, 2018).

Practice ownership aside, conversations regarding an anticipated mass retirement of GPs and a predicted "GP crisis" (Chisholm, 2019) are loud in New Zealand. The IFHC Jan attends is no exception. When difficulties arose filling vacancies for GPs at Jan's IFHC this caused intensified demand resulting in long wait times for GP consultations. The IFHC shared via their public website a cautionary explanation noting their region had the lowest numbers of GPs per head of population in New Zealand and warned that many intend to retire in the next five years. The centre advised they continue to advertise to fill these vacancies, but in the interim, they encourage patients to plan routine appointments well in advance to avoid extended delays. The shortage of GPs and subsequent difficulties for patients to access health care at primary care centres, as well as new arrangements introduced to work around these difficulties are taken up in later analysis chapters.

Meanwhile, nurses account for a significant and stable portion of the primary health and primary care workforce. In New Zealand roughly 15% of the nursing workforce work within primary health and primary care (NCNZ, 2019). However, of those in primary care, only a very small number of nurses and NPs have stakes in practice ownership, although this trend is increasing (Cassie, 2019). The remainder of nurses (both RNs and NPs) are employees of the general practice, thus highly likely employed by GPs. Employment of nurses by GPs has been considered to be disempowering toward the nursing workforce with limited opportunities for professional development and reduced clinical autonomy (Carryer, 2017; Crampton, 2005); however, this was not an avenue or trail this project followed. The role of NPs in the future to shape primary care warrants some attention, particularly in relation to rapid decline in GP numbers.

Increasingly, the contribution of NPs to the New Zealand primary health and primary care workforce is shared in academic literature (Adams, 2020; Adams & Carryer, 2017; Carryer, 2019). However, despite strong evidence supporting the competence and benefits of NPs to primary health care, their employment into general practice is slow to become well established (Adams, 2020; Adams et al., 2020; Adams & Carryer, 2019, 2021).

Carryer (2017) notes that New Zealand has to a small extent invested in the development of NPs and in the upskilling of the RN workforce, in response to the predicted GP workforce crisis. The contribution of RNs and NPs to the future success of primary care is seldom included in conversations about general practice workforce problems and solutions. For example, the message above from the IFHC, reporting the lowest number of general practitioners per head of population, neglects to mention the same region had at the time one of the highest numbers of NPs per head of population.

Integrated Family Healthcare Centre

Integrated Family Healthcare Centres (IFHCs) enter the terrain of this research project through several different avenues. Jan moves her patient enrolment from a small general practice to an IFHC as she follows her GP. Alex mentioned moving to a "massive integrated family health centre that's being run by managers and non-clinical people," suggesting aspects of the IFHC model to be different from smaller general practice, and is a place of interest to look for more information. According to Jan, Doctor M (a GP and private business owner) shared that a single general practice is not an attractive investment, and that being a financial shareholder in a larger IFHC was a means to overcome this concern. These many accounts orientate the enquiry towards the shift in the model of primary care from traditional general practice to the IFHC model, and open more doors to the social.

Looking into the new model of IFHCs reveals political intent (from the then right of centre opposition National party) followed by the operationalising of the health discussion paper 'Better, sooner, more convenient' (BSMC) Ryall (2007), referenced in Table 1 above. After suggesting the Primary Health Care Strategy (King, 2001), under the Labour-led Government, had failed to deliver on promises of quality improvement and the expansion and evolution of primary services, the National party campaigned to provide more personalised, patient-centred service, which was more convenient through extended opening hours, and located closer to home (Ryall, 2007). The vision, that more care could be devolved from hospital settings to primary care, encouraged the establishment of IFHCs where the opportunity to offer additional services by co-located multidisciplinary teams was proposed.

The result of the policy (BSMC) is the increasing popularity of purpose-built large health care centres, noting that these facilities existed in fewer numbers prior to the policy drive. Specifically, facilities evolved via Ministry selection of business plan proposals, which were implemented through new 'alliances' (Lovelock et al., 2017). At these centres, GPs, NPs, practice nurses, clinical nurse specialists - particularly long term conditions specialists - as well as variations of multi-disciplinary team members such as social workers, physiotherapists, podiatrists and midwives, are theoretically co-located at a single site, serving the various needs of an enrolled and casual population. In achieving these large health centres, the closure of many smaller practices (like Doctor M's) took place, alongside the shifting of their enrolled populations (like Jan) to IFHCs. These closures appear multifaceted, but certainly advanced by the operationalisation of BSMC.

In the creation of IFHCs, small practices struggled for many reasons. The increased administrative burden of recording and reporting patient data, planning and carrying out activities to meet national health targets, and auditing requirements disproportionally affect small businesses. This, coupled with increased costs related to administration, equipment and care delivery all made small business increasingly untenable. In addition, the 2008 global financial crisis decreased patient visits, with out-of-pocket payments contributing a smaller percentage of total practice revenue (Ministry of Health, 2012), which again places disproportionate burden on small practices. Further, the workforce planning issues noted above, with a new era of GPs wanting different arrangements such as part-time employment, make larger practices an attractive employment option, further eroding smaller businesses. However, the attractiveness of larger integrated centres, and the BSMC policy, has not always lived up to the promise.

The clues from the accounts of Alex and Jan allude to IFHCs doing something other than the vision of patient-centred, better, sooner, and more convenient primary care. For example, Jan finds it difficult to get the appointment she wants at the IFHC. Alex finds it hard to justify the costs associated with elements such as follow-up appointments and feels some discomfort in the constraints on consultation imposed within the new IFHC model. The analysis chapters of this thesis attend to these and other examples from people at the frontline of primary care. While not excluding other primary care models, it is the new or changing work under the arrangements of the IFHC model that attract the most analytical attention. For additional and important context, briefly, BSMC is located below in the corpus of literature reviewing the strategy and the period of reform in New Zealand health care.

Better, sooner, more convenient has been described as neoliberal (Came, 2014; Young et al., 2017), focusing on individual responsibility for managing health and well-being. The health discussion paper underpinning the reform proposed many ways in which IFHCs could help attend to the issues facing the health of New Zealanders in the primary care setting. For example, the document suggests, "[e]vidence shows a multi-disciplinary approach to supporting chronic-care patients helps improve outcomes, particularly approaches that focus on helping patients self-manage their conditions. This is, of course, consistent with the view that we are all responsible for our own health and should act in ways to enhance it" (Ryall, 2007, p.30). The focus on individual health responsibility is consistent throughout the document. Therefore, the core suggestion is that the new IFHCs could provide the place and people to enable the realisation of the self-management approach. A further example illustrating the neoliberal ideology of the strategy emphasises "delivering more care within available resources" (Ryall, 2007), reflecting the value of efficiency and productivity, which notably is also familiar to NPM.

This is not the first example of neoliberalism in New Zealand health care. During the period from 1984 through to the late 1990s, both Labour-led and National-led Governments enacted neoliberal policies in health and social care sectors (Barnett & Bagshaw, 2020). What is of most interest in the present arrangement is the shift from the 'cradle to grave' responsibility once protected and valued by general practice, to the new model which emphasises individual obligation alongside accountability and efficiency (Young et al., 2017). In this thesis, the lens of institutional ethnography offers a process to explicate the textually mediated practices organised by the cornerstones of neoliberal policy – accountability and efficiency.

Funding

Jan pays (and contests) a patient co-payment for her consultation. Meanwhile, Alex is concerned about the ability of some of his clients to afford the co-payment, and questions if asking for payment for primary care services is justified. These accounts open doors to primary care funding in New Zealand.

The New Zealand health care system is a hybrid of centralised public funding and private market-driven care (as introduced in the above discussion of the Social Security Act (1938) outcomes). Publicly funded health care has developed around a mainstream allopathic model of medicine. The central Government is the primary funder of health services, using funds acquired from taxation, distributed directly to public institutions through a Ministry of Health [the Ministry]. Funding is divided geographically, through 20 district health boards (DHBs). A population-based funding formula is applied to determine the distribution of funding, which considers population age, socioeconomic status, ethnicity and sex (Ministry of Health, 2021c). Rurality and a high degree of deprivation are further compensated through this formula. District health boards are Crown Entities under the Crown Entities Act 2004. These entities are geographically identified systems accountable for planning and funding a range of health services for their population. District health boards purchase and/or provide health care services to their populations. Public hospitals provide secondary and tertiary services, but most primary services are purchased or commissioned via PHOs from private providers.

Primary care funding has been in a state of evolution and altered considerably during the reforms initiated by the Primary Health Care Strategy (King, 2001), which specifically aimed to reduce fees to improve access to care. The establishment of PHOs created a filter for funding between DHB and care provider. Primary health organisations enter into a service agreement with the regional DHB, an agreement which holds PHOs accountable to deliver services based on population health needs. Such needs are determined locally by the DHB, and further fit within national directives

(TAS, 2020). Driven by a strategic shift in focus from the individual to population-based primary health care, capitation funding was introduced for those enrolled with the PHO, with other funding streams available to be used by the PHO for targeted priorities such as those drawn from the PHCS. Enrolment with PHOs is discussed later in this chapter.

Part of the intent of the PHCS was to improve access to healthcare for Māori. Māori (the Indigenous people of New Zealand) represent approximately 15% of New Zealand's population, and experience substantial health inequity and considerably poorer health outcomes than non-Māori. Māori medicine's history as the Indigenous health care model of this country bears little weighting in the prioritisation and allocation of health funding (Durie, 1985, 2000). There is a small portion (less than two percent) of health care funding allocated to Māori health providers (via DHBs) through a variety of service contracts (Ministry of Health, 2017b). Vote Health commits an even smaller portion of funding to the provision of rongoā Māori – traditional healing performed within a Māori cultural context (Ministry of Health, 2020). The apportioning of rongoā funding began only recently (the 1980s) (Ministry of Health, 2014), relative to the nearly century-long history of publicly funded western health care in New Zealand. Prior to 1962, the practice of traditional rongoā was prohibited by the 1908 Tohunga Suppression Act (Norris & Beresford, 2018) which forced Māori to conform to funded biomedical health practices, thus widening the gap between health knowledge, apparent value, and funding.

Other complementary and alternative therapies are available in New Zealand. Some public funding is provided for specific therapies such as acupuncture and chiropractic care. However, this workforce and the health care services they provide are, for the most part, only available privately at a significant cost to the user (Duke, 2005). Yet, Liu et al. (2021) found that the prevalence of use and clinician attitudes and referring practices towards complementary and alternative medicine is increasing in New Zealand. Rongoā Māori and non-Māori complementary and alternative medicines accounted for, the portion of the total budget spent on non-biomedical health care is significantly less than that allocated to western medicine.

Capitation

Capitation is the payment arrangement for general practice providers. Capitation funding flows from the DHB (who receive population-based funding from the Ministry of Health) to the PHO, then to the general practice, as seen in Figure 3. Capitation is paid monthly and reviewed quarterly, at a set amount for each enrolled patient based on perceived need as determined through demographic data (Ministry of Health, 2013). Practices receive capitation payments irrespective of whether the enrolled patient receives care.

As an example, the IFHC at which Jan is enrolled, for the provision of her care (a 65+ year old European female enrolled at the centre), receives $284.8044[15] annually (Ministry of Health, 2020a). This rate increases to $509.8320 for enrolled patients in Jan's demographic who have a high use health card (HUHC). To be eligible for a HUHC, patients must see a clinician at their enrolled practice 12 or more times in one year (Ministry of Health, 2020b), and the practice must submit an application on their behalf.

As well as the high use health card, the current funding arrangements for primary care include other supplementary funding streams. These funding streams have evolved over time to overcome priority challenges to New Zealand's population health and primary care provision. Most notably, primary care for enrolled people aged 13 and under is free to the user, providing the practice has elected to participate in the funding scheme (Ministry of Health, 2019c). Care Plus is another funding initiative designed to support the provision of high-frequency care needs (Ministry of Health, 2019b). Such needs often arise through patients experiencing long term conditions, acute and intensive medical or mental health events, or terminal illnesses. Funding is available to support 5% of the New Zealand population through Care Plus funding; however, provision of funding

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[15] Capitation rates accurate at time of publication. These rates are reviewed annually.

varies between PHOs (Ministry of Health, 2019b). These are two further examples of subsidies and services available within primary care, and through brief exploration, they accentuate the complexity of funding models and provider relationships noted above.

The principal thinking supporting a capitated funding system was that capitation enabled freedom for the primary care providers to allow the most appropriate person to be reimbursed to deliver the required service. Capitation funding, as presented within the PHCS, aimed to shift primary care services away from isolated patient encounters (with a fee for service charged back to the funding authority) towards a model where general practices could prioritise and plan for population-based services thanks to the guaranteed flow of quarterly funding (Downs, 2017). Officially, "[c]apitation funding is designed to encourage proactive management of enrolled populations and better population health outcomes" (Ministry of Health, 2013, p. 1). The effects of these changes have been comprehensively studied,[16] with researchers acknowledging the historical barrier of cost to the patient is only partly addressed through capitation and additional funding streams (Stokes et al., 2017).

Within the capitation model, the practice receives funding per enrolled patient (as outlined above). However, practices continue to charge a partial co-payment to users of primary care services which is a recognised barrier to accessing care with one in seven adults (14%) reporting cost as the reason for deferring primary care (Ministry of Health, 2017a). The impact of co-payments is felt worst by those who are poorer and sicker. There is evidence that New Zealand's cost-related access barriers initially improved post implementation of the primary care reforms (Jatrana & Crampton, 2009). However, patients currently report (formally through the New Zealand health survey) cost as a barrier to accessing primary care services (Ministry of Health, 2019a). This project intersects with some of the effects of capitation, but most significantly, the cost of primary care services to the

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[16] See Howell, B. (2016) for a comprehensive assessment of primary care financing pre and post the implementation of the Primary Health Care Strategy, including extensive commentary on the calculation of capitation, and the effect of capitation payment on the delivery of primary care.

patient appears as a recurrent and troublesome aspect within the accounts of people at the frontline of primary care.

Enrolment

Jan moved from one general practice to another (an IFHC) to follow her GP. In moving, Jan was required to enrol with the new practice. This process requires Jan to fill in her personal details on an enrolment form. Details include name, age, date of birth, address and ethnicity. The administrative team then uses the enrolment form to initiate the formal process of enrolling a new patient with the practice and the PHO. Once Jan is included in the practice's enrolment register, the practice receives (via the PHO) capitation payments (detailed above) for the provision of first-level (primary) services for Jan.

Enrolment is voluntary, and, theoretically, patients can choose which primary care provider they enrol with (Ministry of Health, 2018a). The purported benefits for patients who enrol with a primary care centre include lower costs of consultations (owing to capitation funding), access to health promotion services such as cervical screening, enhanced continuity of care with the same provider, and better information coordination, among others (Irurzun-Lopez et al., 2021). In consideration of these suggested benefits, patients enrolling with a single general practice is seen as pivotal to achieving the strategic themes of the PHCS, particularly in achieving a longitudinal relationship between patient and clinician.

However, enrolment has been identified as a potential site of discrimination and perverse business behaviours. Raymont et al. (2013) revealed that 36.5% of general practices in New Zealand were 'selective' in accepting new enrolees. Selective enrolment here suggests practices may avoid enrolling patients with high needs if their needs are perceived as greater than the cost of delivering the care, and inversely, selectively enrolling those whose perceived needs are lower than the cost of providing care (Irurzun-Lopez et al., 2021; Raymont et al., 2013). Furthermore, transient and high-need individuals were the most likely to be disadvantaged by such selection activity, also known as 'cream skimming' (Cumming & Mays, 2011). There is a power inequality here, with the potential to further disadvantage our most vulnerable populations, seemingly prevented only by good morals of the general practice.

Professor Des Gorman (medicine) University of Auckland, speaking with a journalist about enrolment and capitation funding and their influence on practice behaviours, was quoted as saying:

> It means the incentive for GPs is to enrol as many people as possible who'll never come and see them, then close their books. If I get $500 a year in bulk funding, I'm winning if I see you only once, but I'm winning even more if I don't see you at all. I get money if I don't have to do anything. The best thing you can say about capitation is that it hasn't protected productivity in general practice. The worst you can say is that it has aided and abetted a dramatic fall-off in GP availability (Chisholm, 2019),

As I will show later, enrolment and funding empirically connect to many of the ongoing tensions experienced by frontline participants of this thesis. The purported purpose of enrolment and capitation, coupled with issues identified in the literature, will re-enter many of the analytical conversations to follow.

Consultation

Jan and Alex introduce to the inquiry the familiar concept of medical consultation. Both Jan and Alex describe the consultation event casually. Through their lack of detail, they infer that as a nurse, I must know what goes on during a consultation. A core tenet of institutional ethnography is to "make known what becomes taken-for-granted… by talking with people about what they do" (Frank et al., 2010, p. 34). Questioning what people do before, within, and because of the medical consultation is an empirical focus of this investigation and addressed in analysis chapters. For now, this door to the social is opened through the accounts of Jan and Alex (with more informant accounts to follow). This section briefly traces the contours of the consultation (a seemingly familiar event) as it is constructed through texts.

In an article published in The New Zealand Medical Journal (Gu et al., 2014), the authors put forward the question; what is a 'medical consultation?' noting there is no definition published by authoritative health groups in New Zealand. To answer their question, the authors talked to the structure of patient consultation, namely "introductions, information gathering, exploring the patient's thoughts, feelings and ideas, education (including to negotiate the choice of treatment), and closure (e.g., mini-summaries)" (p. 112). The structure proposed here is built on the assumption that a single person will present for medical consultation with an issue to be treated.

Text mediated discourses such as patient education brochures, general practice guides, social media campaigns, and so on, frequently reference the consultation structure proposed above. Informed by the knowledge from these texts, people enter into the institutional activity of a consultation following this taken for granted structure, as I will show later. A striking example to share now from the New Zealand Ministry of Health website shows the language and key messaging targeting people using health services.

The New Zealand Ministry of Health website is a site where people needing health services in New Zealand are encouraged to seek 'helpful' advice and support for personal health and wellbeing. In the section 'visiting a doctor or nurse,' in a larger font at the top of the page, readers are instructed as to when it is appropriate to use this service; "[i]f you're sick and it's not an emergency, you should visit a family doctor (or 'general practitioner' – GP) or nurse at your usual general practice" (Ministry of Health, 2018e). This narrow description of when to access primary care does not encourage using services to 'live well' or to 'stay well' as promoted in the catchphrase of the updated strategy (Minister of Health, 2016a). Instead, the message here is, general practice is to be used when "you're sick." The primary care consultation model perpetuated here is of a sick patient who has an issue to be treated by a doctor or nurse. The gaps between what frontline clinicians report from their experience, the text mediated discourses above, and the vision of preventative and population health as located in the strategies, raise questions about the practices which govern what actually happens within a consultation.

Improving quality and efficiency as a discourse technology of management

The many texts discussed above, in particular health strategy and reform, coupled with the clues from the accounts of Jan and Alex, situate this study within a growing scholarship of institutional ethnographic work explicating managerial practices that play out in the frontline of health care and other public sectors. Such practices, found to broadly insert private-sector management technologies into frontline work intended to improve efficiency and reduce costs, are recognised as a form of new public management (NPM)[17]. The edited collection by Griffith and Smith (2014) *Under New Public Management* explores several of these practices using the tools of institutional ethnography to show how new managerial practices enter into and coordinate the work of people at the frontline of public sector services. The discussion below introduces the practices of NPM in New Zealand health care, as seen in the social and textual landscape of this study. Later in the analytic chapters these practices are discussed in more detail as they enter into the work of people in this study.

The terminology of NPM is apparent in the language and objectives of several of the health reforms identified in Table 1 and discussed above. The establishment of crown health enterprises in 1993 which were required to act as successful and efficient independent enterprises, signalled a strong shift towards private-sector economic theories (Barnett & Malcolm, 1997). Later, via the inaugural Health Strategy (Minister of Health, 2000), 13 population health objectives emerged, introducing target setting and accounting practices familiar to managerial discourse. For the first time, the standardisation of quality appears as a discourse technology. While New Zealand is widely recognised for its rigorous and widespread adoption of NPM in the late 1980s and early

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[17] New public management, as taken up in this thesis, is described as a general shift in public management styles towards adoption of private-sector management techniques, with a central focus on explicit accounting and cost categorisation, and a broader shift towards public accountability and public administration (Griffith & Smith, 2014; Hood, 1995).

1990s (Chapman & Duncan, 2007; Duncan & Chapman, 2010; Gauld, 2000), it is the more recent iterations that are taken up in the analysis sections of this research project.

Establishing the problematic

As a technical term, problematic refers to “troubling or difficult” experiences in the social world (Bisaillon, 2012, p. 618). The researcher formulates the problematic by talking with people about their everyday world and the troubling or difficult experiences they identify. By paying attention to these moments, particularly the experiences that are at odds with governing version of the reality or experience, the researcher can explore beyond these disjunctures and into the social world (Smith, 2005b). Therefore, the problematic links the local experience to the work of others located elsewhere in the social world. The problematic, through gradual evolution, sets the direction of the inquiry as paths taken reveal further information and doors to open.

The process undertaken in this chapter, opening doors into the social from the position of Jan and Alex, is gathering information to establish the problematic. At the outset of the inquiry, I do not know what direction these doors will take me. However, I know that by exploring beyond the local experience into the social, I will find information about what may be organising Jan and Alex’s experiences.

Before talking with patients, clinicians and others in the social world, areas of interest and questions from current events and literature guided research direction. The focus on patient-/person-centred care was especially notable. This exploration served as an important stepping stone on the journey to this point, and influenced early directions taken. Below is a snapshot of the findings from New Zealand and international research, coupled with grey literature from several layers of health care governance in New Zealand. This summary addresses the topic of person /patient centred care which whilst not the problematic of this study remains as a source of analytic reflection.

The National Government of the time, via the Ministry of Health, had released a draft of the refreshed health strategy (Ministry of Health, 2016a; 2016b), within it, a clear commitment to ‘patient-centred care’ as one of five strategic themes. Internationally, health systems pursuing person/patient-centred care was a familiar sight, indubitably prompted by the Institute of Medicine (IoM) report, *Crossing the Quality Chasm* (Institute of Medicine, 2001). The IoM report, regarded as an internationally influential framework for quality improvement (Barry & Edgman-Levitan, 2012; Moran et al., 2016), presented patient-centred care as a commitment to returning power to the patient, not the health care system.

Further reading of New Zealand strategic health documents revealed underlying person- or patient-centred rhetoric dating back over two decades, see for example (For example; King, 2001; Office of the Health and Disability Commissioner, 1996). There is explicit inclusion in the Institute for Healthcare Improvement’s (IHI’s) ‘triple aim,’ in the refresh of the New Zealand Health Strategy, of which one of the aims is improving patient experience of care (Institute of Healthcare Improvement, 2009; Minister of Health, 2016a). The other two aims, as adopted in the New Zealand Health Strategy, are improved health and equity for all populations and better value for public health system resource (Minister of Health, 2016a). The IoM report, as underpinning logic of the triple aim, defines patient experience and quality of care as care that is safe, timely, patient-centred, effective, equitable and accessible (Berwick, 2002; Institute of Medicine, 2001). In addition to the implicit and explicit commitments to person/patient-centred care, a significant body of literature supported the implementation of person-centred care (see NZ examples; Boon, 2012; Carswell, 2015; Keene, 2018; Taranaki District Health Board, 2014). These tools were supposedly able to guide the foundational establishment and ongoing provision of care that was person-centred across the health care system.

Responding to the directions of implementation guides and international pressure, national and international literature regarding ‘structural barriers’ to person-centred care implementation emerged. Keene (2016) considered the issue of (lack of) time in New Zealand to focus on and deliver person-centred care. West et al. (2005), through their investigation of the United Kingdom

National Health System also identified lack of time as a significant barrier to the implementation of patient-centred care, as well as challenges within the physical environment. Hower et al. (2019) in Germany found that care environments constrained by financial, human and material resources required significant action from staff, such as effective communication and an emphasis on staff wellbeing, to overcome the factors obstructing the implementation of person-centred care. Esmaeili et al. (2014) conducted a thematic analysis of international barriers to patient-centred care, concluding that "nurses lack the organizational coordination, time, motivation, and training to deliver patient-centred care" (p. 7). In the United States of America, Luxford et al. (2011) investigated organisations with a reputation for successful transformative delivery of patient-centred care. The researchers found that change took longer than expected, and that shifting the mindset of employees was a common barrier within these organisations. Luxford et al. concluded that successful implementation requires going "beyond mainstream frameworks for quality improvement based on clinical measurement and audit and [adopting] a strategic organizational approach to patient focus" (p. 514). The above research recognises similar barriers across differing international health systems, thus reinforcing the New Zealand based research on this issue.

Repeating this examination in the New Zealand context felt superfluous given the large volume of relevant international literature on the topic. However, as a nurse, I knew of some of the frustrating, upsetting, and troubling experiences of people at the frontline of primary care that did not align with the rhetoric of person-centred care as presented. With the insights of institutional ethnography, the problems noted within the literature did not contribute to forming the problematic. Rather, navigating the research served as a painfully slow distraction from where this research needed to begin. The troubling or difficult experiences of people at the frontline of primary care are the place to begin this inquiry (*not* from within the person-centred literature) and, therefore, the place where the research problematic lies.

Conclusion

In this chapter, the exploration has looked upwards into the institution of primary care, from the entry position of Jan and Alex at the frontline of primary care. The empirical links from their experience into the institution of primary care, acknowledging the social, political and textual underpinnings at each location have been followed. Throughout the chapter, private ownership of general practice, enrolment in primary care services, and the shift in the primary care model within New Zealand from traditional general practice to large IFHCs has been foregrounded. These features are a combined focus of my inquiry as I came to learn how experiences of Jan and Alex are put together. Within this chapter, aspects of institutional ethnography, such as points of disjuncture and textually mediated social organisation, are introduced (in context) as they relate to the social world. Chapter three picks up from here, exploring the features of institutional ethnography and its application to this research project.

Chapter Three - Mode of inquiry

Introduction

This chapter explores the theoretical complexity of institutional ethnography. The social and contextual beginnings of institutional ethnography are described, with attention to the significant influences on Dorothy Smith and her formulation of institutional ethnography as an alternative sociology. I note the elements of institutional ethnography that I have found most useful in understanding this mode of inquiry as applied to the terrain of primary care. The important elements of institutional ethnography taken up and described here include 'social organisation,' 'texts,' 'work' and 'ideology.' A discussion of the analytical tools 'shell terms' and 'ideological circles' complete this overview of my interpretation of institutional ethnography.

Institutional ethnography as a useful approach to the research

Why institutional ethnography?

The vexing question of which research methodology to use is recognised as one of "the most difficult and confusing decisions for most researchers" (Opoku et al., 2016, p. 32). The objective of the study, the type of research intended, and the researcher's convictions, worldview and interests should factor into the choice of research methodology (Creswell, 2014; Opoku et al., 2016). The research problem investigated in this project is broadly, what brings about troubling experiences (unmet need, difficulties accessing care, impersonal care, trouble navigating systems, places, instructions and so on) for some patients in primary care? As a researcher, I held a basic set of beliefs that aligned with both a constructivist and a pragmatic worldview. Marrying together the research problem with my worldview narrowed the scope of appropriate research approaches. To move forwards, I considered how the research field was known through established research programmes and published works.

At the outset of this project, I knew of the patient experience survey (Health Quality & Safety Commission New Zealand, 2013a) and the primary care patient experience survey (Health Quality

& Safety Commission New Zealand, 2016b). Both surveys purported to measure patient experience to generate an official report of the person/patient-centredness of patient experience, the first within acute care, and the second within primary care. The information gathered from the primary care patient experience survey is then intended for use to “support the system goals for people-centred and whānau-owned care” (Health Quality & Safety Commission New Zealand, 2018, p. 1). Yet, it is impossible to see how the survey, and the people represented within it, inform, influence and improve the “people-centred” experience for those at the frontline of primary care. Knowing of this survey and the data generated from its use, coupled with my on the ground awareness - that patients continued to have troubling experiences not captured by the survey - I reasoned that to investigate these troubling experiences, the project should be positioned outside of the contextualised notions of patient experience (such as the survey). Therefore, in order to investigate this problem, a way to explore patient experience outside of conceptualised theoretical frameworks was required.

Through critical conversation with my supervisory team, considering the research problem alongside my researcher interests and location, early discussions further narrowed the field of appropriate methodologies. I examined case studies (Yin, 2017), phenomenology (Giorgi & Giorgi, 2003), process mapping (Trebble et al., 2010), and ethnography (Hammersley & Atkinson, 1983). Each approach had its merits and flaws. To sample the appropriateness of each, I explored recent applications of these methodologies in research fields closely aligned with my research problem.

Of those explored, process mapping appealed to me for two reasons. Firstly, I was familiar with the use of process mapping from previous clinical roles. Secondly, I understood process mapping as a recognised approach for identifying problems and improving patient experience (Phillips & Simmonds, 2013). Trebble et al. (2010) describe process mapping as a method to ‘see’ and understand patients' experiences, utilising patient journeys, noting it is emerging as a useful approach in health design and quality improvement.

At the same time, I was introduced to institutional ethnography via the work of Willis et al. (2015): 'understanding missed nursing care using institutional ethnography.' Willis et al. interrogated nurses' experience of missed nursing care. In a similar vein to process mapping, the researchers sought to see and understand the nurses' experience of a process in action. The fundamental difference is that their analytical attention lay with the power relationships and hierarchies of the institution, which organised the nurses' experience of what could be said and done, which goes beyond the policy/practice gap which process mapping pursues. The researchers found that many of the texts (policies, standards and so on) intended to promote clinical effectiveness, productivity and efficiency, could organise improved care "but they also run the risk of reducing the clinician's critical insights through routinization and standardization" (Willis et al., 2015, p. 6). Through institutional ethnography, researcher attention shifts from process mapping to looking beyond people's experience to provide an empirical description of the social terrain. Where process mapping begins within managerial knowledge, institutional ethnography instead questions how the managerial knowledge is put together. I recognised that inquiring about patient experiences through a framework such as process mapping risked producing knowledge that represented the managerial or administrative ways of knowing about patients, potentially excluding or talking over the actual experiences that were troubling me.

Returning to what I knew of the patient experience survey, and the ongoing tensions recognised by both patients and clinicians, institutional ethnography appeared congruent with my research problem and worldview. In particular, the ability to generate findings that show *how* the troubling processes come about for patients and clinicians held great appeal. From reading institutional ethnographic works such as Melon (2012), Rankin (2003), Rankin and Campbell (2006) and Mykhalovskiy (2001), I came to see the contribution of institutional ethnographic research in making visible the (troubling) everyday experiences brought about by organisational and political changes.

Finding and describing the social processes which put together the everyday world is no small undertaking. Institutional ethnography commits to revising the relations of knowing - how we know about social organisation (Smith, 1996a). Realising that dominant knowledge (ways of knowing) could obscure the presentation and interpretation of some modes of health research (Waters, 2015), the "alternative sociology" (Smith, 2005b) provided by institutional ethnography delivers a robust alternative to dominant methods of inquiry and knowledge production.

Institutional ethnography offers a well-developed theoretical framework for exploring the experiences of primary care patients in New Zealand beyond the knowledge of local practice and frameworks. Cupit (2018) agrees on the importance of looking beyond the local and dominant setting when studying health care practices. Cupit recognises health care practices are "increasingly determined, not only by the individual skills and expertise of those whose work can be seen at the frontline, but also policies, guidelines, and other management devices developed away from the frontline" (p. 57). To do justice to this research, I sought to gain a comprehensive understanding of the theory and practice of institutional ethnography.

Learning, procuring, and leveraging knowledge on institutional ethnography

Extensive reading, generous conversations, international workshops and serendipitous encounters shape the knowledge I hold of institutional ethnography. As a student new to institutional ethnography, I read widely and deeply both theoretical and applied works. Beginning with the enormously helpful explanatory work by Campbell and Gregor (2004), I then read (carefully and in short bursts) Dorothy Smith's three milestone texts (Smith, 1987; 1990a, 1990b), alongside several of her accompanying publications (Smith, 1974, 1996a, 1999, 2001, 2005a, 2005b, 2006a, 2006b, 2008). These densely theoretical texts were complemented with published books of institutional ethnography in practice (Diamond, 1992; Griffith & Smith, 2014; Rankin & Campbell, 2006); substantive exemplars of rigorous institutional ethnographic research, providing examples to emulate within my research terrain. In addition, I read explanatory texts and glossaries (Bisaillon, 2012; Campbell, 2003; Carroll, 2011; Stanley, 2018) for pragmatic support. In 2016, at the start of my doctoral journey, I was privileged to attend an institutional ethnography workshop hosted by Dorothy Smith and Susan Turner in Toronto, Canada. While perhaps too early in my journey to reap the full rewards of this learning experience, their teaching and guidance were formative in shaping this research project.

In addition to theoretical readings and teachings, I grew my knowledge of institutional ethnography through monthly discussions with a group of peer learners and institutional ethnography experts. Meeting online, the group discussed emerging challenges for personal projects, as well as wider discussions of theory application. The questions, comments, challenges and suggestions originating from this group were instrumental in clarifying, rescuing, and moving forward with this project. The methodological discussion that follows summarises what I have learned and continue to learn from these many sources.

Institutional Ethnography as a method of inquiry

This study was undertaken following the theoretical framework and analytical tools of institutional ethnography (Campbell & Gregor, 2004; Smith, 2006b). What follows is a short consideration of the historical foundations of institutional ethnography, how these foundations inform the position of this research project, and lastly, a look at the specific tools used to conduct this research.

Historical, political and sociological influences

Smith, a feminist and activist, developed a sociology from women's standpoint to create a *sociology for people* (Smith, 2005). The catalyst of Smith's pursuit of an alternative sociology stemmed from long developed and strong held ethical and political principles. For example, Smith wrote of her evolving awareness of the systemic exclusion of women in society. An exclusion that Smith asserts was reinforced by the pervasive dominance of men and the white upper-class male worldview of sociology, which had claimed to explain the very systems of exclusion and inequalities Smith experienced. This awareness, coupled with her rejection of the survey methods and mathematical sociology Smith had learned in her undergraduate and graduate training spurred her formulation of an alternative sociology (Stanley, 2018). Smith's alternative sociology, institutional ethnography, opposed the sociological methodologies that dominated the era, offering instead a situated women's experience or standpoint through which to explicate the social world.

Institutional ethnography allowed Smith to research from within, constructing a counter-narrative that could talk back to the objectified ways people had previously been known about in sociology. Researching from within the particularities of people's everyday worlds, the researcher adopts a specific standpoint; situated within or alongside those experiencing the troubling aspects of the socially organised world (see Chapter 1). Constructing a counter-narrative requires uncovering social relations and the organisation of these relations (see Chapters 5, 6 and 7). Talking back to the ruling relations that operate to suppress, oppress or control people through an interest that is not theirs is the end goal of an institutional ethnography (see Chapters 8 and 9). For this reason, the concepts of social and ruling relations are emphasised here, whilst other concepts are briefly outlined to support the reading of this research.

In conceiving of an alternative approach to sociological inquiry, Smith says she borrowed many ideas from other thinkers and writers from across her years of study and engagement in sociology and activism. Smith says:

> Of course this method does not come from nowhere. It has both visible and invisible preceptors from whom, in the long course of trying to find a different way of thinking sociologically, I have learned. The most important among them have been George Herbert Mead, Maurice Merleau-Ponty, Karl Marx, and Harold Garfinkel, though there have been many others (Smith, 1987, pp. 8,9).

From Mead, Smith borrows the theory of significant symbol complements, conceptualising language (as happening through speaker and hearer) as coordinator of consciousness and actions into a social act (Smith, 2005b). Mead, as Smith interprets, identified that language and gestures can evoke a social organisation between speaker and hearer; that people's experience determines the responses to the language or gesture; thus, to be repeated equates to the social organisation of experience (Smith, 2005b). Put more clearly, that language and gestures in action organise what comes next within a social act as people fill the language and gestures with experiential knowledge. Smith blends the ideas of Mead with the work of Valentin Volosinov, Mikhail Bakhtin, Alfred Schutz and Alexander Luria (among others) as she reformulated her own understanding of discourse (Campbell, 2003; Carroll, 2011). Eventually, Smith found her unique position, that knowledge is essentially social. By this Smith understands that knowledge referred to or represented in discourse, texts, gestures and so on is spread, shared, spoken, or read among "participating subjects" and organises social action (Smith, 1996b, p. 174).

Smith also credits a significant amount of her early thinking and the origins of institutional ethnology to her reading of Marx and Engels' *The German Ideology* (Kearney et al., 2018; Smith, 2005a). In particular, as Smith came to understand the social, she credits Marx and Engels' work for their "ontology of a social science that sets aside concepts, speculation, and imagination in favour of engaging with actual people's actual activities" (2005a, p. 209). Drawing from their ontology, beginning with actual people outside of concepts, Smith further grew the notion of exploring social relations exclusive of the constructed and abstracted way the world was known about by sociology of the time (Carroll, 2011). Instead, combining Marx's materiality with her feminist position to begin research from a situated standpoint *inside* and *alongside* those whose everyday activities were suppressed, subordinated or controlled by the constructed and abstracted ways of knowing (Stanley, 2018).

Institutional ethnography shares concern with Garfinkel's ethnomethodology (1967) for the everyday activities that produce and maintain social order. Further, Smith and Garfinkel both profoundly reject the notion of abstracting or theorising findings; instead, remaining firmly grounded in the everyday experiences of people doing 'work.'[18] Departing from Garfinkel's theoretical perspective, where he saw the 'reality' of the individual or group as the discoverable, Smith's ontology is, in contrast, materialist. The actual practices, and the interaction between practices and material objects, in particular texts, are the 'what' through which Smith's institutional ethnography explores social organisation.

Perhaps still the most significant organiser of Smith's alternative sociology is her commitment to feminism and activism. In the following section, I examine the significance of Smith's history with feminism, and the legacy of feminist standpoint and analysis.

Feminist standpoint

In formulating her alternative sociology, Smith, began with the premise that women have been and continue to be excluded from the ruling apparatus of society. As a female sociologist in a male dominated world, whilst simultaneously holding the social role of mother and wife, Smith came to see the ways in which she was excluded, talked over, conceptualised, and marginalised, in her social position as a woman and as a single mother. Through years of observation, research, and resistance, Smith asserts that the society (social world) that excludes women is manufactured by those in dominant positions – positions of ruling.

Griffith and Smith make visible the situations of single-parent women, in particular the problematic occurrences of invisible labour such as mothering and educational work. For example, in Smith's early work with Alison Griffith, both took up the standpoint of female single parents as they experienced the schooling system (Griffith & Smith, 1987). The arrangement of government and schooling at the time organised and labelled the single woman's experience as an inability to participate normally in the educational work required to support their child. In taking this standpoint, Griffith and Smith demonstrate that through a counter-narrative to that produced

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[18] Smith and Garfinkel both refer to 'work' as the activity under investigation, however, Garfinkel's interpretation of work aligns with the formal workplace understanding, whereas Smith has extended the notion of work to the generous conception of work.

from within the education system, the work of education at home is very much gendered labour (2005). Thus, Smith's early work was both strongly feminist theoretically *and* adoptive of the standpoint of women.

Whilst Smith began here, with a clear feminist standpoint, she has since reconfigured the ontology to focus more on the analysis of institutional relations, thus making institutions accessible ethnographically (Stanley, 2018). Institutional ethnography remains a feminist sociology, though the feminist standpoint is less prominent. Smith avows that institutional ethnography "has to work for both women and men. It has to be a sociology for people" (Smith, 2005b, p. 1). Consequentially, researchers at numerous standpoints now take up institutional ethnography. The common thread between researchers is that the social position of their standpoint is alongside people who are potentially vulnerable, marginalised or excluded from the ruling apparatus. For example, Deveau (2016) uses institutional ethnography from the standpoint of people with a disability working within the institutional relations of workplace accommodation. Elsewhere, George Smith, a political activist and close associate of Dorothy Smith, applied the research strategy to explicate service delivery for people living with HIV/AIDS (G. Smith, 1990).

The current project adopts the standpoint of people at the frontline of primary care – the patients and clinicians. Intentionally analysing the work done by patients and clinicians from their experience, in terms of accessing, navigating and negotiating care, enables the explication of how health services and health care is organised.

The emergent ontology and epistemology

Smith locates the ontology of institutional ethnography as resistance to, or an alternative to, the problems capturing 'mainstream sociology' (Smith, 2005b). The overarching ontology rejects traditional social inquiry, instead recognising that knowledge is socially constructed and that through the dissemination of such socially constructed knowledge, people's everyday lives come to be socially organised (Campbell & Gregor, 2004; Smith, 1987, 1999, 2005b).

Smith's critique of mainstream sociology, underpinned by Marx and strongly influenced by her learnings from the women's movement of the 1970s, meet at a point where the ontology of institutional ethnography comes into view for all readers. However, without recognising the rich history of institutional ethnography, it is difficult to make the necessary "ontological shift" from ideological understandings to concrete social practices (G. W. Smith, 1990, p. 633) required to see and think as an institutional ethnographic researcher.

Reading of the ontological shift undertaken by scholars of institutional ethnography helped in my understanding. For example, Deveau (2009) presented two personal accounts: one of an epistemological shift and the other of an ontological shift. Firstly, ontologically, the shift pertains to how we focus on social relations and the actions of people. Deveau suggests in institutional ethnography, agency is transferred from speculative and abstract concepts (like person-centred care and quality improvement) back to the practices and activities of the embodied knower (the patient), which allows us to come to understand things the way we do. It is a shift from *why* to *how*. *How* do things happen the way they do? *How* do person-centred care policies unfold in the work of the patient, as opposed to *why* patients are affected by person-centred care policies? This shift lifts all blame and sees only the actual doing – this shift allows the researcher and reader to see the world as socially organised.

Epistemologically, institutional ethnography works by locating the point of contradictory ways of knowing: experientially and ideologically (Campbell & Gregor, 2004). Institutional ethnographers map this point, literally, and say this is how they know what they know, and they ground their knowledge in the data of experience. Such data and experience must come from the inhabited standpoint location, but the explication is of the social world he or she inhabits (Kearney et al., 2019). Deveau wrote about his own epistemological shift, through which he came to see "that the problem of disability is located in society, instead of in me" (2009, p. 4).

Smith has been explicit in *not* positioning institutional ethnography within established sociology (Stanley, 2018). Smith herself says, “the sociological strategy I have developed does not belong to or subject itself to the interpretive procedures of any particular school of sociology” (Smith, 1987, p. 9). She is generous with the user application of this social strategy, never wishing for institutional ethnography’s tools to force conformity, instead ensuring the commitment to exploration and discovery is honoured in the everyday world (Smith, 2006). Like many other institutional ethnographies, this project takes up some of the many tools available, determined by the terrain, the data, and the direction of analysis. For a recent revision of the social ontology of institutional ethnography, see McCoy (2021), whose insights make accessible the complex thinking’s of Smith through a modern lens.

Informed by the above ontology and epistemology, the analytic aim of this project is to make visible the material features of (some) people’s troubling everyday experiences at the frontline of primary care, to make sense of how their activities are socially organised. From these findings, the aim is to further show whose interest the work organisation serves.

Principles of procedure

The section below defines and describes the ‘principles of procedure’ of institutional ethnography. Smith introduces us to the principles of procedures:

> Institutional ethnography is a commitment to exploration and discovery … It is not intended to confine, discipline, or subordinate your own experience of institutional ethnographic work. Though there are certainly some definite principles of procedure, there are also many ways of realising them in practice (Smith, 2006b, p. 1).

Consideration of how these procedures are taken up in the present study are interlaced within the related definitions. For readers unfamiliar with institutional ethnography, Bisaillon (2012) produced a useful glossary that complements the concepts emphasised below.

Social organisation and relations

Social organisation is an ontological assumption of institutional ethnography. Social organisation encompasses the notion that humans are social beings: people's ongoing actions in their everyday lives are socially organised to happen as they do, and that knowledge too, is never neutral, rather it is also socially organised (Bisaillon, 2012; Rankin, 2017a). As conceived by Smith (1990), social relations then assert that people's actions in one place must be connected to the actions and goings-on of people in another place. Thus, people are connected by social relations, representing social organisation in action (Campbell & Gregor, 2004). While one person's location in relation to institutional power and organisation may be different to another's (such as Jan and Alex as patient and clinician), what they can know and do (their activities) are socially organised and connected by social relations (Campbell & Gregor, 2004). The work of the institutional ethnographer is to trace and explicate what is happening, connecting, and coordinating people at various locations.

An accessible example of social organisation and social relations is that of driving a car and following the road rules. Road rules are known (social), written (textual), and communicated visually and textually, such as a 30 kilometre per hour sign at a site of road works that intends to create an immediate local generalising effect. The driver's knowledge of driving the car is socially organised by road rules, which were constructed somewhere else, by someone else. Yet these relations work together to coordinate every driver on the road like an orchestra, even though we cannot see the conductor. Save for road signs, the social and technical organisation cannot be seen in the final product of people driving cars. There is, however, an element of reading and interpretation of the text-based discourses required, which brings into discussion the notion of *objectivity* (Smith, 1990).

While the same 30 kilometres per hour text is shared with all drivers who pass the sign, drivers must read and interpret the standardising and organising message. The course of action in response to the textual organisation will vary relevant to each driver's constitutive practice of reading and interpretation, and indeed by their knowledge of the social. A driver may respond very differently to the sign based on their experience of the social. A driver who sees no other cars or people on the road may not slow down to within the 30-kilometre limit as the sign commands, yet the same driver with a police car behind them would likely comply explicitly with the textual coordination. This decision is informed by the additional experiential knowledge they possess of the role of the police in activating speed infringement notices and fines. Elements of objectivity are not always so obvious, however, understanding how a text is read and interpreted and further subject to objectivity is analytically important.

Although a relatively benign example, it can be seen how mass and largely invisible standardisation and communication resulting in socially organised activity can come about, with additional recognition of objectivity. The power orchestrating the social organisation of road rules is reasonably well understood by motor vehicle drivers as governed by land transport rules and bylaws (authoritative texts) and enforced by law enforcement agents such as the New Zealand police (by the actioning of texts such as the Policing Act 2008). Within health care, power, governance and privilege are less clear. This level of organisation that is not visible is what institutional ethnographers seek to explicate (Deveau, 2009).

Patients and clinicians, much like the driver of a vehicle, respond to textual and social cues within the health care environment which organise their experience. Meanwhile, the people who organise, manage, or govern health care workforce and primary care are (some of) the orchestrators of the socially organised experience. The social processes entered into by both patients and clinicians, and the relationship between these social processes and the institution of primary care, formulate the central analytical focus of the present study. Where the social relations appear to organise, manage or govern with a suppressive effect, these relations are identified explicitly as ruling relations (see below).

From the example shared in chapter one, Alex describes a course of action happening within the concept of a medical consultation. Alex introduces known social norms of the consultation and acknowledges several textual organisers such as the fee for service, the patient's list, time and managerial obligations. Both patient and clinician are seen in this example, entering into a taken for granted highly organised social process of a medical consultation. However, like not following a speed restriction sign, Alex displays objectivity, informed by their nursing education and in response to the patient's individual needs, which appear to exceed the institutionally standardised and managerially governed consultation practice. Alex works around or outside of the textually organised rules of the consultation, such as time and matters attended to in the consultation. In seeking to understand more about this highly organised process, looking into the ways in which Alex works around and within the rules illuminates points of researcher interest. When considering the patient in this example, generally they lack awareness of the rules, relations and knowledge that organises their experience of the consultation to happen as it does. Yet, they do recognise when the care does or does not meet their needs.

If social organisation is taken up in institutional ethnography to assume that people's everyday experiences are organised to happen as they do, and that power is embedded within the intended control, then people at the frontline of primary care are participating in social processes that may not best serve their needs. These are known methodologically and analytically as ruling relations (Smith, 1990b).

Relations of ruling (ruling relations)

Ruling relations differ from social relations; specifically, social relations are typically neutral, whilst ruling relations are embedded with authoritative, dominant knowledge and power (Smith, 1990b). Such dominant and authoritative forms of power are used to regulate, manage, and rule society and the social world (Bisaillon, 2012; Smith, 1990). For example, concepts are a form of ruling relation used to organise and rule people (Deveau, 2009). Smith conceives of this ruling as a form of social consciousness that arises outside of the life, actions, context, and conditions of actual people (Smith, 1996). Concepts, such as solo parent, immigrant, mentally ill, and unemployed (to name a few), are constructed from dominant knowledge, held by various socially powerful positions such as Governments and professional organisations (Smith, 1990). Further, these concepts facilitate social control through texts (introduced in Chapter one and discussed further below). Texts coordinate the social control established by a concept to maintain a ruling function.

By inserting a ruling conceptual frame over the experience of the person and their lived experience, their unique lived experience is obscured. Instead, they are recognised institutionally by the conceptual or ideological way of knowing (Campbell, 2001) and agency is given to the concept and not the individual. For instance, a solo parent is recognised in the social welfare system, and thus the individual, as a solo parent, is organised socially by the ruling relations embedded in benefit arrangements. There is no place for the lived experience of the parent and their everyday/every night world (except as evidence of concept) in the calculation and distribution of social welfare. The institutional interests are infused into the construction and maintenance of social welfare and financial support, not in the interests of the individual whose circumstances situate them as a solo parent. Further, Smith sees that the concepts, such as solo parent, go on to actively form and coordinate the activities and consciousness for those people who are objectified by the concept (Smith, 1996).

Modern ruling practices organise the social through a network of texts and text mediated practices. Such practices of social control have become so familiar and accepted, even if they achieve a degree of organisation that people may not be ordinarily willing to do, or find comfortable. I offer the following example of my mother as an active participant in taking up and activating the ruling relations of community medical emergency practices and procedures. This useful example enabled me to *see,* through the lived experience of my mother, the complex practices that shape people's actions through conceptual ruling relations and see for whose interest such actions serve.

On the evening of the 11th of January, 2018, while on holiday with friends and partway through my doctoral research programme, my mother phoned me. She had arrived home from work to find my 61-year-old father, apparently deceased. She had called the emergency services, who dispatched police and paramedics to their home. While waiting for emergency services to arrive, the 111 operator (who was responding to cues from a computerised algorithm prescribed for 'community cardiac arrest') instructed my mother to begin CPR. My mother is not a medical professional. She was not legally authorised to confirm my father's death. Despite knowing from her expert position of standing in front of my father in the chair where he rested peacefully that my father was indeed deceased, the official account had not yet been constructed to confirm this; therefore, the 111 operator persisted, my mother was to "begin CPR." At this moment, both the operator and my mother were active participants of the ruling practices that organised the social through text mediated practices. The 111 operator was an active participant in the activation of the ruling relations of a community cardiac arrest, which is embedded exclusively in medical knowledge of death. Despite her situational knowledge, my mother became an active participant in the conceptual role of witness to a community cardiac arrest and (despite her troubling and contradictory experiential knowledge) began chest compressions as instructed.

Shortly after the arrival of emergency services, my mother was relieved of her role in the community cardiac arrest. My father was *officially verified* as deceased, and conceptually, shifted from a 'community cardiac arrest' to an 'unexpected death.' In New Zealand, 'unexpected' deaths must be managed by emergency services who are governed, in this moment, by the Coroners Act, 2006. Following the textually constructed concept of an unexpected death, a strict set of data was then obtained by emergency services, including time, place and date of the assessment on a formal document, which constructed the official account. My Dad, in that moment, was conceptualised (by biomedical knowledge) as an unexpected death, to be dealt with by those authorised to medically and legally manage such an event according to the Coroners Act, 2006.

While the people in their professional roles of 111 operator, paramedic and the police officer were professional and respectful in their interactions with my mother, there was no room for her embodied experience of grief, trauma, shock and sadness in the essential information gathered and the construction of the official account. Only upon the conclusion of the interviews from police and paramedics, and their departure from the scene was my mother released from the conceptual role of witness. On reflection, it is possible to see how she was ruled by this concept. She carried out the course of action required of emergency services (the institutional interest) by a person when assuming the social role in a cardiac arrest as governed by law and medicine.

I learnt of these experiences, and the relations that ruled my mother's actions, through talking with my mother, followed by a brief investigation into the texts that govern frontline emergency services in a sudden-death situation. Similarly, following informant accounts from talking with patients and clinicians will reveal the relations of ruling that construct the troubling experiences as the patients know them to be (DeVault & McCoy, 2006; Smith, 1996a). Finally, the institutional interests behind and within the ruling apparatus of primary care will become visible through following the concepts, texts, and discourse that coordinate and maintain the social control of people when participating at the frontline of primary care.

Institution

Institutional ethnography examines the social organisation of state functions (institutions), for example, health services education, regulation of health workforce, social welfare/benefits, police, justice, immigration, and marriage, DeVault and McCoy define institutions, as treated in institutional ethnography, as an empirical site for inquiry "directing the researcher's attention to coordinated and intersecting work processes taking place in multiple sites" (2006, p. 17). The work and aim of an institutional ethnography project requires exploration of particular sites of coordinated work practices which shape the conditions of an institutional work complex (DeVault & McCoy, 2006). Researching within an institution in this way necessitates interviewing for and tracing the presence of institutional knowledge as carried through texts, discourse and courses of action entered into by people within the institution (McCoy, 2006).

This project is carried out within the institution of primary care. From patient enrolment to appointment booking and attending a consultation, the work practices account for some of the threads followed within this institution. The knowledge both discretely held within primary care, and that which extends into the wider institutions of business, health care, government, social services and so on, both ground and connect this project to an institution and to the wider spheres of work and knowledge within which people at the frontline of primary care participate.

Texts, as a concept, researcher tool, and mode of organisation

The term text is understood inclusively to locate any material thing carrying words, numbers or images that can be and is replicated in multiple copies so that the consciousness of anyone looking, reading, or hearing, is coordinated by the same words, numbers, images, or sounds as any other (Smith, 2008). Texts, recognised in this way, are everywhere. People enter into text related social processes in the course of everyday activities, such as receiving a parking ticket, paying bills, ordering from a menu or watching television, to name just a few. Such texts are the means by which socially constructed knowledge enters people's lives and work. People routinely engage with and use texts in their everyday work. This introduced knowledge from the text can be seen in the organisation of what people say, know and do in their everyday work (Turner, 2006). With this understanding, texts and textual analysis are of methodological importance in conducting an institutional ethnography. Specifically, the investigation of social and ruling relations requires explication of the ways in which people take up and activate texts, and of the knowledge located within the text.

As a research tool, explicit tracing of texts identified by participants in the course of doing work is necessitated to see how texts organise and mediate "what can be said and done" (DeVault & McCoy, 2006, p. 34). Investigating texts used by people at the frontline of primary care in this way deems that analysis of texts is not a 'textual analysis' of written content as such. Rather, by using Marx's idea of materiality, texts are considered as material things with standardising and organising capability. As such, texts are "constituents of social relations" (Campbell, 2001, p. 323). Texts actively inform, entertain, direct, record, standardise, and otherwise persuade (Stanley, 2018). This coordinating capacity is accomplished via the *activation* of the text; when they are read, filled in, followed or completed in the doing of everyday work. Through perpetuation of the textual organisation – in what we say, know and do - the ruling perspective is maintained (Campbell, 2006). Therefore, explicit tracing of texts mentioned or identified in participants' accounts of their everyday work is essential to the ethnographic exploration.

To interrogate a text is to ask, what does this text accomplish, and for whom? The interrogation of texts extends the reach of knowing beyond what is locally observable into the territory of translocal social relations and organisation. By exploring the interrelations between empirical everyday activities (the local), and the texts encountered, the research can explicate a segment of the social relations and the textual realities of ruling (Smith, 1990a). From this extended position, the permeation of how texts enter into and organise everyday activities becomes visible (Smith, 2006b).

For example, an emergency department nurse undertaking an admission assessment of a patient is organised to ask questions directed towards the completion of the admission assessment form. Their line of questioning is organised by the need to complete the text. Upon completion of the text, and following necessary digital steps, the person is shifted into the category of 'admitted.' This example demonstrates the organisation of the nurses' activity and reveals the power of text to objectify subjective knowledge – the experienced actuality of the patient becomes objectified to fit the assessment form, and thus confirms their entry into a category of admitted.

The scope of texts that coordinate everyday work for people at the frontline of primary care is vast. This study takes up a small handful of texts for thorough explication while recognising the presence and potential power of unexplored texts within the terrain.

Work

Work is defined in a particular way within institutional ethnography and reflects the material understanding institutional ethnographers hold of the everyday world. As used in this project, the concept of work references any intentional activity that takes time and energy. On addressing the problem of how to see work, Dorothy Smith began from her experience of the women's movement and decided to start "where the housework did" (Smith, 2003, p. 61). In doing so, work takes on a broad definition and includes otherwise unrecognised forms of work. In taking up work from this position, it has come to be known as the "generous conception of work" (Smith, 2005b, p. 210). This way of knowing about work originated in the Marxist-feminist group *Wages for Housework,* who insisted that housework must be recognised as work: it took time, effort, and was done under definite physical and relational conditions (Smith, 2005b). Such detailed descriptions of work give gendered and class-based divisions of labour a platform on which to be seen (DeVault, 2014).

The expanded and generous usage of the term work in institutional ethnography opens up aspects of what people do that may otherwise be missed and go unrecognised by the everyday usage of the word. Another early example that informed Smiths' thinking was the work of childcare (Smith, 1987), which could be recognised as unpaid labour, largely done by women. An additional example from Tim Diamond recognises long term care residents waiting at the dining table to be served their evening meal as work (Diamond, 1992). In this extended institutional ethnography, Diamond shows the deliberate conditions under which long term care residents take up the mundane or otherwise disregarded work of preparing and waiting for their meal. Through the attention to the notion of work, the required ontological shift described above is realised in the researcher's analytical focus.

Taking up the notion of work becomes a point of analytical interest when the work process identified (for example, waiting for meal service) becomes a “recurrent and troubling feature” (Ng et al., 2016, p. 3) for informants. By listening closely to people’s descriptions of their work, traces of recurrent or troubling tensions or contradictions may be found. Upon uncovering recurrent, troubling or contradictory work, identifying and detailing the work process becomes imperative to the research process and progress. The focus of further explication (analytic commitment) is then directed toward the investigation of social organisation, seeking clues where one form of knowledge is dominating or displacing another - ultimately linking the everyday work experience described by the informant to the ruling discourse and relations of the institution.

Ideology

Smith challenges the distinction between facts and ideologies. She explains that ideology is made up of “ideas and social forms of consciousness [that] originate outside experience, coming from an external source and becoming a forced set of categories into which we must stuff the awkward and resistant actualities of our worlds” (Smith, 1987, p. 55). On the other hand, Smith explains that (so-called) facts and factual accounts are produced through the objectification of knowledge, data, statistics, files and so on. Both ideology and the production of facts cancel the subject by introducing or impressing a ruling apparatus (Stanley, 2018). The ideological and authoritative categories may then be used in control, or ruling, of social activity.

From a dominant position, facts and ideology as produced by the institution carry institutional knowledge which may be used to dominate and perpetuate the social control. Cupit (2018) identifies researcher concern when people “act according to institutional knowledge which is at odds with their (or others’) local, embodied experience,” which she identifies as ideological practice (p. 61). An example of this ideological practice can be seen in Chapter six through the production of patient experience data. Smith (2005b) further recognises that ideology and ideological knowledge, such as patient experience data, is then transported within an institution, often through the employment of shell terms (see discussion of shell terms below). This understanding of ideology is important in the recognition of ideological circles, also discussed below, and in the analysis of the primary care patient experience survey in Chapter seven.

Discourse

Smith is particular in her theorising of discourse. Smith shares with Foucault an interest in discourse as present in texts, power and governance (Smith, 1987). However, in line with the standard Marxist critique of Foucault, where Marxists argue the subject is denied agency under Foucault's theory (Smith, 1990b), Smith's uptake of discourse repositions the text *within* the social. DeVault and McCoy (2006, p. 44) clearly articulate Smith's conception of discourse including her departure from Foucault:

> "In Foucault's work, and in work taking up his approach, for example, the notion of discourse designates a kind of large-scale conversation in and through texts; Smith works with a wider notion of discourse that is consistent with her social ontology and her commitment to grounding inquiry in the activities of actual individuals. For Smith, discourse refers to a field of relations that includes not only texts and the intertextual conversation, but the activities of people in actual sites who produce them and use them and take up the conceptual frames they circulate. This notion of discourse never loses the presence of the subject who activates the text in any local moment of its use" (2006, p. 44).

Therefore, discourse is understood as a central feature of ruling practice in contemporary society, specifically as the social relies on text-based discourses and forms of knowledge (DeVault & McCoy, 2006). Within institutional ethnography, the researchers approach to text-based forms of knowledge (for example, literature), is therefore different to other sociologies. The concepts discussed in the literature (strategies, research, patient education texts and so on) are recognised as forming part of the discourse. That is, the texts/literature inform the discourse in ways that are organising what can be seen in people's everyday activities. This observable discourse is specialised in the way in which people talk about things – things that carry knowledge from somewhere else into the institution in which they participate. Therefore, as part of discovering how things are put together, the words and actions people put into place to make sense of what they are doing are discoverable as the local, and possibly ruling discourse.

Healthwork

Healthwork collectively describes work practices done by people with respect to their health within contemporary health care practice (Mykhalovskiy & McCoy, 2002). Jan, for example, undertakes work orientated to facilitating and maintaining the relationship she has with her GP, in light of booking systems that now favour any clinician from within Jan's "health care team." For Jan, her healthwork involves multiple phone calls, navigating booking systems, travelling across town to the new provider location, and paying for the services provided (among others). Meanwhile, the healthwork of another patient may be similar or entirely different. What is important is the recognition that work practices are undertaken by everyday people under the circumstances of using primary care services.

Shell terms

A shell term is a practically useful notion of institutional ethnography. First published by Smith in 2005 (Smith, 2005b), she credits the linguistic analysis works of Hans-Jörg Schmid for the original concept. Schmid (2012), studied a class of abstract nouns which he found to be 'conceptual shells', in that they lacked specific content. The open-ended nature of the abstract noun allows the speaker or reader to fill the shell "with substance extracted from the local actualities of his or her work" (Smith, p. 113). Common examples identified by Schmidt in the everyday world include *idea, place, thing, fact* and so on. "This place is beautiful" highlights a circumstantial shell term, where *place* requires situational knowledge to fill the shell with meaningful content. Shell terms are not always so obvious, institutional ethnographers need to be particularly diligent to identify their use so as not to fall into the trap of authoritative knowledge.

In taking up 'shell terms' in her alternative sociology, Smith (2005b) alerts researchers to the presence of institutional discourse that equally lacks specific content. As a point of separation, shell terms located in institutional discourse displace the presence of people doing work, extending the concept to include actions and ideologies. Examples of institutional discourse from institutional ethnographic researchers include *arrested* (See Smith, 1990a), where being arrested becomes an institutional course of action to be filled by a situational account; *best practice* (See Grace, 2015) who recognised shifting definitions of best practice as dependent on context for meaning in HIV/AIDS care; and Corman's (2007) application where he locates *autism* as a category (shell) which the practitioner must fill with everyday actualities to make the diagnosis institutionally meaningful. In this thesis, I recognise multiple instances of shell terms in action, the most prominent (and problematic) being patient- or person-centred care. Patient- or person-centred care is used differently in the local setting (see Chapter 5) to how it is activated in a managerial setting (see Chapter 8), which is different yet again from how it is known about in a global context.

Ideological circle

In the course of institutional ethnographic inquiry, particularly when the research intersects with new public management practices, sequences of actions that appear as circular carrying institutional knowledge (for example, ideology or accountability) from one place to another frequently emerge within the analysis. Smith identifies these as institutional circuits, and most commonly, ideological circles and accountability circuits (Smith, 1990b, 2008). Smith describes these circuits by saying:

> The circularity of the modes in which government and public institutions become accountable are also modes that ensure that accountability will be essentially divorced from the actualities of the everyday lives of those who participate. Though the new public

> management may have intended to increase the accountability of government to citizens, the circularity of its textual realities means that its management is effectively insulated from the actualities of people's everyday lives, doings, and work (Smith, 2008, p. 26).

In this research, whilst anticipating an accountability circuit (more on this in Chapter seven), in tracing the analysis from the bottom up, and subsequently top down, sequences of actions carrying government and health care ideology emerged instead. This finding is attended to later as an ideological circle. Below is a short summary of this institutional ethnographic concept.

Ideological circles/circuits appear increasingly prevalent where professionals undertake processes that categorise people. For example, in the construction of a person as 'mentally ill' through standardised and generalised systems of professional documentation, the "messiness of social life has to be transformed into a form in which it can be processed as data and this standardises what happened and about what" (Stanley, 2018, p. 61). I have applied this notion of tidying up the messiness in the discussion of patient experience, as collected and subsequently known through the primary care patient experience survey. Chapter seven shows how the account of what actually happens for the patient is assembled within an interpretive schema which privileges dominant ideologies and priorities, followed by organisational practices which further distance the patient from the process and reinforce the dominant ideologies and priorities in future practice.

Chapter three conclusion

In this chapter the theoretical complexity of institutional ethnography is explored, with attention to the specific tools taken up in the current research. This chapter hints at some of the researcher challenges in applying institutional ethnography to a social problem. However, the reward of rich and valuable findings related to those who are marginalised, invisible, and managed make the researcher angst worthwhile. Moving into Chapter four, the practical application of institutional ethnography adds to the methodological understanding established here, bringing to life the dense theoretical foundations that shape this institutional ethnography.

Chapter Four - Method: Conducting the study

Introduction

This study uses institutional ethnography to explore what brings about troubling experiences including unmet need, difficulties accessing care, impersonal care, trouble navigating systems, places and instructions for some patients in primary care. From the standpoint of people at the frontline of primary care, I have listened to what they say and know, and used this to provide clues to direct this inquiry. Following what patients and clinicians say and know reveals how the multiplicity of their experience, tensions and disjunctures emerge organically within the research puzzle and are connected to social relations.

This chapter describes the practical methods employed in this study, caveated at times by the particular challenges of implementing an institutional ethnographic approach. The chapter begins with informant (participant) recruitment, followed by a discussion of the approach taken to interviewing and making sense of the interview data, and the reasons behind these choices.

One important decision must be declared upfront in this chapter regarding the treatment of informants and their locale. Clinicians and patients came from a range of primary care settings including three IFHCs. In order to reduce any identification, the IFHCs are at times spoken of as one entity and factors potentially identifying each entity are blurred across the three settings. This decision relates to this method chapter as well as the analysis chapters which follow.

Ethical approval for the study

This study underwent full ethical review, with approval granted by the Massey University Human Ethics Committee: Human Ethics Southern A Committee, at their meeting held on December 21, 2016. Approval was valid for three years, as per ethics notification reference SOA 16/63 (see appendix B). Further approval was obtained from Mid Central Health, authorising access to patients from the Mid Central region (see appendix C). There was no further data collection after December 2019.

Informant recruitment and interviewing

Recruiting informants was an iterative process, taking place over two years as the research project moved along the research trajectory from frontline (local) into the institution (extralocal) of primary care and beyond. Patient (local) participants made up the first round of recruitment, followed by clinicians. Patient and clinicians' accounts (such as those of Jan and Alex) orientated the focus of the project. Troubling aspects of their accounts make up the many disjunctures, and thus points of departure for further investigation. Patient and clinician accounts were supplemented with interviews with other IFHC members and wider governance of primary care, primary health care, and health care in New Zealand. Extralocal informants encompass a diverse range of people, professions and locations. While not directly active at the frontline, their position in the institution of health care provided unique insight into the social relations organising frontline work. That is, the knowledge held by these informants makes visible aspects of the social organisation of what can be said and done by the frontline of primary care.

In the following sections, the distinction between standpoint, local and extralocal informants is first discussed. Then, a detailed account of the recruitment and interviewing of patient participants, followed by the recruitment and interview processes for clinicians and extralocal informants. As interviewing was an iterative process, dipping in and out of data collection and analysis, some aspects of analysis methodology are included in the recruitment and interview discussions.

Distinguishing standpoint from local and extralocal informants

Early in the analytical stage, as the ethnography moved into the social from patients to clinicians, I became aware that both patients and clinicians are drawn into the same institutional relations in the provision of primary care. I had first thought their differences in situated knowledge would collide, like that seen between patients and health care professionals of Cupit's (2018) institutional ethnographic study. Cupit found patient and health care professionals to hold remarkably different locations in proximity to the relations of power and ruling of what could be said and done in the space of preventative medicine. Yet, I found clinicians' work and knowledge contributed to, as opposed to collided with, the troubling disjunctures apparent in patient experiences of institutional processes of emerging interest. While this project remains committed to the standpoint of patients, the need to include the clinicians' experiences as frontline informants at times is recognised. So, while not initially recruited as local/standpoint informants, clinicians and their experiences are included retrospectively as frontline informants during analysis. However, the recruitment and interviewing of clinicians is discussed outside of patient recruitment and interviewing, as these were two distinctly separate processes within the study.

Patient participants

Recruitment of patient participants started six months into this research project following receipt of ethical approval. Upon establishing relationships with local primary care centres[19] and obtaining permission from both the centres and the district health board (see appendix C), recruitment began. Primary care practice nurses at the centres identified adults who had recent multiple encounters with the New Zealand health care system to participate in the study (see appendix E for letter of invitation to participate).

I specifically sought out patients who had amassed multiple experiences with health care services, recognising their experiences likely traverse multiple relationships and places. Through talking with people who had multiple health care encounters, it was hoped that participants would hold widespread expert knowledge of various common social practices, thus offering multiple doors into the work processes that affect them. I did not target specific patient demographics. However, any demographic information discussed in the context of this research is shared to provide insight

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[19] Primary care centre used were selected for their large patient population size to reach a diverse group of people for whom anonymity could be accomplished owing to population size and characteristics. The region this research takes place in hosts several similarly sized primary care centres, thus similar concerns for anonymity within the region are somewhat mitigated.

and appreciation of the everyday circumstances of the participant experiences, which is discussed as it contributes to the analysis of data.

Within institutional ethnography, participants are not the object of analysis; rather, it is how their experience is organised and controlled that is of interest and is a means of acquiring and enriching our understanding of the institutional process. Further, in concentrating the interrogation on an institutional process, the population sampled is essential for their expert knowledge of their position in the process, not their personal characteristics. Thus, institutional ethnographic research purposively samples an institutional process rather than a population. The goal of the research is not to be representative of the broader population, but rather to understand a phenomenon or process in-depth. Smith, in the early formulation of this goal, stated:

> [s]ociology beginning in people's everyday/everynight experience takes for granted that experience is as varied as people are. It does not seek to supersede this variety by constructing a version that overrides all others. Differences in experience arise in a matrix of everyday/everynight activities and how they are entered into and coordinated with others' activities (Smith, 1996a, p. 172).

Supported by this understanding, the decision to recruit participants with multiple and varied experiences offers potential for many accounts of a process from different perspective, but, as I discovered, carries the risk of revealing too many processes, problems, and paths to follow.

To recruit such participants, the study employed the assistance of practice nurses who had contact with people living with long term conditions and complex health care needs. The practices nurses were asked to identify adult patients (18 years or older) who had recent extensive contact and multiple encounters with the New Zealand health care system across any setting except mental health.[20] During a regular consultation, the practice nurses gave a letter of invitation and information sheet to potential patient participants who met the selection criteria.[21] After reviewing the invitation to participate, patients were invited to contact the researcher by phone or email. Following the first contact from an interested participant, further information, including a consent form, was sent by post or email, allowing one week for the potential participant to consider their involvement and ask further questions prior to study participation.

Recruitment of patient participants took longer than expected. After the initial engagement with primary care centres, several weeks passed by with no interest from potential participants. I began investigating alternative recruitment approaches when a small wave of potential participants made contact in quick succession. All potential participants who made contact (10) went on to participate in the study.

Of these 10 participants, while selected purposively for their experiences as patients, the final composition of the interview participants happened somewhat by chance. That is, their "varied circumstances and situations" arose organically (DeVault & McCoy, 2006, p. 32). Participant characteristics undoubtedly contributed to a diversity of experience and indeed influenced some of the paths followed. However, through interview and analysis, it can be seen that each informant was drawn into the same social setting and a common set of social practices, irrespective of their unique characteristics. Thus, the rigour comes from tracing the same process from the various

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[20] Patients using mental health services were excluded for two reasons. Firstly, the mental health system possesses a unique set of social and ruling relations that extend beyond the scope of this thesis. Secondly, it was not deemed necessary to access this vulnerable and highly researched population, as it is possible to understand the institutional process without further burdening this population. For similar reasons, current in-patients and persons living in long term care facilities were also excluded.

[21] Participants were required to have sufficient competence to provide consent to be interviewed.

participant positions, drawing on each new informant to check the account as it is built and filling in the social map with their unique approaches as they introduce new, corroborating, supplementary or correcting information. For example, as I listened to each new patient informant, I considered what I knew from previous informants and how each new informant's account fitted with emerging maps of institutional processes. This consideration, plus other aspects of interviewing is discussed below.

Informed consent

All research participants were required to consent to being interviewed, for the interview to be recorded, and to have their interview data included in the research project.

Minimisation of risk of harm

It was not expected that harm would come to participants from participation in the research project. However, it was important as the researcher to be aware that participants may feel uncomfortable talking about a sensitive topic. Although, a study conducted by Decker et al. (2011) found that participation in sensitive topic research seems less likely to cause distress than initially anticipated. Additionally, other studies analysed by Decker et al. found that personal benefits to the participants were often reported as greater than the perceived negative effects. This is not to suggest there was no risk. Instead, the risk was not likely to be sufficient to jeopardise the research.

In addition to measures taken within the interview experience, other actions were encouraged to promote a positive experience for participants. As recommended by Mealer and Jones (2014), participants were encouraged to engage in self-reflection following the interview by way of either journaling or discussing with a peer. Participants did not require researcher interventions in response to stress or distress from participation.

Minimisation of risk of harm to researcher

Interviewing alone poses a potential risk to the researcher. Interviews arranged at the participant's home required an assessment of the suitability and safety of the environment. Interviews were conducted during the daytime and an independent person was made aware of researcher whereabouts and the expected duration of the interview.

Interviewing participants

Patient interviewing took place within the first 12 months of the research project. Due to the potential sensitive topics discussed in the interview, best practice was followed, allowing the participant to choose an interview location where they feel most comfortable (Elmir et al., 2011; Mealer & Jones, 2014). All patients chose to be interviewed at home, often over a cup of tea. On four occasions, the participant's partner was also home, and on two of these occasions, the partner volunteered significant and valuable information to the discussion such that I consented the partner to include their contribution in the construction of what is known from the experience of patients.

The intention throughout this study is to keep the lived experience of the people at the frontline of primary care in view while navigating the institution and social that extends from their position. To achieve this focus, institutional ethnography starts with "the concrete features of people's activities as opposed to the abstracted, heavily interpreted meanings people derive from their activities" (Ng et al., 2016, p. 3). For this project, this means asking patients what they actually do (or did), that is, the way they go about and know of their everyday world when their everyday activities interconnect with primary care. However, interviewing in a way that orientates towards the social requires substantive preparation and practice.

Navigating interviews to elicit focussed descriptions of institutional processes from informants is a unique skill required of the institutional ethnographer. I found interviewing instruction from deep and repeated readings of prominent institutional ethnographers to be highly valuable in learning such interview navigation (see DeVault & McCoy, 2006; DeVault & McCoy, 2012; McCoy, 2006; Rankin, 2017a for useful instruction). Before interviewing, drawing on the written work of these institutional ethnographic scholars, I established an interview approach that focussed questioning on actual practices and actions undertaken rather than opinions. I supplemented this interview approach with a toolkit of questions, points to look out for, and useful nudges to prevent interviews from straying too far "off track" (see appendix G) (Bisaillon & Rankin, 2012). Through repeated practice across each new interview, I learned to be astute to the person's narrative, to select appropriate moments to interrupt and nudge, ensuring informant descriptions were both meaningful as an account and robust as a description of an institutional process.

Interviews were audio-recorded and later personally transcribed. During interviews, I opened my discussions with patient informants by asking them to share with me their experience of using health care. I listened carefully for moments of an interface between the person and *something* or *someone,* and the task/action/process the interface achieved. In line with institutional ethnographic interviewing (DeVault & McCoy, 2006), the questions which followed were not, and could not be, standardised. The interview takes place in a moment of analytical evolution – each response provided by the informant offers new insight into a process or activity. Each question that follows is an opportunity to explicate a process further, from a different position or circumstance, to learn how things work.

When people talked about their participation in work processes, for example, booking appointments, waiting in the waiting room, or completing a survey, the door opens to learn more about the process and the social. When appropriate, I asked people to explain this process to me in detail, seeking confirmation or correction to my understating of their experience as required. For example, when Louise, a patient informant, said she "found a new GP," I noted this down, and when appropriate, asked her to explain how she went about this, and where possible, explored where her knowledge originated for doing this activity. When Jan said she "made an appointment" she looked at me quizzically when I asked her to explain to me how she did that. The answers provided from these probing questions provided my most analytically useful descriptions of patients' work knowledge.

Interviewing in this way facilitated robust descriptions of patients undertaking practical activities in the everyday world of primary care. These practical activities reveal the person's position within the recurrent and routine activities of primary care which are the social relations this research makes visible. From this very early data, I could begin to locate and trace points of connection among participants located at different places of the institutional terrain. The detail informants provided revealed what they knew of the process in which they were involved. Sometimes, these processes caused stress or distress for the informant, for example, the frustrations of Jan navigating the booking system at the new IFHC to see her doctor. In these moments, where the chafe between person, process and institution became apparent, wherever possible I followed the sequences of action into the social of primary care. As people's experiences are unique, despite purposive selection (described above), the research process was reliant entirely on both their individual experience and what they choose to disclose within the interview. Each interview took between 45 minutes and an hour, and at the conclusion, patients often thanked me for listening to their stories. Patient participants commented that they appreciated being listened to and having their experiences included in research they felt was meaningful.

Although not analytically useful (even cautioned against by Rankin (2017b)), given the nature of the topics I was discussing with patients when interviewing, I found myself drifting into people's opinions and speculative explanations. McCoy (2006) calls this an "analytical drift," however, my interest was not analytical. Rather I believe it was to acknowledge for the participants that I cared for how they felt and respected their perspective. Melon (2012) recognised similar interviewing habits during her master's thesis, suggesting this was useful for rapport development. This practice sat comfortably alongside the more traditional elements of the interview, such as notetaking, recording, and questioning noted above, which risked a sterile of forced atmosphere.

Within the interview, further to making notes for questioning lines, I noted all texts participants mentioned in their descriptions and discourses the participants were drawing on to describe their everyday experiences. For example, when both Jan and Jane (patient participants) identified they did not have "enough points" to qualify for specialist intervention, I asked what they meant by this, but did not challenge their understanding. Instead, I noted the discourse through which they had learned to make sense of their experience as a place to investigate further. Following each interview, I made additional notes of my immediate thoughts, feelings, learnings, and questions that arose. These notes were both a practice of researcher reflexivity, as well as useful in guiding the emerging research into the long process of making sense of the data.

Making sense of the data

True to most institutional ethnographic studies, the process of moving into the social was neither orderly nor distinct (McCoy, 2006). In attempting to organise data from patient informants, I filled A3 pages with sketches of processes, teasing out the sequences of actions I could see taking place. By mapping patients' individual journeys, the hooks and doors from their experience into the social slowly came into view. From their unique positions within the social, the hooks and doors presented endless opportunities to follow. Take, for example, Louise, one of my first patient informants whose early map is shared below.

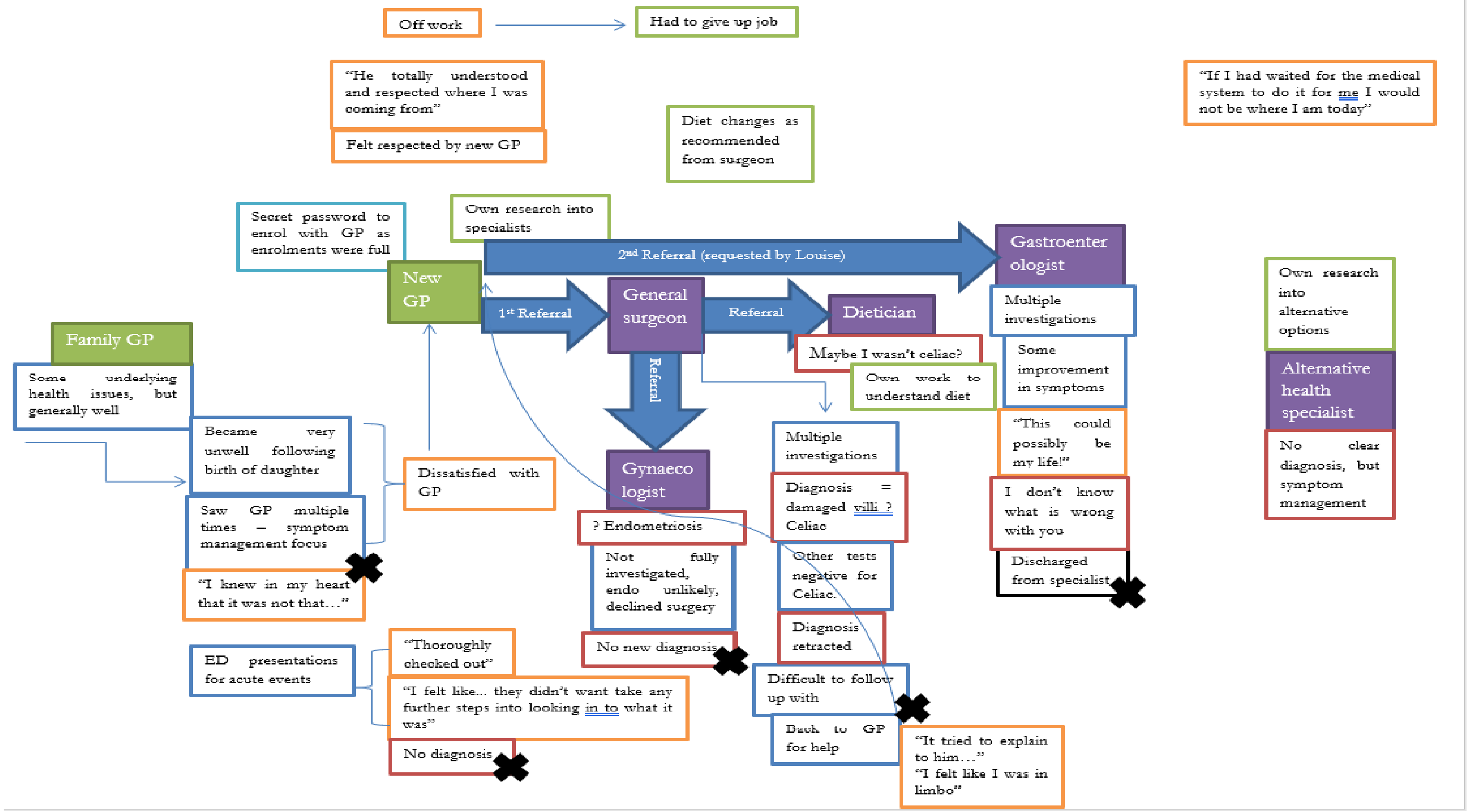

Figure 4. Early map of Louise's account of accessing health care

For those well versed in institutional ethnography, this map will appear somewhat chaotic, confusing, and unrecognisable as a map of an institutional ethnography. At the time this (and other) patient maps were created, the analytical intent was to trace the work patients participated in during their everyday experiences as they geared into aspects of the health care system. Then, to follow those aspects identified as troubling as an entry point into the social. Early maps such as the one above, on reflection, did not show the work of patients. Rather, they focused on the journey of patients between different health care locations, between different health professionals, and for Louise, between different investigative procedures, diagnoses and treatments. There are moments where their work is present but often hidden in misguided institutional assumptions. This step of 'not quite institutional ethnography,' while deeply frustrating, was necessary for my development as an institutional ethnographer.

I spent a considerable amount of time wallowing in the data from patient accounts. Convinced the research problematic must be hiding in plain sight. I visited and revisited interview transcripts ad nauseum, each time hoping to see something missing, and in parallel, reading and re-reading of publications holding analytical instruction in an attempt to make sense of the data in front of me. In my rudimentary understanding of institutional ethnographic analysis, I was assured that "the problematic is generated from the data" (Rankin, 2017b, p. 3). Returning to the patient accounts, I made lists of the moments of disquiet, of the difficult encounters, and the times that the patient's knowledge was at odds with what I understood from different positions within the institution of primary care. For example:

- Louise found it difficult to get her needs met within a primary care consultation.
- Louise felt rushed and that the GP did not have time to look at the big picture of her total health concerns.
- Jan was satisfied with how her health needs were dealt with, but was dissatisfied with the new challenges of accessing these services.

- Jan, at a new IFHC, had difficulties seeing her preferred GP.
- Tim (a patient informant who is introduced later) had difficulties securing an appointment in time to meet his needs.
- Tim found the new digital technology systems of his IFHC did not reflect the availability of appointments.
- Alice (a patient at an IFHC) found the new service impersonal and felt it lacked privacy in the large open plan design.
- Helen (a support person for her husband) expressed frustration at the lack of navigation within different parts of the health care system.
- Helen and Louise both experienced difficulties with referral pathways and knowing whom to ask for help.
- David (another patient informant) described a positive experience within acute specialist services, but shared many challenges of living with his long term health issues and the lack of continuity in support once he was back in the primary setting.

This list is a snapshot of the seemingly infinite problems and paths into the institutional complex from the position of patient informants. Through talking about these patient experiences with academic supervisors and with people well versed in institutional ethnography, the analytic guidance pointed towards *what is contested, what is counted, what is visible, and what is invisible?* I knew of other accounts of patient experience of care – most notably the primary care patient experience survey. The primary care patient experience survey makes *visible* the patient experience, but from a *contested* definition than what patients know of their experience. Locating my analysis alongside the terrain of (contested) official knowledge of patient experience provided a way to focus the analysis; to identify small problematics or points of disjuncture to scaffold the analysis into a comprehensive problematic.

Departing from the misguided maps, I formulated, reformulated, and completely departed from the notion of finding a single problematic at this point in the research process. Instead, to move on from the wallowing, guided by the emerging gap between embodied experience of patients and authorised patient experience data, I developed a series of questions to guide the approach to the study. These questions (below) provided a place to begin entering the matrix of the social. These were:

- What do patients say and do to access, navigate, and effectively use primary care services?
- What do patients *know* about what they say and do?
- What is organising what can be said and done?
- How are strategic documents (institutional governance texts) taken up in primary care practices?

Moving on from patient participants – from the local into the extralocal

Identification of extralocal participants occurred on completion of first phase interviews. Clues from patient informants' experiential accounts became doors into the social of primary care. Smith conceives of extralocal informants who are "those at work on the other side of a particular story," as "further resources of knowledge" (Smith, 2005b, p. 151). The knowledge held by the extralocal informants I spoke with formulates the connection from local informants' work into the social of primary care. For example, a patient mentioned a booklet used to navigate the discussions within their consultation. Interviews with frontline staff could then provide an understanding of how the booklet introduces courses of actions within the consultation for patients and/or clinicians. Alternatively, further resource of knowledge could be the author of the text inquiring how they came to write this text and where does their knowledge come from?

By focussing on the analytical questions above, such as, what do patients say and do to access, navigate, and effectively use primary care services? I identified people/texts/processes positioned on the other side (or outside) of the troubling aspects within a patient's account. I subsequently spoke with seven extralocal informants such as GPs, NPs and RNs, alongside tracing several texts and processes. Whereas patient informants provided a rich description of their everyday experiences with primary care, interviews with extralocal informants aimed to elicit an understanding of how primary care experiences, like making and attending appointments, work.

GP, NP, RN or clinician?

At the time of writing this thesis there are over 600 NPs working in the New Zealand health setting and especially in primary health care. In many instances they are the primary provider for a panel of enrolled patients and must deliver care within the same structural constraints as preferred by their GP colleagues/business owners. It is however clumsy to write GP/NP at every instance hence I have frequently used clinician where it is not relevant whether it is a GP or an NP and nurse where it is a registered nurse. Where I use GP alone, I refer to matters related to political positioning, business ownership, policy documents, advertising material and more. Where the comment refers to a specific participant in the study then I have identified them as NP, GP or nurse accordingly.

When identifying extralocal informants, it was the professional participant's position in the social world, what they know from that position and how their work is coordinated, that is of interest at this point. I did not seek out specific clinicians, such as clinicians identified by the patient informants. Rather, anyone who held the knowledge through their professional position and could contribute to the emerging social terrain, was considered for interviewing. The decision to trace participants by social position rather than follow the professionals identified by the patient participants experience serves two purposes and is supported by Norstedt and Breimo (2016). Firstly, patient participant confidentiality is protected, as patients are not linked to the professional participants. Secondly, professional participants are not put in an uncomfortable position of risking disclosure of information protected by patient confidentiality, or of feeling personally scrutinised by the research.

Extralocal recruitment

Extralocal participants were recruited by one of two methods, depending on their position. Clinicians were recruited via snowballing, beginning with an initial clinician contact already known to the researcher. The first contacts were asked to pass on an invitation to participate and an information sheet (see appendix F) to persons who held professional roles that were identified as of interest because they were part of the textual work processes seen in the interviews. I was not informed who had received invitations to participate. Again, contact with the researcher had to be initiated by the prospective participant, after which the same process as with patient participants was followed.

Alternatively, I approached potential informants directly by email if available, or by appropriate communication channels depending on the potential participant's relationship to the research, using publicly available contact information. For example, through author details of a text, or publicly visible roles such as ministry employees. Initial contact involved an introduction to the researcher and the project. Invited participants were given an information sheet to consider. Participants were followed up one week after initial contact with an email or phone call to enable the potential participant to ask for further information or clarification, discuss the individual's interest in participating, and, if agreed, negotiate an interview time and location.

As with patient informants, professional informants could choose their interview location, with all choosing office settings and local cafes. These interviews were recorded and manually transcribed.

Table 2 below shows the final composition of informants, alongside other data sources.

Standpoint informants	Patients		9
	Patient’s support person		2
	Total		**11**
Extralocal informants	General Practitioner		3
	Nurse Practitioner		1
	Registered Nurse		3
	PHO informant		3
	DHB informant		2
	Government informant		2
	Academic informant		2
	Authors of texts		2
	Total		**18**
Examples of further ethnographic data collected	NZ Doctor discussion forums Academic journal commentary Local, regional and national legislative, strategic, guiding, and planning documents Patient education resources Social media platforms		

Table 2. Composition of research informants and ethnographic data

Generalisability of the population or of the problem?

In Smith’s own words, referencing her early explorations of single mothers, she describes the irrelevance of striving for representativeness:

> When we look *at* the school *from* the standpoint of women, we do not require a sample; we are not trying to generalise from a small number to the characteristics of a larger population. Rather we are trying to explore how the institutional practices of the school penetrate and organise experience of different individual women as mothers… And we want to ‘hold’ our perspective by moving from the experience of the women we interviewed to the complementary organisation of the school [Smith’s emphasis] (Smith, 1987, p. 187).

For those employing institutional ethnography, this means that the aim is for generalisability of the phenomena – the institutional practice and the relations which organise the practice- and not to produce a description of a representative and generalisable population. Likewise, it is not my aim to achieve generalisability of frontline participant characteristics in this study. Instead, the project aims to highlight how the ruling relations have generalising effects on institutional practices and people at the frontline of primary care.

Therefore, building rigour into the research is accomplished through the accurate accounting of people's lives and the interface with the institutional practices within which they participate. The strength of the data relies on the discovery of how people's lives are organised, using the tools of institutional ethnography to visually map and textually show how knowledge works to organise everyday actions within the social. Thus, the methodical analysis of local experience can make sense of experiences at different locations. Rigour or robustness is then confirmable through applying findings to similar everyday practices at different locations with different actors and seeing the same relations organising the same experiences. As Campbell (2006) says of her research into management strategies in health care institutions:

> I can claim that what was happening among the nurses was part of something generalizable about "quality management" in that setting and indeed the management of health care more broadly… while this incident may be specific to one time and place, and one set of actors and their experiences, the relations that organize those experiences can be demonstrated to be general (p. 105).

That said, individual characteristics (as discussed in the analysis chapters) lead to analytical challenges in early data analysis as "not all stories seem to be pointing in the same direction" (Campbell & Gregor, 2002, p. 95). Accounts from people of different ages and resource such as social and financial support pointed to seemingly different problems. Institutional ethnography recognises that it requires persistent analytical reflexivity to avoid these variations of characteristics pulling the researcher "towards the kinds of categorical analysis embedded in ruling activities" (DeVault & McCoy, 2006, p. 32).

Reflexivity

Approaching this investigation as a registered nurse, unavoidably positions me as a knowledgeable insider. My familiarity inside the institution of health care held the potential to obstruct both data collection and analysis. Rankin (2017a) warns of the risk of 'institutional capture': when one's insider knowledge competes with or entirely thwarts the researcher's ability to see the social world without imposing the researchers own professional training. Avoiding institutional capture during interviewing was achieved through active reflexivity; consciously checking and rechecking of data completeness, and for the absence of thorough explanation of professional or institutional speak. Interview transcripts were highlighted to identify any institutional language that lacked meaningful explanation, which gave an opportunity to fill gaps in future interviews, or to return to the participant for further explanation when appropriate. However, while diligent in monitoring for capture throughout interviews, researcher capture in other aspects of the research project went undetected for some time.

I began this study from an insider location within a conceptual and ideological formulation of nursing. From this professional location, I concede that for a substantial portion of this research project, I was caught up in and captured by the circulating ideologies and authoritative knowledge of the institution (Rankin, 2017b; Smith, 2001), specifically, of person/patient-centred care. As addressed in Chapter seven, the most significant effect of this capture was the assumption that person-centred health strategies were *doing something* in organising the work of people at the frontline of primary care.

Ethical approval and the accompanying challenges

Gaining ethical review board approval for this project was an early test of my comprehension of the empirical position of institutional ethnography. To describe in a way that was administratively useful to the human ethics committee the nuances of institutional ethnography, as related to my request to recruit and interview patient participants, was challenging. I knew I needed to talk with patients. I knew their work was connected to higher levels of institutional organisation. What I did not know, and could not provide to the ethics review board, was *who* or *about what* my next research steps would entail. The iterative and emergent nature of this work and how it would progress was murky at best. DeVault and McCoy explain the diverse nature of institutional ethnographic investigations as "a process rather like grabbing a ball of string, finding a thread, and then pulling it out." They say further that "institutional ethnographers know what they want to explain, but they can discover only step by step whom they need to interview or what texts and discourses they need to examine" (DeVault & McCoy, 2012, p. 383). I was, recognisably in hindsight, captured by the authoritative knowledge of health care and health work, as I could not see outside of the ideological frames of concepts such as person-centredness and taken for granted institutional structures.

The test of the ethics review process was to explain how I would proceed safely and ethically with the project, within the standardised textual format required by the ethics committee. Aligned with the experience of New Zealand based institutional ethnographer Sue Adams (2017), the application I was required to complete was a "complex and lengthy form requiring information in ways that did not appear to entirely suit an institutional ethnographic approach" (p. 117). To counter this, my application centred largely on my ability to act ethically within a loosely framed research problem, as opposed to a traditional positivist research paradigm with clearly defined research parameters which the ethics application appeared to favour.

Consideration of cultural implications for Māori

Te Tiriti o Waitangi (the Treaty of Waitangi) is a nationally significant treaty that governs relationships between Māori (Indigenous people of New Zealand) and the Crown. Te Tiriti is a foundational text for all health care policy, delivery, and research in New Zealand. Central to this agreement as a researcher is a commitment to ensure research is responsive to Māori, promotes equity and offers the potential address Māori health needs and Māori priorities (Hudson et al., 2010; Reid et al., 2017). At the outset of the research process, I sought cultural guidance from a respected Māori health leader and cultural competency facilitator. I met with Huataki Whareaitu, who was supportive of my inquiry. Huataki provided specific advice for engaging with people who identify as Māori and offered insight into the applicability of my research approach to the creation of knowledge within Māori custom and values. In particular, Huataki noted the mode of inquiry aligned with Māori perspectives, in that the integrity of what the participants say is maintained and protected through the maintaining of standpoint and rejection of abstraction, thus honouring participation and protection of Māori. This integrity of participant contribution is fundamental to all methods employed and decisions made in this research project.

Wrong turns, mistakes and pitfalls

My journey of doing institutional ethnography has not been without its challenges. The evolution of the research problematic was slow; I attribute this to the complex and seemingly infinite terrain of primary care, coupled with initial findings that opened up a vast number of troubling experiences at numerous points of patient and clinician experience. Attempting to connect these experiences together induced a research process likeable to navigating the Labyrinth. Alex Pattakos' metaphor of the Labyrinth as life's journeys appropriately describes my circular and convoluted process; "We are never really lost… but we can never quite see where we are going." (2010, p. 28).

The temptation to pull all threads and follow all paths generated substantially more data than I could feasibly manage within this thesis. I also (too often) found myself buried deep in government archives, following clues of referenced texts and traces of institutional knowledge about frontline health care. Rankin (2017b) cautions of this institutional ethnographic "pitfall," saying "without a clear sense of what is being explicated, the researcher is at risk of losing analytic focus and may drift toward an unwieldy conglomerate of ethnographic data that lacks coherence in regard to unravelling a puzzle in everyday life" (p. 7).

As an example, I performed an extensive ethnographic tracing of the specialist referral process following the disjuncture identified in the accounts of Louise and Jane, where the referral process appeared to do something other than secure a specialist appointment. My explication included interviewing clinicians making referrals, those who receive referrals, inquiries about 'referral triage meetings,' and thorough tracing of the referral text, and rules governing the referral and triage process. This information was not included in the final analysis as it did not contribute to the immediate troubling conditions which make up the eventual problematic. Such unwieldy explorations may not be formally included in this thesis, but the learnings have no doubt informed my bigger picture understanding of how health care and governance works.

Chapter four conclusion

This chapter describes the practical methods of institutional ethnography as employed in this study. Research location, participant recruitment, interviewing, and data analysis are described, including the researcher troubles and pitfalls found along the way. This chapter describes key decisions regarding research design, such as researcher standpoint, and analytical progression from patient account into the social world of primary care. Ethical requirements and cultural considerations are detailed, including institutional and professional approval, with relevant documents included in the appendices.

Chapter Five – Analysis part one: Accessing primary care services

Introduction

This chapter is the first in the series of three analysis chapters, drawing on ethnographical fieldwork. In this chapter, I take up the accounts of patients attempting to gain access to primary care, and the many aspects and avenues patients engage with to do this work. Coupled with these accounts are data from clinicians, who share their experience and troubles with access from within the institution. Clinicians (nurses, nurse practitioners, general practitioners and so on) must navigate the same set of regularised practices as patients, but from a different position. Regularised refers here to "the routine and ordinary nature of recurrent or typical social processes" and further that, "this regularisation obscures the social organisation of what people do" (Ng et al., 2016, p. 3). As these chapters will show, most clinicians are working towards the same goals as the patients. I refer to these combined efforts as 'primary care access.' Behind these efforts is a complex set of organisational practices, funding mechanisms, scheduling rules, workforce planning, and so on. Subsequent chapters explore some of these rules, practices and procedures.

In undertaking data analysis, it was helpful to think of the patients and clinicians alike as passengers on a bus trip. Catching a bus requires people to participate in route planning, ticket purchasing, locating bus stops, the formal exchange of a bus pass upon boarding and appropriate conduct while on the bus. In undertaking such socially learnt behaviours, it is implied that people have knowledge of the rules and processes involved in catching a bus. Everything people actually do to catch the bus is of course visible, but what is not visible or visible in varying degrees is the knowledge of how these rules and processes have come about, how they are governed, and the reasons and controlling factors that determine how the processes are set up.

Similarly, patients and clinicians in primary care participate in processes that are visible to them, but often they go about them with little consciousness. There are instructions on how to make an appointment, how to call people from the appointment list, and on what can be achieved in a consultation. These are visible. But the knowledge of how they have arisen and controlled is a mystery. The socially learnt behaviours and knowledge required to participate at each stage of primary care come into view by explicating the social organisation underneath. These data chapters are presented as the process of accessing (catching the bus), attending (being a passenger on the bus), following up (how to get back on the bus), and a consideration of the operational, managerial, and international knowledge which constructs and maintains the stages of the journey. At each stage of the process there are ruling relations that determine how each process is enacted – making visible these ruling relations is the analytical goal of this thesis.

The graphic below (Figure 5) visualises the work processes that shape the first three analysis chapters. As the analysis proceeds, the wheel will populate with the work and processes addressed within the chapter. This is not a map of work processes as recognised by institutional ethnography, rather, a roadmap for the reader to support chapter navigation.

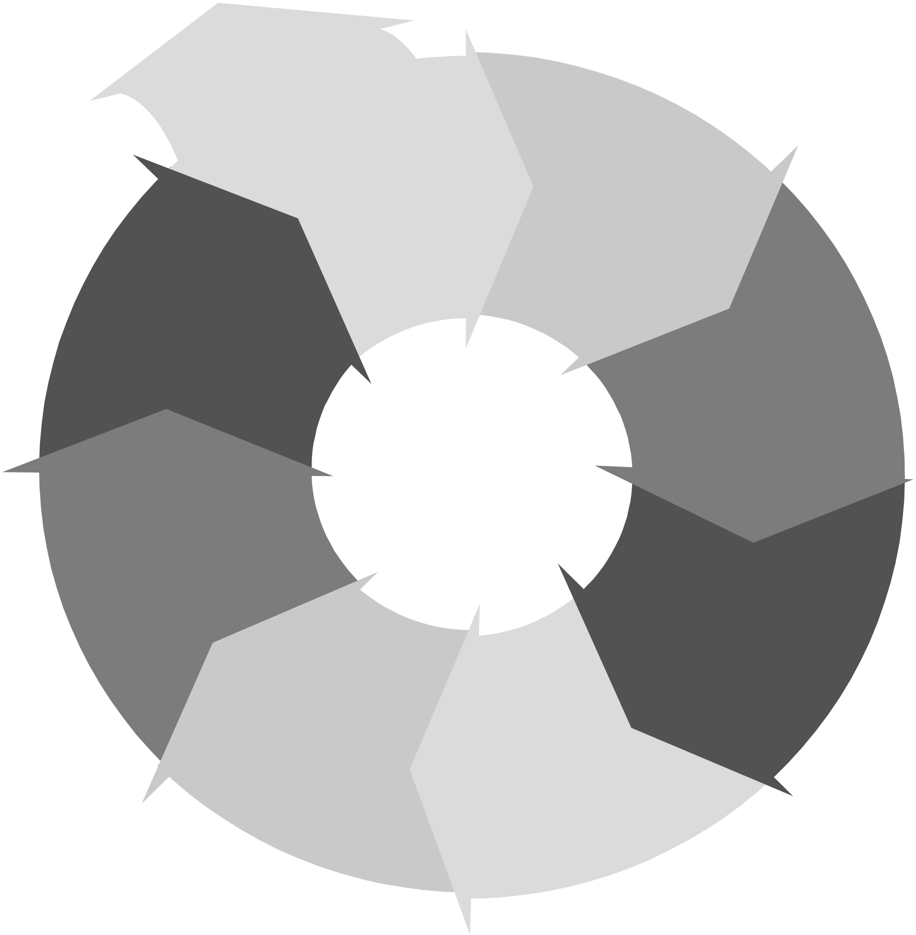

Figure 5. Progress wheel through frontline analysis (A)

In what follows, I offer stories of patients' efforts to access primary care services in New Zealand. The patients whose experiences contributed to this analysis came from many different social positions and conditions. These differing positions offer insight into some of the influence of social conditions on healthwork. Where relevant, I share this information as I introduce each patient. However, the analytical attention remains on the various ways the patients all look after their health within the common rules, practices and procedures of primary care. This chapter lays the foundations for the remaining analysis chapters. The tensions and puzzles arising from patient accounts shared here are the entry point to further explication of the social and shape this project's analytic direction and work.

Catching the bus

This thesis began (Chapter 1) with an extended introduction to Jan and Alex. Jan was "pushing" for access to primary care with her GP, and Alex worked around the rules of primary care to meet their patient's needs. Returning briefly to the tensions of Jan, this discussion then pursues issues of access further through the accounts of new patient informants.

To recap, Jan had a family GP, Doctor M, with whom she was satisfied with her patient-clinician relationship. Doctor M sold his small general practice to join a growing trend in the reorganisation of primary care to partner in a large conglomerate health care centre known as an IFHC. It appears from Jan's account that she has developed a relationship with her GP that fits with the conceptualised notion of person-centred care, as it is known about in the literature. That is, she feels she is listened to, that he knows her, that she is treated with respect, and is happy with the decisions made in her best interests. Further, the relationship between Jan and her GP espouses continuity of care (Jatrana et al., 2011), a concept promoted in the Primary Health Care Strategy as an outcome of patient enrolment.

The problem for Jan is that, despite enrolment, since Doctor M joined the IFHC, she has found it difficult to get to see him when she makes a doctor's appointment. She knows many other clinicians are working within the one centre. However, she enrolled with the centre specifically to stay with Doctor M. Jan's healthwork[22] is now clearly orientated to facilitating and maintaining her relationship with this specific GP. In the following conversation, Jan describes the process she has learnt to ensure she successfully secures an appointment with her GP (as opposed to another clinician at the same practice):

> JAN: I'll ring up, he [Doctor M] could be a bit of a problem, might take a while to get into him, you know. This new system they've all got, this push '1' for this, and they all tell you "sorry we are too busy to take your call now" and I think… you can't all be busy… But I always <u>push</u>, for him. You know, I'll just say, "look, I want to see Doctor M please"…
>
> INTERVIEWER: Can you tell me more about how you "push" for Doctor M?
>
> JAN: I particularly say, "I want to see Doctor M. I won't see anybody else." Unless I'm dying, then I'd have to. I'll say; "I want an appointment to see Doctor M please."
>
> INTERVIEWER: What happens next, after you say you will only see Doctor M?
>
> JAN: Well you could wait, they'll say; "no, he's got no appointments this week, could you wait a week?" I say, "Geez, just as well I'm not dying." Yeah, but then last week when I rang, "oh" she said, "no appointments," oh then she said, "We've got one on Tuesday." I said, "Yeah, I'll have that one." Yeah. Because he is very good.

The work of challenging the booking system is relatively new for Jan. Despite not having access to knowledge of how the appointment booking system works at the IFHC, Jan has learned through experience that when talking with the receptionist, "pushing" for her GP is effective in securing

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[22] Healthwork collectively describes work practices done (without defining what that work might be) by people with respect to their health within contemporary health care practice (Mykhalovskiy & McCoy, 2002)

an appointment with him. She is rewarded for her work with the outcome she is wanting. Jan demonstrates the courage to advocate for herself to secure the patient-practitioner relationship she wants. Securing this relationship requires overcoming institutional processes that are made somewhere else, by someone else (Smith, 1987). In orientating her healthwork towards these work processes, Jan's efforts reveal her work to access everyday care and negotiate that the care she receives resembles what she was accustomed to at the previous practice.

Since I spoke with Jan, the IFHC has introduced a new method of allocating appointments known as 'GP triage.' Tim's account below explores the new work processes for patients and clinicians occurring under GP triage.

Introducing Tim

Tim is a health professional in his thirties. He recently moved to the area, which necessitated that he and his family enrol with a new primary care provider. Familiar with the system of general practice enrolment, Tim visited the centre closest to his home and completed the process of enrolling his family. The centre was 'closed' to new enrolees within the region, but 'open' to people moving into the area. This is a common rule within the DHB, with many practices identifying their books as closed. Upon enrolling, Tim received a welcome pack, including an introduction to the team at the IFHC, an explanation of health services offered by the practice, and a guide for patients on how to use the services at the IFHC. Tim knew he required the services at the IFHC for ongoing prescriptions of his long term medications and the ad hoc health needs of him and his family.

One day, Tim was walking through the IFHC on unrelated business. He decided, opportunistically to make an appointment with the GP to arrange an alternative for a medication he was taking that he knew would no longer be available in New Zealand. Tim knew this task – prescribing an alternative medication – had to be done by his doctor and required a face-to-face assessment. Tim reported to the reception desk and asked for a routine appointment with his GP. The receptionist told him that she could not book an appointment to see a GP, despite Tim's knowledge of the need for that type of appointment and his willingness to take any available time, regardless of the wait. Instead, he had to wait for a phone call from a GP who would "triage" his request the following morning.

Tim understood the GP triage to be a process for the GP to determine *if* or *when*, you needed to be seen by a doctor. When I asked Tim if he knew why the practice was now booking appointments in this way, he said, "All I got was, 'this is just the new way of doing things.' That's all I was told." I asked Tim what the outcome was of the GP triage phone call, laughing, Tim told me, "He asked me what I wanted an appointment for, I told him, and he booked me one the following week."

Tim has an excellent understanding of how health systems work. He is able to draw on his insider professional knowledge to use the health system effectively. Yet, during the process of asking the receptionist for an appointment, Tim's knowledge was not sufficient to grant access to an appointment booking. There is a work process here, and Tim cannot control it. Under this new system, Tim had to do more work – ensure he was free when the GP called, repeat his request for an appointment, and justify the reason for his request – to secure a resource he previously had access to in only one step. The introduction of GP triage is achieving *something*, but from the patient's standpoint, it adds another layer of complexity and organisation to booking an appointment.

I was curious about alternative mechanisms for patients to activate the appointment booking procedure. Tim showed me through the different layers of the IFHC app and explained the different functions. He could check his results from any laboratory testing, and he could see the 'objective findings'[23] from previous primary care appointments. The app also had features where patients can request repeat prescriptions or book appointments. I asked Tim why he did not use the app to book his appointment. To answer my question, he showed me, in real-time, the outcome

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[23] Height, weight, blood pressure, heart rate and temperature

of using the app to book an appointment. Under the “make an appointment” tab, using a drop-down menu, Tim selected an appointment with “my provider” (indicating his regular GP whom he is enrolled with). Once Tim had selected his provider, he then chose the option of the “next available appointment.” This action produced a response from the app indicating the next available appointment with his regular GP was in eight weeks’ time.

Tim understands (just as Jan does) that this does not truly reflect the availability of appointments. Tim knew that booking an appointment with a staff member, not a software application, would enable the rules of appointment booking to be worked around. Further, Tim knew that more acute issues were seen faster. Tim needed to resolve the issue of changing medication sooner than in eight weeks. Therefore, Tim knew that he needed a person with deeper access to the booking systems to overrule the booking software effectively. The app does not communicate this information. As a textualised, standardised fill in for an administrative staff member, the app has no ability to assist patients with appointment navigation beyond its binary communication to booking systems. In the patient’s experience, it appears that the app is an inadequate substitution for person-to-person communication.

The tricky work of negotiating appointment booking systems and the issues described by Jan and Tim will be familiar to many health users and health care centres alike. Patients in this study perceived these to be issues of centre capacity (“they have more patients up there than they know what to do with”), with a shrinking workforce (patients were acutely aware of the looming mass retirement of GPs in New Zealand), and saw it as a consequence of the larger “impersonal” IFHC design. The concerns here for patients extend beyond the way access is known about as an official concern for policymakers (see, for example, Ministry of Health, 2018c), who prioritise the removal of cost barriers, geographical isolation and transport, and ‘other’ isolation such as cultural and social. Jan is looking for access to *her* GP; to the extended and trusting patient-provider relationship she has established. Tim is looking for access to a routine appointment, but the new GP triage process placed a work barrier between him and the appointment booking. Further, the alternative booking process, the app, was not equipped to manipulate the rigid booking systems in Tim's interest.

There is another factor to recognise here; the way the IFHC knows about access. The procedures implemented by the IFHC to improve access (app bookings and GP triage) reveal traces of how the centre knows about, and is actively changing, procedures to access primary care. Changes to the way patients access primary care are visible in Tim's account. Tim's account also points to a curious withholding of information about *why* these changes are happening. Additionally, patients appear to be left out of education regarding the navigation of the new processes. The gap between the IFHC's attempts to reform access and patients' understanding of how access to primary care works adds further tension to patients' negotiation of access to care. In changing the way the practices think about access, the accounting logic of booking systems is enacted. The practice achieves maximum capacity of consultations and GP triage capacity. These processes have replaced the familiarity of the solo practice GP who often maintained a degree of oversight of bookings, and could disrupt the scheduling system at their discretion, as seen in Flad's (2009) dissertation.

Patients' frustration with not being able to see their GP and having to seemingly work harder to negotiate access to primary care, occurs in ways that are not recognised by policymakers and are contradicted by the reform of access processes by the IFHC. Their concerns for access are recurring, time-consuming, and institutionally invisible. These frustrations form a disjuncture, which I take up in the development of the projects' problematic and explicate further in the following analysis chapters.

So the right people get seen

In order to find out what others at different locations knew about the new processes such as GP triage, I spoke with a primary care nurse at an IFHC. Kate is involved in clinical governance at an

IFHC, which includes quality improvement and addressing strategic clinical goals at the centre. From the knowledge she holds in this position, Kate described the events that led to the introduction of GP triage. From her role in clinical governance, Kate was aware that the IFHC attempted to modify the management of patients' access to their GP via the introduction of the GP triaging process. This change was apparently rationalised by results of the Primary Care Patient Experience Survey (Health Quality & Safety Commission, 2016b). Kate noted the IFHC's survey results reported low scores for the domain of coordination.

Coordination, according to the survey resources, relates to coordination, integration and transition of care (Health Quality & Safety Commission New Zealand, 2016a, 2018). Coordination as a concept is measured by an accumulation of 14 questions within the survey such as "is there one GP or nurse you usually see?" and "Are you confident that your GP or nurse is aware of your medical history?" (more about the survey and its results in Chapter 7). Kate described patient "complaints" emerging from the survey results including "not being able to see their own doctor" in line with this domain. The account from Kate, coupled with interrogation of the purported logic of GP triage enables a deeper look into the authorised and ideological accomplishment of quality improvement.

> KATE: The themes that have come back is that a lot of the complaints are actually happening up at the hospital… but we certainly follow up all our complaints. And the themes would be: not being able to see their own doctor. That would be one of the top ones, or just dissatisfied with something that has happened, or a waiting list.
>
> INTERVIEWER: What actions or responses have been taken following the feedback that patients are unhappy about not being able to see their own doctor?
>
> KATE: What we try to do, and what you have to recognise is that we are in a position, and this is going to get worse, where we have got ageing doctors – and the next 10 years are going to be awful – and so it's about them using phone triage, so they can talk to their

doctor, it's about them booking earlier, booking ahead, and also recognising that we work as a team. I don't think, in general, I think people want it 'like the old way.' There hasn't been a lot of publicity that the reality is going to be quite different, and the use of NPs, nurse prescribers… so I think there is going to have to be a lot of work done there. There needs to be re-educating, and also a changing of expectations. We know that they want, you know, when they had the little two GP practice, you could ring up, and they could fit you in and Bob's your Uncle. The reality is, those two GP's are now 70, they want to retire, and nobody wants to take on those extras… I think there needs to be some real education around that.

INTERVIEWER: Can you talk to any specific actions either you or the practice have done in response to the feedback that patients are unhappy about not seeing *their* GP?

KATE: Well, there is phone triage, and that gets done by a senior GP.

INTERVIEWER: Can you explain to me how that works?

KATE: So they [patients] phone in and say they need to be seen, so they are put on the phone triage list for a doctor to phone them back, and hopefully, it's their doctor, and they will phone them back and say, "well, what is the problem?", assess them over the phone, and say, "well, yes, you need to be seen today," and they have appointments they can be booked in to, or they can say, "well, actually, no, I want you to go and have this test, etcetera, and I'll book you in for next week to come and be reviewed." Or, they will do a consult over the phone, and say, "I will give you this prescription," or whatever it is they think is best.

And the evidence is, that in the past, the people that rang up at half-past eight and were the first in, got the appointments. So they didn't actually necessarily need those appointments on the day, so we've got smaller available appointments because we haven't

> got enough GPs, it is about re-balancing that, so the right people get seen in a timely fashion.
>
> INTERVIEWER: Do patients seem happy with this alternative arrangement?
>
> KATE: Yup, they like talking to their doctor (laughs). There is a fee attached to it, depending on if they have a full consult, just a prescription or whatever. But it's actually cheaper. And they can do it from work. So it's quite patient-centred.

Triage is taken up here as an analytical point of interest because it is the process of triage that has been introduced as a procedural fix to the problem of low coordination scores as problematised by the survey. The nurse locates triage as an activity of quality improvement, designed to overcome officially reported patient dissatisfaction with "not being able to see their own doctor." Quality improvement in this example is located in the nurses' knowledge of patient-centred care. Kate's account also hints at triage doing something else - reorganising, and *reprioritising* patients' access to care. As Kate said, "so the right people get seen in a timely fashion." Furthermore, the account gives a clue that the nurses' interest (and perhaps the institutional interest) was not the patients' dissatisfaction. Rather, resources were used inappropriately or not by the "right people." There is a question here, specifically, whose interests does this reformed process serve?

Triage, as the process is described above, is a method of assessment for the distribution of health care resources (the GP's time) and enacted here as patients' needs exceed available resources. The evidence base for implementing GP triage emerges from managing demand, workload, cost, and patient satisfaction (Murdoch et al., 2015). Appointment booking is recognised as a site of inefficiency and ineffectiveness, for which GP triage can reorganise and resolve, which apparently helps patients secure appointments. From this logic, GP triage appears to serve both managerial and patient interests.

Triage is of managerial interest. First, triage provides a method of allocating the businesses most expensive resource (GPs) to the core earning activity of consultation. Phone triage enables diversification of the GPs consultation potential, where a full consultation over the phone is charged to the patient at the same rate as a face-to-face consultation and takes less time. Second, implementing the phone triage system is seen as an act of quality improvement, improving patients' access to their GP. As evidence, a general manager of a New Zealand family health care centre shared the managerial and financial perceived success of implementing GP triage; "We've gone down from about 10 FTE[24] GPs to about eight, but we've increased our capacity by a third, which means we're seeing a third more patients on a daily basis with fewer GPs," (Counties Manukau Health, n.d.-a, p. 1). There was no mention of whether the patients were more or less satisfied with the change in process.

Phone triage (and consultation) further offer a way of enhancing the GPs earning potential beyond financial viability. It is a good business decision. The nurses' account reveals how the business logic is carried into professional practice under the premise of cost efficiencies and the ideology of patient-centred care. I suggest this is a false discourse of patient or person-centredness. Instead, the action is occurring to serve the interests of the business.

The Health Navigator New Zealand website[25] encourages the implementation of GP triage and reinforces the financial benefits of the model. The website boasts that "Because GP triage is quicker and more efficient than face-to-face appointments and frees up appointment time for patients who need it, you may find that your practice can see the same number of patients with reduced FTE (full-time equivalent) GPs" (Counties Manukau Health, n.d.-b, p. 2). In other words, GP triage can save the business time and money.

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[24] Full time equivalent

[25] The Health Navigator website is a New Zealand focused health resource for consumers and health professionals. The website is officially endorsed by the Royal New Zealand College of General Practitioners for the appropriateness and usefulness of content, and value to patients and GP's.

Marketing methods employed to sell the implementation of GP triage are directed at general practice managers and have a strong focus on efficiency. These methods draw on the ruling discourse of health services research (Mykhalovskiy, 2001), which apply "numerically based form[s] of knowledge that contributes and responds to the treatment of health care as a managerial problem in need of 'fixing'." (p. 148). An example of this discourse is the following quote from a conference presentation; "If I told you that 50% of the requests you get for same day appointments could be resolved on the phone, would you believe me?" (Health Care Home Collaborative, n.d., p. 2). So practice managers and GPs work from the knowledge that GP triage is quicker and more efficient than an appointment, thus resolving time constraint issues. Patients are aware of these same issues, but experience constrained access differently. Yet, despite some of these purported benefits being passed on to patients such as freeing up appointment time for patients who need it, Tim noted that patients did not receive education on the purpose of GP triage, but were expected to participate in the process regardless, introducing new work for the patients.

Triage text and process at work

In the convention of institutional ethnography, I followed the work processes introduced under the auspices of GP triage. I traced the exchange between patient and general practice reception staff, finding that the first steps of triage (before the patient speaks to the GP) draws both parties into a new work process. Kate, from the extract above is opening a window on work processes that are mysterious to patients. Her knowledge of what is happening behind the scenes, and why, is useful to explicate how patients are organised to work at accessing their primary provider in new ways. From Tim's account, this happens without any explanation or understanding of why it must now be done this way. Patients are organised to accept an additional barrier to their access (phone triage) because of the scarcity of people and time, about which we can assume patients know little.

The following is a triage script, found in a change package for the implementation of GP triage, and listed as a resource on the Health Navigator New Zealand website. Reading this script, maintaining patient standpoint, a new layer of patient-work processes becomes visible.

Patient: *I would like an appointment.*

Receptionist: *When do you want the appointment for?*

Patient: *Today, please.*

Receptionist: *Is it due to you being unwell or for some other reason?*

Patient: *Unwell.*

Receptionist: *Do you feel that you need to be seen today?*

Patient: *Yes.*

Receptionist: *We currently have a high demand on our appointments. I can get our phone doctor to call you back to see how he/she can help you today. Advise that he/she will call back in around [X] minutes (alter as the template indicates).*

Actions for the receptionist to complete:

- *Put on doctor triage template*
- *Follow PMS process for notifying patient contact/arrival*
- *Write the number that the patient needs to be called back on in the note line*
- *If the patient indicates that they can be seen another day then book as appropriate.*
- *If the patient indicates that it could be something else, e.g. RX [prescription], lab results/form, referral or just advice, then put on the nurse template.*
- *Please put any calls added to the nurse template in the urgent 8-9am slot so they can be audited easily.*

The concept of unwell is noteworthy in this brief scripted exchange. The receptionist's questions coordinate the exchange of information from patient to receptionist to a controlled pathway. An apparently objective screening undertaken by the receptionist reveals the privilege of unwell in accessing primary care services. “Today” activates the first work process, and “unwell” activates the second. The combination of the two responses achieves access to the work process of same day GP triage. An alternative combination may activate the process of an appointment booking on an alternative day, although Tim found this not to be the case at the IFHC he attended. While the patient is central to activating the pathway, it does not appear that the patient’s needs are at the centre of the process and its implementation. Instead, patients using this tool are hooked into institutional interests (clinician capacity, restricted appointment allocation, use of resources) that are connected to wider principles of business and NPM, which emerges as a ruling relation in the coordination of work at the frontline of primary care.

Arguably, the evolution of GP triage is influenced by the manufacturing sector priorities inspired by NPM, particularly managing people (employees) as resources and, conversely, patients as a commodity. In applying these principles to quality improvement, improving the flow of commodities (patients) through a facility (general practice) through GP triage is a logical tool to address the defect (too many patients, not enough appointments) in the organisational system. However, unlike an assembly line that deals with identical items and standardised processing, individuals are invariably unique.

The criteria used in establishing eligibility of GP triage is based on the actuality of limited GP resources, and the economic principle of rationing. There are a finite number of seats on the bus. It is this limited resource that contributed to the initial concern from patients of not being able to see their GP. The concerns of this IFHC appear to be “quicker and more efficient” management of patients to protect their scarce resource which hints that NPM practices including efficiency and competition for resources are at work. However, from the patient's location, with their individual and uniquely personal reasons and needs to see a clinician, participating in this process may or may not meet their needs or validate their concerns. Tim sees this as an unnecessary step in the seemingly simple patient task of booking an appointment. On the contrary, Kate understands, from her perspective, this process to be person/patient-centred.

Kate is captured by her institutional knowledge of clinical governance and the problem of the ageing GP workforce. Kate knows that the newly substituted "care lite" (Cupit, 2018, p. 168) processes now in place do not meet the needs of patients, but her capture prevents her from asking *what is important for patients?* She appears focused instead on believing that what is needed is correcting the knowledge and practices of patients so that they can adapt to the reduction of resources and "so the right people get seen." This conflict between limited resources, an excess of patient need, and the logic of NPM applied to the issues is another point of disjuncture to follow into the social of primary care. Who decides who gets a seat on the bus?

In explicating this thread, I found an alternative narrative. Nurse leader informants located at PHO level described the transformative potential of this triage activity, which they preferred to call "prescriber triage." Prescriber triage here recognises that the phone triage process can be undertaken by a clinician with the ability to conduct a comprehensive assessment, request appropriate further investigations, and prescribe appropriate therapies. Therefore, in their vision, this can be completed by a designated nurse prescriber, a nurse practitioner, or a general practitioner. This interpretation of prescriber triage draws on the ideas of the PHCS, which called for the advancement of nursing to respond to future population health needs (King, 2001). In discussing the role of prescriber triage further, the PHO leaders describe how the process should meet the unique needs of the patient beyond a binary division of consultation versus no consultation. Here, more ideas of the PHCS, particularly person-centred care, underscore the PHO nurse leaders' knowledge. In contrast to this knowledge, triage as it has been taken up in practice does not always reflect these ideas.

The PHO nurse leaders recognise the capture and control of medicine in many current triage practices. As seen above with the IFHC GP triage process and the education targeted at practice owners and leaders, doctors are placed at the centre of the process where they operate as a gatekeeper to appointment bookings. Further, triage as it is promoted and enacted privileges NPM ideologies of efficiency and cost reduction. Despite this, the PHO leaders see the potential for patients to learn to use this process for individual benefit and convenience - to have processes customarily reserved for the face-to-face consultation completed from the convenience and comfort of their home or workplace. The capture and control of medicine and NPM in this purported quality improvement initiative is taken up in Chapter seven.

Introducing Helen

Returning to the local position of this research, I explore some of the issues of accessing care from a different but similarly restricted position held by Helen, one of my generous patient informants. Helen is semi-retired, and has enjoyed a busy but fulfiling life with her husband, Ian. They live at home, and in recent years Helen has become the primary caregiver for Ian, who now suffers from Alzheimer's disease.[26] Helen described to me the exhaustive work of navigating health care services between their GP, specialist physicians and Alzheimer's support services while concurrently providing the everyday/everynight care for Ian. Helen described how relentless this work was and often felt she was forced to take charge in an unfamiliar environment. Helen's healthwork is orientated differently to Jan. Like Jan, Helen has had to learn to manoeuvre effectively through primary care appointment making. However, Helen does not appear to be constrained by financial barriers, and does not describe any hesitation in seeking out primary care appointments for her husband, for whom she is the primary carer. Helen's problems arise from a lack of clarity in where to get help, and how to access the different services.

To return to the bus analogy, Helen is not sure which bus to catch. She describes the ongoing efforts required to co-ordinate Alzheimer's care for her husband, specifically, the back and forth between GP services and specialist providers. Helen's ongoing healthwork is orientated towards

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[26] A chronic, progressive disease that damages memory and other important mental functions.

initiating and maintaining continuity of care between different locations. Helen's needs do not fit within the textual representation of access as seen through GP triage, nor access as it is known about and problematised by national level policymakers. Helen requires access to the right person who can help her navigate the care her husband requires. This can be difficult for her, as making an appointment at the general practice requires Helen to articulate her needs, without being truly certain of what these needs are: "I just know that I need help."

Helen requires the GP to activate the necessary pathways available for Alzheimer's care, but these pathways are not visible to her. These pathways are not published on the bus timetable, and she cannot access them on her own. She describes the frustration of not knowing where to go next and how she overcomes this gap through more work (research) to learn about the services and to understand how she and Ian could access them as required.

> HELEN: There's been no follow up! Nobody ever follows up… you're just left to your own devices… There was no information forthcoming from the doctor about where you go and what you do, so we just, I just had to sort of find it all out for myself.

Helen could not do this healthwork (advocating for her husband, bridging the gaps between care locations, learning how to care for her husband) without significant financial resources and leveraging of her professional skills and knowledge of communication. On one occasion, after unsuccessful navigation of appointment booking systems – Helen could not see the person she knew she needed to see - she instead worked to bypass the booking systems and turned up at the clinic. Helen said, "And then yesterday I just fronted up, I just went in, and said look, I just need five minutes, I need to know what's happening." Through Helen's actions, she was able to talk with the person who was central to the navigation of Ian's care and identify where to go next.

Through her work to bridge these gaps, Helen's account hooks into the fragmented services spread across primary health care in New Zealand. Fragmentation is a recognised concern for primary health care, with policy goals to provide integrated care (Cumming, 2011) and a focus on wellness

(Minister of Health, 2016a). The theoretical premise of integrated care promises "new models of care which see the patient rather than the institution at the centre of service delivery and which aim to promote a more seamless patient journey across community, primary, and hospital sectors, greater use of primary and community care, and the shifting of care 'closer to home'" (Ministerial Review Committee, 2009, p. 4). The promise of integrated care is part of the foundational logic of an IFHC. Interestingly, through her research and perseverance, Helen does the work of bridging the gaps of access and gaps between services, not an IFHC. This work is invisible to those who measure the success of such services. Further, the frustrating work for Helen is a disjuncture that contributes to the emerging problematic of this study. Institutional processes designed to facilitate patient access do not accommodate navigational needs, despite the institutional understanding and apparent prioritisation of integrated care within these processes.

Preparing for an appointment

Until now, this chapter has looked at the work of patients to gain access to a primary care appointment with an IFHC. The IFHC booking system appears ruled by the limited resource of GP/NP hours which structures, through the rigid text of the booking system, how appointment availability is delivered. Appointment booking is further controlled by the constructed outcome of the GP triage process. These work processes define how the everyday practice of making an appointment is carried out by and for patients. Once successful in this work of making an appointment, the patient then undertakes further work to *prepare* for the appointment.

Preparing for an appointment requires knowledge of how the appointment works, including who does what, the expectations of the patient, the expectations of the clinician, and the potential appointment outcomes. Experience in past appointments is often the foundation of this knowledge, and varying experiences can influence expectations. Alongside this knowledge, health care centres attempt to inform patients in advance about how the appointment works. Under headings such as "getting value from your visit," clinics produce information sheets for patients.

Such information is found in multiple locations, such as websites, waiting rooms, and welcome packs, and enters into the patient's knowledge of how things work. Patients describe using this information to prepare for their appointment.

One such information sheet from a local primary care centre shares online 'tips' for patients to help them with their appointments, such as:

1. Make the right appointment.
2. If you have more than one health concern, make a list and show it to your GP or Nurse when you come. Together you can agree on which items are the most important and need the most attention. More minor things can be dealt with if there is time.
3. If you have a long list, ask for a longer appointment. Trying to get too many things dealt with can mean rushing and important things can be missed.

The primary care centre is encouraging the patient to engage in work before making an appointment. The work requested by the centre attempts to organise the patient to set priorities and to align their expectations with what the centre provides – the centre is inserting the institutional knowledge into these texts with the aim of organising patient work. The centre's institutional knowledge is informed by business practices and dominant biomedical ideology which emphasises the biological nature of health and health care. To illustrate this underpinning knowledge transferred into the expectations of the patient, the text above introduces the business concern for the right appointment, and the right length of time for the appointment, revealing the importance of time as a commodity to the business. Additionally, health concerns, which are further itemised as "most important" through to "minor," is presented as the purpose of accessing these primary care services, which sustains the acute medical focus of the appointment. Thus, in following these instructions, the patient's expectations become aligned with the centre's priorities.

While this text may appear to be inert, through reading and responding to the instructions of the text, patients are influenced in their course of actions when making an appointment. In encouraging patients to consciously prioritise their health concerns, the text can be seen as activating patients' responsibilities, thus shaping a new form of work. Patients become responsible for adhering to the appointment's constraints, assessing and itemising their health concerns, and reducing the number of issues they expect to be addressed. This new work reflects self-management discourse, like the neoliberal elements of Better, sooner, more convenient (see Table 1) and other health initiatives such as Care Plus (Ministry of Health, 2019b). The new work is informed by clinical and administrative rationale, from which the patient's actions support the objectives of orderly consultation and timeliness. Despite thorough searching, I could not find evidence to support the use or value of lists made by patients, except for anecdotal evidence from clinicians who felt the list was useful to prioritise and control the consultation and keep within the 15-minute timeframe. The 15-minute timeframe is shown in the following chapter as both a discrete and interconnected relation within the primary care consultation.

In addition to the text from the primary care centre, several other texts came to light as contributors to the coordination of patients' work as they prepare for appointments. Shared below (Figure 6) is one example found on a New Zealand based Facebook page under the administration of The Royal New Zealand College of General Practitioners. The image is one of a series of infographics offering tips to patients to plan and prepare for "GP appointments." This tip encourages patients to message the GP in advance via a Patient Portal (a communication system used by some primary care providers), to let the GP know what the patient's appointment is about.

GP APPOINTMENTS TIP #6

If your GP offers a Patient Portal it can be a good idea to send them a quick message before your appointment, letting them know what you are coming in for.

#youandyourGP

Figure 6. GP appointments tip #6 image from facebook account 'you and your GP,' retrieved 08/10/2018

This image shares several messages with the reader. Firstly, it reinforces the message of primary care as a health care relationship between patients and GPs. All other members of the primary care team are invisible in this image. Most notably, NPs, who also provide primary care services to enrolled patients. The image itself, and the graphics chosen, further reinforce the biomedical foundations of primary care, with all graphics representing physical assessment and pharmacological treatment. As in the earlier example, I suggest these are traces of the institutional knowledge of the authors. In this case, The Royal New Zealand College of General Practitioners – the professional body and postgraduate institute for New Zealand GPs (RNZCGP, 2021) - hold the institutional interest of GPs, which is carried through their infographics above to people using primary care services. As in the previous example, this image also places the work and accountability of communication on the patient as their responsibility, thus growing the account of what these texts are achieving (or intended to achieve). I invited the RNZCGP Facebook page administrator to talk with me about the education campaign to further explore the institutional interest behind the images. However, after initial interest, the administrator later declined to participate, stating I was welcome to use the images but that they did not feel they had any more information to offer this project.

Irrespective of supporting informant interviews or further information, texts such as the ones above provide valuable insight into the landscape of the social world this research is positioned within. Combining data like these examples with the accounts from frontline participants adds to the construction of analytical accounts of how things are organised for the frontline (Rankin, 2017a). That is, what can be said and done by the people at the frontline of primary care.

Another point of entry into the social of texts preparing patients for appointments (as I have grouped them here) came from a patient informant, Mary, who picked up a booklet in the primary care centre waiting room while waiting for her appointment to see the GP. Mary had a stroke several years earlier. She described how she felt like a burden to her family and primary care team, as she had ongoing physical disabilities and health care needs resulting from her stroke, including trouble remembering things. Mary did what she understood as being a good patient, which included following instructions diligently. On this occasion, that included picking up a patient booklet directing Mary to "know what to ask" (ACC, 2016, p.1) in the consultation. Mary hoped this would help with her memory troubles, saying, "I don't want to be like I am and feeling a bit helpless at times." She showed the booklet to me during our interview at her home.

The booklet, called *Know What to Ask,* is an A5 booklet designed for all users of health care, encouraging the patient, referred to as the "consumer," to "get all the information you need, so you can understand your treatment and know about your tests or medicine" (ACC, 2016). The booklet offers a series of suggested questions to ask the clinician, broken down into four categories: treatment, test, medicine and surgery questions. The booklet also has ruled blank pages encouraging the patient to "write questions, answers and other notes in." There are a further 15 points the patient is encouraged to remember, which relate to speaking up, following up, making sure risks such as allergies are accounted for ("Make sure your doctor knows about any allergies…"), and errors are avoided. Interested in the knowledge and intentions behind this text, I emailed a request for further information to the email address recorded on the back of the booklet.

Know what to ask is a resource created by a national organisation – ACC[27] – originally for patient safety week which is an annual sector-wide week promoting a topical patient safety issue. The focus of patient safety week was preventing serious harm by reducing treatment injury (previously known as medical misadventure) across primary and secondary care. Speaking with the author of the booklet, a member of the Treatment and Safety team within ACC, she shared that the booklet's primary goal is to reduce miscommunication related patient harm. The author worked from an ACC database of treatment injury reviews and identified communication as a major issue in the occurrence of treatment injuries. The author understood the booklet to assist by "help[ing] patients be proactively involved in their own care" (ACC informant). According to the ACC informant, the booklet was well-received by general practice, who encouraged the "upskilling of patients" (ACC informant).

As in the other examples of text-mediated patient preparation work shared above, this text introduces new responsibilities for the patient, which now includes preventing harm. *Know what to ask* shares active characteristics with the other examples, whereby patients are encouraged to undertake actions that strategically support the IFHC and ACC goals. In the case of Mary, she is drawn into the work of careful appointment planning through the use of the know what to ask booklet. I make no analytical claim of the benefit/value/harm/or otherwise of these text-mediated practices. Rather, I aim to highlight the growing prevalence of shifting work which is enforcing

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[27] ACC is a New Zealand Crown entity responsible for administering the country's universal no-fault accidental injury scheme, governed by The Accident Compensation Act 2001 (Accident Compensation Corporation, 2018)

the routinised, standardised delivery of primary care, from the practice and clinician to the patient under the guise of improving care.

Waiting

Returning to people's everyday work at the frontline of primary care, this analysis now considers people's actions once they arrive at their general practice/IFHC for an appointment. After successfully navigating appointment booking systems and preparing accordingly for their appointment (with or without textual instruction from various institutional locations), many participants described the familiar, and increasingly troubling, process of waiting. Like people waiting at the bus stop (at the right stop, at the right time, with the right ticket and the right luggage), patients undertake waiting work prior to their appointment, as well as new and shifting waiting work at the time of their scheduled appointment. This next section briefly considers the changing nature of waiting work. Waiting work is of analytical interest as, just like appointment booking, the primary care patient experience survey measures patients' experience as they enter into and interact with primary care processes and procedures prior to the appointment. Thus, theoretically this work is institutionally visible and institutionally important as a purported measure of person-centred care. This section considers the actual experience of people undertaking this work, and later, an explication of the contextual way this work is recognised is included in Chapter seven.

Returning to the frontline, patient informants Tim and Jan shared with me their experiences with reception services and pre appointment patient registration processes, both noting these as a point of *new* tension. The new work, brought about for patients under new models of care such as IFHCs, is central to this analysis. These new day-to-day activities are another point of entry into the shifting and standardised/routinised design of primary care practices and processes, contributing to this project's emerging problematic.

The first account comes from Tim, who introduces the physical work of queuing and waiting for a primary care appointment. Tim's account draws attention to the ways the IFHC he attends communicates their message to patients of expected waiting practices.

> TIM: I go up to reception, and I am directed to whichever line I am meant to go down.
>
> INTERVIEWER: How do you know what line you are meant to go down?
>
> TIM: So one line is for booked appointments, and the other line says something like 'other.' So I usually go down the booked appointments only line, and then the person will call you forward, and it could be any of the four or five people [reception staff] so there is no obvious linear relationship with the line. So then you state your appointment booking, and the name of the doctor. Then they will say "okay, head over to 'daffodil' waiting area." They all have names, and you say, "Well, where's that?" and they say "follow the yellow line." There are several different areas. And then you sit and wait to be called by whoever you are there to see.
>
> So then the doctor comes and gets you from the waiting room, and you follow them to their room. It's quite a rabbit warren. After the appointment, you have to find your way out, which can be quite tricky. I've often gotten lost in the back end of the building. It's quite a disorientating area. Then you go back to reception. It's probably the other line now (laughs). You get called up and you pay for your appointment.

Jan described her change in experience after she moved her enrolment to the IFHC. Jan's account provides further entry points into the social terrain of standardised practices introduced by the IFHC.

> JAN: [Y]ou haven't got the same relationship. In the little practice, you walk up to the reception; "Hey Jan!" see? There [large IFHC], you line up and wait and there might be three girls and you don't know any of them, you know, whereas in the smaller practice you

> knew them all, they say “Hi” to you. Yes, it’s less personal being bigger, and you notice too when you go there, it’s a big room, the waiting room… you would call it impersonal, a lot more impersonal. At [the IFHC] you go around the corner and sit, whereas before you could even talk to the other reception girls if you want… But these ones, no, they just give you the bit of paper and around the corner, you go and sit.

Tim and Jan’s accounts show the contradictions between a centre’s espoused person-centredness, and the actualities of the everyday experience. IFHCs claim to be person-centred, yet the processes of waiting are not designed to meet the patient’s needs for privacy, personalisation or comfort. All of which would be considered if the process was designed to centre on the person. IFHCs communicate their expectations with patients through signs and environmental aspects such as the coloured carpet tiles or lines on the walls. These are communication practices shared with large commercial enterprises such as airports and movie theatres, where the goal is to efficiently process a large volume of people through standardised processing methods. As noted above, the analytical interest here is heightened by the relationship between patients’ experiences of these processes and the measurement of person-centredness through the primary care patient experience survey, as discussed in Chapter seven.

Having established the problems for people at the frontline of primary care accessing services, this chapter now considers the work organisation of access as it extends into the social of the institution of primary care.

Looking up into the institution

To make sense of this chapter through the lens of institutional ethnography, moving from the local (frontline) to the translocal (differently located people and texts), which organises what can be said and done in the encounters described by Jan, Tim, Kate, and the other informants is essential. As a reminder for the reader, institutional ethnography is founded on the premise that the social world is purposefully organised to happen as it does. Further, institutional ethnography maintains that knowledge is spread, controlled, and changed by disseminating and activating texts (Smith, 2001). The frontline actions and responses described in the accounts above, such as appointment booking, GP triage, navigating services and attending the practice, can be traced to institutional texts, to which this project attempts to draw empirical connections to explain how the frontline experience is organised. Looking up into the institution of primary care, just as the small hero does (see page 24), the everyday activities of people accessing primary care services are connected to a vast array of texts, places, people and organisations. Significant to this project is the connection from patient and clinician to the appointment booking system. That is, the frontline experiences, as shared in this chapter, are traceable up to the appointment booking system, which is a text located away from the frontline.

The appointment booking system is recognisable as a text, which, when activated, controls access to the resource of clinicians. However, while the appointment booking system is a tool of the institution it does not hold ruling power. Instead, the appointment booking system connects the accessing work of people at the frontline of primary care to the ruling relations of access by carrying the coordinating knowledge from institution to frontline. This is the knowledge, coordination and ruling relations I wish to uncover. In following the threads of appointment booking systems further up into the social world, the system connects to two prominent institutional frameworks.

The first, as described within the accounts above, is the knowledge of business coupled with the ideology of NPM. Appointment booking is informed by ruling practices of the institution that privilege efficiency and cost reduction. These aspects of NPM are visible in the account from Kate the RN, who knows of GP triage as a tool for allocation of patients to the GP/NP resource. Kate's description reveals the framework of NPM as the dominant knowledge when she relays the benefits of GP triage, "so the right people get seen at the right time." Kate's understanding of access to appointments shows how the ideology of NPM is privileged over the ideology of improved access and continuity of care as per the PHCS (more on this in Chapter 7). I show in the upcoming chapters how NPM ideology further organises what can be said and done within the consultation.

The second significant ruling apparatus becomes visible by following the appointment booking system into the practice's database where patient information is held. Information used to populate appointment booking systems comes from prerecorded details of patients enrolled at the practice, such as name, date of birth, and phone number. Enrolment with a nominated provider coordinates patients to access primary care services with their nominated provider. By using a nominated provider, such as an IFHC, patients are hooked into the processes and procedures of the provider, alongside all other enrolled patients. Primary Health Organisation enrolment is first introduced in Chapter two. Seen in Table 1, enrolment originates from reforms initiated from the PHCS. The PHCS works, through activating enrolment among other changes, to achieve the primary health objectives of the New Zealand Health Strategy (King, 2001; Raymont & Cumming, 2013). The following three exerts from the PHCS show the intent of such reform:

> To achieve the New Zealand Health Strategy goals and the vision of the New Zealand Disability Strategy, primary health care services need to be organised and delivered in a way that ensures the best health and independence for populations (King, 2001. p. 4).
>
> The Primary Health Care Strategy provides direction for District Health Boards in bringing about these changes. It sits below the New Zealand Health and Disability Strategies umbrella, creating an overall framework for the organisation and delivery of primary health care. District Health Boards will work through Primary Health Organisations to achieve the health goals locally (King, 2001. p. 4).
>
> People will be encouraged to join a Primary Health Organisation in order to gain the benefits associated with this population approach and to improve the continuity and co-ordination of the services that they receive. Most people will enrol with a provider of first-

> contact services (a general practice or a local health clinic) that is part of the organisation (King, 2001. p. 7).

In short, through the arrangement, patients enrol with a PHO through a nominated primary care centre, and for their enrolment, the primary care centre receives (via the PHO) capitation payments for the provision of first-level (primary) services. The sequences of actions from enrolment, seen through Jan as she changes her chosen provider to follow Doctor M to receive care at the IFHC, activates capitation funding paid to the practice for the provision of her care.

In entering into this sequence of actions, patients, like Jan, Tim, Helen, and Mary, use only the services of their enrolled practice for their day-to-day care, despite their frustrations. While patients are "free to seek care wherever they wish" (King, 2001. p. 8), if they were to access primary services elsewhere, they would be charged a significantly higher consultation fee (called a casual rate) of $90 to $115.[28] Additionally, without enrolling with a practice or when using the services of another practice, patients are not eligible to receive subsidised or free health promotion services such as cervical smears, vaccinations, and long term condition reviews. The PHCS states, "if a person chooses not to enrol, they will still be entitled to seek care – but they may miss out on some preventive services because they are not in the identified population" (King, 2001. p. 9). Thus, the ongoing relationship between patient and practice is textually formalised by patient enrolment, by which patients are connected to the practice through funding, information and access.

Enrolment as a ruling relation

The activities in the accounts shared by patients in this chapter happen under the conditions brought about by patient enrolment. For example, Jan and Tim describe their work to secure appointments at the respective IFHC with which they are enrolled. This work is troubling at times for both Jan and Tim. The formal relationship of enrolment organises patients' access to

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[28] Cost estimate based on internet search of New Zealand primary care centres with casual rates advertised on their website.

appointments. Patients are organised to use their enrolled practice (to access the benefits of capitation) and thus are limited to appointment scheduling processes of the enrolled practice. Further, patients compete with other enrolled patients for the limited number of appointments, as seen in Jan's account where she must wait longer to ensure continuity, and Tim's account where he must navigate GP triage as an additional step to secure a GP/NP appointment. Based on the accounts of patient informants, I suggest that enrolment at IFHCs plays an organising role in some of the troubling experiences patients described. Yet, the premise of enrolment in the foundational document (the PHCS) is "to improve the continuity and co-ordination of the services that they receive" (King, 2001. p. 7). Who then controls patient enrolment? And who is accountable for achieving the intent of patient enrolment?

From talking with people in ownership positions at general practices it appears the enrolment process is controlled by them as the health care provider. Importantly, the decision whether to take on new enrollees is made at the health care provider level. An informant, a GP who is also a practice owner, shared that their practice had closed their books and was not taking on new enrolments at the time of our conversation. When asked how this decision was made, the GP cited that the practice had "too many patients for the number of doctors." There was no further measure or rule for this decision, according to the GP.

Despite an exhaustive investigation, I could not find clear guidelines to support when a general practice should close for further patient enrolments in any governing texts. This statement on an MoH website, intended for public education, provides loose guidance: "A general practice may 'close its books' if it can't safely take on any more patients. If this happens, the practice should refer you to their PHO for help with finding another practice. The PHO may put you on a waiting list and arrange for you to get care in the meantime" (Ministry of Health, 2018e). Therefore, each individual practice appears to hold control for the number of patients enrolled with the practice at any one time, without traceable accountability to the quality goals of the PHCS. There is, apparently, an onus on practices to consider safety when making this decision. Thus, the troubling aspects of making an appointment and competing with other enrolled patients for access to primary care services appear organised by the individual practice and their subjective interpretation of safety, and perhaps other priorities or objectives of the practice.

One informant, Mike, a GP and IFHC shareholder, provided extralocal knowledge on patient enrolment. Mike saw enrolment as competitive and as a measure of business success where more patients are enrolling, leads to more capitation funding, allowing the practice to continue to expand. The IFHC where Mike is a GP and shareholder keep their enrolment books open at all times, while most practices in the same region are closed to new enrolments (according to PHO records). Mike's understanding locates enrolment firstly as a financial transaction that is essential for business growth, and secondly as a measure of success for services delivered in a competitive market, where attracting new patients affirms success. When asked about how the practice deals with patient enrolment, notably, that the practice does not close their books, Mike said:

> MIKE: It is competitive... as long as we can improve access. Because actually working the way we're working, we will out compete you [other primary care providers]… if you think of it as a competitive market, if you're seen to be successful, and you work in a different way… So if we start changing the way we treat people, then others have to do the same thing; otherwise they get out competed.
>
> INTERVIEWER: With the current capitation funding model, the new patients would bring that funding with them. How does that work with your project?
>
> MIKE: Well, that's right, because they bring their money with them, they bring their capitation. If the money follows the person, then we get more and more money. The point is that's the vision. We change the way we treat people, they bring their money, and we just keep growing.

When asked how the practice deals with the ever increasing patient numbers, Mike said, "people want to work with us" and that as more patients enrolled, the practice would expand by hiring more clinicians to meet the demand. Mike appeared to be actively recruiting local clinicians - GPs and NPs – to support this intended growth in enrolment. Enrolment practices described in this account show the individual practice's power to control the enrolment process and embed institutional knowledge and agendas into the process (such as competition and profit). This finding suggests that enrolment operates as a ruling relation, organising the experience of people at the frontline of primary care. Moreover, it highlights the emerging disjuncture between enrolment as it is realised, and the intention of enrolment as described in the PHCS.

Guided by the disjuncture between enrolment as experienced and as promised, the research project moved away from informants in the local and extralocal level and into the translocal social world. Data from the translocal social world offers a way of pulling the thread (DeVault & McCoy, 2002) of the inquiry to reveal the social and ruling relations progressively. Knowing that the PHCS orchestrated the establishment of enrolment, I located different sources of knowledge about the PHCS (people and texts) to understand how the ruling relations of patient enrolment organise patient experience.

The PHCS is a text arising from the highest level of government in New Zealand. It is the defining text that brought about the significant restructuring of primary care and primary health care governance, introducing PHOs and enrolment to improve health care and reduce inequities (King, 2001). Yet, the rationale and intention supporting the reforms present as problems for the people I spoke with when they could not achieve the purported benefits. This raises questions about the accountability between care provided and care as intended within the premise of PHO enrolment. To answer this question, following the analytical guidance of institutional ethnography, I traced patient enrolment further into the textual hierarchy and governance terrain of primary care.

Subsequently, I spoke with people differently located within the planning and execution of the PHCS and PHO enrolment.

Primary Health Care Strategy, enrolment, and textually mediated work

I spoke with a Chief Executive of a PHO, to learn how the PHCS works in practice. I asked the CEO directly what work do they (or others) do in response to the PHCS? They gave examples from practice, such as efforts to improve access for transient migrant populations through the use of vouchers, transport provision, and walk-in clinics. The underlying principles of the PHCS inform the actions the CEO described (as per the PHO's interpretation), such as reducing inequality and improving access. While the principles informed the actions, the actions were a unique course taken by the PHO according to their local interpretation. When asked about reporting requirements to the Ministry of Health for achieving these goals, the CEO noted that the priority indicators determined reporting, such as smoking cessation or improving childhood immunisation rates. From an accountability perspective, the basic foundations of the document as an aspirational vision to coordinate high quality care for all New Zealander's became reliant on an individual's moral consciousness and interpretation within their professional position to fulfil the theoretical ideas located within the PHCS. Yet, accountability for the implementation of the PHCS is included in high level contractual agreements as identified below.

The text formalising the relationship between PHO and general practice is the PHO Service Agreement, also known as the back to back contract (TAS, 2020). This contract carries the roles, functions and responsibilities between each provider and the PHO. Of significance to this analysis, the PHO Service Agreement requires "implementation of the New Zealand Health Strategy and other policy and strategy initiatives related to the delivery of health care services" (TAS, 2020, p. 1).[29] This means that primary care providers are contractually obliged to implement the PHCS. I

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[29] "Central Region's Technical Advisory Services Limited (TAS) is owned by the six central region DHBs, which are Crown entities as defined by the Crown Entities Act 2004. The relevant legislation governing TAS operations is the Crown Entities Act 2004. TAS' ultimate parent is the Crown. TAS' primary objective is to provide professional services to the NZ health sector. TAS does not operate to make a financial return" (TAS, 2017).

question, what does implementation of the PHCS look like, given that, as shown by the PHO CEO, the basic foundations of the strategy intended to coordinate quality care lack direction for implementation?

As noted, the PHCS is a text. A reminder to readers, a text, as recognised and understood by Smith (2008), is any material thing carrying words, numbers, images or sounds. Importantly, the text *can be and is* replicated in multiple copies so that the consciousness of anyone looking, reading, or hearing, is coordinated (though not determined) by the same words, numbers, images or sounds as any other. The PHCS is a material thing carrying words, numbers and images. It is widely distributed to key actors of health care planning and delivery for the purpose of strategic guidance of the sector. Yet, as this analysis begins to show, only some aspects of the strategy are carried through courses of actions to people at the frontline of primary care.

To understand more about the intent of the PHCS, in particular, the intended actions from the uptake of the strategy, I spoke with Jon Foley,[30] an economist involved with writing the PHCS. Jon said of the strategy:

> It was written as a visionary document, but there was an eye towards how could this be implemented. In other words, it was not in any way meant to be simply a policy document. It was meant to be something that could be taken up and implemented.

Jon suggested there was intent to write a further 'how to' text to support the implementation of the strategy, but that the team ran out of time and money. Jon noted this to be a frequent issue in high level governance in New Zealand.

> We probably didn't do enough work, probably because there wasn't enough time, in translating the policy document into essentially an operational document that the DHB's could pick up from whoa to go, and say, okay, we start here, this is how we form a PHO,

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[30] Jon has agreed to be a named participant in this research

> this is what we do next, this is how we know we've got a good one, this is how we prove it.

Similarly to the PHO CEO, Jon talked about the ideas of the PHCS, suggesting that these conceptual practices could be implemented to achieve quality health care. I wanted to know what informed Jon's knowledge of good care, and how he understood good care in relation to the strategy. Below, Jon's comments show his use of the ideological discourse of good primary health care. These comments locate Jon's knowledge in health research, and show his participation in translating this knowledge from research to policy. Jon said:

> Tenants of the strategy came from research on what a good primary health care service looks like, what are the characteristics you should look for? And trying to put those into a policy document that could be implemented as a strategy. So think like, putting life to what is meant by the continuity of care, putting life to population health, putting life to the coordination of care, what does that really mean?
>
> We tried to put the policy behind a PHO that would be able to carry out those characteristics. The document was meant to be pretty straightforward and accessible to the public. It was meant to be based on what was known to be effective primary health systems but not in a highly technical or academic way, but more in a way that communicated to people.

Jon's comments reinforce the findings from the PHO CEO, whose actions appear to carry out the principles of the strategy. As suggested, the CEO's actions arise from professional goodwill, more so than an organised response to the PHCS. On this, Jon said; "It comes down to the leadership of the PHO, because there is not enough of an oversight structure to hold them accountable, in the way it is currently structured." Meanwhile, the people at the frontline I have spoken with show that these ideas are not reaching them in their everyday experiences of accessing care under the implementation of the PHCS. Or, in the case of Mike above, saying: "as long as we can improve access… we can out compete you,” the application of the ideas of the PHCS such as improved access and by proxy quality improvement, are malleable to the interpretation or agenda of powerful individuals.

The analysis presented here is one example where the concepts described at the outset of this project – person-centred care, continuity of care, and care coordination – are linked empirically from people at the frontline of primary care up into the institution of primary care. What is visible here is a gap between the promise of these concepts, and the courses of actions required to realise the promise. In particular, the promise of enrolment is very different from the on-the-ground experience described by Jan, Tim, and the others. Enrolment, as a textual interpretation of the PHCS appears lost in translation, where the activity of enrolment introduces contradictory tensions between business and PHO objectives.

The emerging problematic

Many small disjunctures arise from the accounts shared in this chapter. Jan undertakes new and troubling work to maintain her relationship with her GP. Tim describes new tensions when booking a routine appointment. Kate, the RN, understands GP triage to be patient-centred, yet it appears to be creating more work for patients and further restricting access to care as and when patients would like. Helen finds navigation between services brings about significant and challenging personal work. Mary undertakes new healthwork to prepare for appointments as she believes her complex needs are a burden to health services.

As a point of entry into the social of primary care, each disjuncture connects to a range of practices occurring within an emerging ruling relation. Irrespective of individual patient characteristics, the presence of the same rigid rules and processes within which each person is attempting to work to gain access to primary care become visible. The person was unique, but the health care system, in contrast, was operating through a standardised model of care. Every patient was required to *enrol* with a general practice. Every patient was required to *make* and *attend* general practice appointments. Every patient had to *wait* for their appointment. How the patients' work was "shaped and orientated" (McCoy, 2006, p. 115) towards these processes, and how the processes were connected to higher-level texts and organisation became the analytic focus of this research. Each of these stages are represented in the image below, showing the movement along the circular continuum of analysis this thesis follows.

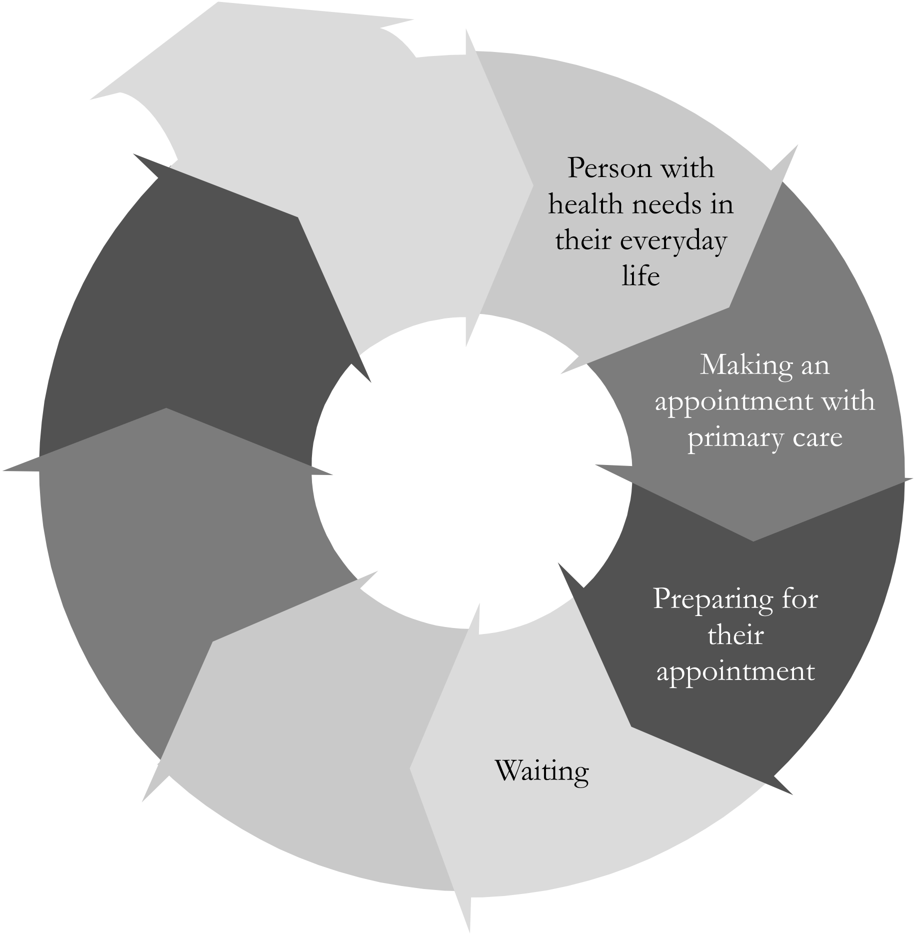

Figure 7. Progress wheel through frontline analysis (B)

Each patient account in this chapter holds traces of engagement with the same standardised, regularised social processes. The finding of the rigid practice model calls into account the usefulness of person-centred care policies and strategies. What is the use in talking about care that centres on the person, when the foundational structures of the practice model appear to centre work processes towards a standardised set of routine practices? Patient work identified above demonstrates that patients appear to be organising themselves to 'fit' (Cupit, 2018)[31] within an organisation-centric model, rather than the espoused person-centred design.

Based on these opening findings, the problematic, as an analytical frame for the remainder of the project, I aim to explicate is: the gap between a patient's actual experience of regularised care practices and the promise of person-centred health care.

Chapter five conclusion

This chapter begins in the everyday world of people, going about the everyday work of being a patient accessing primary care services in New Zealand. From the accounts provided of this work, several troubling processes are identified under changing frontline conditions. These processes appear to enter into patients' everyday work, creating new and increasing work, such as GP triage (Tim), the need to return to the gatekeeper (Helen), or the example of Jan where she must work harder to access her doctor. These accounts introduce tensions between good primary health care principles such as improved access, coordination of care and continuity of care, as promised in the PHCS, and the actual care experienced by people at the frontline. The PHCS should carry these principles to the frontline under the conditions established through PHO enrolment. Yet, some of the work processes informants describe, privilege the ideologies of NPM and business practice, while the ideas of the PHCS appear only discursively in talk and text.

The findings from this chapter open up the terrain of the institution of primary care, with each discovery pointing to an empirical path to follow. The remaining analysis chapters take up these discoveries, shifting the location of analysis and inquiry (but not standpoint) further into the activities taking place within the consultation. Analysis continues beyond the local circumstances of the patients to explore the social relations shaping patients' experiences, and quite specifically, how these social relations are organised.

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[31] see Caroline Cupit's 2018 Doctoral dissertation for a deep explication of patients undertaking 'fitting work' in relation to preventative medicine.

Chapter Six – Analysis part two: Participating in primary care services

> *"A patient should never weary his physician with a tedious detail of events or matters not appertaining to his disease. Even as relates to his actual symptoms, he will convey much more real information by giving clear answers to interrogatories, than by the most minute account of his own framing. Neither should he obtrude the details of his business nor the history of his family concerns." (American Medical Association & New York Academy of Medicine, 1848, p. 15)*

Introduction

It is hard to deny the exercise of social control over patient behaviours by medicine for as long as modern medicine has been practiced. Verbatim from the American Medical Association's Code of Ethics (as above), this obligation of patients to their physicians demonstrates explicitly taught/learnt social roles of doctor and patient, and the exclusion of the patient as an expert in their own health. The social control intended here promotes the doctor's status in the consultation and subdues the patient to a passive role as a recipient of the doctor's attention. This historical arrangement holds relevance to the data explored in this chapter, as the analysis moves from the work of accessing care (Chapter five) to the control of work within the consultation. In particular, this chapter pays attention to attempts to move away from the physician centric model described above, to a person-centred model of care.

In this chapter, I take up the accounts of patients and clinicians as they participate in the organised activity of primary care consultation. These are the activities that occur within the physical and social location of the primary care centre. Metaphorically, these patients are now passengers on the bus, and as such, are subject to the social and ruling relations of the business. Data from patients and clinicians shared in this chapter introduce concerns such as consultations with unfamiliar clinicians, restrictions on consultations regarding both time and content of the discussion, and in particular, concerns from both patients and clinicians for the reduction of consultation space to a single issue.

The focus of this chapter continues and evolves the research problematic identified in Chapter five; the gap between a patient's actual experience of regularised care practices and the promise of person-centred health care. The accounts from patients explored in Chapter five found a tension between the work of patients to navigate the rules, practices and procedures of accessing primary care, and the quality improvements purportedly introduced to improve primary care access. In this chapter, the exploration and critical analysis focuses on how the interests of the business hold accountable what can be said and done in the consultation. Further, how these interests support, impede or disrupt the clinicians' intention to provide person-centred care.

Time is precious

Time is precious

Let's make the most of our limited time together

One Patient

One Appointment

One Concern

Located on the waiting room walls of general practices are signs for patients to read, many similar to the message above (quoted verbatim from a poster at a local primary care centre). The organisation is informing patients of the social practice expected within the appointment. The message is that general practice appointments are restricted to one patient with one concern. Yet, statistically, New Zealand has an ageing population, noted to be likely to have more than one health condition (Minister of Health, 2016a). In consideration of regular users of primary care, this standardised and restrictive feature of primary care processes becomes problematic. Suppose they deem themselves to have more than one health concern requiring clinician attention. In that case, the individual must learn new processes and undertake additional work, time and cost, to get their needs met within their consultation. This apparent chasm between the standardised constricted appointment on offer here, and the strategic goal of a system that is free to provide for the uniqueness of every user and their needs (Minister of Health, 2016a, 2016b), is central to this thesis. The analytical concern guiding this explication is: how is this standardisation and restriction accomplished, and whose interest does it serve?

Continuity of care

The challenge of providing and receiving continuity of care runs parallel to the concern with standardised and restricted consultations. It seems there is increasing potential for a primary care consultation to be with a clinician who is not familiar with the patient. First introduced in Chapter one, a premise of an IFHC model is patient-centred care, which includes the promotion of continuity of care for those who want it (Lovelock et al., 2017). Yet, both Jan and Alex described wanting continuity of care, but had to work against contradictions in institutionally defined practices, such as appointment booking systems, to achieve this ambition. Here, the tensions from these contradicting practices are extended further into the social terrain, to explicate the activities, actions and consequences of loss of continuity when coupled with other ruling relations within the consultation.

As introduced in Chapter one, Jan worked around the appointment booking system to avoid this problem of seeing an unfamiliar clinician, thus protecting her continuity of care and patient-clinician relationship. Meanwhile, Alex, talked of their concerns when they "[did not know] them [patients] from a bar of soap." While concerned about the patient's negative experience, Alex also discussed the risks involved with unfamiliar and disjointed care. As an effort to manage these concerns ‘on the spot,’ Alex learned to complete the episode of care as much as time would allow. In doing so, Alex’s actions meant that no aspects of the consultation required future appointments; therefore, continuity appears less essential. Despite some clinicians working around these concerns like Alex, and patients like Jan securing her continuity through challenging booking systems, other patients still experience problems that appear to arise from a lack of continuity of care. A patient I spoke with, Louise, introduces these concerns and extends the analysis to reveal other ruling relations of the consultation.

Louise

Louise is in her 30’s, married with two young children. She has a tertiary qualification and, before becoming unwell, was employed full time. Six years ago, following the birth of her first child, Louise became unwell. Her symptoms varied and included “intense tummy and back pain,” headaches, “unable to focus,” tiredness, whole body aches and pains, indigestion, “major weight loss,” and “very inconsistent bowel movements.” Until this point, Louise’s interactions with the healthcare system had been minimal, and she lived what she described as a “relatively balanced life.” Initially, Louise sought care from her clinician, but her health continued to decline. She became progressively more unwell, and her need for health services increased, including acute needs for unmanageable symptoms such as acute pain, gastric upset, and fatigue.

When Louise made appointments to see a general practice clinician, often it was after she had exhausted all her available resources to manage her pain and other symptoms. She was seeking somewhat urgent help, sometimes within a week of a previous visit. Consequently, Louise found that acute appointments (not those pre-booked in advance) were allocated to the next available clinician. This clinician was often someone she did not know and did not share a patient-clinician relationship. She said, “they would give me an appointment with just anyone who was free, and at first I didn’t mind that, but then it started to become a problem as I got sicker.”

As Louise's health declined, the lack of continuity in the assessing clinician became more of a problem. Louise found these repeated situations particularly troublesome as she felt responsible for "filling in" the unfamiliar clinician with her complex history over and over, which took up time and did not make progress on why she was there. Louise spoke of the clinician not having the necessary results, or the time to locate and sufficiently read the results that she was there to discuss. She said:

> It's so hard when it's a new doctor. They don't know me. They don't have enough time to read my history. They just want to know what I am there for today. That's it. But I want them to think about all of my issues together, holistically.

Understanding it was not always possible to see her primary care clinician, Louise ensured she was prepared with all the information about her health to minimise the wasted consultation time with clinicians unfamiliar with her history. She recognises that her medical history is complex, which she infers as being time-consuming for new clinicians to read about and interpret. Louise can see an opportunity to reduce the time spent recounting her medical history by writing a succinct letter detailing the most important issues to her. Additionally, her effort can be seen in her information gathering, such as collecting lab results, referral and specialist notes, and record-keeping work such as a symptom diary. Louise said, "I would take my folder [of notes and results] to the appointment and use them to help fill in the doctor when they said they didn't have all my records." Louise concentrated on freeing up the clinicians' time to present her evidence of being unwell, thus improving the clinicians' ability to address her needs. She did everything visible to her to coordinate herself to fit with the needs of the assessing clinician to improve this process. This extra work for Louise only occurs under the conditions of an unfamiliar clinician.

Text-mediated continuity of care

The increased difficulty described by patients to access continuity of care is occurring despite frequent references to continuity of care in seemingly ruling texts. For example, continuity of care is a central tenet of the Royal New Zealand College of General Practitioners' *Curriculum for General Practice* (2014), which locates continuity of care as a core component of patient-centred care. The curriculum document states:

> General practice… is responsible for the provision of longitudinal continuity of care as determined by the needs of the patient (p. 7).

And:

> The consultation enhances the ongoing relationship between the general practitioner and the patient. In doing so, the general practitioner balances the needs of individuals and communities with available resources and enables them to provide longitudinal continuity of care as determined by the patient (p. 9).

Further, both the PHCS and the RNZCGP standards strongly support continuity of care as a fundamental element of high-quality primary care (Jackson & Ball, 2018). The inaugural Strategy (King, 2001) posited continuity to be achieved through patient enrolment, suggesting that,

> Continuity in primary health care means that people have a usual source of care and can use that source for advice and help over time…. People using the service form important relationships with their provider (p. 7).

The concept of continuity is supported in the Strategy by *benefits* seen in international research. The Strategy drew on the following international evidence to support the vision for a system that supported a relationship with "a particular practitioner" (King, 2001, p.8):

- Better preventative care (Lieu et al., 1994)
- Patients who feel more able to care for themselves in the future (Howie et al., 1999)
- Better recognition of problems (Gulbrandson et al., 1997)
- Less recourse to medication as a first-line treatment (Hjortdahl & Borchgrevink, 1991)
- Better patient compliance with prescribed medication (Becker et al., 1974)

- Fewer hospitalisations (Weiss & Blustein, 1996)
- Lower total costs (Flint, 1987)

These references to the responsibility for, and purported benefits of, continuity of care are found in significant texts that underpin the institution of primary care. Yet the more recent BSMC policy (Ryall, 2007) that facilitated the development of IFHCs in the interests of efficiency and value for money, advocated for the right person, at the right time, in the right place to improve healthcare access which is seemingly in opposition to the notion of continuity of care. That continuity is the trade-off when promoting access in the IFHC model raises new questions, particularly, who benefits from this change?

Despite this apparent evidence and textual commitment, in the account of Louise and as the rest of this chapter goes on to show, there does not appear to be textually organised activity beyond enrolment to translate care continuity into the everyday consultation arrangement. What then is organising the allocation of clinicians to patients, and whose interests does this serve? And further, considering the work seen in Louise's account, how does the new work introduced under the conditions of unfamiliar relationships enter into and organise the consultation?

Not enough time or thinking space

In undertaking the additional work required to bridge the gap from lack of care continuity, Louise found she did not have enough time in the consultation and her needs were unmet. Louise was "sick of running out of time," describing on more than one occasion where the consultation was interrupted by the practice receptionist, who was informing the GP that he was "going overtime" or "getting behind schedule." When talking about time pressure within the consultation, Louise said:

> I don't feel like I've had the time to share everything that I felt I needed to share to give the doctors the whole guts of where I was at. I felt like I had to rush through, to share what I needed to share, so they could quickly give me something to treat me, rather than

> having the time to explain myself, and I often felt rushed. With my first GP, he sort of said to me one or two times that he had other patients to see as well.

For Louise, it seems that her needs cannot be met within a single consultation. The priority for the centre appears to be timeliness, as seen by the interjections from the receptionist, who is concerned the clinician is behind schedule. Also, Louise suspected the clinician was rushing to "quickly give [her] something to treat [her]" rather than being free to attend to her holistic needs. Despite her frustrations, Louise persisted with attending GP appointments at the practice, at significant financial cost, as she says she had "nowhere else to go."

The complexity of Louise's medical concerns continued to grow, and yet, she described her experience within each consultation as an isolated assessment, where the clinician appeared interested in only addressing one of Louise's concerns.

> INTERVIEWER: You talked about how your GP was treating everything as individual. Can you tell me more about how you felt you were being treated?
>
> LOUISE: So I would go to an appointment, and [the GP] wasn't even thinking about or trying to make links to what I had seen him about the week or so beforehand, or anything else that I mentioned. He was focused on 'this is your problem today, let's deal with it, and this is the management strategy for this symptom or this complaint.'

Louise's experience hints at a constrained primary care appointment, where the clinician is attending to a single issue only. There is a work practice happening here, organised away from Louise, that is entering into her ability to have the full scope of her health concerns addressed. Louise believed this constraint was contributing to the lack of progress in resolving or relieving her health concerns as the clinician focussed on the single issue "rather than looking at things collectively and going 'last week you came in with this, today, you've said this' rather than making things collective and looking at things holistically." Coupled with the concern raised above with unfamiliar clinicians, these ruling features of the consultation appear to be doing something other than focussing care on the patient and their unique needs. Further, if the clinician does not know the patient, and the patient presents with complex, evolving, or compounding issues, can the clinician reasonably review, assess, and consider the nuanced issues adequately and safely within 15 minutes?

As noted, Louise's experience of not having enough time is organised by work practices outside of her control. To understand more about this control, this research project follows the trail of clinician knowledge and work practices to show how the consultation is organised, thus revealing how the patient experience is organised to happen as it does.

One appointment: Consultation organisation

The organisation of the primary care consultation is an activity that is taken for granted, with no clear definition in New Zealand (Gu et al., 2014). To bring real meaning to the consultation process, the structure of the consultation first introduced in Chapter two is revisited here. The discussion of consultation structure is filled in with accounts from clinicians as they describe their activities which make up the primary care consultation, beginning with the GP consultation, and then the NP consultation.

General practitioner consultation

General practitioners have 15 minutes to prepare, interview, assess, diagnose, and document each appointment. Megan, a GP at an IFHC, described her work within the 15-minute appointment. She raises tensions between the process expected by patients and managers with her everyday experience. Megan said:

> We've had this model for so long, where it's 15 minute GP appointments, and that's how it is, and you've got to manage everything in 15 minutes, but, actually, that's not always the best way. I think both patients and GP's are driving it, realising that… and you do get

> proactive patients who know that they've got complex issues and they need half an hour so they'll book a double appointment, and you know, like, if there's a chronic patient who you're seeing regularly who always takes a really long time, you can kind of preempt that by saying, well, next time can you book half an hour. But they get charged double, which is what makes it harder, and they know if they come in and just stay in your room for half an hour [after booking only a 15-minute appointment] that that will work for them. And they're always the ones that complain that you're running late…

Megan identifies that the 15-minute consultation is "not always the best way," with the only option being to either run over time or to get the patient to book a double appointment, and consequently pay double. The tension she notes is that the patients who require longer appointment times are those "chronic patient[s]." Megan's understanding suggests that people with chronic (long term conditions) or complex needs should book a double (half-hour) appointment to overcome the restriction of the 15-minute consultation. This suggests that a 15-minute consultation cannot meet the needs of the complex, chronic, or those with a list of issues. Interestingly, Megan says even people with complex needs whom she is "seeing regularly" require more than the 15-minute consultation, suggesting that continuity of care is insufficient to overcome the restrictions of the brief consultation time. This raises several questions, in particular, how is the consultation organised to meet (or not) the needs of all people, and in whose interest is it to protect and persist with the 15-minute consultation?

To explicate this further, Megan's description of the assessment structure she and others follow is a useful place to start. She says:

> Most GP's and I generally follow a sort of HEAPS [history, examination, assessment, plan, safety net[32]] format. So history, examination, assessment, what you think's going on,

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[32] The concept of safety netting to promote clinical patient safety is discussed later in the chapter

> your differential, then your plan, and then your safety netting. And we generally follow that format for each consult.
>
> Then there are some things that we have to document like objective findings, so blood pressure, height, weight etcetera. They get put in with a special code, so then it gets saved in there in a screening tab as well in the main system.

What Megan is describing is a standardised assessment process designed to deal with a single new issue within the consultation. The attention of the clinician is focussed towards the completion of this assessment which places the assessment and plan at the centre of the consultation.

Another GP, Cameron, supported Megan's description of the consultation. Cameron added that he felt a tension when "a patient comes in with a list that you have to triage before you can even start your HEAPS assessment." For Cameron, his concern appeared to be with starting the assessment from the most important issue, and said he would consider other concerns on this list "if [he] had time."

The way Cameron has learnt to approach the assessment echoes Megan's, where patient concerns are itemised and dealt with individually. As the sign on the wall says: "one appointment, one patient, one concern." Both Cameron and Megan use the HEAPS mnemonic to structure their consultation, which they understand to be best practice. The standardised assessment format appears to reinforce these institutional rules within the consultation. Much like the code of ethics from the beginning of this chapter, present-day arrangements appear to maintain the control of the consultation; however, this no longer appears to be for the benefit of the clinician.

Nurse practitioner consultation

This account from an NP, Alex, introduces the NP consultation processes. For reader understanding, NPs working in the primary care environment are employed via a relatively similar means as GPs, and deployed to work with the same populations. While NPs and GPs deliver the same scope and range of primary care services, their practice is underpinned by different paradigms. The NP consultation shared below highlights the professional dilemma in delivering a full 'episode of care' in a single restricted consultation. Alex draws attention to tensions in their work as they try to fit their nursing model into the rules of the consultation. Describing their experience of consultations, Alex said:

> I get 20 minute consults. My consults, I am told by the centre, must follow a very biomedical structure and way of consulting, which is a bit alarming. You do your physical, your assessments, your history taking, you follow your framework. It's quite interesting, I get all these comments from patients like, oh, my doctor never asks me these questions, like about mental health, or how many people live in my house or, the social. A lot of the 'other side' of health, the questions that doctors don't get time to ask.

What Alex is describing is the push and pull between "a very biomedical structure" and the social aspects of assessing that they have learnt to include in their consultation. Alex sees this assessment as the difference between the NP and the GP consultation, as these are the parts doctors "don't get time to ask." Alex talked about how they have worked hard to include the social aspects in their patient interviewing, saying, "I'm quite adamant I'm staying true to my nursing," but also recognising the consultation arrangement as promoted by the centre contradicts this model.

> When I was training, the feedback from the academic supervisor who observed my consults, her first words were, "you're doing really great, you're very confident, but I'm worried that you're going to lose your nurses' touch if you keep going like this." And I asked her why? She said: "I know that your time is short, but somehow we need to get around the fact that we are doing the '15 minute consults' to get people through the door."

In meeting the institutional needs of brief consultations, Alex shares further discomfort in knowing that they may not be able to meet all of the person's needs. In not being able to meet the patient's needs in a single consult, the patient must then return for a follow-up appointment, at full cost to the patient. Alex says:

> Now I've got a person sitting in front of me, and I've got to tell them, "well, we're not 100 per cent sure what is going on with you today. I would like to see you again in two weeks' time." Oh, My Gosh. How do I build up that courage? How do I ethically give myself that okay tick to tell that patient you need to pay another $42 next week or the week after? That does not sit well with me. Because we do not have a follow-up appointment cost. We just have one cost, and that's for all.

These accounts from GPs and the NP hint towards time as the main tension when carrying out their role. This problem appears to be heightened when the patient's needs do not fit within the 15- or 20-minute time slot. As Megan said of patients with chronic conditions, they "always take a really long time… they're always the ones that complain that you're running late." Louise recognised that she felt rushed within the consultation, and could not talk about all that she felt she needed to. It seems both patients and clinicians are aware of the problem, but neither has the authority over the appointment structure to change this problem, aside from booking and paying for a double appointment.

Text-mediated 15-minute consultations

The appointment duration and the sequence of the medical interview are textually organised. The 15-minute appointment model has been shaped by many decades of private general practice, and, more latterly, by business development, accounting practices, and time management software. As discussed in Chapter five, the appointment booking system operates as a text which carries the structure of 15-minute time slots into the frontline experience of participating in a consultation. The 15-minute model has been shown in the discussion above to be poorly suited to meeting the needs of the patient and the clinician. It appears that instead of a being part of the model of care, the 15-minute appointment is instead part of the business model. While promoting aspects of

NPM such as timeliness and efficiency, the 15-minute model predates the arrival of NPM, which raises further questions as to how the model came about, and what the model achieves.

Dr Samantha Murton, President of the Royal New Zealand College of General Practitioners, suggests the funding model controls the 15-minute arrangement: that the combination of capitation, patient co-payment and ACC payments support a system wherein the GP must see a patient every 15 minutes to balance the costs of the business (Turner, 2021). More specifically, as capitation is a fixed income for the business, the patient co-payment as a 15-minute cost unit must cover the gap between capitation and business expense. This reliance on the patient co-payment for practice revenue is suggested to incentivise clinicians to provide a high volume of consultations (Downs, 2017). High volumes of consultations are achieved by increasing throughput efficiencies by means such as reducing the content of the clinical encounter. However, with the migration of health service delivery into the community and the increasing complexity of people's health needs, the patient requires more, not less, from the consultation (Sheridan et al., 2012; Stokes, et al., 2017).

Dr Murton, when speaking to a health care user and writer Sarah Turner, said: "Fifteen minutes is a unit of measurement for funding, that's all it ever was. As a unit for healthcare delivery? It does not work**.** It is impossible to serve health needs in any substantial way within that time" (Turner, 2021, para 16). Alex also recognised this as a tension within their role as an NP, saying: "they expect me to see three patients per hour, and X amount of patients in my NP day, so they can obviously make money for the business, but what about actually meeting my patient's needs?" Dr Murton reiterates these concerns in an interview with RNZCGP, further saying that:

> The landscape of general practice has vastly changed in the last 30 years; patients have increased needs and they're more complex, and our administrative burden is overwhelming, however the funding formula based on a 15-minute appointment has not changed in all that time and makes general practice unsustainable (The Royal New Zealand College of General Practitioners, 2021a, para 19).

These comments further the conflict between the clinicians' responsibility to the patient and to the business, revealing the expectations of the business to be unsuitable and unsustainable. However, it seems that despite this discomfort, clinicians are required to prioritise the business needs over those of the patient.

Financial viability is at the forefront of business management. The relations of financial viability are carried into health care professionals' agenda through budgets and financial plans, shared formally at staff meetings. Kate, an RN, when talking about costs associated with clinical governance and evaluation, showed how the managerial priorities enter her thinking:

> INTERVIEWER: Do you feel the consideration of business is happening in the development of the contributory measures at the clinical governance level?
>
> KATE: Yes, it has to… You have to have a reality of how to keep a general practice financially sustainable. So it *has to* be a consideration. I mean, I like nursing, and I like being employed here, so, if you don't balance the books (laughs)…

Health care professionals like Kate become active participants in the business discourse, specifically in general practice, as the professionals learn to think of themselves as a revenue generating unit. For example, some clinicians knew the number of patients required to be seen per hour for the practice to be financially viable – recognised as the number they must achieve to justify their salary expense. The informants knew that GPs must complete four consultations per hour, NPs must complete three, and two per hour for practice nurses, to meet the financial needs of the practice.[33]

Rankin and Campbell (2006) identified this type of awareness and participation as "the engagement of the healthcare providers in activating the managerial project" (p. 139), where health care

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[33] Interviews were conducted individually, but all informants who talked about the number of patients to be seen identified the same figures, irrespective of their position in the general practice.

professionals take on the targets and efficiencies as their personal work. This participation in the managerial project may explain why the 15-minute model continues to be promoted by clinicians.

Figure 8, below, is another in the series of online images shared by the Royal New Zealand College of General Practitioners. This image carries a message of timeliness, to educate patients to participate appropriately within the 15-minute arrangement, or, to take on more work and cost with a double appointment because "it's important to stick to time." Notably, the image does not alert the patient to the double fee that is attached to booking a double appointment.

Figure 8. GP appointments tip #2 image from Facebook account 'you and your GP,' retrieved 08/10/2018

While Figure 8 promotes patients to be responsible for their appointment duration at the time of booking, elsewhere, GPs have introduced specific patient education to encourage patients to be responsible in the moment for the timeliness of consultations. Australian GPs Knight and Lembke (2018) describe the so-called success of providing textual education to patients regarding the strict timing of consultations, highlighting how patients became engaged with timeliness: taking on responsibility for the timely conclusion of the interaction. The pair described patients actively watching the clock and initiating the conclusion of the consultation as the 15 minutes neared. These texts, which impart the authoritative business knowledge of the health care centre onto the patient, draw the patient into the accountability of these business practices. The timely conclusion of the consultation does not support the patient to meet their unique needs; rather, it supports the clinicians' accountability to the business.

Returning to the sign on the wall at the primary care centre: "time is precious," for which the sign suggests attending to only "one concern" will help to "make the most of our limited time together." Considering how the consultation is organised to run to time, this analysis returns to actions described by patients and clinicians that focus on the timeliness and organisation of the appointment. These actions relate to both patients and clinicians reducing or restricting the content of the consultation through the use of lists, triaging these lists, and self-selection of the issue that is most important.

One concern

Appointment booking systems and funding arrangements provide the textual organisation of the 15-minute consultation. These ruling relations alone do not coordinate the actions within the consultation. Further work organisations are present that support the maintenance of timeliness within the consultation. One particular work process this analysis follows is the restriction of the consultation to one concern. The instruction from practice managers organises the clinicians' work, who must aid the patient to select only their most important issue and control the consultation to work within this rule. With the clinician constrained to address only one concern, the experience of patients and what they can achieve from the consultation is also reduced.

GPs Megan and Cameron described their experience of organising the consultation. Megan said:

> You get patients with lists, like, they come in, and they say, I knew I was coming to see you, so I saved everything up, and it's like, well, actually, "what do you want to deal with on that list today?"

Cameron mentioned above that he helped patients to triage the list "before you can even start your HEAPS assessment" and would deal with more than one issue only "if [he] had time." The restriction of the consultation to a single issue coordinates the work processes of the clinician, and appears to support a timely consultation structure. But, this analysis suggests the restriction is achieving more than good time keeping.

Megan and Cameron describe arranging the consultation around the HEAPS format, which is framed around a single health concern - one assessment is one appointment. While the 15-minute consultation has been historically organised to deliver primary care services, the introduction of NPM principles has increased the burden of data collection and reporting requirements on practices and clinicians (Downs, 2017), such as health targets, clinical performance management, and prescribing practices. The Royal New Zealand College of General Practitioners (2021b) themselves stated that "The 15-minute appointment model – a model that is 30 years old and outdated, doesn't work for patients with complex mental health conditions" (para 4). What can be said and done within a consultation and the ability of the patient or clinician to raise or address more than one issue, particularly if complex, is constrained.

In some settings participants noted the requirement to constrain a consultation to a single issue. This was mentioned by patients and sometimes noted in signage and patient education documents. While the clinicians' work processes appear to support their learned assessment practices of a single issue at the centre of the consultation, business practices may have taken up the single issue as a tool to maintain the 15-minute arrangement. For example, the patient information sheet from a large primary care centre discussed in Chapter five had this advice for patients regarding multiple health issues:

> If you have more than one health concern, make a list and show it to your GP or Nurse when you come. Together you can agree on which items are the most important and need the most attention. More minor things can be dealt with if there is time.

This message from this particular IFHC suggests there is a degree of partnership in the decision-making process that organises the consultation. Notably, though, the message locates time, not need, as the factor that determines what can be said and done. This hierarchy of power was reflected in the accounts of patients. Tim talked of having a list of issues that needed addressing:

> I take a mental list. And usually, my appointments often back up, so I have a big list of things to talk about, and that's a financial decision. And to a certain degree, I get through everything on my list. But I think it's to do with the doctor's willingness, and I make sure I've got everything neatly ordered for them so they can whip through.

Tim achieves more than one issue within the consultation but has organised himself and his list so the clinician can "whip through" the issues quickly. In comparison, Louise attempted to introduce more information or concerns into her appointments and found the clinician not able to make room for anything else. Louise, as a patient, is more complex than Tim, and Tim's list probably fits the scope of "more minor things," rather than new or complex health issues, which is seemingly more suited to addressing in the brief consultation. Louise does consider that she should book longer consultations but says she has "already spent a bomb and got nowhere" with her GP. In the case of Louise, then, in addressing only one issue, the timeliness of the consultation is shored up. Therefore, one issue supports the business needs, and not Louise's, again showing how she struggles to be at the centre of care with her complex needs.

Research literature from New Zealand sits alongside the findings in this study, showing the widespread presence of the ruling relation to limiting the number of issues a patient can raise per consultation. GPs interviewed in Stokes et al., (2017) exploration of primary care professionals' roles in managing multimorbidity in the New Zealand population mention the processes followed by GPs within the consultation. The following interview account[34] shows how a GP navigates a patient with more than one issue in the moment:

> Sometimes if they're got a whole list of things you have to just sort of divide the list up and say, "Look, we'll do this today and maybe we can, we need to do something about these things, but then you can come back and we'll do the other thing. [Participant 2 GP in Stokes et al. (2017, p. 5)]

Here the GP is doing the work of restricting the consultation in a sensitive manner. Interestingly, in restricting what can be achieved in a single consult, this example suggests continuity of care is required to manage additional issues as the GP suggests the patient can "come back and we'll do the other thing." However, this current project found that continuity of clinician or even a follow-up appointment in an appropriate timeframe was difficult for patients to achieve in many settings.

In a separate study by Millar et al. (2018), patient participants reported prioritising their discussion points before the consultation instead of waiting for the clinician to determine the consultation focus. Either way, the scope of the consultation is reduced, and the institutional priorities are accomplished. When this work is done exclusively by patients, as in Millar et al.'s research, the neoliberal undertones of health systems are reinforced, and patients become ever more responsible for the economic success of the business at the cost of personal and community wellbeing.

It is important to recognise the ruling relation of one issue and the encouragement of patients to triage their needs as a tool to accomplish neoliberal agendas. The abovementioned practices can further the harm already present within neoliberal health practices where individuals feel the stigma of personal responsibility for their illness/long term condition or poverty (Barnett, 2020). Placing the blame of overflowing consultation needs on the patient, such as Megan's comment about the person with long term conditions "who always takes a really long time" and Louise's experience

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[34] Interview data shared with permission from research team.

of being told, "I have other patients to see you know?" is troubling. Rather than recognising the rule as the problem, these clinicians are captured by ideas of patients at fault, which perpetuates the stigma and harm.

Returning to a quote from Alex shared in Chapter one, their awareness, as an NP, of institutional rules, coupled with their discomfort with the consequences for patients when adhering to the business rules, exemplifies the contradiction. Significantly, Alex does not appear to be captured by the neoliberal focus. Alex says:

> Our practice; we are *only* allowed to, we are supposed to ask the patient, "what is your most important concern for today?" and we will address that, and you need to make another appointment for the others. How scary is that? How scary is it that that patient had to build up the financial resources to come and see you with their five problems, and today, sit in front of you, only for you to go, "sorry, you need to pick one of them."

Alex also knows about the directive from management to address only one issue for each patient in a single consultation, just as the previous clinician in the accounts above. Alex is aware, as an employee, of the pressures of maintaining a financially viable business which are made intentionally visible by management. However, Alex's nursing knowledge competes with the authority of the practice manager, which challenges their ability to practice in a way that satisfies their professional need to complete the episode of care and to meet the needs of the patient fully. Alex wants to be responsive to the patient's unique needs in each consultation, a core component of being person-centred, but their tension suggests this way of working does not fit in the ruling relations organising the consultation. From their location, Alex is not able to simultaneously be a good NP and a good employee. In the following example, Alex shares their challenge in working within the business rules while providing care to the best of their professional knowledge:

> So I had a 29-year-old female come to see me: She had headaches, tummy ache, we started talking, and she's under a lot of stress at home, a lot of financial trouble, starting a new

> job, a four-year-old at home. And we got to the point where we talked about sexual health, and she said, "oh no, I'm not on any contraception," so I asked her, "are you trying for a baby at this stage?" so said, "oh, please no! That would just add to the stress." She's got all these things going on but never thought of contraception and preventing putting extra stress on her already stressful life. And she's been seen by quite a few medical staff in the last three weeks, and nobody asked her about that. I was quite concerned. That's what I'm trying to describe, the social, the understanding, and do we have enough time for that? No. So you rush through your consult, and now I need to make sure that she gets contraception, etcetera, then we get to the diagnosis.

In this example, this clinician is doing the empirical work of being person-centred and is operating outside of the single issue focus seen in other clinicians' accounts. Alex demonstrates involvement in and care for every aspect of the person sitting in front of them. They deal, with decorum, to the many difficulties the patient brings, not just their single biomedical problem. Alex shows empathy, respect and engagement with the patient, assessing them holistically, and together reaching an agreed decision, meeting many hallmarks of person-centred care (Håkansson Eklund et al., 2019). Remember, IFHCs promote on their website and patient enrolment packs they deliver person-centred care. But, the administrative rules stipulating one issue per consultation work directly against Alex's ability to be person-centred.

Models of care and the ruling relations

There is a relationship emerging in the data above between the time afforded to a consultation, the model of care that can be delivered within that time, and the ability of patients to have their needs met. The reductive medical assessment structure as described by Megan appears to fit the 15-minute consultation window. However, as Megan suggests, it "may not always be the best way." The 15-minute consultation undermines the ability of the clinician to be responsive to the patient's multiple unique needs should they deem it clinically necessary. The clinicians are institutionally organised to be issue-centred. Therefore, the clinician is not free to attend to the whole person, owing to employee accountability as coordinated through professional organisation imperatives. Moreover, in restricting consultations to a single issue and limiting the time to 15 minutes, the consultation is structured to prioritise the disease or health deficit over prevention and overall well-being. The clinicians' work, in this way, is organised *away* from person-centred care. Being able to respond to the actual context of something is disappearing.

Patient accounts such as Louise's reveal the frustration for patients who feel this model of care does not meet their needs. Louise appears to be seeking a clinician to slow down, consider her complex history alongside the new or worsening concerns she now faces, and assess her holistically as a unique individual. Meanwhile, Alex, an NP, describes a model of care that appears well matched to the complex needs of patients like Louise, but there is great difficulty for Alex to deliver this care in the allocated time. This finding aligns with significant literature demonstrating increased patient satisfaction and improved outcomes when care follows the nurse practitioner model of practice (Carryer & Adams, 2017; Laurant et al., 2018; Martínez-González et al., 2014). It is frustrating then, that NPs appear caught up in the restrictive consultation rules of GPs and are not free to deliver care to the full breadth of their model without consequences.

Lyndon Keene, a senior policy and research adviser for the Association of Salaried Medical Specialists, said in personal communication (March 3, 2017), "My overall view is that there is increasing pressure on clinicians to do things more quickly when most of the evidence supporting patient-centred care is to slow down." However, as this analysis suggests, patients' experience is shaped not just by time but also by the clinicians' assessment model. This raises the question of whether the traditional assessment model as employed by the primary care sector can indeed deliver person-centred care as it is presently arranged. General practitioners are an increasingly scarce resource and facing a workforce crisis and burnout (RNZCGP, 2020). Instead, it is perhaps time to rethink the historical model of care where the acute assessment model fails to adequately embrace complexity of the person as a whole (Browne & Tarlier, 2008; Carryer & Adams, 2017). As Dillard-Wright and Shields-Haas (2021) argue, "Ignoring holistic health and well-being to focus on singular medical tasks and disease processes is reductive, violent, and contrary to humanization as a disciplinary focus for nursing" (p. 199).

There is a shifting workload, driven by the PHCS, which aimed to advance the roles of nurses and others to support the management of increasingly diverse population needs (Finlayson et al., 2009; King, 2001). In practice, people with long term conditions and people with simple requests are reallocated to clinicians other than GPs and NPs. In shifting this workload to other team members, the GPs and NPs should then be free to "slow down" and deliver person-centred care for the remaining patients. However, Megan suggests this shift leaves the GP/NPs "with the most complex cases." Megan shared this about how she perceives the shifting workload where she works:

> With a massive population that's ageing and chronic conditions are becoming a bigger burden, and with less GPs, there had to be a shift in workload. And that's where the long term conditions nurses and the nurse specialists coming through has made such a huge impact. For example, the diabetes nurse, I can't remember the last time I changed someone's insulin dose because they just do all that. But because of that shift, what we're left with are the complex cases.

There is an interesting point to be made here in the defining of complexity. It can be determined by the level of co-morbidity, significant illness and pharmacological challenges. But nurses are also taught about the intersections of deprivation, ethnicity, rurality, any form of marginalisation or vulnerability. Megan above appears to be making assumptions about the nature of complexity from a biomedical perspective only.

It seems that while the 15-minute consultation, framed around a single issue to support diagnosis and prescribing, was initially considered an effective way to manage primary care consultations, it no longer suits the needs of the patient or the clinician in a context of long term conditions and mental health and addiction concerns. Additionally, there is now greater awareness of the contribution of socio-economic determinants and health literacy and the need to factor these into a useful consultation. The arrangement now represents the needs of the business and is reinforced as a unit of funding. Meanwhile, patients require something different. Some clinicians are acutely aware of this tension, where there is a conflict between their knowledge of patient needs and their responsibilities as an employee. However, despite shifting workloads and changing needs, it appears that the clinicians' accountability to the practice to address one issue and remain within the allotted time is more powerful than their professional accountability to the patient.

Clinical safety as an alternative explanation

The HEAPS format used by GPs, Megan and Cameron includes 'S' for safety net. Safety netting is a way of promoting patient safety in the consultation and "aims to empower patients and protect healthcare professionals" (Jones et al., 2019, p. e74). While safety netting is considered best practice, there seems little consensus on what it is or when it should be applied. Multiple descriptions of safety netting in primary care are found in the literature, including ways of communicating uncertainty around the diagnosis; providing information to the patient on red flags and symptoms to watch out for; when to seek reassessment; follow-up appointments; diagnostics; and referrals (Jones et al., 2019). Safety netting in the consultation is considered especially important for children, those who are acutely unwell or have multi-morbidities, and those with mental health issues (Jones et al., 2019).

Wider explication of one problem per appointment revealed different logic internationally. Attempts have been made to establish one issue within the powerful ideologies of clinical safety. For example, when searching for general information for patients regarding primary care appointments, a general practice in England had a message on its website stating:

> We kindly ask that all patients try to stick to our one problem per consultation policy. The main reason for this is **clinical safety**… presenting the clinician with multiple problems means there is a real increased risk that mistakes will be made and things missed as the clinical may be inclined to rush, particularly if other patients are waiting" (The Chorley Surgery, n.d.[their emphasis]).

This example was not unique and reflects a safety-focused health policy trend. However, while this assumes safety, by restricting the patient to stick to one problem during the consultation, the consequence is that patients themselves are being asked to determine what is diagnostically critical to their health issue.

As an ideological concern, safety has strong traction in New Zealand health care policies, often discussed hand in hand with quality ideologies (Health Quality & Safety Commission New Zealand, 2013b; Merry et al., 2017). Within health care delivery, the introduction of practices to improve safety *and* quality of care are increasingly common, often in conjunction with the standardisation of practice. Other institutional ethnographic research, such as Boonen et al. (2018) has demonstrated how a safety-focused, standardised and electronic method of checking and administering medication subordinated health care workers' situational knowledge of safe medication administration practice. Findings from Boonen et al.'s (2018) ethnographic study of nurses' barcoded medication administration challenge the safety discourse. The researchers identified unchallenged dominant discourses of safety that overruled genuine safety measures in practice, highlighting the problem of standardised solutions to unique safety issues.

The ideology of safety may have similar potential in the organisation of primary care encounters. Should the standardised notion of one issue be taken up as a matter of clinical safety in New Zealand, the clinicians' accountability to institutional safety may be used to overrule their situational knowledge of risk and safety for the person sitting in front of them. This was powerfully demonstrated in the accounts of both Alex (clinician) and Louise (patient). This paradox between standardisation and safety comes to a head in chronic disease management, where the balance of safety for clinicians and safety for the patient clash. Patients living with long term conditions require considered, culturally and socially appropriate goal setting, self-management support and personalised integrated care (Askerud et al., 2020; Carryer et al., 2014), not a clinician whose assessment capacity is reduced to a single biomedical health concern, regardless of the reasons supporting this restriction.

Patients like Jan, with her co-morbidities and care requirements associated with the natural ageing process, represent the largest population of users of primary care. The New Zealand population is ageing, and more people live with long term conditions (Ministry of Health, 2016a). Multimorbidity is recognised as the current norm in New Zealand's over 65 population, and at present is associated with poorer health outcomes and more frequent use of health care services (Stokes, et al., 2017). People presenting with complex and enduring needs do not fit in a restrictive single issue consultation. At present, patients like Jan are responsible for ensuring all of their care needs are met, despite the standardised and regularised practices that appear to make it increasingly difficult for these patients to do so.

Transfer of accountability

The accounts from patients and clinicians suggest a shift in accountability from practice to clinician, and from clinician to patient. This shift is happening alongside the promotion of a consumer-based and person-centred rhetoric which obfuscates what is actually happening. For example, enrolment with a primary care provider is promoted as a consumer choice, with the familiar freedoms of an open marketplace. However, as Louise and Tim found, the limited availability of practices enrolling new patients severely restricts the person's ability to exercise freedom of choice. Patients are accountable for personal wellbeing, but are limited in how they can achieve this within a primary care relationship. And as Jan found, once enrolled in a patient-practice relationship, her ability to choose her clinician was hampered by the rules of the practice's booking system. In labelling these practices consumer-based or person-centred, the work of patients to navigate enrolment, and take on the workload of securing continuity of care is covered up, and patients are conditioned to believe their role in accessing and using primary care services is normal, or that they are expecting more than the system can routinely offer. To some extent this is a situation of increased accountability for patients and clinicians but with diminished control over the exercise of that accountability.

Elsewhere in the process of using primary care services, the responsibilities continue to shift. Louise and Helen found themselves solely responsible for navigating complex healthcare systems, with the consequences of becoming lost or stuck apparently entirely theirs. Once inside the consultation space, patients are responsible for "know[ing] what to ask," and clinicians find themselves accountable to restrictive practice rules. These practices and rules that hold patients and clinicians accountable appear to be in the interest of the business, ensuring efficiency and routine. However, arguably the clinicians' dominant accountability should be towards the patient and the delivery of safe health care (Wallis, 2013).

In addition to holding patients and clinicians accountable, the texts identified in the coordination of the troubling practices achieve something else. The texts, such as enrolment processes, appointment booking systems, patient education tools, consultation frameworks, and employment contracts are developed by various players in health care: general practices, independent medical interest groups, crown owned enterprises and more. All of these texts identified carry a powerful common interest into the ruling relations. That is, texts reviewed in this project are built on the hegemonic foundation of a doctor centric, biomedical model of primary care delivery rather than the more comprehensive delivery of primary health care as intended by the vision of the PHCS.

A patient can request an appointment, but they must participate in the GP triage system to ensure they have the right issues for the right appointment. Medically unwell patients are prioritised access to GP care. A patient can learn to know what to ask, but part of that knowing includes a socialised understanding of the biomedical approach to primary care. A patient can have a list of issues, but they must learn to triage this list, deciding the "most important" issue. Regardless of the issue in focus, patients must accept the consult is limited to 15 minutes. One patient, one appointment, one concern. These texts and text-based practices are perpetuating the western biomedical approach of knowing the primary care systems' rules, practice and procedures to work (Came, 2014). Any attempts to work outside of the biomedical framework, such as Alex's attempts to conduct holistic assessments, are obfuscated by the powerful ruling relations that bring any alternative care practices back in line with the process that achieve the institutional purpose.

The vast complex of socially organised knowledge through which the small hero (see Chapter one) looks up is embedded with dominant medical understandings and assumptions about how healthcare works. The small heroes are subject to these relations, as seen in the first two analysis chapters. These relations organise their everyday experiences. Further, clinicians are accountable to their employer for maintaining these practices and procedures. As a new layer of accountability, the whole system the clinicians operate within is measured and evaluated through the primary care patient experience survey, as the next chapter explores.

Participating in the discourse

In shifting the work onto patients, some patients took up the discourse of the health world to enable effective participation; recognised as taking up the institutional discourse. Liza McCoy (2006), drawing from Richard Darville's work on organisational literacy, says this about people who are able to participate in the institutional discourse:

> Those who can appropriate the institutional discourse can often move with greater ease through its process; they know what to expect, they can imagine how things work, and they have the language to advocate for themselves and their families (p. 119).

Historically a specialised genre, reserved for those who have privileged access through formal education, the discourse of biomedicine is now more available than ever before, owing largely to the free mass distribution of information on the internet. Not all participants engaged with health research or attempted to take up the institutional discourse. Others, however, undertook substantial personal work to learn about their health.

Louise leveraged health professional contacts as well as internet-based health information to validate, dispute, or compare biomedical knowledge. In reading and interpreting the institutional discourse, Louise encountered substantial health literacy demands significantly greater than those found in day-to-day health access. Considering that health literacy already impacts on consumers' ability to access health information, care and services (Ministry of Health, 2015), Louise's work is all the more impressive, but also out of reach for many. By appropriating the discourse, Louise talked with medical professionals comfortably, even at times using findings to influence clinical decision-making. Interestingly, Louise did not "move with greater ease," in fact, her path was wrought with challenges, perhaps suggesting that not all patients and not all institutional discourse can be used equally, but certainly Louise gained traction and advances from her work and knowledge. Conversely, those who do not have the language or health literacy to participate as Louise did are known to experience worse health related quality of life (Jayasinghe et al., 2016), a concern that disproportionately affects our Māori and Pacific populations (Sa'u Lilo et al., 2020).

In some cases, an approved version of the biomedical discourse was made intentionally available to certain populations. Helen was provided with recommendations for education sessions to attend to learn formally how to care for her husband with Alzheimer's disease. There was an expectation that Helen would attend this education, and further, that she would follow the recommendations. No assistance was offered to enable Helen to attend the sessions. Helen's work to prepare Ian for her brief absence, to arrange for a friend to be with Ian, to leave the house, attend the sessions, return home with armfuls of reading material, and to take time to read and process the information she was given, is institutionally invisible. Helen leveraged her many support networks to enable her attendance at the education sessions. Had she not been so well resourced, thus unable to attend the education, she may have been labelled as unsupportive.

However, the cost of Helen's work to cohere with expectations is personal. She said to me "I don't have time to process it, that's one of the things … because it's happening all the time and so fast, and then there's no one to really talk about it to." When I asked what she had to do to fit this additional work into her life, her reply was simply, "I give up stuff." Helen prioritises the expectations of the health care system over her other everyday activities, but the reward for her efforts is the ability to participate with some authority when accessing care for Ian. Understanding how things work and having the language to advocate for themselves was not always enough, as the same dominant structures of the primary care system continue to rule over the success of their attempts.

Evolving problematic

The dominant structures of the primary care system appear to displace patients from the centre of care. Further, these practices no longer seem suited to meeting the needs of patients. As the population continues to age, multiple diagnoses become even more common and socio-economic indicators continue to influence health status, the 15-minute model must change to meet the needs of the patients and to protect the safety of the clinicians. The present arrangement of a consultation, addressing one issue within a tightly restricted time, as seen in Megan and Cameron's accounts, introduces new work for patients who work within or around the rules to ensure their needs are met. In taking up this new work, and working around the problems brought about by the rules, patients perpetuate the same issues, without any substantive change. It appears that patients save a broken system from failure, and in doing so confine themselves to the same broken system that they accept as the only way to access and receive care.

The changes that are occurring in primary care may further displace patients from the centre of care. Primary care in New Zealand is recognised as evolving from solo practitioner 'cradle-to-grave' care to larger group practices owned by corporations, or less frequently, by trusts (see discussion of workforce planning in Chapter two). With this evolution, the family GP/NP is increasingly replaced with the next available clinician, when the issue needs prompt attention, such as the example in Louise's story. Further contributing to this shift, it is becoming more common for GPs to work part-time as employees of a corporation (Goodyear-Smith, 2015). Working within a for-profit corporation introduces new bureaucracies to the consultation appointment, which have perniciously entered into the work of both frontline clinician and patient.

The accepted social practice of attending primary care appointments is grounded in the ruling class of knowledge owned by medicine. That is, it has come to be known as common sense, that if in need of non-emergency medical care, we make and attend a medical consultation. Louise's account demonstrates her acceptance of this common sense, despite the multiple negative experiences she described, and the lack of improvement in her well-being. Dorothy Smith wrote, while teasing out her early ideas of social organisation and documentary reality: "In taking [the] social organisation of knowledge for granted we confine ourselves within that relation."(1974, p. 258). This analysis suggests the same practices are accepted and repeated just as Smith implied. In returning to the problematic - the gap between a patient's actual experience of regularised care practices and the promise of person-centred health care - the regularised practices come to be seen as socially accepted and reinforced by those using the services.

Finding a 'fit' elsewhere

Recognising the regularised care practices discussed above, it is interesting then to learn that Louise was able to find an alternative form of primary care outside of these rules. Louise's work described above was orientated towards making a fit for herself within the rules of the health care system, yet despite these efforts, she was still unwell and dissatisfied with her care. She recognised that her efforts were not sufficient and that the clinicians did not appear to have the resources to help her any further, saying:

> I suppose I've always had huge respect for medical professionals, which I still do, but in terms of my case, I've realised that they [the doctors] didn't have all the answers, that they weren't prepared to or didn't have the time to look into it further. Their extent of looking into it further was consulting their colleagues. I just didn't feel that they had the time, money, energy or drive to look into things further, to get to the bottom of my issue.

Identifying that the GPs did not have enough time or resources, Louise continued to research her symptoms and conditions alongside her everyday healthwork. Louise wanted to learn what else she could do to support herself. Recognising that despite two years of tireless work and acknowledging the limits she experienced in public primary care, she looked elsewhere for help. She came across an alternative doctor she thought might be helpful for her. When describing the decision-making behind seeking alternative medicine advice, Louise said: "So I felt that at that point if I didn't do anything about it, I was actually going to stay in the same health position I was, or get worse. I knew it would cost a lot of money, but I needed help from someone who had the time and energy to really help me."

Louise recognised that she "had to change [her] whole mind-set" when exiting public primary care. The private GP Louise found works with natural medicine, mainstream biomedical medicine, and homoeopathy. Louise described the patient interface with the alternative GP:

> Her appointments are for an hour, at least, and cost a lot of money. She listened to me. I sent her an email of my whole history, so she had the heads up about what I had gone through, where I was at.

Louise described her logic behind writing the email:

> I thought, I know my appointment is only an hour… I don't want to spend the whole hour talking about my journey; I want help. Because previously I don't feel like I've had the time to share everything that I felt I needed to share to give the doctors and the specialists I was

> seeing the whole guts of where I was at. I had to rush through… so that they would quickly give me something to treat me, rather than me having time to explain myself, and I often felt rushed.

Louise has found this alternative physician to be more holistic:

> She spent time talking to me about everything I had written in that email, and she looked at things holistically, not just as isolated issues or symptoms or complaints. And she gave me some different… she wasn't against modern medicine at all… but she gave me some other medicines to help support my body to recover and to get back to a sort of normal functioning state. Again, these cost a fortune, and eventually, I was able to come off the Prednisone with the support of the other medication she had given me.

The natural health clinic Louise found sits on the cusp of public and private health care. The clinic receives funding through PHO enrolled patients, but also cater for non-enrolled patients who are charged the full consultation cost. The clinic allows for flexibility in their appointment scheduling, arranging the time of the appointment to match the needs of the patient, rather than patient needs being forced to fit a rigid consultation time. To accommodate this, the clinic is also flexible in their consultation costs, but as Louise says it "costs a fortune." The costs reflects the service provided, as opposed to standardised consultation charges observed elsewhere.

In working outside of the 15-minute, one issue per consultation, the private GP is able to attend to Louise holistically. With this attention, Louise believes the private GP has been successful in improving her quality of life. Louise said: "she's got me to where I am today, not that that's the end of my story (laughs)."

Louise's description of her experience with the alternative GP appears congruent with the notion of person-centred care. The personal interaction and treatment the practitioner was able to provide Louise reveals different rules operating in the alternative institutional complex. Time does not appear to be rationed, and services or treatments deemed appropriate for Louise appear to be based on a comprehensive assessment that extends far beyond a single issue or presenting problem. The regularised, standardised processes are not present in this alternative relationship. Unfortunately, the significant financial cost of this care excludes a very large percentage of users of the publicly supported primary care services, leaving the current general practice model their only choice.

Chapter six conclusion

This chapter has explicated the concerns of the constrained primary care appointment. The ruling practices of reducing a consultation to a single issue, and restricted to a 15 minute time slot do not meet the needs of patients living with long term or complex health concerns. The accounts of general practitioners show their adherence to the standard assessment framework (the HEAPS assessment) further reduces the flexibility of the consultation to meet a persons' unique needs. This restricted and standardised actuality, as described by patients, subordinates the fundamental principles of person-centred care. However, *some* patients were able to construct a fit within the standardised model of primary care where they were able to occupy the centre of the care relationship. These patients did so by leveraging various social resources, and by speaking over the rules that were restricting their ability to be at the centre. Ultimately though, it was only Louise who was able to foster a genuinely person-centred relationship with a primary care provider – but to achieve this, Louise had to work outside of the Government funded primary care system, which required a high degree of personal agency and substantial resource commitments and sacrifices.

In concluding this chapter and completing the work processes that populate the wheel diagram below, there are two main outcomes for patients at the conclusion of a consultation. The first, patients exit the consultation process with the necessary text(s) after having a single health issue met. For example, Tim, once he had secured a consult, required a prescription for the medication change, after which he could exit the work processes. Elsewhere, after learning the complex practices and procedures required to both access and successfully use primary care, some patients find themselves back to the start of the patient journey without their needs met. There are no shortcuts to take or levers to pull that advance a patient with unmet needs back into the assessment process. Patients like Louise, who leave a consultation without answers, with ongoing troublesome symptoms, or with an unclear pathway, find themselves back at the start needing to make an appointment with their primary care provider.

The institutional processes are designed to coordinate the flow of patients as they journey through primary care services. Some patients do not or cannot leave primary care. As for passengers on a bus, there need to be many stops at different locations to meet the unique needs of those on board. When those passengers need to get back on the bus, they would expect to hop on where they got off. Similarly, patients in seeking continuity of care and ongoing access to primary care services are not best served by returning to the start each time, with unfamiliar clinicians, or lengthy waits for the next bus. The following chapter which examines the primary care experience survey takes up these issues to see how such problems are recognised and dealt with through the authorised knowledge of patient experience and quality improvement.

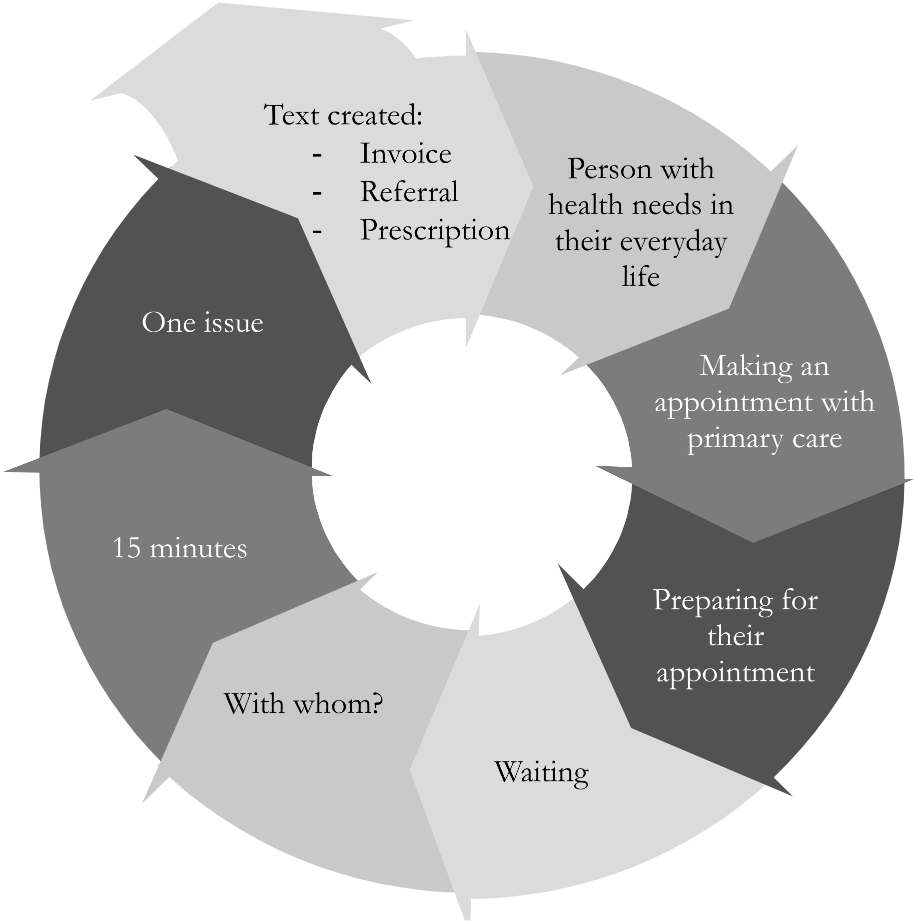

Figure 9. Progress wheel through frontline analysis (C)

Chapter Seven – Analysis part three: Evaluating the experience of patients

"Information is a social product and how it does or does not conform to what it purports to represent can and must be examined" (Rankin & Campbell, 2006, p. 182)

Introduction

The previous data chapters described patients' work to seek, access, follow up, and generally use primary care services to ensure their health needs are met. The standardised model of care and the rules and practices that regularise the social processes of care were highlighted as significant contributors to the research problematic. An explication of the unsettling disjuncture between the on the ground experience of patients and clinicians and the governing texts of primary care in New Zealand, which talk about a person-centred care system, further progressed the problematic.

This chapter interrogates how strategic planners and policy writers come to know of patients' embodied experience formally as 'patient experience.' The analysis explicates the primary care patient experience survey (the survey) (Health Quality & Safety Commission New Zealand, 2016b),[35] showing how a person's lived experience as a patient is constructed into an authorised form of knowledge. Drawing on Smith's (1974) discussion of documentary reality and the crucial point that Smith has called "document time" (p. 260), the analysis examines the processes and moments that knowledge is created and translated for official use. Smith's (1990a) "actuality-data-theory circuit" (p.152) further supports the analysis of patient experience as a data making process. Finally, the analysis considers the "ideological circle" (Smith, 1990a, p. 178) that subordinates patients' knowledge of experience and organises the authorised delivery of person-centred care.

This chapter presents the argument that the knowledge generated through the survey becomes part of a dominant consumer health care discourse that subordinates *what actually happened* as the

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[35] See Appendix D

patient experienced it. Further, the analysis shows that the survey is positioned within the taken-for-granted medical model of primary care and thus cannot speak for patients and the many problems that arise, such as the problems discussed in the two preceding analysis chapters.

Rankin's (2003) critical analysis of hospital-based patient satisfaction data as a taken-for-granted approach to quality care decision-making supports the text analysis constructed here. Further, Rankin and Campbell's work (2006) explicating the accounting logic of health reform, specifically NPM, reinforces the links made between the authorised knowledge generated from the survey and the accomplishment of health care reform. The outcome of this analysis offers a critique of how incentivised funding is used as a means for promoting quality care alongside the use of patient experience and satisfaction data as evidence to inform reform. This raises concern about decision-making and strategic planning to achieve quality care based on patient experience.

The primary care patient experience survey

The primary care patient experience survey (the survey) is a quarterly survey "designed to find out what patients' experience in primary care is like and how their overall care is managed between their general practice, diagnostic services, specialists and hospital staff" (Health Quality & Safety Commission New Zealand, 2021, para 1). The survey (Appendix D) is sent every three months to a national selection of adult patients who are enrolled with and have been seen by participating primary care services, and have a valid email address. First introduced in 2015, and now on its second iteration, the survey is made up of single selection and some short answer questions. Completion of the survey is voluntary and takes approximately 20 minutes.

Although I was aware of the survey at the outset of this research project, I was also referred to the survey by healthcare professionals during fieldwork interviews. Kate, an RN at an IFHC, identified the survey as the principal reason for the introduction of GP triage at the IFHC where she works (Chapter 5). This example suggests information from the survey is at work in the organisation of processes at the frontline of primary care. The purpose of this interrogation of the survey is to empirically connect the data used to inform such decision-making with the actual experience of people at the frontline. Although patient informants interviewed for this project have not participated in the completion of the survey, this analysis shows how their everyday experience is shaped by the patient experience data of others. The history and construction of the survey is examined before analysing how the survey works in practice.

Foundations of the primary care patient experience survey

The following discussion is compiled from conversations with people involved in writing, reviewing, and managing the survey, as well as substantial grey literature and web-based findings. From this investigation, a summary of points relevant to understanding the survey as it is used in practice today are shared below.

Beginning with an informant at the Health Quality and Safety Commission – a Crown entity responsible for the survey - they identified the key motivator for developing the survey was achieving the Institute of Healthcare Improvement's (IHIs) triple aim (Figure 11 below).

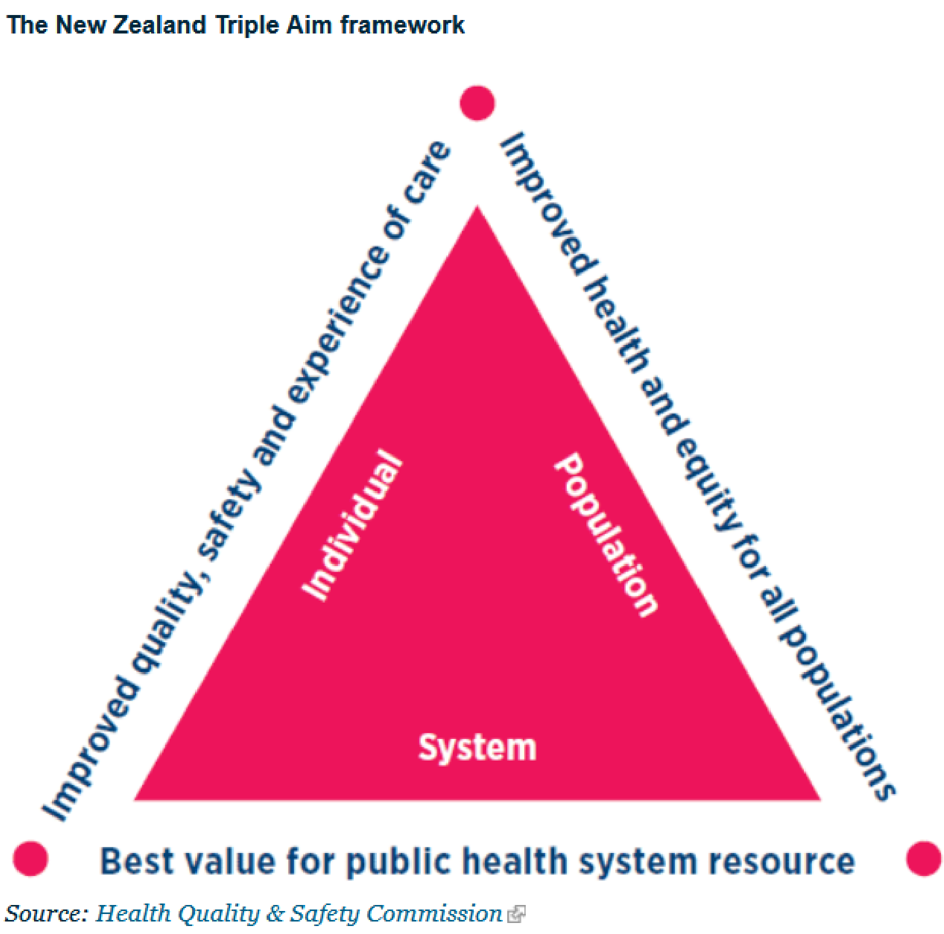


Figure 10. The New Zealand Triple Aim Framework (Minister of Health, 2016b)

New Zealand adopted Triple Aim as the guiding framework for the improvement of healthcare across the public health sector. The Triple Aim framework reportedly addresses a globally recognised unease for rising health expenditure and associated patient safety concerns (Merry, et al., 2017). According to the framework, simultaneous pursuit of the three aims should produce desirable health outcomes for all populations while avoiding wasting resources. The Health Quality and Safety Commission (the Commission/HQSC) was established in 2010, with an expectation from the Government that the Commission would lead quality and safety improvements in the health sector via the adoption of the Triple Aim. Thus, pursuing the Triple Aim is the foundational goal of the Commission (Health Quality & Safety Commission New Zealand, 2022).

The only clue suggesting how New Zealand came to be so deeply committed to the Triple Aim comes from a review of the first seven years on the triple aim, published by IHI researchers Whittington et al., (2015). Within the methods the authors state: "In 2007, IHI began recruiting organizations from around the world to participate in a collaborative to implement what became known as the Triple Aim" (Whittington et al., 2015, p. 263). New Zealand, alongside Australia, England, Canada, parts of the United States, and others, participated in this substantial healthcare quality improvement trial. This statement suggests New Zealand was actively recruited into a health care system goal which originated in the United Stated of America. This coincided with a period of time in New Zealand where healthcare was comparatively well resourced, with very short wait times for primary care services, improvement in inequalities, and increasing survival rates from non-communicable diseases (Ministry of Health and Minister of Health, 2007). Nevertheless, at the highest level of government, New Zealand adopted the Triple Aim as its long term goal.

One of the objectives of the Triple Aim framework is to improve patient experience of care. A survey was decided as the means to measure and monitor progress. The Ministry of Health tasked the HQSC to undertake the survey:

> In New Zealand, measurement of the quality and safety of the health and disability services of the nation is one of the responsibilities of the Commission. A framework of interacting measures has been established in an attempt to achieve this. A set of *quality and safety indicators* address the six aims outlined in the Institute of Medicine's manifesto, *Crossing the Quality Chasm*: safety, patient experience, effectiveness, equity, access and efficiency. This is done explicitly within the framework of the New Zealand Triple Aim. These indicators function at the level of the system, and cover high-level metrics such as, for example, amenable mortality, healthcare cost per capita/GDP and access to primary healthcare (Merry, et al., 2017, p.1103).

The authors above are all members of the Commission, who acknowledge the lineage between the Commission, the IHI triple aim, and the IoM. The same authors addressed the aim of improving patient experience of care, recognising the complexities of measuring experience this aim presents:

> This aim is interesting. Presumably, it is intended to direct attention to the care of individual patients. Experience is distinct from satisfaction, in that it is observable and can be related to predefined desirable or undesirable processes, infrastructure and outcomes. However, as others have commented,[15] there are limitations to using measures of patient experience for the comprehensive assessment of progress towards better healthcare. In fact, experience of care is arguably a reflection of the extent to which care is patient-centred, which is just one element of quality, albeit an important one[8,9] (Merry et al., 2017, pp. 1103-1104).

The survey, therefore, is the primary patient facing quality and safety improvement initiative focussed on the domains of improved quality, safety and experience of care. The survey carries the hierarchical knowledge of the IoM and the IHI into the New Zealand setting. This knowledge translation is further apparent in the development stages of the actual survey document, as discussed below.

To begin writing the survey, the Commission ordered a report to identify patient experience indicators to improve the quality and effectiveness of care and experience (KPMG, 2013). The report, among other background work, considered what was important to patients based on international frameworks from the Institute of Medicine (2001): six domains of patient-centered care, and the work of Gerteis et al. (1993): the Picker Institute Principles of Patient-Centered care. These international frameworks align with the lineage of the triple aim identified above.

In the report, KPMG (2013) recommends four domains as national indicators of patient experience, stating they are closely aligned with current international best practice. These four domains are communication, coordination, partnership, and physical and emotional needs. Each domain is supported by further detail or key elements or indicators to measure the domain. This process effectively determined the national priorities for patient experience and further detailed how the Commission (via the survey) could measure these priorities.

Smith's (1990a) exploration of encoding lived actualities into the relations of ruling is relevant here. The survey is a standardised actor in the process of encoding what actually happened for people experiencing primary care services to formulate an authorised account of patient experience. Smith writes:

> In the process of writing, making corrections, in thinking again about how to address a topic, in thinking through a topic so that it can be first thought, then expressed, adequately, clearly, and well, a text is developed that depends upon and intends to interpretative schema that has entered normatively into its creation (Smith, 1990a, p.153).

What is known conceptually as patient experience, gathered from the literature and assembled by KPMG (2013) for the HQSC, then functions as a predetermined schema where the experience of the patient is seen as we already ideologically know it. This leaves little room for the actual lived experiences of the patients. The four domains identified by KPMG (2013) carry international quality improvement literature, patient-centred literature and institutional knowledge from the IHI and the IoM to the frontline of primary care. It is also notable that New Zealand was recruited into the triple aim agenda thus, this institutional knowledge was intentionally introduced to New Zealand and may well be very limited in its applicability to Māori and Pacifica patients and their specific experiences and concerns. This is a recognisable example of Smith's (1987) position that institutional processes are designed/made/decided somewhere else, by someone else. Identifying the someone and the somewhere illuminates the knowledge and potential agendas embedded within the institutional process.

Following the development of the survey further, early feedback from focus groups regarding preliminary versions of the survey noted that patients wanted more of an opportunity to talk about the care they received in general practice (Woodley, 2015). Specifically, patients wanted to talk about how they were treated by staff, waiting times, the experience of being (or not being) listened to, rude staff, being rushed out the door, the high turnover of doctors, and many other areas that make up *their* patient experience, which they felt should be reportable in a patient experience survey. Yet, as this analysis shows, the institutional knowledge acquired through the survey speaks louder than individual experience.

Primary care patient experience survey in practice

The discussion that follows explores how a patient would pick up and activate the survey, how their answers eventuate as a measurement of quality within primary care, and how this may be followed by changes to processes and/or incentivised funding. Figure 11 on the following page is a map detailing the texts and work involved in the activation of the survey. This map illustrates the wider terrain of primary care that the survey enters into, much of which has been introduced in the preceding analysis chapters. When interpreting the map, data in boxes represent texts such as computer systems, strategies, patient information, the survey, and so on. Data in circles represent work processes undertaken by people as they respond to instructions/directions/processes and as knowledge is transferred or translated by people. Yellow circles further identify moments where this work is done specifically by patients. For example, patients enrol with a primary care centre, they make, prepare for and attend primary care appointments, as seen in the everyday activities of Jan, Tim, Helen, Louise and others in Chapters five and six. The following discussion begins from the yellow star on the map, with some reflection on the work and texts that come before this point.

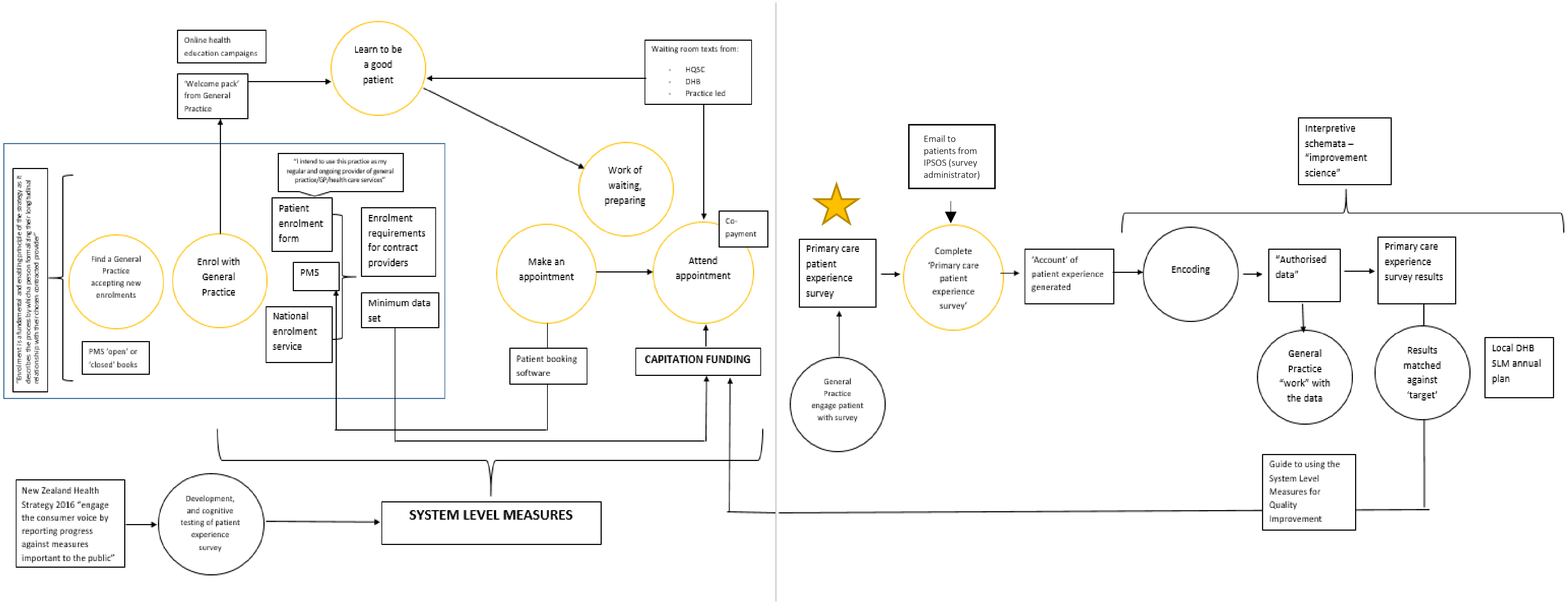


Figure 11. Map of the primary care patient experience survey within wider terrain of primary care

The yellow star on the map above locates the point when the survey enters into patients' everyday activities. As noted above, patients who attend a primary care appointment at participating practices during the week designated as survey week are sent an invitation to participate in the survey via email. To reach this point, patients have navigated general practice enrolment (Chapter 5), they have booked, waited for, and attended a primary care appointment (Chapters 5 and 6), and now they receive the survey invitation.

In their everyday experience of using health care services, patients may first become aware of the survey through a poster on the wall at general practices, such as the ones below.

Patient Experience Survey

Please tell us what you think of our health care service

We want to hear from you!

This week is survey week.

We want to know how you found your experiences with doctors, nurses and staff in the health care system.

The survey is voluntary, and anonymous. You can complete it at home, on a computer, tablet or smart phone. It takes about 15 minutes.

What do I have to do?

You will get an email or text inviting you to take part. Please help us improve the quality of health and disability services in New Zealand by doing the survey.

Ngā mihi nui, thank you!

Figure 12. Patient Experience Survey Poster. Retrieved from https://www.hqsc.govt.nz/assets/Health-Quality-Evaluation/PES/Patient_Experience_Survey_Flyer_English.pdf

Patient experience survey

HEALTH QUALITY & SAFETY COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

We want to know what matters to you.

Our practice is participating in a national survey to find out what your experience with health care is like and how your overall care is managed.

We will share your contact details, including email address and mobile number, only so that you may receive an invitation to complete the survey online.

Your privacy will be protected at all times through the process.

Taking part is voluntary. Your responses will be anonymous. You can choose to say no – talk to your GP or reception team.

The survey is a way for you to help improve care and access to health services in local communities across New Zealand.

Talk to your doctor or nurse if you have any questions.

newzealand.govt.nz

www.hqsc.govt.nz

open
FOR BETTER CARE

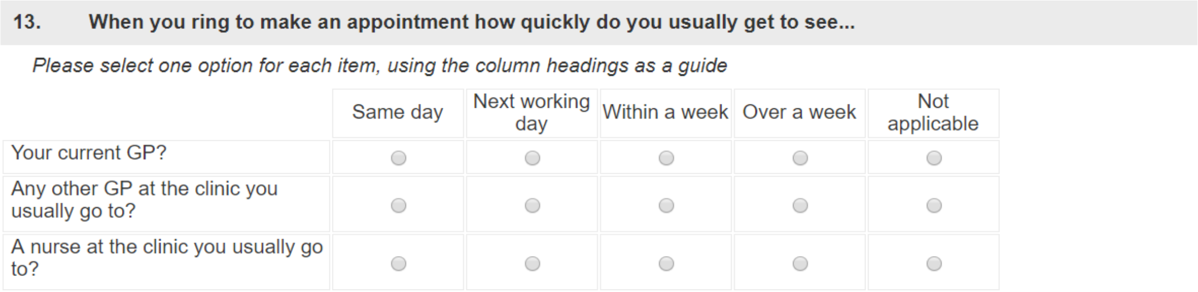
Figure 13. Patient experience survey information poster - https://www.hqsc.govt.nz/assets/Health-Quality-Evaluation/PR/PES/Poster-Aug-2016.pdf

Patients “who attend their general practice during the survey sample week ” are sent an invitation to participate via email (Health Quality & Safety Commission New Zealand, 2020, p. 29). There are two notable points relating to the invitation to participate. Firstly, the invitation is sent only to those who attended a general practice appointment, meaning those who tried unsuccessfully to make an appointment or those that needed an appointment but did not try for other reasons are omitted. Secondly, from a single survey round in 2019, nationally, for 46% of eligible candidates, neither the practice nor the national enrolment system had a record of a valid email address (Health Quality & Safety Commission New Zealand, 2020). As this analysis goes on to show, these issues are endemic to the outcomes of the survey.

Text-reader conversation

In filling out the survey patients are entering into a text-reader conversation. Reading a text, Smith (2005b) explains, is a “special kind of conversation in which the reader plays both parts” (p. 105). Patients, in reading and responding to the survey “activate” the text (McCoy, 2005). Patients filling out the survey become active in the text-reader conversation, where they are active in their part, but the survey remains fixed. In working with the text, patients must align their unique experience with the fixed categories prescribed by the survey. Figure 14 below is an example of the text patients will encounter. This example begins to highlight the challenge of engaging in the text-reader conversation, when the patient may want to say more than is possible, and when the question controls the terms of response.

The framing of the questions fits the conceptual structures already in place in primary care (which are identified as ruling relations in Chapters 5 and 6). As an example, in Figure 14 below, one question reads:



13. When you ring to make an appointment how quickly do you usually get to see...

Please select one option for each item, using the column headings as a guide

	Same day	Next working day	Within a week	Over a week	Not applicable
Your current GP?	○	○	○	○	○
Any other GP at the clinic you usually go to?	○	○	○	○	○
A nurse at the clinic you usually go to?	○	○	○	○	○

Figure 14. Question 13, Primary care patient experience survey.

The conceptual frame of institutional knowledge organises what is asked within the survey. The taken-for-granted structures of making an appointment and having a "current GP" locate this question in the ruling practices and knowledge of primary care. Further, the response, as a measurable outcome, is organised by powerful knowledge from healthcare services research such as the IHI and the IoM, as identified above. Healthcare services research "helps to order activity in health care through the questions it asks and the forms of visibility of health care it offers, all of which are a consequence of a particular configuration of calculative practices, narrative strategies, and forms of expertise" (Mykhalovskiy, 2001, p. 153). Here, the particular configuration is a biomedical-centric understanding of health visits, where the response determines a person's experience of access to care as it is officially known about, thus obscuring the fullness of human activity.

There is no opportunity in the survey for patients to describe their experience that does not fit with the given set of answers. In answering this question about making an appointment, I am reminded of a conversation with Jan (patient informant). Jan described to me how she would "push" (Jan's words) to see her preferred GP. Jan said, "He [preferred GP] can be a bit of a problem to get into… but I just push for him." In answering the question above, Jan may say 'the next working day' for her current GP. However, that answer makes invisible Jan's work of pushing for her usual GP, at a time that suits her. Neither Jan nor the practice benefit from this feedback, as the constraining answers render Jan's patient experience invisible. The interpretive schema to encode what is happening does not count work done outside of these parameters. It appears early in the analysis of the survey, that the survey is not asking the right questions to bring forth feedback that is important to patients like Jan.

Recognising the tension between the patient's actuality and the version of events able to be reported in the survey, I attempted to fill out the survey myself. I felt each question's principles were aligned with areas I would want to give feedback on; however, I was constrained by the multiple-choice answers. The moments where "yes, sometimes" was the appropriate response, the urge to give further information to exonerate innocent actors, or implicate others, or systems, was not wanted by the survey. I felt that critically important details about what actually happened had no place within the survey. The survey's methodology standardised my responses. I could imagine Jan having a few words to say while answering the question "did the reception and admin staff treat you with respect?" being limited to "yes, always; yes, sometimes; no" (HQSC 2016b, p. 3). In an interview with Jan, she commented about her new IFHC's unwelcoming environment. She described her contrasting experience of a previously very familiar receptionist who knew Jan by name and the transition to a large impersonal centre:

> You haven't got the same relationship. In the little practice, you walk up to the reception; "Hey Jan!" see? There [large IFHC], you line up and wait and there might be three girls and you don't know any of them, you know, whereas in the smaller practice you knew them all, they say hi to you.

Jan's experience may not be perceived as a lack of respect as such (highlighting the capture of shell terms and language practices). However, her experience, when translated into the formal account of the patient experience survey, can only be recorded as yes, always/yes, sometimes or no. Thus, valuable feedback that Jan's experience could provide the new practice is lost in the survey because the survey is accomplishing the health care systems agenda, not Jan's. A poor rating given on the survey for the reception and admin staff, if paid institutional attention to, would likely result in customer relations training for the team members when in Jan's reality, she is simply missing the personal "Hey Jan."

The 'key benefits of participating' section of the online information for patients cover letter claims; "The survey enables you to have a voice and the health teams that care for you can hear it through a direct and timely link" (HQSC, 2016c). The voice given to patients as claimed by the key benefits is at odds with the standardised responses of the survey. Returning to the concept of a text-reader conversation, Jan brings different knowledge to the conversation with the text, than those who design or interpret the survey answers. Jan's knowledge of familiar reception staff and personalised greetings collide with administrative understandings of customer service, as they are located differently in relation to institutional relations of power.

Both my attempt at completing the survey, and the hypothetical example of Jan, reveal something more about our silent transaction with the text. The conversation we have with the text is subjective. It is also clearly social. We are utilising socially learnt discourses, including the dominance of primary care and its biomedical foundations, to participate in the text-reader conversation. These are the social relations "learned as a member of society participating in determinate social relations, including those of the discourse in the context of which her interpretive work is done" (Smith, 1990a, p. 153). People participating as patients in primary care learn the discourse and do not question the foundations of the experience. As May (2007) suggests, learning to go and see the doctor is one of our earliest experiences of institutional organisation. In other words, the activity of seeing the doctor is deeply socially engrained, constructing a doctor's visit as a *normal* and unquestioned experience.

This awareness of dominant biomedical discourse is analytically interesting. Rigorous cognitive testing in the early stages of survey development identified which terms made it into the final iteration. Findings from this testing revealed that some of the language used were too unfamiliar, resulting in particular words such as triage and cardiologist removed from the survey (Woodley, 2015). Following this process, a set of institutionally directed questions remained using language the cognitive test participants agreed was familiar. The selected language reveals the degree to which the experience of healthcare is socially learnt through the participation of being a patient. The remaining language of 'GP,' 'appointment,' 'consultation,' 'medical history,' 'prescribed,' and 'dose' are some of the many examples of the *familiar* health discourse, notably the discourse of medicine.

A chance to change the discourse

During the final stages of writing up this dissertation, I participated in a consultation between the Health Quality and Safety Commission and representatives from PHOs across New Zealand. The purpose of the talk was to refresh the survey to keep up to date with approaches to patient care and the latest research around patient experience measurement. During the discussions, concern was expressed with the exclusive use of "GP" or "nurse" and the exclusion of "NP," when nurse practitioners provide a significant and growing degree of care in the primary setting. However, while agreeing that patients experience primary care from a variety of different clinicians, in their view, NP was "too new" and "too unfamiliar" (HQSC survey team member) and therefore would confuse patients completing the survey. Thus, while NP was eventually included as "NP or nurse" in the refresh and marked for "testing with consumers," the bundled inclusion was not the option the PHO representatives wanted.

Frustration with sector understanding of the role of NPs aside, other problems are emerging from this encounter. In agreeing to the changes as they did, the survey refresh team participated (either knowingly or unknowingly) to reinforce the dated assumption that primary care is provided predominantly by a GP. The hesitance to include NP for fear of confusion showed that the survey refresh team were powerfully organised by cognitive testing. The requirement for cognitive testing was used to speak over the request of the PHOs representatives for the collection of NP data which the PHO required to evaluate the role of NPs in patient experience. This exchange raises many questions about the value and capture of the survey questions. The survey appears captured by the institutional knowledge of the IHI, the IoM and the Triple Aim, and further, by the way primary care has always been done, and fails to be a receptive outlet for patients to feedback what is important to them.

Nevertheless, once complete, the survey acts as an account of each participant's patient experience. As a discrete piece of information, their account is available to data analysts and software programmes that are organised to reconstitute the everyday knowledge from the survey and construct an authorised way of knowing about patient experience. The 'virtual reality' (Smith, 1990a) generated from the analysis can be used to make authorised claims of knowledge about patient experience. This moment, where unique information is translated into generalising knowledge, must be explicated to understand what is accomplished through the translation and future use.

Document time

Central to this discussion is the explication of knowledge, particularly the tracing of knowledge as it comes to formally represent patients and their experience. Patient experience survey results, made up of multiple accounts of patient experience as described above, are finalised through textual processes, which Smith (1974) has come to call document time. Smith describes document time as "that crucial point at which much if not every trace of what has gone into the making of that account is obliterated and what remains is only the text which aims at being read as 'what actually happened"' (p. 260). That is, patients and their embodied experience, which they have drawn on to complete the survey, vanishes from view. In their place is a document made up of statistics and values, intended to stand in as the official account of their experience. Smith says of this phenomenon that the "textual real displaces ever her or his own experience of an event which he or her has been a part of" (Smith, 2005b, p. 28). In this case, patients are displaced from their unique experiences and replaced by numerical ratings.

Document time of the primary care patient experience survey

As described above, the patient fills in the survey, which is recognised as activating the text. The next step is to explicate the translation of this text. Institutional ethnographers recognise this as the point at which all individual perspectives become obliterated (Smith, 1974) to produce a conceptualised view of patient experience. Finally, then, to explicate how the survey as a text accomplishes the managerial agenda of health care. The critical observable feature of this workup is the transition in the language of the patient experience. This point of analysis is seeking the process which the actuality, as experienced and spoken in everyday life, for example; "I push to see *my* doctor," becomes available in the administratively useful specialised discourse of the survey as "communication scores." Smith (1990a) locates this point as "the disjuncture between 'lived actuality' and the professional and bureaucratic production of facts, where the discursive schemata generated by our work enters the process of constructing the textual realities of ruling" (p. 149).

This is the moment when the patient's account becomes theorised to enter an 'actuality-data-theory circuit' (Smith, 1990, p. 148). Smith states the circuit shows the "work of a professional intelligentsia articulating data to the social scientific or psychosocial discourse – elaborating theories and conceptual schemata" (p. 148).

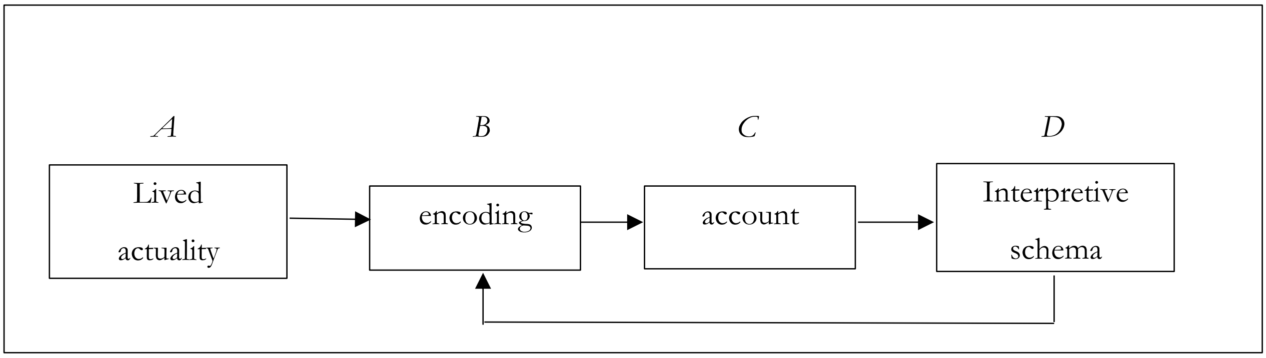


Figure 15. Adapted from actuality to account. (Smith, 1990, p. 152)

To analyse what happens to the survey data, I draw on Smith's (1990) diagram 'from actuality to account' (p. 152) as reproduced above. Here, the ordering work of encoding is explicated to show how the lived experience comes to be measured and reproduced as a standardised account that is knowable and managerially useful to healthcare policymakers and funding streams. In my application, *A,* and *C* occur at different sites, and both sites overlap at *B*. The lived actuality *(A)*, belongs to the patient. The account *(C)*, is the authorised knowledge of how the health system can know of patient experience. The encoding process *(B)* is the activation of the patient experience survey and draws together both the history of the survey; the process of how the survey writers came to formally know of patient experience, such that the survey was seen as an 'accurate' measure of experience; and the text-reader conversation that is entered into by the owner of the lived actuality. The encoding process moves an actuality into an account. Encoding "involves selecting terms and grammatical and logical connections that express the appropriate sequencing" (p. 152). The decisions made here derive from the interpretive schemata the account is intended to support (the arrow from *D* to *B*). These processes can also be seen in the earlier map (Figure 15.).

Completion of the process described above enables the production of authorised data, or officially, the authorised version of patient experience. Patient experience data fills in for patients' lived actualities, to put forward an objective way of knowing *about* patients. This objective way of knowing about patients is then taken up (through texts) into the administrative processes that activate system level measures.

System Level Measure: Patient experience of care

Patient participation in the survey is essential if the data collected is to be large enough for useful analysis. Patients are thus interpellated as follows:

> By taking part in the survey, you would be helping to improve care and access to health services in local communities across New Zealand.
>
> Understanding patients' experience is vital to improving patient safety and the quality of care. It helps us understand the quality of health and disability services. Currently New Zealand does not have a consistent national approach to collection, measurement and use of primary care patient experience information on a regular basis.
>
> (Health Quality & Safety Commission New Zealand, 2016c).

Patient information (above) for the survey locates the purpose of the survey as "improving care and access to health services" (Health Quality & Safety Commission New Zealand, 2016c). At PHO and DHB level, one of the drivers for collecting survey data is to measure performance against a System Level Measure (SLM). SLM's are "agreed improvement milestones" (MidCentral DHB – District alliance leadership team, 2018, p. 1), nationally defined to contribute to the strategic themes of the New Zealand Health Strategy and the notion of "living well, staying well and getting well" (Minister of Health, 2016a, p. 1). According to this strategy, the patient experience survey informs the goal of "ensuring patient centred care" (p. 1). Split into goals and targets, the overall intention or measure is for the DHB to deliver services such that patients experience safe, effective, quality patient-centred care.

Tracing the survey within governing documents, it enters the primary care setting through a commitment between DHB and PHO to achieve "value and high performance" within the PHO

Services Agreement (TAS, 2020, p.119). This document locates SLMs as one of the incentivised measures of value and high performance. The PHO Services Agreement also establishes the formal arrangement of performance funding provided by the Ministry of Health for the achievement of the SLM, of which 20% of the performance payment is dedicated to the patient experience of care.

> (4) We agree that the primary care performance funding provided by the Ministry, from which payments will be made to the PHO as described in clause G.8 to G.10, will be used to build capacity and capability in primary care to contribute towards the achievement of the System Level Measures and National Health Targets. (TAS, 2020, p. 119)

As an annual target for the year 2018/19, one DHB aspires for an "increase in uptake by General Practice Teams participating in the primary care experience survey" (p. 26). Here, the DHB is concerned with collecting the data, rather than the actual data findings. Making use of the findings is delegated to the PHO. For the same period, the regions PHO set the goal that "In Q1 at least 2% of total enrolled population newly register for patient e-portal, increasing to at least 5% between Q1 and Q2, and in at least 10% between Q1 and Q3" (Central PHO, 2019). The PHO justifies this measure of judging their goal of improving patients' experience of care by saying that: "Patient e-portals give people convenient and secure electronic access to their health information, increasing their ability to manage their own health care" (Central PHO, 2019).

The language and assumptions made here bring into view the texts that have materially mediated the institutional production of the knowledge and chosen discourse of person-centred care and patient experience. "Each layer of text is nested in the next" (Rankin 2003). Although not immediately apparent when activated within a colloquial reading of person-centred care, the institutional reading activates a formal, conceptual construction. The intersection of the texts reveals the adopted formal programme the health care institution is working within.

At the time of data collection, the primary care patient experience survey was still in the implementation stage, which accounts for why many of the targets were aligned with increasing survey participation rather than quality measures. Following this, the substantial changes in the primary care space owing to nationwide COVID-19 responses further disrupted the implementation of the survey. However, the inpatient experience survey has been in operation for several years, and is a useful example for predicting the future use of the primary care survey in this discussion.

Using the same SLM milestones how the targets take up the data of the inpatient experience survey to measure improvement becomes visible. For 2017/18, the DHB set the target of an "average score in communication and coordination of care dimensions of the inpatient experience survey is improved to ≥8.4" (MidCentral District Alliance, 2018, p. 26). In this numerical target, all the Jan's (and Hannah's and Janet's) disappear, even if their presence in the survey was not already woefully distorted and inadequate. The managerial agenda of the survey begins to come into view here.

In the image below (Figure 16) the right-hand column shows where the authorised knowledge generated by the survey sits within the evidence of SLMs. The primary care experience is an official contributory measure for "ensuring patient centred care."

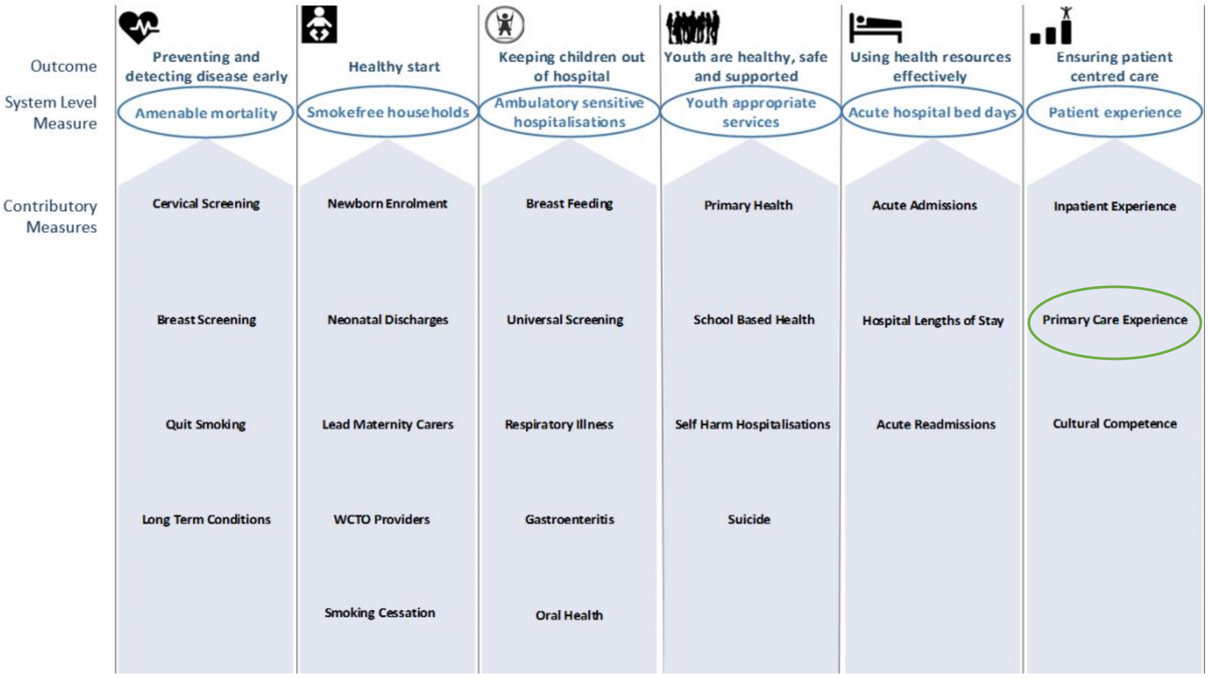


Figure 16. System Level Measures Overview. Retrieved from https://www.centralpho.org.nz/node/627

As a contributory measure, the primary care experience is then broken down into the four domains, as identified back at the conception of the survey. These domains come to be presented numerically as healthcare service research, to identify sites of inefficiencies, and spaces for improvement.

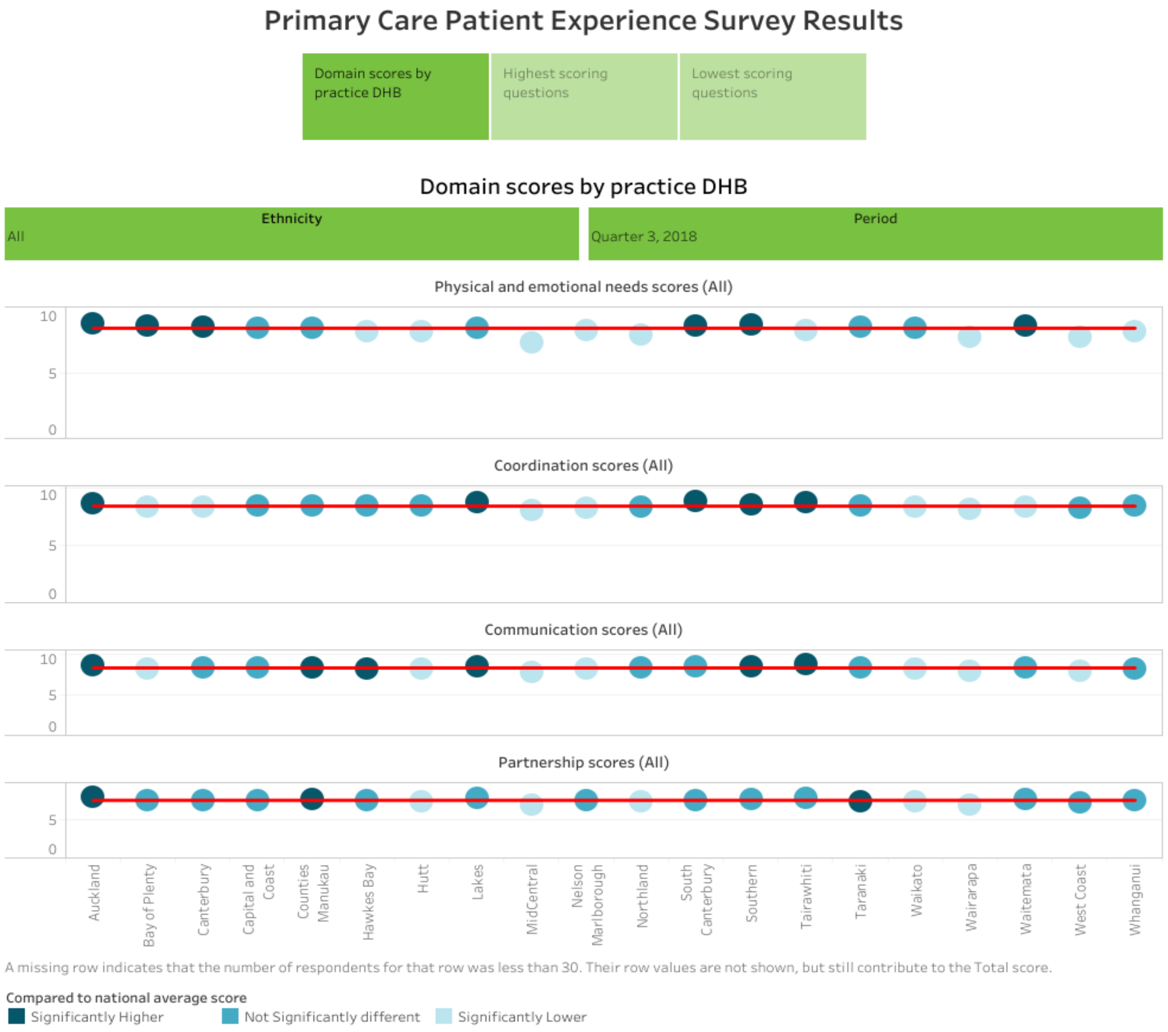


Figure 17. Primary care patient experience survey results

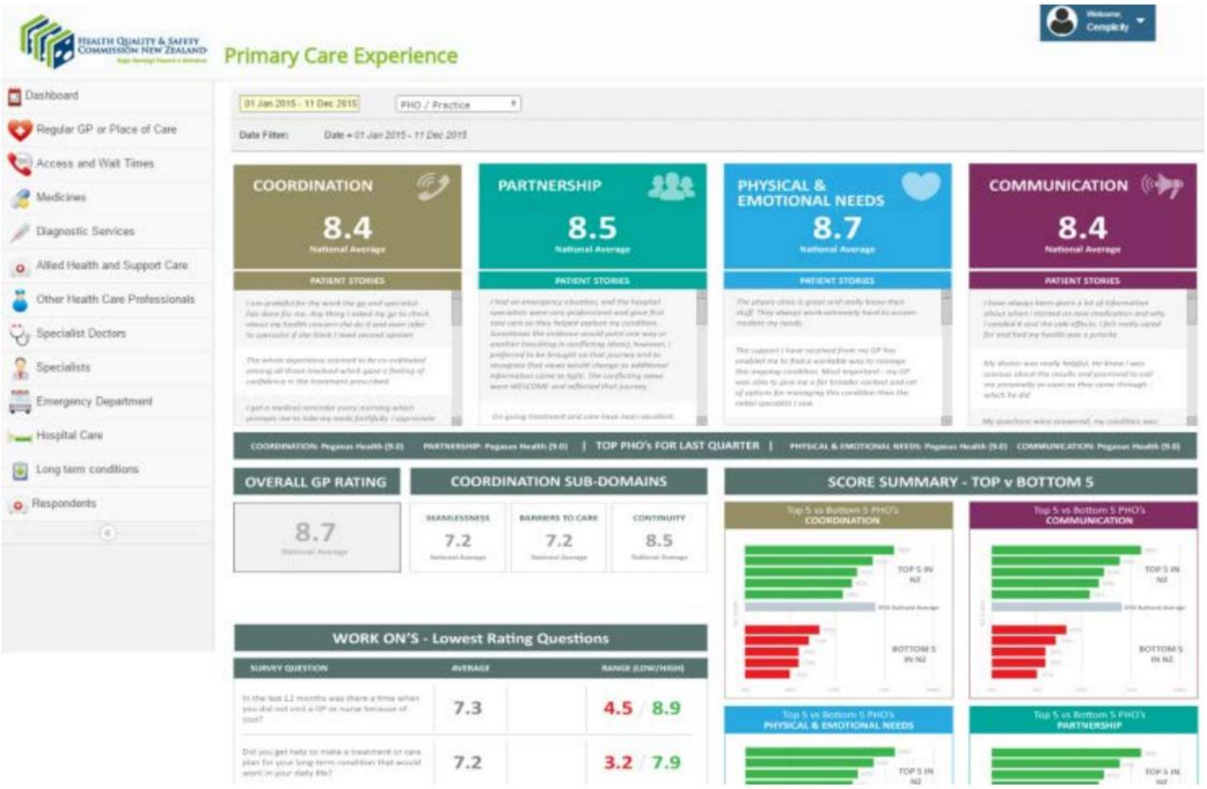


Figure 18. Dashboard view of Primary Care Experience results. Retrieved from https://www.hqsc.govt.nz/assets/Health-Quality-Evaluation/PES/PES_-_primary_care_-_methodology_and_procedures_-_May_2017.pdf

Somehow, Jan's "next day" response gets worked up into a graph resembling that in Figures 17 and 18 above. Current media reports of waits of several weeks are not captured by the survey at all. These results represent the authorised way that patient experience comes to be known.

The abstracted results are managerially useful. These results inform decision-making and funding. The DHB this project traced, set a goal for patients to experience, among other things, patient-centered care: "patients encountering our service experience safe, effective, quality patient-centred care" (DHB System level measure goal, 2017/18). The target set to measure the achievement (or not) of this goal, was "an average score in communication and coordination of care dimensions is improved to greater than or equal to 8.4." Therefore, for this DHB, a score of 8.4 or higher purportedly indicates that patients are having a satisfactory experience by their standards, thus, no change to practice is required. Additionally, by achieving the targets set for the SLM, the practice activates the incentivised performance funding stream.

Here, the patient experience survey serves two major business-like initiatives. This first being competition. Practices are visibly pitted against one another in an online platform where survey results are displayed graphically, including change over time, so comparison can theoretically be made between practices. However, the uptake of this intended competitive motivation is marginal (Ministry of Health, 2018d). Secondly, the survey results activate the SLM pathway, which, if the target is reached, triggers the flow of incentive funding from DHB to PHO, and commonly, PHO to general practice.

Rankin and Campbell (2006) discuss the emerging concern of 'hidden dangers,' embedded in the emerging tick box system towards which new public management principles are steering the health system. The writers acknowledge the checkboxes are a powerful tool of coordination and used appropriately can indeed save lives (such as an operating theatre tool count), but they also warn of the hidden dangers when frontline staff participate in work on behalf of the checklist/pathway/guideline without consideration of professional judgement. Doing work for the *right reason* is critical for a well-functioning health care system. Rankin and Campbell caution that when the work of the checkboxes become well known to those whose work it is coordinating, the risk is for the work to become orientated towards the checkbox. This reengineering of work practices can occur in absence of the 'right reason,' as the drive to complete the checkbox activity becomes the priority.

I argue that incentivised funding awarded based on meeting targets carries the risk of reorganising primary care practices attention towards the target checkboxes, and away from their ability to be person-centred. A general practice nurse shared with me an example from the practice she works at, where for one day per year, a staff nurse is re-allocated from their everyday practice nurse role, to phone up all enrolled patients identified as a "current smoker" to enquire if they were still "current smokers," and to offer "brief advice to quit." To complete the activity, the practice nurse inputs a 'Read Code' (representing the advice given, or action taken) into the patient's medical records. Irrespective of patient engagement with the phone call, this action is sufficient to 'update the smoking status' to activate funding pathways connected to the health target of "Better help for smokers to quit" (Ministry of Health, 2011). This action is in conflict with effective smoking cessation practices identified in health research.

Objectified accounts as they re-enter the actual setting

It is not the intention here to evaluate the survey data nor appraise the scores of the general practices. Instead, the intent is to show how the objectified account of patient experience – constructed from the patient experience survey - is systematically carried back into the actual setting, to fulfil institutional purposes.

There are 20 texts written by the Health Quality and Safety Commission to support the implementation and ongoing use of the survey in general practice (Health Quality & Safety Commission New Zealand, 2019). The texts are to be used by members of the general practice and PHO to guide their interpretation of results, further organising a desirable response to 'what next?' Accumulatively, these texts claim to work towards the realisation of improving frontline care, as summarised in this quote from the New Zealand Health Strategy:

> We can make information work much harder for us. Better and more visible information about real-time health results, including patients' experience of care, can help us improve at the front line and at a national level (Minister of Health, 2016b, p. 25).

The authorised knowledge of patient experience is carried by text from place to place, eventually speaking for the official patient-centredness of a PHO and further split into individual primary care settings. The knowledge originated from patients, who completed the survey from their expert knowledge. Waters (2016) recognised a similar displacement of people from the knowledge intended to speak for them; arguing that "far from being person-centred, as the clinically-controlled evidence currently defining wound care is taken up by decision makers and used to organize nurses' and patients' work processes, what actually happens is institution-centred care." (Waters, 2016 p237).

Information is shared via texts from place to place, with different people using the data to inform decisions and discrete areas of quality improvement. One such institutional recipient of the data is the PHO, which is governed by an elected board. A board member on a DHB/PHO alliance with whom I spoke shared how they found out only through a new role with the Ministry of Health, that the board was responsible for the governance of SLMs. She said, "No one told us… never mentioned."

An alternative measure of patient experience

An alternative survey was undertaken by a team of New Zealand researchers to measure patient experience following a period of primary care reform[36] that attempted to better integrate primary health care, primary care, and hospital services (Lovelock et al., 2014). The researchers identified a contradictory finding between patient and health care provider perceptions of care coordination and integration. The intention in including data from this supplementary survey is to point to a concern that underpins this thesis. The concern is that patients are strongly historically socialised by the experiences of general practitioner service, which focus on diagnosis and treatment of individuals, through acute and isolated episodes of care. Therefore, to ask patients to assess their care, I argue, is fundamentally captured by the notions embedded in the care they have been socialised to accept as good. The additional survey data clearly shows this disjuncture between patient experience and what is known practically by the surveyors as good care. The Primary Care Patient Experience Survey cannot tangibly show this gap, as it measures patient experience data in isolation of professional experience.

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[36] 'Better, sooner, more convenient' reforms Ryall, H. T. (2007). Better, sooner, more convenient: health discussion paper. *Wellington: National Party of New Zealand.*

> "The most striking thing about these data is the major disjunction between patient perceptions and provider perceptions on the process and content of care as measured by the ACIC/MPACIC [assessment of chronic illness care/modified patient assessment of chronic illness care] questions. A glance down the "none of the time" columns of both surveys shows a very significant difference in perception, e.g. for the question: "how often do you... give choices about treatment options?", 0% of staff reported this occurred "none of the time", while 25% of patients endorsed "none of the time". This pattern is repeated across numerous questions." (Lovelock et al., 2014, p. 59)

A second finding from the post-reform survey reinforces my concern for patients' lack of awareness of good care when patient responses revealed high ratings of perceived 'quality of clinical care':

> "Patients' rating of quality of care (Q 32), however, was high with 86% of respondents rating their care as good (17%), very good (29%) or excellent (40%)." (Lovelock et al., 2014, p. 59). Overall satisfaction with the general practice was rated even higher at 41 per cent for 'excellent'

This alternative survey perhaps goes a little further in demonstrating the manner in which findings are influenced by pre-determined patient expectation, the design of surveys and of course who actually receives and completes them. As noted earlier some of those most in need of good primary health care are often neither enrolled not able to afford attending a primary care appointment.

Ticking the quality box

As well as activating incentivised funding pathways, data from the survey is considered authoritative in measuring general practice performance for accreditation. For accreditation to Cornerstone, an accreditation programme designed by the Royal New Zealand College of General Practitioners, one module requires practices to ensure patient experience information is collected and used to improve services (The Royal New Zealand College of General Practitioners, 2022). Specifically, the two points noted below are required to achieve this aspect of accreditation:

> 8.1 The practice surveys its patient population to understand patients' experience of care.
>
> 8.2 The practice uses patient feedback to improve services. (The Royal New Zealand College of General Practitioners, 2020b)

Participating in the primary care patient experience survey and demonstrating improvement to services from these results achieves standards 8.1 and 8.2, which contribute to the wider indicators of the clinical care accreditation known as Cornerstone. An example of this is the change in practice shared by Kate in Chapter five. The IFHC Kate works at recognised low scores reported by patients for the domain of coordination. According to Kate, the GP triage system was introduced to address this concern.

In this example the survey is seen as doing something other than reporting patient experience. The survey is a text used as evidence to justify actions recognised as quality improvement, and to support the sought after Cornerstone accreditation. This process appears independent from the commitment to the SLM between practice and PHO. Using the survey in this way raises questions about the survey and whose interests it serves.

Ideological circle

In this section the analytical tool of ideological circles is applied to present a new understanding of the concerns that have emerged from the preceding analysis. The notion of ideological circles (introduced in chapter 4) will now be used to present a helicopter view of quality improvement. as seen through ideological circles.

This chapter describes how patients' experience is worked up into formal accounts; as institutionally actionable data, informing person-centred care discourse, to be *used* as an 'active discourse' (Mykhalovskiy, 2001). From the active discourse of patient experience and person-centred care, policymakers, DHB and PHO executives, practice managers and the like, can draw on the discourse to make decisions and justify certain forms of action. The forms of action eventuating from the use of the patient experience discourse were analytically puzzling. I was questioning my data, to answer, "how is it that patient experience and person-centred discourse is so prevalent, yet the experience of patients is at odds with the *textual* promise of person-centred care?"

My exploration of patient experience has shown that patients are drawn into socially organised practices built on ideologies that are contradictory to person-centredness. In the example of Louise, she demonstrates the time and effort employed as she attempts to centre health consultations on herself. Her work as a patient gears into the standardised rules and practices of primary care. Louise activates strategies to overcome suspected reasons that clinicians are not focussed wholly on her: she takes notes, writes lists, collates results, and condenses her complex history to free up the clinicians' time and thinking space, to orientate their 15 minutes to centre on her. So, if this is what people at the frontline are experiencing from a system claiming to provide person-centred care, then how, with such a strong emphasis on this concept at the highest level, can the actual experience be so different to the discourse?

In teasing out the sequences of action, the circular loop of data collection (patient experience survey), interpretation, and feedback (accreditation and funding), meaningful but unsettling analytical findings came into view. These elements - sequences of actions of data collection, data interpretation, followed by accreditation and funding - carry the hallmarks of what institutional ethnography recognises as an institutional and accountability circuit. Institutional circuits are increasingly common, perhaps even ordinary in frontline work. These circuits represent a "circular process that coordinate[s] the everyday actualities of experience with the objectified categories and concepts of the institution" (Griffith & Smith, 2014, p. 340). From this aspect of governing, organising what can be said and done through categories and concepts of the institution, accountability circuits arise. Grace, Zurawski and Sinding recognise accountability circuits as "a form of coordination that brings people's front-line work into alignment with institutional imperatives through the activation of texts" (Grace et al., 2014, p. 253). The categories and concepts of the institution organise, through texts, what can (and will) be recorded, reported, measured and actioned upon. The accountability circuits pick up these institutionally chosen categories and concepts, and "focus on making performance or outcomes produced at the frontline accountable in terms of managerial categories and objectives" (Griffith & Smith, 2014, p. 340).

The difference, explored further below, is that the circular sequences of actions uncovered in this study do not appear to hold anyone accountable for the delivery of person-centred care. There is no accountability for shared actions, or evidence of "bringing front-line work into alignment" (Grace et al., 2014, p. 253) with institutional practices that can be seen/measured/interpreted as providing person-centred care. Yet, objectives are set, via the triple aim, carried into the local setting through the channel of system level measures, and worked back up from the frontline into the primary care patient experience survey explicated in this chapter. So, if not accountability, then what are these sequences of actions achieving?

I describe below an ideological circle, a subtype of institutional circuits drawing the reader's attention to the simple fact that the ideological circle is not changing frontline actions, but it is achieving something.

The first ideological circle is constructed from the material actions and texts at the frontline of primary care and begins with enrolment. Patients enrol with a practice and PHO, which triggers a sequence of actions including the flow of capitation funding from DHB to PHO to primary care provider. Patients then attend the practice, where they participate in the evolving efficiencies such as GP triage. The patient is then asked to evaluate their experience based on a set of questions written within the recognisable framework of the taken-for-granted primary care model. Patients draw on the only knowledge they have of how primary care works to complete the survey. Because the patient does not know of any other way of receiving healthcare, and the survey only asks questions about the historically arranged consultation, the whole process becomes self-fulfilling. This leaves very little space for quality improvement and person-centred innovation, as was purported as the logic behind the survey.

The circular flow of money, from enrolment to patient visit to survey triggered incentivised funding is both self-fulfilling and self-reinforcing. Remember, only patients who both made and attended an appointment are invited to participate during survey week. Thus, the survey is unable to report on any who have unmet care needs owing to cost, access concerns, cultural incongruence or one of the many other reasons people struggle to use primary care services. As those voices are not counted, the survey is reporting from a skewed position, one that by nature of having attended an appointment falsely over-reports peoples' success with accessing care. For example, a patient who called to make an appointment, but could not wait the three or more week wait for an appointment would not be counted in the survey, but their experience is certainly one that requires improving. Meanwhile, even though this person does not attend as the wait is too long, the centre still receives their capitation funding. This circular action does not produce any change to the frontline of primary care, rather, it shores up the current antiquated practices.

The survey is asking questions about places of inefficiencies in the patients' experience, most notably about time. Both the capitation funding and the SLM funding reward efficiencies. As noted in the accounts of people at many different locations in the enrolment process, the more patients enrolled at a practice, the more capitation funding received. Efficiencies within the practice then enable more patients to be seen, which also increases patient co-payments. Efficiency, time and money drive the circle forwards. As a circular process, this is difficult to disrupt.

Meanwhile, the discourse of person-centred care and quality improvement also operate in a circular fashion, without achieving meaningful change. Beginning from the IoM, IHI and the Triple Aim, there is a strong presence of person-centred care and commitment to quality improvement. Tools such as the survey, introduced to measure the patient experience and progress towards the triple aim allow everyone to talk the talk, but struggle to shift the ideologies beyond talk. Meanwhile, the survey appears to report a system that is working well, which is at odds with how those at the frontline describe their experience in this thesis. The work done by patients to report their experience of care is building and maintaining the current system, in its flawed form.

Both of the ideological circles described above are traced back to the Primary Health Care Strategy. The first, with enrolment and capitation at its core, is powered by NPM, specifically money and efficiency. The second, which follows the discourse is powered by the ideas and vision of the strategy. However, the second circle does not have any accountability. These are the things that should be happening at the frontline in the interest of the patients, but there is nothing reinforcing it. There are no repercussions if care is not person-centred, as the survey is not asking the right questions to providing meaningful data of the patient experience. The achievement in practice of the ideas that circulate from the PHCS appear to be dependent on the altruism of the people at the practice and PHO levels.

The intersection between new public management and the measurement of patient experience

Healthcare is an increasingly intensively governed terrain. The adage that you can only improve what you can measure is certainly apparent in the increasing measurement of efficiency and productivity in the New Zealand health sector (Knopf, 2017). The environment of growing scrutiny of health informatics, under which the survey has evolved, is consistent with new public management principles (Gauld, 2000; Rankin & Campbell, 2006). In particular, this applies to the introduction of private sector management discourse and methods in public sector services. This discourse is introduced via health targets, such as a six-hour target for emergency department waiting times (Ministry of Health, 2011a) and incentivised targets for smoking cessation (Ministry of Health, 2011b). The survey appears to reinforce NPM methodologies through incentivised funding for targeted achievement performance measures such as patient experience.

Measurements of patient experience (or satisfaction) are used internationally to inform the managerial effort of public accountability (LaVela & Gallan, 2014). Nationally, the survey is an agreed System Level Measure (SLM) of performance, to be monitored by the PHO and DHB, and reported to the Ministry of Health (Knopf, 2017). System Level Measures encourage system-wide performance and are intended to measure accountability, improvement, and research (Ministry of Health, 2018b). Again, these are powerful tools of NPM to place scrutiny on efficiency and other such managerially directed priorities. The survey, as a data collection tool to demonstrate achievement of the SLM, directs attention to the measurement of peoples experience of care to meet the higher "aspirational" goal of "ensuring patient centred care" (MidCentral District Alliance, 2018). The processes and sequences of actions that translate an individual's experience as a patient into institutionally actionable data and reports are a core focus of the discussion that follows.

The strategies and policies which play out in the creation and maintenance of this ideological circle appear to be under the influence of neoliberalism. By neoliberalism, I mean the fostering of an environment that promotes individualism over a collective responsibility for wellbeing, and supports corporatisation and privatisation of previously centralised services which intend to encourage innovation and improve performance efficiency (Adams & Carryer, 2021; McGregor, 2001; Springer, 2012). These are the same features recognised in recent health strategies in Chapter two.

Patient experience is recognised as one of the three pillars of quality in health care (Institute of Medicine, 2001). The other two pillars of quality in health care are reportedly clinical effectiveness and patient safety. New public management strategies reinforce the myth that if you can't measure it, you can't manage it. Therefore, when measuring quality in health care, patient experience is managerially significant. Thus, the survey needs to produce measurable data. With this understanding, the purpose of the survey emerges.

Sustaining domination

Ideology refers to "those ideas and images through which the class that rules the society by virtue of its domination of the means of production, orders, organises, and sanctions the social relations that sustain domination (Smith, 1987, p. 55) – this reality "suits the needs of those who are in power" (Deveau, 2009, p. 11). I suggest the dominant ideologies of primary care are sustained and further reinforced by the continuous feedback of the primary care patient experience survey. The survey affirms a biomedical model of primary care, delivered within a set of standardised rules that further support the biomedical model, thus sustaining the domination of medicine as the centre of primary care.

Newell, in 1975, criticised the dominance of biomedicine in primary health and primary care. Yet, Newell's commentary below remains as valid as ever over 50 years later:

> The biomedical model, with its mechanistic view of disease and over-simplistic biological explanations, has several important implications. First, it paved the way for the depersonalisation of the experience of illness. In attributing the determinants of illness mainly to personal habits and hygiene and separating these from the socio-economic environment, the individual careless enough to become ill was often held morally responsible for their misdemeanour which could be avoided by healthy living.
>
> A second implication of the mechanistic view for medical practice was that single causes of a biological nature were deemed to cause disease and that these demand specific solutions, such as pharmaceutical and scientific medical treatment. This became the preserve and jealously guarded domain of professionally trained doctors and drug companies, admission to whose ranks is rigidly controlled. Professional control of medicine has secured and maintained the hegemony of the biomedical model in the

> ideology of medicine and health care, despite well documented evidence of the strong association between the majority of illness and low socio-economic status. Glamour, status and finance for technocratic medicine and its 'disease palaces' (Maher, 1974) have developed a powerful ideology which is in sharp opposition to the primary health care ethos of those who seek to deprofessionalise medicine (Newell, 1975. p. 158)

The patient, in filling out the primary care experience survey, is drawing upon socially organised knowledge of being a patient. This knowledge occurs under the conditions described by Newell (1975) above. The environment in which their care takes place is a carefully secured and maintained biomedical world.

The patient has learnt, through their experience, to work within the textually organised biomedical primary care system. Patients do not typically know of *any other way* of being a patient or doing patient work. Therefore, when the survey asks "when you ring to make an appointment, how quickly do you usually get to see your current GP…" There is a taken-for-granted assumption that health care works by 1) making an appointment, and 2) with a GP. Patients do not question if this is the right or wrong way to do patient work. They, therefore, do not challenge the experience the survey is generating. This suggests that the survey, and the patients completing it, are captured by the biomedical model of illness centred primary care. Any efforts to provide primary care differently, or to improve the circumstances and concerns with care such as those described in earlier chapters are not captured in the national survey data purported to measure, feedback, and *improve* the very troubles patients reported. They are not captured because questions that might elicit such answers are not asked.

Physician dominated primary care, organised around a medical model to respond with an individual consultation, with diagnosis or intervention, is therefore affirmed. The feedback loop perpetuates the socially constructed institution of primary care. Counter narratives of alternative ways of *doing* and *working* within health are neither visible nor counted. So, despite considerable efforts to implement a broader social approach to primary care and the wider scope of primary health care, many areas of primary care remain stuck.

While SLMs such as the measurement of patient experience may have intended greater accountability, and been genuinely marketed as a driver for quality improvement (Health Quality & Safety Commission New Zealand, 2016c), this ethnography suggests the survey has an alternative coordinating power. That is, the survey coordinates the perpetuation of the same biomedical, doctor-centric ways of doing primary care.

It appears the ability to exercise change within the primary care space is layered with challenges beyond the shortfalls of the survey. While there were some small instances of change in practice such as the introduction of GP triage discussed in Chapter five, the overall ability of the survey to bring about meaningful difference for people at the frontline of primary care is questionable.

Martin Carrell, quality programme manager of a large PHO, noted a concern occurring at the general practice level, which reinforces the analysis of the survey results maintaining status quo. In a recent sector update on the survey, he said: “Some practices have participated in the survey but haven’t really engaged in reviewing and using the results – including some who have never looked at their results since joining the programme.” (Carrell, cited in Ministry of Health, 2018d, p. 3). Participation in the survey achieves accreditation and attainment of incentivised funding, but it does not achieve meaningful change such that the patient experiences more person-centred care.

Chapter seven conclusion

This chapter challenges the notion of quality improvement as presently implemented through the primary care patient experience survey. The primary care patient experience survey, introduced as a system level measure, is purported to measure patient experience but, as this chapter shows, produces official reports of a person/patient-centred healthcare system that differs from patients actual on the ground experiences. The objectification of patient experience causes patients to vanish from view, replacing them with numbers that render invisible the human activity doing such work as making and attending appointments.

This concludes the presentation of findings from this research. Mindful of the rhetoric of patient-centred care, the project has traced the work of patients and clinicians at the front line to secure and deliver such care within established structural constraints. It has become clear through examination of patient and clinician accounts and the patient experience survey that complex feedback loops obscure the lived realities of patient experience and do not capture or facilitate clinician efforts to ameliorate patients' challenges.

Chapter Eight - Discussion

Introduction

There is, as previously outlined, in international literature and in the New Zealand government/Ministry of Health strategy and policy documents a lengthy and clear agenda to work towards making services person/patient-centred. This research project began by exploring the interface between patients and clinicians on the front line of primary care services. The study progressed to explicating national strategies, policy directives and governing activities that organise the interface between patients and clinicians within primary care institutional practices. In the course of this research the analytic lens applied was the degree to which services were or were not patient centred and the work done by patients and clinicians to achieve that objective.

Person-centred care is a concept based on the idea that the needs, values and preferences of individuals seeking health care will be the focus of service delivery rather than those of the organisation (Mead & Bower, 2000; Phillips & Scheffmann-Petersen, 2020; World Health Organization, 2015). However, the findings of this study reveal that overall services remain organisationally designed and driven and that business imperatives take precedence.

Data for this study was collected during a period when particular structures of delivery were in place; namely that of district health boards (DHBs) and primary health organisations (PHOs). These overarching structures support the existence of private business general practice combined with high levels of government engagement and subsidy through fiscal investment and specific policy objectives and health targets.

The work is concluding just a few weeks after an official health reform period in which the major structures (namely DHBs and PHOs) have been dissolved in favour of two national health authorities (Health New Zealand and the Māori Health Authority) and the establishment of locality networks at regional level is in process (Future of Health, 2022c). It appears that there is no substantive alteration to private business operations of general practice and thus it is argued that the findings of this study will remain relevant in the revised context.

Analysis suggests new models of primary care are framed by neoliberal ideas and coordinated by new public management (NPM) practices, with a drive to standardise most activities (Adams & Carryer, 2021; Tenbensel et al., 2021). These practices are changing the work of people at the frontline, reorganising how they experience primary care. In particular, in larger corporate and IFHC models of care, new and evolving standardisation rules challenge the ability of clinicians to be person-centred. These larger centres attempt to fuse a service delivery model that includes person-centred care with strategies to improve clinical outcomes, reduce costs, and increase satisfaction. However, the composition of large facilities housing multidisciplinary teams and enrolling thousands of patients erodes the long-protected patient-clinician relationship and for this and other reasons do not appear to deliver patient-centred care.

This thesis contributes to a growing global body of institutional ethnographic investigations of health systems and the installation of new forms of public management (see the predominant work of Rankin and Campbell, 2006, and collated works in Griffith and Smith, 2014). By tracing the texts organising patient experience, the influence of the global discourse of NPM emerges. For example, this thesis investigates the primary care patient experience survey (the survey), purported to measure person-centredness and found it to be influenced by NPM. The Survey sits within health strategies informed by the ideals of competition and managerialism (Gauld, 2000; Laing & Hogg, 2002; Matheson, 2013; Tenbensel et al., 2011) and later, by promises of incentivising efficiency, improving access, reducing inequalities and increasing public involvement (Gauld, 2009; Knopf, 2017; Tenbensel et al., 2011).

This project adds new knowledge to the terrain of people doing work at the frontline of health care under the social conditions of NPM, particularly the work of patients. In a curated book of institutional ethnographic research on the changing frontline work under NPM ideologies, Griffith and Smith (2014) suggest "there is much to be learned by exploring how new managerial practices enter into and reorganise the work of being a client, a patient, a prisoner and so on" (p. 346). This research contributes to this gap by beginning from the social position of patients at the interface with primary care and following the texts as they hook into national and international NPM discourse.

Salient findings

While explicating the work of people at the frontline of primary care, this project found that despite promising a person-centred care model, primary care is not meeting the needs of every person. Further, despite recognising their needs were not met, many patients, socialised by a lifetime of private primary care, accepted the care they were given without question. Others did not accept the care they were given but felt powerless to change anything or found their efforts unsuccessful. A select few managed the system well. The capacity required to demand anything more escapes many New Zealanders for whom the work of managing health and accessing basic care is in itself challenging. In particular, Māori and Pacific people experience some of the lowest health literacy in New Zealand (Sa'u Lilo et al., 2020), while also carrying an inequitable burden of disease (Ministry of Health, 2019a). Most problematically, this population experience high rates of non-communicable diseases (Ministry of Health, 2019a), which require frequent and ongoing interactions with an array of primary care services.

It appears then that those with the greatest need may be the least likely to have their needs met. This suggests that the inverse care law first noted by Julian Hart (1971) is still highly applicable. Articulate, health literate, and well-resourced patients manage the system well by navigating or disrupting the rules and practices of the institution. But many others receive care as it is organised by the rules and processes of primary care, which may or may not meet their needs, and largely depends on where they are and whom they see. In the lead in to the current health reform process this was frequently referred to by political leaders as "postcode lottery" health system, noting that there was a degree of serendipity in the level and efficacy of services received (Little & Henare, 2022).

Clinicians who contributed to this research recognise that restrictions within consultations are central to the problem. Clinicians noted business agendas, competition for patient enrolment, the volume of patients needing care from a scarce GP/NP resource and the complexity of patients as perpetuating the restrictions within the consultation space. These restrictions organise what can be said and done in the consultation and appear to challenge the clinicians' ability to put the patient at the centre of care. Compounding these concerns, the introduction of NPM principles has increased the burden of data collection and reporting requirements on practices and clinicians (Downs, 2017). Data collection and reporting include health targets, clinical performance management, and dashboard diagnostic and prescribing practices, of which many further displace the patient from the centre of care.

The data from patients and clinicians shows that the Primary Health Care Strategy (PHCS/the Strategy) (King, 2001) and its intentions have been overpowered by the activation of texts intended to operationalise the Strategy. Service agreements (TAS, 2020) between PHOs and general practices brought about enrolment practices designed to gain the benefits of a primary health and population approach, delivering continuity of care. Instead, enrolment is problematic for patients who do not feel their needs are met; that the service is not provided at the right time, the right place, or with the right person. Patients cannot change providers without great difficulty and this is becoming more significant as workforce shortages increase. System Level Measures and Health Targets promote quality improvement driven by national goals from the PHCS (Ministry of Health, 2018a). The results of these quality improvement strategies explicated in this research project do not reflect the frontline experience as described by participants. In their current form, I suggest these quality improvement strategies do not bring about meaningful change for those at the frontline of primary care. Their intent, it seems, is captured by the more powerful healthcare marketplace and the private business model which remain untouched.

These findings bring this discussion back to the small hero from Chapter one. The patient and clinician stand beneath the vast complex of socially organised knowledge that organises what can be said and done by all people at the frontline of primary care.

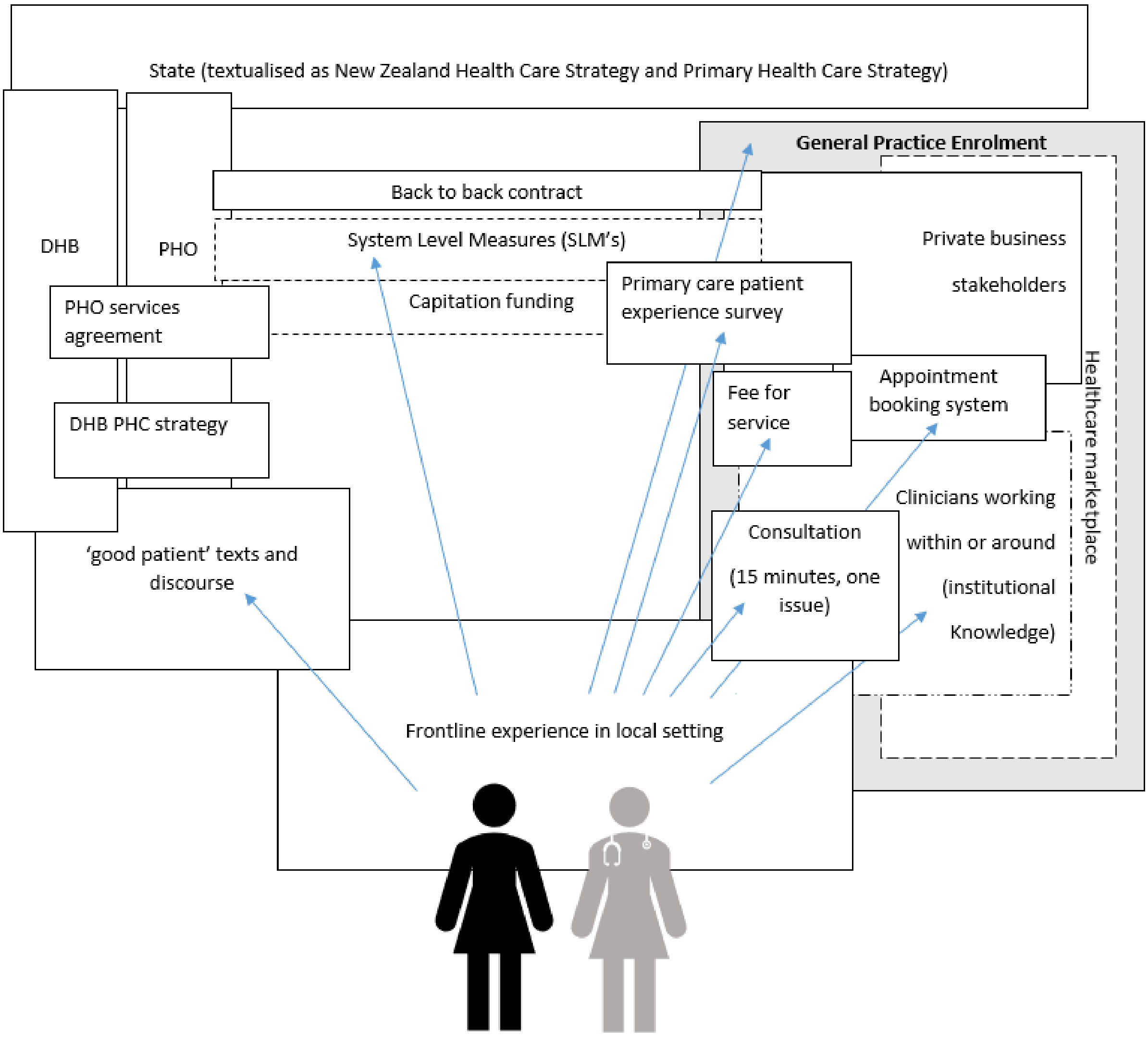

Figure 19. Small hero revisited

At the top of the image, the State is textualised by the New Zealand Health Care Strategy (Minister of Health, 2016a; 2016b) and the PHCS (King, 2001). These strategies should be the most powerful texts overarching all areas of healthcare delivery in New Zealand. These strategies are intended to coordinate high-quality, person-centred healthcare in New Zealand. Yet, the small hero experiencing primary care in their local setting did not experience care as planned by the strategies. This project found that the NPM agenda and the power of private business, which operates as a healthcare marketplace within primary care, displace the goals set within these texts.

Frontline experiences of patients and clinicians are hooked into the standardised and regularised texts and rules of private business. These texts and rules organise the delivery of care by clinicians employed at private practices via a singular patient/clinician consultation, made through booking systems, occurring under the conditions of restricted time and limited scope for addressing multiple issues. In recognising the "actualities of people's everyday lives and experiences" (Smith, 2005, p. 10) as they unfold under the organisation of the standardised texts and rules, the distance and disconnect between the frontline and the intended strategies are apparent.

The small hero diagram shows the empirical connections followed in this research. This project found empirical connections between the local setting and ruling texts and discourse such as consultation rules, appointment booking systems, funding, institutional knowledge, patient education and the Primary Care Patient Experience Survey (Health Quality & Safety Commission New Zealand, 2016b). These are the texts and rules that shaped and organised the experience of people at the frontline of primary care. Several powerful texts maintain this experience and warrant attention in this final discussion.

Primary health organisation enrolment, the grey shaded box above, both establishes and maintains the relationship and control of primary care services. Private general practices are connected textually to PHOs via a PHO service agreement. These agreements establish enrolment practices and capitation funding. The troubling experiences described by patients, as well as the professional disjunctures reported by clinicians, occur within the rules present under enrolment, capitation, and private business. Within this arrangement, the clinicians are held accountable to institutionally driven NPM principles organising them to focus on a single issue, while maintaining efficiency via patient throughputs. These aspects are then reinforced through the System Level Measure of the Primary Care Patient Experience Survey, intended to promote quality improvement. But, as shown in chapter seven, the only traceable connection between survey and patients is a strengthening of business practices and the shoring up of the way things have always been done.

The salient findings of this research are now critiqued followed by discussion as they relate to the future of New Zealand health care.

Access

There is considerable rhetoric around improving access to healthcare throughout high-level texts produced by the government and various government agencies. Problematically access is not defined operationally, but there are many ideological definitions in use. When talking about reform in primary care access, the Future of Health: Te Anamata O Te Oranga[37] (2022b) web page addresses the issue and vision through a lens familiar to previous strategic documents:

> People will have access to the right care at the right time no matter of where they live. Shifting the emphasis towards primary and community care will also allow more people to be cared for close to home, and take a greater role in their own care. Patients and employees will be able to move between areas to access care and work where needed (para 14).

This project showed that access is an official concern for policymakers (see, for example, Ministry of Health, 2018b), who know about access issues formally as cost barriers, geographical isolation

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[37] There is a plethora of names and titles used in reference to current health reforms from the Ministry of Health and others. The 'Future of Health: Te Anamata O Te Oranga' appears to be the umbrella title for the newly formed organisations. As such, 'Future of Health' is used within this discussion in reference to reform documentation.

and transport problems, and 'other' isolation factors such as cultural and social. This study found that access to primary healthcare was problematic as patients understood access differently to the institution. There was a considerable disconnect between what the patients needed and when, and what the health providers delivered or indeed what the health providers told them they needed. Patients defined what they saw as relevant and appropriate access to the healthcare services they needed, at the right time, yet health providers redefined access on their behalf.

Considering the reform intention quoted above, access is once again signalled as a place for change, providing "access to the right care at the right time no matter where they live" (Future of Health, 2022b, para 14). But access must be considered in a far broader application, one which considers the many varied ways in which patients experienced access and the associated challenges and outcomes in this study. Access is both about how to access services in the first place and then once in the service, how to access the right service and person, together with the appropriate interventions. This means outcomes should be the endpoint, not outputs. Yet, at present, access is defined and measured only by those who manage to successfully use the service.

Access is defined in the principles of the Strategy (King, 2001) as "timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay" (p. 2). Access is often connected with the rhetoric of health equity as seen here. That is, improving health access improves health equity. When thinking of access in this way, the barriers align with health equity measures: "Barriers to access to primary health care services include where those services are delivered, how much they cost, whether the service is right for the patient and whether they know about them" (King, 2001, p. 15).

Primary care access, as it is measured for quality improvement purposes, uses data only from those who have enrolled with and accessed primary care services. The survey is, by design, missing the experience of those who could not, or did not for whatever reason, access primary care when needed. Only 95% of the New Zealand population are enrolled with PHOs. Of those who are enrolled, vulnerable populations who for whatever reason do not receive health care are not measured in this narrow understanding of access, as "realised access is easier to measure than potential access" (Levesque et al., 2013, p. 2e). Instead, for meaningful planning and improvement, access must be considered as it relates to health outcomes, rather than a measurement of utilisation alone. Otherwise, the information used for decision-making is meaningless: access by numbers becomes a proxy measure for outcomes and quality. Levesque et al., eloquently summarise this concern:

> Despite ongoing preoccupation with access to health care, we consider that health services research and policy continue to be compromised by a lack of clarity of concepts of access and utilisation, lack of consensus on sub dimensions of access, and ongoing blurring of access as a concept and its determinants (2013, p. 2e)

Continuing to plan for and improve access based on utilisation measures, surveying only those who have successfully accessed care, risks further misalignment between institutionally offered access and actual patient need. The patients in this study who navigated the institutionally ruled access to care wanted and needed access that was not recognised in the Survey, or in the rhetoric of access to which this discussion attends. Who then defines what is access or good access to primary care?

Governance of access

Access to care cannot be untangled from primary care enrolment, as enrolment determines the enrolees' access experience. Patients are required to enrol with a primary care provider to access first-level (primary) services. Enrolment facilitates capitation payments, and in return, patients should pay reduced fees. Other benefits of enrolment should include access to health promotion services such as cervical screening, enhanced continuity of care with the same provider, and better information coordination, among others (Irurzun-Lopez et al., 2021). At some point, this intent of enrolment with PHOs failed to deliver on the promise of the PHCS, seemingly owing to the capture of the business model and the scarcity of resources to allow the patient the freedom of choice.

Through current enrolment practices, patients are more or less restricted to receiving care at a single location or provider because of capitation funding. Yet the Strategy offered that this "will not reduce their freedom to choose between different practitioners where this is valuable to them" (King, 2001, p. 8). Capitation is the payment arrangement for general practice providers. Capitation funding flows from the DHB to the PHO, then to the providers. Alongside enrolment, capitation funding aimed to shift primary care services away from isolated patient encounters towards a model where general practices could prioritise and plan for population-based services thanks to the guaranteed flow of quarterly funding (Barnett & Barnett, 2004; Downs, 2017). Further, the capitation payments to practices intended to give freedom to the provider to address population needs, through developing innovative service models (King, 2001; Finlayson et al., 2009). Practices receive capitation payments irrespective of whether the enrolled patient receives care.

Affordability has not consistently improved and patients report receiving care in the same way they always have and often with more difficulty. If anything, patients are now doing more, and receiving less, as the time and cost of providing care and servicing the ever growing reporting requirements have increased under NPM conditions. Patients work to navigate the rules, practices and procedures of accessing primary care, brought about by texts such as enrolment and capitation funding. The texts then designed to improve the conditions for patients, such as health targets focus only on outputs, while consuming clinician time. Policies, consultation requirements and targets - hallmarks of NPM - organise the clinicians' attention away from the patient and their needs. The survey, which is supposedly a measure of patients' experience, and aims to speak for their needs at a quality improvement level, instead measures these same outputs, showing that quality improvement and quality of care are not synonymous in a NPM climate.

Participating in primary care services

Triage

Access to appointment bookings was found to be a contested space between patients, clinicians, and sector leaders. Patients reported problems accessing the care they wanted, with whom they wanted and when they wanted it. The primary care patient experience survey results conceptualised this as barriers to access, with 21% of respondents saying they wanted care but couldn't get it. This increased to 27% for Māori respondents (HQSC, 2021). Clinicians recognised not all patients accessed care equally, and acknowledged unmet need in their communities.

Triage systems were introduced to respond to these concerns, but whether the triage processes served the patient or the organisation is questionable. While triage appears to triage patient need, albeit privileging acute and medically unwell, the parallel shortage of GPs is undoubtedly motivating the use of triage and filtering of need. Triage attempts to spread the thin GP resource across all patient demand but in the process of fixing one problem may potentially create another. The consequences of this filtering on vulnerable populations needs consideration as an urgent equity issue.

What need is triage attempting to address? Patients wanted to see their own clinician, but the agenda of the triage system is to deal with quick wins without face-to-face consultation. Triage is sold to patients as patient-centred, as they can complete this from a distance and it is sold to the practice as a financial win as more consultations can be completed with less utilisation of clinician time. The quick wins assume patients' needs are biomedical - all about prescribing, rather than person-centred health. It is notable that the relevant PHO referred to this as "prescriber triage," in an attempt to decentralise the clinician from the process, but in the process, confirming the highly biomedical foundations of the purported quality improvement. Triage then becomes another tool for efficiency, controlled by NPM and medicine.

15-minute appointments

The 15-minute appointment model constrained patients in getting their healthcare needs met, and restricted what clinicians could say and do. Tight rules holding the clinicians accountable to the business model, in particular, addressing only one issue per consultation, ensure timely consultations and turnover of revenue. Some clinicians blamed patients with complex needs for causing consultations to run over time, suggesting patients should book (and pay for) double appointments instead. The incentive to deliver a higher volume of patient consultation for greater revenue was noted by Downs (2017). As demonstrated, patients bear the consequences of this profit and efficiency driven model with unmet health needs and through no fault of their own.

The constrained primary care appointment is historically created and perpetuated by the ruling relations of biomedically dominant and westernised healthcare (Gauld 2009; Gauld et al., 2019). The current model of primary care has been unable as yet to address contemporary issues, including more acute work being delivered in primary care due to reduced secondary care resources; the increased ageing demographic together with complex co-morbidities; obesity and lifestyle changes; and growth in mental health and addictions (Carryer & Adams, 2016; Downs, 2017). Challenges for the health workforce remain, not only in terms of the diminishing GP workforce, but also in the acceptance and delivery of innovative models of care, such as NPs, RN prescribers, and the engagement of other allied professionals within the wider primary care team (Adams & Carryer, 2019; 2021; Carryer & Adams, 2017; Goodyear-Smith & Ashton, 2019). In addition, the constrained primary care appointment is then further burdened by administrative tasks and health targets competing for consultation time. In such a context person-centred care is a significant challenge.

Person-centred care is a concept based on the idea that the needs, values and preferences of individuals seeking health care will be the focus of service delivery rather than those of the organisation (Mead & Bower, 2000; Phillips & Scheffmann-Petersen, 2020; World Health

Organization, 2015b). However, the model developed for general practice service is based within the acute model of diagnosis and prescribing (Rocca & Anjum, 2020). The GP centric, one issue per appointment reflects this model. The extra work of patients and clinicians to work around the persisting ruling relations of primary care reveals the places where the institutional circuit must be broken. Access to and accountability for the care provided and received must be reconsidered and determined by patient needs, equitable outcomes and safety for all.

Safety netting

The concept of safety netting is now widely used particularly by GPs in their assessment of patients. The definition and application of this term is variably used, ranging from protecting the GP and their accountabilities to ensuring the patients are receiving the best possible care with appropriate evaluation of interventions (Jones et al., 2009). Safety is also an ideological concern, prevalent in most texts governing healthcare, often hand in hand with quality ideologies (Health Quality & Safety Commission New Zealand, 2013b; Merry et al., 2017). However, paradoxically, patient safety is jeopardised within the 15-minute consultation where patients themselves are required to order and prioritise which symptoms to discuss with their GP/NP.

Safety is perhaps particularly important for people with long-term conditions, mental health and addiction or emotional distress, and very difficult for those with tiredness or fatigue. Patients are organised to present what they identify as one issue, such as feeling dizzy or sick, but they may not report an apparently unconnected symptom, nor a concern about their mood. These institutionally organised issues are compounding. Patients living with mental health and addictions experience more physical health concerns and live with more long-term conditions than those without mental health problems (Allen et al., 2014). Often, physical concerns compete for attention with their mental health needs in a time-constrained, single-issue primary care appointment (Thielke et al., 2007). The reductionist model is potentially dangerous – and even more so for those living in underserved areas with high deprivation, and with limited access to culturally appropriate services.

It is in these communities where co-morbidities co-exist for a high number of the population, and particularly for Māori for whom inequities continue to widen (Goodyear-Smith & Ashton, 2019; Simmonds, et al., 2020). Culturally appropriate and meaningful models of care that facilitate a holistic model of health and wellbeing need to be embedded throughout the health care system (Carryer et al., 2014; Wilson et al., 2021), rather than a clinician whose assessment capacity is reduced to a single biomedical health concern.

Measuring patient experience and quality

Understanding patient experience is at the forefront of international quality improvement agendas and is prioritised by dominant frameworks such as the Institute for Healthcare Improvement's 'Triple Aim' (2008). To gather knowledge on this priority measure New Zealand developed a set of System Level Measures (SLMs) to benchmark and compare data between local, national and international health systems (Ministry of Health, 2018). The primary care patient experience survey (the survey), introduced as an SLM, was purported to measure patient experience, but instead, as demonstrated, produces official reports abstracted from the survey of a person/patient-centred healthcare system that differs from patients actual on the ground individual experiences.

The survey contributes to an ideological circle (Smith, 1990, p. 178) that subordinates patients' individual experience and privileges generic and abstract data about experience gathered via a standardised replicable survey. Data showed that the process of objectively endeavouring to measure patient experience, encoding, and then taking those findings as authorised knowledge, simply perpetuates the existing system, without improving quality of care. The survey data is collected under a framework that recognises a primary care system where illness rather than prevention trigger the encounter, the clinician (usually a doctor) is at the centre, with patients and other health professionals fitting around that centre. The survey is generated from westernised reductionist models of measuring healthcare (IoM, 2001, 2011; IHI, 2009), rendering the results incapable of achieving anything other than more of the same. Such devaluing of the knowledge from an individual's standpoint position (in this case a patient in primary care) has been strongly reflected in other institutional ethnographies (Cupit et al., 2019; McKelvie, 2018, 2019; Rankin, 2003; Rankin & Campbell, 2006).

Using the survey as a means to improve the quality of care reveals the ideology of NPM (Duncan & Chapman, 2010; Tenbensel et al., 2021). The counting, costing, and endless thickening of data obscures and obfuscates the root issues of the socially constructed rules within which patients work in the primary care system. Obscuring and obfuscating these issues will never bring about the deeply required change because the purported measurement of patient-centred care (and the counting/costing/data thickening) is trapped within the way primary care has long been conducted. In failing to look outside the world (institution) in which we operate, the data we rely on to drive change remains colonised by the same expectations and paradigmatic belief (Smith, 1974). Meanwhile, those attempting in good faith to make meaningful changes to the way primary care is delivered, find their valiant efforts to innovate or improve lost or captured by these powerful historical practices (Adams & Carryer, 2019; Gauld et al., 2019; Moore, 2019; Tenbensel et al., 2021).

The restricted access to the survey further challenges the value of the survey. At present the survey provides an incomplete picture as it applies only to the patients who have been able to navigate the socially constructed rules of primary care to secure and attend an appointment. New Zealand recognises 31.1% of the adult population to have an unmet need for primary care services (Ministry of Health, 2019a), yet the survey is only capturing data from those who are *able* to overcome the first hurdles of primary care access. To facilitate quality improvement, in light of mounting unmet need, it seems very sensible to direct quality improvement attention towards not only those who 'walk through the door,' but also to those who have not managed access. It is long overdue to implement an approach that engages with local communities to identify healthcare needs, developing and delivering services that are collaborative and meaningful to promote health and wellbeing.

The overarching structures of health service delivery

New Zealand prides itself on having universal health coverage but the findings of this research suggest otherwise. Universal health coverage means "that all people have access to the health services they need, when and where they need them, without financial hardship" (World Health Organization, 2022, para 1).

The Strategy (2001) embodied a vision which aimed to address the goals of universal health coverage. Equity, access and affordability were key drivers for change. The political and policy discourse leading up to the reforms of 2022 utilised much of the same evidence and arguments for change as were employed prior to the launch of the Strategy (Health and Disability System Review, 2020). Can we see any evidence that current health reforms have seriously addressed the failures of the previous 2001 Strategy?

Reforms

There were some particular findings of interest that are meaningful and relevant today as the health reforms, localities, and other such changes are coming to the fore in New Zealand. Most relevant to this study are the changes proposed to the organisational structure of primary care, and the goals underpinning this change. The available reform information states:

> Primary and community care will be better tailored to the needs of communities, and people will have more opportunities for their voice to be heard on services and how they're delivered. Over time, this will lead to more innovative services which better reflect community priorities and needs, including more accessible digital and virtual care (Future of Health, 2022c, para 13).

As previously noted the existing structures are being replaced with an approach known as localities. Localities are:

> [A] place based approach to improving the health of populations, as well as a mechanism for organising health and social services to meet the needs identified by whānau, community and Iwi-Māori Partnership Boards (Future of Health, 2022b, para 1).

Localities appear to be a network of providers, attempting to integrate services, connecting together nationally procured contracts and funding. Localities are one part of an accumulative attempt to transform the health system to "create a more equitable, accessible, cohesive and people-centred system that will improve the health and wellbeing of all New Zealanders" (Future of Health, 2022a, para 2). Herein lies the findings of interest and the cautions this study offers for the future of New Zealand healthcare.

This thesis explicated the rhetoric of person-centred care, raising concern for the lack of clear definition and implementation at the frontline of primary care. Similar rhetoric without clear definition or action is pervasive through the information being distributed in the lead-up to the era of the new health reforms commencing 1 July 2022. The newest health reforms promise to "give people access to consistent quality care when they need it, to help people live longer in good health and have the best quality of life" (Future of Health, 2022c, para 7). Access to care, as seen in this quote, exemplifies such rhetoric.

How will the imminent reforms address any of this? A goal of the new locality arrangement appears to be the enablement of patients to access care at different locations and providers (Future of Health, 2022b). How this patient freedom is realised and the power of structures and funding to support this flexibility is yet to be seen. Present models in a private business context have proven stubbornly resistant to reform.

Challenges to change

It is not only private business models that have proven resistant to change (Gauld et al., 2019). There are additional elephants in the room which challenge reformative intentions. While the binary of gender is less defined in today's world, the privilege of some work over others remains apparent. "The current episteme in managed healthcare privileges the measurable and calculable over the individual, nuanced and labile" (McKelvie, 2019, p. 227). Those patients and clinicians who prioritised care and nuanced needs over the standardised rules of the institution did so at great cost to personal resources and without recognition or reward.

The work of patients, as an aspect of healthwork (Mykhalovskiy & McCoy, 2002), to compensate for failings in primary care processes is highly gendered. The assumption remains that women will take up the mental and emotional labour of planning, navigating, negotiating, anticipating, and organising (both routine and unexpected) for the encounters with primary care services and the gaps in between. In caring for Ian, Helen is drawn into the invisible labour of appointment scheduling, following up on lost referrals, finding and filling gaps in information transferred between services and chasing appointments, all while taking on the mental load of caring for someone with dementia. Louise works tirelessly to navigate between primary and secondary care settings, following up on clinicians' promises for which they have not followed through, researching, planning, organising her family around time away from them for investigations, and so it continues.

Ciciolla and Luthar (2019) describe the invisible labour of managing a household as the burden of being "captain of the ship" (p. 468). In the same vein, the women I spoke with during this research project routinely kept their ship on course, packed with all the necessary resources, while endlessly organising (and reorganising) the itinerary and menu. The assumption is that this work (planning, navigating, negotiating, double-checking) will be done without recognition or remuneration. If this work were to go undone, bit by bit, the problems for the primary care provider would amass. The effort of making it work is being pushed onto patients and the workarounds of many clinicians.

Similarly it has proved impossible to move away from assumptions of medical leadership and the centrality of biomedicine as a panacea to health concerns (Rocca & Anjum, 2020). Medical hegemony[38] prevails and documents labelled and identified as *primary health care* strategies rapidly become informally described as *primary care* strategies and the focus returns relentlessly to the medicalised setting of primary care. Carryer and Adams (2022) note that “Despite medicine’s vital but narrow contribution to health outcomes, it is accorded enormous prestige, power and high levels of public recognition and deference. In addition, medicine is also rewarded with high levels of remuneration and assumptions of leadership of healthcare teams” (p. 37e).

Primary care in New Zealand is built on the cultural hegemony of medicine. The values and beliefs of medicine underpin all levels of social and political health planning, resourcing and delivery. The power generating this imbalance was originally an outcome of GP lobbying (Gauld, 2013; Wright-St Clair, 2001). However, as I make visible, the hands of many clinicians are increasingly tied, as the needs of large business entities predominate. Clinicians are constrained to a 15-minute model of consultation defined by a single issue, as the population ever increases in complexity of need. General practices are funded for an enrolled population, with few avenues to tailor for the increased complexity and shifting demands for care beyond a single issue (Rocca & Anjum, 2020).

Despite well-intentioned efforts and the desire of clinicians to provide care that is person-centred, the dominance of generic management principles as a key component of NPM has also reduced clinical autonomy to a restrictive model of care and is an additional challenge to change. Teekman

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[38] A Marxist notion where a culturally diverse society (here, diverse understandings and approaches to healthcare) are dominated by the ‘ruling class’ (medicine) who control the culture of that society to the point where the ruling worldview (‘evidence based’ beliefs, biological explanations, values) come to be accepted as a cultural norm.

(2012) raised similar concerns for the autonomy of nursing in the New Zealand hospital setting, where he identified continuous restructuring, coupled with similar generic management ideologies, as powerful organisers of nurses' work activities, reducing nurses' health assessments and their provision of patient-centred care. In similar fashion clinician participants in this study have revealed the constraints on their practice autonomy.

As long as these elephants in the room retain their hegemonic authority it is difficult to see how change will be achieved. Tinkering with the overarching structures of service delivery will not change patient experience in the clinical encounter nor in their journey through episodes of care.

Limitations of the study

The sheer size of the research terrain must be acknowledged as a limitation of this study. Institutional ethnographies spoil the researcher for choice. It is simply impossible to follow every path, and difficult decisions must be made. Smith described, during a guest lecture at the University of Oregon, a very characteristic experience of institutional ethnographic researchers. She has observed herself and others, becoming "trapped" by the temptations of the multiple complex connections which come into view through explication. Smith likens the overwhelming temptation to follow all paths to a gluttonous visit to a smörgåsbord buffet where one piles up their plate only to find they cannot get through it all. With sincerity, Smith says, when choosing what paths to follow, "you do so selectively because if you didn't do it selectively, you'd go nuts" (University of Oregon, 2010). This ethnography has proven itself to be a tempting smörgåsbord of curious and enticing paths to follow.

There are no boundaries to the terrain of institutional ethnography, likewise, healthcare, and particularly primary care is a broad and complex institution. Under the circumstances of a novice institutional ethnographic researcher, I 'followed my nose' into the complex terrain of patient experiences, primary care, clinical governance and health strategy. Out of economic necessity, I have attempted to be selective in the paths followed. Where possible, I have followed the paths with what I determined to be the most considerable influence on the everyday world of being a patient; at times, the decision has been a personal preference or interest.

While vast, the research terrain was also moving. As noted earlier during the time frame of this project, both signalled and actual change in the New Zealand health sector presented a further researcher challenge. This thesis is entering publication at a time of significant health reform in New Zealand (Department of the Prime Minister and Cabinet, 2021; Ministry of Health, 2021a). These reforms propose the most dramatic structural health system changes in over 20 years. However, early indications from information available at the time of publication suggest the problems experienced by those at the frontline of primary care, and explicated within this thesis, will not fundamentally change in the course of these reforms.

Further to the signalled health reforms, the global COVID-19 pandemic and subsequent public and primary health responses continue to change the surface of care delivery. Most significantly, data collected for this project mostly occurred prior to COVID-19 reaching New Zealand. The experiences shared by participants happened under pre-pandemic conditions and thus, could challenge the application of analysis to a post-pandemic health care system. While the pandemic has brought about pockets of innovation and evolution, at the time of publication local primary care centres continue to deliver care via face-to-face consultations, restricted to 15 minutes, and charge a fee for the service.

Changes brought about by the reforms and innovations introduced in response to the pandemic would make for useful future research. In particular, examining any new processes to understand what the changes achieve, and whose interests they serve.

The absence of participants who identify as Māori is both a shame and a missed opportunity. While early consultation with Māori advisors endorsed the approach to the inquiry, without Māori participants the usefulness and application of findings to Māori people, who experience profound inequities when using health care (Goodyear-Smith & Ashton, 2019; Palmer et al., 2019; Rashbrooke, 2013), is contestable. Complexities of recruiting Māori are well noted (Dyall et al., 2013; Pitama et al., 2011). The responsibility to recruit in a culturally appropriate manner lies with the researcher and in hindsight, the recruitment by the practice nurse was not constructive (Francis et al., 2019).

The voice of Māori too has been missed in the critique of the current model of primary care in this study. The IFHC is a business model with a focus on seeing and treating people rapidly. For example, a phone triage system is unlikely to meet the needs of whānau who value whakawhanaungatanga (relationships) and who define hauora (health and wellbeing) differently from the reductionist biomedical model. This world of neoliberal health policies and NPM ideologies, grounded in westernised models of governing, have created institutionally racist structures (Came, 2014; Palmer et al., 2019) which are at odds with a Māori model of healthcare. Having neither patients nor clinicians who whakapapa (identify) to Māori is a severe limitation.

Concluding remarks

The everyday experience of patients and clinicians at the frontline of primary care shared in this study reveals that patients and clinicians are doing a great deal of work to access, receive and provide a variety of primary care services. However, powerful ruling relations displace the patient and their needs as the centre of the care arrangement. Instead, patients are organised to fit within institutional practices which do not appear to meet the needs of patient or clinician.

Where to from here? The challenge is to implement an affordable model of care that can accommodate a variety of healthcare workers while at the same time ensuring that the patient and their whānau are engaged with the healthcare team to promote a patient focus and perhaps retain some degree of care continuity? The experience of participants in this study suggests it takes extraordinary courage from dedicated clinicians to provide a person-centred episode of care, but that, particularly in IFHCs, continuity of the relationship is challenged by rules of the institution which favour efficiency over continuity. Examining the notion of continuity, its contribution to health outcomes, particularly for Māori and other underserved and priority groups is an important consideration for decision makers.

In the interim, patients, socialised by decades of familiar and available family GPs, are now receiving neither continuity of care, nor navigational support in a new and disconnected environment. Yet, patients continue to be informed by the rhetoric of "your GP" and told to make the right appointment and to know what to ask. Immediate changes are required in the communication between system and user, until such time as there is real ability to do things differently. Patients know that care is changing, but they are not told why, or how to work effectively in new environments. These concerns extend into what can be said and done within the consultation, where patients are increasingly managing an array of conditions, but constrained to a single issue in the absence of evidence or logic telling them why.

The drivers of the patient experience explicated in this thesis - NPM, private business models, safety rhetoric, and obligations to meet and report on targets and guidelines - have achieved and reinforced a one-issue appointment arrangement. The idea of addressing a single issue per appointment aligns with the model of an acute and new presentation, which no longer reflects the way primary care is used by many who live with long-term conditions. The Strategy (King, 2001) attempted to disrupt this model, to use the workforce differently, to place the patient and whānau at the centre of care. Instead, the patient seems further away from the centre than ever before. Some clinicians have shown it is possible to work around these rules and self-critique their role in a complex and problematic care environment. If a few more clinicians applied an equity lens to their practice and enacted the principles of Te Tiriti (such as Alex endeavours to do) – services would be quite different. The question remains; how can the care environment support all clinicians to practice to their full professional and social ability?

Moving away from the 15-minute consultation model, which it seems no one likes, is perhaps the best place to start. But there is a balance between cost-effectiveness and efficiency and GPs are an extremely costly workforce, both to train and to employ. Further, it does not seem that in over 120 years of medically dominated primary care much has been done to improve health outcomes and equity. Therefore, what is needed is a shift away from the 15-minute consultation model, and a shift away from GPs as the central provider and gatekeeper of primary care services. How can the health workforce at all scopes of practice, including unregulated health workers, together and with patients, develop models of care that work and promote health and wellbeing for individuals, families and communities?

The answer is going to lie in different ways and approaches, and likely for different people at different times. There is no one size fits all. But the current regularised, routineised rules of primary care leave no room for patients or clinicians to work safely, effectively, and in a way that satisfies both them and those they are caring for. It is time we ensured we can deliver services that are culturally appropriate and safe. Patients and clinicians do both want what works for them – though of course this is compounded by the business model of healthcare. Is it truly possible to achieve different ways and approaches while complying with the institutional agenda of business models that do not accommodate the realities of peoples' complex and varied needs?

This thesis has raised some fundamental questions; firstly, whether person-centred care is actually possible from an affordability and workforce capacity perspective? And secondly, whether the NPM agenda makes person-centred care even possible. After undertaking this research project, and in consideration of the exhaustive research into the current and future challenges the primary care sector is facing (Goodyear-Smith & Ashton, 2019; Ministry of Health, 2019a, 2019b; The Royal New Zealand College of General Practitioners, 2019), I posit the notion that continuing to feed the rhetoric of person-centred care, in the absence of systems or resources that are truly able to put people at the centre of their care may not be the most productive use of time and energy.

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APPENDIX A: New Zealand 'person-centred' legislation and strategy

This appendix identifies New Zealand legislation, strategies, and supporting texts which reference explicitly, or contain concepts that underpin person-centred care, and presented here chronologically[39].

1. Code of Health and Disability Consumers' Rights 1996

Every consumer has the right to;

- be treated with respect
- dignity and independence
- effective communication
- be fully informed
- make an informed choice and give informed consent

2. The New Zealand Public Health and Disability Act 2000

Every DHB has the following objectives: …to foster community participation in health improvement, and in planning for the provision of services and for significant changes to the provision of services. (p. 23)

3. The New Zealand Health Strategy (2000)

The New Zealand Health Strategy… emphasises a health system that is based on co-operation, a system that puts people at the heart of health care. (p. iii)

Active involvement of consumers and communities at all levels: This principle identifies the need to have consumers and communities involved in decisions that affect them. This process should also ensure services at all levels of the health sector fully reflect the needs of the individuals and communities. (p. 9)

4. Improving Quality (IQ): A systems approach for the New Zealand Health and Disability Sector (2003)

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[39] I wish to thank Lyndon Keene, Association of Salaried Medical Professionals Director of Policy and Research, for the personal communications that guided my early 'digging' in the mountains of New Zealand grey literature.

Improvements in quality are necessary to support a vision of people in the New Zealand health and disability system receiving 'people-centred', safe and high-quality services that continually improve and that are culturally competent.

'People-centred' means involving people and being receptive and responsive to their needs and values. It includes both individuals and population groups receiving services. (p. vii)

5. New Zealand Health Strategy: Future Direction (2016)

To make this strategy work, we need to make our behaviours, actions and approaches consistent across the system. We need to put people at the forefront of our thinking and actions. Moving ahead will involve some changes in behaviour, which we can use to identify success, in particular when there is a shift from… service-centred delivery to people-centred services. (p. 14)

6. New Zealand Health Strategy: Roadmap of Actions (2016)

People-powered: The people powered theme reflects the Government's priority of delivering 'better public services' and the opportunity to achieve this through taking more person-centred approaches to providing health services. A person-centred system will involve people not only as users of health services but also as partners in health care. It will support and equip all New Zealanders to be informed about and involved in their own health. (p. 5)

7. System Level Measures (introduced 2016/2017)

Measuring: "Patient experience of care (person-centred care)" (Ministry of Health, 2018b).

APPENDIX B: Massey University Human Ethics Committee Approval

Date: 21 December 2016

Dear Rachel Webster

Re: Ethics Notification - **SOA 16/63 - An institutional ethnography of New Zealand's commitment to patient-centred care**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern A Committee** at their meeting held on **Wednesday, 21**

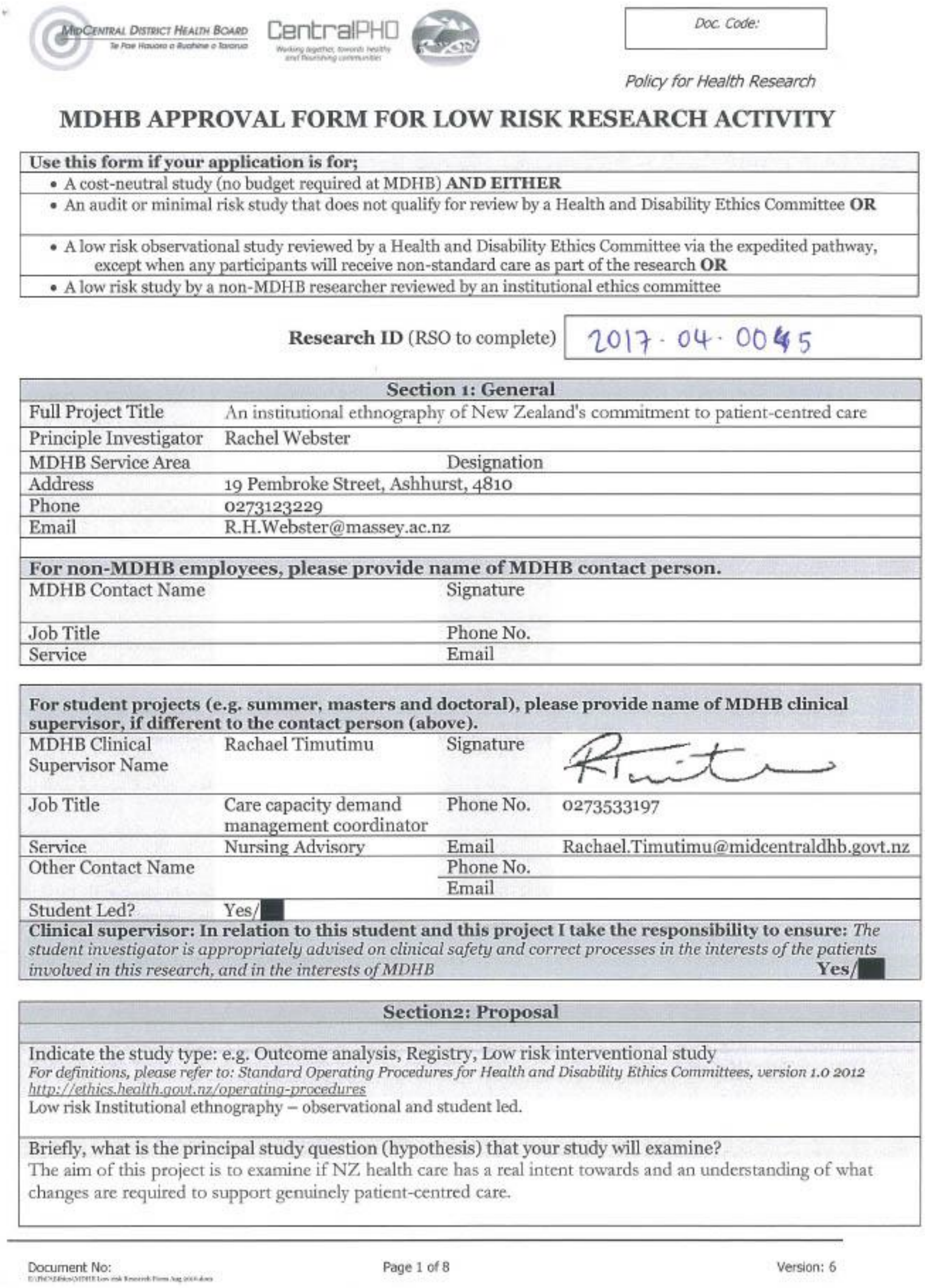
Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Brian Finch
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

APPENDIX C: Mid Central Health Research Approval



MidCentral District Health Board
Te Pae Hauora o Ruahine o Tararua

CentralPHO
Working together, towards healthy and flourishing communities

Doc. Code:

Policy for Health Research

MDHB APPROVAL FORM FOR LOW RISK RESEARCH ACTIVITY

Use this form if your application is for;

- A cost-neutral study (no budget required at MDHB) **AND EITHER**
- An audit or minimal risk study that does not qualify for review by a Health and Disability Ethics Committee **OR**
- A low risk observational study reviewed by a Health and Disability Ethics Committee via the expedited pathway, except when any participants will receive non-standard care as part of the research **OR**
- A low risk study by a non-MDHB researcher reviewed by an institutional ethics committee

Research ID (RSO to complete) 2017 · 04 · 0045

Section 1: General

Full Project Title	An institutional ethnography of New Zealand's commitment to patient-centred care		
Principle Investigator	Rachel Webster		
MDHB Service Area		Designation	
Address	19 Pembroke Street, Ashhurst, 4810		
Phone	0273123229		
Email	R.H.Webster@massey.ac.nz		

For non-MDHB employees, please provide name of MDHB contact person.

MDHB Contact Name		Signature	
Job Title		Phone No.	
Service		Email	

For student projects (e.g. summer, masters and doctoral), please provide name of MDHB clinical supervisor, if different to the contact person (above).

MDHB Clinical Supervisor Name	Rachael Timutimu	Signature	
Job Title	Care capacity demand management coordinator	Phone No.	0273533197
Service	Nursing Advisory	Email	Rachael.Timutimu@midcentraldhb.govt.nz
Other Contact Name		Phone No.	
		Email	
Student Led?	Yes/[redacted]		

Clinical supervisor: In relation to this student and this project I take the responsibility to ensure: *The student investigator is appropriately advised on clinical safety and correct processes in the interests of the patients involved in this research, and in the interests of MDHB* **Yes/**[redacted]

Section2: Proposal

Indicate the study type: e.g. Outcome analysis, Registry, Low risk interventional study
For definitions, please refer to: Standard Operating Procedures for Health and Disability Ethics Committees, version 1.0 2012
http://ethics.health.govt.nz/operating-procedures
Low risk Institutional ethnography – observational and student led.

Briefly, what is the principal study question (hypothesis) that your study will examine?
The aim of this project is to examine if NZ health care has a real intent towards and an understanding of what changes are required to support genuinely patient-centred care.

Document No: Page 1 of 8 Version: 6

Describe what taking part in the study will involve for participants.

If you agree to be part of this research, you will be involved in one, possibly two interviews (a follow up may be required if the researcher needs to clarify something). The interview will be semi-structured, but not standardised. The point of the interview is to learn about what each informant actually does, and how patient-centred care is experienced in your everyday work, and within the institutional process you work with.

- The interviews will be individual, and can be face-to-face at a place of your choosing, by skype, or by phone.
- Each interview is designed to take about 45-60 minutes, and will be done at a time that suits you.
- During the interview, the researcher will ask questions and take notes about observations they have made.
- Following the interview, everything said will be transcribed. You will receive a summary of this, and you will get a chance to edit anything you said. This will take 15-30 minutes.
- The researcher will be available for contact at any time during the research process if a participant requires additional support for any reason related to this research

Risks

- You will not intentionally be exposed to any harm during this research.
- You may experience some discomfort talking about your employer, institutional processes, and sharing personal stories.
- The researcher will take every effort to ensure participants feel comfortable, and participants have the right to decline to answer any particular questions to prevent such discomfort.

Anonymity

The researcher will protect your anonymity in several ways;

- in all research writing, references to individuals or the naming of particular places will be anonymous (through the use of pseudonyms), or by use of job title where appropriate, e.g. "a primary healthcare nurse…".
- stories or accounts of particular experiences will not be recognisable to anyone except the participant. Contextual details will be altered as required to ensure this.

Benefits

- Information used will help to produce a piece of research targeted at improving New Zealand health services commitment to delivering care that is patient-centred.

Brief description of study methods

Institutional ethnography (IE) is a qualitative research approach, The premise of IE is that our daily activities, or what we do in our lives, are coordinated by texts produced by the ruling relations or institutions (Smith, 1999, 2005). By exploring from the local situation and mapping actions and texts we begin to understand how things are put together, and therefore what could be changed to improve a particular situation. IE starts with a 'small hero' (Smith, 2006), in this research our small hero is the health care consumer. The small hero is the person, or group of people whom are in some way marginalised, subordinated or oppressed, possibly unknowingly, by textual organisation (including policies, documents, articles, media etc.). We use our small hero as the entry point into our research problem, by looking up and into our research problem from their standpoint, seeking out the complex social relations beyond their view.

Describe any impact upon MDHB resources (e.g. use of staff time, facilities, consumables).

The only known impact on MDHB resources is the use of staff time. The MDHB employees will be encouraged to use their own judgement to select a suitable interview time, and where possible the researcher will attempt to arrange interview times outside of clinical hours.

Final Reporting Mechanism
Published doctoral thesis

Section 3: Ethical considerations

Complete Section 3 if you HAVE NOT completed an application to the Health and Disability Ethics Committee. If you have completed a HDEC application, do not complete Section 3, but submit the application/approval letter along with this form. If you have submitted an application for ethical approval to an institutional ethics committee(e.g. A University ethics committee), complete Section 3 and also submit the ethics application along with this form

1. What benefits do you expect the study to provide?

Information used will help to produce a piece of research targeted at improving New Zealand health care's commitment to delivering care that is patient-centred. Research demonstrates care that is patient-centred both improves the patient care experience, and creates public value for services (ACSQH, 2011), which suggests this research has potential to be beneficial for all parties involved.

The Ministry of Health have identified in The New Zealand Health Strategy (2016) a target of achieving this standard of care by 2026, making this research timely to their agenda. This is also aligned with other relevant New Zealand health care strategies, including the Māori Health Strategy.

2. What risks do you expect the study to pose?

Just as the research method is emergent, so too are the potential ethical issues embedded within IE research, only the field researcher truly confronts the unanticipated aspects of research while the project is ongoing. The researcher RW is acutely aware of this, and while due consideration has been given to visible ethical concerns; RW is conscious of the need for effective on the spot ethical decision making and practices. As a registered nurse RW is attune to the unpredictable nature of ethical problems, RW has a strong connection to the nursing code of ethics, and the code of ethical conduct for research, teaching and evaluations involving human participants, which will enhance her abilities as a researcher in practice.

Many issues have arisen due to the nature of the methodology, in particular the challenge of proposing research where majority of participants are totally unknown until the research is well underway. Much attention has been paid to this in the consideration of ethical issues.

The following are the key known ethical issues identified for this project;

Respect for Persons;

Due to the unknown identity and circumstances of research participants, owing to the emergent methodology, it is appropriate to prepare for all possibilities. In saying that, it is entirely possible to carry out a well-rounded project without having to access overly vulnerable populations. For this reason, persons with diminished competence, children, and overly researched populations will be excluded from the participant population. Potential participants who identify as mental health service users will also be excluded as integrated care, which has strong links to this project, has been extensively researched with this population.

Participation in this research at all levels is voluntary, and participants may withdraw from the research at any time without personal or professional penalty.

Minimisation of risk of harm;

It is not expected that harm will come to participants from participation in this research. The researcher RW is aware that participants may feel uncomfortable talking to the researcher about a sensitive topic; however a study conducted by Decker, Naugle, Carter-Visscher, Bell, and Seifert (2011) found that participation in sensitive topic research seems less likely to cause distress than initially anticipated. Additionally, from other studies analysed, they found personal benefits to the participants were often reported as greater than the perceived negative effects. This is not to suggest there is no risk, instead that the risk is not likely to be sufficient to jeopardise the research. RW will remain alert for any signs of distress or discomfort, and make appropriate ethical decisions should the need arise.

As recommended by Mealer and Jones (2014), participants will be encouraged to engage in self-reflection following the interview, by way of either journaling, or discussing with a peer. Should any participant require further support due to the distress of the research, the researcher RW will refer them to appropriate professional support services.

Should a situation become overly distressing for a participant, the researcher will first turn off all recording devices and suspend the interview, following which an assessment will be made of the appropriateness of continuing after a intermission, or terminating the interview and seeking further support for the participant[ant if required. As an experienced clinician RW is well positioned to make such decisions.

Risk of harm to researcher;

Due to the potential sensitive topics discussed in the interview it is best practice to allow the participant to choose an interview location where they feel most comfortable (Elmir, Schmied, Jackson, & Wilkes, 2011; Mealer & Jones, 2014).

Interviewing alone poses potential risk to the researcher RW. Should an interview be arranged to be held at someone's home, RW will make an assessment of the suitability and safety of the environment. RW will also ensure another person is aware of whereabouts and expected duration of the interview.

Informed and voluntary consent;

Consent from participants will be informed and voluntary, ensuring all four elements of informed consent are met. Potential participants will be given one week to consider the invitation. Consent will be written; copies of this will be stored securely. There are no foreseeable power relationship issues relevant to this project affecting the nature of consent.

Risk of coercion;

Phase one participants for this research will be chosen purposively. In order to mitigate for coercion, recruitment will be initiated by general practice nurses not related to the research. Potential participants who meet the criteria will be given a letter of invitation, from which it is up to the potential participant to engage with the researcher. The researcher will not be notified of any efforts to recruit, until a participant makes contact. If a potential participant chooses not to accept the invitation to participate they will receive no further contact and will not be penalised in any way.

Respect for privacy and confidentiality;

An assurance of confidentiality will be given to participants; RW will be pro-active in protecting confidentiality. Participants will be identified either by pseudonym or professional title where appropriate. For comprehension of the research, it will at times be important to understand the position of the informant, for contextual relevance. In these circumstances, as recommended by Norstedt and Breimo (2016), participants may be referred to as 'registered nurse', 'doctor' or 'pharmacist' etcetera. National organisations involved in this research exist in the public domain so will by nature be identifiable.

All data will be recorded and processed using pseudonyms or titles as appropriate. Consent forms will be stored in a separate location to the data. RW will be transcribing the data independently.

Decker, S. E., Naugle, A. E., Carter-Visscher, R., Bell, K., & Seifert, A. (2011). Ethical issues in research on sensitive topics: Participants' experiences of distress and benefit. *Journal of Empirical Research on Human Research Ethics, 6*(3), 55-64. doi: 10.1525/jer.2011.6.3.55

Elmir, R., Schmied, V., Jackson, D., & Wilkes, L. (2011). Interviewing people about potentially sensitive topics. *Nurse Researcher, 19*(1), 12-16.
Mealer, M., & Jones, J. (2014). Methodological and ethical issues related to qualitative telephone interviews on sensitive topics. *Nurse Researcher, 21*(4), 32-37. doi: 10.7748/nr2014.03.21.4.32.e1229
Norstedt, M., & Breimo, J. (2016). Moving Beyond Everyday Life in Institutional Ethnographies : Methodological Challenges and Ethical Dilemmas. *Forum : Qualitative Social Research*, 1.

3. What steps will you take to minimise expected risk?
Included above

4. Will you be collecting information directly from individuals? YES / [redacted]
If YES, explain how will you identify and/or approach potential participants?
Phase one participants will be chosen purposively from patients identified by general practice nurses, to whom they are well known.
Recruitment for phase one will be initiated by general practice nurses. Potential patient participants who meet the selection criteria will be given a letter of invitation and information sheet by the general practice nurse during a regular consultation. The researcher will not be informed of who has received invitations to participate. The first contact with the researcher must be initiated by potential participants after reviewing the invitation to participate. Following the first contact from the interested participant, RW will post or email further information including a consent form, and allow one week for the potential participant to consider their involvement, before following up with the participant in a manor agreed upon during the initial contact, e.g. by phone or by email.
Staying true to the IE methodology, the second phase participants will become known to the researcher only after the first phase is complete and the emergent issues are uncovered. These participants are identified as their particular role (e.g. ED registrar, district nurse) has been discovered through mapping of a patient participant's story, to be of interest to the issue being explicated.
Phase two participants will be recruited by one of two methods, depending on their position. Clinicians, such as doctors and nurses will be recruited via snowballing; the researcher RW will begin with an initial clinician contact in either primary or tertiary settings as appropriate. The initial contact will be asked to pass on an invitation to participate and an information sheet to persons who hold professional roles that have been identified as being of interest. The researcher will not be informed who has received invitations to participate. Again contact with the researcher must be initiated by the prospective participant, after which the same process as with patient participants will be followed. Following the completion of the interview, once the next step is known, the participant will be asked to pass on a recruitment pack to the next identified position. Alternatively, potential participants will be approached directly by the main researcher RW, by email if available, or by appropriate channels of communication depending on the potential participant's relationship to the research, using publically available contact information; for example through author details of a text, or publicly visible roles such as ministry employees. Initial contact will involve an introduction to the researcher and the project; Invited participants will be given an information sheet to consider. RW will follow up one week after initial contact with an email or phone call enable the potential participant to ask for further information or clarification, and discuss if the individual choses to participate or not, and negotiate an interview time and location if required.

Local and national organisations are anticipated to be included in the research in the final data collection stages, as identified through the texts located in earlier interviews. Organisations such as the Ministry of Health, in particular the authors of texts and policies such as the New Zealand Health Strategy and health targets, are predicted to be included.

Norstedt, M., & Breimo, J. (2016). Moving Beyond Everyday Life in Institutional Ethnographies : Methodological Challenges and Ethical Dilemmas. *Forum : Qualitative Social Research*, 1.
Rashid, M., Caine, V., & Goez, H. (2015). The Encounters and Challenges of Ethnography as a Methodology in Health Research. *International Journal of Qualitative Methods, 14*(5), 1609406915621421.

5. Will you be collecting information about individuals from a third party? If so, a) what is the party's relationship to the participants, and b) why is it appropriate to gain the information from that person?	[redacted] / NO
6. Will you be obtaining information from health records (patient clinical records)?	[redacted]/NO
7. Will you be accessing health information about identifiable or potentially identifiable individuals (this means you – the researcher - will or might be able to tell the identity of the individuals)? *(if NO go straight to Section 4)*	YES/[redacted]
8. If participants will be identifiable or potentially identifiable, will you obtain the consent of the individuals concerned?	YES/[redacted]

9. If your study involves entering patient data into a registry or database and you will NOT be using a formal process of informed consent, describe what information you will be giving to patients about how their data will be used and if they will have an option to "opt out"

n/a

10. Justify the collection and use of patient information without consent for this study

n/a

11. Explain all measures taken to preserve the confidentiality of the patient information, including how it is stored, which study personnel will have access, and for how long it will be stored before destruction.

Audio recording will be stored as an anonymous audio file. The audio file will be saved anonymously on a personal hard drive which is password protected and only accessible by myself (RW). The audio file will be transcribed within one month of the interview, and any paper copies kept in a locked cabinet in my office. Transcripts will be anonymous.

Consent forms will be stored separate to all data in locked storage within the school of nursing for a period of 5 years.

The researcher – RW, and all supervisors - Professor Jenny Carryer, Dr Mark Jones, Dr Louisa Toffoli will hjave access to consent forms.

Electronic data will be stored on the personal hard drive of the computer of the researcher which is password protected. Paper transcripts will be kept in a locked cabinet in the researcher's office at Massey University filed under pseudonym to protect any connection to consent forms; consent forms will be stored in a locked cabinet at the researcher's home – accessible only by the researcher RW.

Following Massey University research protocol, all data will be kept for five years. Lead supervisor, Professor Carryer, will be responsible for the destruction of this data.

IMPORTANT - If you will not be obtaining informed consent to use identified patient information, and any combination of the below apply, you will need ethical approval from a Health and Disability Ethics Committee

- You are not employed by or contracted to MDHB,
- You will be retaining unique identifiers (e.g. NHI) in your dataset that could link to other databases/registries
- You will be obtaining health information from other health care organisations in addition to MDHB

Section 4 Administration and Declarations

Required for all applicants

Proposed study start date	28/08/2016
Proposed completion date	28/08/2019
I have completed a MDHB Maori Research review form	YES/[redacted]

I will inform MDHB Research Support Officer when study is complete YES/[redacted]

Rachel Webster 13/04/17

SUPPORTING DOCUMENTS CHECKLIST – remember to submit the following with this application form **if relevant**

- ☐ Locality assessment form
- ☐ ✓Ethics approval letter
- ☐ ✓Study Protocol
- ☐ ✓Participant Information Sheets and Informed Consent Forms
- ☐ Questionnaires / Surveys
- ☐ ✓Evidence of Māori consultation
- ☐ Any other supporting documentation relevant to the application

IMPORTANT – submit supporting documents and application form in **electronic** version by email to the Research Office email address (research@midcentraldhb.govt.nz), or as a paper copy to:
Kelly Butler
Research Support Officer
Chief Medical Office
Admin Building

Section 5 MDHB Professional Approval

Clinical Director / Service Manager / Leader / Medical Director / Nursing Leader

Name	Dr Jeff Brown		
Service			
Department			
Job Title	Acting CMO		
Signature	J Brown	Date	8 June 2017
Comments:			

Section 6 Operations Director's Endorsement to Proceed

Name	LYN HORGAN		
Job Title	OPERATIONS DIRECTOR		
Signature		Date 13/6/17	
Comments:			

Section 7 Clinical Board Acknowledgment of Registration

Name	Michele Coghlan		
Job Title	Acting Executive Director, Nursing and Midwife		
Signature	M Coghlan.	Date 9/6/17.	Deputy Chairperson Clinical Board.
Comments:			

Section 8 Office use only		
	Date	Comment
Date Received		
Date Acknowledged		
Application sent for Approval		
Final Endorsement		
MDHB Registration Number		
HDEC Reference Number		
MOU/Contract Number		

APPENDIX D: Primary care patient experience survey

Retrieved from: https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/primary-care-patient-experience/the-survey/

HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

Primary care patient experience survey

December 2018

Survey overview

1. This version of the survey does not show the logic that 'skips' people to appropriate questions based on their answers. Not all people see all the questions.
2. Questions in blue are the main logic drivers of the survey. Respondents will only be asked about things they have indicated are applicable to them. This is represented by the flower image to the right, whereby all patients see questions about their regular GP and place of care but only see other questions (the petals/modules) if they are relevant to the patient's experience.

3. All open comment questions are optional for respondents.

For any questions regarding this survey please contact survey@hqsc.govt.nz.

Introduction

Could you tell us if you are answering this survey on behalf of yourself or someone else?
Single selection (radio buttons)

1. Myself
2. Someone else (Please tell us why)

GP clinic or community health clinic

This section has a few questions about your GP clinic or community health clinic.

Is there one GP clinic or community health clinic you usually go to?
Single selection (radio buttons)

1. Yes
2. No, I do not have a place that I usually go

Next question only applicable to people that answer 'No' to the previous question

You are enrolled at [name of GP clinic or community health clinic]. Is there a reason you don't usually go there?
Large text area

Does the place you usually go to have a phone service, doctor or nurse available during evenings, nights or weekends? (Either there or another place)
Single selection (radio buttons)

1. Yes
2. No
3. Don't know

Is there one GP or nurse you usually see?
Single selection (radio buttons)

1. Yes
2. No

How long have you been going to your current GP or nurse clinic?
Single selection (radio buttons)

1. Less than one year
2. One to five years
3. More than five years

Please answer this next section based on your experiences over the last 12 months

When you ring to make an appointment how quickly do you usually get to see...
Matrix (radio buttons)

	Same day	Next working day	Within a week	Over a week	N/A
Your current GP					

Any other GP at the clinic you usually go to?					
A nurse at the clinic you usually go to?					

Is this acceptable?
Single selection (radio buttons)

1. Yes
2. No (Please tell us why):

How long do you usually have to wait for your consultation to begin with...
Matrix (Radio Buttons)

	5 minutes or less	6-15 minutes	16-30 minutes	More than 30 minutes	N/A
Your current GP?					
Any other GP at the clinic you usually go to?					
A nurse at the clinic you usually go to?					

Is this acceptable?
Single selection (radio buttons)

1. Yes
2. No (Please tell us why):

Did the reception and admin staff treat you with respect?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No

In the last 12 months was there a time when you did not visit a GP or nurse because of cost?
Single selection (radio buttons)

1. No
2. Yes (Please tell us why):

Could you tell us why cost stopped you from seeing a GP or nurse?
Multiple selection (checkboxes)

- ☐ The appointment was too expensive
- ☐ The cost to travel was too expensive

- ☐ I couldn't afford to take the time off work
- ☐ Other (Please tell us):

Was there ever a time when you wanted health care from a GP or nurse but you couldn't get it?
Single selection (radio buttons)

1. No
2. Yes (Please tell us why):

When you contact your usual GP clinic about something important, do you get an answer the same day?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No
4. N/A

Does your GP or nurse explain things in a way that is easy to understand?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No
4. N/A

Are you confident that your GP or nurse is aware of your medical history?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No
4. Don't know

Have you been involved in decisions about your care and treatment as much as you wanted to be?
Single selection (radio buttons)

1. Yes
2. Yes, to some extent
3. No

Does your GP or nurse...
Matrix (radio buttons)

	Yes, always	Yes, sometimes	No
Treat you with respect?			

Treat you with kindness and understanding?			
Listen to what you have to say?			
Spend enough time with you?			

Is there anything you would like to tell us about your experience with your GP or nurse?
Large text area

Now we ask you some general questions so we know which topics to ask about later in the survey

Do you take any medication regularly? This includes vitamins, painkillers, supplements and any prescribed medication.
Single selection (radio buttons)

1. Yes
2. No

In the last 12 months...
Matrix (radio buttons)

Did you have any tests such as x-rays, scans, blood tests or other tests?	Yes	No	Don't know
Have you seen any health care professionals other than a GP or nurse? Some examples are a midwife, physiotherapist, psychologist, social worker, counsellor, pharmacist, or dietitian.	Yes	No	Don't know
Have you seen a specialist doctor, other than a GP?	Yes	No	Don't know
Have you been to the emergency department at the public hospital?	Yes	No	Don't know
Have you stayed in hospital overnight?	Yes	No	Don't know
Do you have a health condition that will last more than six months?	Yes	No	Don't know

Please select which conditions expected to last six months or more you have been diagnosed with

Overall, was your experience with your GP or nurse clinic? *(Please select a number)*

Very poor									Excellent	
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

Multiple selection (checkboxes)

Please select as many options as apply below

- ☐ Anxiety
- ☐ Arthritis
- ☐ Asthma
- ☐ Cancer
- ☐ Chronic Obstructive Pulmonary Disease (COPD)
- ☐ Depression
- ☐ Diabetes
- ☐ Heart disease
- ☐ High blood pressure
- ☐ Long term pain
- ☐ Other mental health conditions
- ☐ Stroke
- ☐ Other

Medication

The next questions are about medication, including vitamins, painkillers, supplements and any prescribed medication you have used during the last 12 months. From now on we'll refer to these as 'medication'.

Were you involved as much as you wanted to be in decisions about the best medication for you?
Single selection (radio buttons)

1. Yes, definitely
2. Yes, to some extent
3. No
4. I did not want to be involved

Here are some questions about your medications prescribed or recommended by a doctor, nurse or pharmacist (outside of hospital).
Matrix (radio buttons)

	Yes, definitely	Yes, to some extend	No	N/A
Was the purpose of the medication properly explained to you?				
Were the possible side effects of the medication explained in a way you could understand?				
Were you told what could happen if you didn't take the medication, in a way you could understand?				

Were you told what to do if you experienced side effects?				

Did you follow the instructions when you took the medication?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No

You said that you did not always follow the instructions when you took the medication. Please tell us why.
Multiple selection (checkboxes)

- ☐ Cost
- ☐ Side effects
- ☐ I forgot
- ☐ I felt better
- ☐ Other (Please tell us more):

Has cost stopped you from picking up a prescription?
Single selection (radio buttons)

1. No
2. Yes

In the last 12 months have you been given the wrong medication or wrong dose by a doctor, nurse or pharmacist (outside of hospital)?
Single selection (radio buttons)

1. No
2. Yes
3. Don't know

Because of the wrong medication or dose, did you...
Matrix (radio buttons)

	Yes	No
Stop taking it?		
Get medical advice?		
Get medical care?		
Get admitted to hospital?		

Is there anything else you’d like to tell us about being given the wrong medication or dose?
Large text area

Is there anything you would like to tell us about your experiences with your medication?
Large text area

Medical tests

Now a few questions about medical tests and scans you may have had in the past 12 months. This includes x-rays, scans, blood tests and other tests.

Was the need for the x-ray, test or scan(s) explained in a way you could understand?
Single selection (radio buttons)

1. Yes, completely
2. Yes, to some extent
3. No
4. I did not need an explanation

Were you told how you could find out the results of your x-ray, scan(s) or tests?
Single selection (radio buttons)

1. Yes
2. No
3. Not sure
4. I did not need an explanation

Were the results of the x-ray, test or scan(s) explained in a way you could understand?
Single selection (radio buttons)

1. Yes, completely
2. Yes, to some extent
3. No
4. Not sure
5. I was told I would get the results at a later date
6. I was never told the results of the tests

Is there anything you would like to tell us about your experiences with x-rays, scan(s) or tests?
Large text area

Other health care professionals

Now a few questions about health care professionals (other than a doctor or nurse) you may have seen or talked to.

Some examples are midwife, physiotherapist, psychologist, social worker, counsellor, pharmacist, and dietitian.

Was there a time when test results or information was not available at the time of your appointment with the health care professional?
Single selection (radio buttons)

1. No
2. Yes
3. Don't know
4. N/A

Were you given conflicting information by different doctors or health care professionals, e.g. one would tell you one thing and then another would tell you something different?
Single selection (radio buttons)

1. No
2. Yes, sometimes
3. Yes, always

How quickly do you usually get to see a health care professional?
Single selection (radio buttons)

1. Less than a week
2. 1–4 weeks
3. 1–3 months
4. Longer

Has cost stopped you from seeing a health care professional?
Single selection (radio buttons)

1. No
2. Yes

Could you tell us why cost stopped you from seeing a health care professional?
Multiple selection (checkboxes)

- ☐ The appointment was too expensive
- ☐ The cost to travel was too expensive
- ☐ I couldn’t afford to take the time off work
- ☐ Other (Please tell us):

Is there anything you would like to tell us about your experiences with health care professionals (other than a doctor or nurse)?
Large text area

Specialist doctors (other than GP)

Now a few questions about specialist doctors (other than GPs) that you may have seen in the past 12 months.

When you were referred to a specialist did you have any difficulties getting an appointment?
Single selection (radio buttons)

1. No
2. Yes

Any comments?
Large text area

In general, how long did you wait from the time you were first told you needed an appointment to the time you went to the specialist doctor?
Single selection (radio buttons)

1. Less than a week
2. 1–4 weeks
3. 1–3 months
4. Longer

Any comments?
Large text area

Has cost stopped you from seeing a specialist doctor?
Single selection (radio buttons)

1. No
2. Yes

Could you tell us why cost stopped you from seeing a specialist doctor?
Multiple selection (checkboxes)

- ☐ The appointment was too expensive
- ☐ The cost to travel was too expensive
- ☐ I couldn’t afford to take the time off work
- ☐ Other (Please tell us):

When you received care or treatment from specialist doctors, did they do the following?
Matrix (radio buttons)

	Yes, always	Yes, sometimes	No	N/A
Ask what is important to you?				
Tell you about treatment choices in ways you could understand				

Involve you in decisions about your care or treatment as much as you wanted to be?				

Any comments?
Large text area

Do the specialist doctors know your medical history and the reason for your visit?
Single selection (radio buttons)

1. Yes, fully aware
2. Yes, aware in part
3. No
4. Don't know

Has a doctor ordered a test (e.g. blood test, x-ray, etc) that you felt you didn’t need because the test had already been done?
Single selection (radio buttons)

1. No
2. Yes
3. Don't know
4. N/A

Does your current GP or nurse seem informed and up-to-date about the care you get from specialist doctors?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No
4. Don't know
5. N/A

Is there anything you would like us to know about how well your GP and specialist doctors are working together?
Large text area

Emergency departments

The next questions are about accessing health care from a public hospital emergency department.

The last time you went to the public hospital emergency department, why did you go there?
Multiple selection (checkboxes)

- ☐ It was clearly an emergency
- ☐ I was told to go to the emergency department by a health care professional

☐ I can’t afford to go anywhere else
☐ Other (Please tell us why):

Is there anything you would like us to know about how well your GP and the emergency department are working together?
Large text area

Hospital stays

The next questions are about your most recent stay in hospital.

Could you please tell us which hospital you received care from?
Single selection (dropdown menu)

Dropdown list of hospitals.

Did the hospital arrange follow-up care with a doctor or other health care professional?
Single selection (radio buttons)

1. Yes
2. No
3. N/A
4. Don't know

Did your current GP seem informed and up-to-date about the plan for follow-up?
Single selection (radio buttons)

1. Yes
2. No
3. N/A
4. Don't know

Did you have to go back to hospital or get emergency care because of complications within a month after being discharged from hospital?
Single selection (radio buttons)

1. No
2. Yes

Is there anything you would like to tell us about your experience of your GP and the hospital working together?
Large text area

Long-term conditions

The next questions are about health conditions that are expected to last 6 months or more. These are referred to as 'long-term' conditions.

How long ago were you first diagnosed for the condition(s)?
Matrix (radio buttons)

	Less than 6 months ago	6-12 months ago	1-2 years ago	2-5 years ago	5-10 years ago	Over 10 years ago	Don't know	N/A
Anxiety								
Arthritis								
Asthma								
Cancer								
Chronic Obstructive Pulmonary Disease (COPD)								
Depression								
Diabetes								
Heart Disease								
High blood pressure								
Long-term pain								
Other mental health conditions								
Stroke								
Other								

Which other long-term condition(s) have you been diagnosed with?
Large text area

Please answer each of the following questions using the column headings as a guide.
Matrix (radio buttons)

	Yes, always	Yes, sometimes	No	N/A
Were you given information you could understand about things you should do to improve your health?				
Did you get help to make a treatment or care plan for your long-term condition that would work in your daily life?				

After a treatment or care plan was made were you contacted to see how things were going?				

Is there anything you would like to tell us about your experience being treated for a long-term condition?
Large text area

We have just a few quick questions about you to help us better understand your answers

Are you...
Single selection (radio buttons)

1. Female
2. Male
3. Gender diverse

Please tell us the year of your birth.
Single selection (dropdown menu)

Which ethnic group or groups do you belong to?
Multiple selection (checkboxes)

- ☐ New Zealand European
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Māori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ Other (such as Dutch, Japanese, Tokelauan) or Prefer not to answer

You selected 'other' as an option for your ethnic group. Which of these ethnic groups do you belong to?
Multiple selection (checkboxes)

- ☐ Other European
- ☐ Tokelauan
- ☐ Fijian
- ☐ Other Pacific Peoples
- ☐ Southeast Asian
- ☐ Other Asian
- ☐ Middle Eastern

- ☐ Latin American / Hispanic
- ☐ African (or cultural group of African origin)
- ☐ Other ethnicity
- ☐ Don’t know
- ☐ Prefer not to answer

In which language(s) could you have a conversation about a lot of everyday things?
Multiple selection (checkboxes)

- ☐ English
- ☐ Māori
- ☐ Samoan
- ☐ New Zealand Sign Language
- ☐ Other language(s), eg, Gujarati, Cantonese, Greek (Please tell us):
- ☐ Would rather not say

Did you need an interpreter to communicate with a health care professional?
Single selection (radio buttons)

1. No
2. Yes, I had an interpreter
3. Yes, I used a family member as an interpreter
4. Yes, but I did not have an interpreter

Any comments?
Large text area

Did the interpreter help you clearly communicate with the health care professional?
Single selection (radio buttons)

1. Yes
2. Yes to some extent
3. No

Any comments?
Large text area

Was cultural support available when you needed it?
Single selection (radio buttons)

1. Yes, always
2. Yes, sometimes
3. No
4. I did not need cultural support

Contact request

Would you like someone to contact you to discuss your feedback in this survey?

Please phone your GP clinic as usual for any medical matters that require a consultation.

This means you will no longer be anonymous.
Single selection (radio buttons)

1. No thanks
2. Yes, I would like someone from my current GP clinic to contact me to discuss my feedback or health experience

Are you happy for the person contacting you to see a copy of your survey response?
This means that your response will no longer be anonymous.

Single selection (radio buttons)

1. Yes, I am happy for them to see a copy of my survey response
2. No, I do not want them to see my survey response – I would like it to remain anonymous

Please tell us your contact details.
Vertical text box list

1. Your name:
2. Email address:
3. Phone number during the daytime:

Please provide some information on what you would like to talk to us about. We can then ensure the right person contacts you.

Large text area

Survey copy request

Would you like to be emailed a copy of your survey response?

Please note that as this survey is anonymous, if you do not request a copy of your survey response now and you have not requested contact from us, we will be unable to obtain a copy for you in future.

Single selection (radio buttons)

1. No thanks
2. Yes, please email a copy of my survey response to [text box]

Thank you for your time and feedback. You have now finished this survey.

We have recorded all your answers so you can now close this window.

Thanks again,

[Practice Signatory]

APPENDIX E: Patient participant information sheet

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

An institutional ethnography of New Zealand's commitment to patient-centred care

PATIENT PARTICIPANT INFORMATION SHEET

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

About the researcher

The main researcher is Rachel Webster, a PhD candidate at Massey University. Rachel is a registered nurse, and has worked for several years in acute care settings in New Zealand. Intrigued by the challenge for nurses to provide patient-centred care - to satisfy both the needs of the patient and the employer - this study has been designed to examine this point of tension, and to explore New Zealand's intent towards achieving person-centred care.

About the project

Patient-centred care refers to a focus on the individual patient and their unique needs and expert opinion of their own health, compared to the old fashioned way - 'because we know what's good for you'. It is a commitment to returning the power to the patient, not the health care system.

The purpose of this project is to examine if patient-centred care is genuinely possible in the New Zealand health system.

This project will question the plausibility of a truly patient-centred care delivery model, while attempting to answer the question; what will help or hinder New Zealand achieving patient-centred care?

You are invited to be a part of this research; to share your voice on your personal experiences of care in New Zealand

This project is supported by a doctoral scholarship from Massey University.

About the participants

This project is seeking between three and nine adults (18 years or older) who have had recent extensive contact and multiple encounters with the New Zealand health care system across any setting, and are willing to share their experiences, good and bad, with the researcher.

From the three original participants, links to other people of interest may be made.

What will participation involve?

If you choose to be part of this research, we need your time and your stories. You will be involved in one, possibly two interviews (a follow up may be required if the researcher needs to clarify something). The interview will be all about you and your experiences of receiving health care in New Zealand.

- The interviews will be individual, and can be face-to-face at a place of your choosing, by skype, or by phone.
- Each interview is designed to take about 45-60 minutes, and can be done at a time that suits you.
- During the interview, the researcher will ask questions and take notes about observations they have made.
- Following the interview, everything said will be transcribed. You will receive a summary of this, and you will get a chance to edit anything you said. You do not need to do this if you do not wish to. If you chose to review and edit, this will take 15-30 minutes, and the researcher is available to help you with this.
- The researcher will be available for contact at any time during the research process if you require additional support for any reason related to this research
- Upon completion, you will receive a summary of the project findings

Risks

- Participants will not intentionally be exposed to any harm during this research.
- There is the potential to feel uncomfortable while talking to the researcher about private experiences.
- The researcher will take every effort to ensure participants feel comfortable, and participants have the right to decline to answer any particular questions to prevent such discomfort.

Anonymity

- The researcher will protect your anonymity in several ways;
  - in all research writing, references to individuals or the naming of particular places will be anonymous (through the use of pseudonyms).
  - stories or accounts of particular experiences will not be recognisable to anyone except the participant. Contextual details will be altered as required to ensure this.

Benefits

- Information used will help to produce a piece of research targeted at improving New Zealand health systems commitment to delivering care that is patient-centred. You have the unique opportunity to be a part of this, and to have your voice heard.

About the data

Raw data will be stored securely in password protected electronic files or locked filing cabinets for five years, after which it will be destroyed by deletion or shredding

Participant's Rights

You are under no obligation to accept this invitation.
If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time, until such time as interview data has been analysed, after which it cannot be removed. This will occur approximately three months after the interview has taken place;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

Project Contacts

You are invited to contact the researcher and/or supervisor if you have and questions about this project.

Named Investigator	Rachel Webster
Role	PhD candidate
Department	College of Health
University	Massey University
Telephone	0273123229
Email	R.H.Webster@massey.ac.nz

Academic Supervisor	Professor Jenny Carryer
Department	College of Health
University	Massey University
Telephone	+64 6 356 9099 extension 85343
Email	J.B.Carryer@massey.ac.nz

You consideration is greatly appreciated.

Yours sincerely,

Rachel Webster

PhD candidate
Massey University

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 16/63. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz

APPENDIX F: Professional participant information sheet

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

An institutional ethnography of New Zealand's commitment to patient-centred care

PROFESSIONAL PARTICIPANT INFORMATION SHEET

You have been identified as a person of interest to this research. Participation is voluntary; however your contribution would be greatly appreciated. Please read this information sheet carefully before deciding whether or not to participate.

About the Researcher

The main researcher is Rachel Webster, a PhD candidate at Massey University. Rachel is a registered nurse, and has worked for several years in acute care settings in New Zealand. Intrigued by the challenge of providing patient-centred care – the push/pull felt between patient and employer - this study has been designed to examine this point of tension, and to explore New Zealand's intent towards achieving person-centred care.

About the Project

Patient-centred care refers to a focus on the individual patient and their unique needs and expert opinion of their own health, compared to the old fashioned way - 'because we know what's good for you'. It is a commitment to returning the power to the patient, not the health care system.

The purpose of this project is to examine if New Zealand health services have a real intent towards and an understanding of what changes are required to support genuinely patient-centred care. By looking at what actually happens in the everyday process of providing patient care, the research will follow and analyse the work processes that contribute to patient-centred care. This project will question the plausibility of a truly patient-centred care delivery model, while attempting to answer the question; what will help or hinder New Zealand achieving patient centred care?

The researchers recognise that health care professionals are often just as powerless as the people they are caring for, bound by institutional processes which may be knowingly or unknowingly controlling their practice. This project hopes to explicate this challenge and explore the controlling mechanisms further.

This project is supported by a doctoral scholarship from Massey University.

How was I identified and why am I being invited to participate in this research?

You have either been identified as your professional role within the health care team/system has become of interest to the research and the wider exploration of an emerging idea or problematic.

What will participation involve?

If you agree to be part of this research, you will be involved in one, possibly two interviews (a follow up may be required if the researcher needs to clarify something). The interview will be semi-structured, but not standardised. The point of the interview is to learn about what each informant actually does, and how patient-centred care is experienced in your everyday work, and within the institutional process you work with.

- The interviews will be individual, and can be face-to-face at a place of your choosing, by skype, or by phone.
- Each interview is designed to take about 45-60 minutes, and will be done at a time that suits you.
- During the interview, the researcher will ask questions and take notes about observations they have made.
- Following the interview, everything said will be transcribed. You will receive a summary of this, and you will get a chance to edit anything you said. This will take 15-30 minutes.
- The researcher will be available for contact at any time during the research process if a participant requires additional support for any reason related to this research

Risks

- You will not intentionally be exposed to any harm during this research.
- You may experience some discomfort talking about your employer, institutional processes, and sharing personal stories.
- The researcher will take every effort to ensure participants feel comfortable, and participants have the right to decline to answer any particular questions to prevent such discomfort.

Anonymity

The researcher will protect your anonymity in several ways;

- in all research writing, references to individuals or the naming of particular places will be anonymous (through the use of pseudonyms), or by use of job title where appropriate, e.g. “a primary healthcare nurse…”.
- stories or accounts of particular experiences will not be recognisable to anyone except the participant. Contextual details will be altered as required to ensure this.

Benefits

- Information used will help to produce a piece of research targeted at improving New Zealand health services commitment to delivering care that is patient-centred.

About the data

Raw data will be stored securely in password protected electronic files or locked filing cabinets for five years, after which it will be destroyed by deletion or shredding

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Participant's Rights

You are under no obligation to accept this invitation.
If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview

Project Contacts

You are invited to contact the researcher and/or supervisor if you have any questions about this project.

Named Investigator	Rachel Webster
Role	PhD candidate
Department	College of Health
University	Massey University
Telephone	0273123229
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Academic Supervisor	Professor Jenny Carryer
Department	College of Health
University	Massey University
Telephone	+64 6 356 9099 extension 85343
Email	J.B.Carryer@massey.ac.nz

You consideration is greatly appreciated.

Yours sincerely,

Rachel Webster

PhD candidate
Massey University

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 16/63. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz

APPENDIX G: Interview toolkit

Introduction from researcher, explain the purpose of the interview – to discuss their recent health service experience, with a few questions about this experience, and further questions about texts/documents they encountered. Does the participant have any questions before the interview starts?

- Please tell me about your recent experience using health care services
    - Pay attention to work, assumptions, shell terms
    - Return to these to fill with details of what they do and how they know what to do
    - "you mentioned ________, could you tell me what you mean by that?"

Possible prompts to illicit details related to using primary care services

- Can you think of a time during this example when you felt respected? Could you elaborate on that?
    - Looking for contextual examples that may be recognised as person-centred care
    - Pay attention to the work being done and by whom
- Can you think of a time when you felt empowered? Would you tell me more about that?
    - Pay attention to the work being done and by whom
- Did you feel like you were involved in the decision-making for your care? Can you tell me a bit about how you were involved and what influenced your decision-making?
    - Pay attention to facilitators and enablers. Texts? People?
    - Where do they get their knowledge from?
- What have you had to do to fit this process into your life?
    - Apply the generous notion of work

Return to any aspects of work, assumptions made, everyday activities that require further information to explain how it works

Regarding any texts mentioned by the participant: (ask to see text if they have a copy)

- Would you please explain to me what you think the purpose of this [text] is?

- How do you think this [text] contributed to the care you received?